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The Impact on Sexuality After Diagnosis and Treatment for a Hematologic Malignancy: Findings From Australia

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All cancers and related treatments have the potential to affect sexuality and sexual function through the impaired body function, altered body image, or from emotional and psychological distress that often accompanies diagnosis and treatment (Park, Norris, & Bober, 2009; Rice, 2000). Some treatments used in hematology-oncology (i.e., high-dose chemotherapy, total body irradiation, and hematopoietic stem cell transplantation) have known effects on gonadal function that can impact sexual desire and function (Yi & Syrjala, 2009). However, research on the impact of diagnosis and treatment on sexuality has predominately been completed in diagnostic groups such as patients with breast or prostate cancer or under the umbrella of the generic category of cancer. With a few exceptions (Beckjord, Arora, Bellizzi, Hamilton, & Rowland, 2011; Richards, Bertolotti, Doss, & McCullagh, 2011), little exploration has been done regarding sexuality in patients with hematologic malignancies.

The current article contributes to the literature by sharing findings on the impact of diagnosis and treatment on sexuality for patients with a hematologic malignancy gathered from a study on survivorship conducted throughout Queensland, Australia. Although sexuality is considered a sensitive topic, the participants in the study discussed sexuality as part of their survivorship experience and many noted an appreciation for the opportunity to talk about such issues in the research. The findings shared in the current article have direct and important relevance to the work of oncology nurses who act as support for individuals

Purpose/Objectives: To present findings on the impact of diagnosis and treatment on sexuality for those diagnosed with a hematologic malignancy.

Research Approach: A qualitative design based on a series of open-ended interviews and one focus group.

Setting: Queensland, Australia.

Participants: 50 participants representing the major hematologic diagnostic groups.

Methodologic Approach: Interviews were recorded, transcribed verbatim, and then coded and thematically analyzed for the research.

Findings: The impact of the disease and treatment on sexuality ranged from participants experiencing no problems or having a brief impact that passes over time, to those who reported serious problems that significantly affected their life satisfaction. Some concerns were raised about the taboo nature of sexuality and the lack of discussion on the topic.

Conclusions: The findings contradict prior research that all patients with cancer will experience an impact on their sexuality by diagnosis and treatment. The current study indicates that a small subgroup of individuals diagnosed with hematologic malignancies are acutely distressed about issues regarding sexuality and require follow-up.

Interpretation: Individuals diagnosed with a hematologic malignancy may have difficulties with their sexuality and will, therefore, require follow-up or assistance. A subset of individuals will require understanding, support, and, for some, referral to follow-up with a specialist. As major obstacles still exist for patients accessing appropriate professional support and advice on sexuality, oncology nursing can provide leadership in this area.

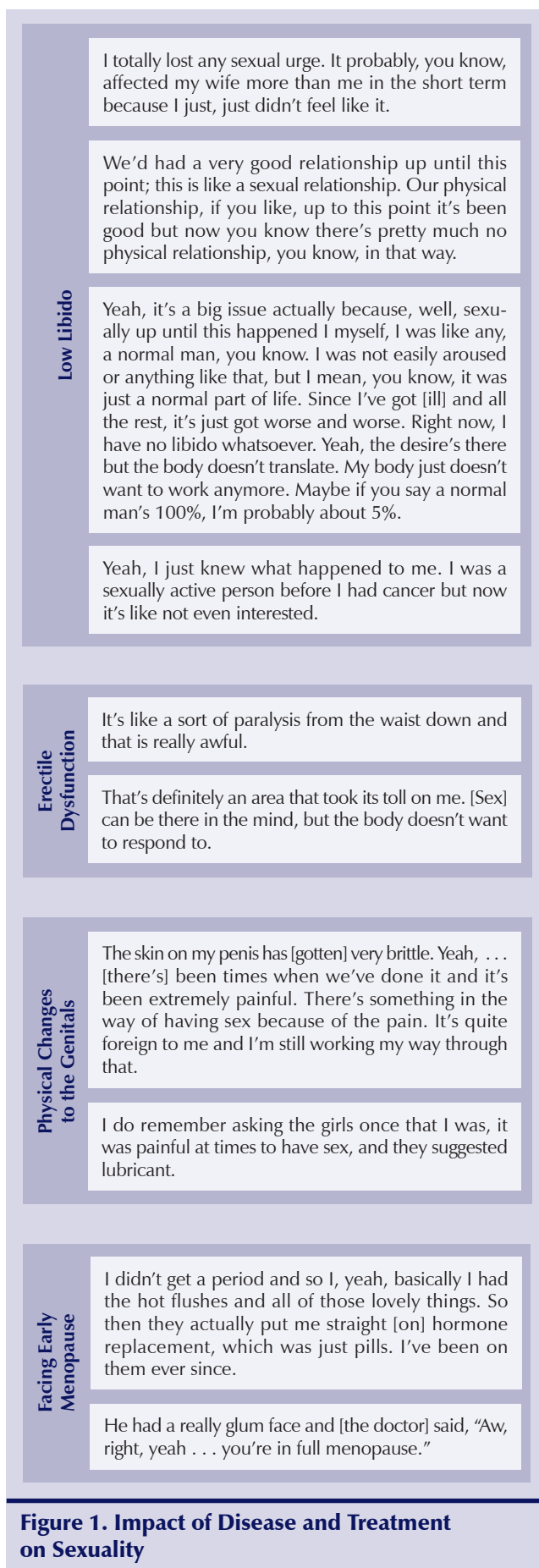


Figure 1. Impact of Disease and Treatment on Sexuality

coping with the challenge of a hematologic malignancy (McGrath & Holewa, 2007).

Methods

The research project was a collaborative initiative of the Leukemia Foundation of Queensland and the International Program of Psycho-Social Health Research. The aim of the research was to document and explore issues associated with the experience of survivorship for patients with a hematologic malignancy. That population's experience of the impact of diagnosis and treatment on sexuality was one of the issues explored through the research.

A full discussion of the research methodology is provided in McGrath, Hartigan, Holewa, and Skaparis (2011, 2012). The qualitative design of the study was conducted through a series of open-ended interviews and one focus group discussion, which were recorded, transcribed verbatim, coded, and thematically analyzed for the research. Ethical approval from the Central Queensland University Human Research Ethics Committee was obtained for the study, and individual consent was recorded.

All participants had to meet the criteria for survivorship: adults with hematologic malignancies at least one year postdiagnosis. Potential participants (N = 118) were contacted to take part in the research; 14 declined to participate and 54 could not be contacted (because of changes in contact information). In total, 50 participants (26 men and 24 women) represented the major hematologic diagnostic groups: multiple myeloma (n = 15), lymphoma (n = 14), leukemia (n = 17), and other (n = 4).

Overall, 11 participants had a bone marrow transplantation and 15 had a stem cell transplantation (allogeneic and autologous transplantations). Because of the unique geography, population, and services provision patterns in Queensland, Australia, a customized regional classification system was designed to ensure that the purposive sample included participants with varying levels of access to hematologic services based on their home address. The sample also ensured a representation of varying ages across the adult life span. Thirty-two of the codes related to participants' experiences with the impact of diagnosis and treatment on their sexuality, forming the basis for the findings presented in the article.

Results

Participants' descriptions of the impact of the disease and treatment on their sexuality was a continuum with some experiencing no problems or none that were an important issue.

No, it's not an issue. Sex-wise, it sort of went right out the door . . . it's only been probably . . . the last three months [partner] and I started having sex again and it was the last thing on my mind.

Others described a brief impact that passed in time.

I was, like, losing my hair, and I gained a lot of weight. Everything got better, my hair started to grow back, so that period in time passes, [the negative impact on sexuality] was only that period in time.

Still, for some participants, difficulties with their sexuality were noted as the most troubling of all issues associated with the disease and treatment.

My sexuality is not good. Well, I suppose it's probably one of my most troubling issues . . . and I don't know if you've talked about that to others, but that's definitely an area that's taken a toll on me.

A range of physical problems in relation to sexuality were stressful, such as low libido, erectile dysfunction (ED), physical changes to genitals, and early menopause (see Figure 1). Those physical problems translated to emotional and relationship problems. For those diagnosed at a young age, finding a partner could be a problem, and ED and low libido could contribute to a sense of failure and depression. A major concern was the impact on their relationship with a significant other (see Figure 2). For participants with those problems associated with sexuality, a range of responses existed for possible strategies to address concerns and seek help (see Figure 3). However, some concerns were noted that the issue of sexuality was somewhat taboo and not readily discussed by doctors. For example, one participant said, "I guess a lot of medical people don't necessarily talk to their patients about it."

Requests were made for more information and support services to be available to assist individuals coping with sexuality problems associated with diagnosis and treatment. Regarding this, one participant said, "I'd be interested to know if there's any more research so that you can find out. I like to know why things happen and that."

Discussion

According to Hordern and Street (2007), diagnosis and treatment for cancer alter intimate and sexual aspects of patients' lives regardless of their age, gender, culture, type of cancer, or partnership status. The findings presented in the current article contradict those conclusions by indicating that the impact of the disease and treatment on sexuality was a continuum that ranged from experiencing no problems, having a brief impact that passes over time, to those who reported serious problems that significantly affected their life satisfaction. In the current study, some participants felt comfortable dealing with the problems by themselves and did not seek assistance. Therefore, a significant practical implication of the findings is that the assumption that all individuals diagnosed with a hematologic

Finding a Partner

When I relapsed the first time, I was dating someone; he couldn't handle it. Basically [I] said, "I can't handle it for the two of us, so bye" (laughs); but yes, we split up. Like, I find it hard to go out and meet someone and the first thing that comes up is . . . I'm not drinking. [They] say like, "Why are you not drinking?" "I'm having treatment" and they just kind of stay away.

When, you know, a lot of people start making, you know, getting boyfriends or girlfriends or whatever, yeah that was pretty hard. I know mum and dad bought me a wig, like I tried it on and stuff and I was like, yeah I really want it but I never wore it.

I haven't had a boyfriend yet and I'm [age] years old. I mean, I think I'm a pretty good catch (laughs). When I was diagnosed was when people start, you know, going out with people and stuff like that, and also just the fact that I don't know how to talk to people, especially my own age because I was in a hospital with nurses that were, you know, five, six years older than me and, you know, I would talk to them.

Sense of Failure

To me, it's part of being a man. It just feels like I've sort of failed a little bit even though I know it's not my fault.

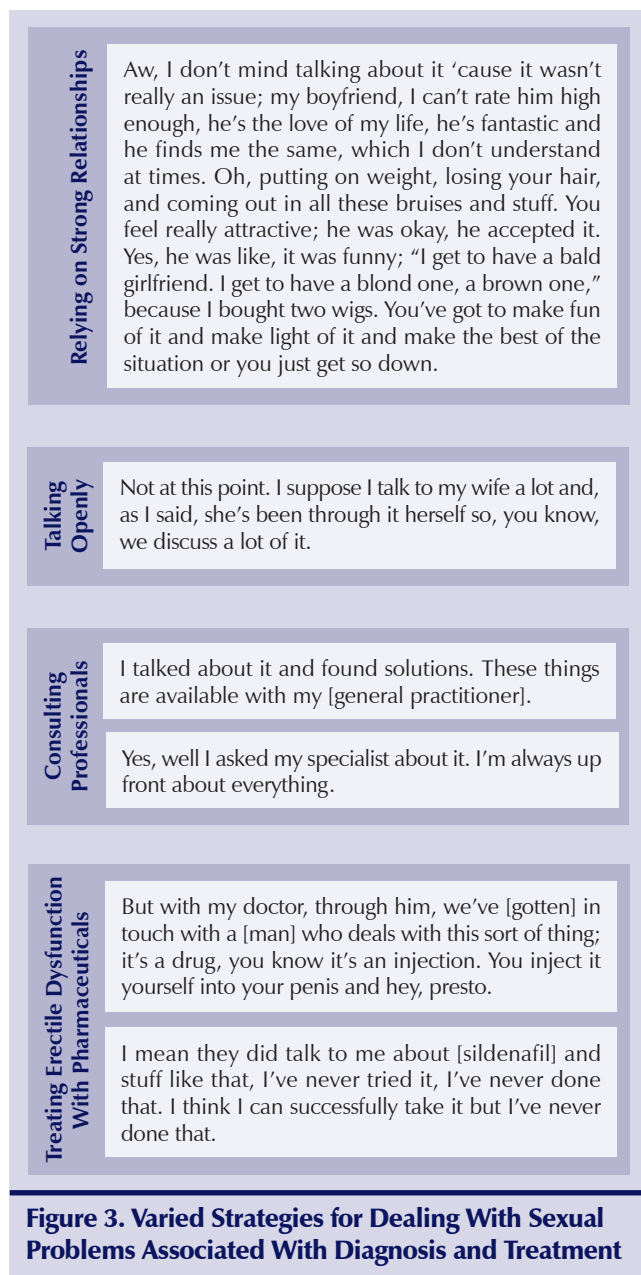
Depression

I think it's probably a major area because some males would probably find it pretty depressing. You know some wives and that may find the same problem.

Stress and Breakdown of Relationships

We still socialized with each other but it's like, you know, don't now have sex, I'm not interested in sex anymore. Like you know cancer just stuffs that sort of. Yes and you try explaining that to someone that hasn't had cancer and they're going, "Oh you're using cancer as an excuse that you don't want to have sex," and all that sort of stuff. They always say, "You can't use cancer as an excuse because you haven't had cancer for 12 months," but, you know, they'll tell you that if they accepted that you have got a problem from cancer, they would, you know, get over it.

Figure 2. Emotional and Relationship Problems Associated With the Impact of Diagnosis and Treatment on Sexuality



malignancy will have difficulties with their sexuality and will require follow-up or assistance is incorrect.

Although the findings highlight a continuum of responses, some participants' difficulties with sexuality were described as the most troubling of all issues associated with the disease and treatment. Research by Jonker-Pool et al. (2004) affirmed that not only do male patients with cancer appreciate being asked whether they need information and support concerning sexuality, but that the information and support are particularly relevant for patients who suffer from sexual dysfunction. Therefore, the second practical implication of the findings is that difficulties regarding sexuality will be serious for a subset of individuals diagnosed with a hematologic malignancy, and who

will require understanding, support, and for some, referral to a specialist for follow-up for their problems.

A range of physical problems was experienced as stressful in relation to sexuality for both men and women including low libido, ED, physical changes to genitals from treatment, and facing early menopause. The physical problems can translate into emotional and relationship problems, such as difficulties finding a partner when diagnosed at a young age, a sense of failure, depression, stress, and possible breakdown of existing relationships. A major concern was the impact on the partner relationship. The findings specific to hematology resonate with the broader literature on patients with cancer that record the complex effects of treatment on sexuality and the negative effect on sexual desire and function (Galbraith & Crighton, 2008; Kaplan & Pacelli, 2011; Reese, 2011). A caveat to that discussion is demonstrated by research by Recklitis, Sanchez Varela, Ng, Mauch, and Bober (2010), which found no differences in sexual problems or sexual satisfaction for patients with Hodgkin lymphoma when compared with a set of controls. In addition, the research demonstrated that, in the long term, survivors' sexual functioning did not differ from the non-cancer control group; consistent with the message from the current study that some, but not all patients, will experience problems with sexuality.

For those with problems associated with sexuality, a range of possible strategies for either addressing concerns or seeking help existed. In terms of assistance, a strong partner relationship based on unconditional acceptance, support, and finding other ways to express physical affection was important. Some of the men in the study indicated that the use of pharmaceuticals for assistance with erectile problems was helpful. Bruner and Calvano (2007) reported that many pharmacologic and nonpharmacologic interventions exist to treat erectile function; however, success rates are variable and long-term compliance is generally low.

An emerging body of literature documents the importance of providing the opportunity for patients to discuss issues of intimacy and sexuality with their health professionals (Hordern & Street, 2007). However, the current study's findings indicate that major obstacles still exist in regard to accessing appropriate professional support and advice. Understandably, some participants were unsure of the benefits of seeking assistance. That finding resonates with Southard and Keller's (2009) work, which stated that physicians often fail to recognize the importance of sexuality when assessing their patients. Although only a small minority of patients with cancer has issues of sexuality addressed by health professionals, many patients wished someone had discussed this topic with them (Southard & Keller, 2009). Research by Hautamäki, Miettinen, Kellokumpu-Lehtinen, Aalto, and Lehto (2007) revealed that discussions on those issues

are uncommon with 98% of the healthcare professional respondents in their study; many participants stated that they talked about those issues with less than 50% of their patients. Only 35% initiated these discussions. Initiating discussions on the impact of treatment on sexuality is noted as potentially uncomfortable for healthcare professionals and patients (Kaplan & Pacelli, 2011). Indeed, as Rice (2000) argued, issues relating to sexuality are among the most poorly addressed topics in cancer care and possibly can be attributed to a lack of knowledge and expertise. Therefore, the third practical implication of the findings is that expecting issues of sexuality to be routinely addressed by the treating hematologist is unrealistic. As the key factor documented for not raising the issue of sexuality is lack of training (Hautamaki et al., 2007), one way forward to improve the situation is for more intensive education on how to open discussions on this sensitive topic. The BETTER model (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) as presented by Lee (2011), is a helpful and concise model for basing assessment and intervention regarding sexuality for patients with cancer. The findings presented in the current article indicate that many patients would be appreciative of nurses' efforts to communicate on that topic.

Implications for Nursing

The findings indicate that not all patients with a hematologic malignancy will experience problems with sexuality because of diagnosis and treatment. For those who do experience problems, they can be acute and require access to a range of follow-up support such as counselling and referral to specialist advice, including the possibility of pharmaceutical assistance. Oncology nurses who provide

much of the clinical and psychosocial care of patients with hematologic malignancies are well placed to engage in discussion on sexuality. The research indicates that patients are not likely to have issues of sexuality addressed by their medical practitioners or specialists. The discussion of sexuality is a sensitive, but appreciated, topic that requires skills and ongoing training.

Conclusion

For a subgroup of individuals diagnosed with a hematologic malignancy, the provision of assistance in dealing with sexual problems associated with diagnosis and treatment is an important component of follow-up care. Oncology nurses who are well placed in relation to their provision of holistic patient care can provide active listening, information, support, and suggest follow-up medical assistance if necessary.

The author gratefully acknowledges Barbara Hartigan, Maryanne Skarparis, and Bev Mirilo from the Leukaemia Foundation of Queensland for their contribution in organizing the funding for the project and for supporting the conduct of the research. Also, the author acknowledges the contribution of the research staff employed to work on the project, including Hamish Holewa, B. Sc (Comp Sci), B Ed, Grad Dip HEcon, Nicole Rawson-Huff, B Sc, Bo McGrath, BA, Michael Bouwman, LLB, Mary Anne Patton, B Sc, and Emma Phillips, BA, LLB. The author also thanks CQUniversity where the data were collected and Griffith University, where the analysis and write up were completed.

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Digital Object Identifier: 10.1188/12.ONF.595-600

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1. Is sexuality still taboo among healthcare providers? Does a difference exist between type of provider (e.g., nurse versus physician)?
2. How comfortable are you talking about sexuality with your patients? How about your nursing and physician colleagues?
3. What do you think the biggest challenges are in raising this topic with patients and colleagues?
4. The current study suggests that not all patients with hematologic cancer have difficulties with this aspect of life, contrasting other studies that found that it does. Is there something inherent in the current study that may have led to this finding and how do you go about making sure that this does not prevent you from making a mistake with your patients?

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