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Sexuality after hematopoietic stem cell transplantation: A mixed methods study

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ABSTRACT

Purpose: This study examined patients' experiences of sexuality following hematopoietic stem cell transplantation. A secondary aim of the study was to explore healthcare provider-patient communication about sexuality.
Methods: A mixed methods design was employed with an embedded qualitative-quantitative approach whereby the quantitative data were used to supplement the qualitative results. Participants (8 male and 3 female) participated in semi-structured interviews and also completed the FACT-BMT questionnaire. *Results*: Qualitative themes that emerged included: changes in sexual function (such as with desire and arousal), changes in relation to self (such as with body image, sexual identity), changes in relation to others (such as with current relationships, starting new relationships, fear of exposure to 'germs') and the experience of discussing sexual health concerns with healthcare providers. Quantitative data from the FACT-BMT revealed that participants reported low satisfaction with their sex life but remained interested in sex. The majority of participants reported dissatisfaction with the appearance of their body and most were not concerned about fertility.
Conclusion: This study documents the physical and psychosocial sexual health concerns reported in male and female recipients of HSCT. Concerns were present even for those many years post-HSCT. Implications include suggestions for healthcare providers regarding patient education and assessment of sexual health changes in patients throughout the HSCT trajectory and continuing well into survivorship.

1. Introduction

Hematopoietic stem cell transplantation (HSCT) is a treatment modality, used with curative intent, in the management of hematological malignancies and other non-malignant conditions (Bevans et al. 2017; Majhail and Rizzo, 2013). Advances in HSCT in recent years have led to improved outcomes in survival, yet HSCT remains associated with significant risks of long-term morbidity and diminished quality of life (Andrykowski et al., 2005; Hwang et al., 2012; Syrjala et al., 2012). The impact of HSCT on sexuality and in particular, on sexual function, has been the subject of a number of original studies (Astarita et al., 2016; Dyer et al., 2016; El-Jawahri et al., 2018; Noerskov et al., 2016; Norskov et al., 2015; Tierney et al., 2015; Yoo et al., 2018) and review articles (Carter et al., 2018; Syrjala et al., 2012; Thygesen et al., 2012) with incidence rates of sexual dysfunction in the literature ranging from 6 to 46% in males and from 33 to 80% in females post HSCT (Bevans et al., 2017).

In their review on HSCT and sexuality, Thygesen et al. (2012) report on 14 quantitative studies that examined sexual function after HSCT. The authors found that sexual dysfunction is common following both autologous and allogeneic HSCT. While some sources suggest that some degree of recovery of sexual activity may occur within the first 2 years post-HSCT, many survivors continue to experience profound sexual dysfunction even 5–10 years post-HSCT (Thygesen et al., 2012). The partners of patients who have undergone allogeneic HSCT are also negatively impacted. Polomeni et al. (2016) found that 75% of both patients and partners reported negative effects on their sexual life, and 30% of patients and 50% of partners reported negative effects on their couple life. Thus, sexual difficulties may also impact the general well-being of couples' relationships (Polomeni, 2016).

Sexuality has been defined as "a person's behaviors, desires, and attitudes related to sex and physical intimacy with others" (National Cancer Institute, n.d.). For the purposes of this paper, we have adopted this broad definition of sexuality such that it includes not only physical

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aspects (like sexual function) but also considers the "complex social, psychological and relational context within which sexuality and intimacy are experienced" (Perz et al., 2013, p. 2). Within the HSCT population, such sexual changes may include aspects of sexual function such as: vulvovaginal changes (e.g. dryness and stenosis) and dyspareunia in women, erectile dysfunction (ED) and ejaculatory changes in men, and diminished sexual desire in both men and women. Additional changes in sexuality may be associated with relational challenges, concerns with body image, and changes in fertility affecting both genders (Carter et al., 2018; Dyer et al., 2016; Li et al., 2015; Syrjala et al., 2012; Thygesen et al., 2012).

The etiology of changes in sexuality following HSCT is likely multifactorial and may be related to treatment with chemotherapy or radiotherapy, graft-versus host disease (GVHD), medications used to prevent and/or treat complications of HSCT, as well as comorbidities predating or unrelated to HSCT (Lee et al., 2002). Changes in sexual function etiologically attributed to HSCT may be a consequence of the impact of treatment on neurovascular, hormonal and/or psychological functioning (Li et al., 2015; Thygesen et al., 2012; Yi and Syrjala, 2009). While the topic of sexuality after HSCT has been studied by others, much of the work to date has focused on sexual function rather than on sexuality in a broader sense, including additional aspects such as body image, fertility and intimate relationships. Additionally, there are few qualitative studies that have sought to examine the impact of such changes on the patient and their relationships.

1.1. *Purpose*

The purpose of this study was to better understand the experience of sexuality in patients who had undergone HSCT. A secondary aim of the study was to learn more about the experience of discussing concerns pertaining to sexuality with healthcare providers.

2. Methods

Ethics approval for the study was obtained from the University of Calgary Conjoint Health Research Ethics Board. Informed consent was obtained from study participants.

2.1. *Design*

This study used a concurrent embedded qualitative-quantitative mixed methods design (Creswell and Plano-Clark, 2007), whereby quantitative data were used to supplement qualitative data. The qualitative portion of the study used a qualitative descriptive methodology, with data collection through patient interviews. Qualitative descriptive study is one of the most frequently used methodologies in clinical practice disciplines (Sandelowski, 2000a). Qualitative descriptive study is considered to be more interpretive than quantitative methodology and in particular, qualitative description seeks to understand and discover a phenomenon of interest with an emphasis on description (Bradshaw et al., 2017). Qualitative description differs from other qualitative methodologies; it does not specifically focus on culture (as ethnography does), does not endeavor to explore lived experience (as phenomenology does) nor does it intend to build on or create new theory (Bradshaw et al., 2017). Rather, qualitative description "strives for in-depth understanding but with an emphasis first on literal description and then on understanding of human phenomena through analysis and interpretation of meaning" (Bradshaw et al., 2017, p. 2).

Participants also completed the Functional Assessment of Chronic Illness Therapy-BMT (FACT-BMT) (McQuellon et al., 1997). These data were used primarily to characterize the sample and assess participants' function. Therefore, data relating to sexual phenomena were examined at the individual item level.

2.2. *Sample accrual*

A non-probability, purposive sampling approach was used to recruit participants. Individuals were invited to participate in the study if they satisfied the inclusion criteria: having undergone allogeneic or autologous HSCT, attendance at outpatient Bone Marrow Transplant clinics at a Canadian cancer centre during the data collection period, ability to understand and speak English, ability to tolerate a 30–60 min interview, and age ≥18 years old.

2.2.1. *Recruitment*

Participants were recruited via poster advertisements placed around the outpatient clinics in the cancer centre. Interested participants contacted the primary researcher listed on the poster (RB), who then met with interested individuals to provide any additional required information. Informed consent and the study procedure were completed with those that elected to participate. All potentially interested individuals (n = 11) ultimately decided to participate in the study.

2.3. *Data collection*

Consenting participants completed the FACT-BMT questionnaire, followed by the semi-structured interview (conducted by RB). The majority of interviews took place in private rooms in the outpatient clinic; several interviews took place in participants' homes and one interview occurred at a coffee shop as requested by the participant. Regarding the latter, no other people sat nearby. Interviews were audio-recorded and transcribed verbatim. Data collection occurred over a 20-month period, at which point participant accrual was terminated due to expiry of study funding. Closure of the study at this time did not allow follow-up with participants to seek their input regarding our interpretations.

2.3.1. *Semi-structured interview*

The semi-structured interview guide was derived from a study examining patient perspectives on sexuality in palliative care (Lemieux et al., 2004); permission was granted from the primary author for its application to the bone marrow transplant context. Of note, the interview questions were not changed with the exception of changing the clinical setting from palliative care to bone marrow transplant. The interview guide comprised of 12 questions with several prompts (Appendix).

2.3.2. *FACT-BMT-4*

The FACT-BMT Version 4 is a 47-item questionnaire comprised of subscales that assess physical well-being, social/family well-being, emotional well-being, functional well-being as well as additional concerns specifically related to HSCT (McQuellon et al., 1997). Respondents are asked to reflect on the past seven days when completing the questionnaire. Participants respond on a Likert scale, ranging from 0 ('not at all') to 4 ('very much'). Higher scores indicate better quality of life (QOL) (FACIT.org). Specific items relating to sexuality, fertility and QOL are examined at an individual item level.

2.3.3. *Demographic and health information*

Demographic and health information including diagnosis, treatment, medical comorbidities, GVHD status, and medications, was obtained via chart review and the use of a demographic/health information form completed at the time of the interview.

2.4. *Data analysis*

Statistical information was computed using Microsoft Excel 2016. Descriptive statistics were computed for several variables (age, time since transplant, FACT-BMT scores; see Table 1 for full list of variables). Content analysis is the preferred approach in qualitative descriptive

Table 1
Demographic information.

Participant ID	Diagnosis	Gender	Age at time of transplant x = 41 mdn: 44 range: 17-62	Age at time of study x = 46 mdn: 47 range: 26-64	Type of transplant	Time since transplant (mos) x = 29 mdn: 24 range: 2–86	Chronic graft versus host disease
1	Follicular lymphoma	Male	44	47	Allogeneic, matched sibling	42	Mouth, skin, liver
2	Aplastic anemia	Female	47	49	Allogeneic, matched sibling	24	None
3	Acute myelogenous leukemia (AML)	Female	41	42	Allogeneic, matched sibling	20	Mouth, liver
4	Secondary acute myelogenous leukemia (AML)	Female	42	45	Allogeneic unrelated donor (A antigen mismatched)	39	Mouth, lungs, vagina
5	Acute myelogenous leukemia (AML)	Male	53	56	Allogeneic, matched unrelated donor	25	Mouth, lungs, eyes
6	Multiple myeloma	Male	43	43	Autologous	3	n/a
7	T cell acute lymphoblastic leukemia (ALL)	Male	17 19	26	Allogeneic, matched sibling x 2	86 69	Lungs
8	Myelofibrosis	Male	47	47	Allogeneic, matched sibling	2	None
9	Mantle cell lymphoma	Male	46	47	Autologous	3	n/a
10	Multiple Myeloma	Male	62	64	Autologous	19	n/a
11	Myelofibrosis	Male	31	36	Allogeneic, unrelated donor (A antigen mismatched)	53	Mouth, lungs, gastrointestinal tract, eyes

studies (Sandelowski, 2000b), and interview data were analyzed using the constant comparative method outlined by Thorne (2000).

Transcripts of participants' responses were read and coded, independently, by two of the authors (RB & LW) in order to identify and extract significant statements and themes. The assistance of a seasoned qualitative nurse researcher (SR) additionally reviewed transcripts and provided mentorship on the coding process.

3. Results

3.1. Sample characteristics

Study participants included 3 women and 8 men who had undergone HSCT for treatment of a variety of disease types. Participants were on average 43 years of age at time of transplant with ages ranging from 17 to 62 (males) and 41–47 (females). The average time since transplant was 29 months (range 2–86 months), with one participant having received two transplants. The majority of participants were married. At the time of transplant, 9 were married/common-law, one was in a dating relationship and one was single. At the time of the study, 2 had since divorced or separated, and the dating participant had become single. For full demographic information see Table 1.

3.2. Quantitative results

3.2.1. FACT-BMT

FACT-BMT overall scores ranged from 56 to 134 out of a possible 148. See Table 2 for all FACT-BMT and subscale scores. Several items pertaining to sexuality and QOL were examined as individual items (satisfaction with sex life, interest in sex, appearance of body, and concerns about ability to have children and QOL; see Figs. 1–5 for range of responses. Of interest, all but one participant indicated that they had no concerns with fertility. In terms of sexual satisfaction, only one participant indicated that they were 'very much' satisfied with their sex life. Despite qualitative findings indicating reduced sexual desire (discussed below), the majority of the sample (n = 6) indicated that they were still interested in sex ('quite a bit' or 'very much') while only one participant suggested that they were 'not at all' interested in sex. The majority of participants indicated dissatisfaction with the appearance of their body, with only 2 participants reporting that they liked the appearance of their body 'quite a bit' or 'very much'.

3.3. Qualitative results

Major themes that emerged during the qualitative analysis included: changes in sexual function, changes in relation to self, changes in relation to others, and the experience of discussing sexuality with their health care provider (Fig. 6). All participants stated that sexuality was important to them, even at times when they were quite unwell, for example one participant shared, *"You know what? I'm not dead yet. And I might be really sick but maybe sex is something I can take comfort in …"* [4]. While a number of participants mentioned that the importance of sexuality to them had not changed after HSCT, their expression of sexuality had changed. For example:

> *"I think the worst part is just not having contact … it doesn't have to be full on sex in a bed … might help to get through certain nights and things, just to hold another person like that and, it might help the other … the spouse too, right? … if your last few times, are just to be like that, it doesn't have to be sex, but touching and stuff, holding …" [11]*

3.3.1. Changes in sexual function

Both female and male participants reported experiencing changes in sexual desire and arousal, including physical changes in the body (such as vaginal atrophy and dryness and structural changes affecting the penis), reduced sexual response (such as decreased arousal, lubrication

Table 2
FACT-BMT scores & subscale scores for individual participants.

	Total Score		Subscale Scores				
	FACT-G	FACTBMT	Physical well-being	Social well- being	Emotional well-being	Functional well-being	BMT Subscale
	(0–108)	(0–148)	(0–28)	(0–28)	(0–24)	(0–28)	(0–40)
	X = 80 SD: 19 Mdn: 83 Range: 41- 100	X = 109 SD: 23 Mdn: 111 Range: 56-134	X = 22 SD: 6 Mdn: 23 Range: 628	X = 20 SD: 6 Mdn: 22 Range: 728	X = 20 SD: 3 Mdn: 20 Range: 16-24	X = 18 SD: 7 Mdn: 19 Range: 5-25	X = 29 SD: 6 Mdn: 28 Range: 15-37
1	95	132	27	23	21	24	37
2	98	129	27	26	20	25	31
3	93	127	24	22	23	24	34
4	83	111	18	23	23	19	28
5	74	101	23	13	19	19	27
6	52	86	21	7	16	8	34
7	76	104	23	21	18	14	28
8	100	134	28	28	24	20	34
9	95	121	24	24	23	24	26
10	73	101	16	22	18	17	28
11	41	56	6	14	16	5	15

Note: Participant data are presented in order of the chronology of when the interviews were conducted.

Fig. 1. Responses for item pertaining to satisfaction with sex life.

Fig. 2. Responses for item pertaining to interest in sex.

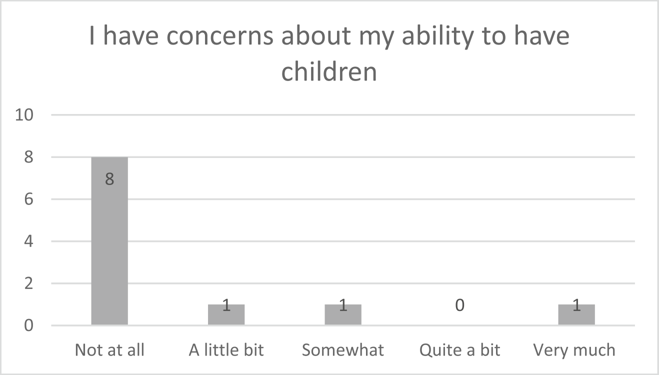

Fig. 3. Responses for item pertaining to fertility.

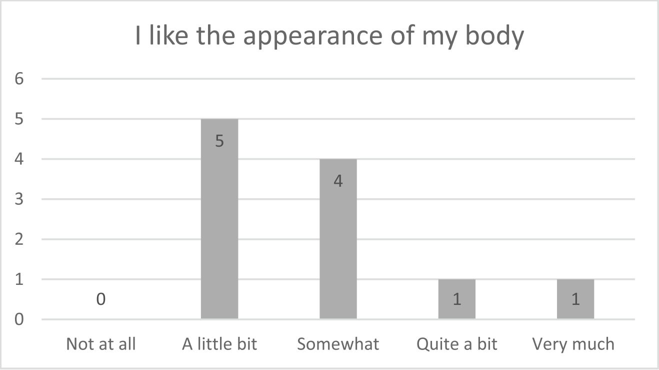

Fig. 4. Responses for item pertaining to body image.

and erection) and changes in sexual interest.

3.3.1.1. Desire. All but one participant described a reduction in sexual desire following the diagnosis of the underlying hematological condition and/or subsequent transplant. Both male and female participants acknowledged this change in desire and how it impacted them, their partner, or both parties. For example:

> *"I'd say it's changed …. since I'm sick … it's decreased … my interest in sex has decreased quite a bit. I guess the main way is I just don`t seem to have any interest or desire. It`s just something that … it just seems like in my own mind, almost like never comes up."* [10]

> *"My libido has changed certainly. I know part of it is from the drugs and from not feeling good and being tired … but this is more than … just being tired. It's just not feeling like it. And that was only after the transplant."* [4]

In some cases (like the two above), the loss of desire was simply acknowledged, but for others it appeared to be associated with a sense of loss or sadness:

> *"It's hard for me because, you know, it's a 50/50 partnership and …, I don't want to not be interested. That's … that's hard on me. Worse than it [intercourse] being painful is the fact that I don't really feel like it …"* [4]

> *"Yeah, if there was a magic pill I could take that would give me the level of desire back that I had, I would take it cause I, I really miss that. You*

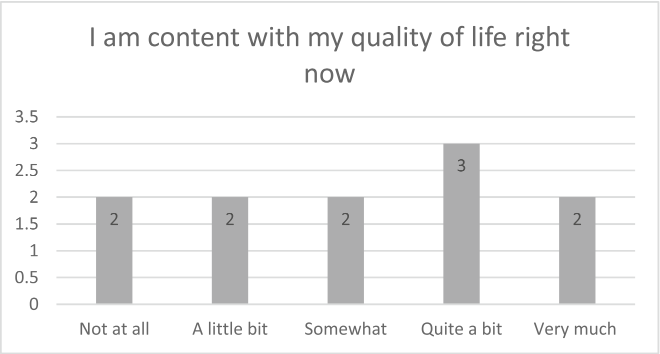

Fig. 5. Responses for item pertaining to quality of life.

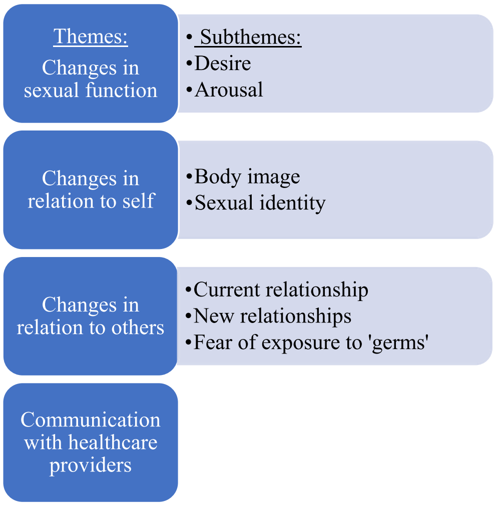

Fig. 6. Main themes and sub-themes that emerged during analysis.

> *know, if I saw a beautiful woman, if I allowed my mind to go there and fantasize … (snaps fingers) … and not just get an erection it's that … that, I call it the tingly desire feeling you get … and I haven't felt that in a long time..”*[5]

In contrast, one young, single participant described that his desire remained intact:

> *“In* terms *of desire to have sex, yeah, it's still there, that's still normal. I still want to have sex. I still would like to pursue relationships that involve sex.”* [7]

3.3.1.2. Arousal. All of the women in the sample had experienced treatment-induced menopause resulting in vaginal dryness that interfered with intercourse and pleasure. Women articulated that vulvovaginal changes resulted in painful intercourse and absence of sexual pleasure:

> *“[*Arousal *is] … a huge issue … My tissues are so dry vaginally, that they can tear and crack and bleed, so that is a big concern. We've tried having intercourse about four times and every time … it truly was painful I mean there was absolutely no pleasure there whatsoever and we were using copious amounts of lubrication and it just didn't feel good at all.”* [2]

Several women expressed that pain with sexual activity had a significant negative impact on arousal, as illustrated by this participant's comment, *“If it's painful, then it's kind of hard to get aroused because it hurts.”* [4] The same woman talked about how her pain was a barrier not just for her own arousal, but also potentially for her husband, illustrating the impact of sexual function changes on the partner's sexual experience:

> *“Then my husband is … he's always worried about hurting me … And that's the other thing … for my husband, is that like, ‘you're bleeding’ … for him, then it's like another thing that makes him self-conscious …”* [4]

Men also reported experiencing substantial difficulties with arousal, predominantly manifesting as ED. In particular, a number of men cited problems with achieving erections, insufficient firmness of erections, or difficulty sustaining erections. For instance, one participant stated:

> *“If I try really hard, I'd call it half an erection … it's certainly not rock hard by means and if I let my mind wander for two seconds it's gone … I have to work to keep it …. and I can't keep one long enough to have satisfactory intercourse.”* [5]

Similarly, another participant explained, *“… I can get hard but it don't stay hard and I have no feeling … to keep it going. It's kind of like pushing a rope or putting a marshmallow in a coin slot ….”* [9] He went on to further explain that the difficulties he had experienced with erections had impacted his ability to reach orgasm, *“I become aroused, but I can't follow through to orgasm. It just falls off and goes back to sleep again. It's no soldier standing at attention, it's an old veteran on a couple duffle bags.”* [9].

One man described how even though he retained erectile ability, he experienced diminished sensation that impacted arousal and orgasm:

> *“I could get* aroused *but it … there's no feeling to take me to orgasm. I'd lose the arousal … I can get hard but it don't stay hard and I have no feeling … to keep it going … you can pull and pull and pull and there's nothing there.”* [9]

Erectile difficulties were noted by men when participating in sexual activity both with a partner as well as by oneself, as one participant described:

> *“It's more* **…** *difficult, to maintain arousal or maintain erections. An example, if I was masturbating, I might be able to get an erection but if there's a pause in it … I might lose that and then it's hard to get an erection again or you may not be completely erect, you may only be semi-there.”* [7]

Several participants mentioned that they had tried medications to assist with erectile function. One participant acknowledged the planning required for him to be able to obtain an erection and that the reduced spontaneity impacted his sexual experiences:

> *“Nothing can really be spur of the moment … I carry one of the Cialis® pills in my wallet. So that if, this looks like it may be going somewhere, I'm prepared. But even that … it requires planning and forethought and removes some of the spontaneity that can take place … the fact that it requires forethought is one more thing on the checklist that you have to do which normal people don't.”* [7]

Others were unable to really comment on ability to become aroused, because the barrier to sexual activity was in their lack of desire, *“Interviewer: Have you had any difficulty with arousal? “Yeah … I don't seem to … uh, nothing like that. I don't get … I really don't have any interest in that at all.”* [10].

3.3.2. Changes in relation to self

Participants recounted how treatment had impacted how they related to themselves in terms of body image and sexual identity. Changed body image and sexual identity were common for both female and male participants.

3.3.2.1. Body image. The majority of participants acknowledged that changes in appearance secondary to HSCT had an adverse impact on their body image. This participant described the impact of side effects of his treatment on his physical appearance, *“… just looking at some of the pictures … you look pretty rough and then if you're on prednisone you get … moonface … I lost all my muscle I used to have … I used to be pretty built*

… I lost teeth because of methadone …” [11]. One participant explained how he felt that the changes in his physical appearance reduced his perceived attractiveness to potential partners and thus limited his ability to develop new sexual relationships:

> *“With general body image, because I'm in ill health, it's harder to stay in shape and so because of that, it's like, am I able to compete with people who have good health, good body … you know, how do I compete with that? Or, do you lower your standards? Or do you just go for what's available? It does make a difference, especially, I find, in the homosexual community, which is very shallow in my opinion; it's a lot about body image and a lot of times I find … I don't measure up. So … in terms of like, do I feel attractive enough to actually get sex? The issue is there.”* [7]

3.3.2.2. Sexual identity. Several participants explained how the changes they experienced in sexuality impacted their sexual identity and even their sense of self more generally. For example, one participant articulated that he felt his illness and treatment impacted his awareness of and formulation of his sexual identity and orientation:

> *“… in terms of the GLBT issue … treatment may have even helped that because I was questioning sexuality but not to any real degree just because I was busy with life. But when I was forced to be at home, alone, I had more time to get a little more introspective as well … just with being ill, you tend to look inward …”* [7]

Other participants felt that physical changes, such as those that affected appearance, influenced their identity as well. This participant described how changes in his physical appearance altered his sense of self to the point where he felt he had lost who he was:

> *“I remember the first time I looked in the mirror … when I got up to go to the bathroom and I literally fell to my knees sobbing because I didn't recognize the person that I saw … I'm trying to fight tears off now talking about it … I've mourned the loss of who I was. I was stronger physically … I feel I look older than what I was … Now, I'd say I'm 90% of what I used to be … I've got a much bigger heart … some say it's the girl blood that makes me cry so easily.”* [5]

Concurrently, in this quote, he described mourning this loss and embracing some changes, including his increased emotionality and sensitivity, a process that took place during the 2 years since his transplant. Additionally, other participants felt that their loss of fertility had altered their sense of self. One participant explained that even though he was not particularly concerned about having more children, the loss of fertility, to him, was shocking and “brutal”. This loss of fertility represented a loss of a part of himself:

> *“It's like, you're going to go through this and you won't be able to have kids and you're just like, ‘what? I can't have kids? What's going on?’ So, I think, once a guy hears that, it's like, you know, a whole part of you kind of … vanishes into thin air … it's a shock. It's brutal.”* [6]

Similarly, another participant described how the loss of fertility contributed to reduction in the fullness of her life. Her loss of fertility was one component of many losses that left her feeling like she had to start rebuilding from the ground up:

> *“I was at the peak of my life. I had the world by the tail before I was diagnosed … and … in the course of one year, not only was I diagnosed and went under treatment, my entire life was stripped from me. I am literally starting from scratch. And the fact that I can't have children is even a further reduction of my life … I have to start completely over.”* [3]

3.3.3. Changes in relation to others

Participants described changes in how they related to others and the impact that treatment had on their relationships. This was true for established and new relationships alike. For example, a number of participants reported that fears of exposure to ‘germs’ had prevented them from engaging sexually. Additionally, sexual changes were reported to impact relationships, but so too did other physical changes.

3.3.3.1. Impact on current relationship. Several participants discussed how the diagnosis and treatment had affected their relationship with their intimate partner. For some the changes were directly related to sexuality, as these participants recall: *“I don't have sexual feelings toward my wife … we're not very close physically.”* [10]. Another shared, *“… before the transplant and before the ATG [anti-thymocyte globulin] we had a beautiful physical relationship and now since the transplant, well, we haven't had any intercourse for two years … well, actually going on three years now”* [2]. One participant talked about how he noticed that his partner withdrew from him during his treatment, with regard to physical intimacy. He articulated the impact of this burden and the need to work to overcome this barrier in their relationship:

> *“… because they're, you know, ‘aw, you're sick, I'll just leave you alone for two or three months' right? And see how it goes … and it … becomes like a little wall that you gotta kind of jump over once in a while … it becomes bothersome. It really does.”* [6]

A handful of participants explained that while they were not personally distressed by the changes in sexuality, they were concerned about the impact on their partner. It was this impact on the partner that was the source of their distress:

> *“I choose life and the sexuality for me … it would never bother me … it wouldn't bother me if my libido stayed like this, it wouldn't bother me for the next 10, 30 years but it's my husband that I love and I worry about … not me.”* [2]

Particularly compelling was one participant's belief that her loss of desire and the difficulties it presented to their relationship contributed to the demise of their marriage:

> *“When I was going through treatment and I had no desire … like in fact, it was so bad one time, I looked at my husband … in rejection ….and he felt that … I know he felt that and I know that was what contributed to the end of our marriage …”* [3]

Perhaps unique to the post-HSCT population, a concern that came up repeatedly, was that participants may be exposed to pathogens during partnered sexual activity and physical intimacy. Several participants explained how this apprehension subsequently affected their intimate relationships and sexual experiences. For example, one woman talked of her partner's inhibition, *“… my husband was actually really afraid to touch me and get physical with me just because he didn't want to give me any germs.”* [2] Others shared that their own fear impeded specific kinds of sexual activity:

> *“Like I don't want to get sick, so … there's a lot of things you cut out. Oral [sex] … for instance. You know, I'm just scared as hell to perform orally on her because of bacteria and that kind of thing right now.”* [9]

Other participants commented that similar concerns impeded non-sexual physical affection, and described the negative impact this had on the intimacy in their relationship:

> *“I was definitely fearful. I was very cautious … I didn't want my husband to give me a hug … or I would hold my breath for a kiss … I would never take the chance for that. So our intimacy suffered because of that …”* [3]

3.3.3.2. Impact on new relationships. Four participants who were not in a relationship (one separated, one divorced, two single) at the time of the study reported an impact of cancer and treatment on their ability to form new relationships. One participant in particular clearly articulated the challenges he had encountered with dating following cancer and treatment, particularly with worry that the effects of his treatment could cause harm to a potential partner, *"Within the first year and a half of my transplant, because of the lingering chemicals that stay in your body … I thought, if I get a girlfriend now, will I be able to have sex with her … will my fluids transpose the chemicals into her body? … would it be harmful?"* [1]. Such worries contributed to trepidation in entering the dating scene. He further talked about the impact his cancer diagnosis had on considering a future with a potential partner:

> *"The* problem *with dating a person like myself, is the conversation always keeps coming back to me and my cancer and it seems to take over the conversation, which I don't mind … but 9 times out of 10 so far … that's pretty much the end of the dating scene with that person. It's almost … I get the sense that it's … not that I'm damaged goods but it's like … it reminds them that there's a finite level to the distance that I can go with this person in their lives …. "* [1]

While these four participants did not explicitly mention 'fear of germs' as a barrier to starting new relationships, this phenomenon may also be applicable to both those in current relationships and those starting new ones.

3.3.4. Communication about sexuality with healthcare providers

Most participants indicated that they had never been asked about sexuality by their healthcare providers. In addition, several participants disclosed that while they had mentioned they had concerns about sexuality to their healthcare providers, their concerns had not been acknowledged or addressed.

Specifically, this participant shared, *"Yeah I kind of mentioned it once or twice when I came out of the stem cell [transplant] … I don't think they caught on …"* [6] Another talked about the screening form given to her at every follow-up visit to identify areas of concern:

> *"… I have my little checklist … at every appointment … it's [sexuality] on there, I know it because I know what's on the list but nobody ever asks. And I don't think that that's right … don't think that just because you're sick … I mean, yeah maybe you're not thinking about it [sex] at all but maybe you are …* [4]

Each participant agreed that health care providers should discuss the potential impact of HSCT on sexuality. Participants asserted that sex is important and should be addressed, *"… people should be aware that's something that if they want to deal with it or need to deal with it or want help with it … that they know that it's possible … that they're able to do that."* [10].

Participants felt that sexual health was an important part of life that significantly influenced overall quality of life. Overall, they felt that sexual health, being a normal part of life, should be routinely addressed in the health care context:

> *"… I do* think *it is very appropriate and something that does need to be addressed because … it really does affect people's well-being. It's a normal part of human life and chemo is not a normal part. So if you can get as much normal back into the life of a cancer patient as possible, that would be good"* [7]

All participants felt that it was appropriate for healthcare providers to discuss sexuality with patients throughout the disease and treatment trajectory, and some participants offered insights into the most optimal timing. Several patients articulated that such discussions should not occur immediately after diagnosis, *"Well not the initial diagnosis, that's for sure. I don't think it should be discussed then because the shock of it … the shock of it is overwhelming."* [6]

> *"Well* certainly *not within five minutes of diagnosis. 'Alright you're gonna be dead in two months if you don't have a transplant … by the way … how's your sex life?'!! 'Well it was good until you gave me that news!'"* [5]

4. Discussion

As reported in the literature (Syrjala et al., 2005; Thygesen et al., 2012; Yoo et al., 2018), the most common physical changes reported by women in this study were changes in vulvovaginal health, dyspareunia, and diminished sexual desire. All female participants reported significant changes with vulvovaginal tissues such as profound dryness and/or bleeding that were also associated with pain. Not surprisingly, women reported such symptoms had an adverse impact on sexual arousal and desire. These findings are important as it may be possible to improve arousal and desire if vulvovaginal symptoms and painful sexual activity are addressed (Carter et al., 2018).

Only one woman in this sample had history of vulvovaginal GVHD, which notably, had been self-reported and had not been documented in her chart. Vulvovaginal changes are often underreported, infrequently assessed and subsequently, inadequately treated (Hamilton et al., 2017; Noerskov et al., 2016). Vulvovaginal GVHD may develop insidiously and patients may not experience significant symptoms until GVHD has become quite advanced (Tirri et al., 2015). Conversely, other patients may experience profound changes such as burning, dryness, irritation, pruritus, and changes in the vulvar architecture (Ciavattini and Clemente, 2015; Shanis et al., 2012; Spiryda et al., 2003; Van Dam et al., 2017). If sexually active, they may also note difficulty or pain with intercourse and genital sexual touch (Ciavattini and Clemente, 2015; Spiryda et al., 2003; Tirri et al., 2015; Van Dam et al., 2017). Given that routine vulvovaginal assessment has not yet been widely adopted as part of routine post-HSCT care, and because vulvovaginal changes may develop silently, it is imperative that female patients are educated on potential changes that may arise post HSCT. Instruction on how to perform self-exams and information about the types of changes to monitor should be part of this education (Kornik and Rustagi, 2017; Zantomio et al., 2006). Such information should also be extended to patients' partners if they are available and willing, particularly as they may be the ones to observe such changes. Vulvovaginal GVHD and vulvovaginal changes secondary to hypoestrogenism may mimic one another or, may occur concurrently (Tirri et al., 2015). Routine assessment for such changes and early treatment of both hypoestrogenism and vulvovaginal GVHD may prevent severe symptoms from occurring (Kornik and Rustagi, 2017; Van Dam et al., 2017).

Similar to other studies (Dyer et al., 2016; El-Jawahri et al., 2018; Lee et al., 2002; Noerskov et al., 2016; Syrjala et al., 2008; Yoo et al., 2018), the majority of male participants in this study reported difficulties with diminished desire as well as with erectile function and in particular, difficulty with achieving and sustaining erections. The etiology of erectile dysfunction (ED) after cancer treatment may be a consequence of altered vascular, nerve, or hormonal function, in addition to psychogenic factors (Voznesensky et al., 2016). In their prospective study examining ED in 24 patients treated with autologous or allogeneic HSCT, Chatterjee et al. (2000) found that cavernosal arterial insufficiency was present in 11/14 patients who had received TBI and 3/10 patients who had received high dose chemotherapy. In a study assessing the efficacy of testosterone replacement therapy (TRT) and sildenafil for ED in 8 men after HSCT, Chatterjee et al. (2002) found all except one patient had evidence of cavernosal arterial insufficiency, with all patients demonstrating favourable responses to combined TRT and sildenafil. Hypogonadism post HSCT has been well documented in the literature (Orio et al., 2014; Savani et al., 2011; Syrjala et al., 2012) and may contribute to both low sexual desire and ED (Li et al., 2015; Syrjala et al., 2012; Yi and Syrjala, 2009). Hypogonadism post-HSCT may be a consequence of TBI, chemotherapy, and also medications such as corticosteroids and opioids. For example, high doses of corticosteroids suppress endogenous hypothalamic and adrenal hormones (Yi and Syrjala, 2009).

While not formally diagnosed as having penile GVHD, one participant reportedly developed Peyronie's disease post HSCT. Peyronie's disease has been described as a potential manifestation of penile GVHD

(Grigg et al., 2002; Jain et al., 2015; Mueller et al., 2013). Penile GVHD has also been reported to cause scarring or adhesions in the penile vasculature, which may contribute to ED. Additional manifestations of penile GVHD include inflammation, rashes, lichen sclerosus type lesions, irritation and may cause associated discomfort and/or sexual dysfunction (Hamilton et al., 2017; Jain et al., 2015; Mueller et al., 2013). Penile GVHD remains infrequently reported and like vulvovaginal GVHD, is likely also underdiagnosed and undertreated (Mueller et al., 2013).

Given the small sample, correlations were not calculated, but we did observe for trends qualitatively where reasonable. We did not note any obvious distinctions between sexual health concerns and either type of transplant (autologous vs allogeneic) or time since transplant, though this may be due to small numbers of each type of transplant. Other authors have documented similar changes in sexual health in both allogeneic and autologous HSCT populations (Bevans et al., 2017; Li et al., 2015; Thygesen et al., 2012; Watson et al., 1999). The etiology of sexual health changes in post-HSCT recipients remains unclear as changes may be a consequence of pre-HSCT treatment regimens or high-dose chemotherapy, used in both allogeneic and autologous HSCT, or may be due to total body irradiation or GVHD, which are only relevant for the allogeneic population. Further studies aiming to distinguish the impact of these various factors on sexual function are necessary. Additional exploration of possible differential impact of these factors on sexual health more broadly, including impact on body image, sense of sexual self, and intimate relationships is also necessary.

Several participants who were many months post-transplant reported significant concerns with sexual health. In contrast one participant was only 2 months post-HSCT and reported very minimal sexual concerns. Many participants experiencing significant physical effects and complications related to HSCT also reported sexual concerns, while others experiencing only minimal physical symptoms still indicated significant issues with sexuality. One might expect patients with continued complications, such as those with GVHD, to report worse sexual function compared with patients who have no complications; however, this does not appear to always be the case.

It is imperative to consider the etiology of changes in sexual function. For example, the majority of women who undergo HSCT with an alkylating agent and/or total body irradiation (TBI) used as conditioning, will experience premature ovarian failure (Tirri et al., 2015; Li et al., 2015). If untreated, women may experience significant vulvovaginal changes that impact their sexual functioning, even in the absence of any active post-HSCT complications such as GVHD. On the other hand, patients who are being treated for active GVHD can experience direct genital involvement of GVHD that often profoundly impairs sexual function. Sexual function can also be impacted by side effects from the medications used to treat GVHD (Guida et al., 2016; Li et al., 2015; Wong et al., 2013). For instance, corticosteroids may cause weight gain and cushingoid characteristics, which may adversely affect body image (Li et al., 2015; Yi and Syrjala, 2009). Additionally, corticosteroids can affect endogenous hypothalamic and adrenal hormone production, with ensuing adverse effects on sexual function (Li et al., 2015). The impact of treatment and related complications on sexuality, therefore, remains very complex and individualized and as such, requires ongoing assessment throughout the disease and treatment trajectories, irrespective of type of transplant.

In addition to the physical changes encountered by participants, an array of psychosocial concerns was also reported. Both male and female participants in our study discussed the negative impact of changes in their physical appearance; several participants felt that changes in appearance directly affected their relationships and sexual activity. Male participants described similar dissatisfaction with body image as did female participants. Changes in sexuality posed a challenge for partnered and single participants alike, with both male and female participants citing the impact of changes in sexual function on their relationship or, if single, on the ability to become involved in new relationships. The impact of changed sexual function on the partner's well-being was frequently expressed in our study. Novel to this study was the finding that participants were apprehensive about participating in sexual activity due to concerns about being exposed to pathogens, with some even avoiding physical intimacy such as hugging or kissing. To the best of our knowledge, this has not been documented in the HSCT scientific literature, despite being a commonly reported concern in clinical settings.

Most participants in our study did not have concerns with fertility; several participants had already had children and one participant had banked sperm prior to starting treatment. The results of the FACT-BMT would suggest that most participants were not “concerned about their ability to have children” which might lead us to believe that fertility is not an issue for this study sample. However, while one participant indicated during the interview that he was not “concerned about having children”, he perceived the loss of fertility to have a significant impact on his sense of self and sexual identity. This finding is something that would not be captured by the low mean scores on the FACT-BMT fertility item. The participant that did respond on this item as highly concerned, reported that her inability to have children contributed to the breakdown of her marriage, indicating that the impact of loss of fertility can be profound.

Similar to other studies (Astarita et al., 2016; Bober et al., 2016; Flynn et al., 2011; Stead et al., 2001; Wendt, 2017), participants in our study reported both lack of education on changes in sexuality as well as lack of routine assessment of sexuality after HSCT. While the majority of participants indicated that they had not been routinely asked about sexual health concerns, all felt that it was both appropriate and desirable for healthcare providers to ask about such concerns. In fact, it has been demonstrated that when queried, patients will respond to sensitively asked questions about sexuality at nearly the same rate as questions about other health-related quality of life topics (Syrjala, 2008). As sexual health concerns can arise at any point along the disease and treatment trajectory (Flynn et al., 2011), early and revisited discussion should be part of routine care. Prior to HSCT, patients and partners should be provided with information and education on potential alterations in sexual health that may arise after HSCT (Tierney et al., 2015).

5. Strengths

While the impact of HSCT on sexuality has been previously reported by others, this is the first study that we are aware of to use a mixed methods approach. An advantage to using such a design is that qualitative data provide an enriched context for interpretation of quantitative findings. Furthermore, the quantitative findings can be used to help describe characteristics and functioning of the study sample in a meaningful way that can allow comparison to other samples.

In contrast to other qualitative studies on sexuality post-HSCT (Astarita et al., 2016; Norskov et al., 2015), this study includes participants who underwent both allogeneic and autologous transplant, rather than just allogeneic (Norskov et al., 2015) and extends the exploration beyond one year (Norskov et al., 2015) to a range of 0.25–5.75 years post-transplant. The study includes participants of both male and female genders, in contrast to focusing only on females (Astarita et al., 2016). In fact, this sample had more male than female participants. Other authors have indicated that women tend to report sexual concerns more than men (Humphreys et al., 2007; Watson et al., 1999; Yi and Syrjala, 2009), however, this study demonstrates the profound impact that sexual changes after HSCT have on men's lives. This study also integrated questions about changes in sexuality with exploration of how health care providers might better prepare patients for these changes.

6. Limitations

The goal of descriptive qualitative studies is to gain insight into a particular phenomenon or specific experience rather than to generalize the results of the study to a broader population (Onwuegbuzie and Leech, 2007). However, there are some limitations to the diversity of this particular sample and therefore it is not fully representative of the broader demographics of this patient population. In addition, very few women participated in this study and we notably, had an absence of younger women altogether. We found this surprising, particularly given the evidence that sexual issues are both common and distressing for young women after a cancer diagnosis (Burwell et al., 2006; Dizon et al., 2014; Stabile et al., 2017). Therefore, the lack of diversity of the sample may have impacted our findings, such that issues unique to young women (e.g. childbearing, formation of sexual identity) may be missing from this report.

It is difficult to say with certainty that we achieved saturation. The notion of data saturation in qualitative studies has been questioned and even disputed within the literature, with some arguing that the very idea of exploring individual perspectives on any particular phenomenon precludes the possibility of true saturation (Bradshaw et al., 2017). However, we do not intend that these results be generalizable but rather hope that the study compels readers to further contemplate the potential adverse effects of HSCT on sexuality.

The cross-sectional design also limits the scope of characterization of sexual difficulties to one point in time. An individual's sexuality is influenced by numerous factors throughout disease and treatment trajectories and concerns with sexuality may improve or worsen over time. However, many survivors demonstrate significant sexual concerns persisting beyond 5 years after HSCT (Syrjala et al., 2008). The cross-sectional design of this study also precludes a pre-transplant assessment of sexual health concerns. While it is possible that participants' concerns predated HSCT (Liptrott et al., 2011; Yi and Syrjala, 2009), a number of participants articulated changed sexual function only after HSCT, and the way in which their sexuality had changed after treatment. An additional limitation is that individuals self-selected to participate in the study and thus, it is difficult to know if the experience of those who chose to participate would be similar or different from that of individuals who chose not to participate. Finally, while the interview questions were quite generic to sexuality and sexual health, the adaptation of the interview guide from the palliative care setting to the HSCT setting may represent another potential limitation.

7. Future research

Participants in this study reported both physiological and psychosocial changes that affected their sexuality after HSCT. There is a paucity of literature regarding strategies to manage such changes after HSCT. Extrapolating from studies that have looked at management of sexuality after treatment for other types of cancer, a biopsychosocial approach to care is advocated (Katz and Dizon, 2016; Kingsberg et al., 2017; Walker et al., 2015) where interventions are intended to deal not only with physical aspects of sexual function but also psychological and relational aspects as well.

More research is needed to better understand the etiology of changes in sexual function post-HSCT. For women, better understanding of the etiology of vulvovaginal changes post-HSCT is necessary, in particular comparing and contrasting the impact of GVHD and hypoestrogenism on sexual function. Distinguishing between the two entities is critical as the treatment approach differs for each. Similarly, better understanding of the causal mechanisms of ED post-HSCT is essential. Improved understanding of these mechanisms should allow for more effective interventions. In addition to the need for studies on the efficacy of medical interventions, the impact of psychoeducational interventions should also be assessed. Researchers should endeavor to include more single participants as well as participants with more diverse sexual orientations, and those from a variety of cultural backgrounds. Partners should be included, if available, in order to better ascertain their perspectives and subsequent needs.

8. Conclusion

Changes in sexuality are prevalent after HSCT and include not only physical but also psychosocial aspects of sexual health, underscoring the importance of a multidisciplinary, biopsychosocial approach to care. Considering the multi-factorial nature of sexual changes, comprehensive assessment is imperative in order to select appropriate intervention. Pelvic health should not be overlooked in the context of HSCT, in particular in individuals who are experiencing GVHD symptoms. Changes in sexuality may arise at any point along the disease and/or treatment trajectory, with patients continuing to experience sexual difficulties many years after transplant. Education regarding the nature of sexual changes should be provided pre-emptively and assessment of sexual concerns should be undertaken early and revisited frequently throughout the course of treatment and survivorship.

Note: Participant data are presented in order of the chronology of when the interviews were conducted.

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Appendix

Open-ended question

1. What does sexuality mean to you?

Prompts

1. How important is your sexuality to you?
   a. Was it important to you before becoming ill?
   b. Is it important to you now?
2. How do you express your sexuality?
   a. How did you express your sexuality before becoming ill?
   b. How do you express your sexuality now?
3. Has your sexuality changed since becoming ill?
   a. How has it changed?
   b. When did it change?
   c. Have you been able to talk about it?
   d. If yes, with whom?
   e. If no, why not?
4. Are you interested in expressing your sexuality at the present time?
5. If you have partner, what affect, if any, has your illness had on your partner's sexuality?

Semi-structured questions and probes

1. Do you currently have a partner?
2. Are the following barriers to your sexuality?
   a. Not being interested in sex
   b. Not being able to get aroused
   c. Not being physically able to participate
   d. Difficulty with vaginal dryness
   e. Painful intercourse
   f. Difficulty with erectile function
   g. Not feeling desirable
   h. Fear of harming oneself during sexual activity
   i. Fear of passing on chemotherapy, radiation, infection or cancer
   j. Changes in or loss of fertility
3. If in a relationship at this time, have the changes in your sexuality

affected your relationship? If yes, in what way?

4. If not in a relationship at this time, have the changes in your sexuality affected your ability to start a new relationship? If yes, in what way?
5. We would like to ask you a few questions about your experiences with health professionals. The term 'health professional' refers to your family physician, hematologist or transplant physician, nurse practitioner, nurses, occupational/physiotherapists, social workers, pharmacists, psychologists, chaplains and other specialists. Have you ever brought up the subject of sexuality with a health professional? If yes, with whom?
6. Has any health professional ever asked you about your sexuality since you were diagnosed with your current illness?
   a. If yes, who asked you?
   b. When were you asked?
7. Is it appropriate (at any time) for health professionals to ask about your sexuality?
8. When would be the best time for health professionals to ask about your sexuality?
   a. At the time of diagnosis
   b. After the initial workup has been done
   c. During treatment
   d. After treatment has been completed
9. Is there a time when it would not be appropriate for health professionals to ask you about your sexuality?
10. Is it easy for you to talk about sexuality?
    a. If no, why is it not easy?
11. How could health professionals make it easier for you to talk about sexuality?
12. Has this interview process been helpful at all?
    a. If yes, in what way
13. Is there anything you would like to add about your experience?
14. May we meet again if any responses need to be clarified?

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