

2019-07-19

The Experiences of Individuals Re-engaging in Sexual Relationships Following a Bone Marrow Transplant

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Shartau, K. (2019). The Experiences of Individuals Re-engaging in Sexual Relationships Following a Bone Marrow Transplant (Master's thesis, University of Calgary, Calgary, Canada). Retrieved from <https://prism.ucalgary.ca>.

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The Experiences of Individuals Re-engaging in Sexual Relationships Following a Bone
Marrow Transplant

by

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A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES
IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE
DEGREE OF MASTER OF NURSING

GRADUATE PROGRAM IN NURSING

CALGARY, ALBERTA

JULY, 2019

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Abstract

More than 50,000 individuals worldwide receive a bone marrow transplant annually, and this incidence is increasing. Sexual function is a common long-term concern after a bone marrow transplant (BMT). Studies have demonstrated though important to patients, healthcare providers are often remiss in addressing these concerns. Thus, Straussian Grounded Theory was used to seek a deeper understanding of the process BMT patients undergo to reintegrate their sexual relationships following a bone marrow transplant. Qualitative themes that emerged included: identifying importance, taking responsibility, seeking resources, and navigating the partnered-relationship. Gender permeated each of these themes. These events occurred in a non-linear process of seeking a new normal and could apply at any time point during the treatment trajectory. The core category of 'seeking a new normal' refers to the process participants will go through while searching for 'normalization' and trying to get back to the condition they were in before diagnosis. Gaining an understanding of the process patients go through when integrating back into their sexual lives post-transplant will facilitate awareness about the impact a transplant can have on a patient's sexual health.

Keywords: sexual health, bone marrow transplant, qualitative research, grounded theory

Acknowledgements

I would first like to thank Kathryn King-Shier. My sincere and heartfelt gratitude and appreciation to a wonderful supervisor for providing me with the guidance and support I needed to succeed. Thank you for being such a fantastic and encouraging supervisor. I would also like to express my deepest gratitude to committee members Shelley Raffin-Bouchal and Reanne Booker for sharing their time and expertise.

Dedication

This study is dedicated to my parents and fiancé who have continually provided moral, emotional, and financial support. Thank you for always being there for me!

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List of Abbreviations

| | |
|-------|---|
| BMT | Bone marrow transplant |
| FYNN | Finding Your New Normal |
| GVHD | Graft-versus-host disease |
| HCP | Healthcare provider |
| HSCT | Hematopoietic stem cell transplantation |
| OASIS | Oncology and Sexuality, Intimacy and Survivorship Program |
| SGT | Straussian Grounded Theory |
| TBCC | Tom Baker Cancer Centre |
| TBI | Total body irradiation |

Chapter 1. Introduction

Sexual health is an important aspect of overall well-being; one often overlooked within the oncology population. According to the World Health Organization (2002), sexual health is a state of physical, emotional, mental and social well-being related to one's sexuality. Sexual health is a central aspect of a human being and is influenced by facets such as age, gender roles, sexual orientation, intimacy, and reproduction (World Health Organization, 2002). For this study, sexuality and sexual relationships are identified as aspects of sexual health. Researchers have suggested that healthcare providers (HCPs) consider sexual health is a low priority issue at cancer diagnosis and during treatment (Kotronoulas, Papadopoulou, & Patiraki, 2008).

Holistic care is the practice of treating the person as a whole and including a “mind-body-spirit-emotion-environment” approach (Klebanoff & Hess, 2013, p.1). It is important to incorporate a holistic approach into care, but it seems that in specialized areas such as oncology, aspects of holistic care, such as sexual health, can be overlooked. The lack of focus on sexual health has raised concerns regarding gaps in care that need further exploration to improve nursing care and patient outcomes.

Significance

A hematopoietic stem cell transplant (HSCT), or bone marrow transplant (BMT), is an intensive therapy for life-threatening hematological diseases with the aim to cure (Gruber, Fegg, Buchmann, Kolb, & Hiddemann, 2003). Today, more than 50,000 individuals worldwide are transplanted annually, and this incidence is increasing (Ha, n.d.). Within the last decade, medical advances have increased access for patients having transplants, reduced drug toxicity rates, and increased survival rates

(Noerskov, Schjødt, Syrjala, & Jarden, 2016). There is more hope for surviving a transplant, however, it is still associated with significant morbidity and mortality (Lee et al., 2001; Savani, Griffith, Jagasia, & Lee, 2011). As survival rates for transplants have improved in the past two decades, attention to long-term complications has not kept up (Humphreys, Tallman, Altmaier, & Barnette, 2007; Lee, 2011; Tierney, Palesh, & Johnston, 2015; Yi & Syrjala, 2009). Transplant survivors are experiencing increased comorbidities and long-term side effects that are affecting their quality of life (Dyer et al., 2015; Lee, 2011). One of the most common long-term concerns after a BMT is sexual dysfunction and sexually-related health concerns; nearly one-half of patients experience impaired sexual function post-transplant (Lee et al., 2001; Thygesen, Schjødt, & Jarden, 2012; Yi & Syrjala, 2009).

Satisfactory sexual health contributes greatly to the quality of a cancer patient's life (Krouwel et al., 2015). Many nurses deem sexual health an important issue to address, yet it remains a low priority issue and is frequently not addressed in daily practice (Hautamäki, Miettinen, Kellokumpu-Lehtinen, Aalto, & Lehto, 2007; Krouwel et al., 2015; Leonardi-Warren et al., 2016). Sexual health is not often included in the care plan despite nurses proclaiming to treat the 'whole person' (Odey, 2009). Sexual health can easily be overlooked as a key component of a holistic approach to care as it may not be considered with the same priority as treating cancer (Mercadante, Vitrano, & Catania, 2010). The majority of cancer patients report sexual health issues as a concern and are willing to discuss them with their health professionals (Kotronoulas et al., 2008). Despite wanting to talk about their concerns, patients often remain silent, and thus, this conversation rarely happens, leaving patients feeling dissatisfied

(Krouwel et al., 2015). Consequently, concerns regarding patients' sexual health are not to the quality standard they should be, which negatively impacts patients' quality of life (Hautamäki-Lamminen, Lipiäinen, Beaver, Lehto, & Kellokumpu-Lehtinen, 2013).

Chapter 2. Literature Review

Cancer is a category of diseases characterized by cells that divide uncontrollably; there are over 100 different varieties of cancer, each classified by the type of cell that is initially affected (World Health Organization, 2017). Cancer is one of the leading causes of morbidity and mortality worldwide, with approximately 14 million new cases in 2012 (World Health Organization, 2017). The number of new cases is expected to rise by approximately 40% over the next 15 years; this rise is mainly due to a growing aging population (Canadian Cancer Society, 2015). Current available estimates suggest one in two Canadians (49% of men and 45% of women) is expected to develop cancer in their lifetime and one in four Canadians (28% of men and 24% of women) is expected to die from cancer (Canadian Cancer Society, 2017).

Hematological (or blood-borne) cancers are the fourth most frequently diagnosed cancer in Canada, and the number of Canadians living with, or in remission from blood cancer has increased by 25% from 2014 to 2016 (The Leukemia & Lymphoma Society of Canada, 2016). These cancers can be categorized into leukemia, lymphoma, myeloma, and other less common blood-related diseases, such as myelodysplastic syndromes and myeloproliferative neoplasms (The Leukemia & Lymphoma Society of Canada, 2016). They involve blood cells, bone marrow, lymph nodes, and other parts of the lymphatic system (The Leukemia & Lymphoma Society of Canada, 2016). An estimated 138,100 people in Canada are currently living with, or are in remission from hematological cancer (The Leukemia & Lymphoma Society of Canada, 2016).

A BMT is an intensive therapy that aims to cure life-threatening hematological diseases (Gruber et al., 2003). Before the BMT, a patient receives high doses of chemotherapy, frequently in combination with total body irradiation (TBI) (Lee et al., 2001; Wendt, 2017). There are two main types of transplants: autologous, which uses the patients' stem cells; and allogeneic, which uses stem cells from a donor. The individual's disease will determine whether they require an autologous or allogeneic transplant (Lee et al., 2001; Wendt, 2017). Autologous transplants are thought to be less dangerous but are associated with a greater risk of relapse than allogeneic transplants (Lee et al., 2001). Allogeneic transplants place the patient at greater risk of complications due to the risk of graft-versus-host disease (GVHD) and complications of long-term immunosuppressants used for prevention and treatment of transplant rejection (Johns, 1988; Lee et al., 2001). GVHD is characterized by donor cells identifying the patient's cells as foreign and consequently attacking the patient's cells (Johns, 1988).

With medical advances, there is more hope for surviving a bone marrow transplant, however, it is still associated with significant morbidity and mortality (Lee et al., 2001; Savani et al., 2011). As survival rates for BMT have improved in the past two decades, attention to long-term sequelae and complications is important (Humphreys, Tallman, Altmaier, & Barnette, 2007; Lee, 2011; Tierney, Palesh, & Johnston, 2015; Yi & Syrjala, 2009). BMT survivors are experiencing increased comorbidities and long-term side effects that are affecting their quality of life (Dyer et al., 2015; Lee, 2011).

A common long-term concern after a BMT is sexual dysfunction and sexually-related health concerns; nearly one-half of patients experience impaired sexual function post-transplant (Lee et al., 2001; Thygesen, Schjødt, & Jarden, 2012; Yi & Syrjala, 2009). Sexual health is defined by the World Health Organization (2002) as a fundamental aspect of well-being that includes physical, emotional, mental, and social well-being about sexuality. Sexuality forms a crucial part of one's identity; the most common sexual identities being 'male' or 'female' (Muir, 2000). Expressing one's self and experiencing intimacy and love is a basic human need and may also be associated with the physical act of sexual intercourse (Muir, 2000). Sexuality is not often included in the care plan despite nurses proclaiming to treat the 'whole person' (Odey, 2009). The practice of treating the person as a whole is referred to as holistic care and includes a "mind-body-spirit-emotion-environment" approach (Klebanoff & Hess, 2013, p.1).

Satisfactory sexual health contributes greatly to the quality of a cancer patient's life (Krouwel et al., 2015). Many nurses deem sexual health an important issue to address, yet it remains a low priority issue and is frequently not addressed in daily practice (Hautamäki, Miettinen, Kellokumpu-Lehtinen, Aalto, & Lehto, 2007; Krouwel et al., 2015; Leonardi-Warren et al., 2016). Since sexual health may not be considered a healthcare concern relative to treating cancer, it can be easily overlooked as a key component of a holistic care approach (Mercadante et al., 2010). The majority of cancer patients report sexual health issues as a concern and are willing to discuss them with their health professionals (Kotronoulas et al., 2008). Despite wanting to talk about their concerns, patients often remain silent, and thus, this conversation rarely happens leaving them feeling dissatisfied (Krouwel et al., 2015). Consequently, concerns regarding

patients' sexual health are not adequately addressed, which negatively impacts patients' quality of life (Hautamäki-Lamminen et al., 2013).

There is abundant literature addressing the sexual health needs of oncology patients, but there is less research focused on the sexual health experiences of those who have received a BMT. Transplant recipients can suffer different side effects than other oncological diagnoses depending on treatment including chemotherapy, hormonal treatments, TBI, and medications for chronic GVHD (Krouwel et al., 2015; Lee et al., 2001; Tierney, 2008; Yi & Syrjala, 2009). The goal of conducting this literature review is to report the state of knowledge related to the bone marrow transplant population's experiences of their sexual health since their BMT. This integrative review was guided by the following question: What are the experiences of individuals re-engaging in sexual relationships following a BMT?

Synthesis and Analysis

Undertaking an integrative review and synthesis of the literature enabled themes to emerge. The themes that emerged from this review were the psychosocial, social, and physiologic factors that have impacted the sexual health of individuals post- BMT.

Psychosocial factors.

Psychological distress in cancer patients encompasses anxiety, anger, depression, fear of reoccurrence, decreased self-confidence, lack of self-esteem, and negative body image (Astarita, Caruso, Barron, & Rissmiller, 2016; Lee, 2011; Muir, 2000; Noerskov et al., 2016; Yi & Syrjala, 2009). Multiple authors have found psychological distress correlated with poor sexual satisfaction, decreased sexual relationships, and diminished quality of life (Astarita et al., 2016; Lee, 2011; Muir, 2000; Noerskov et al., 2016;

Tierney, 2008). A key component of psychological distress is an altered body image, which may affect feelings about the self as a sexual being (Noerskov et al., 2016; Tierney, 2008). The impact body image can have on sexual health is evident in a patient's statement explaining "I do not feel as a woman anymore: my body has changed, I feel unattractive, and I have no sexual desire" (Poloméni, Lapusan, Bompont, Rubio, & Mohty, 2016, p. 253). In addition to having a poor body image, some individuals may experience a decrease in their sense of masculinity or femininity due to infertility, leading to self-esteem issues (Li et al., 2015; Tierney, 2008). Changes in body image perception and self-esteem are associated with the occurrence of depression and anxiety following a BMT; together these can alter sexual desire, arousal, and orgasm phases of the sexual response cycle (Auchincloss, 1991; Li et al., 2015; Muir, 2000). An association between reduced sexual activity and poor emotional function following a BMT has also been observed (Astarita et al., 2016; Watson et al., 1999; Yi & Syrjala, 2009). As enhanced sexual health is shown to reduce emotional stress and improve psychosocial outcomes post-treatment, achieving a well-functioning sex life is significant for patient outcomes (Noerskov et al., 2016; Tierney, 2008; Yi & Syrjala, 2009).

Social factors.

Sexuality can have a negative effect on an individual's social well-being; of which the social relationship with the intimate partner is most directly affected (Astarita et al., 2016; Poloméni et al., 2016; Tierney, 2008). For single individuals, it can be hard to explain the effects of chemotherapy treatment, GVHD affecting the genitals, and decreased sexual responsiveness to potential intimate partners (Yi & Syrjala, 2009). Even for individuals in established relationships, life can be negatively impacted post-

transplant due to patients' sexual health concerns (Poloméni et al., 2016). Numerous factors may contribute to sexual dissatisfaction and hinder couples from re-establishing intimacy and their sexual activity (Lee, 2011; Tierney, 2008). Some of the factors that influence a patient's relationships and their social well-being include: poor communication about what has changed, expressing what feels good and what does not, appearance insecurities, fear of failing to become aroused, feelings of closeness, and role shifting during treatment and recovery (Lee, 2011; Tierney, 2008). Having a BMT can alter the relationship dynamic between couples, and these relationship problems will not be solved on their own and often require conversation and problem solving from the couple (Yi & Syrjala, 2009). Researchers have identified that patients may attach great importance in being able to talk with their partners about their sexual needs and new changes so they can both have a mutual understanding of sexual desires (Flynn et al., 2011; Noerskov et al., 2016). Therefore, it is imperative to assess sexual health from this social aspect as individuals may withdraw further from sexual attempts and intimacy if they have problems discussing this sensitive subject with their intimate partner (Auchincloss, 1991).

Physiologic factors.

BMT patients may experience physiologic limitations affecting their sexual health and the energy to be sexually active (Lee, 2011; Noerskov et al., 2016). Diverse physical changes can affect an individual's body image and their sense of being sexually attractive following a BMT (Yi & Syrjala, 2009). Physical symptoms from BMT treatments include limited strength and stamina, fatigue, infertility, GVHD, vaginal alterations, and erectile dysfunction (Tierney, 2008; Whedon, Stearns, & Mills, 1995).

Approximately one-half of BMT patients report fatigue as their major physical concern (Noerskov et al., 2016; Whedon et al., 1995). One study participant's partner identified "we are a couple, but our sexual life is very poor: he has erection difficulties and he is discouraged by his fatigue" (Poloméni et al., 2016, p. 253). Feeling energetic is important for sex to be part of routine life, if not, thoughts of sex and fantasies may be ignored, as found in the study by Noerskov et al. (2015) where patients reported more interest in sexual activity once fatigue subsided. Following treatment, patients' needs shift from a sense of survival to a reprioritization where sexuality becomes more important (Noerskov et al., 2016; Yi & Syrjala, 2009).

More than half of allogeneic transplant survivors experience physical symptoms related to chronic GVHD affecting their sexual health and increasing sexual dissatisfaction (Noerskov et al., 2016; Thygesen, Schjødt, & Jarden, 2012). GVHD can develop anywhere in the body, however, in the genitals, it can lead to vaginal stenosis, dryness, scar tissue, rash, and loss of libido (Lee, 2011; Li et al., 2015; Thygesen et al., 2012). High-dose corticosteroids used to treat GVHD may cause changes in physical appearance affecting sexuality and body image (Lee, 2011; Noerskov et al., 2016; Thygesen et al., 2012). Consequently, it is important for HCP's to understand how physical changes can affect a patient's body image and sexual health post-transplant. Addressing physiologic concerns is essential in helping to restore intimacy and sexual health in BMT survivors to improve their quality of life and health outcomes (Poloméni et al., 2016).

The sex of the BMT survivor is another important factor in the experience of sexual health (Lee, 2011; Molassiotis, 1997; Yi & Syrjala, 2009). Females typically

report symptoms of vaginal dryness, painful intercourse, difficulty achieving orgasms, and lack of attractiveness as reasons for sexual inactivity and dysfunction (Lee, 2011; Yi & Syrjala, 2009). Males commonly report premature ejaculation, difficulty obtaining and maintaining an erection, and a lack of sexual interest as sexual health concerns (Yi & Syrjala, 2009). In general, females focus on body image and want to experience relationships and emotional intimacy, whereas males often seem to focus on physical attraction and physical performance (Wendt, 2017). Furthermore, longitudinal studies following BMT survivors reveal that both sexes experience an increase in sexual health concerns from baseline to one-year post-transplant with females typically experiencing more sexual health concerns than males (Humphreys et al., 2007; Lee, 2011; Noerskov et al., 2016).

Researchers have also found that women often report more sexual health concerns than men; it is possible men may have more sexual health concerns which are underreported (Frank, Anderson, & Rubinstein, 1978; Humphreys et al., 2007; Noerskov et al., 2016). It is important for healthcare professionals to understand that women may be more likely to report sexual health concerns than men, and there are sex/gender differences in how a patient re-engages in sexual relationships post-transplant.

Limitations in the Current Literature

There is a lack of literature regarding sexual health which adequately answers the proposed research question describing the experiences of individuals re-engaging in sexual relationships following a BMT. At the time the study was conceived there were two qualitative articles found that focused on the patients' experiences of sexual health following a BMT; both were undertaken using phenomenology, one only focused on the

allogeneic population, and the other was focused only on women (Astarita et al., 2016; Nørskov, Schmidt, & Jarden, 2015). Additionally, many of the studies found in this literature review focus on patients at one-year or greater post-transplant; this limits the capacity of HCP's to have insight into the concerns of early survivors.

Future Directions

This integrative literature review reveals that BMT patients will encounter many psychosocial, social, and physiologic issues that will affect their experiences in how they re-engage in sexual relationships. Yet, very few researchers have approached this important recovery issue from a patient's or from a qualitative perspective; most work done to date has been quantitative. Thus, additional qualitative studies describing patients' personal experiences of re-engaging in sexual relationships post-transplant are needed. By conducting qualitative research, the hope is to gain a better understanding of who along the way, socially and clinically, is helpful in addressing patients' sexual health needs. Additionally, including both sexes, as well as allogeneic and autologous transplant patients, would be important as each of these groups experience different sexual health concerns, which impact how they re-engage in sexual relationships.

The timing of sexual health conversations can be crucial to validate the legitimacy of sexual health and functioning and to help set the stage for further conversations (Tierney, 2008). Sexual problems in survivors may have an acute onset and can occur immediately after treatments or during the recovery process (Andersen, 1990). Authors have found, especially in women, if sexual function had not returned by one year, the effects were likely to persist for several years (Syrjala et al., 1998; Yi & Syrjala, 2009). Thus, studies assessing baseline sexual function and again within a year's time would be

a recommendation and essential element to providing treatment and psychological support for those suffering from sexual health concerns (Syrjala et al., 1998).

Summary

Sexually-related health concerns are one of the most common problems post-BMT; nearly one-half of all survivors will experience sexual health problems. (Humphreys et al., 2007; Lee, 2011; Lee et al., 2001; Thygesen et al., 2012; Yi & Syrjala, 2009). Patients who undergo a BMT may suffer many psychosocial, social, and physiologic concerns affecting their sexual health, adversely influencing their quality of life if not addressed early and thoroughly (Humphreys et al., 2007; Tierney, 2008). Despite the common occurrence of sexual health issues, multiple authors have identified that at least half of patients indicated their healthcare professional failed to discuss the effects of BMT on sexual health (Milroy & Jones, 2010; Wendt, 2017). Discussions with a HCP can significantly reduce sexual health concerns (Humphreys et al., 2007). To understand patients' experiences of re-engaging in sexual relationships post-transplant further qualitative research is needed. Ultimately, increased awareness and understanding of the sexual health needs of patients are required to improve quality of life outcomes and manage or help alleviate sexual health concerns in BMT survivors.

Chapter 3. Methods

Purpose of the Study

There is little research focused on the sexual health experiences of those who have received a BMT. Transplant recipients can suffer different treatment side effects than other oncology patients depending on treatment (Krouwel et al., 2015; Lee et al., 2001; Tierney, 2008; Yi & Syrjala, 2009). The purpose of conducting this research was to gain a better understanding of facilitators to addressing patients' sexual health needs. The aim was to understand patients' experiences post-transplant and to increase awareness of their sexual health concerns and whom along the way, socially and clinically, were helpful in addressing their sexual health needs. The hope was to understand *when* patients want to talk about their sexual health concerns, *what* they want to talk about, and the *process* patients undergo to reintegrate into their sexual relationships following a BMT. This study was guided by the following question: What are the experiences of individuals re-engaging in sexual relationships following a BMT?

Researcher's Perspective

I come to this research based on my experiences in the oncology setting (i.e., as a Registered Nurse working on a hematology, oncology, and bone marrow transplant unit). In that role, I have seen that sexual health assessments are often not included, or rarely addressed, in the admitting process or throughout patients stay in the hospital. As nurses are usually the front line workers who spend the majority of their time with patients, it is important to acknowledge issues and take action to make a change. My nursing philosophy is characterized by providing holistic and individualized care to every patient. Nursing is more than treating an illness and should focus on delivering quality of care,

which is individualized to each patient. I believe it is important to incorporate a holistic approach to patient care, but it seems that in specialized areas, such as oncology, various aspects such as sexuality can be overlooked.

Research Design

Grounded theory methods, based on Strauss and Corbin, guided this study. The focus of Straussian Grounded Theory (SGT) is recognizing and narrating the meaning and understanding of human experiences and actions (Corbin & Strauss, 2015).

The Straussian paradigm asserts a relativist ontology and subjectivist epistemology that reality is a subjective experience that can have multiple interpretations and there is no 'one truth' (Levers, 2013). Strauss and Corbin (1994) embrace pragmatism and symbolic interactionism and believe individuals react to situations through interpretation of meaning. People interpret social situations and derive meaning from experiences that can affect their behavior, and meaning is attached to the experience of the situation rather than intrinsic to any object, circumstance, or person (Blumer, 1969). Examples of this concept are found amongst the many facets of sexual health including age, gender roles, and sexual orientation, whereby human perception and social influences are influenced by these facets (Mercadante et al., 2010).

Sampling Strategy

A convenience sampling strategy was first used. Flyers were placed in strategic places in the Tom Baker Cancer Centre inviting potential participants to volunteer for the study. Potential participants were also approached at the Tom Baker Cancer Centre (TBCC) and the Holy Cross Centre. Given that there were more men volunteering to participate, selective approaches were used to garner more women for the study. Thus,

there was a combined convenience and theoretical sampling approach. The inclusion criteria were: adult (18+) who had undergone a BMT (allogeneic or autologous); able to read and speak English sufficiently to understand the information and to participate in the interview; and in a relationship (as defined by the individual as they need to have a partner with which to engage in a sexual relationship; e.g. dating, married, cohabitating). The exclusion criterion was that patients must not have had a cognitive deficit or psychiatric diagnosis that could limit their capacity to provide informed consent or engage in an interview of this nature. Participants were recruited until theoretical saturation occurred; this was the realization that recruitment could conclude as no new data were found, and new data were no longer contributing to the ability to build the emerging theory.

Participant Recruitment

Participants were recruited between October, 2018 and April, 2019. After receiving management approval at the TBCC BMT clinic and ethics approval from the Health Research Ethics Board of Alberta, flyers (Appendix A) were placed in strategic positions at the TBCC. The flyer contained a telephone number and email to which potential participants could respond to learn more about the study. An in-service was also held at the TBCC BMT clinic to inform clinic nurses about the study and participant recruitment details. The researcher attended the BMT clinic 2-3 days per week to recruit participants. On the other days, clinic nurses screened patients who fit the inclusion criteria and provided them with a recruitment flyer. Three participants provided their contact information at the time of recruitment; the others responded at a later time by

email or telephone. All interested participants were contacted (by phone or email) and a time arranged to obtain informed consent (Appendix B) and conduct the interview.

Data Collection and Analysis

Once the purpose of the study and what would be required of the participant was explained, informed consent was obtained. Thereafter, demographic data (Appendix C) were collected from each participant. These data enabled characterization of the study sample. Once all of the participants had been interviewed, the demographic data were entered into IBM SPSS Statistics 23 and analyzed using descriptive parametric (e.g., mean, standard deviation) and non-parametric (e.g., percentage) statistics as appropriate. Qualitative data collection and analysis occurred concurrently. For clarity however, they will be explained separately. The main method of data collection was through semi-structured interviews. Interviews were undertaken at a place that was quiet and where the participant felt comfortable. Most interviews (8/10) were undertaken by telephone and two were in person at the TBCC. The interviews lasted approximately 30-60 minutes, and all were audio-recorded. Field notes were also taken to document the researcher's observations, thoughts, and ideas. The beginning interview questions were generated based on literature and my personal experience working with the BMT population; all questions were reviewed and approved by the committee members (Appendix D).

Audio-recorded interviews and field notes were transcribed by a professional transcriptionist who signed a confidentiality agreement. The transcriptions were typed in as a WordTM document.

Analysis of the data begin almost immediately as they were collected and was undertaken using constant comparative methods (Corbin & Strauss, 1990). Constant

comparative analysis involves continuous comparisons between the data, and emerging codes and categories for the purpose of developing a greater understanding (Corbin & Strauss, 1990). Subsequent interviews were undertaken keeping the evolving concepts and themes in mind. This enabled clarification of the emerging analysis.

Data analysis was undertaken using open coding, axial coding, and selective coding. After the audio-recorded interviews were transcribed, open coding, which included a line by line assessment of what has been said was undertaken (Corbin & Strauss, 2015). Labels or codes were then given to the sections of text (transcript) that represented common concepts; one piece of data may have had numerous codes, and as many codes as possible were identified.

Memoing (note-taking) was utilized to record and keep track of ideas and thoughts about the codes, category development, and questions that developed from the analytic process (Corbin & Strauss, 1990). Memos were integrated into the analysis by helping the researcher navigate unanswered questions, allowing for reflection of what was going on, and helping piece together connections between the emerging data.

Axial coding was undertaken next, which pieced data together in new ways and helped link a category with its emerging sub-categories (Corbin & Strauss, 2015). The main goal of axial coding is to be continually asking questions and making comparisons, by using an inductive and deductive approach of relating subcategories (Corbin & Strauss, 2015). Categories were inductively generated from the data, and a network of attributes were developed around them (Böhm, 2004). At this step, statements within the data were coded and assigned categories. These codes/categories were then compared with other statements in the same and different categories within the data. Memoing was

utilized in this process to organize the possible linkages of these categories and portray background of the emerging theory.

Selective coding was then used to identify one category to be the core category, and related all other categories to that category, validated the relationships and categories, and filled in categories that need further improvement (Corbin & Strauss, 2015). At this stage, categories were integrated with a higher level of abstraction, and as the inter-relationships became more dense and apparent, one dominant core category was selected (Corbin & Strauss, 2015). An example of the coding process is illustrated in Appendix E.

Though SGT advocates for the incorporation of an eight-level conditional matrix to integrate coding, we concentrated on the smaller-scale elements in the interviews and analysis: ‘action pertaining to the phenomenon,’ ‘interaction,’ and ‘group, individual, and collective’ elements.

Rigor

As a researcher I took responsibility to ensure my research promotes rigor and credibility (Corbin & Strauss, 2015). Credibility is imperative in a qualitative study such as grounded theory and many measures were undertaken to promote rigor and credibility throughout the study process. Credibility refers to how accurate the description of the phenomenon and is associated with the researcher’s ability to engage with the participants and allow them to genuinely share their experiences. All study participants were engaged and were willing to share their thoughts and experiences of how their bone marrow transplant has affected their sexual health. Credibility of the process and findings was enhanced by engaging in theoretical sampling, and ensuring data accuracy. Routine team meetings were held throughout the process to discuss the ongoing analysis and

reflect on memos; this helped to ensure theoretical sensitivity. Theoretical sensitivity is the ability of the researcher to generate concepts from the data and relate them to the abstract and is a method of guarding against biases appearing in the results of the study (Corbin & Strauss, 1990). Discussions of reliability and potential bias were resolved through dialogue during team meetings. Communication with peers assisted the researcher in being open to new ideas and remaining grounded in the data.

The use of memos and coding provides a pathway for other researchers to understand the thought process for category and theory development and adds to the credibility of the grounded theory study (Corbin & Strauss, 2015). As there were more men volunteering to participate in the study, theoretical sampling was used to help contribute to a group of participants who were theoretically representative of the population who had undergone a bone marrow transplant and to help obtain a fair representation of both genders. Data accuracy was maintained by thoroughly studying the transcriptions of interviews (Corbin & Strauss, 2015). Rich descriptions of the experiences of individuals re-engaging in sexual relationships following a BMT enhanced the transferability of the study; meaning the findings have meaning to other individuals in similar situations (Cooney, 2009).

Ethical Considerations

This study was approved by the Health Research Ethics Board of Alberta. Sexual health is a particularly sensitive topic that needed to be highly respected. All participants were kept anonymous (i.e., any transcripts shared with committee members had the participant names and identifiers removed; data were kept secure). All individuals have the right to self-determination, full disclosure, and privacy. Thus, a pamphlet which

explained the purpose and background of the study and the participant's roles, as well as any risks such as potentially sensitive or upsetting questions, was distributed to each participant. Counseling and psychosocial contact information was available to patients in need. The consent form explained how the final results will be stored and used, and clarified how to contact the researcher should concerns arise. As indicated earlier, all participants signed an informed consent following a detailed explanation of the study and their role and responsibilities. Participants were allowed to withdraw from the study, meaning their data would not be used in any dissemination activity, for up to two weeks following their participation. No participants withdrew from the study

Chapter 4. Findings

Ten BMT patients participated in this study between October, 2018 and April, 2019. Most all were recruited through poster advertisement while four were recruited through the BMT clinic. Eight interviews were undertaken by telephone and two were in person at the TBCC. All interviews were audio-recorded and transcribed for analysis.

Characteristics of the Study Sample

As identified in Table 1, seven men and three women participated in this study. Their ages ranged from 29 to 68 years (mean age men=44.29 years; standard deviation (SD) =16.84; mean age women 41.70 years; SD=15.70). Eight participants were married, one was in a committed relationship, and one was dating. All participants appeared to be heterosexual. Seven participants identified having an allogeneic transplant, and three had an autologous transplant. Half (n=5) of the participants had Acute Myeloid Leukemia. Four participants reported being less than one-year post-transplant, while the others were 2-14 years post-transplant.

Table 1. *Characteristics of the Study Sample*

| Pseudonym | Age at time of Transplant (years) | Marital Status | Diagnosis | Type of Transplant | Time Post-Transplant (years) |
|-----------|-----------------------------------|------------------------|--------------------------|--------------------|------------------------------|
| Allan | 60 | Married | Multiple Myeloma | Autologous | 4 |
| Nancy | 28 | Committed Relationship | Biphenotypic leukemia | Autologous | <1 |
| Charles | 35 | Married | Chronic Myeloid Leukemia | Allogeneic | 9 |
| Bob | 54 | Married | Multiple Myeloma | Autologous | 14 |
| Betty | 55 | Married | Myelodysplastic syndrome | Allogeneic | 4 |
| Trevor | 26 | Married | Acute Myeloid Leukemia | Allogeneic | 8 |
| Brody | 27 | Married | Acute Myeloid Leukemia | Allogeneic | <1 |
| Matt | 22 | Dating | Acute Myeloid Leukemia | Allogeneic | 2 |
| Justin | 46 | Married | Acute Myeloid Leukemia | Allogeneic | <1 |
| Kate | 36 | Married | Acute Myeloid Leukemia | Allogeneic | <1 |

The Model

This model (see Figure 1) offers an explanation of the process participants went through during their illness and identifies the ways that participants navigated change and how they sought a ‘new normal.’ Overall, the participants were undergoing a process of ‘opening intimate conversations’ with their partners, healthcare providers, and even in their own minds about how they would re-integrate sexual relationships into their lives. Having these intimate conversations often helped in targeting sexual recovery and affected the ease of transition in dealing with the transition to a ‘new normal.’

Categories

The four categories which emerged from the data were: identifying importance, taking responsibility, seeking resources, and navigating the partnered-relationship. Gender permeated all of these categories. These events occurred in a non-linear process of seeking a new normal and could apply at any time point during the treatment trajectory. The core category that explains what was going on was ‘seeking a new normal.’

Timeline: Symptoms Prior → Diagnosis → Treatment → Symptoms Post → Transition to Outpatient → Life Post-Transplant

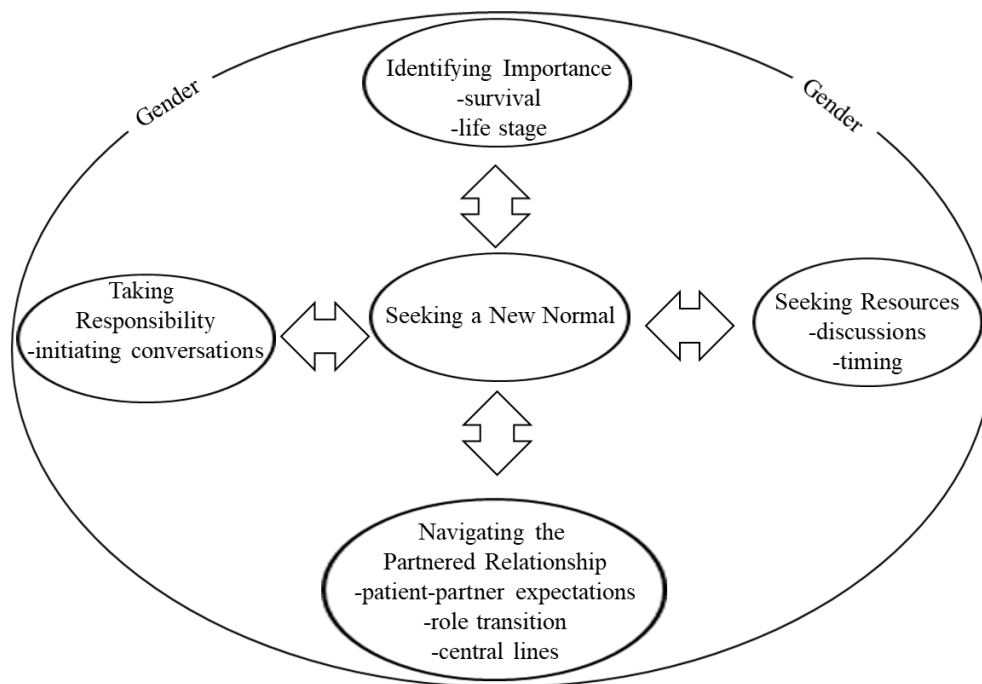


Figure 1. An Intimate Conversation: Targeting Sexual Recovery.

Core Category

Seeking a new normal.

The core category of “seeking a new normal” is defined as the process each individual will go through while searching for ‘normalization’ and trying to get back to the condition they were in before diagnosis. The participants in this study consistently spoke about how to ‘navigate a new normal’ while reintegrating back into life post-transplant. The central idea is that the transplant process resulted in participant searching for ‘normalization’ and getting back to where they were before diagnosis. Most participants recognized they would never return to the state they were at before diagnosis. They were searching for a better understanding of what their ‘new normal’ would look like and trying to accept the changes that they identified. The core category of seeking a new normal ties each category together and describes the presenting concern of the sexual health needs in the BMT population. The majority of participants’ sexual health needs had not been fully addressed or met; most participants were still discovering themselves and trying to navigate new changes. It seemed some participants were able to return to their state of ‘normal’ at a faster rate than others. Even those participants with minimal sexual health concerns and who stated they were happy with the way things were, still talked about their journey of seeking a ‘new normal’ post-transplant. Seeking a new normal was not always directly related to sexual health concerns; redefining their relationship with their partner or learning to deal with other concerns along the way were issues participants were dealing with when defining a new normal. Allan (60 years old, married) talked about his new normal like this: “So now I am back to what I am not going

to call it normal life, but back to regular, I guess.” Another participant described ‘new normal’ in another way when he said:

New normal, it means letting go of expectations that we might have had from who we were pre-cancer, I think it means, it’s kind of a complete re-defining of what that is. After having been through that experience, it definitely was a transition.
(Brody, 27 years old, married)

Matt (22 years old, dating) put it another way; “I don’t really believe in the whole getting back to where you were before the transplant; I don’t think I will ever be back there again, it’s more of the navigating the new normal.” Trevor (26 years old, married) just wanted to ‘have a normal life’ and described it this way:

So for a mediocre life, I didn’t want to survive the transplant and just have a shit life after that. If I was going to be weak and feel weak the rest of my life, I didn’t want that; I wanted to do as much as possible and have a normal life, like it never happened.

Brody (27 years old, married) also spoke about how time and the process of the transplant affected the ‘new normal.’ He said:

We got to a point where we were just focussed on, you know, first off getting through remission and then staying there and then making it through transplant. And now, finally looking at some return to normalcy and redefining what normalcy looks like because we have come back to baseline, but we are not the same people anymore.

Others, though they wished they could have a ‘new normal,’ did not see that happening.

Kate (36 years old, married) said: “I can’t get back to normal, and I definitely have a little bit of PTSD from all the things that have happened to me.”

Six of the ten participants were actively seeking assistance in managing post-transplant sexual health concerns. Many participants identified that utilizing resources, such as the OASIS (Oncology and Sexuality, Intimacy and Survivorship Program) Clinic,

or psychosocial counseling, helped them feel supported during their illness journey and made the process of ‘seeking a new normal’ an easier transition. Nancy (28 years old, committed relationship) poignantly described her experience:

I actually feel physically like my sexual health has kind of deteriorated, but now it has created and just strengthened my beliefs in what my sexuality and sexual intimacy looks like. Before I wanted to incorporate these into my sexual life, like having more foreplay and that sort of thing, I would've wanted that kind of stuff, but I wasn't sure how to vocalize it. Now that I've gone through this experience and although it's really set me back on a physical level, it has projected me forward in an emotional and mental way because if it hadn't gotten so bad, I don't know if I would have ever sought help to work through that sort of thing.

Identifying Importance

This element represented a phase in the process when the participants identified a value or opinion about their sexual health and sexual needs. When these were deemed important to the participant, he/she was less likely to accept negative changes as part of their life and more likely to seek help in navigating their new normal. Each participant identified the degree of importance that sexual health had for them. Post-transplant sexual relationships were not as spontaneous and often required more effort. Though not all of the participants recognized sexual health as an important aspect of their life, the majority (8/10) acknowledged the importance of maintaining a healthy sexual relationship with their partner. One participant expressed his view about the importance of sexual health by stating: “I don't see it as being a major problem between my wife and I. Our relationship is basically as it has always been its just there's the one part is not there anymore” (Allen, 60 years old, married). Kate (36 years old, married) though, described it another way when she said: “It is super important to have that intimacy, I still have a lot of touching

and hugging and kissing in my life, just not sex and probably, hopefully, will have sex (someday).”

The importance of sexual health changed throughout the different phases of the timeline and was dependent on the significance placed on survival, stage of life, and gender.

Survival.

Survival refers to the reality of living through and enduring the BMT process. Every participant identified that there was a time in their cancer journey in which sexual health was not a concern: the concern was to survive. Indeed, there were times in this journey when discussions about sexual health were absolutely not a priority. However, this changed over time. Betty (55 years old, married), expressed her view about the importance of sexuality during her diagnosis and treatment phase when she said: “It would maybe be too overwhelming, oh my goodness, why are we talking about this; let’s talk about how I am going to survive.” Allan (64 years old, married), described it in another way: “I can’t remember anywhere along the way where you know sexual health was specifically discussed, but then again you have to be fair to them [HCP’s] they’re concerned about keeping me alive.” Brody (54 years old, married), expressed it this way:

Prior to this, my wife and I had good intimacy, but after I got sick of course there was nothing to do with sexual health at all, it was survival, it was being able to do one or the other.

Some participants tried to be sexually active throughout treatment and soon after their transplant, but for the majority, it was not until they transitioned home and symptoms resided that their sex life became more of an important matter to address.

Nancy (28 years old, committed relationship) described her experience this way: “During

that time [treatment] I would say that my desire definitely had decreased I was probably sexually active maybe 3- 4 times during that whole period.” Trevor (26 years old, married), had a different experience and described this: “Even during treatment...I still had sex just fine.”

Life stage.

Refers to the differences in behaviors or attitudes that occur throughout the lifespan. Many of the younger participants indicated that sexual health was brought up by their doctors in regards to fertility; this helped to initiate sexual health conversations.

Matt (22 years old, dating), described this experience when he said: “Prior to my transplant and the radiation and chemo that was definitely addressed [sperm banking].”

Another young male participant had a similar experience and described it this way:

I knew that prior to starting chemo it all went very fast, but we did do some sperm banking prior to starting chemo. This had been a long dream of ours to have kids naturally, so we attended an information session on IVF and met with the doc to discuss that. (Brody, 27 years old, married)

Several participants also commented on younger versus older age and how this may have an impact on how an individual values the importance of sex. Some participants discussed how the importance of sex has changed as they have grown older. A few older participants discussed the importance of sex in their lives:

I guess the way that I look at it is as you get older things stop working. You know I am going to be 65 ...(soon). I realize I just sort of look at it as just another thing as you get older, just something you know that stops working or however you want to put it. (Allan, 60 years old, married)

For me in my 50s when I was in menopause, I did not have as much space in my life (for sex).... Where before it was like more part of the daily routine it was something I would think about. Once I hit menopause it didn't have the same priority so yeah that would not even be a worry or a question or like that's the last thing of my worries kind of thing. (Betty, 55 years old, married)

In contrast, several younger participants described how age impacted their sexual health.

Nancy (28 years old, committed relationship), described it this way:

I also think the fact that I am a bit younger they put that into consideration that younger people are more generally active sexually. I think they made that a part of the focus with my treatment plan and especially because my partner was at most of the appointments they kind of the kind of treated us like a unit.

Kate (36 years old, married) described life stage another way when she said: “Also other things that kind of change a little bit, when you’re older I think they do, they have for me, sex is not as important as it used to be.”

Regardless of age or stage of life, most of the participants identified that sexual health is an important issue to address and the majority were wanting to talk about their concerns and were accepting help from HCP’s.

Taking Responsibility

This category referred to who took responsibility to initiate sexual health conversations.

Initiating conversations.

Each participant identified that someone needed to take responsibility for initiating conversations, but who should be responsible for initiating sexual health conversations was uncertain. One participant expressed her view about whose responsibility it should be to initiate the conversation by stating: “I strongly feel for me that the oncologist makes the most sense as in who would bring it up, like it fit for me because that’s who I was seeing weekly” (Betty, 55 years old, married). Matt (22 years old, dating) however, thought the psychosocial department should be involved. He said: “I think it should be the responsibility of the psychosocial department, they should try

and talk to someone about it, I know some people are very private about it and don't want to talk about it at all." Brody (27 years old, married), believed it should be a shared responsibility and said: "I would say perhaps there should be some onus on the part of the medical staff that we see, however, I think it's a two-way street too." Trevor (36 years old, married), described it this way: "I don't think it matters but probably in my age group you know, that was in my late 20s, you probably just let the patient talk about it himself."

Of the seven participants who had sexual health conversations, four of those conversations were initiated by the HCP. Those who did not have conversations with their HCPs described their experiences. They indicated that their HCP had never asked them about their sexual health. Trevor (26 years old, married), described his experience when he said: "My doctor, my main doctor, he never really talked about that. If I would've asked, I'm sure he would've given me the best information, but I never asked." Another participant concurred that the HCPs did not initiate conversations. Brody (27 years old, married) said: "No, it was never initiated by the doctors or nurses that we saw in the clinic." A couple of participants noted that even though they had identified sexual health concerns to their HCP, their issues were not fully addressed. One participant talked about a questionnaire form he was given at this follow-up visits to identify specific concerns:

They give you a questionnaire, it says do you have any issues with any of this, and it's a page long, sleeping, drowsiness, pain, etc. There is one point about sexual health, but if you were to ask me do they discuss it or offer anything, I would say no. You know asking one question, I don't think they are actively looking at sexual health. (Allan, 60 years old, married)

Though some participants stated they did not have any sexual health conversations with a HCP, they still spoke positively about their experiences. Many of the participants supported their medical team and offered ideas (i.e., timing and priorities) as to why these conversations may not be initiated and routinely happening.

I think often times, especially in a clinic where you know, as much as the doctors try to be there to address all the needs of the patient, they have busy schedules. Sometimes you only get to see them for 5 or 10 minutes and so, I think the priority is to look after the physical symptoms and physical health of the patient as they make progress. (Brody, 27 years old, married)

I don't think that question [sexual health] was asked at any time. Don't get me wrong I am definitely not criticizing the people at the bone marrow transplant clinic; I am very grateful for what they have done for me. I am in no way shape or form saying that they messed up, they have done an absolutely marvelous job of taking care of me. (Allan, 60 years old, married)

Some participants stated they were open to initiating conversations, but they did not follow through. Only one woman and two men initiated sexual health conversations. Justin (46 years old, married), said: "I never brought it up; I don't know if they were supposed to; I don't recall it being a topic of discussion." Allan (60 years old, married), described his outlook on the experience when he stated:

I have never brought it up. I am guessing that if I did bring it up when I was in the clinic, they would find somebody to talk to me be... Knowing how hard they worked there and how diligent they are about taking care of me like I am pretty much sure that if I did say something they would say 'Yeah we will get right on that' sort of thing, but I haven't brought it up.

Some participants stated that sexual health can be an uncomfortable and 'taboo' subject to discuss and this may affect how conversations are initiated and who initiates them. For example, Brody (27 years old, married) expressed how uncomfortable sexual health can be to talk about when he said: "And maybe that's a role for something like

psychosocial services to do instead, but once again, as I mentioned, it's a taboo subject, and not everyone is comfortable bringing it up." Kate (36 years old, married), described it another way when she said:

I think it's such a weird sensitive topic that a lot of people would be uncomfortable bringing it up or they would assume that there are not resources for somebody like that, so I would bring it up to them to take away the awkwardness.

Though the majority of participants identified that sexual health is an important topic to address, the ambiguity of who initiates these conversations was a barrier affecting the occurrence of conversations.

Seeking Resources

This category refers to individuals searching for the appropriate help and advice and finding the right time to discuss their sexual health. Finding the appropriate resources and the right time to discuss sexually-related concerns was noted to have an important impact on how participants viewed their journey and their process of seeking a new normal.

Discussions.

Refers to the conversation's participants have had about sexual health. Two of the women were currently attending the OASIS Clinic, which is a program at the TBCC dedicated to patient education, assessment, and treatment of sexual difficulties as a result of treatment for cancer. Other participants described having conversations with psychosocial counseling services, gynecologists, and their family doctor. Conversations about sexual health varied among participants. Some participants were open to

discussions with HCP, some kept their concerns to themselves, and others kept their concerns between themselves and their partner.

We haven't really talked too much about sex, he's kind of a super quiet guy, but I talk, like we do talk about it you know. But I'm pretty sure that he knows and he can just tell, we don't have to talk about it. (Kate, 36 years old, married)

To tell you the truth, there hasn't really been someone that we have talked to about this a great deal, except with each other. Today was the first real time we brought it up with another health professional. I think we will be talking about that more in the future, but otherwise, I mean it's kind of been something that we kept between the two of us. (Brody, 27 years old, married)

Her and I just talked about it, and she more so went to her friends and talked about like self ways of dealing with everything because I was in no condition to have sex or any desire, I was very sick. (Matt, 22 years old, dating)

There seemed to be an association between those who had sexual health discussions and their increased interest in seeking additional resources post-transplant. The participants who had the opportunity to discuss sexual health concerns seemed more optimistic about accepting help and getting assistance in redefining normalcy. Brody (27 years old, married), described it this way: “The biggest thing we have been doing is attending regular counseling from psychosocial services at the Tom Baker.” Another participant described her experience when she said:

Trying to get that level of normalcy that a person would have without having all of that happen to them; I am not sure how anyone could recover from that without having like a psychological therapist walk them through it. (Nancy 28 years old, committed relationship)

In contrast, the participants who had never discussed sexual health through their illness had no intentions in seeking resources and getting help. Allan (60 years old married), expressed his outlook on sexual health when he said: “Sexual health was one of

...(those topics) that I just don't bother with now because I sort of look at it as 'Well just another fact of life. That's the way it's going to be.'"

The participants also had varying views regarding the frequency of discussions and the availability of resources. Some participants were pleased with the availability of resources, and others were unsure of what programs and recourses existed. One participant indicated how pleased she was with the resources being offered when she said: "I really have all the resources available. I think people have been extremely vigilant and willing to talk about it, and so I don't feel like I have a lack of support" (Betty, 55 years old, married). In contrast, others felt there was room for improvement and that the availability of resources could have been better vocalized. Kate (36 years old, married), described the desire to talk to someone when she said: "I think it would be kind of a nice thing, if somebody could come in to talk to you about your sexual health. I don't know how other people would react to that." Another participant put it another way:

I think that Tom Baker has been incredible at making sure that patients are reminded that it [sexual health] is important for them. But also just being able to let women know, I don't know what men have for help, but letting them know about the OASIS Clinic. (Nancy, 28 years old, committed relationship)

One participant who had not accessed any resources or had any discussions about sexual health was unsure if he would be interested in accepting help if it has been offered.

I am not 100% sure. If they said to me something like 'We are having a seminar on sexual health after transplant next Wednesday' or something like that, I don't know whether I would go or not. You know if my wife said we've got to go to this then yes I would go, but on my own, I don't know if I'm ready to go to it or not. (Allan, 60 years old, married)

Timing.

Timing refers to a particular period when sexual health conversations may be best suited to the individual. Participants noted there were different times throughout the trajectory of their illness in which having a sexual health conversation would have been most impactful.

Several participants identified the importance of briefly addressing sexual health before treatment, so they were aware of what to expect.

I think ...it would be really useful to bring it up around the diagnosis Then when they are getting close to the transplant just checking in with their sexual health level. Then after the transplant in the first three months checking in with the patient again around then to see what options there are to work on sexual health because it such an important part of our health in general. (Nancy, 28 years old, committed relationship)

I think very early on in the treatment process it would be good to talk about it, but not like in the weeks, two weeks before your transplant, that kind of thing...There are much bigger issues going on and much more significant things, but I know I feel like I was talked to a little bit about it, prior to everything. (Matt, 22 years old, dating)

The majority of participants felt that discussion about sexual health was not an important or relevant concern until they transitioned home and were feeling better mentally and physically. Participants indicated that they wanted to discuss sexual health issues when they felt physically ready to reengage in sexual activity with their partner.

That transition and as my health continues to improve, then yeah, I would say hopefully that aspect of our relationship you know, is not so much put on the back burner, but I will be able to focus on and rediscover that once again. (Brody, 27 years old, married)

Finding the appropriate resources and the right time to discuss sexually-related concerns has an impact on how participants viewed their journey and their process of seeking a new normal. It was apparent that those who were aware of available recourses

and had the opportunity to discuss their sexual health benefitted and had a more positive outlook about the changes associated with their sexual health. Nancy (28 years old, committed relationship) put it this way:

When I first met the people at the OASIS Clinic, I was depressed about sex. I wanted to be able to be intimate with my partner and let him experience pleasure almost more than I did because I felt it was so hard on the relationship. But as I have been going to that OASIS Clinic now for four months, I think it's helped me to empower myself and get what it is that I need in order to build on my sexual health. I found when I needed information or had questions, they were all very helpful.

Betty (55 years old, married) added:

There's not one thing that was given to me that I haven't tried or considered, and when I do try them I am not disappointed. I think it's really up to me; they have given me all the tools basically.

Impact on Navigating the Partnered Relationship

Navigating the partnered relationships refers to how an individual and their partner dealt with shifting relationship dynamics throughout the trajectory of the illness. Participants referred to how their partner's roles changed over time; evolving from caregiver to intimate partner. When one member of a couple developed a serious illness, both partners' lives were affected. In many instances, participants described times throughout their treatment when they thought their expectations or ideas did not match up with their partners when it came to re-engaging in their sexual relationship. Feelings of frustrations or guilt were often expressed, and each participant seemed to deal with these concerns in a different way.

Patient-partner expectations.

This refers to the potential match/mismatch between participants' and their partners' ideas and expectations of what should be happening in their relationship

currently or in the future. Betty (55 years old, married), described a mismatch of ideas regarding her sexual relationship with her husband when she said: “I don’t feel hopeless about it; it’s not like ‘Oh my God I will never have sex again.’ I think my husband at times feels that way, but I don’t.” Brody (27 years old, married), described it this way: “You know, for a time there, I think it probably affected my wife’s emotional health more than it did mine.” Bob (54 years old, married), put it another way: “It was taxing on the family, my wife would come down, and sometimes would bring down my sons, it was long trips, and slowly that thing called caregiver fatigue was setting in.” Betty also expressed her view on the emotional toll it can have on a relationship when she said:

That’s where I feel the most guilty and stressed out because he’ll just masturbate and take care of himself. I’m just starting to accept that, and I don’t want to accept that. I don’t think it’s healthy to not have a sex life at all. I am not prepared to give up altogether, but he is feeling somewhat helpless; there’s nothing he can do to alleviate the pain. He can only try and get me interested for a cuddle, and I’ll do something for him, but I don’t want him to do too much for me because I don’t want to go there so yes it’s frustrating absolutely, but it’s not like we have a choice.

Kate (36 years old married) described her experience this way:

Now you’re starting to get better, and things should be going back to normal, but it doesn’t happen just like that, it takes a lot of work. One of the things that I did do to move that transition was I talked to my therapist a lot like to communicate that to my partner. At first, there was a lot of anger because I felt insecure and I felt like I was associating sex with pain so I felt afraid, and not that my partner was going to hurt me but that I would have to experience pain so that my partner could experience pleasure.

Whether an individual was married, single, or in a relationship, the participants spoke about challenges they were trying to overcome when reintegrating back into their sexual relationships following transplant. One participant explained that despite the

strong foundation and communication skills he and his wife had prior to his diagnosis, it was still challenging to navigate their sexual relationship post-transplant.

But we have been together for a long time, so it wasn't like that was new territory for us, and then we got hit with the leukemia and had to kind of re-evaluate a little bit...about what this intimacy would look like and how do we get back to where we were before you know, it's a gradual process. (Brody, 27 years old, married)

In contrast, another participant spoke about the challenges he encountered when he became single again and was navigating new relationships post-transplant. Matt (22 years old, dating), described it this way: “And now like it’s definitely navigating the new normal with this new girl that I have been seeing because I have to explain things to her and I need someone who understands what I’m going through.”

Role transition.

This refers to the shift that the BMT participant’s partner or spouse makes between being a caregiver and romantic partner. The participants noted this transition was occasionally a challenge. Brody (27 years old, married) noted the difficult transition his wife was dealing with when he said: “I think for my wife there’s a bit of a mental block to overcome when it comes back to this caretaker-patient dynamic. She’s got to get over being afraid to go there once again.” Nancy (28 years old, committed relationship), described her experience this way:

When I started getting back to a level of health where I could kind of take care of myself without a caregiver, going from the role of caregiver to intimate partner was a difficult transition, especially in the bedroom. He was going from being a caregiver that was making sure that all of my basic needs were being met to slowly taking that out of his realm of requirements and taking an intimate role. That was difficult.

Central lines.

Several participants also articulated that their central venous catheter access lines were a big factor associated with when they, or their partner, felt physically ready to reengage in sexual activity again. Brody (27 years old, married), expressed his view about the impact a central line can have on a relationship when he stated: “I had a central line in my chest and she was kind of afraid to get to close in a sense like she wouldn’t even kiss me for a while because she was afraid of getting me sick.” Kate (36 years old, married), described it this way: “Looking at a bunch of cords (like a central line) hanging out of somebody’s body, it wasn’t for me and, you could never forget that you have cancer, so how are you supposed to relax.” Justin (46 years old, married) described the removal of the central line as a pivotal moment of when a person may contemplate resuming a physical relationship with their partner:

I would say if you are looking at timing, probably after the central lines come out, if most people get those, that’s probably the real barrier to resuming anything physical I would think. When I got home, of course, my wife didn’t want to come near that for risk of infections, pulling it out [central line], that type of thing. We kept our distance when I had the line in, like we always slept together and we would cuddle and hug, but she didn’t like it touching her. She didn’t want to risk pulling it or hurting me, and then when it was out; we just cuddled closer and then just progressed baby steps.

Gender

Gender refers to the socially constructed roles, behaviors, expressions, and identities of girls, women, boys, men, and gender diverse people (Canadian Institutes of Health Research, 2015). There were three women and seven men interviewed for this study; the women seemed to have a more ‘common’ experience, where men seem to have a more varied experience in regards to side effects and seeking out help.

All three women experienced psychological, treatment-related, and specific sexual health-related symptoms post-transplant. Only one out of the three women initiated any sexual health conversation, yet, all three women were seeking help in some form to deal with sexual health side effects. The women generally complained of side effects including graft versus host disease, hair loss, increased vaginal dryness and pain, pelvic floor muscle tightness, depression, and decreased sexual interest and arousal. One woman described her experience by stating “I am finding that physical pain on top of my low sex drive, you put those two together and it’s kind of a lost cause” (Betty, 55 years old, married). Another participant described her experience this way:

After the transplant, of course, I was quite weak for the first three months I would say, so sexual activity was pretty rare after January. Once that was over going back to being sexually active again was quite difficult because of tightness and also dryness. I was severely dry and tight, so it was quite painful, it wasn’t exactly a pleasurable experience, so that’s when I started going to the OASIS clinic. (Nancy, 28 years old, committed relationship).

Men generally stated their side effects included issues such as hair loss, mucositis, graft versus host disease, weakness, fatigue, erectile dysfunction, decreased sexual desire, and depression. Brody (27 years old, married), expressed his experience when he stated: “I went through the usual symptoms people do, hair loss, mucositis, a bit of throat pain too, but most of that cleared up fairly quickly, or at least on schedule. By mid-November, I was an outpatient once again.” Matt (22 years old, dating), described it this way: “I realized after attempting to have sex with someone, I definitely got early-onset erectile dysfunction.”

Unlike the women who all had suffered sexual health concerns post-transplant, some of the men experienced no sexual health concerns at all. Men also seemed to recover

from physical side effects post-transplant faster than women. Trevor (26 years old, married) expressed his experience when he said: “It’s the fact that I was determined to get back to normal as fast as possible, and I mean fast; we’re talking weeks... weeks later, I was doing sports.” Another participant described it in another way:

Probably most of June I was physically that of a 78-year-old, short walks, tired, not a lot of energy and therefore no sexual interest or appetite. Then in July and since then, I have pretty much bounced back very quick; this is what the specialist tells me. (Justin, 46 years old, married)

Two of the men had non-sexual side effects associated with transplant (e.g., hair loss, fatigue). However, one of these men was utilizing resources and receiving help with transitioning redefining intimacy with his partner. Another two men had no identified issues at all and, consequently, these men did not seek out any help. And the final three men all had sexual health issues post-transplant. Only two out of the three men with sexual health concerns were receiving help, and these two men had also initiated the conversation with their HCP.

In terms of gender differences in regards to seeking a new normal, all three women agreed they may never return to the same degree of normalcy they had before treatment, and they were all are seeking help in navigating their new normal.

In terms of normalcy for men, all men agreed they were not entirely back to the degree of normalcy they were at prior to their transplant. Of the seven men, four were okay with where they currently were in life and not seeking help in navigating their ‘new normal;’ of these four men only one was dealing with sexual health concerns. The other three men stated they were not okay with where they were in life and thought it was important to seek help in navigating these changes; two out of the three were dealing with

sexual health issues. One male participant was seeking help in dealing with sexual health concerns and expressed his view on gender inequality when he stated: “It’s just a gender thing it seems like that into that you’re just a dirty old man that wants these pills, I have never been like that” (Bob, 54 years old, married). Another participant, who was not actively seeking help for his erectile dysfunction, described his lack of communication as a ‘typical guy’ mentality when he stated:

I’m sure if you ask my wife she will say he doesn’t talk about feelings or something like that. She would’ve said the same thing 15 years ago so you know I’m a typical guy; guys don’t talk about that kind of ...you know feelings and all that airy-fairy stuff. (Allan, 60 years old, married)

The Timeline

The timeline of events identified included: symptoms prior (sexual health issues identified before diagnosis), diagnosis (the confirmation of illness), treatment (the point in time when the participant received their bone marrow transplant regime), symptoms post (sexual health issues arising after their transplant), the transition to outpatient care (moving from the inpatient to outpatient setting), and life post-transplant (the period of transition and returning to life post-transplant). The timeline represents the critical stages that each participant went through during their illness. At each stage in the timeline, the five non-linear categories (described above) could be present. The transition through the illness trajectory, and the participants’ experience and attitude throughout the process, impacts how well supported a participant feels in redefining and seeking a new normal. Matt (22 years old, dating) described his timeline journey like this:

There were no real issues before, and then I got my diagnosis and things just kind of stopped in terms of sex for many months leading up to my transplant. I was very sick in and out of the hospital all the time. I spent two months in the hospital

prior to my transplant. Yeah, so nothing was happening there [sex], and then afterward I would say in about the three-month recovery time nothing really was going on, once I kind of recovered things kind of got back to normal.

Every participant described their illness journey differently, hence, there is no right or wrong time to discuss sexual health; it is dependent upon the individual. Throughout the six phases in the timeline, each participant's experiences varied in terms of identifying importance, taking responsibility, seeking resources, and navigating the partnered relationship.

Symptoms prior.

One participant described the impact his physical symptoms had on his sex life when he stated: "Basically from the start, like from the time the summer of 2014 my back was so sore that sex was the last thing on my mind at that point in time" (Allan, 60 years old, married). In contrast to another participant who had no concerns at all and described it this way: "I had no real issues before, and then I got my diagnosis" (Matt, 22 years old, dating).

Diagnosis.

Betty (55 years old, married), described having minimal time to adjust to any changes when she said: "Things deteriorated within two months after being told of the diagnosis, so you barely have time to adjust to having a condition." Trevor (26 years old, married), described his experience at the time of diagnosis this way:

They thought there was a high likelihood that I would never be fertile again, so they had me go to a sperm bank clinic before we started chemo. There is very little time between once you know, you have cancer (diagnosis) and when you start (treatment) so they don't want to waste any time.

Treatment.

A female participant described her experience when she was receiving treatment when she said: “The bone marrow transplant to me was the easiest part all of the treatment” (Betty, 55 years old, married). On the other hand, Justin (46 years old, married), described his experience in this way: “It (BMT) knocks you off, I was in the hospital all of May, obviously weak, tired, no energy, muscle atrophy was crazy noticeable, I was a big guy going in, and my muscles just turned to jelly in that short time.” Allan (60 years old, married), described the impact treatment had on his sexual health when he said: “Basically, since my treatment, our sex life is nonexistent.”

Symptoms post.

Nancy (28 years old, committed relationship), described her sexual health symptoms when she said: “After the transplant was when I started to notice more of the changes going on ‘down there.’” Another participant described his experience this way:

Yeah, it affected my general condition, because you’re weak especially after transplant, you’re very weak, and I think you see yourself as weak and undesirable, and I don’t know that I was thinking about sex at that time at all.
Trevor (26 years old, married)

Transition to outpatient care.

Brody (27 years old, married), most poignantly described the struggled he and his wife went through they transitioned roles from caregiver back to loved one:

It’s a game-changer when it comes to relationships. We have talked about this a bit, and it has been the transition from being best friends and husband and wife to that of a caretaker and patient. It’s not like I am completely dependent on her as I was when I was an inpatient, but yeah she does a lot still.

Life post-transplant.

Kate (36 years old, married) discussed the transition back home is when she started to feel more like her normal self again when she stated:

I am doing OK; I'm doing a lot better than I was before transplant, which was very bad. Now I am getting back to normal, in fact, I am feeling so normal, so I'm feeling so normal that it's starting to get away from me a little bit, I am trying to get back to my life, we will see about that.

Even four months post-transplant, Bob (54 years old, married) explained he still needed more time recovering before he could resume his sex-life. He described the experience like this: "It was about a four-month period of recovery I was feeling more myself in terms of sexual health, you know, oh I feel better, and eventually I could see myself getting back into our sex life." Justin (46 years old, married) on the other hand, had an optimistic outlook on his recovery when describing his experience:

It's only been eight months, so everyone is pretty happy with my strength recovery. Our new normal, we are very aware of infections and crowds, but also we are not living a bubble life we are going out, we go to movies, we go out for supper. I am not hiding from the stuff that happened to me, and we are just going forward every day.

On the whole, the participants indicated there is not necessarily a right or wrong time to talk about sexual health while dealing with an illness. Each participant needed different resources and wanted to bring up sexual health discussions at different times throughout their journey. It seems many participants valued the importance of having open communication, but the notion of when to have these conversations and the resources each participant's needs was highly individualized. Thus, the importance of a HCP touching base throughout the journey to understand what individuals want to talk about and when they think is the most appropriate time to have these conversations would be

imperative to ensure sexual health needs are being met. Though not every participant described having sexual health concerns or even thought their sexual health was a significant issue that they wanted to address, if discussions and resources were offered this may have changed the trajectory of their illness experience and how they viewed their sexual health or process of navigating a new normal.

Chapter 5. Discussion

The experiences of individuals re-engaging in sexual relationships following a BMT were explored in this study. The main categories and sub-categories, identified as impacting the experience of re-engaging in sexual relationships were: identifying importance (*survival, and life stage*), taking responsibility (*initiating conversations*), seeking resources (*discussions, and timing*), navigating the partnered relationship (*patient-partner expectations, role transition, and central lines*). The participants' gender often influenced how they experienced these elements of the process. The study findings have helped to further illuminate the experience of what patients go through when integrating back into their sexual lives post-transplant. This enhanced understanding may resonate with nurses, and other HCPs to enhance awareness of the importance and impact a transplant can have on a patient's sexual health.

Seeking a New Normal

Participants stated that they were seeking a new 'normal' post-transplant and the identified elements that had an impact on how they were navigating changes in their lives. Indeed, 'returning to a new normal' is a multifaceted and holistic concept and often includes the desire to return to former social relationships, jobs, sexual relationships, and generalized life as it was prior to a diagnosis (Baker, Zabora, Polland, & Wingard, 1999). Respondents in the study by Nørskov et al. (2015), also described the longing to return to 'normal' everyday life and have the degree of normalcy they had before their BMT. Similar to findings by Zabora, Smith, Baker, Wingard, and Curbow (1992), some participants in our study were attempting to return to a state of normalcy they were used to, while others believed that life would never return to the state it was

prior to their BMT and they were trying to navigate their 'new normal.' Due to a lack of education and discussion, several participants in this study were wondering if what they were experiencing was normal. Consistent with a study undertaken by Hordern and Street (2007c), it was common for patients to be searching to understand if their physical and emotional changes affecting their sexuality were normal and how to live with their new changes. Some participants in the study by Hordern and Street (2007c) expressed feelings of being let down by HCPs who could not provide them with information and strategies to assist them in living with new changes as a result of their cancer and treatment. Contrary to the study by Hordern and Street, many participants in our study were searching for normalization but described feeling grateful for the care they received and justified reasons as to why their HCP may not have initiated certain conversations.

A few participants in this study were yet to have a conversation with their HCP regarding any sexual health concerns they were experiencing. The uncertainty of whose responsibility it was to initiate discussions often lead to a lack of conversation; consequently, patients were often unaware of available resources; this can potentially impact the transition and integration back to normal life and resuming a sexual relationship. Participants who had utilized resources and had discussions about the changes they were experiencing agreed that these conversations were important and helped them feel better supported in their transition of 'seeking a new normal.'

Relationship changes and roles can affect couples' sexual health and their reintegration process; if one's partner has difficulty transitioning from the caregiver role back to loved-one, this could hinder the process back to normal life (Zabora et al., 1992). Participants in our study often expressed that their partner was affected by the illness and

was attempting to understand and navigate new changes; some couples were continuing to seek help to ease this adjustment. Consistent with the study by Baker, Zabora, Polland, and Wingard (1999), many individuals and their families faced numerous difficulties trying to reintegrate and return to normal post-transplant. Ensuring supports and resources are accessible for patients and their partners is important with the transition of reintegrating back into sexual relationships and navigating changes that many couples will encounter.

Identifying Importance

Similar to other studies, the majority of individuals in this study reported that sexual health was important to them, even at times when participants felt quite unwell, but it is not always a prioritized concern (Booker, Walker, & Raffin Bouchal, 2019; Nørskov, Schmidt, & Jarden, 2015). The importance of sexual health was prioritized differently by participants throughout the phases of their illness. Consistent with findings by Nørskov et al. (2015), it was not until after the transplant and reintegration home when participants started to feel better, had an increased interest in their sexual health, and contemplated having sex with their partner again. Hordern & Street (2007a), as well as Nørskov et al. (2015), also identified that participants apprehensive thoughts about surviving and relationships affected how sexual health was prioritized. Throughout the diagnosis and treatment trajectory, all participants agreed that survival was foremost on their minds and many lost interest in their sexuality. It is important to appreciate patients' priority concerns to ensure when discussions and educational information about sexual health are provided, it is done respectfully and at a time best suited to the individual's needs.

Several participants agreed their sexual health was not as important to them as it was in their younger years. Many of these participants associated sexual health with fertility and indicated since they already had a family, sexual relationships were not a concern. Some younger participants believed that their HCP initiated discussions and addressed their sexual health concerns because of their younger age. As reported by other authors, HCPs more often asked younger patients about their sexual health concerns and an ageist attitude towards sexual health was apparent (Southard & Keller, 2009; Lemieux, Kaiser, Pereira, & Meadows, 2004). Though sexual functioning declines with age, and older age at the time of transplant is associated with lower sexual well-being, many older individuals are sexually active and believe sexual health is an important aspect of their life (DeLamater & Sill, 2005; Gott & Hinchliff, 2003; Heinonen, Uutela, Zevon, Barrick, & Ruutu, 2001). Thus, the importance of acknowledging the potential age bias that older individuals lose interest in sex should not be under-estimated.

Taking Responsibility

Participants were typically open to having sexual health conversations with their HCP and attached great importance of being informed about the possible changes and side effects they may encounter following treatment. Consistent with the literature, despite being important, most participants indicated that their HCP had never asked them about their sexual health and they were unsure whose responsibility it should be to initiate these conversations (Booker et al., 2019; Hautamäki, Miettinen, Kellokumpu-Lehtinen, Aalto, & Lehto, 2007). Participants felt that their HCP, including nurses, physicians, and the psychosocial department, are appropriate persons to initiate discussions about sexual health. Most participants thought the responsibility should be on

the HCP, but some thought it was a two-way street and was just as much their responsibility to initiate conversations about any concerns. Studies in other patient populations also reflected these results (Eeltink et al., 2018; Hautamäki et al., 2007; Lemieux, Kaiser, Pereira, & Meadows, 2004).

In contrast, the majority of HCPs do not routinely discuss sexual health and, nurses particularly prefer and often wait until the patient or physician initiates these discussions (Eeltink et al., 2018; Oskay, Can, & Basgol, 2014). Patients do not commonly initiate these conversations and often agree it would be helpful for the HCP to initiate discussions; leaving the initiative to the patient can contribute to silence and leave the impression sexual health is not important (Flynn et al., 2012; Ussher et al., 2013). According to Flynn et al. (2012), those who asked a HCP about sexual health problems often had worse sexual functioning than those who did not seek assistance. This leaves the question of what degree of sexual health problems exist for those who do not seek help and whose sexual health concerns are left unaddressed. It is important that patients are informed about the impact a BMT can have on their sexual health as they would benefit from understanding that sexual problems are not uncommon and that treatment and support are available (Eeltink et al., 2018). The majority of patients may not be aware of how their treatment may affect their sexual health, therefore, whether the patient raises questions or not, the responsibility of the HCP to initiate these conversations is critical (Flynn et al., 2012; Tierney, Palesh, & Johnston, 2015).

Consistent with other findings, several of our study participants identified they brought their sexual health concerns to their HCP, but these concerns were not adequately acknowledged or addressed (Booker et al., 2019). There have been numerous gaps

identified by patients and HCPs that affect how conversations are initiated and who initiates them. Consistent with the literature, time constraints (for the HCP), focus on survival (by the patient), embarrassment, the taboo nature of the subject, and preconceived notions are potential reasons as to why this topic is avoided (Eeltink et al., 2018; Hordern & Street, 2007b; Jonsdottir et al., 2016). Despite recognizing these gaps, additional research in understanding how to overcome them and improve sexual health conversations could be important to improve patient outcomes.

Seeking Resources

The majority of our study participants were willing to discuss the impact their illness has had on their sexuality, but with whom they had these discussions varied based on the individual. Some participants were comfortable discussing their concerns with any HCP, while others preferred to discuss this with someone with whom they had built a trusting relationship, and others kept their concerns to themselves or between them and their partner. The participants who initially had a challenging time sharing their sexual health concerns with a HCP, and who often only shared concerns with their loved one, typically changed their mind by the end of treatment and were more open to accessing help and discussing their concerns. The thought of finding the ‘right person’ with whom they were able to share intimate sexual health details was supported by Hordern & Street, (2007c). It is important to recognize that some individuals may not desire to share intimate details with every HCP and some may seek out someone based on certain traits which make them feel most comfortable (Hordern & Street, 2007c; Sporn et al., 2015). Despite this, and in keeping with findings by Wendt (2017), the majority of participants

were willing and comfortable to chat about their sexual health with any HCP who raised the subject.

Not every one of our study participants received information regarding potential sexual health concerns related to their transplant. Infrequent discussions about sexual health in cancer patients have been reported by numerous other researchers (Humphreys et al., 2007; Wendt, 2017). Researchers have reported that less than half of patients typically have no discussions of sexual health with their HCP (Flynn et al., 2012; Humphreys et al., 2007). In keeping with findings from Flynn et al. (2012), less than half of our participants identified they were unsure what sexual health side effects to expect and were not provided with any education regarding the changes they may encounter. This often left these participants wondering if what they were experiencing was ‘normal.’ Supported by the research done by Hordern and Street (2007c), our participants identified they wanted to know if what they were experiencing was normal and appreciated knowing what side effects they may experience post-transplant; reiterating the importance of providing information to patients early in their treatment. According to Lee (2011), having open discussions about sexual health is the most important intervention for patients with or at risk of sexual dysfunction. Individuals who have discussions about sexual health before their transplant have reported fewer concerns with sexual problems in recovery (Humphreys, Tallman, Altmaier, & Barnette, 2007; Mosher, Redd, Rini, Burkhalter, & DuHamel, 2009). Regardless of the difficult nature of discussing the subject, having open communication is essential in identifying and treating problems; avoiding sexual health concerns can significantly and negatively affect an individual's quality of life (Flynn et al., 2012).

Sexual health concerns can arise at any point along the illness trajectory, and several participants offered insight into the most optimal times at which they would like to have sexual health discussions. Several of our participants expressed the importance of briefly discussing sexual health early on in the treatment process and then having these discussions again when they transition home. Others noted that they were so overwhelmed with their diagnosis and the thought of ‘surviving,’ that having any discussions about their sexual health early on would not have been beneficial to them; insights into optimal times to discuss sexuality was supported by the research done by Booker et al. (2019) and Olsson, Athlin, Sandin-Bojö, and Larsson (2013). Similar to other studies, it was not until the majority of our study participants were back home and starting to feel better that they expressed an increased interest in resuming a sexual life. When life was returning to normal is when individuals were more likely thinking about seeking assistance in dealing with specific sexual health concerns (Olsson et al., 2013; Nørskov et al., 2015).

The timing of when to have sexual health discussions is important to explore since not all patients are the same; information should be given in a time and manner individually adjusted to each patient’s wants and wishes (Olsson et al., 2013). Providing support during and after treatment can affect patient outcomes and improve sexual function (Humphreys et al., 2007; Li et al., 2015; Schwartz & Plawecki, 2002). Though some participants identified they may not want information early on, it is important for the HCP to initiate discussions and provide some education. Having early interactions regarding sexual health enables the patient to recognize that supports are available; patients are then able to pursue help at a time best suited to them. According to Lemieux

et al. (2004), informing patients early on about the side effects of chemotherapy and other treatments on sexual health can help minimize physical harm if having sexual intercourse and helps destigmatize sexual problems. Information should be given in a timely and individualized manner, but it is important for the HCP to touch base with the patient early on in treatment letting them know resources and programs are available should at any point they become interested.

Navigating the Partnered Relationship

Sexual health changes post-transplant were a challenge for not only the participant but for their partner as well. The partners' expectations of what their sexual life may look like did not always align, often leaving one partner feeling like they were disappointing the other. Consistent with the findings by Booker et al. (2019), participants in this study revealed that it was often their partner who was afraid of physical intimacy; they feared harming or making the transplant patient ill. A common concern raised in our study was the safety of engaging in sexual activity when the transplant patient had a central venous catheter line. This concern had an impact on both partners. The removal of the central venous catheter line was frequently a factor affecting when a couple decided to reengage in sexual activity. To the best of our knowledge, despite being a concern reported in the clinical setting, the effects of having central venous catheter lines on intimacy have not been documented in the hematopoietic stem cell transplantation literature.

Consistent with other literature, a renegotiation of sexual and nonsexual intimacy was important to some couples to ensure they still had that 'closeness' with their partner (Hawkins et al., 2009). Nonsexual intimacy, such as cuddling and hugging, was an

important part of allowing couples to feel connected and eased their way to return of sexual intimacy (Hawkins et al., 2009). Participants noted that their sexual relationships became more of a priority and were less spontaneous post-transplant. Several couples had to reevaluate what intimacy looked like and were also navigating how to return to where they were before, if possible.

Similar to findings of Astarita et al., (2016), participants in our study often spoke of feelings such as frustration or guilt and were concerned about their partner's sexual (dis)satisfaction. The expectation that sexual responsiveness should return as it was before the diagnosis can be a mismatch of expectations between couples, and this is often compounded by a lack of communication (Yi & Syrjala, 2009). Several participants spoke about their feelings regarding the current status of their sexual relationship with their partner. None of the participants felt hopeless that they were not currently having sexual intercourse, but identified their partner might feel differently. Allowing the partner to be included in discussions can be beneficial and is noted to help maintain strong communication for years after and increases the attempts at sexual activity (Hordern & Street, 2007a; Yi & Syrjala, 2009).

Being single can pose additional concerns for those suffering sexual health concerns post-transplant (Yi & Syrjala, 2009). Similar to findings in our study, it can be difficult for single post-transplant patients to explain their current sexual health to a new partner; they need to find someone who can be understanding and accepting (Yi & Syrjala, 2009). Relationship status can also hinder sexual health conversations with a HCP as single patients are often excluded from such discussions (Ussher et al., 2013). Both single participants in our study were seeking help for sexual health concerns as they

were navigating new relationships; this reiterates the importance of providing resources for any individual regardless of relationship status.

Participants in this study spoke about navigating their relationship with their loved one and the hardships they experience as their roles changed throughout the illness trajectory. Study participants identified that their own preoccupation with surviving, and their partner's focus on making sure their physical and emotional needs were being met, made their partner's transition from a caregiving role back to loved one difficult to navigate. Consistent with other studies, these role changes within a relationship can potentially influence a couples' intimacy and affect their sexual interest and activity (Nørskov et al., 2015; Yi & Syrjala, 2009). Hawkins et al. (2009), identified that partners often describe an emotional toll of being the caregiver and often feelings of worry, stress, and exhaustion left them with little desire to re-engage in a sexual relationship. Several participants in our study stated at times throughout their illness, they thought their loved one's mental health was more affected than their own. Caregivers of cancer patients play an important role but often have significant unmet needs which can be an additional factor affecting their sexual relationships (Armoogum, Richardson, & Armes, 2013; Hawkins et al., 2009). Poloméni et al. (2016), recognized though some patients had difficulties and feared upsetting their partner regarding their changed sexual lives, most couples were not dissatisfied and often felt closer to their partner. Many of the participants in our study indicated this experience had made them reevaluate their relationships, and they actually felt closer to their partner than before their transplant. The participants who had strong communication when their partner valued their conversations and expressed how it often helped strengthen their relationship. This is consistent with

findings by Flynn et al. (2011), who found that cancer patients often expressed a need to discuss sexual desire, pain, appearance, and sexual changes with their partner. It is important that patients, and their partners, are educated on the possible impact a changed caregiving role may have on their partnership and sexual relationship.

Gender

Patients can experience diverse physical and psychological changes following transplant and cancer treatment, which can have an impact on their sexual health (Poloméni et al., 2016). Sexual health concerns of women and men may be quite diverse both quantifiably and subjectively. Consistent with the literature, women in this study reported a greater number of sexual health concerns relative to men (Heinonen, Uutela, & Zevon, 2001; Humphreys, Tallman, Altmaier, & Barnette, 2007). As also reported in the literature, women's sexual functioning problems typically got worse over time and men usually recovered from sexual dysfunction at a faster rate ((Astarita et al., 2016; Humphreys et al., 2007; Thygesen, Schjødt, & Jarden, 2012). Other authors have found that despite men typically recovering from sexual dysfunction at a faster rate than women, there tends to be a persistent decline in sexual satisfaction and negative outcomes on sexuality in both genders post-transplant (Noerskov, Schjødt, Syrjala, & Jarden, 2016; Wong et al., 2013).

Some of the most common symptoms reported by women following BMT are a lack of sexual interest, vaginal dryness, depression, and pain (Humphreys, Tallman, Altmaier, & Barnette, 2007; Thygesen, Schjødt, & Jarden, 2012). All of the women in this study identified concerns about vaginal changes including dryness and tightness that was associated with pain. Similar to other studies (Humphreys et al., 2007; Thygesen et

al., 2012) the majority of the men who participated in this study reported concerns with erectile dysfunction, decreased sexual desire, depression, fatigue, and concerns with their physical appearance.

Despite identifying having sexual health concerns, none of the men in our study were involved in any sexual health programs or support groups; in comparison to the two women who were involved in the OASIS program. During the multidisciplinary OASIS pilot project in Edmonton, from January 2014 until February 2016, the clinic received 130 referrals; 101 female and 29 males (Turner, Robinson, Wiebe, Jurak, & Hutchinson, 2017). Throughout this study, it was unclear why men seemed more willing to share their sexual health experiences and concerns in a research study, yet were not involved in any programs. The majority of women were involved in sexual health programs and having discussions with their HCPs, yet when approached to participate in this study, they declined to share their experiences. Other authors (Booker et al., 2019; Noerskov, Schjødt, Syrjala, & Jarden, 2016; Wendt, 2017) also had more males than females who participated in their research study.

Given our study findings, we were left with two questions: (1) Do women seek more assistance regarding sexual health because they experience greater side-effects post-transplant?, and (2) Is women's higher rate of seeking sexual health assistance relative to men, due to their greater willingness/comfort in disclosing their concerns?

Flynn et al. (2012) found that men with non-sex specific cancers thought discussions about sexual health were more important than women. Further, previous research has suggested that women typically get therapeutic help from their social support networks where men often benefit more from support provided by healthcare

professionals (Fife, Kennedy, & Robinson, 1994). However, contrary to this previous research, and consistent with findings from others (Frank, Anderson, & Rubinstein, 1978; Noerskov et al., 2016), our study revealed more women deemed these conversations important and more often reported sexual health concerns to a HCP, while most men who had physical sexual health concerns did not. Since the women in our study were already receiving help for their concerns, a possible inference is that the men who participated in this study may have found the interview process cathartic and therapeutic. There seems to be a gap in understanding why men typically volunteer more often to be part of studies involving sexual health but may not be as involved in programs. Given that men may benefit from more support provided by a HCP, a greater understanding of these gender differences could be important in learning how to provide better support for men in the future.

Study Strengths and Limitations

While there are many studies undertaken about the impact a BMT has on sexual health (Humphreys et al., 2007; Noerskov et al., 2016; Syrjala et al., 1998; Tierney et al., 2015), the majority have used quantitative methods. To our knowledge, this is the first study using a grounded theory approach in gaining a better understanding of patient's experiences post-transplant with a focus on sexual health.

The study included participants who had either allogeneic or autologous transplants, rather than only allogeneic transplants (Nørskov et al., 2015). We included both men and women, as opposed to focusing only on women (Astarita et al., 2016). Similar to the study by Booker et al. 2019, we extended the time frame of exploration including participants less than one year to greater than five years post-transplant.

Finally, we demonstrated the profound impact sexual health could have on a patient and their family, affecting some almost immediately post-transplant.

This study has some limitations to consider. A relatively small sample size (though consistent with grounded theory research (Strauss and Corbin), could render limited generalizability of the results. Participants were self-selected, and those who volunteered to participate could have a different experience from those who declined. In addition, we had very few women participate in the study. Our study sample came from the same treatment centre within Calgary, Alberta, and was limited to those who spoke English. Thus, the diversity of the sample was limited and would not be fully representative of the broad-ranging demographic characteristics of the BMT population.

Implications for Practice

Interventions focusing on increasing awareness about the importance of sexual health and the lack of initiation of conversations by HCPs are essential in addressing patients' sexual health needs. HCPs need to recognize that patients may often be too embarrassed to raise a sexual health concern and typically wait for the HCP to raise the issue (Hautamäki et al., 2007; Watson et al., 1999). Increasing awareness of the importance of sexual health, and the unmet needs of BMT patients may make this topic more significant, and ultimately, responsibility may be addressed.

There is a lack of specific sexual health programs and support groups for patients and their partners (Krouwel et al., 2015; Tracy, McDivitt, Ryan, Tomlinson, & Brotto, 2016). Offering programs can help alleviate the uncomfortable nature of the subject and has been shown to instill hope in individuals that their sexual lives could improve (Tracy et al., 2016). Currently at the TBCC in Calgary, Alberta the OASIS Sexual Health Clinic

exists at the tertiary level of care and within the first three months of the program being piloted received 39 patient referrals; the program's pilot funding expired in the Spring of 2018 (Turner et al., 2017). Currently, the OASIS clinic is now held once a month and is part of the TBCC programs being funded from Alberta Health Services Cancer Control operations (R. Booker, personal communication, May 13, 2019). Once a month the TBCC also offers a program for women called the 'Low Down on Down There.' In the past, there has also been a workshop offered at the Prostate Cancer Centre on intimacy after prostate cancer; to the best of our knowledge, this workshop is no longer offered (R. Booker, personal communication, May 13, 2019). Within the Canadian cancer care context, there are different sexual health programs and services; some centers have more robust clinics compared to others (Turner et al., 2017). Cancer patients in Alberta report high levels of disappointment with regards to the quality of sexual health education they were provided during treatment (Turner et al., 2017). The women in this study who attended the OASIS clinic provided positive feedback about the clinic and stated it helped them rebuild their sexual health; the participants felt supported and empowered by the clinic. Due to limited staffing, funding, and availability for consultations at tertiary cancer sites, sexual health programs are not to the quality standard they should be to meet current demands (Turner et al., 2017). With high referral numbers, this demonstrates that there is an interest in specialized clinics and signifies the need for additional sexual health resources and education for cancer patients (Turner et al., 2017). Further developing patient education modules, increasing staff training, and hiring a full-time sexual health clinic lead are a few recommendations to help increase sexual satisfaction, ensure patients are better supported, and increase quality of life outcomes (Turner et al., 2017).

The lack of training and education focused on initiating and discussing sexual health concerns with patients' needs to be addressed. Many patients would prefer and often wait for their HCP to initiate conversation, therefore, recognizing the importance of initiation and educating our HCPs on how to effectively open discussions with patients is important to address the concern (Tracy et al., 2016). As a lack of training seems to be a barrier in initiating discussions, HCPs (particularly nurses and physicians) need training on how to initiate these discussions, leaving the patient to decide if they want to continue the discussion or not (Krouwel et al., 2015). One way to resolve this lack of discussion would be to implement in-services and training to help HCPs initiate these discussions and have more frequent discussions (Astarita et al., 2016; Li et al., 2015; Tracy et al., 2016). Another recommendation would be to implement a standardized sexual health assessment or framework for HCPs to follow; currently, there does not seem to be any standardized sexual health assessment tools (Hordern & Street, 2007a; Oskay et al., 2014). As many nurses often lack the initiative or comfort to begin a sexually-related conversation, the addition of workplace guidelines may provide structure and help nurses overcome this barrier (Kaplan & Pacelli, 2011). Increasing the opportunities for communication between the HCP and patient about sexual health would potentially enable a smoother transition in navigating changes and adapting to a new normal.

The most appropriate timing along the illness trajectory to discuss sexual health issues seemed to be very individualized. Early intervention discussions, such as during the consent for treatment process, and then revisiting the topic periodically typically results in reduced sexual health concerns and helps normalize the subject to allow the patient and their partner to raise concerns at a later time (Stilos, Doyle, & Daines, 2008;

Li et al., 2015; Tierney et al., 2015). Sexual health concerns may occur immediately following transplant and can continue to increase in severity after one year; if not resolved by one year, they will typically still be present at year three. (Syrjala et al., 1998; Yi & Syrjala, 2009). Thus, assessments pre-transplant, regular follow-ups post, and long-term follow-up is valuable to ensure early detection and continued support of issues which may arise (Li et al., 2015; Molassiotis, 1997).

Implications for Future Research

Research aimed at assisting patients and their partners in living with new changes impacting their sexual health post-transplant needs to be further developed. We did not explore the experience of the partner post-transplant; from our understanding, the partners are also navigating new changes. Additional qualitative research exploring the experiences of both the patient and their partner may add to the research and help to build a better understanding of a couple's adjustment throughout the BMT trajectory.

Additional research regarding how gender differences may impact how HCP's provide education would be informative and would provide a better understanding of what supports need to be in place to adequately address the sexual health concerns of both women and men. There are data to suggest that men benefit more from support from their HCPs, and they may require more structured support (Heinonen et al., 2001). Exploring patients' experiences and understanding of these potential gender-based differences may provide a foundation for HCPs when providing support and resources.

A lack of education and clinical support for nurses is a barrier contributing to the poor incorporation of sexually-related discussions (Ussher et al., 2013; Saunamäki & Engström, 2014). Further research to gain an understanding of what individualized

educational opportunities would be most beneficial in helping all HCPs incorporate sexual health conversations into their daily assessments. Educational programs and training have been trialed and demonstrated that nurses often felt more comfortable and confident initiating sexual health conversations following these opportunities (Jonsdottir et al., 2016; Smith & Baron, 2015). Despite the positive outcomes, there still appears to be a gap in this area indicating that additional research may help increase the understanding of how to adequately implement and sustain educational opportunities. The outcome of this training would optimistically ensure the frequency of conversations increases and that the percentage of HCP's initiating conversations improves.

The incorporation of supplementary resources and programs accessible to patients throughout their illness could be significant in helping patients navigate changes and transition back into their sexual relationships. Shannonhouse et al. (2014), implemented an 8-week wellness-oriented support group program called "Finding Your New Normal" (FYNN), which covered multiple topics, including sexuality. The results revealed positive outcomes for the participants and demonstrated the need for the implantation and additional research on the outcomes of these types of programs (Shannonhouse et al., 2014). A sexual health clinic pilot study by Tracy et al. (2016), was generally helpful in providing cancer patients with information to those experiencing sexual health concerns; providing these resources early on may result in a cost-savings benefit in the long run for the healthcare system. Even though clinicians in this pilot study agreed it was useful, there was relatively little demand for this type of clinic (Tracy et al., 2016). Even with the optimistic outcome of piloted educational programs, there are minimal standardized sexual health programs in place. More resources and programs are

needed for patients to improve strategies for sexual counseling and self-management. Supplementary research on the long-term outcomes of educational programs could help increase our understanding of the impact it has on patient outcomes and the need for permanent programs.

Conclusion

While there are many studies undertaken about the impact a BMT has on sexual health (Humphreys et al., 2007; Noerskov et al., 2016; Syrjala et al., 1998; Tierney et al., 2015), the majority have used quantitative methods. Our study was the first grounded theory study exploring the experiences of individuals re-engaging in sexual relationships following a BMT. Conversations about sexual health are part of a holistic care approach and are noted to contribute to improved patient outcomes. Unfortunately, despite the common occurrence of sexual health issues, at least half of patients indicate that their HCP failed to discuss the effects of a BMT on sexual health (Milroy & Jones, 2010; Wendt, 2017). Navigating numerous concerns related to treatment, many of which impact sexual health, leaves individuals often searching for a better understanding of what a ‘new normal’ would look like and trying to accept these changes. This study provided valuable insights into a better understanding of when patients want to talk about their sexual health concerns, what they want to talk about, and the impact treatment has when re-engaging in relationships post-transplant. Findings from this study increase awareness of BMT patients’ sexual health needs and should help increase awareness about the needed sexual health conversations between HCPs and patients. Further research is needed to aid in breaking the silence of the unmet sexual health needs in the BMT population. In the future, additional research on this topic would lead to an increased

frequency of sexual health conversations and improved resources and programs that would benefit patients and enhance their quality of life.

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APPENDIX A: RECRUITMENT FORM

Bone Marrow Transplant Participants Needed For A Study On Sexual Health

Participants Needed

**WHO:**

- Adults (18+) who have undergone a bone marrow transplant
- Able to read and speak English sufficiently to understand the information and to participate in the interview
- Be in a committed relationship (need to have a partner with which to engage in a sexual relationship)

WHAT:

- Participation in this study will entail agreeing to participate in an interview that may last up to 60 minutes

The purpose of this research is to gain a better understanding of patients sexual health needs. The aim is understanding patient's experiences post-transplant and to increase awareness of what patients consider are their sexual health concerns along the way. The hope is to understand *when* patients want to talk about their sexual health concerns, *what* they want to talk about, and the *process* patients undergo to reintegrate back into their sexual relationships following a BMT.

Interested?

Please contact the primary researcher:

Call: 403-220-8069

Email: kristi.shartaul@ucalgary.ca

APPENDIX B: CONSENT FORM**Informed Consent Form for Participation in a Research Study****Experiences of Individuals Re-engaging in Sexual Relationships Following a Bone Marrow Transplant**

Protocol ID: HREBA.CC-18-0269

Primary Researcher: Kristi Shartau, RN, BN
Master of Nursing Student
University of Calgary
403-220-8069

Primary Investigator: Kathryn King-Shier, RN, PhD, FESC
403-220-8069

Study Team: Shelley Raffin Bouchal, RN, PhD
Reanne Booker, MN, BScN, NP

The primary researcher's role involves gathering data (by conducting interviews), analyzing the data, and writing the final report. This study is being undertaken to fulfill the requirements for a Master of Nursing thesis.

The primary investigator is the individual in charge of overseeing the research project. The primary investigator is responsible for the preparation, conduct, and management of the project to ensure all requirements are met.

WHY AM I BEING ASKED TO TAKE PART IN THIS RESEARCH STUDY?

You are being invited to participate in a research study because there is much to learn about the sexual health experiences of those who have received a bone marrow transplant. Conversations about sexual health are part of a holistic care approach and may add to improved patient outcomes. Despite the common rate of sexual health issues, patients sometimes indicate that sexual health concerns following a bone marrow transplant are not discussed. There are limited studies focused on the sexual health experiences of those who have received a bone marrow transplant. The studies done have not adequately addressed the patient's perspective on the impact treatment can have on reintegrating back into normal life and relationships.

The purpose of conducting this research is to have a better idea of patients' sexual health needs following a transplant. The aim is to understand patients' experiences post-transplant and to increase awareness of patients' sexual health concerns. The researchers hope to understand when patients want to talk about their sexual health concerns, what

they want to talk about, and the process patients undergo to reintegrate back into their sexual relationships following a transplant. In the future, data collected on this topic would hopefully lead to improved resources and programs that would benefit patients and enhance their quality of life.

This consent form provides information about the study to assist you in making an informed decision. The primary researcher will discuss this study with you and will answer any questions you may have. You are encouraged to ask questions. When your questions have been answered to your satisfaction, you can decide if you want to participate or not.

Taking part in this study is voluntary. You may choose whether or not you take part. If you choose to participate, you may leave the study at any time without giving a reason or without penalty. Deciding not to take part or deciding to leave the study early will not result in any penalty or affect current or future care or employment.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

Up to 20 people will take part in this study. We plan to enroll about 20 people at the Tom Baker Cancer Centre.

WHAT WILL HAPPEN DURING THIS STUDY?

You have been asked to participate in an interview. The interview will be scheduled at a time and place suitable for you. The study-specific interview for research purposes will be conducted by the primary researcher, Kristi Shartau. This interview will be conducted with or without the primary investigator, Kathryn King-Shier, present. You will be asked questions about your age and marital status. Then you will be asked several open-ended questions about your bone marrow transplant journey and its effect on your sexual health. The interview should take no longer than 90 minutes. The interviews will be recorded digitally and transcribed (turned into written records) for the purpose of data analysis. After reviewing your interview transcript we may wish to contact you again if any clarification is required. The recording will be deleted after transcription with scribed copy stored in a secure location at the University of Calgary.

WHAT ARE MY RESPONSIBILITIES SHOULD I DECIDE TO PARTICIPATE IN THIS STUDY?

There are no other requirements than those identified above.

WHAT WILL HAPPEN IF I CHOOSE TO WITHDRAW FROM THE STUDY EARLY?

You do not have to participate in this study. Your contribution to this study is voluntary. You may withdraw from the study at any time without affecting your health care. You

may withdraw from the study before or during the interview; you may request that the recorded interview be deleted by telling the primary researcher that you wish to withdraw. If you decide to withdraw after the interview and before the interview data have been analyzed, you may request that the recorded interview and transcription be deleted/destroyed by telling the primary researcher that you wish to withdraw. You can also withdraw by calling the following number and leaving a message (403-220-8069). If any information comes available that may affect your decision to participate in this study, you will be informed as soon as possible.

If the interview is completed and data analysis has been started, you cannot be removed from the study and the collected data will be used.

WHAT ARE THE RISKS OF PARTICIPATING IN THIS STUDY?

Very few risks are associated with this study. You may find that some of the questions asked about a cancer diagnosis and sexual health concerns could bring up upsetting memories. If you do not want to answer a certain question, you can say so.

If you feel any distress from participation in the study, counseling services are available. You can self-refer or be referred by the study team to the Department of Psychosocial Resources at the Tom Baker Cancer Centre.

WHAT ARE THE POTENTIAL BENEFITS OF PARTICIPATING IN THIS STUDY?

Participation in this study may or may not be of personal benefit to you. The information obtained from this study may help to increase awareness of healthcare professionals about patients' sexual health needs. The information obtained may also help improve conversations between healthcare professionals and patients.

HOW WILL MY PERSONAL INFORMATION BE KEPT PRIVATE?

If you decide to participate, the primary researcher and investigator, as well as the study team, will only collect information they need for this study. They will do everything that they can to make sure that this data are kept private. Any information shared in this study will be kept anonymous. This means that you cannot be identified.

All data and transcripts will be in a secured laptop database. The laptop will be encrypted and password protected. The only person who will have access to this laptop will be the primary researcher. All study team members will require verbal consent from the primary researcher before accessing data. A master list of all participants name and contact information will be kept on the primary researcher's laptop. An additional list with all identifiers removed will be encrypted and password protected on the primary researcher's laptop.

Once the research study is complete, the data will be locked in the primary investigator's office. All study data will be kept for five years. At five years, the primary investigator will shred and delete files, and the remains will be discarded in a confidential recycling bin.

The audio recordings will be stored in a secure location and viewed only by members of the research team. The recordings will be kept until they have been transcribed, and then they will be destroyed.

No data relating to this study that includes your name will be released outside of the study site. Nor will it be published by the researcher. Only the research study team is allowed to disclose information collected from the study to other team members. Sometimes, by law, the researcher may have to release information including names. Therefore, complete confidentiality cannot be guaranteed. However, every effort will be made to make sure that your information is kept confidential.

Individuals of recognized organizations may look at your records for quality assurance purposes. They may also look at your records to verify that the information collected for this study is correct and follows proper laws and guidelines. The first organization is the Health Research Ethics Board of Alberta which oversees the ethical conduct of this study. The second organization includes members of the regulatory audit team at the Tom Baker Cancer Centre for assurance purposes.

Even though the chance that someone may identify you from the study data is very small, it can never be fully eliminated. Every effort will be made to keep your information private, and to follow the ethical and legal rules about collecting, using, and disclosing this information.

By signing this consent form, you are allowing the study team to collect, use, and disclose information about you from your personal medical records.

A copy of the consent form that you sign to enter this study may be included in your medical record/hospital chart.

WILL THERE BE COSTS INVOLVED WITH PARTICIPATING IN THIS STUDY?

Depending on the location, parking will be a required cost.

WILL I BE COMPENSATED FOR PARTICIPATING IN THIS STUDY?

You will not be paid for taking part in this study. If you suffer injury as a result of participating in this research, no compensation will be provided to you by the University

of Calgary, Alberta Health Services, or the Researchers. You have all your legal rights. Nothing said in this consent form alters your right to seek damages.

WHAT IF SOMETHING IS DISCOVERED ABOUT ME DURING THE STUDY?

During the study, the research team may learn something about you that they did not expect. For example, they may find out that you have another medical condition in addition to your cancer diagnosis. If any new clinically important information about your health is obtained as a result of your participation in this optional research, you will be given the opportunity to decide whether you wish to be made aware of that information. The researcher will explain the process, which may include genetic counseling to help you understand what this result could mean for you or your blood relatives, such as your siblings and/or children.

WHAT ARE MY RIGHTS AS A PARTICIPANT IN THIS STUDY?

You will be told, promptly, about new information that may be relevant to your willingness to stay in this study.

You have the right to be informed of the results of this study once the entire study is complete. If you would like to be informed of these results, please contact the researcher.

Your rights to privacy are legally protected by federal and provincial laws that require safeguards to ensure that your privacy is respected.

By signing this form you do not give up any of your legal rights against the hospital, researchers, institutions or their agents involved for compensation. Nor does this form relieve these parties from their legal and professional responsibilities.

IS THERE ANY CONFLICT OF INTEREST RELATED TO THIS STUDY?

There are no conflicts of interest related to this study. The researcher will not receive any direct benefit from conducting the study.

WHO DO I CONTACT FOR QUESTIONS RELATED TO THIS STUDY?

If you have questions about taking part in this study, you should talk to the researcher or primary investigator. These persons are:

Kristi Shartau 403-220-8069
Kathryn King-Shier 403-220-8069

If you have questions about your rights as a participant or about ethical issues related to this study and you would like to talk to someone who is not involved in the conduct of the study, please contact the Office of the Health Research Ethics Board of Alberta.

Telephone: 780-423-5727

Toll-Free: 1-877-423-5727

UNDERSTANDING AND SIGNATURES PAGE

| | <u>Yes</u> | <u>No</u> |
|---|--------------------------|--------------------------|
| Do you understand that you have been asked to take part in a research study? | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you understand why this study is being done? | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you understand the potential benefits and risks/discomforts of taking part in this study? | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you understand what you will be asked to do should you decide to take part in this study? | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you understand that you are free to leave the study at any time, without out having to give reason or without penalty? | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you understand that we will be collecting information about you for use in this study only? | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you understand that by signing this consent form that you do not give up any of your legal rights? | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you feel that you had enough time and opportunity to consider the information provided to you by way of asking questions, having conversations with others and considering your options? | <input type="checkbox"/> | <input type="checkbox"/> |

If a potential participant has answered “no” to any question above, please make sure to go over the relevant information with them until they do understand it. **Only once they are comfortable with all the information can you accept their decision to participate in the study.**

By signing this form, I agree to participate in this study.

Signature of Participant

Printed Name

Date

STUDY TEAM ACKNOWLEDGEMENT

I believe the person signing this form understands what is involved in this research study and has freely decided to participate.

Signature of Person
Conducting
the
Consent Discussion

Printed Name

Date

If you decide to participate in this study, you will need to sign and date this consent form. You will be given a copy of this signed and dated consent form before participating in this optional research.

APPENDIX C: PATIENT DEMOGRAPHIC FORM

Interview Date: ___/___/___
 D M Y

Patient Information:

Cancer Diagnosis:

Type of Bone Marrow Transplant:

Age at time of interview:

Sex: ___M ___F

Marital Status:

Single with Committed Relationship


Married

APPENDIX D: BEGINNING INTERVIEW QUESTIONS

- (a) What it was like going through cancer treatment and undergoing a bone marrow transplant?
- (b) Sexual health can mean a lot of different things to different people; what does the term sexual health mean to you?
- (c) After undergoing a bone marrow transplant, did you have any sexual health concerns or questions? Did you have any concerns before the transplant?
- (d) Do you believe your sexual health concerns were addressed during treatment?
- (e) Was there a specific time where sex became a focus and you felt more open or wanted to talk about any sexual health concerns?
- (f) Who along the way socially or clinically was helpful in addressing your sexual health needs?
- (g) Do you believe it is any one person's responsibility to address sexual health concerns?
- (h) Tell me about the re-integration of your sexual relationships since completing treatment? Did anything change, and how did you address these changes?
- (i) After your transplant, did your relationship with your partner change due to any sexual health changes? If so, how did you manage those changes?

APPENDIX E: CODING EXAMPLE

Coding Example: Identifying the Importance of Sexual Health

| Text | Open Coding | Axial Coding |
|---|---|---|
| <p>“Prior to this, my wife and I had good intimacy, but after I got sick of course there was nothing to do with sexual health at all, it was survival, it was being able to do one or the other.”</p> <p>“I knew that prior to starting chemo it all went very fast, but we did do some sperm banking prior to starting chemo. This had been a long dream of ours to have kids naturally, so we attended an information session on IVF and met with the doc to discuss that.”</p> | <p>No Issues Prior</p> <p>Timing/Importance Priorities/Treatment</p> <p>Diagnosis/Family Planning Assessing Future Options</p> <p>Discussions/Education Partner Involvement</p> | <p>Survival</p> <p>Identifying Importance</p> <p>Life Stage</p> |
| <p>Level of Abstraction Low</p> |  | <p>High</p> |