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Patients' experience of sexuality 1-year after allogeneic Haematopoietic Stem Cell Transplantation

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A B S T R A C T

Purpose: This study explores how patients' experience of sexuality is influenced by physical, psychological and social changes one year after undergoing haematopoietic stem cell transplantation (HSCT).
Methods: A qualitative study using semi-structured in-depth interviews. The respondents (n = 9) were recruited from the Department of Haematology, Copenhagen University Hospital, one year after HSCT. The interviews were analysed from a phenomenological-hermeneutic perspective.
Results: Bodily changes and symptoms related to chronic graft vs. host disease led to physical limitations or altered body image, which directly or indirectly resulted in sexual dysfunction or problems with intimacy. Symptoms related to chronic GVHD, could explain experiences of sexual dysfunction. Sexual needs were deprioritized as survival became paramount. The experience of changed social roles, both in family life and social network, affected self-image and identity. Finally, communication about sexuality and sexual needs was of significant importance to the current state of their relationship.
Conclusion: Physical body alterations, challenges in mastering their new life situation and identity changes affected sexuality and sexual function one year after HSCT. As symptoms resided, sexuality and sex life became more and more prominent in their thoughts and lives. Increased focus is needed on sexuality and sexual dysfunction in the HSCT clinical setting.

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Introduction

The issues of sexuality and sexual dysfunction are greatly underrepresented in research, clinical practice and preventive healthcare despite its public health relevance (Park et al., 2009; Stead et al., 2003; Thygesen et al., 2012; Yi and Syrjala, 2009). Evidence suggests that sexual dysfunction is a threat to the joy of life and marital relationships, and can lead to stress and impaired coping ability in chronically ill patients (Christensen et al., 2011b; Derogatis et al., 2007; Derogatis and Burnett, 2008; Flynn et al., 2011; Hordern and Street, 2007; McKee and Schover, 2001). Yet, sexuality is a neglected topic in public health and there is a need to understand the complex relationship between sexuality, health and disease (Christensen et al., 2011a). The World Health Organization (WHO) applies a health concept within the bio-psycho-social paradigm in which sexuality is defined as a central aspect of being human throughout life, and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction (WHO, 2014). Additionally, sexuality is found to be influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors (WHO, 2014).

The era of allogeneic haematopoietic stem cell transplantation from a donor (HSCT) has been revolutionary in the treatment of haematologic malignancies. Although HSCT has been successfully used to treat various malignant and non-malignant, typically life-threatening diseases, HSCT is associated with risk of significant physical and psychosocial morbidity (Abou-Mourad et al., 2010). Transplantation-related morbidity is evident throughout the course of HSCT, beginning with pre-transplantation conditioning and extending well into the post-transplantation recovery phase (Socie et al., 1999; Yi and Syrjala, 2009). This aggressive therapeutic modality is associated with numerous short and long-term toxicities that might potentially cause changes in sexuality and sexual

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functioning (Mosher et al., 2009; Yi and Syrjala, 2009). As survival rates for HSCT improve, there is subsequently an increased need for addressing long-term complications, including sexual dysfunction (Abou-Mourad et al., 2010; Bhatia, 2011). Thygesen et al. (2012) identified in a systematic review that patients following HSCT were found to report in varying degrees an altered sex life and several sexual changes, and the aetiology of these changes differed between the sexes (Thygesen et al., 2012). Long-term sexual complications include decreased libido, vaginal alterations, erectile and ejaculatory dysfunctions, premature menopause, dysfunction in sexual hormones, dyspareunia and infertility (Socie et al., 1999; Syrjala et al., 2005; Thygesen et al., 2012; Tierney, 2004). Furthermore 45% males and 33% females following treatment with HSCT experienced a decline in the quality of their sexual life (Molassiotis et al., 1995, 1996). One of the major determinants of sexual dysfunction in allogeneic HSCT patients is chronic graft versus host disease (GVHD) (Syrjala et al., 1998, 2008). GVHD is a complex immune-related inflammatory response, where donor-immune-cells (graft) identify the body (host) as foreign and therefore attack its cells and tissue (Mattson, 2007). GVHD can manifest anywhere in the body; however, in the genitals it can lead to vaginal stenosis, scar tissue and adhesions in blood vessels, rash and increased sensitivity in the skin (Lara et al., 2010; Yi and Syrjala, 2009; Zantomio et al., 2006). Furthermore, the primary medical treatment of GHVD is glucocorticoids, which have many known side effects that can lead to physical and psychological changes (Sanders, 2002).

A holistic approach to sexual matters is essential since the genesis behind sexual problems is rarely unambiguous (Denman, 2004). Overall, the existing body of knowledge indicates that sexual dysfunction is a long-term complication following HSCT. However, only quantitative studies of sexual dysfunction in patients following HSCT are available (Thygesen et al., 2012). In order to gain a deeper understanding of how people experience their sexuality after treatment, it is necessary to achieve descriptions based on their own understanding, intentions, norms and values. A deeper understanding of experiences following HSCT may reveal important patterns in relation to sexuality and psychosexual issues (Crabtree and Miller, 1999). Furthermore, little is known about sexual changes from a biopsychosocial framework experienced by patients following HSCT. Therefore, this study explores how the patient's experience of sexuality is influenced by physical, psychological and social changes one year after HSCT.

Methods

The study is a qualitative phenomenological hermeneutic study based on semi-structured interviews. To explore the patient's experience of everyday life, we applied a semi-structured interview guide with open-ended questions (Appendix 1). Interpretation of the interview text is based on Lindseth and Nordberg's phenomenological hermeneutic approach, which is based on the French philosopher Poul Ricoeur's theory of interpretation (Lindseth and Norberg, 2004). Ricoeur stated that interpreting a text is to see something new in what is already taken for granted and to disclose a sort of being-in-the-world (Riceur, 1973).

Respondents

The sample included nine patients who were approached at their one-year control visit following HSCT at the out-patient department. The study was conducted at Rigshospitalet, Copenhagen University Hospital, at the Department of Haematology, Stem Cell Transplantation Unit. The Unit treated a total of 94 patients in Denmark in the study period (Hovgaard). Inclusion criteria were patients who were >18 years, eleven to thirteen months post HSCT who provided informed consent and had the ability to understand, speak or read Danish. The exclusion criteria were cognitive problems, relapse, hospital admission and unethical reasons. An opportunistic sample was chosen because of the small number of patients available. 17 patients were assessed for eligibility and 8 were excluded because of relapse (n = 2), ethical reasons (n = 1), hospital admission (n = 1) and gender balance (n = 3). A total of 9 patients were included in the study, and the characteristics of the respondents are summarised in Table 1.

Data collection

Eligible patients were introduced to the study by the primary investigator and clinical nurse specialist Kristina Thygesen (KT). Respondents had the choice of being interviewed at home or at the hospitals outpatient Stem Cell Transplantation unit. All chose to be interviewed at the hospital, and the interviews were all conducted at the one year control visit following HSCT by KT. The interviews lasted between 22 and 45 min, were digitally recorded and transcribed verbatim by a professional typist. In addition, 'field notes' were written immediately after each interview.

An initial interview was used as a pilot to assess the respondents' understanding and acceptance of the content and sequence of questions. Themes and questions were not changed after this interview. The interview guide was based on a review of the existing literature and followed with flexibility in the sequence of topics according to the respondents' responses.

Ethical issues

Each respondent received verbal and written information regarding the purpose of the study, including the right to withdraw from the study and assurance of confidentiality according to the basic principles for research stated in the Helsinki Declaration and Northern Nurses Federation. Written informed consent was obtained before the interview, reminding the respondents of the voluntary nature of the interview. Respondents were considered vulnerable individuals, and due to the sensitivity of the subject of study, they were given written information about the themes in the guide before the interview. The study is registered by the Danish Data Protection Agency and approved by The Joint Ethics Committee of the Capital Region of Denmark (approval nr. H-C-FSP-2010-12).

Data analysis

Data were managed by the qualitative computer software package NVivo version 9. The interpretation of the interview text was carried out by two researchers (KT, MJ) and is based on Lindseth and Nordberg's approach, inspired by Poul Ricoeur's theory of interpretation (Lindseth and Norberg, 2004). The analysis was performed on three levels: a naive reading, structural analyses and a critical analysis and discussion (Lindseth and Norberg, 2004; Riceur, 1973). *Naïve reading* is the first impression of the interview text as a whole, achieving an immediate understanding of the content. *Structural analysis* is carried out on three levels: "what is said" (quotes), "what the text speaks about" (meaning), and finally, the text is structured into main themes and subthemes (interpretation). In the *critical analysis*, the interpretation continues with a discussion of findings in a dialectic pattern between explanation and comprehension achieved by cross analysing and discussing the naïve reading, the validated themes, and external literature relevant for the topics. This "final act of comprehension" is used to

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