

Lived Experience of Comfort on Sexuality and Fertility for Survivors of Hematopoietic Stem Cell Transplants: Phenomenological Study

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Abstract

Purpose: To grasp the scope of sexuality and fertility within the lived experiences of comfort and discomfort among allogeneic stem cell transplant survivors.

Methods: We employed a qualitative approach through van Manen's phenomenology of practice. The phenomenon was revealed via phenomenological interviews, incorporating narratives and illustrative episodes that captured the lived experiences of 20 survivors. We gathered descriptions of these experiences from participants from July 2020 to May 2021. During our phenomenological reflection on these accounts, we adhered to stages like epoché, reduction, and vocative, as outlined by van Manen (1).

Results: The exploration of comfort within the realms of sexuality and fertility yielded several themes: desire and the relationship; immunosuppression as a limitation on sexual activity; the body does not correspond to desire; the future: fertility and the couple's relationship; the challenges of disclosure and intervention.

Conclusion: The findings indicate that survivors have long-term challenges with sexual expression and activity, stemming from the physical constraints of GVHD, perceptions of their immunosuppression, and the significance of their partnership, all of which translate into requirements for nursing care.

Implications for Cancer Survivors

Considering the experiences of these participants and the observed comfort linked to the sexuality of AHSTC survivors, we can contemplate the care practices and recognize sexuality as a field of action for nurses in this context to enhance comfort for these individuals.

Introduction

Allogeneic Stem Cell Transplantation (AHSTC) offers a realistic prospect of curing oncological diseases or permanently addressing chronic hematological, immunological, or metabolic disorders. However, it is a lengthy process fraught with changes and complications stemming from the individual's condition, treatment, and even family, social, and community factors that may affect their well-being. Those undergoing AHSTC experience a multifaceted process filled with unique sensations, emotions, thoughts, and experiences, presenting a challenge to healthcare due to their specialized and extended care needs. The emergence of cancer survivors as a distinct group with particular needs, owing to the after effects or complications of their treatments, is now acknowledged (2, 3). With early cancer detection and more effective treatments, the trajectory of the disease has shifted, resulting in a growing population of individuals who survive cancer and live on for many years post-diagnosis (4).

Recognizing that each individual experiences situations and circumstances uniquely, we have embraced the definition of a survivor by Carlyle et al. (5) which considers a person who has finished treatment and is in remission. Survivors of Allogeneic Stem Cell Transplant (AHSTC) live with chronic conditions, facing multiple discomforts due to lifestyle changes, altered expectations, projects, meanings, distress, and the

adoption of specific therapeutic regimens. Given this reality, and considering the holistic functioning of humans, it becomes crucial to address the complete pattern of the individual's life process, particularly in how they perceive comfort (6). Comfort is simultaneously a noun, verb, adjective, a state, a process, and an outcome (7). Despite its complexity, comfort is essential in holistic human care, a fundamental concept in Nursing, and a vital part of the care process (7, 8).

Research interest in the concept of comfort in nursing has been growing (7, 8). Kolcaba categorizes comfort into three types: relief, ease, and transcendence. However, the experience of comfort in patients who have survived TSA remains underexplored. The chronic conditions associated with TSA survival are becoming more common and significantly affect the survivors' lives and daily activities (9). The rising number of transplant process survivors, thanks to advancements in treatment effectiveness and broader application across pathologies, prompts a reflection on the life challenges these individuals encounter. These challenges lead to various life alterations and highlight diverse health needs that require comforting responses, thereby presenting challenges to healthcare during the survival period ((6).

The impact of this situation on personal, familial, and social levels is acknowledged, as well as the accompanying instability and insecurity. Despite understanding that the severity of complications and necessary life adjustments in intimacy and sexuality can affect comfort during transplantation and survival, the actual experience of comfort in this domain remains unexplored.

The sexual and emotional aspects of a person's life are significantly affected following an allogeneic hematopoietic stem cell transplant (AHSCT). Often, this issue is overlooked by both patients and caregivers. The myriad of physical, endocrine, and genital complications associated with chronic graft-versus-host disease (cGVHD) are complexly linked with psychological disorders(10–12).

Investigating the meaning individuals assign to their experiences helps identify their needs and provide appropriate responses. Since the interpretation of experiences varies from person to person, grasping the daily reality of survivors and considering the key aspects that define the concept of comfort is crucial.

Methods and design

Design

To grasp the lived experience of comfort, we employed a qualitative method based on van Manen's (2014) phenomenology of practice (1, 13).

Theoretical framework

Comfort, being a broad and multifaceted concept, requires elucidation within the lived experiences of AHSCT survivors. Therefore, exploring these experiences through phenomenology can lead to insights that promote equitable, respectful, and comforting care. Phenomenology, as a philosophical method for examining experience, is a human science focused on the meaningful structure of lived experiences.

Hermeneutic significance is bestowed upon these experiences when they are reflected upon and imbued with memory ((14)

Setting and participants : The study involved individuals who had received allogeneic stem cell transplants and were under outpatient follow-up. Eligible participants were those who: (i) were aged 18 or older; (ii) had been survivors and undergone AHST for a minimum of three months; (iii) showed no signs of disease relapse; (iv) could verbally communicate, providing information pertinent to the study, and articulate their emotions and feelings. A total of twenty individuals shared their experiences as survivors for this research (Table 1). The participant count was determined with the aim of gathering detailed accounts of personal experiences to form experiential examples, revealing the essence of these experiences. Sufficient narratives were obtained to create a representative and coherent structure that addressed the central research questions (15) The collection of experiences ceased upon reaching twenty participants, at which point the narratives provided a rich, intricate, and nuanced understanding of the experiences, unveiling a previously unexplored realm.

Table 1
Characterization of the participants

Survivor name (Fictitious)	Age	Sex	Diagnose	Years after ASCT	Presence of GVHD
Isabel	52	Female	Monomac Syndrome	4	yes
Amélia	43	Female	Acute Myeloid Leukemia	5	yes
Alice	44	Female	Non-Hodgkin Lymphoma	5	yes
João	45	Male	Acute Myeloid Leukemia	5	yes
Anita	33	Female	Acute Myeloid Leukemia	2	No
Camila	40	Female	Non-Hodgkin Lymphoma	2	No
Santiago	43	Male	Non-Hodgkin Lymphoma	2	Yes
Rodrigo	50	Male	Acute Lymphoblastic Leukemia	4	Yes
Carmo	41	Female	Acute Lymphoblastic Leukemia	4	Yes
Afonso	58	Male	Acute Myeloid Leukemia	3	Yes
Mafalda	42	Female	Hodgkin Disease	12	Yes
Matilde	49	Female	Hodgkin Disease	1	No
Tiago	60	Male	Non-Hodgkin Lymphoma	8	Yes
Diana	45	Female	Acute Myeloid Leukemia	2	Yes
Sara	44	Female	Acute Myeloid Leukemia	2	No
Diogo	32	Male	Acute Lymphoblastic Leukemia	9	Yes
Francisco	49	Male	Myelodysplastic syndrome	5	Yes
Miguel	50	Male	Chronic Myeloid Leukaemia	1	No
Raquel	44	Female	Acute Lymphoblastic Leukemia	10	Yes
Duarte	60	Male	Acute Lymphoblastic Leukemia	3	Yes

Data collection

Following van Manen's (16) guidelines, the principal investigator did a phenomenological interview the study participants were asked to focus on a particular experience, describing the event by specifying it as close as possible to what was lived, in relation to feelings, mood, and emotions; paying special attention to what was felt and how, "what sounds were felt", leading the survivor to highlight what was lived during this experience, as if they were returning to the moment. The interviews were carried out in a place chosen by the survivor, guaranteeing the person's privacy, in a comfortable space: at home, in a garden, at the hospital, on a terrace.

In an approximation to reality, we also used the collection of illustrative material from sources such as literature, in this case literature written by the survivors themselves, of the participants' choice, which served as catalysts for reflection, in order to illustrate and expose aspects that further elucidated the phenomenon, clarifying it (17) To complement the lived experience descriptions, after completing the transcription, it was returned to each survivor who added information, experiences that were lived in order to complement the lived experience descriptions.

Data analysis

To describe the lived experience of AHST survivors, we identified the themes that emerged from the lived experience descriptions. In this process, we sought to capture the themes "by removing appropriate phrases or capturing in simple statements the core meaning of the themes" as suggested by van Manen ((13) p. 93). The process used to identify the themes of the phenomenon under study was developed in four moments: (i) first, after the transcription and compilation of all the lived experience descriptions, a holistic reading was performed so as to capture the meaning and sense of the whole (van Manen, 1990, 2014). (ii) then a detailed and reflective reading of the descriptions was performed, where we tried to identify the essential and revealing phrases of the lived experience under study, (iii) in a third moment, the thematic units extracted from the descriptions that show essential themes related to the phenomenon were highlighted. The essential themes allowed guidelines for the discovery of the major dimensions of the lived experience and "make the phenomenon what it is, and without which the phenomenon could not be what it is" (13)). At this stage, looking at all the sentences and group of sentences was guided by the question: what do these sentence or group of sentences reveal of the lived experience described? We used software Maxqda to support the discovery of the themes.

From here emerged the relationship with the themes and subsequent construction of the text illustrating the results of the study. We do not attribute meaning to the number of occurrences of each experience, an experience had relevance to construct the final meaning picture. This phase of the research was trustworthiness and confirmability of the phenomenological reflection with experts in the field of qualitative research and methodology. (iv) Next, we proceeded to phenomenological writing with the objective of constructing a text evoking the description of human actions, behaviours, intentions and experiences as they are uncovered. Given that the aim was to build an evocative text that accessed the experience as it is lived by people, it was important to use sources that allowed illustrating the meaning of the phenomenon under study, shared by some of the participants(1).

Ethical Considerations

Before each description of lived experiences was collected, participants completed a free and informed consent form, having read it and resolved any uncertainties. The research process ensured the complete confidentiality and anonymity of the participants. They were informed of their right to withdraw from the study at any time without affecting their care. The first author anonymized the participants' identities, and no other staff member could access patient identifiers. The Research Ethics Committee of the Instituto Português de Oncologia de Lisboa, Francisco Gentil EPE (UIC Code 1314), approved this research, which adhered to the Declaration of Helsinki (1964). Phenomenological interviews were recorded and supplemented with notes. Only the participants and the principal investigator had access to these materials. The research upheld confidentiality, anonymity, and the principles of beneficence and non-maleficence, in line with the EQUATOR communication standards.

Results

The experience of intimacy and sexuality is a crucial aspect of a survivor's comfort life, significantly impacted by the journey of illness, treatment, and the subsequent survival period. Within the intimate sphere of sexuality, the AHSCT process can alter multiple facets.

i. Desire and the relationship

Throughout the illness and treatment phase, a decrease or absence of sexual activity is commonly reported. Individuals often do not feel capable of engaging in sexual activity, lacking the necessary physical, psychological, and emotional resources to incorporate it into their lives. In the survival phase, individuals attempt to reclaim the aspects of sexuality that were suppressed, becoming cognizant of new challenges and restrictions. It is noted that libido often diminishes during the illness and may persist even after treatment has concluded. The path to regaining libido is multifaceted, extending beyond hormonal changes, and profoundly affects self-esteem and self-image, thereby influencing the living situation and the dynamics within the partnership. Afonso, Alice and Anita said:

Afonso: "Indeed, there has been a change in sexuality, and it remains unresolved. My libido has significantly decreased! For a long stretch, and even now, it's inconsequential; it doesn't cross my mind, it's absent. Occasionally, there's a flicker, but it's not a part of my life. It's not particularly troubling to me, but it does affect my relationships, which I consider occasionally. It's a profound side effect, indeed."

Alice: "Considering your intimate life, I understand there are alternatives to sex, which remains significant. The sex life is still out of sync, and the relationship suffers from this disconnection."

Anita: "I've observed a decline in sexual activity compared to before the illness. However, it seems to be a gradual change because my libido is now improving."

The dynamics between partners and their roles during an illness significantly influence the resumption of sexual activity, and this is interpreted uniquely by each couple. The continuous presence and the shift

from being a partner to a caregiver can complicate the return to sexual intimacy. Raquel and Santiago said:

Raquel: *"My husband and I became mere shadows, remnants of the young, joyful, and hopeful couple we once were (...) his primary role evolved into that of a 'carer' (...) he was more than my spouse; he became akin to my father and brother."*

Santiago: *"It has changed. It has changed because being together constantly makes things more complex. For instance, when we tire of something, we take a walk, and it dissipates, right? Since we're not separated all day due to work, our dynamic shifts. That feeling of 'nostalgia,' right? Nostalgia drives our desire to be together. While it has, on one hand, brought us closer, on the other, it has also made us too comfortable and, paradoxically, more distant in a way. It's more of the same, essentially!"*

On the other hand, her partner stepping back from the caregiver role hindered the growth of sexuality and intimacy within another couple's relationship, Afonso experienced *"After such a long absence of contact, it's challenging to reconnect. Thankfully, beyond the initial shock of my wife no longer being a caregiver, there are other forms of intimacy and strong bonds that compensate for the losses. Time will tell what unfolds (...)."*

ii. Immunosuppression as a Limitation on Sexual Activity

Participants shared their experiences of prolonged immunosuppression, describing a sense of vulnerability to disease and its effect on their sexual and intimate experiences as individuals and as couples. The fear of infection, the imperative to avoid illness, and the necessity of maintaining infection control post-transplant shape their sexual lives. The Covid-19 pandemic has intensified these fears due to the increased risk of contagion, with partners often being more exposed as they continue to shop, work, and perform other activities outside the home. Afonso explained: *"With the pandemic, the inability to kiss for an extended period, especially post-transplant, has compounded over time. Even contemplating a simple, light kiss raises the question, 'Can I?' The absence of such contact makes it difficult to reengage."* Camila felt the same *"I strive to provide her with all the love and pleasure possible, despite the constraints of our current situation. It's been a year and a half, and I'm still not ready to forego any form of protection."*

iii. The body does not correspond to desire

Physical pain and mobility limitations act as barriers to sexuality within the couple's relationship. The discomfort linked to osteonecrosis and the cutaneous and articular manifestations of GVHD complicates movement and restricts these individuals from participating in sexual activities. Carmo shares: *"It's been non-existent for a long time. Walking is a struggle, as is simply turning over in bed. With the lockdown, since he goes to work, our time together is minimal. We're hardly ever close; he sleeps in the office, and I sleep in the bedroom, sometimes with my daughter. The lack of intimacy has persisted since my pneumonia in 2019. The last occurrence was some time back, following my hip surgery. There*

was a phase before my diagnosis when intimacy ceased, and my extended stays in Lisbon also contributed to that absence. Post-surgery, I was on the path to recovery, but then regressed. The pneumonia, the eight months in the hospital, and my complete immobility took their toll. Now, even with slight movement, pain is a constant. I deeply miss the intimacy, but I am at a loss for what to do." Francisco shared, "(...) *I experience significant pain at night. Any movement or touch to my legs causes pain. Consequently, I've started sleeping in a different room. We haven't shared a bed since."*

Changes in lubrication are noticeable, with mucosal dryness resulting from treatments or the onset of menopause leading to discomfort and restricting sexual activity. Sara noticed: "*Initially, we observed that my skin was extremely dry, which I believe is due to the chemotherapy. However, our desire to be together never waned."* Raquel felt "*Lubrication is altered, I felt dry, no matter how much stimulation I had and this consequently caused pain during sexual activity."*

Sexual impotence, in the case of men, limits the fulfillment of sexual activity and causes discomfort, given the impact this limitation has on self-image and self-concept. It interferes with the survivor's sense of masculinity. João said: "*It's changed, it's changed. It's changed, and just yesterday I went to the endocrinologist and reinforced this again with the doctor. There was a time when I couldn't get an erection. I take the intimacy part to mean sexuality, because all the other intimate parts are impeccable. There was a long period after the transplant when I couldn't.(...) I have to admit that I've never been the same again in that respect, unfortunately. Although the medication continues to help, unfortunately there are things that haven't gone back to the way they were before. It's like anything, sometimes it goes well, sometimes it goes badly, sometimes not so well, sometimes we just stop there."* Tiago revealed "*I've tried to resume sexual activity, it's part of life, isn't it? A man wants to feel capable of fulfilling a relationship. I've been undergoing treatments to regain my erectile capacity, but it's not easy."*

iv. The Guilt of Not Matching Their Partner

The wish to resume or sustain an active sexual life often clashes with physical limitations, libido, and self-image issues, causing guilt in some survivors. This guilt stems from the perception of not fulfilling their role in the relationship or meeting their partner's expectations regarding intimacy and sexuality. Alice shared "*I'm not hesitant to discuss these matters, to acknowledge the tremendous challenge of intimacy. (...) But if it weren't for my husband, who looks beyond, it would be incredibly hard to cope. I might even describe it as a sense of guilt, despite knowing deep down that I'm not at fault. It's feasible to claim innocence yet still feel guilty. It's feasible! I never chose to have lymphoma, to enter menopause, which I have, or to develop osteoporosis, nor any of the issues that typically come after 60, which are exacerbated at 40 or even in my 30s, with all the complications they bring to one's intimate life."* Diana adds "*It's truly challenging because it involves aspects of the relationship that aren't central. Understanding is key, recognizing our frailties, acknowledging that we wake up at night craving sleep. We need rest. Communication always helps. We seek respect and must also comprehend the other's perspective, striving to reconcile as soon as possible. (...) Availability isn't always present, yet we learn and must exhibit determination. It's not always to our liking, but we endeavor to accommodate without*

compromising ourselves. Personally, I value these situations more, having experienced them during breastfeeding, and now, I shed tears when I think 'I might not have been here.' It matters to both parties, and fortunately, it signifies that the passion persists. Keeping the flame alive through life's challenges is never simple."

GVHD can manifest in the vaginal mucosa, resulting in vaginal stenosis that impedes penetration and may lead to discomfort. Those who endure this condition frequently report a reduced sense of femininity. It significantly impacts current relationships and obstructs the development of new ones, affecting their sense of fulfillment as women. Amélia shared *"The gynecological graft hinders my ability to have sex. It bars me from initiating a relationship because I am unable to engage in sexual activity. This makes me feel less of a woman, which is the most devastating aspect. I suffer from stenosis. The condition used to cause me daily pain, but that has ceased. Now, the one thing I am unable to do is have sex."* Isabel revealed *"I feel embarrassed to admit it, but it significantly impacts me intimately. Since my transplant, graft-versus-host disease has affected my mucous membranes, particularly my vagina. I have hypertrophy and am unable to have sexual intercourse—it's as if I've become a virgin again. It's quite obstructive in that sense. Additionally, I've had some difficulty discussing these issues with my doctor due to embarrassment. My husband, being older, doesn't seem too concerned. He's actually more at ease now, thinking, 'I'm old, she's young, and that's just how it is.' He used to be very suspicious and jealous, but now he's calmer, yet I still feel uneasy."*

v. The future: fertility and the couple's relationship

Fertility concerns are significant for some survivors, as infertility may result from their treatments. After completing treatment, when they feel ready, the possibility of having children is a concern, and infertility confirmation can bring sadness. Camila felt *"I would like to give my son a sibling, but I doubt that's possible, and it's uncomfortable discussing it with friends. It's a realization that comes later; had I known what I know now, I would have chosen to have children earlier. The decision to focus on my career or to have children was based on my career in business, but in hindsight, having children earlier would have been better. I was younger, had more energy to care for a child, to play, and to enjoy the activities that bring me joy without the fatigue from illness or life's demands. My son could have had a sibling to share experiences with, but currently, he only has his father and mother."* João expresses deep regret, lamenting that X., in her previous relationship, chose not to become a mother as it did not resonate with her. He mourns the lost opportunity, especially since she had expressed a desire for it, and he is saddened by her infertility. At this juncture in the survivor's journey, the choice to safeguard fertility prior to initiating treatment is reconsidered. There's a sense of sorrow over the inability to maintain the option of parenthood. João shares, *"When I was admitted to the hospital, Dr. X. informed me on a Friday that it was too late; we couldn't delay until Monday for me to go to the MAC for preservation. It was truly unfortunate, a significant loss, because I had postponed it with the intention to proceed, as it was absolutely logical, given that X. would have been an extraordinary mother."*

Understanding the impact of the process on the endocrine system is necessary to adjust life expectations concerning the menstrual cycle and reproductive function. Anita shares, *"The concern is not fertility but menstruation. I'm uncertain if I will recover; it's not confirmed whether my ovaries are still functional. This worries me—not the infertility, since I was infertile before the cancer, but because, as a thirty-two-year-old woman, hormonal regulation through my menstrual cycle is important. If it doesn't resume, there could be other consequences. My doctor advised taking the pill to regulate my endometrium, yet ovarian failure hasn't been ruled out. Honestly, the most disheartening aspect is the inability to have children, although that was the case even before the cancer. Nevertheless, I can still become a mother."* Matilde expressed, *"Everything has changed, everything has changed. It's only now that I'm seeing an endocrinologist; I'm uncertain if I'm menopausal. All I know is that my periods have stopped for years, and I'm unsure if it's a result of the chemotherapy or if I've entered menopause. I'm in the dark about my condition, and that's a barrier for me; I can't even consider pregnancy. Currently, I'm unaware of my health status, which is clearly problematic. During treatment, the side effects, including reduced libido and painful intercourse, make it challenging. The lack of a conducive atmosphere complicates matters for both the patient and their partner, requiring patience and a gentle approach."*

Despite their experiences and the uncertainty of their clinical conditions, some survivors desire to become parents again but hesitate due to the fear that their health might deteriorate, potentially causing distress for their future children and placing a burden on their partner. João expressed: *"Some time ago, we contemplated adoption, but it's a complex process. Even though X. is thriving with an excellent career, my health and her ability to be there for both the child and me are concerning. If a serious issue arose, her potential role as a single mother, given her career obligations, would pose significant management challenges."* Mafalda shared: *"I dream of having two or three children and living happily ever after, but that demands stability. At present, I don't even consider it... For me, the idea of having children is not an option. I'm relieved I don't have any! It wouldn't be right for a child to endure a mother constantly in the hospital, perpetually at death's door. The constant fear of losing their mother is something I wouldn't want for my child, nor would I want to be such a mother."*

vi. The Challenges of Disclosure and Intervention

Regarding sexuality, individuals often find it challenging to discuss their feelings with healthcare professionals. This difficulty arises partly from uncertainty about how to communicate such information and partly because these issues are deeply personal, necessitating a trusting relationship with the professional. Despite these challenges, survivors recognize the importance of seeking tangible solace through the professional's involvement in this private aspect of their lives to discover the most effective strategies for overcoming these issues. We can interpret this from the following statements of Isabel, Matilde e Raquel:

Isabel: *"I had always assumed the endocrinologist would be in charge of monitoring me, especially since she said she would. I attempted treatment but quickly abandoned it, and surprisingly, my partner was content. Menopause often diminishes that desire, you know."*

Matilde: *"There's another aspect that warrants distinct attention – our sexual and intimate lives are not discussed enough, yet I believe they're significant."*

Raquel: *"Since I didn't have any professional support, what did I do?! I bought technical books, more technical sex books, no Grey's Shadows or anything like that, because that just turns you off. Technical sex books that also give you some tips on sensuality, but above all they teach you how your body works, how a man's body works, because in a sexual relationship there are two bodies that have to be managed, and it helped me a lot. What's more, they also have the good sense to include tips, seduction tips for ourselves, also to pamper ourselves and not only that, they influence us to get to know our bodies in order to know what we like. That's where I found help."*

Discussion

The participants in our study reported that their process of recovering their sexuality involved rediscovering their roles in the relationship with their partner, overcoming their position as a patient, in addition to the caregiver spouse reassuming the role of partner. In the study by Shartau et al. (18), participants described moments when they thought that their expectations or ideas did not match those of their partners when it came to rediscovering their sexual relationship, and feelings of frustration or guilt were often expressed, which is also presented in our study. Shartau et al. (18) added that even participants with minimal sexual health concerns who said they were satisfied with the way they were living this area of their lives still talked about their journey of finding a new normal post-transplant. The search for a new normal was not always directly related to sexual health concerns - other elements, including redefining their relationship with their partner or learning to cope with other concerns, entered into this process. In our study, the fracturing of relationships after the AH SCT process was also found, with the justification being a mismatch of perspectives on the meaning of life for both the survivor and their partner.

This finding is discussed in the literature, but it is difficult to make sense of it. In the study by Langer, Yi, Storer, & Syrjala, (19), the longitudinal picture of the relationships of people with HSCT and their spouses is positive, in that most marriages survive the transplant and the recovery process, which requires changes in the marital relationship on the part of the spouse; however, it is emphasized that female spouses are more vulnerable to decreases in relationship satisfaction. In survivor time, people try to find/build a future perspective. Fertility is questioned and becomes an element that influences the intimacy of these people, as mentioned by some of the survivors who took part in our study. Infertility can be one of the side effects of the treatments these people have undergone (20, 21) When the treatment process has been overcome and the person feels capable, concern arises about the ability to bear a child, as advocated by Liang et al., (22), and Kotronoulas, Papadopoulou, & Patiraki, (23)

In the study by Mosher, Redd, Rini, Burkhalter, & DuHamel, (20), a quarter of survivors had moderate to high levels of concern about infertility, adding that the majority (54%) of HSCT survivors under the age of 40 reported a high level of concern about infertility. Feelings of depression are associated with infertility,

which is also advocated by Hayden et al., (24), and Shanklin, Snowden, & Greenfield (25) to which the participants in our study add the doubt of the body's ability to resist a pregnancy. In addition, the psychological burden associated with infertility may explain some of the sexual dysfunctions (26). It is mentioned by the participants in our study that the decision to preserve fertility before starting treatment is, at this stage of the survivor's life, re-evaluated.

These people generally have a restricted window of time in which to decide on and adopt fertility preservation strategies. The classic procedure of freezing oocytes/eggs may represent the best option to be offered to people undergoing HRCT. However, not all patients are considered eligible for cryopreservation strategies, due to the requirement to start chemotherapy immediately, which is not in line with the time needed to carry out the procedure (27, 28). This situation accompanies the person and the time for fertility preservation is questioned; survivors have reported feelings of regret at not having been able to maintain the chance of generating a life. Survivors assume that their fertility situation needs to be assessed and monitored. They say that this part of their existence is overlooked by the multidisciplinary team, but that it is important for the construction of the survivor as a person. Fertility-related support and care provide an opportunity to improve patient knowledge and satisfaction, and offer hope (29).

The support process should be as fluid as possible and should include both the articulation of the various care units, as well as financial and psychological support. Psychosocial support for cancer patients is important throughout the cancer journey and this includes the decision-making period and family planning procedure, both in the treatment period and in the survivorship period. Oncofertility decision support systems have been developed for use in pediatric and adolescent patients (30), and are useful for overcoming the challenge of reproductive knowledge in adults (29). Alsuliman et al., (31) defined A Comprehensive Review and Guidelines from the Francophone Society of Bone Marrow Transplantation and Cellular Therapy and "offered to patients in the form of questions and answers to facilitate discussions between patients and caregivers to improve the management of sexual and emotional life after transplant".

Some of the survivors in our study, although they have the desire to become parents again, feel that they should not do so, because they mention the fear of causing suffering to their partners and children related to feeling the instability of the clinical situation. Therefore, it needs to be clarified and supported through endocrinology, gynecology, urology and psychology consultations in order to find reliable ways to manage the problem.

Strengths and limitations

This study allows unveiling a necessary phenomenon such as comfort in a population which has recently increased in number and requires nursing intervention. A limitation of this study is the fact that it was conducted in only one hematopoietic cell transplantation unit and that the results cannot be generalised.

Conclusion

Understanding the lived experience of intimacy, sexuality and fertility comfort of the survivor to AHST allowed immersing in what is the meaning and what acquires meaning for people who live this time.

We can see from the descriptions of the phenomena experienced that each physical symptom is interpreted in the relationship with the partner, becoming a discomfort reflected in the relationship with the other. There is a new body after AHST and a new way of experiencing intimacy, sexuality and fertility. The new meaning of life leads to a redefinition of roles in couples and expectations for the future. This is an area in need of intervention and accompaniment so that intimacy goes beyond the walls of each relationship and becomes the domain of intervention by health professionals.

It prompts health professionals to consider the importance of understanding these personal experiences to reevaluate holistic care practices and address the unique needs of each individual undergoing AHST.

Clinical Implications

With the results of this study, we were able to understand how physical changes such as pain, cGVHD, impotence and altered libido are interpreted in relation to comfort with oneself and one's partner. We realize that these are aspects that interfere with the sense of accomplishment, self-image and self-perception. These are aspects that cause discomfort with oneself and guilt about not being able to fulfill one's desires and those of one's partner.

At the same time, we realize that these are aspects that remain a non-priority in care, something that is silenced by survivors and hidden from the focus of care by health professionals. Rethinking intervention in this area is important.

We understand that fertility preservation is still something that is put aside when treatment for an oncological disease begins. We must rethink priorities and give importance to fertility preservation and streamline these processes before starting therapeutic protocols.

Abbreviations

Allogeneic Hematopoietic Stem Cells Transplant (AHST), Graft Versus Host Disease (GVHD)

Declarations

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Author contributions

All authors contributed to the conception and design of the study. Material preparation and data collection was performed by the first author Lúcia Bacalhau. The analysis was continuously discussed with the co-author Patrícia Pontifice- Sousa. The first draft of the manuscript was written by Lúcia Bacalhau and Patrícia Pontifice-Sousa has read, commented and approved the final manuscript.

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Consent to participate: Written informed consent was obtained from all individual participants included in the study and the participants' identities were protected by a nickname.

Consent for publication The authors affirm that human research participants provided informed and written consent that anonymised excerpts of their interviews could be reproduced.

Competing interests The authors declare no competing interests. All authors declare that they have no conflicts of interest.

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