

Research Article

Embracing Time: The (Dis)Comfort of Life After Allogeneic Stem Cell Transplants

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Academic Editor: Mobil Akhmedov

Special Issue: Allogeneic and Autologous Stem Cell Transplantation

OBM Transplantation	Received: September 19, 2024
2025, volume 9, issue 1	Accepted: January 22, 2025
doi:10.21926/obm.transplant.2501233	Published: February 06, 2025

Abstract

Allogeneic Stem Cells Transplantation (ASCT) and, consequently, the chronicity associated with this life event has a growing prevalence and a significant impact on the life and daily life of each person who experiences it. The growing number of ASCT survivors highlights the need to reflect on the unique challenges they face throughout their recovery. To understand the meaning of the encounter with time in the lived experience of comfort for survivors of ASCT. Qualitative approach using van Manen's phenomenology of practice. We uncovered the phenomenon through phenomenological interviews, which integrated narratives and illustrative episodes that reflected the lived experiences of 20 survivors. Descriptions of lived experiences were collected from participants between July 2020 and May 2021. The following themes emerged from the ASCT survivor's lived experience of comfort related to time: giving time to live, time for what is important, time for the future, and living the time of day. This study reveals the importance of time for the survivor, the anguish of the time of discomfort, and creativity in the search to live the time of comfort provided by the ASCT.



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Keywords

Survivor; comfort; time; stem cells transplantation/bone marrow transplant; phenomenology of practice

1. Introduction

ASCT can cure oncological diseases and chronic hematological, immunological, or metabolic conditions. However, it entails a complex and prolonged recovery journey marked by physical, emotional, and social challenges. Those undergoing ASCT are subjected to a complex process engenders multidimensional and specific sensations, emotions, thoughts, and experiences. They challenge the healthcare system due to their need for specific and prolonged care. It is increasingly recognized that a new group of people, blood cancer survivors, has specific needs related to the sequelae or complications resulting from the treatments they have undergone [1, 2]. The advent of early detection techniques and the advent of increasingly effective treatments have transformed the prognosis of cancer, resulting in an increasing number of individuals surviving cancer and living beyond cancer for extended periods of time [3]. ASCT survivors who have completed the specific treatment but who still have a prolonged need for specific care. They live with chronic situations and are responsible for a certain amount of discomfort. Survivors of ASCT are subjected to many alterations and changes across various domains of life, requiring specific care and a need for comfort. The concept of comfort in holistic human care is an indispensable element in nursing and represents the most essential dimension of the caring process [4, 5]. In the context of ASCT survivors, comfort can be defined as a multifaceted state of physical, emotional, and psychological relief that fosters a sense of well-being and stability amid the challenges of recovery. It encompasses alleviating physical symptoms such as pain or fatigue, the emotional reassurance provided by a supportive environment, and the psychological peace that comes from managing uncertainty and adapting to life posttransplant. Comfort is not static but evolves over time, influenced by the survivor's ability to navigate changes in health, relationships, and daily routines. It is both an outcome of effective care and a subjective experience tied to the survivor's perception of safety, resilience, and quality of life [5].

In recognition of the fact that each individual will experience the situation and circumstances in a personal manner, we have adopted the concept of 'survivor' as defined by Denlinger et al. [6]. In this context, the term 'survivor' refers to someone who has completed treatment for their disease and is in remission, as previously mentioned. ASCT survivors live with a chronic situation, which can result in several discomforts. These include changes in lifestyle, expectations, projects, and meanings, as well as anguish and the incorporation of specific therapeutic regimes into their lives. Given the integral functioning of the human being, it is imperative to attend to the total pattern inherent in the person's life process. This requires an understanding of how they experience comfort [7]. The concept of comfort is multifaceted, encompassing a noun, a verb, an adjective, state, process, and outcome [4]. Despite its complexity, it is a core concept in holistic human care and an indispensable element in nursing. It represents the most essential dimension of the caring process [4, 5].

This condition leads to numerous changes across various aspects of life, creating diverse health needs that require a comfort-oriented response. Consequently, it presents significant challenges for healthcare during the survival period [7]. It is acknowledged that this situation has a personal, family, and social impact, characterized by instability and insecurity. The concept of time emerges as a significant and pervasive element in the description of the lived experience. Time plays a crucial role in ASCT survivors, influencing their recovery, emotional resilience, and overall perspective on life. The transplant journey itself is lengthy, encompassing preparatory treatments, stem cell infusion, and a prolonged recovery period [8]. Survivors often measure their progress through these stages, with time serving as a tangible marker of milestones, such as the end of neutropenia or the resumption of daily activities. These milestones not only signify physical healing but also provide a sense of achievement and hope.

Recovery is a gradual process, and survivors become acutely aware of the time it takes for their bodies to heal. Energy levels, immune system function, and overall health may take months or even years to stabilize. This extended timeline introduces uncertainty, with many survivors grappling with fears of relapse or complications. Time, in this context, can be a source of both anxiety and resilience as they navigate the unpredictability of their health outcomes.

The objective of this study was to gain insight into the concept of time in the lived experience of comfort among individuals who have undergone allogeneic stem cell transplantation, employing a phenomenological approach.

2. Methods

This article represents a portion of the findings from a doctoral thesis in Nursing. This study employed van Manen's phenomenology of practice to explore the essence of comfort in ASCT survivors. This qualitative approach provided a framework for uncovering the depth and complexity of comfort as a lived experience [9, 10]. Given the complexity and breadth of the concept of comfort, it is of the utmost importance to elucidate its meaning for survivors of ASCT. By examining the lived experiences of ASCT survivors through phenomenological methods, insights can be gained that will promote equitable, respectful, and soothing care. Phenomenology is a philosophical method for examining experiences. As a human science, it is focused on the interpretive structures of human experiences. The significance of these experiences is determined by reflection and the subsequent embedding of the expertise within the memory, as observed by van Manen [9, 10].

The phenomenology of practice is sensitive to the realization that life as we live it and experience it is not just rational and logical. It is transparent, subtle, enigmatic, mysterious, inexhaustible, transcendent and existential, which we can only access through poetry, aesthetics, media, and evocative language [9]. The researcher aims to understand human nature to make it more prosperous and more meaningful. To this end, van Manen suggests six research activities: (i) focusing on the nature of the lived experience; (ii) investigating how the experience is lived rather than how it is conceptualized; (iii) hermeneutic phenomenological reflection; (iv) describing the phenomenon through a process of phenomenological writing and rewriting; (v) remaining completely committed and oriented towards the phenomenon of study; (vi) balancing the research context by considering the parts and the whole [10].

2.1 Participants

The selection of survivors was based on several factors, including age, gender, clinical diagnosis, the presence of family, the occurrence of graft versus host disease (GVHD), and the duration since the stem cell transplant. This approach ensured the representativeness and significance of everyone's experience in understanding the studied phenomenon [9]. Our study sample consisted of individuals who had undergone ASCT and were being monitored as outpatients at the time of the research. We applied the following inclusion criteria: (i) age over 18 years; (ii) having undergone ASCT at least three months prior; (iii) no evidence of disease relapse; and (iv) the ability to express themselves verbally, provide relevant information, and articulate emotions and feelings.

Using these criteria, we recruited a sample of 20 participants. Our objective determined the sample size to obtain rich, detailed descriptions necessary for constructing experiential examples that reflected diverse lived experiences. We aimed to gather sufficient data to develop an illustrative and coherent framework addressing our research question [9]. Data collection ceased once we determined that the material gathered was comprehensive, containing specific, profound, and nuanced representations. This process resulted in the final sample size of 20 participants.

In this study, participants were recruited from a bone marrow transplantation unit. The recruitment process was conducted voluntarily, ensuring that all individuals fully understood the purpose, objectives, and implications of the research before providing their informed consent. By focusing on ethical recruitment practices, we emphasized participants' autonomy, assuring them that their decision not to participate would impact the care they received. This approach allowed us to engage with patients who were willing and able to contribute their experiences, ensuring a rich and meaningful exploration of their perspectives within the context of the study.

The selection of participants was driven by gathering descriptions of lived experiences that would facilitate the depiction in experiential examples, thus revealing the experience as genuinely lived. Enough descriptions of lived experience were gathered to construct an illustrative and coherent framework addressing the research questions, as guided by van Manen et al. [10]. The collection of lived experience descriptions was concluded upon reaching 20 participants. At that point, it became apparent that the accumulated material encompassed specific, profound, and intricate facets of the lived experience, thereby enabling the exploration of this new realm.

2.2 Data Collection Methods

Descriptions of lived experiences were collected from participants between July 2020 and May 2021.

Thus, the experiential material was collected from 20 phenomenological interviews with survivors who had undergone allogeneic stem cell transplantation (see Figure 1). The interviews took place in a place chosen by the participants, a quiet place for a fluid conversation, as proposed by van Manen [9, 10].

OBM Transplantation 2025; 9(1), doi:10.21926/obm.transplant.2501233

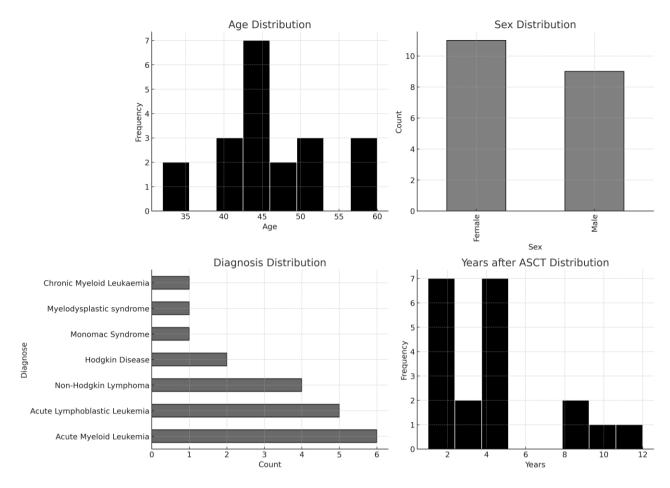


Figure 1 Characterization of the study participants.

The phenomenological interviewing carried out had two specific aims: it was used as a means of exploring and reaching experiential narrative material that contributed to understanding human phenomena, and it served as a vehicle for developing conversation about the meaning of experience. With authorization, the interview and narrative material were recorded and transcribed verbatim for detailed analysis. Following the guidelines of van Manen, the subjects of the study were asked to focus on a particular experience, describing the event by specifying it as closely as possible about feelings, mood, and emotions; paying special attention to what they felt and in what way, i.e., "what sounds they felt", leading the survivor to highlight what they experienced as if they were returning to the moment [9].

Using easy-to-understand language, we guided the collection of these descriptions in the interviews, making sure that the person's description was specific in terms of what they felt and what they experienced. To complement the experiential material, after completing the transcription, it was returned to each survivor, who added information and lived experiences to complement the experiential material. An avenue of communication with the researcher was also made available if the survivor had any relevant aspects to share.

2.3 Data Analysis

In analyzing the narrative texts of the lived experience of the survivors of ASCT, we identified the themes that emerged from the experiential material. In this process, we tried to capture the themes

by extracting the appropriate phrases or capturing in simple statements the core of the meaning of the themes, as van Manen suggests [10]. The process used to identify the themes of the phenomenon under study took place in four stages: (i) Firstly, after transcribing and compiling all the experiential material, we proceeded to read it globally, holistically, to grasp the meaning and sense of the whole [9, 10].

The reading was guided by the question: which phrases can capture the meaning or central significance of this text? (ii) a detailed and reflective reading of the descriptions was then carried out, where we tried to identify the essential phrases that revealed the experience under study, guided by the question: which phrases or set of phrases seem particularly essential or revealing of the experience under study? The whole process of reading and analysis was carried out without losing sight of the guiding question of the study, and (iii) in a third step, the thematic units extracted from the descriptions that fall within the essential themes related to the phenomenon were highlighted. The essential themes guided discovering the significant dimensions of lived experience and making the phenomenon what it is, without which the phenomenon could not be what it is [9].

At this stage, the look at all the sentences and groups of sentences was guided by the question: what do these sentences or groups of sentences reveal about the lived experience described? This led to the relationship between the themes and the subsequent construction of the text, illustrating the study results. At the same time, at this stage of the analysis, we used Maxqda, a software program specializing in qualitative data analysis, to help us recognize the phrases that reveal the experience and associate them with essential themes. Once the vital themes had been constructed, the sentences within them were analyzed to construct the sub-themes and identify the units of meaning within them. This research phase was validated with experts in qualitative research and methodology. (iv) Phenomenological writing was constructed to construct an evocative text describing human actions, behaviors, intentions, and experiences as they are unveiled [9, 10].

2.4 Methodological Rigor

We ensured quality by following van Manen's evaluation criteria for phenomenological studies [9]: (i) heuristic questioning, so that the text constructed seeks to induce a sense of contemplative wonder and questioning about the importance of the survivors' experience of comfort; (ii) descriptive richness, we constructed a text that contains rich and relevant experiential material; (iii) interpretive depth, the text offers reflective insights that go beyond an understanding of everyday life; (iv) distinctive rigor, i.e. the text remained constantly guided by a self-critical question of the distinctive meaning of the phenomenon; (v) strong and interested meaning, the text expresses the sense of what was lived; (vi) experiential awakening, the text awakens pre-reflective experience through evocative language; (vii) conceptual epiphany, the study offers a more profound and more original vision and perhaps an intuitive or ethos-inspired understanding of life's commitments and practices.

2.5 Ethics Statement

Before each collection of lived experience descriptions, participants completed a free and informed consent form, ensuring all doubts were clarified. The research process maintained strict confidentiality and anonymity for all participants. The study received approval from the Research Ethics Committee, which conducted it (UIC/1314) and adhered to the Declaration of Helsinki (1964)

[11] standards. Phenomenological interview recordings were made, supplemented by additional notes. Access to these materials was restricted solely to the participants and the lead researcher, upholding confidentiality, anonymity, and the principles of beneficence and non-maleficence.

3. Results

Time was manifested in the lived experience of comfort in the following themes:

- (i) **Giving time to live**: This theme revolves around allocating time to meaningful experiences, relationships, or activities that enrich one's life. It emphasizes the importance of not rushing through life but intentionally spending our time. Doing so creates a sense of fulfillment and connection to what truly matters.
- (ii) Time for what is important: In this context, time is prioritized according to what holds significance in one's life. It refers to spending time with loved ones, pursuing passions, or focusing on personal growth. This theme suggests a deliberate approach to time, where people actively choose where their energy and attention go, often at the expense of less meaningful distractions.
- (iii) **Time for the future**: This theme likely focuses on how the ASCT survivors invest in the future through planning, learning, or taking actions that will have long-term benefits. It suggests that the present is often viewed as a foundation for the future, and by managing time wisely today, they create opportunities and possibilities for tomorrow.
- (iv) **Living the time of day**: This theme highlights being present and embracing the moment. It refers to living in the "here and now," appreciating the rhythm of daily life and enjoying the small moments that make up our daily experience. It speaks to mindfulness and the ability to fully experience each moment without being preoccupied with the past or future.

3.1 Giving Time to Life

For survivors, comfort stems from the assurance that ASCT extends their lives, enabling them to invest time in meaningful pursuits and relationships. For those who perceive themselves to be undergoing a disease process with the potential to result in mortality and who have previously experienced processes of confronting the end of their days, having a treatment that enables them to live and enhances the quality of their remaining years is a source of comfort for these individuals. The opportunity to undergo an ASCT is viewed as a privilege, allowing patients to transcend the disease process and embrace a quality of life beyond the limitations imposed by their condition. This sentiment is reflected in the following statements:

Anita: "As transplant recipients, we feel immense gratitude for the opportunity to prolong our lives in a more optimal manner, and to avoid the futility of wasting time."

Tiago: "It is preferable to expend the entirety of one's allotted time on this Earth in the pursuit of continued existence rather than to perish without having had the opportunity to engage in discourse on the matter."

3.2 Time for What Is Important

The concept of comfort can be defined as the ability to live one's life in a way that is meaningful and valuable. This period is characterized by individuals who hold significant personal and social

values, such as family members and close friends. The value and meaning attributed to each individual are paramount, and their presence is a priority in the time spent after overcoming the illness process and its treatment.

Camila: "The entirety of my time is at my disposal, and I choose to spend it with my son."

Priorities undergo significant shifts because of the illness and subsequent treatment. Diana states, "I am currently residing with my children and husband, as well as my extended family. Consequently, I am frequently at home, as I do not frequently leave. I sometimes reflect on how beneficial it is to be at home with my children and husband."

Diogo: "I have always placed a high value on family and friendships, but my perspective has shifted significantly in this regard."

3.3 Time for the Future

Those who survive attempt to make plans, to devise strategies to realize their dreams and desires in daily life. However, although they are very ambitious, they are influenced by daily limitations or by the awareness of the possibility of a relapse of the disease that led to ASCT, which is very uncomfortable. The survivors' discourse reflects a desire to live, constrained by their lived experiences and the limitations of the present and the past.

Anita: "Currently, there is an improvement in my condition, I am stable, and I am beginning to consider the future."

Carmo: "We must recuperate. I am not suggesting that the preceding four years have been without progress; we have continued to function and engage in activities to a certain extent. However, the preceding two years have undoubtedly presented a significant challenge in terms of recovery." "I have been confined for a considerable period and am now seeking to expand my horizons by encountering new experiences."

Rodrigo: "I aspire to lead a fulfilling life, although I am uncertain whether I possess the requisite skills. To provide for my family and witness my children's growth and development."

For the participants, levels of discomfort appear to correlate directly with the length of the survival period. A comparison is drawn between the period following the transplant and the time spent before and during the transplant process. The period following the transplant is regarded as one of the most distressing, exceeding the levels of discomfort associated with hospitalization in a protective isolation unit. This is related not only to the accumulation of side effects from the therapeutic plans that have already been carried out, but also to the complications that arise after the transplant and the expectations of overcoming the illness and achieving the desired state of comfort, as evidenced by the following statements:

Afonso: "I felt considerably better before the transplant. I had fully recovered and was in relatively good health before the transplant."

Francisco: "Indeed, it has been a challenging process."

Mafalda: "The period following the transplant was invariably more challenging than the preceding phase."

Furthermore, graft-versus-host disease (GVHD) and the therapy employed to control it represent a significant source of discomfort for these individuals, extending beyond the acute phase of GVHD to encompass the chronic effects of the disease and the associated therapy.

Isabel: "The only factor that has had a more deleterious impact is the disease against the host issue. The timeline for its resolution is unclear."

Tiago: "The only factor that could be more detrimental to my well-being is the current issue with the graft-versus-host disease. Its progression is unpredictable, and it has the potential to persistently affect my quality of life, either intermittently or continuously."

In the people we spoke to, discomfort is also felt about the delay in achieving what is desired. There is a need to return to life before the illness. The realization of what is experienced alters the perception of the transplant. The process of achieving a cure becomes long and limits the construction of the desired comforting experience. The length of the illness and treatment process influences the comfort of those who experience them, i.e., the longer the recovery, the more discomfort is experienced and felt. The delay in achieving the desired comfort frustrates the survivor:

Alice: "I was expecting a change, much faster, a difference, a much greater discrepancy to the good now I was coming home and there wasn't. (...)The moment doesn't come when the person has the feeling and says 'I'm done!"

Carmo: "Everything has happened to me. I was expecting it to happen for two years until the spinal cord and everything straightened out. Now, four years and a half later, I wasn't expecting it."

Tiago: "It's a long process with lots of complications."

3.4 Living the Time of Day

Living through the days is felt necessary to the survivor in relation to the comfort provided by having an ASCT. Survivors want to enjoy the time they have been given after the transplant, so the way they occupy their time is essential to them. However, due to the prolonged period of inability to carry out a professional activity, the obligation to retire, and the limitations inherent in their state of health, inactivity can become uncomfortable.

The survivor needs to feel useful, yet this time is corrupted by downtime. Being at home while their peers are carrying out their professional activities generates feelings of loneliness because although the person tends to look for occupations, these do not promote professional development or the construction of a meaningful evolutionary future. The activities carried out are solitary and seek to occupy the multiplying time. To get around the suffering of loneliness and inactivity, the person is forced to find something to do with their time, to occupy it:

Anita: "It's hard, some days it's hard. You want to do something useful and do something you enjoy, something other than just sitting on the sofa watching TV, having a goal!"

Mafalda: "The days are all the same. Do the days go by slowly? Yes, because I'm not happy like this. Sometimes, I feel like I'm waiting to die! I used to be happy working. As they teach us, work dignifies people, which also brings dignity."

Rodrigo: "That changed a lot, it affected me. Because I spent a lot of time doing nothing, I didn't do anything."

The time of inactivity and social isolation leads to these people becoming more isolated from the social and cultural world. On a professional level, for those who can resume their professional activities, there is a feeling of lost time, time that has fallen short of some learning and professional development:

Afonso: "Yes, although I work on distance learning projects, there was a lot of time when I couldn't, I couldn't even read, I couldn't... there were a few moments when I managed to do something, but with much effort. (...) But you lose contacts, you lose a lot. It takes a lot of effort to recover, and it's physically and intellectually exhausting."

João: "I realize I'm missing out on learning and knowledge; I try to keep up, but away from personal contact with people, it's difficult... I feel I'm missing out. Working in a group stimulates you, but now I don't have that!"

To fill the time of the day, in a search for comfort, the survivor finds meaning in the ability to carry out activities in the field of art. To take refuge from what has happened and forget the moments of discomfort in the process of transition:

Afonso: "(...) my refuge here used to be listening to podcasts, as I work in this field and I do, it was my great refuge, because there are times when you can't read, television?! I don't go to bed without listening to something because if I go alone, I remember those moments."

Rodrigo: "I played guitar to feel useful and to pass the time. Was I able to play the guitar without seeing? Yes, I could do the chords, yes. If you know the chords, then it's always the same."

Writing has made the human experience visible and shared with others. It has also enabled individuals to establish and organize future goals by articulating and committing to life objectives:

Duarte: "I even wrote a memoir, a book of projects. I'm going to do this and that. I would always jot down my ideas and plan them out. I never set deadlines because I came to see that deadlines could be very unreliable."

Raquel: "Writing the book was beneficial for me. Documenting my life on paper might assist others, and it helped me to structure my thoughts."

For some, composing poetry offers a refuge that fosters comfort in the creation:

Alice: "Since I'm unable to touch anything, I write. To conclude, revisiting the start of our discussion, what is comfort? These moments are times of immense comfort."

Painting has also surfaced as a way of artistic expression, which the survivor hadn't mastered before the process she went through, but which she has sought out as a way of expressing herself and filling her time:

Alice: "More recently, I've found a lot of benefit in picking up canvases and starting to paint. It's encouraging and makes me eager to create another piece and continue."

Anita: "I began painting because it was difficult to spend so much time at home. I wanted to occupy my time, but importantly, with beneficial activities."

Photography has become a way to contemplate the world around us. It is a safe activity that involves reflection on what is seen, editing the captured images, and sharing them, which promotes interaction with others. It requires time, dedication, and attention, qualities that are valuable for personal development:

Alice: "I found a sense of purpose that fulfilled me. Moreover, photography offers a lasting record. During the days I spent receiving treatments, I would look at the photos I had published on my mobile phone and take pleasure in them."

4. Discussion

Comfort is intricately connected to the timing of life events, the treatment process, and recovery. Discomfort arises alongside comfort, shaped by physical, psychological, and relational changes, daily challenges, and the uncertainty of the future. We understand that living through the post-transplantation process affects the different areas of the survivor as a biopsychosocial, cultural, and spiritual being and is revealed in every dimension of the person as something limiting, but at the same time, drives the process of seeking better comfort. The time is essential for the state of comfort. On the one hand, it is desirable to enjoy it, and creativity is developed to occupy the time. Still, on the other hand, it is uncomfortable because of what is impossible or limited to experience due to the physical limitations and social constraints imposed by immunosuppression.

Going beyond the hope of a cure, the survivors in the study add the sense of comfort of giving life to the days, developing the feeling of enjoying the time of life provided by the ASCT. The relief referred to by Kolcaba is understood in the encounter with the time of life made possible by ASCT and the opportunity to achieve a cure, the encounter with a process that allows an answer to be given to the health problem encountered [4].

In our study, the participants mentioned that the unpredictability of the occurrence and duration of GVHD causes anguish and despair in the survivors. The literature states that the time after ASCT involves a slow process with a high risk of changes for the person experiencing it and that these changes, such as GVHD, continue for a long time, from the transplant to long after it [12-15]. This idea is corroborated by the account of one of the nurses who took part in the study by Zamanzadeh et al., who said that she had witnessed people dealing with transplant complications for years and eventually passing away, which highlights the fact that these people have to face death for years after undergoing ASCT, causing them to feel uncertain about their life situations [15]. The survivors in this study described the process of treating GVHD as uncomfortable, feeling as if their lives were going backward, returning to an awareness of the vulnerability of their health situation.

The time after the end of the treatment process is considered, also in our study, a time of recovery and improvement, however, when people feel their body weakened or influenced by the treatments carried out for a prolonged time, without a defined term, they suffer psychological exhaustion. Managing expectations of improvement and healing influences the search for and finding of comfort in each survivor's experience. Failure to fulfill expectations of healing and improvement leads to feelings of deep sadness and depression. The authors Mosher et al. [16], in their study on the psychological impact of ASCT, concluded that although depression was not more prevalent in patients with physical problems at 1 year, at 3- and 5 years post-transplant, survivors with residual physical limitations were more prone to depression. Thus, it seems that ongoing

physical complications have more significant psychological repercussions in the long term than in the short term [16].

At the same time, living each day holds significance for the survivor, emerging as a meaningful aspect of the experience of comfort.

The prolonged period of incapacity to carry out professional activity, the obligation to retire, the limitations inherent in the state of health, and the period of inactivity as conditioning factors that promote discomfort and cause isolation, depression, and discouragement have been the subject of reflection. The literature emphasizes that unemployed survivors with lower incomes and diminished functional status are likelier to have a lower quality of life in multiple domains [7, 16]. We focused on studies that address survivors' unemployment.

When the survivors in our study reflect on returning to work, they rethink their previous way of life since, after experiencing the illness, they want to enjoy their family, live with less stress, and make the most of the time they have been given. They express the need to occupy time according to their needs, abilities, and interests. The survivors in the study were interested in areas of art and creativity. Finding new forms of expression and unknown skills was important for some survivors. It was seen as a development of the person, as it gave rise to the continuity of their presence and the encounter of activity over time. Writing, painting, photography, listening to podcasts, and playing a musical instrument are positive strategies identified by these survivors as providing comfort. Other authors [17-20] refer to the importance of family support and personal conditions for developing resilience during recovery from ASCT.

These themes transform from an external, mechanical view of time to a more personal, embodied, and fluid relationship with temporality. In this transformation:

- Time is no longer simply measured; it is lived as an ongoing experience shaped by values, relationships, and actions.
- Time becomes malleable: rather than being a rigid framework to fit within, time can be bent or expanded based on the individual's focus and needs.
- The future is connected to the present: the linear progression of time is transcended, with a focus on creating the future in the present through deliberate choices and mindful engagement.
- The present becomes a space of meaning: time is no longer an abstract, distant notion but an immediate experience that can be entirely inhabited and appreciated.

This lived temporality transformation represents a deeper engagement with time that is no longer merely about managing hours and minutes but weaving a meaningful, intentional, and deeply felt experience of temporality.

Cancer survivors are growing and require new interventions to meet their needs [12, 21]. Cancer interferes with all areas of quality of life, and the consequences of treatment, which may arise or persist for years, often have repercussions on the well-being of survivors. The increase in the survival of these people awakens us to the challenge set by the WHO: it is not enough to give years to life, but it is crucial to provide life to years so that we move beyond the exclusively technological and biomedical aspect, towards the humanization of care, investing in the way people live their days.

This study makes it possible to uncover a necessary phenomenon such as comfort in a population that has recently increased in number and requires nursing intervention.

5. Study Limitations

A limitation of this study is that it was carried out in a single stem cell transplant unit, so the results cannot be generalized. While a robust methodology for exploring lived experiences, phenomenology has inherent limitations that must be considered. This approach seeks to uncover the essence of participants' experiences, prioritizing depth over breadth. The emphasis on personal narratives also means that findings may not be generalizable to broader populations, limiting the scope of its applicability. Using a sample size of 20 in a phenomenological study presents additional challenges. While such a size is typically adequate for qualitative research to achieve thematic saturation, it may not fully capture the diversity of experiences within the studied population. Conversely, a smaller, carefully selected sample might allow a deeper exploration of individual experiences but risks excluding essential variations. The balance between depth and representativeness remains a challenge in studies of this scale. In conclusion, while phenomenology and van Manen's methodology are valuable tools for exploring the depth and complexity of human experiences, their limitations must be carefully acknowledged.

As a recommendation for future research, the study should be carried out in other transplant centers, and it would be relevant to carry out the study in the population of autologous transplant survivors. Understanding the phenomenon of time of comfort during the time of allogeneic transplantation and the stay in the isolation unit seems interesting and necessary for the development of a comfort nursing intervention for patients undergoing ASCT.

6. Conclusions

The comfort experience is shaped by the time afforded through treatment, the well-being derived from overcoming illness, and the daily pursuit of meaningful activities. As a state of lived experience, the time of discomfort accompanies the understanding of what is lived, intertwines, and 'contaminates' comfort in the relationship with physical, psychological, and relational changes, daily life, uncertainty, and fear of the future. What is lived is threatened by the possibility of a future with limitations and suffering, which remains in the survivor's continuous life of comfort.

We understand that living through the time after the transplant process affects the various areas of the survivor as a biopsychosocial, cultural, and spiritual being and reveals itself in every dimension of the person as something limiting but, at the same time, driving the process of seeking better comfort. The length of days is essential for the state of comfort. On the one hand, it is desirable to enjoy it, and creativity is developed to occupy the time. Still, on the other hand, it is uncomfortable because of what is impossible or limited to experience due to the physical limitations and social constraints imposed by immunosuppression.

Acknowledgments

This project was supported by Universidade Católica Portuguesa de Lisboa.

Author Contributions

Lúcia Bacalhau: Conceptualization; Data curation; Formal analysis; Funding acquisition; Investigation; Methodology; Project administration; Resources; Software; Writing-original draft. Patrícia Pontifice-Sousa: Supervision; Validation; Writing -review & editing.

Competing Interests

The authors have declared that no competing interests exist.

Data Availability Statement

Ethical approval precludes the data being used for another purpose or being provided to researchers who have not signed the appropriate confidentiality agreement. Specifically, the ethical approval specifies that all results are in aggregate form to maintain confidentiality and privacy and pre-cludes individual level data being made publicly available. All aggregate data for this study are freely available and included in the article. Interested and qualified researchers may send requests for additional data to Lúcia Bacalhau <u>lbacalhau@ucp.pt</u>.

References

- 1. Edgington A, Morgan MA. Looking beyond recurrence: Comorbidities in cancer survivors. Clin J Oncol Nurs. 2011; 15: e3-e12.
- Dovern E, Nijland SJ, van Muilekom MM, Suijk LM, Hoogendoorn GM, Mekelenkamp H, et al. Physical, mental, and social health of adult patients with sickle cell disease after allogeneic hematopoietic stem cell transplantation: A mixed-methods study. Transplant Cell Ther. 2023; 29: 283.e1-283.e9.
- 3. Leung D, Fillion L, Duval S, Brown J, Rodin G, Howell D. Meaning in bone marrow transplant nurses' work: Experiences before and after a "meaning-centered" intervention. Cancer Nurs. 2012; 35: 374-381.
- 4. Galán GN. Case study on the use of instrument of Katherine Kolcaba middle range theory: From comfort. Rev Enferm Neurol. 2010; 9: 94-104.
- 5. Kolcaba K, Steiner R. Empirical evidence for the nature of holistic comfort. J Holist Nurs. 2000; 18: 46-62.
- 6. Denlinger CS, Carlson RW, Are M, Baker KS, Davis E, Edge SB, et al. Survivorship: Introduction and definition. J Natl Compr Canc Netw. 2014; 12: 34-45.
- 7. Islam MS. Treat patient, not just the disease: Holistic needs assessment for haematological cancer patients. Oncol Rev. 2018; 12: 83-89.
- 8. Rasmussen DM, Elverdam B. Cancer survivors' experience of time-time disruption and time appropriation. J Adv Nurs. 2007; 57: 614-622.
- 9. van Manen M. Phenomenology of practice: Meaning-giving methods in phenomenological research and writing. Walnut Creek, CA: Left Coast Press; 2014.
- 10. Van Manen M. Researching lived experience: Human science for an action sensitive pedagogy. London, UK: The University of Western Ontario; 1990.
- 11. World Medical Association. Declaração de Helsínquia da Associação Médica Mundial [Internet]. Ferney-Voltaire, France: World Medical Association; 2013. Available from: https://www.ucp.pt/sites/default/files/2019-03/declaracao-de-helsinguia 2013.pdf.
- 12. Brice L, Gilroy N, Dyer G, Kabir M, Greenwood M, Larsen S, et al. Haematopoietic stem cell transplantation survivorship and quality of life: Is it a small world after all? Support Care Cancer. 2017; 25: 421-427.

- 13. Fiuza-Luces C, Simpson RJ, Ramírez M, Lucia A, Berger NA. Physical function and quality of life in patients with chronic GvHD: A summary of preclinical and clinical studies and a call for exercise intervention trials in patients. Bone Marrow Transplant. 2016; 51: 13-26.
- 14. de Vere Hunt I, Kilgour JM, Danby R, Peniket A, Matin RN. "Is this the GVHD?" A qualitative exploration of quality of life issues in individuals with graft-versus-host disease following allogeneic stem cell transplant and their experiences of a specialist multidisciplinary bone marrow transplant service. Health Qual Life Outcomes. 2021; 19: 11.
- Zamanzadeh V, Valizadeh L, Sayadi L, Taleghani F, Jeddian A. Life in limbo: Experiences of Iranian hematopoietic stem cell transplantation recipient patients and nurses in a qualitative study. Int J Hematol Oncol Stem Cell Res. 2013; 7: 25-33.
- Mosher CE, DuHamel KN, Rini C, Corner G, Lam J, Redd WH. Quality of life concerns and depression among hematopoietic stem cell transplant survivors. Support Care Cancer. 2011; 19: 1357-1365.
- 17. Campo RA, Wu LM, Austin J, Valdimarsdottir H, Rini C. Personal resilience resources predict post-stem cell transplant cancer survivors' psychological outcomes through reductions in depressive symptoms and meaning-making. J Psychosoc Oncol. 2017; 35: 666-687.
- 18. Cuhadar D, Tanriverdi D, Pehlivan M, Kurnaz G, Alkan S. Determination of the psychiatric symptoms and psychological resilience levels of hematopoietic stem cell transplant patients and their relatives. Eur J Cancer Care. 2016; 25: 112-121.
- 19. Luo RZ, Zhang S, Liu YH. Relationships among resilience, social support, coping style and posttraumatic growth in hematopoietic stem cell transplantation caregivers. Psychol Health Med. 2020; 25: 389-395.
- 20. Rozveh AK, Nasrabadi AN, Ghiyasvandian S, Sayadi L, Vaezi M, Amjad RN. Resiliency, the lived experience of patients undergoing hematopoietic stem cell transplantation. Int J Hematol Oncol Stem Cell Res. 2019; 13: 189-195.
- 21. Kiss TL, Abdolell M, Jamal N, Minden MD, Lipton JH, Messner H. Long-term medical outcomes and quality-of-life assessment of patients with chronic myeloid leukemia followed at least 10 years after allogeneic bone marrow transplantation. J Clin Oncol. 2002; 20: 2334-2343.