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ORIGINAL RESEARCH

The Lived Experience of Adult Cancer Survivors After Hematopoietic Stem Cell Transplantation: A Qualitative Study From Saudi Arabia

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Background: Hematopoietic stem cell transplantation (HSCT) is a high-intensity treatment with the potential to extend the life expectancy of some patients with cancer. The aim of this study is to explore the lived experience of cancer survivors who underwent HSCT from Saudi Arabia.

Material And Methods: This study adopted a qualitative descriptive research design using semi-structured in-depth face-to-face interviews. A purposive sampling method was used to recruit eleven patients with cancer who underwent HSCT at an adult oncology center in Saudi Arabia. The interview guide was developed by the authors based on the multi-dimensional health-related QOL model. Participants were asked about their daily activities, problems with coping, quality of life, and personal stress/worries about the future. Data collection was ceased when thematic saturation was reached. Inductive thematic analysis was conducted by two research team members.

Results: Seven male and four female participants were interviewed (range of age 18 to 51 years). Interviews lasted between 60 and 75 minutes. Five major themes emerged in this study. The first was Physical Well-Being based on four sub-themes: independence, self-efficacy, health outlook (health perception), and pain. The second theme was Psychosocial Impact based on the subthemes: stigmatization, depression, and social strains. The third and fourth themes were Social Support and Coping with the Disease, with the subthemes: avoidant coping, meditation and faith. The fifth theme included psychosocial/physical stability and optimism.

Conclusion: Exploring the lived experiences of cancer survivors can inform supportive health care management. Patients who underwent HSCT reported a series of challenges at the physical, psychosocial, and social levels. Further quantitative research studies are recommended to confirm the impact of HSCT on the QOL of cancer survivors in the Saudi Arabian context.

Keywords: stem cell, quality of life, transplantation, survivors, qualitative research

Introduction

Hematopoietic stem cell transplantation (HSCT), commonly known as bone marrow transplant, is a well-established therapy for a variety of hematopoietic system abnormalities, as well as several other life-threatening diseases. HSCT involves the injection of healthy hematopoietic stem cells into patients. The first allogeneic transplantation was conducted in 1957, and since then, the use of HSCT has increased globally.[1] Indications for HSCT comprise congenital and metabolic disorders, hematopoietic system, metabolic disorders, and autoimmune illness.[2] In Europe, over 40,000 peripheral blood HSCTs are done annually.[3] In the Middle East North African Region, the Kingdom of Saudi Arabia became the first Arab country to launch HSCT with a total of 6184 HSCTs performed between 1984 and 2016.[4]

Even if recovery is achieved after HSCT, the emerging and persistent late complications of HSCT might prevent full recovery. These complications can be contributed by both the underlying disease or transplant-related factors. Late

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complications in Allo-HSCT recipients have been intensively researched, but the impact of this transplant on the quality of life (QOL) of recipients has received less attention. To date, most researchers have focused on assessing survival and organ toxicity. In the past two decades, exploring the impact of HSCT on the QOL of cancer survivors became a prime research interest and an integral part of health care management of HSCT recipients.[5] HSCT is efficient in managing and possibly curing haematological malignancies.[6] Many studies showed that more than 60% of patients report good to outstanding QOL after one to four years of HCT.[6] Nevertheless, relapse after HSCT might negatively affect the QOL of patients. Last but not least, other factors influencing the QOL include the patient's age and clinical prognosis.[7]

Patients who undergo HSCT face both physical and psychological challenges. Common complications after HSCT include infections, gastrointestinal alterations, pain, fatigue, allergic reactions, and graft-versus-host disease.[8] Long-term complications of HSCT include cataracts, cardiac diseases (cardiomyopathy, congestive heart failure, myocardial infarction), pulmonary diseases (fibrosis/interstitial pneumonitis), bone diseases (myelodysplasia), thyroid diseases (thyroid cancer, hypothyroidism), hepatobiliary toxicity, leukaemia, skin cancer (basal cell, squamous cell, melanoma), renal insufficiency, short stature, osteopenia/osteoporosis, and avascular necrosis.[8,9] In terms of the psychological effects, fear, agony, and isolation significantly impact patients undergoing HSCT both socially and emotionally, thus disrupting their QOL.[8] Besides the physical and psychological challenges, these patients might be overwhelmed with other factors such as referrals, treatments, hospitalization, transportation, financial burdens, job absenteeism, and interrupted social relationships. These patients also experience changes in their lifestyle, such as reduced physical activities due to treatments that impair their muscle strength and endurance.[10] Therefore, despite its anticipated benefits, the journey with HSCT is demanding.

Evaluating the QOL of patients who underwent HSCT and identifying its influencing factors inform and improve clinical decision-making. A previous study showed that clinicians can screen and prioritize the clinical problems reported by their patients who underwent HSCT while addressing their preferences.[11] Understanding the changes in the QOL of these patients informs and facilitates care coordination. It aids in monitoring the changes in patients' health overtime and evaluates their response to treatments. Patients might not be able to lead a "reasonably normal" life, so their fear of complications or disease recurrence and its impact on their QOL needs to be explored.[12] Moreover, their lived experience is framed by socio-cultural influences. Since individuals differ in their coping measures with cancer management, it is imperative to explore the lived experience of patients after HSCT in under-researched populations such as Saudi Arabia. The Saudi Arabian population is known to be generally conservative, tribal, and religious, though Western cultural norms have been disseminated in this population. This indicates that the lived experience of patients with cancer and undergoing HSCT in Saudi Arabia might differ from those residing elsewhere. This gap in knowledge is evident in literature, so the aim of this study is to explore the lived experience of patients with cancer in Saudi Arabia who underwent HSCT and to determine how HSCT impacted their QOL.

Method

Study Design and Setting

This study adopted a qualitative descriptive research design using semi-structured in-depth face-to-face interviews. Participants were recruited and interviewed in a private room at the Adult Stem Cell Transplant & Cellular Therapy at King Abdulaziz Medical City, a tertiary care specialized center under the directory of the Saudi Ministry of National Guard-Health Affairs. This center provides comprehensive high-quality care for adult patients in need of stem cell transplant and cellular therapies. The division performs different types of Stem Cell Transplant procedures including an Autologous transplant (using the patient's own cells) and an Allogeneic transplant using stem cells from a donor. Following the official launching of the transplant program in March 2010, the center performed over 1000 transplants for adult patients.

Data Collection

A purposive sampling method was used to recruit eleven patients from a cancer registry at an adult oncology department of a tertiary health care center. Eligibility criteria included being an adult patient (>18 years of age) diagnosed with various types of cancer and underwent allogeneic HSCTs, regardless of their gender, marital status, race, and ethnicity. Patients were

excluded if they were non-Arabic language speaking, complaining of mental health impairment or not able to commit to a face-to-face interview after informing them about the study objectives.

A doctoral nursing student informed patients about the aim of the study and screened them for eligibility criteria. After agreeing to participate and signing a written informed consent, study participants were accompanied to a private room where interviews were performed. Interviews were performed between October and December 2023, and each lasted between 60 and 75 minutes. Study participants were made comfortable by providing them with refreshments. To enhance the quality of data collection, the student was asked to debrief the meetings with the research team following the interviews. The debriefing provided an opportunity to reflect on the interview process and identify of areas of improvement.

Study participants were first asked to introduce themselves to collect background information. The interview was guided by open-ended questions on various issues related to their life experiences with cancer and its impact on their QOL. These questions, shown in Table 1, were developed based on the multi-dimensional health-related QOL model proposed by Victorson et al in Figure 1.[13,14] Victorson et al conceptualized and highlighted the spectrum of health-related QOL issues that cancer survivors commonly encounter and presented recommendations for future research directions and applications that can have lasting effects on the well-being of cancer survivors.[13,14] Based on their review of literature and empirical work over 15 years, Victorson et al classified these issues into three discrete domains, the physical, mental and social health that represent a highly interrelated and dynamic system. This multidimensional health model was originally presented by the charter of the World Health Organization.[13,14] Participants were asked to elaborate about their daily activities, coping measures, various QOL aspects, and personal stressors/worries about future. They were asked about their social network and support they received during their treatments. Participants were also asked about their future expectations at the personal, professional, and family levels.

The interview questions were translated from English to Arabic language and back translated independently by two research team members, following the WHO recommended process of instruments' translation and adaptation.[15] Two experts in stem cell therapy and nursing revised the questions to confirm its ability to capture the experiences of study participants. Three patients with cancer who underwent HSCT were asked to participate in a pilot study to test the validity of the study measures and to assist on the future solicitation of research participants. They were recruited from the targeted site and asked if the questions are linguistically accurate, culturally appropriate, socially acceptable and if they have additional points. Those who participated in the pilot test of the questions were not enrolled in the study.

Table 1 Interview Guide

	Daily activities
1	What has been the most significant shift in your daily routine? In terms of activities, potential issues such as pain and medicine side effects should be considered.
2	What kind of help do you have, and who provides it?
3	Which aspects of your disease/therapy-related social network (stigmatization, sexuality, and close pals) annoy or please you? Do you think transplantation has impacted these kinds of connections?
4	How much of the hospital staff's help do you receive?
	Problems with coping
5	How are you coping with your current situation? What about your family? Is that important to you?
	Quality of life
6	What is the best word to express how you feel about your quality of life? Was it necessary for you to give up any of your favourite pastimes because of the transplant?
7	Do you need assistance with any of your daily routines, such as bathing, dressing, or moving around?
	Personal stress/worries about the future
8	How do you see your personal, professional, and familial futures?
	Closing questions
	Are there any other aspects you would like to talk about?

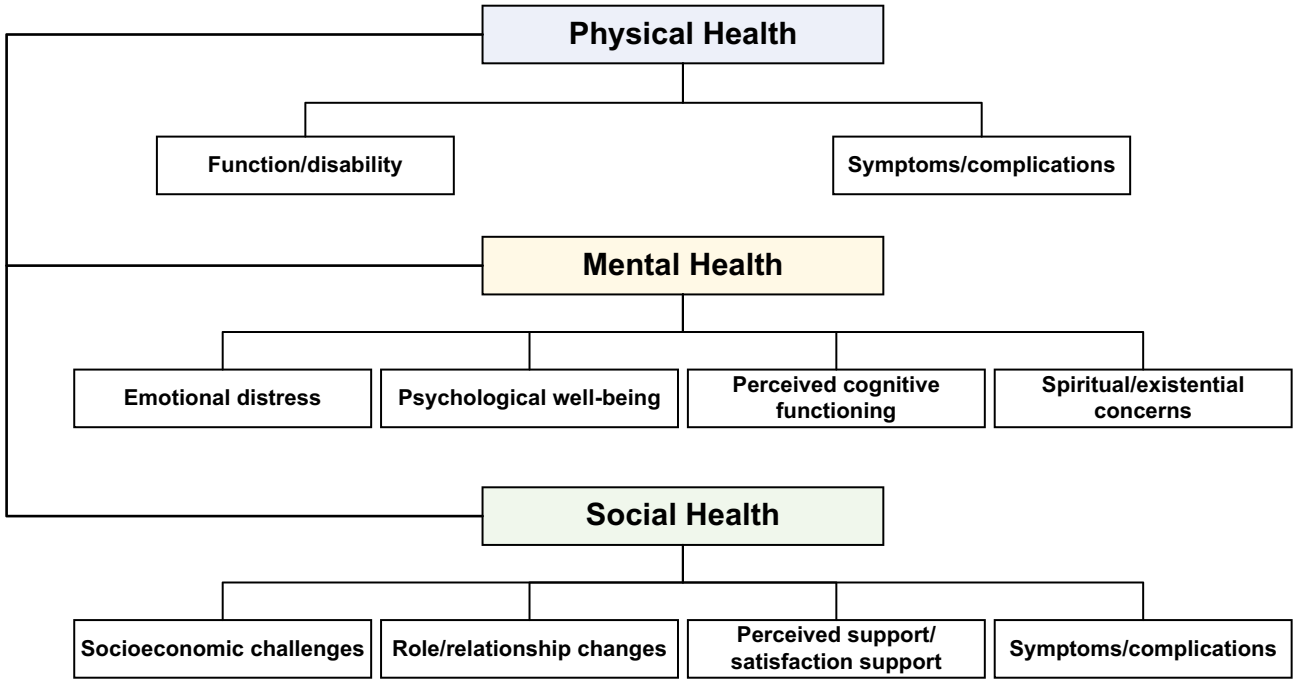

Figure 1 Conceptual Framework of Health-Related Quality of Life and Cancer Survivors.[13]

Data Management and Analysis

Recruitment of participants was stopped upon the authors' determination that data saturation had been achieved, as no new themes emerged. Using an audio-recorder application, interviews were recorded and transcribed by the research team while preserving the participants' identities. The accuracy of transcripts was verified by checking them against the audio recordings. Forward-backward translations (Arabic to English) of the transcribed texts were conducted by two bilingual translators independently. The research team compared between the two versions of the transcripts and the discrepancies were discussed with the team after revisiting the original records. Data were first broken down into smaller samples, and codes were simultaneously applied. The data was reread, and the assigned excerpts to codes were confirmed. In case the codes did not match, additional codes were considered and revised. Transcripts were initially coded in Arabic language (the native language of participants) before being translated into English by the research team. NVivo software was used for coding, organizing the data, and thematic analysis of full transcripts using a constant analysis and a mind-mapping approach. A bottom-up inductive coding approach involved observation, seeking patterns, and interpreting contextual data. Thematic analysis was performed by two research team members after familiarizing themselves with the coded data, independently. By consensus, emerging themes were identified, reviewed, and refined so that a thematic map is created. The research team compared the themes to the concepts in the multi-dimensional health-related QOL model proposed by Victorson: physical health (Function/disability, symptoms/complications), mental health (emotional distress, psychological well-being, perceived cognitive functioning, spiritual/existential concerns), and social health (socioeconomic challenges, role changes, perceived support, and complications) while observing for the emergence of new ones. Finally, a complete narrative of the findings was generated, and selected interviewee quotes for each theme and subtheme were presented.

Increasing Rigour

The interviewer received training on interviewing skills, maintaining consistency and rigour. The interviewer focused on techniques to remain neutral and non-judgemental and to sustain the interviewees' engagement in the subject matter. The interviewer declared no prior relationship with participants, fostering objectivity and minimizing bias. Interviews with participants were performed in their preferred language to ensure their understanding of the questions and their ability to

easily express their thoughts. Transcript accuracy was verified by checking them against the audio recordings. The Consolidated Criteria for Reporting Qualitative Research checklist guided the reporting of this study.

Ethical Considerations

The study was approved by the Institutional Review Board at King Abdullah International Medical Research Center, King Saud bin Abdulaziz University for Health Sciences, at the Saudi Ministry of National Guard Health Affairs, Riyadh, Saudi Arabia. This study followed the recommendations of the International Conference on Harmonization for Good Clinical Practice (ICH-GCP) and in compliance with the Declaration of Helsinki.

Results

Sample Profile

Seven male and four female participants were interviewed during their follow-ups after undergoing HSCT. Their age ranged between 18 and 51 years. The medical diagnoses of these participants included Sickle Cell Disease (SCD), Sickle Cell Anemia (SCA), Hodgkin Lymphoma (HL), Classic Hodgkin lymphoma (CHL), Pernicious Anemia (PCD), Acute Myeloid Leukemia (AML), Non-Hodgkin Lymphoma (NHL), Acute Lymphoblastic Leukemia (ALL), Serum Amyloid A (SAA), Autoimmune Disease (Autoimmune DSE), Beta Thalassemia Major, Chronic Myeloid Leukemia (CML), Myelodysplastic Syndrome (MDS), Central Nervous System Hemophagocytic Lymphohistiocytosis (CNS-HLH), and Bone Marrow Failure (BMF). Table 2 presents more details on the participant characteristics.

Five major themes emerged in this study. The first was the Physical Well-Being that emerged from four sub-themes: independence, self-efficacy, health outlook (health perception), and pain. The second theme was the Psychosocial Impact of cancer based on the subthemes: stigmatization, depression, and social strains. The third and fourth themes were Social Support and Coping with Cancer, with the subthemes: avoidant coping, meditation and faith. The fifth theme is related to the general Perception of the QOL, including psychosocial/physical stability and optimism. Each of these themes is presented in Figure 2 that illustrates the link between the themes and the proposed theoretical framework. The structure of this figure was inspired by the work of van Leeuwen et al 2018 who developed a patient-reported outcome measures that captured the full range of issues relevant to disease-free cancer survivors.[16]

Physical Well-Being

Several participants reported limitations or changes in their day-to-day physical functional abilities after asking them to describe a typical day. Other participants were able to maintain their normal daily routine. Some indicated that the negative consequences of treatments had substantially altered their daily routine. Several subthemes were observed.

Table 2 Demographic Characteristics of Participants

Participant Number	Age/Year	Gender	Diagnosis	Date of SCT	Social Status	Number SCTs	Type of SCT
Participant 1	26	Male	SCA	18-Mar-2021	Single	1	Allogeneic
Participant 2	20	Female	BMF	12/03/2019	Single	1	Allogeneic
Participant 3	48	Male	HL	28-Mar-2013	Married	1	Allogeneic
Participant 4	19	Female	CHL	05/02/2018	Single	2	Allogeneic
Participant 5	39	Male	SCA	21-Feb-2019	Married	2	Allogeneic
Participant 6	18	Female	SCD	13-Oct-2022	Single	1	Allogeneic
Participant 7	23	Male	HL	14-Nov-2017	Single	1	Allogeneic
Participant 8	20	Male	ALL	13-Aug-2013	Single	1	Allogeneic
Participant 9	29	Male	HL	12-Nov-2020	Single	2	Allogeneic
Participant 10	46	Male	ALL	11-Aug-2016	Married with Kids	1	Allogeneic
Participant 11	51	Female	ALL	11-Oct-2018	Single	1	Allogeneic

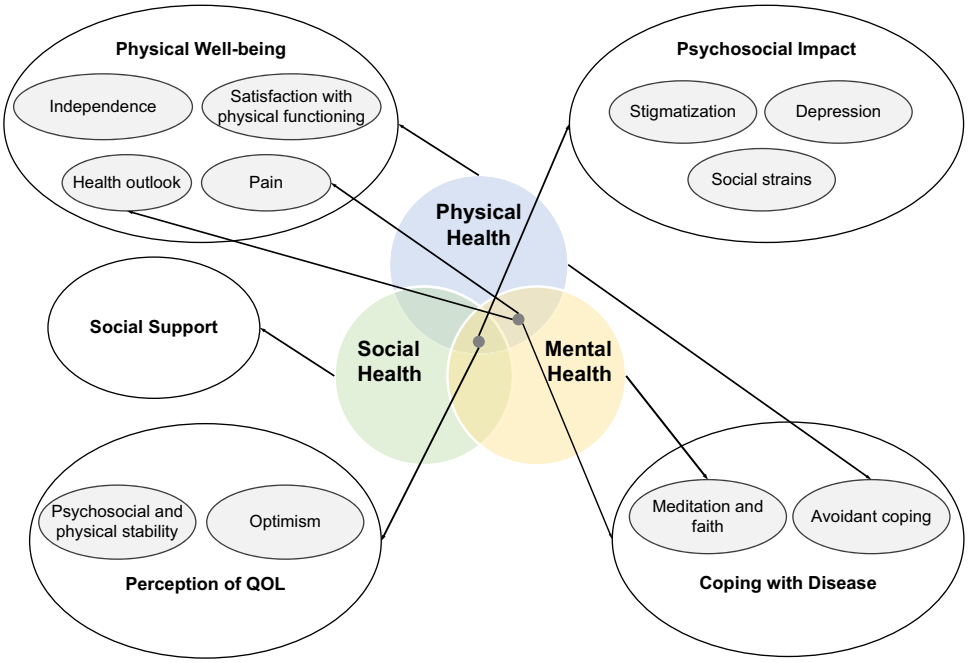

Figure 2 The three-dimensional theoretical framework developed by Stewart et al (1992) is utilized to conceptualize and link the generated themes and sub-themes of this study with three-dimensional theoretical framework of health.[17] Some indicators are specifically linked to one of the three dimensions, while others are linked to two or three.[16]

Independence

Participants stated that HSCT allowed them to lead a normal and independent life. This had a positive impact on their physical wellbeing. One participant indicated that he is eager to share his successful treatment story with other cancer patients to support them in recovery. The following excerpts explain:

PT# 5: *Before transplantation, I was completely reliant on my parents and relatives, (.). I could not rely on myself (.). My life is now as normal as any other normal person's."*

PT# 3: "Life is better (.) I was in fourth stage of cancer and with multiple stem cell transplantation, but praise and gratitude be to God, it came back well. I wish to pass on my experience to cancer patients who are psychologically affected to the point where they are confining themselves. I wish I could come to say that having cancer is like fighting either to defeat it or to be defeated, or you give up, and this is a colossal failure".

PT# 2: *Before transplantation I could not walk long distances and I would get extremely exhausted, and I felt discomfort in my feet and after transplantation my feet are becoming stronger and I am able to walk long distances without exhaustion.*

Self-Efficacy

Participants were confident with their responsibilities at home and towards their family members, that is mainly in their ability to support their families, significantly improving their psychological well-being. They stated:

PT # 5: I am doing my responsibilities at home and with my family members in a very excellent way, and I do not have any problem".

PT# 3: "I am willing to put forth every effort. particularly with my close family. I used to be like a man who didn't anticipate death. This is why I've changed emotionally for the better".

Satisfaction With Physical Functioning

Some participants expressed an overall satisfaction with their day-to-day physical activities. Only one immunocompromised participant expressed dissatisfaction and social restraint. Another participant expressed a lack of energy due to pain from the medical illness.

PT # 5: In the past if I would go out two steps, I had to return to the hospital if I had a cold. After stem cell transplantation I can go back and forth and travel independently".

PT # 4: Before transplantation, I was a person with high immunity able to visit places with full gatherings. Transplantation restrained me to visit places that I love like restaurants.

PT# 8 "Prior Stem Cell Transplantation I was depending on my parents and after the transplantation I am totally independent on myself in performing my personal things and studying (...) and attending my medical appointment alone".

PT# 11: "I have been fighting the illness for the past years, believing that I will be able to overcome it and get well, but feeling ill and pain from the disease made me lack of energy".

Health Outlook (Health Perception)

Participants expressed a positive health outlook post HSCT. Although their anticipated outcomes were not fully achieved, their general health improved and their life became more stable. In addition, one participant stated that it was life changing after the transplantation "feels like a new-born". Others indicated their desire to share their successful treatment story with other patients struggling with cancer. Some stated that they felt better over time. For example:

PT# 5: "Before the transplantation, I was not able to go outside the house (.) it caused me a lot of difficulties (...) but after the transplant, thank God, my life became normal and I'm like a new-born".

PT#4: "My overall experience with transplantation has improved my health and made my life more stable, although I did not achieve all of the desired outcome".

Pain

Participants shared their experience with the excruciating pain prior treatment. However, they reported a considerable improvement in their pain levels post-transplant. One of the participants stated that he still experienced pain, "being free from pain is a blessing".

PT# 2: Before the transplantation, it was painful and I was in very dull situation suffering from unstoppable bleeding even with medication (...) crying all the time and no one was aware of it but after transplantation, the bleeding stopped and my life is becoming better and I just feel happy.

PT# 3: "You cannot believe what the pain that I lived with; I was expected to die (...) my wife would express my pain as a person experiencing death (...) after transplantation I went from the death phase to a recuperative person".

PT#1: *"Because of my illness, I was always in a terrible mood, and I used to keep the pain inside me, not wanting to bother anyone about it. I was constantly isolated, lonely, confined, suffering from great pain, going to the hospital once a week, sometimes once a month, depending on the severity of the pain and the frequency of the episodes; I am still impacted by this, and I haven't yet broken free from this vicious loop. It was nearly two years ago. Now there is no pain or concern about physical health, which is a blessing".*

Psychosocial Impact

Being diagnosed and living with cancer negatively impacted patients psychosocially prior SCT. The emotions of the patients ranged from denial, to anger, to final acceptance, and eventually coping with the disease. The psychosocial status

of participants after transplantation was explored resulting in the following subthemes: stigmatization, depression and social restraint.

Stigmatization

Although participants did not feel stigmatized by their families or society, they felt some degree of inferiority complex. Post transplantation, a positive change in the patient's morale occurred due to the significant changes in their health. The participants explained:

PT# 3: "Although I feel that some people usually say you have an evil eye (they believe that cancer is an evil eye), however, I don't have a concern about this, and I don't believe it".

PT# 2: I do not feel stigmatized, I would love to pass my experience to cancer patients to benefit from what I have been through (...) Before the transplantation, I was a different person, isolated, alone and annoyed.

PT# 1: To be honest, I had an inferiority complex as a result of the condition (.). people kept asking me about it, which just added to my sense of inferiority. The disease has the strongest impact on you because you feel like an incomplete person.

Depression

Participants expressed some degree of depression due to overthinking about the long-term effects of cancer, cancer treatment and life expectancy. One participant explained that the repeated inquiries about his disease had negative psychological impact. Another participant claimed that she was clinically diagnosed with depression, since she lacked psychological support from her family.

PT# 4: *I visited a psychiatrist, and he said that I have depression (...) Most of my need is psychological support from my family (...) especially to my school.*

PT# *3: I feel healthy and active, and I mean to be dedicated to my responsibilities, but simply thinking about my life expectancy is painful.*

Social Strains

Some participants indicated that transplantation has given them a new life and enhanced their social obligation. Accordingly, they wanted to dedicate more time for social engagement, particularly with family and parents. In contrast, two participants developed a phobia of infection due to post-transplant immunosuppressant therapy and they indicated that they avoided social gatherings and public spaces, which prevented them from being socially productive and active.

PT# 4: "Before I didn't like talking too much. Now I am able to select and pick up the person that I can talk to (...) I avoid frustrated people (...) I look to the person that I can communicate with".

PT# 1: Because the immunosuppressants I am taking suppress my immunity, I am trying to isolate myself as much as possible. I have a phobia of infection."

PT3: My morale has improved since the transplantation; previously, I was an isolated and unsocialized person."

PT#7: My worries about failure of the transplantation due to exposure to infection led to a sense of social isolation (...) and the lack of help from people has triggered in me the desire for social withdrawal".

Social Support

Participants shared a common point of view that family members – mainly spouses, siblings, and parents – played an important role in their support throughout the process of the disease diagnosis and treatment. Their role was viewed as highly positive and supportive. Friendships were valued by participants as important in conjunction with the support of family members. Interacting with a supportive social network was a significant strategy adopted by participants. Some

participants stated that their social interaction was limited to immediate family members, including the father, mother, and siblings, though they wanted to interact with a broader social network. One participant stated that interacting with colleagues is limited to work only.

PT# 5: "My family members who are with me praise to Allah, hopefully, we do not need any support".

PT# 9: "I would like to invest every minute in my life (…) especially with my mother and my brothers".

PT# 8: "the empathy is the one stems from love not pity (…) the empathy I want is not from people it is from parents".

PT# 10: "My wife is the greatest support to me without her wouldn't have managed my life she is always there for me".

Coping With the Disease

Accepting the circumstance was the most common method for adjusting to the disease and therapeutic conditions as reported by most participants. Two subthemes were identified by participants as an effective strategy to cope with their medical condition after the transplantation. These emergent subthemes include avoidant coping, meditation and faith.

Avoidant Coping

Some participants adapted to disease and therapeutic conditions using avoidant coping strategies to control anguish about living with their disease.

PT# 4: "I always think about the future and link it to my past (...) I am trying to adopt the concept of not worrying about my past and future and focus on my day to be happy".

PT# 2: "I love children and as a negative consequence, the transplantation deprived me of having children by 99% (...) now I totally avoid them so I will not be attached to them and become normal".

Meditation and Faith

Some participants declared their confidence in "Almighty Allah", believing that cancer is a test from Allah and that only "He" can help them survive this situation.

PT# 3 "Praise to God now I am ready if I am diagnosed with cancer again (…) I am going to a merciful God".

PT# 1: "I always blamed myself, saying why did I have to suffer from these two diseases? Why? I always asked God's forgiveness? Now I apologize for what I thought of first. (...). I realized that God's gift is very great. I mean, if He intends a thing, He says it to 'be'. There is a simple reason for everything".

Perception About Quality of Life

Although the disease burden and the consequent adverse effects of HSCT had a significant influence on the participants' daily lives, they still emphasized on the good aspects of their everyday lives. In addition, they generally focused on the psychosocial aspects, emphasizing changes in their characters, enhancing morale and perspectives on life, as well as their attitude toward having a meaningful purposeful life. The majority specified the significance of prioritizing their values and investing and dedicating their time to make significant changes in their lives. The main subthemes are psychosocial stability and optimism.

Psychosocial and Physical Stability

Some participants understood and perceived the QOL to be socially and physically active, developing and maintaining relationships with friends and family, and being productive members in the society. Others expressed their emotional sensitivity in being loved and accepted by society.

PT# 4: "My friendship with others is crucial (...) Friendships, feelings, feelings of love that you see from your brothers and the people around you (...) I am a very sensitive person, so I enjoy getting love from everyone. I aspire to achieve great things. These are the positive impacts of transplantation".

PT# 1: "Quality of life entails productivity and, more importantly, the ability to function well. These activities are related to my life. These activities can be either at the level of the job, sports, or social activities".

PT# 8: "Quality of life means that life is simple, beautiful and pure and free of any complexities and this is what I have felt after the transplantation (...) it is related to health and wellness".

Optimism

The majority of participants expressed positivity in life and a desire to excel academically and professionally to secure their future. Participants also indicated that their past suffering from the disease has made them more optimistic to make a new start to achieve what they had missed out.

PT# 4: "my future is brilliant, the transplantation changed my communication skills (...) I am not regretting my experience with the disease it is passed, and I have learned a lot (...) this made me open-minded always looking for development".

PT#1: "On a professional level, this is the most important thing I am considering; I was concerned that my disease might hinder in terms of acceptability. I frequently came across situations on social media where a person was rejected because of anemia and hence was not considered for this position. I avoided doing and thinking negatively about the issue. But now, things have changed I can perform my profession".

Discussion

Exploring the lived experience of cancer survivors who underwent HSCT in Saudi Arabia provides a profound understanding on how patients perceive cancer and report life changes after its treatment. Bone marrow transplant was first performed by Georges Mathé in 1956, and in 1984, Saudi Arabia became the first Arab state to perform HSCT.[4] The Saudi Arabian population is relatively conservative and attached to its religious principles. For instance, the Saudi Food and Drug Authority approved stem cell therapy after securing a fatwa (a religious decree) in 2003 making it permissible to obtain, grow and use stem cells for therapeutic or scientific research purposes.[18] Some patients with cancer in Saudi Arabian might hesitate to undergo HSCT driven by their opposing religious beliefs, poor knowledge, unknown expectations, or fear of complications. Therefore, it is imperative to share the lived experiences of patients who underwent HSCT to persuade patients with cancer who are considering HSCT in the future. The themes identified in this study are not limited to the Saudi Arabian context, since the experience with cancer and its treatments might be commonly reported among other populations or settings with similar sociocultural features. Even if there were sociocultural differences in how individuals perceive cancer and HSCT, it is integral to share the benefits of various strategies adopted by these patients to cope with the consequences of cancer and its treatment.

Independency was evident among study participants, indicating that several cancer survivors were able to regain their personal routine within the first year after HSCT.[5] Some participants reported that the negative consequences of cancer therapies substantially altered their daily routine prior to the transplant. This finding was similar to a previous study in which allo-HSCT recipients reported an improved psychological wellbeing, including less emotional problems and role restraints, more personal life satisfaction, and less fatigue.[19] It was viewed as a sense of personal accomplishment when conquering the difficulties posed by their disease and transplant. A relationship between the professional activity, quality of life, and happiness was previously reported.[20] Many reasons contribute to the change in life functions, such as the physical health and the capacity to retrieve professional status. These findings align with the themes in this study since the majority of participants experienced a positive impact on their physical well-being following the HSCT.

Self-efficacy stems from the person's confidence in his or her abilities to attain a desirable outcome.[21] The ability to execute strategies that avoid, identify, and treat symptoms in patients with cancer is known as self-efficacy in symptom management.[22] Self-efficacy is a vital aspect in the effective adaptation to the long-term conditions associated with

cancer.[23] Patients with cancer and undergoing HSCT who have a strong self-efficacy report less pain, exhaustion, and psychological distress, as well as an overall better perceived health and QOL.[24] Studies indicated that self-efficacy has been linked to clinical symptoms in patients with cancer, including pain, anxiety, and distress.[25,26] As a result, nursing interventions are integral to boost self-efficacy during the HSCT process.[22] Earlier studies indicated that physical symptoms, distress, and QOL have been identified as important elements in the patient's experience before and after transplantation.[27,28] Similarly, both anxiety and psychological distress were frequently found in HSCT patients.[29]

A lack of social support is associated with a high risk of post-HSCT depression, occurring in one-third of all patients.[30] Core family values are commonly practiced in Saudi Arabia, and family is a central pillar of the Saudi Arabian society. It forms the basis of most people's social circles, and also provides financial and emotional support.[31] Female gender was linked to higher post-transplant depression, which was seen in nearly a third of all transplant patients.[19] A study in Saudi Arabia confirmed an association between hopelessness and the perceived social support among patients with cancer, especially among females.[32] This indicates that the nature of social support in certain settings such as Saudi Arabia might have been a key contributor to overcoming the stressors associated with cancer.

Social support was considered important not only at the physical and emotional aspects but also served as a -distraction.[33] A study investigated whether social support, self-efficacy, and optimism were associated with physical and emotional well-being one year following bone marrow transplantation. It found that high levels of social support, optimism, and self-efficacy prior transplantation predicted better emotional and physical health after one year, highlighting the significance of addressing these psychosocial components prior BMT.[34] In early studies on cancer survivors, it was indicated that they preferred to rely on family and friends to help them deal with psychological challenges.[35] Self-reliance and problem minimizing have been identified as obstacles to obtain psychosocial assistance in rural communities.[36,37] After HSCT, the majority of the participants reported positive thinking and minimal stress, courtesy to a supportive social network.

The majority of potential HSCT patients assume that successful HSCT and disease eradication will restore their life function prior to disease diagnosis.[38] Failing to achieve this expectation may result in inferior psychological adjustment and a lower level of QOL in survivors. Persistent distress and depression might also result in a slower or worse return to normal function. As a result, potential HSCT patients should be advised that, even if the underlying illness is addressed, HSCT survivors may still experience deterioration in their QOL.[39] Findings in this study are consistent with the findings of a previous study that showed the varying degrees of psychosocial impact following HSCT, such as inferiority complex, depression, and social restraint.[27]

Previous studies emphasized the importance of adopting behaviours to divert the attention of patients from cancer. It was beneficial among 61% of HSCT survivors.[33] This type of avoidant coping strategy involves various activities, such as staying busy, avoiding thinking or worrying about treatment, and even not talking about it. Spirituality and beliefs have been shown to play an important role in patients' positive coping mechanisms during cancer treatment.[40] This allows patients to better adjust to their disease and live a meaningful life.[41] Health fatalism could also be detrimental to patients' perception about cancer and its treatment.[42] Individuals with high levels of spirituality often believe that life events – whether it is health or illness – are fixed in advance and human beings are powerless to change them.[43] A previous study from Iran showed that fatalism was higher among women with no experience of mammography compared to those with a positive history.[44] Spiritual beliefs and fatalism are commonly used in Islamic philosophy and Persian literature denoting the belief in the pre-ordained Decree of God. In contrast, patients with the less spirituality levels had significantly poorer QOL than the group with higher spirituality levels.[45] This is supported by a report that patients who lacked spirituality had a greater risk of all-cause mortality after one year of HSCT.[46]

Life-threatening diseases such as cancers and intensive treatments such as HSCT can result in major changes, such as a greater concern about life and stronger interpersonal relationships.[47] Optimism is regarded as crucial to the QOL because optimists adopt more effective coping mechanisms than pessimists, whose techniques are linked to psychological stress and avoidance of good health behaviours.[48] Optimism was helpful to adjust for changes in 89% of participants in one study.[33] This entailed enthusiastic feelings about life and being certain that the therapy will be beneficial. Apparently, optimism supported adjustment.

A significant link was discovered between professional activity, QOL, and well-being.[20] According to a qualitative study, patients who are able to work had a better QOL. As a consequence, the inability to work or resume former employment led to a significant reduction in QOL.[5] Earlier research demonstrated that optimism and social support are linked to improved post-transplant coping and better QOL.[49,50] Findings in this study corroborate the conclusions of these studies. The higher degree of optimism among patients with cancer was most likely linked to their past disease-related suffering and changes in their general physical and psychological well-being.

Some of the themes that emerged in this study were similar to those depicted in the multi-dimensional health-related QOL model of van Leeuwen, while others were unique to the Saudi Arabian context.[16] In terms of physical health, satisfaction with the physical functioning theme aligns with the functional abilities. Independence aligns with the level of disability constructed in the model, health outlook aligns with the symptoms and pain with complications. In terms of mental health, mediation/faith aligns with spiritual/existential concerns, depression aligns with psychological wellbeing, yet social strains/stigmatization did not align with any construct in the model. This can be attributed to the cancer-related stigma in Saudi Arabia. One study stated that stigmatization is generally low in this country, yet cancer severity predicted stigmatization, especially among older individuals and males.[51] This might not be present in other countries. In terms of social health, social support aligns with the perceived support construct, the psychosocial aspect aligns with the emotional distress, and physical stability aligns with symptoms/complications, yet avoidant coping and optimism were not aligned with any construct in the model. Avoidance coping involves cognitive and behavioral efforts oriented toward denying, minimizing, or avoiding stressful demands that are an individual related factor, rather than context related.[52] Optimism is hopefulness and confidence about the future or the success of something that can be influenced by individuals' spiritual beliefs or fatalistic views.

Study Limitation

This study has to be seen in light of a few limitations. Interviews were conducted at one tertiary health care center, but with patients from multiple regions. It is not expected that the QOL of patients with cancer who underwent HSCT varies between regions. In addition, some factors that might influence the QOL were missed by the study participants. This includes the interaction with spiritual figures, pre-transplantation procedures, the location of the health care, the travel burden, and private nature of family relationships.

Conclusion

This is an early attempt to explore the multi-dimensional health-related QOL of patients with cancer who underwent HSCT in Saudi Arabia. Cancer survivors in Saudi Arabia often place a higher value on their QOL than on life expectancy. The emerging QOL themes of patients with cancer who underwent HSCT in Saudi Arabia aligned with the constructs presented in the multi-dimensional health-related QOL model of van Leeuwen that are physical well-being, psychosocial impact, social support, coping with disease, and perception of QOL. Some constructs were unique to the Saudi Arabian population, such as social strains, stigmatization, avoidant coping and optimism.

Findings in this study have a number of implications on clinical practice and research. In terms of clinical practice, this study can guide health care practitioners about the actual physical, psychological, and social needs of patients with cancer who underwent HSCT. This enhances the effectiveness of patient education and quality of health care plans, taking into consideration the cultural aspects of the Saudi community. Cancer survivors face a plethora of health-related challenges prior HSCT, and this study highlighted how HSCT enhanced the QOL for these patients. Both health care practitioners and families of patients with cancer should strive to improve the patients' QOL. In terms of research, this study presented a deeper understanding of the QOL concerns and long-term recovery following HSCT. There is a pressing need to further explain the nature of relationship between the emerging themes and various factors, through quantitative methodologies and among larger samples. These factors may include individual, social, disease and treatment related characteristics of patients who survived cancer and underwent HSCT.

Abbreviations

HSCT, Hematopoietic stem cell transplantation; QOL, quality of life; SCD, Sickle Cell Disease; SCA, Sickle Cell Anemia; HL, Hodgkin Lymphoma; CHL, Classic Hodgkin lymphoma; PCD, Pernicious Anemia; AML, Acute Myeloid

Leukemia; NHL, Non-Hodgkin Lymphoma; ALL, Acute Lymphoblastic Leukemia; SAA, Serum Amyloid A; Autoimmune DSE, Autoimmune Disease; CML, Chronic Myeloid Leukemia; MDS, Myelodysplastic Syndrome; CNS-HLH, Central Nervous System Hemophagocytic Lymphohistiocytosis; BMF, Bone Marrow Failure.

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

Disclosure

The authors report no financial competing interests.

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