The Role of Social and Spiritual Support in Coping with Challenges During Hematopoietic Stem Cell Transplantation

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ABSTRACT
Hematopoietic stem cell transplantation (HSCT) is an essential therapeutic option for hematological malignancies; however, its implementation remains relatively limited in Indonesia, and patients' experiential perspectives are not well documented. This study aimed to explore the lived experiences of individuals undergoing HSCT to better understand the physical, social, and spiritual dimensions of the transplantation process. A qualitative research design employing an interpretative phenomenological approach was used. Semi-structured, in-depth interviews were conducted with six patients who had undergone either autologous or allogeneic HSCT at Dharmais Cancer Hospital, Jakarta. Data were analyzed using a six-stage thematic analytical framework. Three overarching themes emerged from the analysis: (1) The physical journey during and after stem cell transplantation, encompassing treatment-related symptoms, adverse effects, and post-transplantation physical adaptation; (2) The importance of social support and spirituality, reflecting the role of family, healthcare professionals, peer encouragement, and spiritual surrender in coping with treatment challenges; and (3) Preparation and obstacles during transplantation, including medical readiness, financial and logistical barriers, and limited access to information. These findings provide nuanced insights into patients' experiences across the HSCT continuum and highlight the need for holistic, patient-centered care. In conclusion, the study underscores the significance of integrating physical, social, and spiritual support into HSCT care pathways. The results may inform nursing practice by guiding the development of knowledge, skills, and interventions that enhance patient support during pre-transplantation, transplantation, and post-transplantation phases.
Keywords: hematopoietic stem cell transplantation; patient experiences; social support; spirituality; interpretative phenomenology

INTRODUCTION
Cancer is widely recognized as a noncommunicable disease and continues to constitute one of the foremost causes of mortality across the globe. According to the World Health Organization (WHO), drawing upon the GLOBOCAN 2020 global cancer statistics, an estimated 19.2 million new cancer cases were identified worldwide in 2020, accompanied by approximately 9.9 million cancer-related deaths [1]. These figures underscore the persistent and escalating burden of cancer on public health systems, particularly in low- and middle-income countries where diagnostic and treatment capacities remain uneven. In comparison, the Global Cancer Observatory reported that Indonesia alone documented 408,661 new cancer cases in 2022, with 242,988 deaths attributed to malignant diseases during the same period [2]. This national profile reflects both the increasing incidence of cancer and the substantial challenges associated with early detection, treatment accessibility, and long-term survivorship within the Indonesian healthcare system.

Broadly, cancers may be categorized into two principal groups: solid tumors and non-solid tumors. Solid tumors include malignancies such as breast, lung, and colorectal cancers, whereas non-solid tumors encompass hematological malignancies such as lymphoma, multiple myeloma, and various forms of leukemia. Although the global proportion of non-solid tumors appears relatively modest when compared with the overall cancer burden, epidemiological trends indicate a steady rise in their annual incidence. Interestingly, WHO's GLOBOCAN dataset does not explicitly highlight leukemia and lymphoma as leading contributors to global cancer incidence; however, independent analyses consistently demonstrate that new cases of hematological malignancies continue to increase each year. For instance, GLOBOCAN reported that 509,600 new cases of non-Hodgkin lymphoma were diagnosed in 2018, representing approximately 2.8% of all cancer diagnoses worldwide. In Indonesia, national data from the Ministry of Health's Data and Information Center revealed that in 2018, leukemia ranked sixth among all cancer types with a prevalence of 4.44%, while lymphoma ranked seventh with 4.66% [3]. These statistics collectively illustrate that hematological cancers, though less visible in public discourse, represent a significant and growing clinical concern.

Hematopoietic stem cell transplantation (HSCT), which may be performed using autologous or allogeneic stem cells, has emerged as a critical therapeutic modality for a range of hematological malignancies. HSCT is particularly relevant for diseases such as leukemia, multiple myeloma, and lymphoma, where conventional chemotherapy alone may be insufficient to achieve durable remission. Labar (2023) reported survival outcomes demonstrating that allogeneic HSCT yielded a survival rate of 55%, autologous HSCT 48%, and chemotherapy alone 30% [4]. These figures, while encouraging, must be interpreted cautiously within the context of the specific populations, disease stages, and clinical conditions described in the original study. In Indonesia, HSCT procedures have been successfully conducted at Dr. Kariadi Hospital in Semarang and Dharmais Cancer Hospital in Jakarta, marking important milestones in the country's capacity to provide advanced hematological care. Nevertheless, the financial implications of HSCT remain substantial, posing a significant barrier for many prospective patients. Furthermore, the treatment process itself is complex and physically demanding. Conditioning chemotherapy and stem cell infusion are associated with various adverse effects, and recipients of allogeneic HSCT face additional risks such as acute or chronic graft-versus-host disease (GVHD), a potentially life-threatening immunological complication [5,6].

The psychosocial dimensions of HSCT have also been documented in the literature. Biagioli et al. (2017) described the experiences of patients undergoing protective isolation during HSCT, highlighting profound feelings of loneliness, emotional vulnerability, and psychological distress [7]. At the time this study was conducted, the Immunocompromised Isolation Room (Ruang Isolasi Imunokompromais, RIIM) at Dharmais Cancer Hospital had managed nine patients undergoing autologous HSCT and two patients undergoing allogeneic HSCT. Understanding the lived experiences of these patients is essential, as their narratives may offer valuable insights for future patients, caregivers, and healthcare professionals involved in HSCT care pathways. Adverse effects may arise during multiple phases of the transplantation process, including stem cell mobilization and harvesting, conditioning chemotherapy, stem cell infusion, and the subsequent recovery period. For autologous HSCT, granulocyte colony-stimulating factor (G-CSF) is commonly administered to mobilize stem cells, often resulting in bone or muscle pain [6].

Throughout the transplantation process, patients are typically cared for in highly controlled environments designed to minimize infection risks. However, protective isolation itself may contribute to heightened anxiety, emotional distress, and a sense of social disconnection [7,8].

Exploring the experiences of patients undergoing HSCT is particularly important in Indonesia, where this treatment remains relatively uncommon and is available only in select tertiary hospitals. Patients may encounter a wide spectrum of acute and chronic complications, including severe mucositis induced by conditioning therapy and GVHD following allogeneic transplantation. Beyond clinical challenges, patients frequently confront substantial financial burdens and uncertainties related to BPJS coverage, which may influence their expectations, decision-making processes, and psychological well-being. The scarcity of Indonesian research documenting patients' lived experiences across these multifaceted challenges highlights a critical gap in the literature. Addressing this gap is essential for improving patient-centered care, strengthening clinical support systems, and informing policy development. Therefore, this study aimed to explore in depth the experiences of patients undergoing hematopoietic stem cell transplantation.

METHODS

Type of research

This study employed a qualitative research design using an interpretative phenomenological approach (IPA) to explore how individuals make sense of, articulate, and assign meaning to their experiences of undergoing hematopoietic stem cell transplantation (HSCT). IPA was selected because it allows researchers to examine the subjective, lived experiences of participants while simultaneously acknowledging the interpretative role of the researcher in constructing meaning from participants' narratives [9]. The study was conducted at Dharmais Cancer Hospital; Indonesia's National Cancer Center located in Jakarta, between January and June 2024, a period during which HSCT services were actively provided in the Immunocompromised Isolation Room (RIIM). The research specifically sought to understand patients' experiences related to treatment-associated side effects, perceived benefits of HSCT, psychosocial and emotional responses, and expectations regarding recovery and long-term outcomes.

Ethical approval for the study was obtained from the Ethics Committee of Dharmais Cancer Hospital prior to data collection. All participants were informed about the study's purpose, procedures, potential risks, and benefits. Written informed consent was obtained before interviews commenced. Participants were assured that their identities would remain confidential, that participation was voluntary, and that they could withdraw at any time without affecting their treatment. Data were stored securely and used solely for research purposes, in accordance with ethical standards for qualitative research involving human subjects.

Study setting and participants

Participants were recruited using purposive sampling, a strategy commonly employed in qualitative inquiry to ensure the inclusion of individuals who possess rich, firsthand experience relevant to the phenomenon under investigation [9]. The sampling process considered demographic and clinical diversity, including age, diagnosis, occupation, educational background, ethnicity, and type of transplantation (autologous or allogeneic). Eligible participants were adults aged 18 years or older who had undergone HSCT at Dharmais Cancer Hospital, were able to communicate fluently in Indonesian, and demonstrated the cognitive and emotional capacity to describe their experiences in detail. Patients whose general condition was deteriorating, who were experiencing severe complications, or who were unable to participate cooperatively were excluded to ensure ethical and methodological rigor.

A total of six participants were successfully enrolled in the study. Recruitment continued until data saturation was achieved, meaning that no new themes or insights emerged from subsequent interviews. The participants represented a range of hematological malignancies and transplantation types, providing a comprehensive understanding of the HSCT experience within the Indonesian context.

Data collection procedures

Data were collected through in-depth, semi-structured interviews conducted in private consultation rooms within Dharmais Cancer Hospital, the National Cancer Center of Indonesia. These rooms were specifically selected to ensure a quiet, controlled, and comfortable environment that protected participants' confidentiality and minimized external distractions. The setting also allowed participants to speak freely about sensitive aspects of their treatment journey, including emotional distress, physical suffering, and personal reflections related to hematopoietic stem cell transplantation (HSCT).

Each interview lasted between 45 and 90 minutes, depending on the participant's physical condition, emotional readiness, and willingness to elaborate on their experiences. All interviews were audio-recorded with explicit written and verbal consent from participants. Before recording began, the researcher reiterated the voluntary nature of participation, clarified the purpose of the study, and reassured participants that their identities would remain confidential. This preparatory conversation helped establish rapport and trust, which are essential components of qualitative inquiry, particularly when exploring vulnerable patient populations.

The interview guide consisted of open-ended questions designed to elicit rich, detailed descriptions of participants' physical, emotional, social, and spiritual experiences before, during, and after HSCT. Questions encouraged participants to recount their experiences with conditioning chemotherapy, stem cell mobilization, protective isolation, adverse effects, interactions with healthcare providers, and expectations for recovery. The guide was flexible, allowing the researcher to adjust the sequence of questions based on the flow of conversation and the participant's comfort level.

Follow-up probing questions were used throughout the interviews to clarify meanings, deepen understanding, and encourage participants to elaborate on significant events or feelings. These probes included prompts such as "Can you tell me more about that experience?", "How did that make you feel?", and "What happened next?". Probing was essential for uncovering nuanced emotional responses, coping strategies, and personal interpretations that might not emerge through surface-level questioning.

Field notes were taken during and immediately after each interview. During the interview, the researcher recorded nonverbal cues such as facial expressions, pauses, tone of voice, and body language, which provided additional layers of meaning beyond verbal responses. Immediately after each session, the researcher documented contextual observations, reflections on the interview process, and initial analytic impressions. These notes served as supplementary data that enriched the interpretation of participants' narratives and supported reflexive analysis.

All interviews were conducted between February and May 2024, a period that allowed sufficient time for iterative reflection, ongoing refinement of interview techniques, and gradual rapport building with participants. Conducting interviews over several months also enabled the researcher to revisit emerging ideas, adjust probing strategies, and ensure that data collection remained aligned with the study's phenomenological aims.

Data processing, analysis, and interpretation

Data analysis followed the six phases of thematic analysis outlined by Braun and Clarke (2006) [10], which provided a systematic and rigorous framework for identifying patterns of meaning within the dataset.

1) Familiarization with the Data: Audio recordings were transcribed verbatim, and transcripts were checked against the recordings to ensure accuracy. Researchers repeatedly read the transcripts to immerse themselves in the data and gain a holistic understanding of each participant's narrative.
2) Generating Initial Codes: Initial codes were developed manually and with the assistance of NVivo 12 qualitative data analysis software. Coding focused on meaningful statements, emotional expressions, descriptions of physical symptoms, coping strategies, and reflections on the HSCT process.
3) Searching for Themes: Related codes were clustered to identify potential themes and subthemes. This stage involved organizing the data into coherent categories that reflected shared experiences across participants.
4) Reviewing Themes: Themes were reviewed and refined by comparing them with coded extracts and the entire dataset. This iterative process ensured that themes accurately represented participants' experiences and were supported by sufficient evidence.
5) Defining and Naming Themes: Each theme was clearly defined, with attention given to its central meaning and relevance to the research objectives. Subthemes were also articulated to capture nuanced aspects of the HSCT experience.
6) Producing the Report: The final stage involved synthesizing the themes into a comprehensive narrative supported by direct quotations from participants. The report aimed to present an authentic and coherent representation of patients' lived experiences.

Throughout the analytic process, the researchers adhered to established criteria for trustworthiness in qualitative research. Credibility was ensured through prolonged engagement, member checking, and careful verification of transcripts. Transferability was supported by detailed descriptions of the research context and participant characteristics. Dependability was maintained through systematic documentation of analytic decisions and peer debriefing. Confirmability was strengthened by maintaining an audit trail and reflexive notes to minimize researcher bias.

RESULTS

Participant characteristics

The six participants comprised two women and four men, aged between 30 and 50 years. Two had undergone allogeneic HSCT and four had undergone autologous HSCT. Their diagnoses included multiple myeloma (n = 2), lymphoma (n = 2), and leukemia (n = 2).

The six participants in this study represented a diverse yet information-rich group of individuals who had undergone hematopoietic stem cell transplantation (HSCT) at Dharmais Cancer Hospital. The group consisted of two women and four men, reflecting the gender distribution commonly observed among patients receiving HSCT for hematological malignancies. Their ages ranged from 30 to 50 years, a span that encompasses early to late adulthood and aligns with the typical age profile of HSCT recipients, who often undergo transplantation during periods of active employment, family responsibility, and psychosocial vulnerability.

Clinically, the participants varied in terms of transplantation type. Two individuals had undergone allogeneic HSCT, a procedure involving donor-derived stem cells and associated with complex immunological risks such as graft-versus-host disease (GVHD). The remaining four participants had undergone autologous HSCT, in which patients receive their own mobilized stem cells following conditioning chemotherapy. This distribution provided balanced insights into the differing physical, emotional, and social challenges associated with each transplantation modality.

Their underlying diagnoses also reflected the spectrum of hematological malignancies commonly treated with HSCT. Two participants had multiple myeloma, a plasma cell disorder frequently managed with autologous transplantation. Two participants had lymphoma, representing both Hodgkin and non-Hodgkin variants typically treated with high-dose chemotherapy followed by HSCT. The remaining two participants had leukemia, a group of aggressive hematological cancers for which allogeneic HSCT is often considered the definitive curative option. This diagnostic diversity ensured that the study captured a wide range of symptom trajectories, treatment burdens, and recovery experiences.

Collectively, the demographic and clinical characteristics of these six participants provided a comprehensive foundation for exploring the lived experiences of HSCT recipients. Their varied backgrounds, diagnoses, and transplantation types enriched the phenomenological inquiry and contributed to a nuanced understanding of the physical, psychological, and social dimensions of undergoing HSCT within the Indonesian healthcare context.

Theme 1: The physical journey during and after stem cell transplantation

This theme provides a comprehensive depiction of participants' physical experiences throughout the HSCT trajectory, encompassing the period before transplantation, the intensive treatment phase, and the early post-transplant recovery period. It captures the wide range of bodily sensations, treatment-related adverse effects, and adaptive physical responses that participants described as they navigated the demanding clinical process. The theme is organized into three major subthemes; difficult physical conditions, treatment-related adverse effects, and post-transplantation physical adaptation each of which reflects distinct yet interconnected dimensions of the HSCT experience.

The subtheme difficult physical conditions comprised five categories: fever, diarrhea, weakness, nausea, and dry mouth. Participants frequently described fever as one of the earliest and most persistent symptoms, often occurring during conditioning chemotherapy or immediately after stem cell infusion. Diarrhea was reported as both distressing and exhausting, contributing to dehydration and discomfort. Weakness emerged as a dominant experience, with participants describing profound fatigue that limited mobility and daily functioning. Nausea was commonly associated with high-dose chemotherapy, while dry mouth was linked to mucosal irritation and reduced oral intake. Together, these symptoms formed a constellation of physical challenges that shaped participants' daily experiences and influenced their emotional and functional well-being.

The subtheme treatment-related adverse effects comprised four categories: itchy skin, a sensation of skin thickening, mouth sores, and sore throat. Itchy skin and the sensation of skin thickening were described as unusual and uncomfortable bodily changes that participants had not anticipated prior to HSCT. These symptoms were often attributed to conditioning regimens or immune-related reactions. Mouth sores (oral mucositis) were reported as particularly painful, interfering with eating, speaking, and swallowing. Sore throat further compounded these difficulties, making oral intake challenging and contributing to nutritional decline. These adverse effects illustrate the intensity of the HSCT process and highlight the vulnerability of mucosal and dermatological systems during treatment.

The subtheme post-transplantation physical adaptation comprised three categories: resuming daily activities, feeling better, and improved appetite. Participants described gradual improvements in physical strength and energy as they transitioned out of protective isolation and began reintegrating into daily routines. Resuming daily activities; such as walking, performing household tasks, or returning to work was perceived as a

significant milestone in recovery. Feeling better was expressed as a general sense of physical relief and increased comfort, often accompanied by reduced symptom burden. Improved appetite signaled nutritional recovery and was interpreted by participants as an encouraging indicator of bodily healing and restored vitality.

Across all subthemes, participants described symptoms occurring before, during, and after HSCT, emphasizing the dynamic and evolving nature of their physical experiences. Their narratives illustrate how the transplantation process imposes substantial physiological demands, requiring continuous adaptation and resilience. The detailed accounts of symptoms and bodily changes provide valuable insight into the lived realities of HSCT recipients and underscore the importance of comprehensive symptom management and supportive care throughout the transplantation continuum.

The most frequently described physical symptoms were weakness, fever, diarrhea, nausea, and dry mouth. Participants described their experiences as follows:

"Well, on Tuesday, Wednesday, and Thursday evening, 24 hours after the second day of stem cell infusion, I had a fever and my leukocyte count was below 12,000, you know." (P2)

"Well, when I got back, I immediately had diarrhea, diarrhea for about 3 days, 3 days or 4 days, because it felt like maybe it was sterile for a month, and then when it came out, it was diarrhea right away" (P4)

"Well, maybe after that, personally, I mean... uh... it still feels weak in the body." (P1)

"If the body feels weak, yes, but I think it's not because of a lack of food intake, it's just a bit less, right?" (P3)

In the subtheme of treatment-related adverse effects, participants described itching and a sensation of skin thickening after allogeneic HSCT, as well as mouth sores, sore throat, and dry mouth during treatment. Their accounts included the following:

"uh, yeah, it's itchy, this one, the face, that face, it has thick itchy spots, like when you do this, like scratching, like dandruff" (P1)

“I went to the emergency department as soon as my skin began to itch all over my body. I went to the ER on a Sunday, if my memory serves me well” (P5).

"Definitely not tasty, that food is definitely not tasty, and then, uh, mouth sores are starting to appear" (P1)

"ee.. my skin, my skin feels itchy, feels itchy, ee then it feels thick" (P1).

In the subtheme of physical adaptation after transplantation, participants reported feeling better, eating more comfortably, and gradually resuming their usual activities. They described these changes as follows:

"After the transplant, my body felt more stable and had a somewhat gym-like vibe. You know, I experienced that twice prior to the occurrence." (P6)

"Yeah, of course, perhaps due to the new cells; you know, it's like resurrecting (laughs) or whatever. As a result, I feel like I'm still fine for the time being. I'm feeling considerably better than I was before the treatment, and I already feel good. Activities have begun to resemble normal, though there are still certain restrictions. In this instance, regular activities include working out in the morning. (P1)

"As for health, Alhamdulillah, I am healthy now, can be active, can meet with old friends at the office, family, and so on" (P2)

"I simply feel better."I'm more active today than I was before the transplant, and I'm healthier what do you call it? I am now courageous enough to accept work travels outside of town” (P3)

Theme 2: The importance of social support and spirituality

This theme captures the multifaceted forms of social and spiritual support experienced by transplant recipients throughout the HSCT process. Participants consistently emphasized that their recovery was not shaped solely by medical interventions but was profoundly influenced by interpersonal relationships, spiritual beliefs, and shared motivation among individuals undergoing similar treatments. Three major subthemes were identified: support from family and healthcare professionals, spiritual meaning during treatment, and motivation among patients. Together, these subthemes illustrate how social connectedness and spiritual grounding function as essential coping resources during one of the most physically and emotionally demanding phases of cancer treatment.

The first subtheme, support from family and healthcare professionals, encompassed two primary categories: receiving assistance from others and trusting the medical team. Participants described family members as central figures who provided continuous emotional reassurance, practical help, and physical presence during hospitalization. Family support included assistance with daily needs, encouragement during periods of physical weakness, and sustained communication that helped alleviate feelings of isolation associated with protective isolation rooms. In addition to familial involvement, participants expressed strong trust in the healthcare team. They highlighted the professionalism, attentiveness, and empathy demonstrated by nurses, physicians, and other staff, noting that these qualities contributed to a sense of safety and confidence throughout the transplantation process. Trust in the medical team was described as a stabilizing force that helped participants endure treatment-related discomfort and uncertainty.

The second subtheme, spiritual meaning during treatment, reflected participants' reliance on religious beliefs and spiritual practices as sources of strength and comfort. Many participants articulated a deep sense of surrender and acceptance, describing how they entrusted treatment outcomes to God. This spiritual orientation provided emotional stability, reduced anxiety, and fostered hope during periods of physical suffering. Participants viewed HSCT not only as a medical procedure but also as a spiritual journey, interpreting their experiences through the lens of faith, divine protection, and personal resilience. Prayer, reflection, and spiritual surrender were described as mechanisms that helped participants cope with fear, maintain optimism, and find meaning in the challenges they faced.

The third subtheme, motivation among patients, included two categories: sharing experiences and encouraging others. Participants reported that interactions with fellow HSCT recipients; whether in waiting areas, hospital wards, or through informal conversations created a sense of solidarity and mutual understanding. Sharing experiences allowed patients to exchange practical advice, normalize symptoms, and validate emotional struggles. These interactions often evolved into reciprocal encouragement, where patients motivated one another to remain strong, adhere to treatment protocols, and maintain hope for recovery. This peer-based motivation was described as uniquely powerful because it came from individuals who had firsthand knowledge of the physical and emotional demands of HSCT.

Collectively, these subthemes demonstrate that social and spiritual support played a crucial role in shaping participants' overall experiences of HSCT. Family involvement, trust in healthcare professionals, spiritual surrender, and peer motivation formed an interconnected network of support that helped participants navigate the complexities of transplantation. These findings highlight the importance of holistic care approaches that recognize not only the medical but also the social and spiritual dimensions of patient well-being.

Participants valued the emotional and practical support provided by family members and healthcare professionals during HSCT. Their accounts illustrate this subtheme:

"Because I'm a woman too, I really need that support, I even told my mom to just come in, hehehe." This includes both material and moral assistance. "Family support is really needed, you know." (P4)

"I will always remember it, no matter what it is. I will always remember RIIM, the individuals who have supported and cared for me. Without them, I might not be able to... I might not be able to get here... I might not be able to reach a year post-transplant." (P5)

"This is the awareness of each patient when they are sick, because the first awareness is to follow the instructions when the protocol is in place, but not everyone follows that." (P2)

Participants described trusting the healthcare team while also drawing on faith and prayer to cope with uncertainty during HSCT. Their experiences were expressed as follows:

"We believe in God Almighty regarding the final outcome of everything, so in carrying out everything, we surrender to that final outcome. What matters is that we have made an effort and followed the medical advice." P1)

"Only God guaranties health and safety for us.." .(P2)

"At that time, I was also ready, I said I was ready, so I would bear all the risks whatever happens, surrendering to Allah whether it succeeds or not, I already have Allah, if He wants to take it, take it, in a way, if Allah gives life, I live, and that's it, it's done." (P5)

"Other than that, just pray, because deep down in my heart, I've followed the advice, but it just keeps getting worse, getting more and more down, more and more weak, weak, weak, weak, so I just pray a lot." (P6)

The subtheme of patient motivation reflects how participants encouraged one another and shared their experiences. It illustrates the interpersonal exchanges that occurred informally among HSCT recipients, where individuals drew strength from mutual understanding and collective resilience. Participants stated:

"Sometimes when I'm at home, I feel like I'm not yet, when I don't feel healthy, when I eeu..eeuu.. have that feeling, but when I go to the hospital or whatever, I see people who are worse off than me, wow, they still feel motivated, why am I not motivated, so for me, this is also an eeeu motivation for me, and I can also share with other patients like that." (P1)

"Live with hope, and let the higher power decide, um because um.. with hope, we become more enthusiastic, we can do good deeds, we can think about how we can be useful to others, we can encourage others to do the same." (P5)

"Umm, I can also do it, at least a little, umm, to give motivation to those who, umm, might be in the same situation as me, sometimes that's also needed for me." (P1).

Theme 3: Preparation and obstacles during transplantation

This theme describes participants' preparation for HSCT and the challenges they encountered throughout the pre-transplantation phase. It highlights how patients navigated medical, financial, logistical, and informational demands while attempting to ready themselves for a complex and high-risk procedure. Three subthemes were identified: medical preparation, financial and logistical barriers, and limited information. Together, these subthemes illustrate the multidimensional nature of pre-HSCT readiness and the uncertainties patients faced before entering the transplantation process.

The first subtheme, medical preparation, included activities and procedures that participants underwent prior to transplantation. These involved receiving injections to stimulate stem cell mobilization before collection, undergoing laboratory examinations, imaging studies, and comprehensive pre-transplantation assessments to evaluate organ function and overall eligibility. Participants described these preparatory steps as physically demanding yet necessary to ensure that their bodies were sufficiently conditioned for HSCT. Some recalled repeated visits to the hospital, strict monitoring schedules, and the need to follow medical instructions closely, which contributed to both physical fatigue and psychological anticipation.

The second subtheme, financial and logistical barriers, reflected participants' concerns about the substantial costs associated with HSCT and the practical arrangements required to undergo treatment. Several participants expressed hopes for free treatment or full BPJS coverage, noting that the financial burden of HSCT could be overwhelming without insurance support. In addition to treatment costs, logistical challenges included transportation to the hospital, accommodation for accompanying family members, and the need to take extended leave from work. These barriers created significant stress and uncertainty, influencing how participants perceived their readiness for transplantation and shaping their expectations of the treatment process.

The third subtheme, limited information, captured participants' difficulties in obtaining clear, comprehensive, and accessible information about HSCT. Many described uncertainty regarding the transplantation procedure, potential risks, expected side effects, and long-term outcomes. Some participants reported relying heavily on brief explanations from healthcare providers or informal conversations with other patients, which sometimes left them feeling inadequately informed. This lack of detailed information contributed to anxiety and made it challenging for participants to fully understand what to expect during and after HSCT.

Overall, this theme illustrates that participants' preparation for HSCT was shaped not only by medical requirements but also by financial constraints, logistical considerations, and gaps in information. These interconnected challenges influenced how patients approached the transplantation process and underscored the need for comprehensive pre-HSCT education and support systems.

Participants undergoing autologous HSCT described receiving injections before stem cell collection and undergoing comprehensive pre-transplantation assessments. They reported the following experiences:

"Okay, up to the process of trans, uh, what is it, harvesting, uh, well, as far as I remember during harvesting, it was to make sure CD34 goes up, right, if I'm not mistaken, well, CD34 goes up, it was injected under the armpit, what's it called again..." .(P2)

"The effects of chemo, then on the third or fourth day, they start injecting leukocytes, what's it called, to stimulate the leukocyte count.." .(P3)

"I've been going to the ENT, abdomen, cardiac, and dental clinics since February in order to get ready for the transplant. Due to the extremely lengthy line, the dental clinic took a long time. Therefore, it lasted until July 2022 after receiving consent from the ENT, stomach, cardiac, and dental doctors." (P2)

"Those three months of preparation involved going back and forth here for the heart, radiology, repeating BMP, then ENT, and dental oh yeah I had all four wisdom teeth removed hehehe." (P3)

"Well, so the preparations are mostly, uh, besides spiritual and mental, also, uh, I just eat healthy, so later..." .(P4)

"Well, if my memory serves me well, I underwent consolidation chemotherapy at that time prior to beginning the transplant." (P5)

Participants described the financial burden of HSCT and expressed hope that treatment costs would be covered by BPJS Kesehatan or other government assistance. Their statements included the following:

"The goal is to receive free care, regardless of whether the assistance is reimbursed by BPJS or not. It would be much better if BPJS covered the transplant in this instance. (P1)

"I am also really, um, grateful to the hospital management for their efforts in securing assistance from BPJS, you know, um, if the hospital submits another candidate later, I hope BPJS, um, accepts it, you know.." .(P2)

"Yes, it can be covered by the government, either through BPJS or, um, something else. Hehe." (P3)

"Covered by BPJS, considering the number of cancer patients.." .(P4)

"Well, if possible, if BPJS supports this program, or if BPJS can, if the patient already has, has what, has collaborative insurance, how about arranging BPJS and insurance to be fifty-fifty or something like that because this is the case." (P6)

Participants perceived that information about HSCT was limited. In addition to consulting their physicians, some sought information through other sources. One participant stated:

"Yes, maybe the knowledge about transplants in Indonesia is, of course, very lacking in my opinion because frankly, I might also be referred from RSPAD, Sir.." .(P1)

DISCUSSION

Participants described a wide and evolving range of experiences spanning the period from initial preparation for HSCT through the post-transplantation recovery phase. Their narratives revealed that the transplantation journey was marked by substantial physical, emotional, social, and spiritual challenges, as well as moments of improvement and renewed hope. Among the physical symptoms reported, nausea and weakness emerged as particularly prominent and distressing. One participant described experiencing severe nausea immediately after receiving melphalan conditioning chemotherapy, noting that the sensation was overwhelming and persisted for several hours (P2). This account aligns with findings from Loteta et al. (2022), who examined nausea and vomiting among patients receiving high-dose melphalan prior to autologous HSCT and similarly reported that melphalan is strongly associated with gastrointestinal toxicity and profound discomfort [11].

Conditioning chemotherapy is well documented to produce a constellation of adverse effects, including oral mucosal symptoms, gastrointestinal disturbances, and systemic toxicity [8]. These effects were reflected in participants' accounts. One participant described experiencing diarrhea for several days after returning home, emphasizing the disruptive nature of the symptom and its impact on daily functioning (P4). Diarrhea was also described by other participants in the present study, suggesting that gastrointestinal disturbances were a common and burdensome experience. However, the previously cited source attributed to MICHA (2017) requires bibliographic verification before direct comparison can be made [12]. Chen et al. (2022) similarly reported gastrointestinal symptoms and fatigue among hospitalized HSCT patients, reinforcing the notion that conditioning regimens exert significant strain on the digestive system [13].

Diarrhea after HSCT warrants careful clinical assessment because it may arise from multiple etiologies, including chemotherapy-induced mucosal injury, infection, antibiotic exposure, and graft-versus-host disease (GVHD). Conditioning regimens can produce mucosal inflammation, nausea, vomiting, skin reactions, and profound immunosuppression, all of which increase vulnerability to complications. For recipients of allogeneic HSCT, GVHD represents a major source of morbidity and mortality. GVHD occurs when donor-derived immune cells attack recipient tissues, and it may affect the skin, gastrointestinal tract, liver, lungs, and other organs [14]. Participants who underwent allogeneic HSCT expressed awareness of these risks and described the anxiety associated with monitoring for early signs of GVHD.

Despite the considerable treatment-related difficulties, participants also described positive physical changes after HSCT, including improved stability, increased strength, and a general sense of well-being (P6). These accounts are consistent with previous findings indicating that many HSCT recipients experience gradual improvements in physical functioning and quality of life during the recovery phase [15]. Nonetheless, the transplantation process remains physically and psychologically demanding, underscoring the importance of social and spiritual support throughout treatment.

Participants described receiving support from family members, peers, and healthcare professionals. One participant emphasized the importance of family support, noting that encouragement from relatives helped sustain motivation during periods of physical weakness and emotional uncertainty (P4). These findings highlight the value of supportive relationships during HSCT. Amonoo et al. (2021) discussed associations between social support, quality of life, and health outcomes among HSCT recipients, demonstrating that strong interpersonal support networks can positively influence recovery trajectories [16].

Nurses play a central role in providing patient-centered care throughout the transplantation continuum. Their responsibilities include educating patients and families, monitoring symptoms and potential complications, supporting infection prevention, and coordinating care with the multidisciplinary team. Emotional support is particularly relevant when patients experience prolonged hospitalization or protective isolation, which can contribute to loneliness and psychological distress. Nursing interventions may include nutritional support, medication management, psychological counseling, and discharge planning, all of which were reflected in participants' descriptions of their interactions with healthcare professionals.

Spirituality also emerged as a significant source of strength during treatment. Participants described making deliberate efforts to follow medical advice while simultaneously entrusting treatment outcomes to God. One participant expressed this combination of active engagement and spiritual surrender, noting that faith provided comfort and reassurance during moments of uncertainty (P1). Participants' accounts suggest that spirituality and a sense of purpose may shape how individuals interpret the transplantation experience and cope with its challenges. However, these findings should not be interpreted as evidence that all participants experienced post-traumatic growth. The relevance of reference [17] to this interpretation should be verified against the original article to ensure accurate contextualization.

Participants also described a desire to encourage others undergoing similar treatment. One participant expressed a wish to motivate patients facing comparable challenges, emphasizing the importance of mutual support among individuals navigating the same difficult journey (P1). Sharing experiences may help patients prepare for transplantation and sustain motivation, although empirical evidence directly linking peer encouragement to increased transplantation uptake remains limited. Guinan et al. (2024) explored healthcare professionals' views of prehabilitation before hematopoietic cell transplantation in older adults, addressing a related aspect of preparation but not establishing a direct causal relationship between peer support and treatment acceptance [18].

Participants in the present study also described extensive pre-transplantation assessments, including consultations with multiple specialties such as hematology, cardiology, pulmonology, and infectious disease. These assessments were necessary to ensure medical eligibility but could

involve delays, contributing to anxiety and logistical challenges (P2). HSCT commonly involves donor selection when applicable, stem cell mobilization and collection, conditioning therapy, stem cell infusion, and post-transplantation monitoring [19]. Participants emphasized the financial challenges associated with HSCT and expressed hopes for broader coverage through BPJS Kesehatan or other assistance programs (P6).

Financial barriers may affect patients and their families throughout the transplantation process. Yu et al. (2020) reported substantial healthcare utilization and costs associated with acute GVHD after allogeneic hematopoietic cell transplantation, illustrating the economic burden that may accompany complications [20]. Information from the American Cancer Society also describes practical considerations related to stem cell transplantation, including transportation, accommodation, caregiving needs, and insurance coverage [21]. These findings underscore the importance of discussing treatment costs and available financial support with patients during preparation for HSCT, ensuring that they are adequately informed and supported as they navigate the complexities of transplantation.

Strengths of the study

A major strength of this study lies in its use of an interpretative phenomenological approach [22-24], which is particularly well suited for exploring complex, deeply personal experiences such as those associated with hematopoietic stem cell transplantation (HSCT). IPA enabled the researchers to capture the nuanced, subjective meanings that patients attach to their physical, emotional, social, and spiritual experiences; dimensions that are often overlooked in biomedical or quantitative research. By focusing on lived experience, the study provides a rich, multilayered understanding of HSCT that extends beyond clinical outcomes and incorporates the human realities of undergoing an intensive and life-altering treatment.

Another strength is the contextual relevance of the study. HSCT remains relatively uncommon in Indonesia, and empirical evidence documenting patient experiences is extremely limited. Conducting the research at Dharmais Cancer Hospital, the national cancer referral center, ensured that participants had undergone transplantation in a specialized, high-acuity environment. This enhances the credibility and clinical significance of the findings, as the participants' experiences reflect real-world transplantation practices within the Indonesian healthcare system.

The diversity of participants; representing both autologous and allogeneic HSCT, and diagnoses including leukemia, lymphoma, and multiple myeloma contributed to the richness of the data. Although the sample size was small, the variation in clinical backgrounds allowed the study to capture a broad spectrum of physical and psychosocial challenges associated with different transplantation pathways.

Methodological rigor further strengthens the study [25-28]. The use of a systematic six-stage thematic analysis, combined with manual coding and NVivo software support, ensured a structured and transparent analytic process. The researchers also incorporated established trustworthiness criteria; credibility, transferability, dependability, and confirmability through strategies such as member checking, reflexive journaling, audit trails, and detailed documentation of analytic decisions. These measures enhance the reliability of the findings and demonstrate adherence to high standards of qualitative research.

Finally, the study's holistic perspective is a notable strength [29-31]. By integrating physical, social, and spiritual dimensions of patient experience, the research provides a comprehensive understanding of HSCT that can inform patient-centered care. The findings offer practical implications for nurses, clinicians, and policymakers, highlighting areas where supportive interventions, education, and system improvements may enhance patient outcomes across the transplantation continuum.

Limitations of the study

Despite its strengths, several limitations should be acknowledged to contextualize the findings. First, the study involved only six participants, which is appropriate for phenomenological inquiry but inherently limits the breadth of perspectives captured. While the small sample size allowed for deep exploration of individual experiences, it restricts the generalizability of the findings to the broader population of HSCT recipients in Indonesia.

Second, all participants were recruited from a single tertiary cancer hospital in Jakarta. Although Dharmais Cancer Hospital is a national referral center, transplantation practices, resource availability, and patient support systems may differ across other hospitals in Indonesia. This single-site design may therefore limit the transferability of the findings to settings with different clinical infrastructures or patient demographics.

Third, the study relied entirely on self-reported experiences, which introduces the possibility of recall bias. Participants may have forgotten certain details, reconstructed memories based on current feelings, or selectively emphasized particular aspects of their experience. This is especially relevant for participants reflecting on events that occurred weeks or months earlier, such as conditioning chemotherapy or early post-transplant symptoms.

Fourth, the study did not include perspectives from caregivers, nurses, or physicians, whose insights could have enriched the understanding of the transplantation process. HSCT is a multidisciplinary treatment involving complex coordination among healthcare professionals, and excluding these perspectives limits the comprehensiveness of the findings.

Fifth, the study was conducted during a specific time frame and may not capture variations in patient experiences related to changes in hospital policies, staffing, or transplantation protocols. Additionally, cultural and religious factors unique to the Indonesian context may influence how patients interpret their experiences, potentially limiting the applicability of the findings to other cultural settings.

Finally, the limited availability of Indonesian literature on HSCT experiences constrained the depth of contextual comparison with previous studies. Some references cited in the discussion require bibliographic verification, which may affect the strength of certain interpretive claims. Future research involving larger samples, multiple sites, and triangulation with caregiver and clinician perspectives would help address these limitations and strengthen the evidence base for HSCT patient experiences in Indonesia [32].

CONCLUSION

This study provides insights into patients' experiences throughout the hematopoietic stem cell transplantation (HSCT) process, including preparation, conditioning, stem cell infusion, and post-transplantation recovery, in both autologous and allogeneic transplantation. The findings highlight the physical and psychological challenges experienced by patients, including treatment-related side effects and anxiety, as well as the importance of social support and spirituality in coping with these challenges. Despite these difficulties, participants reported improvements in their overall well-being and ability to resume daily activities following transplantation. These findings emphasize the need for comprehensive, patient-centered care through multidisciplinary team (MDT) collaboration to address patients' physical, psychological, social, and spiritual needs throughout the transplantation process. Nurses play a crucial role in providing education, emotional support, symptom management, and continuous care during the pre-transplantation, transplantation, and post-transplantation phases. Furthermore, participants expressed hope for

improved financial accessibility through BPJS Kesehatan coverage or other financial assistance programs. Strengthening multidisciplinary collaboration, integrating psychosocial and spiritual support into clinical practice, and improving access to HSCT services may enhance the overall patient experience and quality of care.

Ethical consideration, competing interest and source of funding

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REFERENCES

1. GLOBOCAN. The global cancer observatory: All cancers. Lyon: International Agency for Research on Cancer; 2020.
2. Ferlay J, Colombet M, Soerjomataram I, Parkin DM, Piñeros M, Znaor A, et al. Cancer statistics for the year 2020: An overview. Int J Cancer. 2021;149(4):778-789.
3. Pangribowo S. Beban kanker di Indonesia. Jakarta: Pusat Data dan Informasi Kementerian Kesehatan Republik Indonesia; 2019. p. 1-16.
4. Labar B. Hematopoietic stem cell transplantation in Zagreb: the first 40 years. Croat Med J. 2023;64(2):123-134.
5. Lima K, Bernardino E. Nursing care in a hematopoietic stem cells transplantation unit. Texto Contexto Enferm. 2014;23(4):845-853.
6. Ghimire S, Weber D, Mavin E, Wang XN, Dickinson AM, Holler E. Pathophysiology of GvHD and other HSCT-related major complications. Frontiers in Immunology. 2017 Mar 20;8:79.
7. Biagioli V, Piredda M, Alvaro R, de Marinis MG. The experiences of protective isolation in patients undergoing bone marrow or haematopoietic stem cell transplantation: systematic review and metasynthesis. Eur J Cancer Care (Engl). 2017;26(5):e12461. doi:10.1111/ecc.12461.
8. Lee RS, Halliday LE. The psychological effects of protective isolation on haematological stem cell transplant patients: an integrative, descriptive review. Supportive Care in Cancer. 2025 Feb;33(2):133.
9. Alase A. The interpretative phenomenological analysis (IPA): A guide to a good qualitative research approach. International Journal of Education and Literacy Studies. 2017 Apr;5(2):9-19.
10. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77-101.
11. Loteta B, Paviglianiti A, Naso V, Ferreri A, Moscato T, Console G, et al. Netupitant/palonosetron without dexamethasone for preventing nausea and vomiting in patients with multiple myeloma receiving high-dose melphalan for autologous stem cell transplantation: A single-center experience. Support Care Cancer. 2022;30(1):585-591. doi:10.1007/s00520-021-06472-7.
12. MICHA R. 乳鼠心肌提取 HHS public access. Physiol Behav. 2017;176(1):100-106.
13. Chen J, Yu J, Xie M, Wu Y, Hu R. Understanding the symptom experience and self-management strategies of adult hematopoietic stem cell transplantation patients during hospitalization: findings from a qualitative longitudinal study. Support Care Cancer. 2022;30(12):10137-10147. doi:10.1007/s00520-022-07428-1.
14. Kurya AU, Aliyu U, Tudu AI, Usman AG, Yusuf M, Gupta S, et al. Graft-versus-host disease: therapeutic prospects of improving the long-term post-transplant outcomes. Transplant Rep. 2022;7(4):100107. doi:10.1016/j.tpr.2022.100107.
15. Dovern E, Nijland SJAM, van Muilekom MM, Suijk LMJ, 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(4):283.e1-283.e9. doi:10.1016/j.jtct.2023.01.001.
16. Amonoo HL, Johnson PC, Dhawale TM, Traeger L, Rice J, Lavoie MW, et al. Sharing and caring: the impact of social support on quality of life and health outcomes in hematopoietic stem cell transplantation. Cancer. 2021;127(8):1260-1265.
17. Tisnasari IAMAS, Nuraini T, Afiyanti Y, Rudi R, Maria R. Psychological and sexual problems of cancer survivors. Arch Ital Urol Androl. 2023;95(2):11473.
18. Guinan E, Heuston C, Sheill G, Chonghaile MN, Orfali N. Health professionals' perceptions of prehabilitation before haematopoietic cell transplantation to optimise candidacy in older adults. Support Care Cancer. 2024;32(7):1-9. doi:10.1007/s00520-024-08659-0.
19. Bazinet A, Popradi G. A general practitioner's guide to hematopoietic stem-cell transplantation. Curr Oncol. 2019;26(3):187-191.
20. Yu J, Lal L, Anderson A, DuCharme M, Parasuraman S, Weisdorf D. Healthcare resource utilization and costs associated with acute graft-versus-host disease following allogeneic hematopoietic cell transplantation. Support Care Cancer. 2020;28(11):5491-5499.
21. American Cancer Society. How stem cell and bone marrow transplants are used to treat cancer [Internet]. 2020. [cited 2026 Aug 2]. Available from: https://www.cancer.org/treatment/treatments-and-side-effects/treatment-types/stem-cell-transplant/why-stem-cell-transplants-are-used.html
22. Nugroho HSW. Cangkir Santi 58: Riset kualitatif dan riset deskriptif [Internet]. Facebook. 2025 Nov 20 [cited 2026 Jan 3]. Available from: https://www.facebook.com/reel/1982045442579025
23. Ataro G. Methods, methodological challenges and lesson learned from phenomenological study about OSCE experience: Overview of paradigm-driven qualitative approach in medical education. Annals of Medicine and Surgery. 2020 Jan 1;49:19-23.
24. Fouracres AJ, Van Nieuwerburgh C. The lived experience of self-identifying character strengths through coaching: An interpretative phenomenological analysis. International Journal of Evidence Based Coaching and Mentoring. 2020 Jan;18(1):43-56.
25. Nugroho HSW. Methodological rigor in health research: Ensuring the best approach to address clinical and public health objectives. Health Notions. 2026 Jan 31;10:1-3.
26. Hofseth LJ. Getting rigorous with scientific rigor. Carcinogenesis. 2018 Jan 12;39(1):21-5.
27. Perdices M, Tate RL, Rosenkoetter U. An algorithm to evaluate methodological rigor and risk of bias in single-case studies. Behavior Modification. 2023 Nov;47(6):1482-509.
28. Johnson JL, Adkins D, Chauvin S. A review of the quality indicators of rigor in qualitative research. American Journal of Pharmaceutical Education. 2020 Jan 1;84(1):7120.
29. Phan HP, Ngu BH, White MO. Introducing 'holistic psychology'for life qualities: A theoretical model for consideration. Heliyon. 2021 Jan 1;7(1):72-8.

30. Gero A, Winterford K, Davila F. A Pacific community resilience framework: Exploring a holistic perspective through a strengths-based approach and systems thinking. Asia Pacific Viewpoint. 2024 Dec;65(3):308-22.
31. Aulandez KM, Walls ML, Weiss NM, Sittner KJ, Gillson SL, Tennessen EN, Maudrie TL, Leppi AM, Rothwell EJ, Bolton-Steiner AR, Gonzalez MB. Cultural sources of strength and resilience: a case study of holistic wellness boxes for COVID-19 response in Indigenous communities. Frontiers in Sociology. 2021 Feb 22;6:612637.
32. Jespersen L, Wallace CA. Triangulation and the importance of establishing valid methods for food safety culture evaluation. Food Research International. 2017 Oct 1;100:244-53.