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Exploring the Role of Family and Healthcare-Provided Social Support in the Quality of Life of Patients with Hematologic Malignancies: A Qualitative Study

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ABSTRACT

Objective: Hematopoietic stem cell transplantation, while an effective treatment for hematologic malignancies, is associated with substantial physical, psychological, and social challenges that may significantly impair patients' quality of life. This study aimed to explore the lived experiences of patients with hematologic malignancies, focusing on the role of perceived social support and cognitive flexibility in shaping quality of life.

Methods: A mixed-methods (quantitative–qualitative) design was employed. The qualitative phase followed an interpretative phenomenological approach. Data were collected through in-depth semi-structured interviews with patients hospitalized in a hematopoietic stem cell transplantation unit. Participants were selected using purposive sampling until data saturation was achieved. Data were analyzed using thematic analysis based on Braun and Clarke's framework.

Results: Four main themes emerged: (1) experiences of psychological distress and perceived stress related to illness and treatment; (2) perceived social support (emotional, informational, and instrumental) from family members and healthcare providers as a protective factor for quality of life; (3) cognitive flexibility as a key adaptive mechanism facilitating emotional regulation and meaning reconstruction; and (4) the interaction between perceived social support and cognitive flexibility in mitigating stress and enhancing quality of life.

Conclusions: The findings suggest that quality of life in patients with hematologic malignancies is strongly influenced by psychological and social resources, beyond medical factors alone. Strengthening social support and cognitive flexibility may contribute to more effective psychosocial interventions and improved quality of life in this population.

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Introduction

Hematologic malignancies, including leukemia, lymphoma, and multiple myeloma, constitute a group of cancers that affect the hematopoietic system, bone marrow, and lymphatic system. Due to their aggressive nature, complex clinical course, and intensive treatment regimens, these diseases impose substantial challenges on patients. In recent decades, remarkable advances in medical treatments—particularly the use of hematopoietic stem cell transplantation—have significantly increased survival rates and the likelihood of recovery among patients with hematologic malignancies. However, these advances have been accompanied by considerable physical, psychological, and social consequences that can profoundly affect patients' quality of life (Wang et al., 2022). Hematopoietic stem cell transplantation, as one of the most advanced yet challenging therapeutic approaches for hematologic malignancies, is a prolonged, exhausting, and highly stressful process. Prior to transplantation, patients undergo intensive chemotherapy, followed by extended periods of hospitalization and isolation. These conditions are associated with severe immunosuppression, increased risk of infection, pain, extreme fatigue, and substantial restrictions in social interactions (Al-Jawahri et al., 2021; Majhail et al., 2019). Such circumstances not only threaten patients' physical health but also contribute to psychological distress, including anxiety, depression, loneliness, hopelessness, and a diminished sense of control over life—factors that collectively lead to a marked decline in quality of life.

Quality of life is recognized as a key indicator in evaluating treatment outcomes among patients with cancer and has increasingly become a central goal of supportive care within healthcare systems. The World Health Organization defines quality of life as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (World Health Organization [WHO], 2020). Accordingly, quality of life is a multidimensional construct encompassing physical, psychological, social, functional, and spiritual dimensions.

In patients with hematologic malignancies, these dimensions are simultaneously and interactively influenced by both the disease and its treatment. From a physical perspective, patients frequently experience symptoms such as pain, chronic fatigue, nausea, reduced functional capacity, and treatment-related side effects (Greenix et al., 2020). Psychologically, anxiety, depression, stress, fear of disease recurrence, and concerns about the future constitute central aspects of patients'

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lived experiences (Ravindran et al., 2019). Socially, limitations in family, occupational, and social roles, reduced interpersonal interactions, and increased dependency on others are common challenges (Shah et al., 2019). Furthermore, the spiritual and functional dimensions of quality of life—encompassing a sense of meaning, purpose, and overall life satisfaction—are profoundly affected when individuals face a life-threatening illness (Peterman et al., 2021).

Research indicates that quality of life in patients with hematologic malignancies fluctuates considerably across different stages of the disease trajectory. At the time of diagnosis, psychological shock, fear of death, and uncertainty about the future often result in a sharp decline in psychological quality of life. During active treatment—particularly throughout the transplantation process—quality of life typically reaches its lowest levels, and several months are often required for partial recovery (Pidala et al., 2009; Wang et al., 2022). Even during follow-up phases and after apparent recovery, fear of disease recurrence and difficulties in returning to normal life may continue to threaten patients' quality of life (Wynes et al., 2013). Beyond medical factors, growing evidence suggests that psychological and social variables play a decisive role in shaping patients' experiences of quality of life. One such factor is illness perception, defined as individuals' beliefs and interpretations regarding the severity, controllability, and consequences of their illness. Threatening perceptions of illness are associated with higher levels of stress, poorer adjustment, and lower quality of life (Mosher et al., 2020). Likewise, perceived stress arising from cancer diagnosis, aggressive treatments, and uncertainty about the future can exert widespread negative effects on patients' mental health and social functioning (Ravindran et al., 2019).

In this context, perceived social support has emerged as one of the most important coping resources for patients with cancer. Social support refers to the availability of affection, empathy, information, and practical assistance from others and may manifest in emotional support (empathy, care, and reassurance), informational support (providing information, guidance, and explanations about the disease and its treatment), and instrumental or practical support (tangible and caregiving assistance) (Shah et al., 2019). Numerous studies have demonstrated that perceived social support plays a protective role against negative psychological outcomes of illness by reducing stress, enhancing hope, and strengthening individuals' sense of control, and is consistently associated

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with higher quality of life among patients with cancer (Ruiz-Rodríguez et al., 2022; Yoon et al., 2018).

For patients with hematologic malignancies, the importance of social support is further amplified due to the unique conditions of treatment, particularly prolonged periods of isolation. Family members, as the closest source of emotional and practical support, and healthcare professionals, as the primary providers of care and information, represent two fundamental pillars of the patients' support network. The quality of interactions with family and healthcare staff, levels of empathy, clarity of information, and availability of practical support can significantly influence patients' illness experiences and ultimately their quality of life. Despite substantial quantitative evidence demonstrating the association between social support and quality of life, a considerable proportion of existing research relies primarily on questionnaires and statistical analyses. Consequently, patients' lived experiences of social support and the meanings they attribute to these supports—particularly within the cultural context of Iran—have received limited in-depth exploration. Qualitative research provides an opportunity to give voice to patients and to uncover the subtle, contextual, and often hidden dimensions of their experiences of social support and quality of life. Therefore, conducting a qualitative study focused on the role of different types of social support (emotional, informational, and instrumental) provided by family members and healthcare professionals in shaping the quality-of-life experiences of patients with hematologic malignancies can contribute meaningfully to the existing literature and generate valuable evidence for designing effective supportive interventions. A deeper understanding of these experiences may offer practical guidance for healthcare providers, nurses, psychologists, and policymakers in the field of oncology, ultimately contributing to the enhancement of quality of life among this vulnerable patient population.

Material and Methods

Study Design

The present study is a qualitative investigation employing an Interpretative Phenomenological Analysis (IPA) approach, conducted with the aim of elucidating the lived experiences of patients with hematologic malignancies regarding the role of different types of perceived social support

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(emotional, informational, and instrumental) provided by family members and healthcare professionals in shaping their quality of life.

IPA focuses on gaining an in-depth understanding of individuals' subjective experiences and the meanings they attribute to these experiences. This approach is considered particularly appropriate and widely recommended for exploring complex, emotionally laden phenomena such as cancer diagnosis and exposure to aggressive medical treatments (Smith, Flowers, & Larkin, 2009).

The selection of this approach was based on the subjective, multidimensional, and context-dependent nature of quality of life and perceived social support. These constructs cannot be fully captured through quantitative instruments alone and require an in-depth exploration of patients' lived experiences within the real-life context of illness and treatment. Moreover, given the unique circumstances of patients undergoing hematopoietic stem cell transplantation—such as prolonged hospitalization and isolation—a qualitative approach enables access to deeper and less visible layers of patients' experiences.

Research Setting

The study was conducted in the hematopoietic stem cell transplantation (bone marrow transplantation) unit of a specialized center for the treatment of hematologic malignancies. Due to the nature of the treatment, strict isolation protocols, and the high vulnerability of patients, this unit constitutes a highly stressful and distinctive environment. Conducting interviews within this setting allowed for the exploration of patients' lived experiences under real-world treatment conditions.

Participants and Sampling Method

Participants consisted of patients diagnosed with hematologic malignancies, including leukemia, lymphoma, and multiple myeloma, who were undergoing hematopoietic stem cell transplantation. Purposeful sampling was employed to recruit participants who possessed rich and meaningful experiences relevant to the phenomenon under investigation (Polit & Beck, 2021).

Inclusion Criteria

Definitive diagnosis of a hematologic malignancy confirmed by a specialist physician

Hospitalization in the hematopoietic stem cell transplantation unit

Ability to communicate verbally and articulate personal experiences

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Willingness to participate in the study and provision of informed consent

Exclusion Criteria

Unstable physical or psychological condition that impeded participation in interviews

Withdrawal of consent or unwillingness to continue participation at any stage of the study

The number of participants was determined based on data saturation, meaning that sampling continued until no new codes or themes emerged from subsequent interviews (Guest, Bunce, & Johnson, 2006).

Data Collection Methods and Instruments

Data were collected through in-depth semi-structured interviews. This method allowed the researchers to maintain a coherent interview framework while retaining sufficient flexibility to pursue new topics introduced by participants during the interviews (Creswell & Poth, 2018).

Interview Guide

The interview guide was developed based on the study objectives, the Wilson and Cleary quality of life model, and a review of relevant literature. Interview questions focused on the following domains:

Patients' overall experiences of quality of life during the treatment period

Experiences of stress, concerns, and psychological challenges

Patients' perceptions of their illness and treatment process

Experiences of receiving social support (emotional, informational, and instrumental) from family members

Experiences of interaction and support from healthcare professionals

The role of social support in stress reduction and disease adjustment

Experiences of cognitive flexibility, changes in perspectives, and emotional regulation

Interviews were conducted individually in a calm environment, with careful consideration of patients' physical conditions. Each interview lasted between 30 and 60 minutes. With participants' consent, all interviews were audio-recorded and subsequently transcribed verbatim.

Data Analysis

Data analysis was performed using Thematic Analysis following the six-phase approach proposed by Braun and Clarke (2006). This method was selected due to its flexibility and its capacity to identify meaningful patterns within qualitative data.

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The analysis process involved the following steps:

Familiarization with the data: Repeated reading of interview transcripts

Initial coding: Identification of meaningful units related to quality of life, social support, and cognitive flexibility

Searching for themes: Grouping similar codes and developing preliminary themes

Reviewing themes: Examining internal coherence and distinctions among themes

Defining and naming themes: Identifying main and sub-themes

Producing the final report: Interpreting themes in relation to the theoretical framework and existing literature

The analysis process was iterative and conducted concurrently with data collection to facilitate analytical depth and ensure the identification of data saturation. To enhance the rigor and trustworthiness of the qualitative findings, the criteria proposed by Lincoln and Guba (1985) were applied:

Credibility: Achieved through in-depth interviews, prolonged engagement with the data, and iterative review of codes and themes

Transferability: Ensured by providing rich, detailed descriptions of the research context and participant characteristics

Dependability: Maintained through meticulous documentation of research and data analysis procedures

Confirmability: Supported by minimizing researcher bias and maintaining an audit trail of analytical decisions

Ethical Considerations

The study was conducted after obtaining approval from the relevant Research Ethics Committee. Prior to data collection, the purpose of the study was explained to all participants, and written informed consent was obtained. Participants were assured of the confidentiality of their information, anonymization of data, and their right to withdraw from the study at any stage without consequences. Given the physical and psychological vulnerability of participants, interview timing and conditions were arranged with sensitivity and strict adherence to professional ethical standards.

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Results

Analysis of the data obtained from semi-structured interviews with patients diagnosed with hematologic malignancies and hospitalized in the hematopoietic stem cell transplantation unit led to the extraction of a set of main themes and sub-themes that elucidate patients' lived experiences of quality of life within the context of illness, treatment, and isolation. The findings indicate that quality of life is a dynamic, multidimensional phenomenon that is strongly influenced by psychological and social factors. Among these, perceived social support and cognitive flexibility emerged as two central constructs that play a critical mediating role in reducing perceived stress, reshaping illness perceptions, and improving patients' overall quality of life experience.

Overall, four main themes and several related sub-themes were identified, which are presented in detail below.

Main Theme 1: Experiencing Stress and Psychological Distress in the Context of Illness and Treatment

Most participants described the experience of being diagnosed with a hematologic malignancy and entering the hematopoietic stem cell transplantation process as being accompanied by high levels of perceived stress**.** This stress was not only related to the life-threatening nature of the disease and uncertainty about the future but was also influenced by the specific conditions of treatment, physical side effects, and social restrictions.

Sub-theme 1.1: Diagnostic Shock and Fear of the Future

For many patients, receiving the diagnosis was described as a critical turning point in life. Participants reported feelings of shock, disbelief, fear of death, and concern about their own future and that of their families. These experiences, particularly during the initial days of hospitalization, had a profound negative impact on their psychological quality of life.

Sub-theme 1.2: Psychological Burden of Aggressive Treatments

Intensive chemotherapy, severe physical side effects, extreme weakness, and pain were identified as major sources of psychological distress. Many participants stated that physical incapacity and increased dependence on others intensified feelings of inadequacy and diminished self-esteem.

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Sub-theme 1.3: Stress Related to Isolation

The isolation conditions of the transplantation unit, restrictions on family visits, and disruption of social connections contributed to heightened feelings of loneliness, social withdrawal, and helplessness. This factor was identified as one of the most significant threats to patients' emotional and social quality of life.

Main Theme 2: Perceived Social Support as a Psychological Shield Against the Erosion of Quality of Life

One of the most prominent findings of this study was the pivotal role of perceived social support in shaping patients' quality of life experiences. Patients experienced social support not merely as external assistance, but as a vital source of security, meaning, and hope.

Sub-theme 2.1: Emotional Support from Family as a Source of Comfort and Hope

Most participants identified their family as their primary source of emotional support. Phone calls, affectionate messages, and emotional presence—even in the absence of physical contact—helped reduce feelings of loneliness and foster hope. This form of support played a crucial role in maintaining motivation to continue treatment and endure difficult conditions.

Sub-theme 2.2: Emotional Support from Healthcare Professionals and the Feeling of Being Valued

Empathic behavior, respectful communication, and humane attention from healthcare professionals were described as decisive factors in patients' more positive experiences of quality of life. Participants reported that feeling understood and supported by physicians and nurses made the treatment process more tolerable.

Sub-theme 2.3: Informational Support and the Reduction of Uncertainty

Receiving clear, honest, and understandable information about the illness, treatment process, and potential side effects helped patients reduce ambiguity and fear associated with the unknown. This type of informational support enhanced patients' sense of control and promoted more active participation in treatment-related decision-making.

Sub-theme 2.4: Instrumental Support and Facilitating Life During Physical Impairment

Practical assistance from family members and healthcare staff—such as help with treatment-related tasks, daily activities, and provision of supportive facilities—played an important role in reducing both physical and psychological burden. This type of support was

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particularly effective during periods of severe physical weakness and directly contributed to improvements in patients' quality of life.

Main Theme 3: Cognitive Flexibility as a Psychological Adaptation Mechanism to Illness

Cognitive flexibility emerged as a central theme, playing a significant role in how patients confronted their illness, managed emotions, and interpreted their quality of life experiences.

Sub-theme 3.1: Redefining the Meaning of Illness

Some participants were able to reinterpret their illness not merely as a threat, but as an opportunity to reassess life priorities, interpersonal relationships, and the meaning of living. This cognitive reframing contributed to reduced negative emotions and an increased sense of meaning in life.

Sub-theme 3.2: Acceptance of Reality and Adjustment of Expectations

Accepting physical limitations and treatment conditions helped patients adjust unrealistic expectations of themselves and their lives. This acceptance represented an important manifestation of cognitive flexibility and contributed to reduced internal conflict and enhanced psychological calmness.

Sub-theme 3.3: Emotion Regulation Through Cognitive Reappraisal

Patients with higher levels of cognitive flexibility demonstrated greater ability to manage negative emotions such as anxiety, anger, and hopelessness. By changing their perspectives, employing cognitive coping strategies, and focusing on controllable aspects of their situation, these individuals reported a more favorable quality of life experience.

Main Theme 4: The Interaction Between Social Support and Cognitive Flexibility in Shaping Quality of Life

The findings revealed that perceived social support and cognitive flexibility do not function independently; rather, they operate within an interactive and mutually reinforcing process. Adequate social support facilitated the development of cognitive flexibility, while patients with higher cognitive flexibility were more capable of effectively utilizing available social support.

This interaction led to reduced perceived stress, more adaptive illness perceptions, and ultimately an improved quality of life experience. Participants reported that through the combined influence of these two factors, they were able to experience greater hope, meaning, and a sense of control over their lives—even under the demanding conditions of treatment and isolation.

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Overall, the findings of this study indicate that the quality of life of patients with hematologic malignancies is the result of a complex interaction among perceived stress, illness perceptions, perceived social support, and cognitive flexibility. Emotional, informational, and instrumental support from family members and healthcare professionals, together with patients' capacity for cognitive adaptation and emotional regulation, play a decisive role in enhancing the lived experience of quality of life in this patient population.

Discussion

The aim of this qualitative study was to elucidate the lived experiences of patients with hematologic malignancies during hospitalization in the hematopoietic stem cell transplantation unit, with particular emphasis on the role of perceived social support and cognitive flexibility in shaping their quality-of-life experiences. The qualitative findings demonstrated that patients' quality of life is a multidimensional, dynamic phenomenon that is strongly dependent on the interaction of psychological and social factors and cannot be adequately explained solely within a biomedical framework.

Perceived Stress in the Context of Transplantation and Decline in Quality of Life

The findings revealed that patients experienced the hematopoietic stem cell transplantation process as one of the most stressful periods of their lives. Stress arising from diagnostic shock, uncertainty about the future, severe treatment-related side effects, and prolonged isolation simultaneously affected the physical, psychological, and social dimensions of quality of life. This finding is consistent with previous research identifying perceived stress as one of the strongest predictors of reduced quality of life among patients with cancer, particularly those undergoing bone marrow transplantation (Wang et al., 2022; Spanjaart et al., 2021).

Within the Wilson and Cleary quality of life model, perceived stress is situated at the level of psychological status and may influence quality of life indirectly through its effects on functional status, illness perceptions, and health-related behaviors. The qualitative data from the present study provide concrete, experiential confirmation of this theoretical pathway, illustrating how stress profoundly threatens patients' lived experiences of illness and treatment.

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Perceived Social Support as a Protective Buffer Against Psychological Erosion

One of the most salient findings of this study was the prominent role of perceived social support as a protective factor against the negative consequences of stress and illness. Patients experienced social support not only as practical assistance, but more importantly as a sense of availability, being seen, and feeling valued. This subjective perception of support played a crucial role in reducing anxiety, fostering hope, and making the harsh conditions of treatment more tolerable.

Emotional support from family members and healthcare professionals, particularly under isolation conditions, helped patients manage feelings of loneliness and social disconnection. This finding aligns with studies that have identified social support as one of the strongest predictors of quality of life in patients with cancer (Yoon et al., 2018; Psillidis et al., 2020). Moreover, the findings highlighted the importance of informational support from healthcare professionals; clear and transparent communication reduced uncertainty and enhanced patients' sense of control—an aspect that has received relatively limited attention in prior research.

At a theoretical level, these findings reinforce the position of social support within the social domain of the Wilson and Cleary model, demonstrating that perceived social support can buffer the adverse effects of perceived stress and weaken pathways leading to diminished quality of life.

Cognitive Flexibility as an Internal Mechanism of Adaptation to Illness

The qualitative findings indicated meaningful differences among patients in their cognitive approaches to illness and treatment. Patients with higher levels of cognitive flexibility demonstrated a greater capacity to redefine the meaning of illness, accept reality, and regulate negative emotions. These individuals were able to perceive the illness not merely as a catastrophe, but as part of their life trajectory or as an opportunity to reassess priorities and values.

This finding is consistent with previous research identifying cognitive flexibility as a key factor in adaptation to chronic illness and stress reduction (Ravindran et al., 2019). Within the conceptual framework of the present study, cognitive flexibility functions as a psychological resource that attenuates the negative relationship between perceived stress and quality of life.

Interaction Between Social Support and Cognitive Flexibility

One of the most innovative findings of this study was the identification of a bidirectional interaction between perceived social support and cognitive flexibility. The qualitative data showed that adequate social support provides a foundation for the development and strengthening of

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cognitive flexibility, while patients with greater cognitive flexibility are better able to utilize available social support effectively. This interaction offers a rich, experiential explanation for the quantitative findings of the study, which demonstrated the mediating roles of these two variables in the relationship between perceived stress and quality of life.

This finding suggests that effective interventions aimed at improving the quality of life of patients with hematologic malignancies should be multilevel in nature, simultaneously focusing on strengthening supportive social networks and enhancing patients' cognitive and emotional capacities.

Conclusion

The findings of this qualitative study indicate that the quality of life experienced by patients with hematologic malignancies undergoing hematopoietic stem cell transplantation emerges from a complex interaction among perceived stress, illness perceptions, perceived social support, and cognitive flexibility. In the face of intense physical, psychological, and social pressures, social support and internal cognitive resources play a decisive role in maintaining psychological balance and enhancing quality of life.

Specifically, the results demonstrate that perceived stress profoundly shapes patients' lived experiences of illness and treatment, posing a serious threat to quality of life; perceived social support—particularly emotional and informational support from family members and healthcare professionals—functions as a key protective factor; cognitive flexibility enables patients to reinterpret the meaning of illness, manage negative emotions, and adapt to new circumstances; and the interaction between these two factors provides an in-depth, experiential explanation of the indirect pathways to improved quality of life identified in the quantitative phase of the study.

Practical Implications

Based on these findings, it is recommended that:

- Psychosocial interventions in transplantation units focus on strengthening family-centered social support and teaching cognitive–emotional skills;
- Healthcare professionals, alongside medical treatment, place greater emphasis on empathic communication and transparent information provision;

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- Support programs be designed and implemented in a manner that is sensitive to the cultural context of Iran.

Finally, the use of a mixed-methods approach in this study demonstrated how qualitative data can meaningfully enrich and contextualize statistically identified relationships in the quantitative phase, thereby contributing to the development of more effective interventions aimed at improving the quality of life of patients with hematologic malignancies.

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Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving human participants were reviewed and approved by ethics committee of Islamic Azad University.

Author contributions

All authors contributed to the study conception and design, material preparation, data collection and analysis. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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