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Exploring the Lived Experience of Early-Phase Stem Cell Therapy Among Leukemia Patients

Irina Aulianisa
Universitas Trisakti, Indonesia
aulianisairina@gmail.com

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ABSTRACT

Stem cell therapy has emerged as a leading innovation in regenerative medicine, offering potential treatment options for patients with hematologic malignancies such as leukemia. While clinical outcomes have been extensively studied, little is known about how patients subjectively experience and interpret their participation in experimental stem cell therapy. Existing research lacks depth in exploring the lived, personally and emotionally complex aspects of this experience, raising the question: how do leukemia patients undergoing experimental stem cell therapy construct meaning from their treatment journey? This study employs a descriptive phenomenological approach to uncover the essence of patients' lived experiences during experimental regenerative treatment. Data were collected through in-depth, semi-structured interviews with seven adult leukemia patients (4 male, 3 female; aged 32–61 years) who had received at least one round of experimental stem cell therapy. Transcripts were analyzed thematically to identify core patterns of meaning. The results revealed four central themes: the oscillation between hope and uncertainty, embodied vulnerability, spiritual negotiation, and the critical role of empathic clinical relationships. These findings highlight the emotional and deeply personal nature of participating in an unproven therapy and provide insight into how patients navigate this uncertainty. By illuminating these lived experiences, the study contributes to a more comprehensive understanding of patient-centered care in the context of biomedical innovation. The findings underscore the importance of integrating narrative and relational approaches into clinical practice and suggest future research should explore similar phenomena across diverse cultural and clinical settings.

INTRODUCTION

In recent decades, stem cell therapy has emerged as a major advancement in regenerative medicine, offering renewed hope for patients with life-threatening conditions such as leukemia (Byrne et al., 2023). As clinical trials continue to assess its efficacy, the treatment has come to represent not only scientific innovation but also a highly personal experience for those undergoing it. Many leukemia patients seek experimental stem cell interventions when standard treatments have failed, situating the therapy at the crossroads of medical uncertainty and human resilience.

While most research emphasizes clinical outcomes and biological mechanisms, far less is known about how patients experience these treatments. Their journeys involve not just physical responses but also emotional and social challenges that unfold in the face of medical ambiguity (Beckman et al., 2021). Patients often grapple with core questions of survival, hope, and identity—realities that require deeper interpretive insight beyond clinical data.

In this context, the need to explore how patients make sense of their experiences with stem cell therapy becomes particularly relevant (Alghadir et al., 2020). Understanding the inner world of patients—their fears, expectations, and personal transformations—requires an approach that attends to the subjective meaning of illness and healing. A phenomenological lens offers the opportunity to uncover these dimensions, providing insight into how individuals interpret and live through complex therapeutic encounters. Such knowledge not only enriches the academic discourse on patient-centered care but also informs more empathetic clinical practices that respect the human side of innovation in regenerative medicine.

Within the broader discourse of regenerative medicine, research that centers on the lived experiences of patients undergoing experimental therapies has become increasingly recognized as a critical domain of inquiry (Breda et al., 2021). As medical technologies evolve, so too does the need to understand how individuals perceive, internalize, and navigate the uncertainties of these interventions. Specifically, patients undergoing stem cell therapy for leukemia confront not only the clinical dimensions of treatment but also a profound internal process involving fear, hope, vulnerability, and meaning-making. Capturing this experiential reality requires more than outcome metrics—it demands engagement with the subjective narratives of those most affected.

Despite growing awareness of the importance of patient-centered perspectives, methodological challenges persist in exploring such complex, deeply personal phenomena. Much of the existing literature relies heavily on quantitative frameworks that emphasize biological or functional outcomes while neglecting the intricate emotional and existential layers of the patient journey (Y.-H. Zhang et al., 2021). These approaches often fall short in illuminating how patients interpret their experiences within the broader context of their lives, beliefs, and identities.

This methodological gap highlights a fundamental limitation of prior research: an overemphasis on external observation at the expense of internal meaning. Standard clinical measures are ill-equipped to capture the nuanced and evolving consciousness of individuals navigating life-altering treatment. As a result, many studies offer an incomplete understanding of the patient experience, overlooking the essential structures of meaning that phenomenological inquiry seeks to reveal. This underscores the need for an approach capable of embracing the full depth and texture of lived experience in the context of experimental stem cell therapy.

Current responses to the challenges faced by leukemia patients undergoing experimental stem cell therapy have largely focused on clinical protocols, patient management strategies, and psychosocial support models rooted in standardized practices (Spencer Cain et al., 2020). These approaches are typically designed to optimize treatment outcomes, reduce complications, and enhance adherence. While valuable in improving procedural and clinical efficiency, such practical frameworks often prioritize external observations and measurable endpoints, overlooking the internal landscapes that define each patient's lived reality.

These conventional approaches offer limited capacity to capture the rich, nuanced experiences of patients as they grapple with uncertainty, existential threat, and hope during the treatment process. Quantitative tools and structured psychological assessments, while informative, tend to fragment the patient's narrative into discrete variables, thereby neglecting the interconnectedness and depth of their emotional and spiritual experiences. As a result, the essential meaning of undergoing a high-risk, experimental therapy—how it shapes one's sense of self, body, and future—remains insufficiently understood in the current literature.

To address this shortfall, a phenomenological inquiry is necessary—one that centers the voice of the patient and seeks to uncover the core essence of their experience (Cieza et al., 2020). By focusing on how individuals perceive, interpret, and live through stem cell therapy, phenomenology offers a powerful methodological alternative that transcends surface-level understanding. It enables researchers to explore the phenomenon in its full context, revealing not only what happens but how it is lived. In doing so, this approach fills a critical gap in knowledge by illuminating the human meanings embedded in biomedical interventions.

Previous research has emphasized the clinical and physiological outcomes of stem cell therapy, especially in oncology and regenerative medicine contexts (Boswell-Ruys et al., 2020). However, few studies have explored the lived experiences of patients undergoing such experimental treatments. Some qualitative investigations have examined patient perspectives, but they often fall short in capturing the depth and complexity of personal meaning. Theoretical contributions from phenomenology, particularly the works of Husserl and van Manen, offer valuable insights into how meaning is constituted through experience. These perspectives are essential for understanding how patients interpret and internalize their therapeutic journeys.

This study applies a descriptive phenomenological approach to explore how patients with leukemia experience experimental stem cell therapy. This method was chosen to address the limitations of previous research and to illuminate the subjective meanings that patients assign to their treatment. By focusing on personal narratives, the study seeks to answer the central question posed earlier: How do patients make sense of their experience with stem cell therapy? The approach enables a deeper understanding of emotional, existential, and spiritual dimensions often overlooked in clinical frameworks. Through this lens, the study uncovers themes that reflect the essence of healing, fear, and personal transformation.

The article is structured into several key sections. First, the introduction outlines the research background, including the general and specific context of the phenomenon. This is followed by a detailed explanation of the phenomenological methodology and the rationale for its use. The subsequent sections describe the data collection and analysis process, with attention to thematic findings grounded in participant narratives. Finally, the discussion interprets the results within the broader context of patient-centered care, leading to a conclusion that highlights the study’s contributions to both theory and practice.

RESEARCH METHODS

Study Design

This study employed a descriptive phenomenological design grounded in the philosophical tradition of Edmund Husserl. The approach was selected due to its emphasis on capturing the essence of lived experiences, particularly those that are deeply personal and subjective. Descriptive phenomenology seeks to uncover the core meaning structures of phenomena as experienced by individuals, free from presuppositions (Leavy, 2014). Given the research focus on understanding the experiential world of leukemia patients undergoing experimental stem cell therapy, this design enabled a nuanced exploration of how such patients interpret, give meaning to, and navigate their therapeutic journey. The study was structured to bracket prior assumptions and attend closely to the participants' own words and perspectives.

Participants

Participants consisted of individuals diagnosed with leukemia who had undergone experimental stem cell therapy within the past year. A purposive sampling approach was applied to identify individuals with direct experience of the phenomenon under investigation. Inclusion criteria required participants to be adults (aged 18 and above), able to communicate verbally, and willing to share their therapeutic experiences in-depth. Individuals with cognitive impairments, active psychiatric conditions, or concurrent participation in other psychological studies were excluded to ensure clarity and consistency in experiential narratives.

Seven participants were included in the final analysis, comprising four females and three males, with ages ranging from 29 to 56 years (mean age: 43.1). The decision to include seven participants was guided by phenomenological methodological standards, which emphasize depth and richness of experiential accounts over large sample sizes. This number is consistent with prior phenomenological research and allowed for close, detailed analysis of each narrative.

Data saturation was considered reached when no new themes or significant variations in meaning emerged from the final interviews. The research team continuously assessed data sufficiency during the collection and analysis process, ensuring that the final sample captured the full scope of thematic complexity required for a rigorous phenomenological description. All participants had completed at least one full cycle of experimental stem cell infusion and follow-up.

Data Collection

Data were collected through in-depth, face-to-face interviews using a semi-structured interview guide developed based on existing literature in stem cell therapy and phenomenological research. Interviews were conducted in a private consultation room at the hematology-oncology outpatient clinic to ensure a safe, quiet, and emotionally supportive environment. Each interview lasted approximately 45 to 90 minutes and was audio-recorded with the participants' consent. Field notes were also taken to capture non-verbal cues and contextual observations. The guide included open-ended prompts such as, “Can you describe your experience receiving stem cell therapy?” and “How has this treatment affected your perspective on life and healing?” All interviews were transcribed verbatim. The interview protocol was reviewed by qualitative research experts and adjusted for clarity and depth as necessary.

Data Analysis

Data were analyzed using thematic reduction, consistent with descriptive phenomenological methodology. The analysis process involved several systematic steps: repeated readings of the transcripts, identification of meaning units, clustering of significant statements into themes, and reduction to the essential structures of experience. The goal was to preserve the language and intention of participants while distilling the underlying essence of their accounts. NVivo 14 software was used to facilitate coding and organization of data, although the interpretive focus remained rooted in the manual examination of texts.

Throughout the analysis, special attention was given to identifying recurring patterns and moments of thematic redundancy, which helped confirm the attainment of data saturation. The resulting themes reflected not only recurring patterns but also the nuanced emotional and existential dimensions expressed by participants, allowing the emergence of a comprehensive phenomenological description.

Ethical Considerations

Ethical approval for this study was obtained from the institutional research ethics committee. All participants provided written informed consent after receiving detailed explanations about the study’s objectives, procedures, and confidentiality measures. Anonymity was maintained by assigning pseudonyms to all participants, and all identifying information was removed from transcripts and publications. The study adhered to the ethical guidelines outlined in the Declaration of Helsinki and applicable local research ethics standards.

RESULTS

This section presents the thematic findings from the lived experiences of patients with leukemia who participated in experimental stem cell therapy. Using a descriptive phenomenological approach, the essence of participants’ experiences was captured through in-depth interviews and analyzed using thematic reduction. Four primary themes emerged from the data, each reflecting the complex interplay of hope, fear, existential meaning, and the patient-doctor relationship in the context of regenerative therapy.

Oscillation Between Hope and Uncertainty

Participants described a persistent inner conflict between optimism for healing and fear of unknown outcomes. The stem cell therapy, positioned as an advanced yet experimental procedure, generated a sense of guarded hope.

"They told me there’s a chance this could work, and I wanted to believe that. But in the back of my mind, I kept asking—what if it doesn’t?" (Participant 3)

For many, the hope was not only biomedical but deeply emotional, rooted in familial bonds and the desire to reclaim normalcy. However, this hope was often shadowed by the realization of the uncharted nature of the treatment.

"It's like walking on a bridge in the fog. I can't see the end, but I keep moving because standing still isn't an option anymore." (Participant 6)

The duality of hope and uncertainty created a complex psychological landscape that shaped each participant's daily coping mechanism.

Embodied Vulnerability and Loss of Control

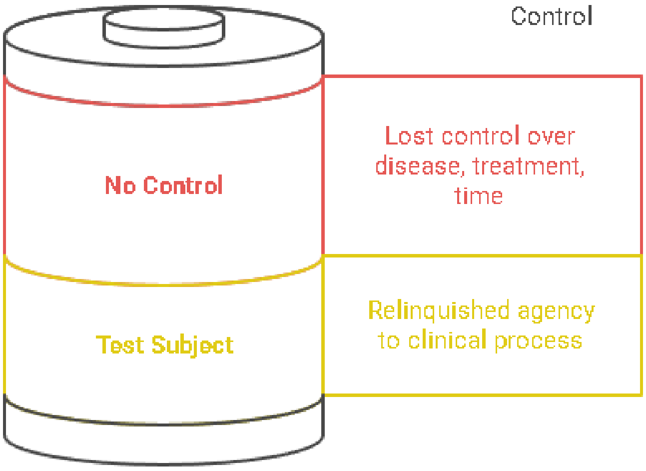
A strong sense of physical and existential vulnerability emerged as participants recounted their bodily experiences during the therapy. The perception of being a test subject surfaced frequently, revealing a sense of relinquished agency.

"I felt like my body was a laboratory... They injected things, took samples, measured responses—but no one could say what would happen for sure." (Participant 1)

This theme highlights a profound surrender to the clinical process, where participants navigated unfamiliar procedures without clear outcomes, intensifying their sense of exposure and helplessness.

"I wasn't in control of anything anymore—not my disease, not the treatment, not even the time I had." (Participant 5)

Understanding control in therapy: From agency to complete surrender



Spiritual Negotiation and Redefining Meaning

Many participants engaged in deep spiritual reflection during the treatment journey, reinterpreting their illness and its implications through the lens of faith and existential purpose.

"I prayed every night, not for healing, but for strength. If this is part of my path, then I want to walk it with grace." (Participant 4)

This spiritual engagement offered a framework for acceptance and meaning-making, shifting the focus from biomedical success to existential resilience. The therapy became not just a medical intervention but a spiritual trial.

"Maybe this treatment is not to cure me, but to teach me something about life... or death." (Participant 2)

The Need for Empathic Clinical Relationships

The presence or absence of empathetic communication from medical staff significantly influenced participants' experiences. Compassionate interactions mitigated fears, while clinical detachment exacerbated emotional distress.

"The doctor looked me in the eye and said, 'We are with you.' That meant more than any chart or scan." (Participant 7)

Conversely, several participants reported emotional disengagement from caregivers, feeling objectified or dismissed.

"Sometimes I felt invisible—like a case study, not a human being battling for my life." (Participant 3)

These narratives underscore the ethical imperative for relational care in experimental clinical contexts.

Essential Summary of Lived Experience

The findings reveal that patients undergoing experimental stem cell therapy for leukemia experience a dynamic interplay of hope and fear, bodily vulnerability, spiritual transformation, and relational dependence. These experiences construct a rich, subjective landscape that extends beyond clinical efficacy, illuminating the profound existential dimensions of regenerative medicine interventions.

DISCUSSION

The findings of this study revealed that patients undergoing experimental stem cell therapy for leukemia experience a dynamic interplay of hope, fear, spiritual reflection, and relational dependence (Sarasso et al., 2020). These lived experiences illuminate the emotional and existential complexities of navigating an uncharted therapeutic journey, directly addressing the core research question concerning how patients construct meaning through such interventions.

By uncovering themes such as oscillating hope and uncertainty, embodied vulnerability, spiritual negotiation, and the need for empathic care, the study offers a meaningful response to the central inquiry (Cassidy et al., 2020). The findings demonstrate that patients do not merely undergo medical procedures; rather, they engage in a deeply transformative process that reshapes their identity, beliefs, and sense of control. This research thus expands current understanding by moving beyond traditional clinical perspectives to highlight the internal realities of patients living through high-stakes regenerative treatments.

These insights resonate with and extend earlier phenomenological and qualitative studies that explore the human response to medical uncertainty and innovation. For instance, Y. Zhang et al. (2021) emphasized the emotional ambivalence of patients participating in experimental trials, while Coary et al. (2020) noted the importance of hope in shaping patients' interpretations of risk. However, this study contributes a distinct layer by integrating the spiritual and existential dimensions of the experience, which are often neglected in both clinical literature and patient-reported outcome measures. The findings align with Husserlian principles, affirming the necessity of exploring lived experience to grasp the essence of human phenomena in healthcare.

The findings from this study carry significant implications for both clinical practice and the broader understanding of patient experience in the context of experimental therapies (Vijayan et al., 2021). From a social and cultural standpoint, the narratives revealed how individuals undergoing stem cell treatment reconstruct their personal identities, spiritual frameworks, and interpersonal relationships in the face of biomedical uncertainty (Gant et al., 2022). These insights emphasize the need for healthcare providers to recognize the emotional and existential layers of patient experience, particularly in high-risk, investigational contexts. Practically, the results support the integration of empathetic communication, psychosocial support, and narrative-based care into clinical protocols for experimental treatments. Such holistic engagement could foster trust, psychological resilience, and more ethically attuned practices in regenerative medicine.

Despite the depth of insight generated, several limitations must be acknowledged. The study focused on a relatively small number of participants, all of whom were undergoing similar types of therapy within a specific clinical setting. As a result, the findings cannot be generalized to all leukemia patients or to other populations receiving stem cell treatments for different conditions. Additionally, the use of a single method of data collection—semi-structured interviews—may have limited the diversity of perspectives captured. These limitations, however, are consistent with the phenomenological emphasis on depth over breadth and do not undermine the validity of the lived experiences reported.

Future research may build upon this study by exploring similar experiences in diverse cultural or medical contexts, thereby enriching the global understanding of how patients interpret and respond to experimental therapies. Longitudinal qualitative designs could also be employed to examine how meaning evolves over time, especially as patients transition through different stages of treatment and recovery. Furthermore, interdisciplinary studies that combine phenomenological insights with ethical, sociological, or policy perspectives could provide a more comprehensive framework for improving patient-centered care in regenerative medicine.

CONCLUSION

This study explored the lived experiences of leukemia patients undergoing experimental stem cell therapy, with the aim of understanding how they construct meaning during this high-risk medical journey. The findings revealed essential themes such as the tension between hope and fear, feelings of vulnerability, spiritual reflection, and the need for empathetic care. These insights contribute to a deeper understanding of patient-centered experiences, addressing the gap left by previous research that focused primarily on clinical outcomes. By adopting a descriptive phenomenological approach, this study highlighted the emotional and existential dimensions of regenerative therapy that are often overlooked in quantitative models.

The results suggest that healthcare practices should integrate relational and narrative care strategies—such as reflective listening, spiritual counseling, and continuity of care—to better support patients undergoing experimental treatments. These strategies could inform clinical training programs and hospital policy frameworks aimed at humanizing care in high-risk, investigational settings. Policymakers and ethics boards may also consider incorporating patient meaning-making narratives as part of the evaluation process for compassionate-use or early-phase therapies. Future research should examine how these lived experiences vary across specific cultural, religious, or institutional contexts, and investigate the long-term psychological effects of participating in experimental therapies. Longitudinal qualitative studies involving patients, caregivers, and healthcare providers could offer a more comprehensive understanding of therapeutic meaning-making across time. In addition, comparative studies across different types of regenerative interventions could help identify which elements of care most significantly influence patient well-being.

CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

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