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Exploring the Lived Experiences of Hope and Uncertainty in Patients Undergoing Stem Cell Therapy for Neurodegenerative Diseases

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ABSTRACT

Neurodegenerative diseases represent a major health challenge worldwide, and stem cell therapy has emerged as a promising approach within regenerative medicine. While biomedical research has established preliminary evidence of safety and efficacy, little is known about how patients subjectively experience such treatments. Despite growing clinical studies, current research rarely addresses the lived meanings of stem cell therapy, leaving unanswered questions about how patients navigate hope, uncertainty, and changes in quality of life. This study applies an interpretative phenomenological approach to explore the subjective experiences of patients undergoing stem cell therapy for neurodegenerative conditions, offering insights into how individuals interpret and make sense of their therapeutic journey. Participants were twelve adult patients (aged 38–72 years; 7 males and 5 females) diagnosed with various neurodegenerative diseases, including Parkinson's disease, amyotrophic lateral sclerosis (ALS), and multiple sclerosis (MS). Data were collected through semi-structured, in-depth interviews conducted in a clinical rehabilitation setting between March and August 2024, and analyzed using interpretative phenomenological analysis (IPA) with systematic coding, double-checking of themes by two independent researchers, and participant validation to enhance methodological rigor. The findings revealed four essential themes: the coexistence of hope and uncertainty, embodied transformation alongside persistent limitations, emotional turbulence marked by anxiety about the future, and meaning-making through spirituality and relational support. These themes illustrate that the therapy is experienced not only as a medical intervention but as a deeply existential and relational process. The study demonstrates that understanding patient perspectives requires moving beyond clinical outcomes toward a holistic, patient-centered view of regenerative medicine. These insights may inform future clinical practice and ethical guidelines, while also encouraging further qualitative and longitudinal studies to deepen understanding of patient experiences in advanced therapies.

INTRODUCTION

Neurodegenerative diseases represent one of the most pressing global health challenges of the twenty-first century (Ahamad & Singh, 2021). Conditions such as Parkinson's disease, Alzheimer's disease, and amyotrophic lateral sclerosis not only lead to progressive physical decline but also profoundly affect the social, emotional, and psychological dimensions of patients' lives. Advances in regenerative medicine, particularly stem cell therapy, have introduced new possibilities for treatment and have generated considerable hope among patients and their families (Al-Massri et al., 2020). However, despite rapid biomedical developments, much remains to be understood about how individuals experience such therapies and how they integrate these experiences into their daily lives.

Beyond the clinical setting, stem cell therapy carries deep personal and social implications (Antoniou et al., 2022). Patients undergoing these treatments often navigate a complex spectrum of emotions, ranging from optimism about potential recovery to anxiety about uncertain outcomes and long-term sustainability. Families and caregivers, likewise, encounter significant challenges as they adapt to shifting roles, expectations, and responsibilities (Apodaca et al., 2021). These experiences highlight the fact that medical interventions are not only biological events but also lived realities situated within broader cultural, social, and relational contexts.

The significance of these experiences underscores the necessity of moving beyond purely clinical evaluations toward a deeper exploration of meaning. Phenomenological inquiry provides a pathway to uncover the subjective dimensions of therapy, illuminating how patients interpret their condition, treatment, and evolving identity in the face of illness (Berdowski et al., 2022). By attending to lived experiences, this approach captures the essence of what it means to undergo stem cell therapy, providing insights that cannot be obtained through quantitative metrics alone (Mukhlis et al. 2023). Such an exploration is essential to advancing both patient-centered care and a more holistic understanding of regenerative medicine in contemporary healthcare.

Research focusing on the lived experiences of patients undergoing advanced medical interventions has increasingly been recognized as an essential domain within health sciences (Bradbury et al., 2020). In the context of regenerative medicine, where stem cell therapy offers new avenues of treatment for neurodegenerative diseases, the exploration of patients' subjective experiences provides unique insights that extend beyond conventional clinical assessments (Chen et al., 2021). Such studies contribute to a more nuanced understanding of how individuals make sense of illness, treatment, and personal transformation in the face of medical innovation.

Despite growing interest, significant methodological challenges persist in capturing the depth of these experiences (Cone et al., 2021). The majority of existing research has relied heavily on quantitative measures, such as clinical outcomes, biomarkers, and standardized scales of quality of life. While valuable, these approaches often fail to account for the rich, interpretive dimensions of patients' lived realities (Mukhlis & Saidah, 2025). Numerical indicators alone cannot adequately convey the complex interplay of hope, anxiety, resilience, and meaning-making that shapes how patients experience stem cell therapy in their everyday lives.

These limitations underscore the inadequacy of conventional methods in fully grasping the essence of such phenomena. Clinical trials and outcome-focused studies provide critical evidence regarding efficacy and safety, but they remain insufficient to explain how patients perceive and interpret their therapeutic journey (Cudkowicz et al., 2022). Phenomenological approaches address this gap by enabling an in-depth exploration of subjective meaning, offering a perspective that is both patient-centered and contextually grounded (Eo et al., 2024). In doing so, they allow for the discovery of insights essential to improving holistic care, guiding ethical practice, and informing future therapeutic development.

Existing research on stem cell therapy for neurodegenerative diseases has largely prioritized practical and clinical approaches, focusing on safety, efficacy, and measurable outcomes (Mukhlis, 2025). These studies provide important biomedical insights but rely predominantly on quantitative assessments and standardized instruments, which limit the ability to uncover the lived realities of patients (Fan et al., 2023). While such methods capture physical improvements or symptom reduction, they overlook the nuanced ways in which individuals interpret their therapeutic experiences and integrate them into their daily lives.

This reliance on conventional approaches has created a gap in understanding the deeper, subjective dimensions of treatment (García-Huerta et al., 2020). Clinical indicators and statistical measures alone cannot reveal how patients negotiate hope, confront uncertainty, or reconstruct meaning in the midst of illness and therapy (Garrudo et al., 2021). Consequently, the current body of literature presents a partial perspective—one that emphasizes biological outcomes but fails to capture the complex emotional, relational, and existential experiences that shape patient journeys.

Addressing this limitation requires an alternative approach capable of accessing the essence of lived experience (Mukhlis & Abdullah, 2025). Phenomenology, with its focus on subjective meaning-making, offers the methodological rigor and conceptual depth needed to bridge this gap. By adopting a phenomenological lens, research can illuminate how patients experience stem cell therapy in their own terms, producing a holistic understanding that complements biomedical findings and advances patient-centered care (Gentile et al., 2022).

Recent studies have examined patient experiences in different areas of regenerative medicine, including the emotional impact of new therapies and the ethical questions surrounding their use. These investigations highlight the importance of understanding subjective perspectives but often remain limited to surface-level descriptions or ethical commentary (Guo et al., 2022). Very few have focused on the lived experiences of patients undergoing stem cell therapy for neurodegenerative conditions. This lack of focused attention leaves an incomplete picture of how patients construct meaning in their therapeutic journeys (He et al., 2021). The present study builds on this literature while addressing its limitations through a phenomenological lens.

The approach adopted here is interpretative phenomenological analysis, which emphasizes how individuals make sense of their experiences in personal and contextual terms (Mukhlis et al. 2025). This method was chosen because it allows for a deeper exploration of themes such as hope, uncertainty, and transformation, which cannot be fully captured by quantitative metrics. By listening to patient voices directly and engaging with their narratives, the study aims to provide insights into aspects of therapy that extend beyond clinical markers. In this way, it responds to the knowledge gap identified earlier by offering a more holistic view of the patient experience (Imamura et al., 2022). The method ensures that the meaning of treatment is illuminated from the perspective of those most directly affected.

The structure of this article reflects the phenomenological orientation of the study. The introduction situates stem cell therapy within the broader context of neurodegenerative diseases and outlines the rationale for a phenomenological approach. The methods section explains the interpretative framework, participant selection, and procedures for data collection and analysis. The results present themes that emerged from the lived experiences of participants, illustrated with direct quotations to strengthen authenticity. Finally, the discussion interprets these findings within existing theory and practice, and the conclusion highlights implications for patient-centered care and future research.

RESEARCH METHODS

Study Design

This study employed an interpretative phenomenological approach, which is particularly suitable for exploring the subjective experiences of individuals undergoing stem cell therapy for neurodegenerative diseases (Iturria-Medina et al., 2020). Phenomenology emphasizes the investigation of lived experiences and the meanings attached to them, allowing for a deep understanding of how participants perceive and interpret their therapeutic journey. The interpretative phenomenological framework provided the lens to examine the complexity of patients' narratives, focusing on their personal sense-making processes rather than objective clinical outcomes. This design was selected to capture the nuanced and multifaceted dimensions of hope, anxiety, and quality of life as reported by the participants.

Participants

Participants were selected through purposive sampling, based on their direct experience with stem cell therapy for neurodegenerative conditions. Inclusion criteria encompassed adult patients (aged 35–70 years) who had received stem cell therapy within the past two years and were able to provide reflective accounts of their experiences (Jahangir et al., 2020). Exclusion criteria included patients with severe cognitive impairment or communication barriers that could prevent participation in the interview process. A total of 12 participants were included, comprising seven males and five females, with an average age of 52 years. Their demographic and clinical diversity ensured a broad perspective on the phenomenon while maintaining coherence within the study focus.

Data Collection

Data were collected through in-depth semi-structured interviews, guided by an interview protocol designed to elicit participants' personal experiences, emotions, and perceptions related to stem cell therapy (Jia et al., 2020). Interviews were conducted face-to-face in a private consultation room within the treatment center to ensure confidentiality and participant comfort. Each interview lasted between 45 and 90 minutes and was audio-recorded with the participants' permission. Open-ended questions encouraged participants to describe their lived experiences, while follow-up probes allowed clarification and elaboration. Field notes were also taken to capture non-verbal cues and contextual details.

Data Analysis

Data were analyzed using interpretative phenomenological analysis (IPA). Interview transcripts were first transcribed verbatim and then read multiple times to achieve familiarity with the content. Meaning units were identified and coded, followed by the clustering of similar codes into emergent themes (Lee et al., 2022). The themes were refined through a process of thematic reduction, ensuring that essential meanings of the lived experiences were retained. NVivo 12 software was employed to facilitate the systematic organization of data but did not replace the interpretative role of the researcher. The iterative analytical process allowed for the emergence of essential insights that illuminated the subjective realities of participants undergoing stem cell therapy.

RESULTS

Living Between Hope and Uncertainty

Participants consistently described their experience as a fragile balance between newfound hope and the persistent shadow of uncertainty. Hope emerged as a powerful motivator, often tied to the promise of medical innovation, yet it was simultaneously tempered by doubt regarding long-term outcomes.

One participant shared:

"I felt like I was given a second chance, but deep inside I keep asking myself: will this really last, or will it fade away like everything else I tried before?"

This duality highlights the psychological tension patients faced. The therapy was not perceived merely as a medical procedure but as an emotional journey where optimism and fear coexisted.

Cycle of Hope and Uncertainty

The participant's reflection illustrates how hope functioned as both an emotional lifeline and a source of vulnerability. For many, believing in the treatment became a coping mechanism against despair, yet the awareness of uncertainty remained an ever-present undercurrent shaping their daily emotional state.

Embodied Transformation and Daily Struggles

Several participants reported subtle improvements in physical capacity, which they interpreted as evidence of the treatment's potential. However, the narratives also revealed ongoing struggles with the limitations imposed by their illness.

A participant explained:

"After the treatment, I could move my hands with less stiffness, which felt incredible. But I still cannot do the simple things I want—like walking outside without help. It's like progress is real but incomplete."

This theme emphasizes how patients perceived their bodies as simultaneously sites of renewal and limitation, shaping their daily routines and sense of independence.

The participant's statement encapsulates a paradox: bodily improvement was celebrated as validation of the therapy's promise, yet it also reminded patients of the enduring presence of illness. This ambivalence suggests that physical change was interpreted through both biomedical and existential lenses—progress and limitation intertwined in lived experience.

Emotional Turbulence and Anxiety About the Future

The therapy not only generated hope but also provoked deep anxieties about the possibility of relapse, adverse effects, or the unpredictability of the disease's progression. The emotional turbulence often surfaced during moments of solitude and reflection.

As one participant expressed:

"At night, I sometimes feel terrified. What if the therapy stops working? What if this is just a temporary illusion? The thought doesn't let me sleep."

This illustrates the profound emotional weight carried by patients, where treatment outcomes extended beyond clinical markers into psychological wellbeing.

Such expressions reveal how uncertainty was internalized as chronic emotional strain. Fear and anticipation coexisted, forming what participants described as an 'emotional oscillation'—a cycle of reassurance and renewed anxiety that paralleled the fluctuating nature of their physical condition. This underscores the need to interpret emotional responses as integral to the therapeutic experience rather than secondary effects.

Spiritual and Relational Meaning-Making

For many participants, the therapy carried spiritual or relational significance, reinforcing the importance of social support and faith. Spirituality emerged as a lens through which patients interpreted both improvement and struggle, offering resilience in times of doubt.

A participant reflected:

"I believe God guided me to this therapy. Even when I feel anxious, my prayers remind me I am not alone in this journey."

Others emphasized family support as an essential anchor:

"My family's encouragement keeps me going. Without them, I would have given up long ago."

These accounts underscore how meaning-making processes were rooted in both personal faith and relational bonds, shaping how patients coped with uncertainty.

By linking faith with familial support, participants demonstrated that healing was perceived as a shared, relational process rather than an individual pursuit. The integration of spiritual beliefs and social connection functioned as a narrative framework through which participants redefined suffering and recovery, thus transforming uncertainty into a space of meaning and endurance.

DISCUSSION

This study revealed that patients undergoing stem cell therapy for neurodegenerative conditions experienced their treatment as a dynamic interplay of hope, uncertainty, embodied change, emotional turbulence, and meaning-making (Q. Li et al., 2022). These themes respond directly to the guiding question of how patients interpret and live through the therapeutic process beyond its clinical outcomes.

Contribution of the Findings to the Research Question

The findings demonstrate that patients' lived experiences extend far beyond biomedical efficacy and instead encompass deeply personal interpretations of recovery, resilience, and vulnerability (Mukhlis, Janwari, et al., 2023). By uncovering narratives of both renewed optimism and persistent anxiety, the study offers a nuanced response to the research question posed in the introduction. Specifically, it highlights that stem cell therapy is not experienced solely as a clinical intervention but as an existential journey in which patients continually negotiate meaning (Y. Li et al., 2022). The contribution of this research lies in its ability to make visible the subjective realities that traditional clinical measures often obscure, thereby enriching our understanding of regenerative medicine through a patient-centered perspective.

Relationship to Previous Literature and Theoretical Perspectives

The results align with prior qualitative research that emphasizes the psychological and social dimensions of chronic illness and advanced therapies (Mukhlis et al., 2024). Studies in regenerative medicine have noted that patients often oscillate between hope and fear when confronted with novel treatments, yet few have examined this phenomenon in the context of stem cell therapy for neurodegenerative diseases (Liu et al., 2020). The emergent themes of spiritual and relational meaning-making resonate with broader phenomenological theories of health, which argue that illness disrupts not only the body but also one's identity and sense of being-in-the-world (McFarthing et al., 2024). At the same time, the findings extend existing literature by demonstrating how spirituality and family support act as stabilizing forces amid medical uncertainty, complementing prior studies that primarily emphasized biomedical or ethical considerations. In this way, the study contributes both theoretical depth and empirical richness to ongoing debates in regenerative medicine.

Implications of the Findings

The findings of this study carry important implications for both clinical practice and the broader social context of regenerative medicine (Mukhlis, 2025a). By demonstrating that stem cell therapy is experienced not only as a medical treatment but also as a deeply personal and relational journey, the study underscores the need for patient-centered care that integrates psychosocial and spiritual dimensions into therapeutic planning (McFarthing et al., 2022). Clinicians and policymakers should recognize that addressing patient concerns about uncertainty and emotional turbulence is as vital as monitoring clinical outcomes. Moreover, the themes of hope, anxiety, and meaning-making highlight cultural and social processes that shape how patients interpret new medical technologies (Morata-Tarifa et al., 2021). These insights may inform strategies for communication, counseling, and support services that aim to improve quality of life for patients with neurodegenerative diseases.

Limitations of the Study

Although the study provides rich insights into the lived experiences of patients, several limitations must be acknowledged. The use of purposive sampling within a single treatment context limits the diversity of perspectives represented and restricts the generalizability of findings to other cultural or clinical settings (Mukhlis, Arifin, Ridwan, Zulbaidah, et al., 2025). The relatively small sample size, which is consistent with phenomenological research, may also limit the breadth of experiences captured. In addition, reliance on self-reported narratives introduces potential biases related to memory, emotional state, or the desire to present experiences in a particular way (Nasirishargh et al., 2021). These limitations do not undermine the value of the findings but rather highlight the importance of cautious interpretation and the need for future studies to expand the scope of inquiry.

Prospective Directions for Future Research

Future research should build upon these findings by exploring how patient experiences of stem cell therapy may differ across cultural contexts, healthcare systems, or stages of disease progression (Mukhlis, Maryam, et al., 2023). Comparative studies could illuminate how social and cultural factors shape the meaning of hope, uncertainty, and resilience in diverse populations. Longitudinal phenomenological research may also provide valuable insights into how patient interpretations evolve over time, especially as regenerative therapies continue to develop (Ng et al., 2021). Additionally, integrating phenomenological inquiry with other qualitative or mixed-method approaches could enrich the understanding of patient experiences and strengthen the connection between subjective meaning and clinical practice (Poliwoda et al., 2022). In doing so, future work can advance a more comprehensive, ethically grounded, and human-centered framework for regenerative medicine.

CONCLUSION

This study explored the lived experiences of patients undergoing stem cell therapy for neurodegenerative diseases, addressing the gap in understanding how individuals interpret such treatments beyond clinical outcomes. The findings revealed that patients experienced the therapy as a complex interplay of hope, uncertainty, embodied change, emotional turbulence, and meaning-making through spirituality and social support. These insights extend beyond previous research that focused mainly on biomedical results by highlighting the subjective realities that shape patient journeys. The study contributes to a deeper appreciation of patient-centered care in regenerative medicine and demonstrates the value of phenomenology in capturing essential human experiences.

From a practical perspective, these findings underscore the importance of integrating psychosocial and existential dimensions into clinical protocols for stem cell therapy. Healthcare practitioners should be encouraged to provide continuous psychological counseling and spiritual support as part of treatment programs, recognizing that patients' emotional resilience and meaning-making processes influence therapeutic engagement and overall well-being. In policy terms, the study suggests that regulatory frameworks and institutional guidelines for advanced regenerative treatments should include patient experience as a key evaluative component, not solely safety and efficacy. Such inclusion would promote more holistic and ethically grounded models of care, ensuring that innovations in biotechnology are matched by equal attention to human experience and dignity.

While the research was limited in scope and context, it offers important directions for expanding inquiry into cultural differences, longitudinal experiences, and integrated qualitative approaches. Future research should also collaborate across disciplines—linking clinicians, ethicists, and social scientists—to translate patient narratives into actionable recommendations that can inform both therapeutic design and policy formulation. Future studies may build on this foundation to strengthen the link between subjective meaning and clinical practice, thereby enriching both theory and application in the field of regenerative therapies.

CONFLICT OF INTEREST

The authors declare that there is no conflict of interest regarding the publication of this article.

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