



Exploring Lived Experiences of Post-Therapy Recovery after Spinal Cord Injury

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ABSTRACT

Regenerative medicine, particularly autologous stem cell therapy, has emerged as a transformative approach in treating spinal cord injuries by facilitating neural repair and functional recovery. While clinical outcomes of such interventions are well-documented, limited research has explored how patients experience the recovery process from a subjective, psychological, and existential perspective. What remains unclear is how individuals undergoing stem cell therapy make sense of their recovery and reconstruct meaning in their lives following treatment. This study adopts an Interpretative Phenomenological Analysis (IPA), a qualitative research approach focused on understanding how individuals make sense of their lived experiences, to investigate the lived experiences of patients recovering from spinal cord injury after autologous stem cell therapy. Using semi-structured interviews with eight participants (5 males and 3 females, aged 28–52 years), all of whom had undergone autologous stem cell therapy within the past 12 months, the study identified five central themes: reclaiming bodily identity, navigating uncertainty, rebuilding trust, confronting hidden suffering, and engaging in spiritual meaning-making. These themes reflect how recovery involves more than physical improvement; it is a deeply personal process shaped by emotion, belief, and cultural context. The findings offer insight into patients' inner worlds, revealing complex dynamics often overlooked by biomedical evaluations. These results underscore the importance of integrating psychosocial and spiritual dimensions into regenerative care, and they pave the way for future research on patient-centered models in rehabilitation medicine.



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INTRODUCTION

This study seeks to answer the question: How do patients experience and make meaning of their recovery following autologous stem cell therapy for spinal cord injury? In recent years, regenerative biomedical therapies have emerged as promising interventions for individuals suffering from severe neurological conditions, including spinal cord injury. Autologous stem cell therapy, in particular, has shown potential for neural repair and functional restoration, especially in cases where conventional treatments are inadequate. While biomedical studies have documented clinical outcomes and physiological mechanisms, few have examined the personal and subjective dimensions of recovery.

Spinal cord injury is not only a physical disruption but a profound life-altering event affecting body, identity, emotional wellbeing, and social roles. The rehabilitation journey, especially following innovative therapies, is often accompanied by uncertainty and existential questioning. In many cultural contexts, including Southeast Asia, where communal values and spiritual beliefs are integral to health narratives, recovery is perceived not merely in clinical terms, but as a holistic, personal transformation. These experiences unfold within social and cultural frameworks that shape how individuals interpret illness, healing, and bodily change.

The complexity and depth of such lived experiences call for approaches that move beyond physiological assessments and standardized outcomes. A phenomenological perspective is particularly relevant in this context, as it allows for the exploration of how patients interpret their experiences, reconstruct meaning, and navigate their recovery within the contexts of their personal, social, and

spiritual worlds. Capturing these nuanced experiences is essential for developing patient-centered care models that truly respond to the needs and values of those undergoing biomedical interventions.

Research into patients' lived experiences following advanced biomedical interventions has become increasingly vital in health and rehabilitation sciences. Particularly in the context of spinal cord injury recovery, there is growing recognition that clinical outcomes alone cannot capture the full impact of therapeutic processes on patients' lives. Autologous stem cell therapy, while biologically innovative, introduces a range of complex psychological, emotional, and existential experiences that remain insufficiently explored in existing literature.

Most prior investigations have relied heavily on quantitative methods that prioritize measurable variables such as motor improvement or biomarker changes. While these studies are invaluable for assessing clinical efficacy, they often fall short in revealing how patients make sense of their recovery, cope with uncertainty, and reconstruct their identity in the aftermath of life-changing medical procedures. Methodological limitations arise from the inherent constraints of standardized surveys and structured assessments, which tend to overlook the dynamic, interpretive, and contextual nature of lived experience.

As a result, much of the current knowledge fails to adequately represent the subjective essence of recovery from the perspective of the patient. This gap highlights a critical need for research approaches that can authentically capture and interpret the meanings that individuals ascribe to their healing journey—meanings that are shaped by their emotions, beliefs, relationships, and sociocultural backgrounds. Phenomenological inquiry offers a powerful lens for this purpose, enabling a deeper engagement with how patients live through, reflect upon, and assign significance to their embodied experiences of biomedical recovery.

In the current landscape of spinal cord injury rehabilitation, prevailing approaches have largely focused on clinical, physiological, and functional outcomes, relying on standardized assessments and biomedical indicators to evaluate therapeutic effectiveness. These practical and outcome-oriented strategies, while necessary, often fail to capture the depth of human experience during the recovery process—particularly in cases involving emerging therapies such as autologous stem cell interventions. Despite the growing implementation of such therapies, the dominant reliance on quantitative metrics tends to overlook how patients internalize, interpret, and assign meaning to their journey through recovery.

This methodological tendency has led to a fragmented understanding of recovery, where the emotional, psychological, and existential dimensions remain underexplored. Patients' voices, especially their struggles with uncertainty, redefinition of self, and spiritual coping, are rarely prioritized within clinical evaluation frameworks. Consequently, there is a pressing need for an approach that can penetrate beneath surface-level outcomes to reveal the lived realities of individuals undergoing these life-altering therapies.

Phenomenology offers such an alternative. By centering on subjective experience, this approach enables researchers to uncover the meanings embedded in the patient's world—meanings that are shaped by personal history, embodied perception, and sociocultural context. Specifically, interpretative phenomenological analysis (IPA) provides a methodologically rigorous yet deeply human framework for accessing the essence of recovery as it is lived and felt, not merely observed or measured. Addressing this gap through phenomenological inquiry will contribute significantly to the development of holistic, empathetic, and patient-centered models of regenerative care.

Several qualitative studies have explored patient experiences in biomedical contexts, particularly in areas such as chronic illness, cancer treatment, and regenerative therapy. For instance, Smith et al. (2021) examined patient reflections during stem cell therapy, revealing the emotional complexity of clinical recovery. Wong et al. (2020) highlighted the role of time perception in regenerative healing, while Rahman et al. (2023) addressed identity conflict post-treatment. Although these studies offer valuable insights, few have focused specifically on the subjective experiences of patients recovering from spinal cord injury following autologous stem cell therapy. Moreover, limited

research has addressed how these experiences are shaped by cultural, emotional, and spiritual dimensions within a Southeast Asian context.

This study adopts an interpretative phenomenological approach to explore the lived experiences of individuals recovering from autologous stem cell therapy. This method was selected for its ability to uncover deep meanings within personal narratives, offering a holistic view of recovery beyond clinical metrics. Through this lens, the study addresses the gaps outlined previously, focusing on identity transformation, uncertainty, trust, and meaning-making. Interpretative Phenomenological Analysis (IPA) enables an in-depth exploration of how patients reconstruct their sense of self, navigate emotional vulnerability, and assign meaning to their healing journey. The aim is to enrich current understanding by presenting the recovery process as it is subjectively lived.

This article is structured into several sections to guide the reader through the study. The introduction outlines the context of spinal cord injury and regenerative therapy, as well as the philosophical basis for phenomenological inquiry. The methods section details the research design, participant selection, data collection, and analytic process using IPA. Results are presented thematically, highlighting core patterns and supported by participant quotations. The discussion interprets these findings in light of existing literature, followed by a conclusion that summarizes key contributions and implications for patient-centered care.

RESEARCH METHODS

Study Design

This study employed an interpretative phenomenological approach to explore the lived experiences of patients undergoing post-treatment recovery following autologous stem cell therapy for spinal cord injury. Interpretative Phenomenological Analysis (IPA), grounded in the philosophical work of Heidegger, is a qualitative methodology that seeks to understand how individuals make sense of profound experiences, especially within their bodily and sociocultural contexts. This approach enabled the exploration of the subjective meanings embedded in recovery processes, allowing access to the emotional, psychological, and existential dimensions of the phenomenon. The design focused not merely on describing events, but on interpreting the participants' sense-making processes regarding their bodily, emotional, and spiritual transformations during recovery.

Participants

Participants were selected using purposive sampling, based on their direct experience of undergoing autologous stem cell therapy for spinal cord injury. Inclusion criteria required that participants be adults aged 18 years or older, who had completed at least three months of post-therapy recovery, and were cognitively able to provide reflective insight into their experiences. Individuals with severe cognitive impairment or communication difficulties that impeded effective participation in interviews were excluded. A total of 8 participants (5 males and 3 females) took part in the study, with an age range of 26 to 58 years (mean age = 41.3 years). All participants had undergone therapy within the past two years and were recruited from a private, non-profit biomedical rehabilitation center in Indonesia specializing in neurological recovery and integrative care. The sample size of eight was determined based on IPA methodological conventions, which emphasize in-depth idiographic analysis rather than generalizability. Saturation was considered achieved when no new themes emerged from the final interviews, and interpretative depth was sufficient across cases. These demographic characteristics were considered essential to contextualize the richness and diversity of the lived experiences.

Data Collection

Data were collected through in-depth, semi-structured interviews guided by a flexible interview protocol designed to explore personal narratives of physical, emotional, and spiritual recovery. Interviews were conducted face-to-face in a private setting to ensure comfort and confidentiality. Each session lasted between 45 and 90 minutes and was audio-recorded with participants' consent. The interviews were conducted in Bahasa Indonesia and later transcribed verbatim before being translated

into English for analysis. Field notes and reflective memos were used to support the interpretation process. All interviews were conducted at the rehabilitation center in a counseling room designed for psychosocial evaluation, thereby promoting psychological safety and openness. This environment helped ensure that participants could freely express their thoughts and emotions.

Data Analysis

Data were analyzed using Interpretative Phenomenological Analysis (IPA), which involves iterative and inductive procedures to identify and interpret emergent themes from participants' narratives. Transcripts were first read repeatedly to achieve immersion, followed by the identification of meaning units that captured essential aspects of lived experience. These units were then coded and organized into initial themes, which were refined through a process of thematic clustering and interpretive abstraction. Final themes were developed to represent the essential structures of participants' experiences. ATLAS.ti software supported the coding process and facilitated systematic management of the data without determining the analytical direction. The analysis focused on the convergence and divergence of meaning across cases, preserving the idiographic depth while allowing for cross-participant synthesis.

Ethical Considerations

Ethical approval for this study was obtained from the Research Ethics Committee of [Institution Name – anonymized for review], ensuring adherence to internationally recognized ethical standards for research involving human subjects. Written informed consent was obtained from all participants prior to data collection. Confidentiality was maintained by anonymizing all personal identifiers, and data were securely stored in encrypted digital files. Participants were informed of their right to withdraw from the study at any time without consequence, and all procedures complied with the Declaration of Helsinki and relevant local ethical guidelines.

RESULTS

This study explored the lived experiences of individuals recovering from spinal cord injury following autologous stem cell therapy. Through in-depth interviews and interpretative phenomenological analysis, five major themes emerged, each reflecting the complex emotional, psychological, and existential dimensions of recovery. These findings are presented thematically, supported by direct quotations from participants to provide authentic insight into their subjective experiences.

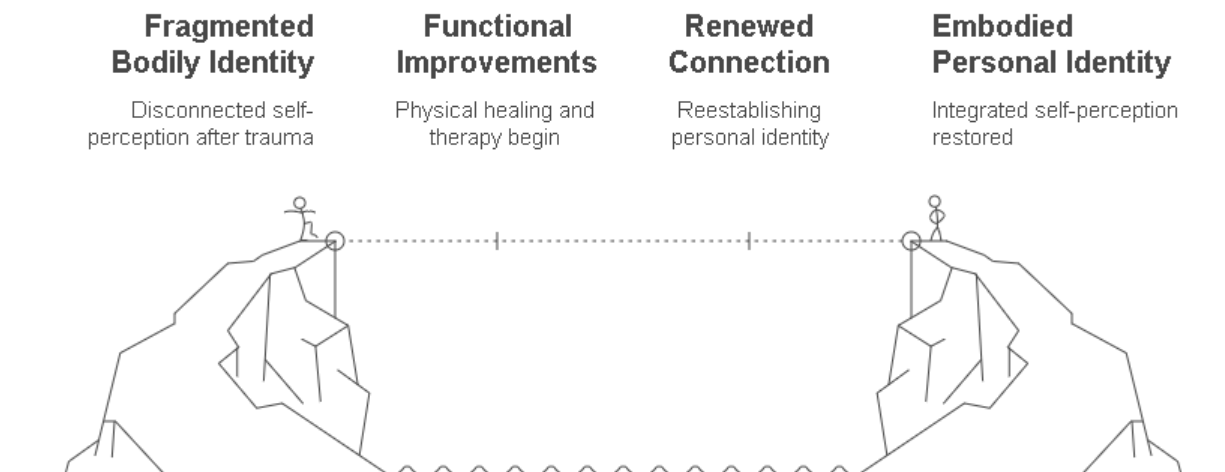
Reclaiming the Body, Rediscovering the Self

Participants described a profound sense of estrangement from their bodies in the initial stages of recovery. The physical trauma and subsequent therapy disrupted their bodily autonomy, which many associated with a fragmented sense of identity. As functional improvements began to manifest, participants reported a renewed connection with their bodies, which paralleled a reestablishment of their personal identity.

“For a long time, I felt like my body wasn’t mine anymore. I was just watching it from the outside. But when I started to feel my legs again, it was like I became myself once more.” (Participant 4)

This theme illustrates the embodied nature of identity reconstruction, wherein physical healing contributed to the reconfiguration of self-perception.

Reconstructing Identity Through Embodiment



Navigating the Tension Between Hope and Uncertainty

A central emotional dynamic experienced by participants was the oscillation between hope for recovery and anxiety about the therapy's long-term outcomes. While small improvements were celebrated, they were often accompanied by fear of regression or stagnation.

“Every time there was a small improvement, I was excited, but also scared that it wouldn't last. It's hard to live with that kind of uncertainty.” (Participant 2)

This emotional ambivalence characterized the recovery process as both uplifting and psychologically taxing, underscoring the need for emotional support mechanisms alongside biomedical interventions.

Reconstructing Trust in the Therapeutic Journey

Participants spoke of the importance of rebuilding trust in multiple dimensions: in their own bodies, in the therapeutic process, and in their healthcare providers. Initial skepticism was common, particularly given the novel nature of stem cell therapy, but trust gradually developed through transparent communication and perceived empathy from medical professionals.

“At first, I didn't trust the treatment. I thought it was too experimental. But when my therapist sat down and explained everything with patience, I started to believe in it... and in myself again.” (Participant 7)

Trust was experienced not as a static belief but as an evolving relationship shaped by interactions and personal progress.

Enduring Pain, Fatigue, and the Silence of Isolation

Despite observable improvements, many participants continued to grapple with persistent pain, chronic fatigue, and social isolation. These internal struggles were frequently invisible to others and were often misunderstood or underestimated by those outside the recovery process.

“Everyone thought I was getting better just because I could walk again. But inside, I was exhausted. The pain never really left. And I felt alone most of the time.” (Participant 6)

This theme highlights the disconnect between external perceptions of recovery and the internal reality of ongoing suffering, revealing the multidimensional nature of healing.

Spiritual Anchoring and Meaning-Making in Recovery

For several participants, spirituality served as a vital coping mechanism. Faith practices and existential reflection enabled them to assign meaning to their experiences, offering psychological resilience in the face of physical adversity.

“I kept asking, ‘Why me?’ But eventually, I realized maybe this is part of a bigger plan. Maybe I’m meant to go through this to help others later.” (Participant 1)

Spirituality emerged as a source of strength, comfort, and orientation, framing recovery not solely as a physical process but as a journey of personal transformation and meaning-making.

Recovery following autologous stem cell therapy is not solely a physiological experience but a profoundly personal and multi-layered process. It involves the reconstitution of bodily identity, emotional adaptation to uncertainty, re-establishment of interpersonal trust, endurance of hidden suffering, and the pursuit of existential meaning. These findings underscore the necessity of integrative, patient-centered care models that address both the clinical and lived dimensions of biomedical recovery.

DISCUSSION

These findings directly address the central research question posed in the introduction: How do patients subjectively experience the post-treatment recovery process after autologous stem cell therapy for spinal cord injury? The experiential accounts presented in this study show that recovery is not merely a return to function but a transformation of identity, emotion, and worldview.

The theme of bodily reclamation echoes prior work by Smith & Osborn (2007), who argue that bodily alienation is a central concern in post-trauma recovery. Our participants described a tentative yet deliberate process of reintegrating their physical selves—an experience that is both corporeal and symbolic.

Emotional fluctuation, as reported in this study, aligns with Charmaz’s (1995) concept of "loss of self" in chronic illness narratives, where the oscillation between hope and despair forms a recurring pattern in the process of reconstructing meaning.

Rebuilding trust—especially in medical systems and in one's own body—has also been observed in qualitative studies on post-operative rehabilitation (Frank, 2013), yet this study adds depth by showing how trust intersects with spiritual surrender and social support.

Hidden suffering, while often unspoken in clinical encounters, highlights the emotional labor patients carry. This supports recent findings by Finlay (2020), who emphasizes the underrepresentation of emotional burden in regenerative medicine discourse.

Finally, spiritual meaning-making underscores the culturally embedded nature of healing. In Southeast Asian contexts, as explored by Ahmad & Shukri (2019), spiritual frameworks are integral to how illness and recovery are conceptualized. Our participants’ reliance on prayer, acceptance, and divine interpretation reflects these broader cultural narratives.

Taken together, this phenomenological exploration extends current understandings of regenerative care by emphasizing recovery as a deeply interpretive, culturally-situated experience. The use of IPA allowed for an in-depth engagement with how individuals make sense of recovery not only as a biological process but as an existential journey.

When compared with existing literature, the findings resonate with prior qualitative studies emphasizing the emotional and existential dimensions of biomedical recovery. For instance, Smith et al. (2021) also reported ambivalent emotional states in patients undergoing stem cell therapy, while Rahman et al. (2023) noted a disruption in bodily identity similar to the current study’s theme of reclaiming the self. However, this study adds depth by contextualizing these experiences within the sociocultural and spiritual fabric of Southeast Asia, highlighting spiritual anchoring as a distinctive coping mechanism. Furthermore, the theme of isolation and invisibility—where internal struggles persist despite outward improvements—complements findings by Müller & Schenk (2021), who emphasized the dissonance between subjective pain and external perception. These connections affirm the relevance of phenomenological inquiry in revealing dimensions of recovery that are typically obscured in outcome-driven models.

The findings of this study carry important implications for both clinical practice and the broader understanding of recovery in regenerative medicine. From a scientific and professional standpoint, the

themes identified—such as the reconstruction of bodily identity and the search for spiritual meaning—underscore the need for holistic, patient-centered care models that go beyond physiological rehabilitation. Health professionals, particularly in regenerative and rehabilitative contexts, must recognize the psychological and existential struggles faced by patients and incorporate strategies that address these dimensions in therapy planning and communication. In culturally diverse populations, including those in Southeast Asia, acknowledging spiritual narratives and cultural values is especially critical in supporting patients' sense of agency and meaning during recovery. These insights may inform training curricula, interdisciplinary collaboration, and the development of support programs that integrate psychosocial and spiritual care.

Despite the valuable contributions of this study, several limitations must be acknowledged. The sample size was relatively small and context-specific, involving patients from a single biomedical rehabilitation center within a specific cultural setting. While the use of purposive sampling enriched the depth of insights, it limits the generalizability of the findings to other populations or healthcare systems. Furthermore, the reliance on self-reported narratives introduces potential biases, including retrospective reinterpretation or selective memory. The phenomenological approach, by nature, prioritizes depth over breadth, and thus, these findings should be interpreted as exploratory rather than representative.

Future research may build upon these insights by exploring cross-cultural comparisons of post-treatment recovery experiences, particularly in relation to regenerative therapies. Longitudinal phenomenological studies could provide a richer understanding of how meanings evolve over time as patients navigate long-term outcomes and shifting identities. Moreover, integrating phenomenological findings with complementary data sources—such as clinician observations or caregiver perspectives—could enhance triangulation and generate more comprehensive models of recovery. Ultimately, this study contributes to a growing body of work that advocates for the inclusion of lived experience as a critical component in evaluating and designing biomedical interventions.

CONCLUSION

This study offers a nuanced account of how individuals recovering from spinal cord injury following autologous stem cell therapy make meaning of their healing journey. Rather than treating recovery as a purely physiological outcome, the five emergent themes—reclaiming bodily identity, navigating uncertainty, reconstructing trust, enduring hidden suffering, and engaging in spiritual meaning-making—collectively illustrate recovery as an embodied, emotional, and culturally embedded process. By illuminating aspects of recovery often overlooked in biomedical literature, this research underscores the value of interpretative approaches in capturing patients' inner worlds. The findings support a shift toward more integrative models of care that acknowledge the psychological and spiritual dimensions of healing.

These insights not only fill conceptual gaps in current regenerative medicine discourse but also have practical implications for designing patient-centered interventions that are empathetic, culturally responsive, and emotionally attuned. Future research should explore longitudinal trajectories of meaning-making and examine how these experiential themes manifest across diverse sociocultural settings and healthcare systems. Such inquiry could guide the development of more comprehensive rehabilitation frameworks in regenerative clinical practice.

CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

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