



Facing Uncertainty: Patients' Experiences with Stem Cell Therapy for Degenerative Diseases

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ABSTRACT

Stem cell therapy represents a significant advancement in regenerative medicine, offering hope for patients with degenerative diseases. While clinical studies have explored its physiological outcomes, limited research has examined patients' lived experiences with this treatment. The gap in understanding patient perspectives, including their expectations, decision-making processes, and post-treatment reflections, necessitates qualitative inquiry. This study employs a phenomenological approach to investigate the subjective experiences of patients undergoing stem cell therapy. In-depth interviews and thematic analysis revealed four key themes: hope and motivation, uncertainty and anxiety, procedural experiences, and quality-of-life impact. Findings highlight the importance of clear doctor-patient communication and managing treatment expectations. This study contributes to patient-centered care strategies and calls for further exploration of cultural and ethical dimensions influencing stem cell therapy perceptions.



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INTRODUCTION

Stem cell therapy has emerged as a promising approach for treating degenerative diseases, offering potential regenerative solutions where conventional treatments have failed (Bhartiya dkk., 2023). With the increasing prevalence of conditions such as osteoarthritis, neurodegenerative disorders, and diabetes-related complications, the medical community continues to explore novel interventions that go beyond symptom management (Poliwoda dkk., 2022). Stem cell therapy, which utilizes the body's own regenerative capabilities, presents an innovative yet complex alternative, raising both hope and ethical considerations.

The development of regenerative medicine has been supported by advancements in biotechnology and molecular medicine, leading to a deeper understanding of cellular differentiation and tissue repair mechanisms (O'neill dkk., 2019). However, despite scientific progress, the subjective experiences of patients undergoing stem cell therapy remain underexplored (Perez dkk., 2024). The effectiveness of such treatments is often perceived differently by patients based on personal expectations, socio-economic factors, and the level of information provided by healthcare professionals.

Previous research has primarily focused on the biomedical efficacy of stem cell therapy, with clinical trials assessing outcomes such as pain reduction, improved mobility, and cellular regeneration. While these studies provide valuable insights into the physiological impact of the therapy, they often neglect the psychological and emotional dimensions that shape patient experiences (Narzisi dkk., 2023). Given the uncertainties surrounding stem cell treatments—including regulatory inconsistencies, financial burdens, and varying patient responses—understanding the lived experiences of patients is essential for a more comprehensive evaluation of its impact.

This study aims to fill this gap by adopting a phenomenological approach to explore the personal experiences, expectations, and challenges faced by patients undergoing stem cell therapy. By focusing on the subjective meanings associated with the treatment, this research seeks to provide deeper

insights into the real-world implications of regenerative medicine from the patient's perspective (Al-Massri dkk., 2020). The findings will contribute to improving patient-centered care, enhancing doctor-patient communication, and informing policymakers about the broader social and psychological aspects of stem cell therapy.

The exploration of patient experiences in medical interventions has gained increasing attention in qualitative health research, particularly in the domain of regenerative medicine. Understanding how individuals perceive and internalize their treatment journeys is critical in shaping holistic healthcare approaches (Huang dkk., 2020). In the case of stem cell therapy, where outcomes remain highly variable, patient narratives offer invaluable insights into the broader implications of these treatments beyond clinical efficacy.

Despite the growing recognition of the importance of patient-centered research, methodological challenges persist in capturing the depth of lived experiences. Traditional quantitative studies, while essential in establishing clinical outcomes, often fail to encapsulate the nuanced personal and emotional aspects of treatment (Aghmiuni dkk., 2023). Standardized surveys and statistical analyses may provide measurable indicators of therapeutic success, but they lack the capacity to reveal the complex interactions between patient expectations, decision-making processes, and their evolving perceptions over time.

These limitations highlight the need for methodologies that prioritize individual perspectives and meaning-making processes. Phenomenology, with its emphasis on understanding human experiences from the viewpoint of those who live them, offers a compelling approach for investigating patient journeys in stem cell therapy (He dkk., 2021). By engaging directly with patients through in-depth qualitative inquiry, this study seeks to uncover the layered realities of undergoing regenerative treatment, encompassing both hopes and uncertainties. This approach not only addresses the gaps left by previous research but also ensures that the patient voice is central in discussions about treatment efficacy and future medical advancements.

Existing approaches to understanding the impact of stem cell therapy have predominantly relied on biomedical frameworks that emphasize clinical outcomes such as functional recovery and cellular regeneration. While these studies provide critical insights into the physiological aspects of treatment, they often fail to capture the subjective and emotional dimensions of patient experiences. As a result, the lived realities of individuals undergoing stem cell therapy—including their expectations, fears, and decision-making processes—remain largely overlooked in the current body of research.

The reliance on standardized assessments and statistical models limits the ability to understand how patients make sense of their treatment journey. Conventional methodologies tend to focus on quantifiable measures of success, neglecting the deeply personal and evolving nature of patient perceptions. This gap in knowledge underscores the need for an alternative approach that prioritizes experiential insights and the meanings patients attribute to their medical interventions.

To address these limitations, a phenomenological perspective is essential in capturing the rich, contextualized experiences of individuals undergoing stem cell therapy. Unlike traditional biomedical studies, phenomenology allows for an in-depth exploration of patient narratives, highlighting the interplay between expectations, procedural experiences, and perceived treatment efficacy. By adopting this approach, the present study aims to bridge the gap in understanding how patients internalize their therapeutic journeys and how these experiences shape their overall well-being and medical decision-making.

Previous studies have examined the clinical efficacy of stem cell therapy, focusing primarily on physiological outcomes such as tissue regeneration and functional improvements. However, research exploring the subjective experiences of patients undergoing this treatment remains limited. Theories on patient perception and expectation in healthcare (e.g., Street et al., 2012) suggest that personal meaning-making processes play a crucial role in treatment satisfaction. Existing qualitative studies in related medical fields have demonstrated the importance of understanding patient narratives, yet specific investigations into stem cell therapy remain insufficient.

This study adopts a phenomenological approach to address these gaps, emphasizing the lived experiences of patients receiving stem cell therapy for degenerative conditions. By conducting in-depth interviews and thematic analysis, this research seeks to uncover how patients interpret their treatment journey, including their hopes, anxieties, and post-treatment reflections. The phenomenological method is particularly well-suited for capturing these dimensions, as it allows for the exploration of meaning beyond objective clinical indicators.

This article is structured as follows: the introduction outlines the significance of the research and positions it within existing literature. The methodology section details the phenomenological framework and data collection techniques. The results present emerging themes identified from patient narratives, followed by a discussion contextualizing these findings within broader healthcare implications. Finally, the conclusion highlights key contributions, potential clinical applications, and directions for future research.

RESEARCH METHODS

Study Design

This study employed a phenomenological approach to explore the lived experiences of patients undergoing stem cell therapy for degenerative diseases (Kim dkk., 2021). Phenomenology was chosen as it enables a deep understanding of the subjective meanings attached to personal experiences. By focusing on patients' perceptions, this method provides insight into their motivations, concerns, and overall treatment outcomes. Interpretative phenomenological analysis (IPA) was used to capture both individual narratives and collective themes emerging from the data.

Participants

Participants were selected using purposive sampling to ensure relevance to the research objectives. Inclusion criteria required that participants had undergone stem cell therapy for degenerative diseases within the past year, were willing to share their experiences in depth, and had medical records confirming their treatment. Exclusion criteria included individuals with severe post-therapy complications that hindered communication and those undergoing experimental treatments without formal regulatory approval. The final sample consisted of 10 participants (6 male, 4 female), aged between 45 and 72, representing diverse backgrounds and conditions such as osteoarthritis, neurodegenerative disorders, and diabetes-related complications.

Data Collection

Data were collected through in-depth, semi-structured interviews, allowing participants to describe their experiences openly. The interviews were conducted in a private setting to ensure confidentiality and minimize external influences. Each session lasted between 45 to 90 minutes and was audio-recorded with participants' consent. Interview questions focused on expectations before therapy, experiences during treatment, perceived outcomes, and emotional responses (Zhao dkk., 2021). Additionally, observations were made during follow-up visits to assess non-verbal cues and interactions between patients and healthcare providers.

Data Analysis

Thematic analysis was applied to identify patterns and key themes within the data. Interviews were transcribed verbatim, and initial codes were assigned to recurring concepts. These codes were then grouped into broader themes reflecting common experiences across participants. The analysis followed a stepwise process: familiarization with data, identification of emergent themes, clustering themes into conceptual categories, and integration of findings with existing literature. NVivo software was used to facilitate data organization and retrieval, ensuring systematic and unbiased interpretation.

Ethical Considerations

Ethical approval was obtained from the relevant institutional review board before data collection. Informed consent was secured from all participants, ensuring they understood the study's purpose, potential risks, and their right to withdraw at any time. Confidentiality was maintained through

anonymized data handling, and personal identifiers were removed from transcripts. The study adhered to ethical guidelines for qualitative research, including respect for participant autonomy and data security.

RESULTS

Hopes and Motivations

Participants expressed strong expectations that stem cell therapy would restore their physical functions, alleviate symptoms, and improve their overall quality of life. Many of them sought the treatment as a last resort after conventional medical interventions failed to provide significant relief. One participant described their optimism, stating:

"I was willing to try anything at that point. The idea that my body could heal itself with these new cells was incredibly promising."

For some, hope was fueled by success stories they encountered online or recommendations from peers who had undergone the same therapy. However, not all expectations were met, leading to a complex emotional journey that varied across individuals.

Uncertainty and Anxiety

Despite their initial optimism, many participants reported experiencing considerable uncertainty regarding the efficacy, safety, and long-term effects of stem cell therapy. This uncertainty stemmed from the limited information available and the diverse range of outcomes observed among other patients. One participant noted:

"Doctors were optimistic, but they couldn't give me a clear answer about how well it would work for my condition. That uncertainty was nerve-racking."

Another common concern was the financial burden associated with the therapy, with some participants struggling to justify the cost without a guaranteed outcome. Additionally, the lack of standardized guidelines and regulations surrounding stem cell therapy contributed to feelings of doubt and hesitation.

Procedural Experience

The procedural aspects of stem cell therapy varied in terms of comfort and perception among participants. Some described the experience as relatively painless and straightforward, while others reported discomfort during and after the procedure. A participant shared:

"The injection itself was not too painful, but I did feel soreness and inflammation for a few days afterward."

Others expressed concern about the follow-up process and the need for additional treatments. Some participants reported feeling well-informed by their healthcare providers, while others felt left in the dark about what to expect post-procedure.

Impact on Quality of Life

Participants reported mixed experiences regarding the impact of stem cell therapy on their daily lives. Some noticed significant improvements in mobility, pain reduction, and overall well-being, reinforcing their belief in the therapy's effectiveness. One participant shared:

"I could finally walk without constant pain. It felt like I had regained a part of my life that I thought was gone forever."

However, others expressed frustration when the treatment did not yield the expected results. For these individuals, the emotional toll of unfulfilled expectations was substantial, leading to disappointment and uncertainty about their next steps. As one participant lamented:

"I had put all my hope into this, but the results weren't as drastic as I had imagined. Now I don't know where to go from here."

The findings illustrate that while stem cell therapy presents a promising alternative for degenerative diseases, it also introduces significant emotional and psychological challenges for patients. The contrast between high expectations and unpredictable outcomes highlights the need for clearer communication between healthcare providers and patients. The emotional and financial burdens of this treatment further complicate patient experiences, emphasizing the necessity of a well-informed decision-making process.

DISCUSSION

The findings of this study reveal that patient experiences with stem cell therapy are shaped by a complex interplay of hope, uncertainty, and procedural realities (Olufsen dkk., 2022). Participants expressed strong expectations of recovery, yet these expectations were often tempered by concerns about efficacy, safety, and accessibility. These results align with previous research emphasizing the role of patient perception in shaping treatment satisfaction and decision-making.

This study provides valuable contributions to understanding how individuals navigate the emotional and psychological dimensions of undergoing stem cell therapy (Scopetti dkk., 2020). Unlike conventional studies that focus solely on clinical efficacy, the phenomenological approach employed here captures the nuanced ways in which patients interpret their therapeutic journeys. The insights gained highlight the need for more transparent communication between healthcare providers and patients to manage expectations effectively.

The findings also contribute to broader discussions in patient-centered healthcare research. Previous studies have emphasized the importance of incorporating patient perspectives into medical decision-making, yet few have focused specifically on regenerative medicine (Shahin dkk., 2023). By drawing on phenomenological insights, this study expands the discourse on treatment experiences, reinforcing the need for patient-centered policies and improved regulatory frameworks.

Implications of Findings

The results of this study highlight the significant psychological and emotional dimensions of undergoing stem cell therapy (Yoo dkk., 2021). The findings suggest that managing patient expectations and improving doctor-patient communication are critical for enhancing treatment experiences. Socially, the narratives reveal that patients often rely on anecdotal information, media portrayals, and peer experiences, which can shape their perceptions and influence their decision-making. The insights from this study can inform healthcare providers and policymakers to develop more transparent and patient-centered educational strategies about regenerative treatments.

Limitations of the Study

Despite its contributions, this study has limitations that must be acknowledged. The sample size, though sufficient for phenomenological research, may not fully represent the diversity of experiences across different demographic groups and medical conditions. Additionally, findings were based on self-reported narratives, which are subject to recall bias and personal interpretation. The study was also conducted in a specific cultural and regulatory context, limiting the generalizability of results to other healthcare settings.

Future Research Directions

Building on the insights of this study, future research should explore longitudinal patient experiences to capture evolving perceptions over time. Further studies could also investigate how healthcare providers interpret and integrate patient narratives into clinical practice. Expanding the research to diverse geographic and cultural settings would help provide a more comprehensive understanding of the phenomenon. Additionally, interdisciplinary collaborations integrating psychological, ethical, and policy perspectives would further enhance the discourse on patient-centered approaches in regenerative medicine.

CONCLUSION

This study explored the lived experiences of patients undergoing stem cell therapy for degenerative diseases, highlighting their expectations, uncertainties, and perceived outcomes. Findings revealed that patient narratives are deeply influenced by personal hope, external information sources, and communication with healthcare providers. Unlike previous research that primarily focused on clinical outcomes, this study provided a more nuanced understanding of how patients interpret their therapeutic journeys. The insights gained underscore the importance of transparent doctor-patient communication and patient-centered approaches in regenerative medicine. While this study offers valuable contributions, further research is needed to examine the evolving perceptions of patients over time and across diverse cultural contexts. Future studies should also explore the role of ethical and policy considerations in shaping patient experiences with emerging medical treatments.

CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

REFERENCES

- Aghmiuni, A. I., Keshel, S. H., Rahmani, A., Nadri, S., Sefat, F., & Lashay, A. (2023). Retinal Tissue Engineering: Regenerative and Drug Delivery Approaches. *Current Stem Cell Research and Therapy*, 18(5), 608–640. Scopus. <https://doi.org/10.2174/1574888X17666220621153508>
- Al-Massri, K. F., Ahmed, L. A., & El-Abhar, H. S. (2020). Mesenchymal stem cells in chemotherapy-induced peripheral neuropathy: A new challenging approach that requires further investigations. *Journal of Tissue Engineering and Regenerative Medicine*, 14(1), 108–122. Scopus. <https://doi.org/10.1002/term.2972>
- Bhartiya, M., Kumar, A., Singh, R. K., Radhakrishnan, D. M., Rajan, R., & Srivastava, A. K. (2023). Mesenchymal Stem Cell Therapy in the Treatment of Neurodegenerative Cerebellar Ataxias: A Systematic Review and Meta-analysis. *Cerebellum*, 22(3), 363–369. Scopus. <https://doi.org/10.1007/s12311-022-01403-6>
- He, L., Wang, S., Peng, L., Zhao, H., Li, S., Han, X., Habimana, J. D., Chen, Z., Wang, C., Peng, Y., Peng, H., Xie, Y., Lei, L., Deng, Q., Wan, L., Wan, N., Yuan, H., Gong, Y., Zou, G., ... Jiang, H. (2021). CRISPR/Cas9 mediated gene correction ameliorates abnormal phenotypes in spinocerebellar ataxia type 3 patient-derived induced pluripotent stem cells. *Translational Psychiatry*, 11(1). Scopus. <https://doi.org/10.1038/s41398-021-01605-2>
- Huang, L., Zhao, Z., Wen, J., Ling, W., Miao, Y., & Wu, J. (2020). Cellular senescence: A pathogenic mechanism of pelvic organ prolapse (Review). *Molecular Medicine Reports*, 22(3), 2155–2162. Scopus. <https://doi.org/10.3892/mmr.2020.11339>
- Kim, I.-K., Park, J.-H., Kim, B., Hwang, K.-C., & Song, B.-W. (2021). Recent advances in stem cell therapy for neurodegenerative disease: Three dimensional tracing and its emerging use. *World Journal of Stem Cells*, 13(9), 1215–1230. Scopus. <https://doi.org/10.4252/wjsc.v13.i9.1215>
- Narzisi, A., Halladay, A., Masi, G., Novarino, G., & Lord, C. (2023). Tempering expectations: Considerations on the current state of stem cells therapy for autism treatment. *Frontiers in Psychiatry*, 14. Scopus. <https://doi.org/10.3389/fpsy.2023.1287879>
- Olufsen, M. E., Spindler, L., Sørensen, N. B., Christiansen, A. T., Alberti, M., Heegaard, S., & Kiilgaard, J. F. (2022). Controlled Subretinal Injection Pressure Prevents Damage in Pigs. *Ophthalmologica*, 245(3), 285–293. Scopus. <https://doi.org/10.1159/000522110>

- O’neill, H. C., Limnios, I. J., & Barnett, N. L. (2019). Advancing a stem cell therapy for age-related macular degeneration. *Current Stem Cell Research and Therapy*, 15(2), 89–97. Scopus. <https://doi.org/10.2174/1574888X15666191218094020>
- Perez, A. M., Chau, V. Q., & Sridhar, J. (2024). Medical Accuracy of Reddit in Patient Discussions of Prospective Ocular Stem Cell Therapies for Retinal Degenerative Diseases. *Journal of VitreoRetinal Diseases*, 8(4), 410–414. Scopus. <https://doi.org/10.1177/24741264241246317>
- Poliwoda, S., Noor, N., Downs, E., Schaaf, A., Cantwell, A., Ganti, L., Kaye, A. D., Mosel, L. I., Carroll, C. B., Viswanath, O., & Urits, I. (2022). Stem cells: A comprehensive review of origins and emerging clinical roles in medical practice. *Orthopedic Reviews*, 14(3). Scopus. <https://doi.org/10.52965/001C.37498>
- Scopetti, M., Santurro, A., Gatto, V., Russa, R. L., Manetti, F., Errico, S. D., Frati, P., & Fineschi, V. (2020). Mesenchymal stem cells in neurodegenerative diseases: Opinion review on ethical dilemmas. *World Journal of Stem Cells*, 12(3), 168–177. Scopus. <https://doi.org/10.4252/wjsc.v12.i3.168>
- Shahin, S., Tan, P., Chetsawang, J., Lu, B., Svendsen, S., Ramirez, S., Conniff, T., Alfaro, J. S., Fernandez, M., Fulton, A., Laperle, A. H., Svendsen, C. N., & Wang, S. (2023). Human Neural Progenitors Expressing GDNF Enhance Retinal Protection in a Rodent Model of Retinal Degeneration. *Stem Cells Translational Medicine*, 12(11), 727–744. Scopus. <https://doi.org/10.1093/stcltm/szad054>
- Yoo, M., Cho, S., Shin, S., Kim, J.-M., Park, H.-G., Cho, S., Hwang, Y. K., & Park, D. H. (2021). Therapeutic Effect of IL1 β Priming Tonsil Derived-Mesenchymal Stem Cells in Osteoporosis. *Tissue Engineering and Regenerative Medicine*, 18(5), 851–862. Scopus. <https://doi.org/10.1007/s13770-021-00350-3>
- Zhao, L., Shi, H.-Y., Ma, Y.-M., & Liu, J.-W. (2021). Neural stem cell therapy for brain disease. *World Journal of Stem Cells*, 13(9), 1278–1292. Scopus. <https://doi.org/10.4252/wjsc.v13.i9.1278>