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Understanding the Expectations and Challenges of Patients with Degenerative Diseases Toward Stem Cell Therapy: A Phenomenological Study of Personal Experiences

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ABSTRACT

Regenerative medicine, particularly stem cell therapy, offers transformative potential fo managing degenerative diseases by promoting tissue repair and restoration. Despite advancements in biomedical research, the subjective experiences of patients navigating these therapies remain underexplored, particularly concerning emotional, social, and financial dimensions. This study addresses this gap by investigating how patients perceive and make sense of their experiences with stem cell therapy for degenerative conditions. Using a descriptive phenomenological approach, this research uncovered three key themes: the duality of hope and uncertainty, procedural and financial concerns and the vital role of social and familial support. Data were collected through in-depth interviews with 12 participants and analyzed thematically to identify the essence of thei lived experiences. Findings highlight the interplay between patients' aspirations and fears, as well as the critical importance of empathetic communication and supportive environments in alleviating psychological burdens. These insights enhance ou understanding of patient-centered care in regenerative medicine, emphasizing the need to integrate emotional and social considerations into therapeutic frameworks. Future research could build on these findings by exploring diverse cultural and socioeconomic contexts, ultimately advancing inclusive and holistic medical practices.

INTRODUCTION

Degenerative diseases, such as osteoarthritis, diabetes, and neurodegenerative disorders, pose significant challenges to healthcare systems worldwide due to their progressive nature and lack of definitive cures (Al-Massri dkk., 2020). These conditions often lead to diminished quality of life, chronic pain, and functional impairments, placing substantial psychological, social, and financial burdens on patients and their families. As conventional treatments focus primarily on symptom management rather than addressing the underlying damage, the demand for innovative solutions has grown exponentially.

Stem cell therapy has emerged as a promising frontier in regenerative medicine, offering the potential to repair or replace damaged tissues. By harnessing the ability of stem cells to differentiate and promote healing, this technology holds the promise of restoring functionality in conditions once considered irreversible. Despite its potential, stem cell therapy remains a novel and evolving field, marked by procedural uncertainties, high costs, and limited public understanding. This confluence of hope and uncertainty has shaped the experiences and perceptions of patients seeking these therapies.

Previous research has primarily focused on the biomedical efficacy of stem cell therapy, such as its mechanisms, clinical outcomes, and procedural advancements (Biswas dkk., 2024). However, less attention has been given to the subjective experiences of patients navigating this journey. The psychological and social dimensions, including the emotional challenges, financial considerations, and societal stigma often associated with these treatments, remain underexplored in the literature.

This study aims to address this gap by adopting a phenomenological approach to investigate the lived experiences of patients undergoing or considering stem cell therapy (Boespflug-Tanguy dkk., 2023). By exploring the subjective meanings and personal narratives associated with this phenomenon, the research seeks to provide a deeper understanding of how individuals perceive and make sense of their therapeutic journey. This exploration is essential for informing patient-centered care, improving communication, and tailoring therapies to align with the nuanced needs and expectations of patients.

Research on the subjective experiences of individuals navigating complex health conditions, such as degenerative diseases, has gained increasing importance in recent years. Understanding how patients perceive, interpret, and adapt to therapeutic interventions offers invaluable insights into the broader implications of medical advancements. However, the exploration of patient experiences, particularly in emerging fields like stem cell therapy, remains insufficient. The intersection of hope and uncertainty has yet to be fully addressed, emphasizing the need for further inquiry.

Traditional research methods, particularly those rooted in quantitative paradigms, frequently fall short in capturing the nuanced and deeply personal dimensions of patient experiences (Deng dkk., 2022). While quantitative approaches excel in measuring outcomes and establishing efficacy, they often fail to address the emotional, psychological, and social complexities embedded in the lived realities of patients. As a result, the voices of patients—who are directly affected by the therapeutic process—are underrepresented in existing literature.

Phenomenological approaches offer a robust methodological framework to address these gaps, emphasizing the exploration of lived experiences and the meanings individuals attach to them. By focusing on the subjective realities of patients, phenomenology transcends the limitations of data-driven methodologies, providing a richer and more comprehensive understanding of phenomena. In the context of stem cell therapy, this approach is particularly relevant, as it allows for an in-depth examination of the intricate interplay between hope, fear, and the broader socio-economic and cultural factors influencing patient journeys.

Existing studies that engage with the emotional and social aspects of stem cell therapy are limited, often addressing these dimensions only tangentially. This underlines the need for a focused exploration of the subjective experiences of patients, particularly in understanding how they navigate the complexities of this emerging medical field. By addressing these methodological and contextual challenges, the present research contributes to bridging a critical gap in the literature.

Despite the growing body of research on stem cell therapy and its biomedical implications, the subjective experiences of patients remain underexplored. Existing practical approaches to understanding patient engagement—such as surveys or structured interviews—have been predominantly quantitative, emphasizing measurable outcomes like satisfaction rates or clinical effectiveness. While these methods provide valuable insights, they are limited in their ability to capture the nuanced, deeply personal experiences that define the patient journey.

This reliance on reductive methodologies often overlooks the emotional, psychological, and social dimensions of patient experiences, leaving critical questions unanswered. For instance, how do patients perceive and navigate the uncertainty surrounding stem cell therapy? What are their internalized fears and hopes, and how are these shaped by broader social and economic contexts? These are complex questions that cannot be fully addressed through conventional approaches focused solely on metrics or general trends.

Phenomenology offers a compelling alternative by prioritizing the exploration of lived experiences and the meanings patients attach to them (Haghighat dkk., 2021). This method allows for a holistic and in-depth understanding of the interplay between individual perceptions and the broader context in which they occur. In the case of stem cell therapy, adopting a phenomenological lens is particularly pertinent to uncovering the rich, multifaceted nature of patient experiences that have been historically marginalized in scientific inquiry.

This gap in the literature underscores the need for research that employs phenomenological methods to investigate the subjective realities of patients. By doing so, the study aims to provide insights that not only deepen our understanding of patient experiences but also inform the development of patient-centered practices and policies in regenerative medicine.

Previous studies have explored patient experiences in various healthcare contexts, highlighting the importance of understanding subjective perspectives in shaping medical practices. Research on regenerative medicine, including stem cell therapy, has predominantly focused on clinical outcomes, leaving emotional, social, and psychological dimensions underrepresented. Phenomenological approaches have been successfully applied in other areas to illuminate the lived experiences of patients, yet their use in stem cell therapy remains limited. The current study seeks to address this gap by leveraging phenomenology to uncover the nuanced meanings patients ascribe to their therapeutic journeys. By doing so, it contributes to a growing body of literature emphasizing the need for patient-centered perspectives in advancing medical care.

This study adopts a descriptive phenomenological approach, which is well-suited for exploring the essence of patients’ lived experiences with stem cell therapy. This method provides a structured framework to address the knowledge gaps identified, focusing on capturing participants' perspectives in their own words (Lai, 2021). The approach ensures a thorough examination of how patients interpret their encounters with medical, financial, and social challenges. It also reveals the deeper psychological and emotional impacts that accompany these experiences. By prioritizing rich, narrative data, this method answers the call for a more holistic understanding of patient journeys in regenerative medicine.

The article is organized into several sections to provide a cohesive and comprehensive presentation of the research. The introduction outlines the background, knowledge gap, and objectives of the study. The subsequent section details the methodological approach, including participant recruitment, data collection, and analytical procedures. Following this, the results section presents the emergent themes, supported by direct quotes from participants. The discussion contextualizes these findings within the broader literature and highlights their implications for patient-centered care. Finally, the conclusion synthesizes the insights gained and offers recommendations for practice and future research.

RESEARCH METHODS

Study Design

This study employed a phenomenological approach to explore the subjective experiences of patients undergoing or considering stem cell therapy for degenerative diseases (Ludwig & Gamm, 2021). Phenomenology was chosen for its emphasis on understanding lived experiences and uncovering the deeper meanings attached to these phenomena. By focusing on the participants' perspectives, this design facilitated an in-depth exploration of the complex interplay between hopes, uncertainties, and social dynamics inherent in the therapeutic journey.

A descriptive phenomenological approach, rooted in the works of Edmund Husserl, was utilized to capture the essence of participants' experiences as described in their own words. This approach provided a structured framework for identifying and interpreting the key themes emerging from their narratives, ensuring a rigorous and systematic analysis of the data.

Participants

Participants included individuals diagnosed with degenerative diseases who had either undergone or were considering stem cell therapy. A purposive sampling strategy was employed to ensure the inclusion of individuals who could provide rich and relevant insights into the phenomenon under study. The sample size of 12 participants was chosen based on the research goals, which aimed for in-depth, qualitative insights rather than statistical generalization. This number was considered sufficient for data saturation, as it allowed for the identification of key themes while maintaining manageable data complexity. Inclusion criteria consisted of being aged 18 years or older, having a confirmed diagnosis of a degenerative condition, and a willingness to share personal experiences in detail. Exclusion criteria included individuals with cognitive impairments that could hinder effective communication or comprehension.

The sample comprised 12 participants, with an age range of 34 to 67 years (Nabi dkk., 2020). Demographic details included a mix of male and female participants from diverse socioeconomic backgrounds, all of whom had varying levels of familiarity with stem cell therapy. These characteristics provided a broad perspective on the phenomenon while maintaining a focus on the core research questions.

Data Collection

Data were collected through semi-structured, in-depth interviews conducted in a private and comfortable setting to encourage open dialogue. An interview guide was used to facilitate discussions, covering topics such as participants' hopes, concerns, and experiences related to stem cell therapy. The interviews were conducted in-person, each lasting between 60 and 90 minutes, and were audio-recorded with participants' consent.

To ensure clarity and relevance, interview questions were pilot-tested and refined based on initial feedback (Noori dkk., 2023). The setting and scheduling of interviews were tailored to participants' preferences to minimize stress and ensure a conducive environment for reflection. Field notes were also taken to capture non-verbal cues and contextual observations.

Data Analysis

Data were analyzed using a thematic analysis approach consistent with descriptive phenomenology. Verbatim transcription of interviews was performed, and the transcripts were meticulously reviewed to identify patterns and themes. Initial coding was carried out to segment the data into meaningful units, followed by the grouping of codes into broader themes reflecting the essence of participants' experiences.

A systematic process of horizonalization was applied to ensure all perspectives were given equal weight, and essential themes were distilled through iterative comparison and reflection. Software tools such as NVivo were employed to organize and manage the data, facilitating a comprehensive and transparent analytical process. Representative quotes were extracted to illustrate the identified themes and provide authenticity to the findings.

Ethical Considerations

Ethical approval for the study was obtained from the relevant institutional ethics committee. Written informed consent was secured from all participants, ensuring they were fully aware of the study's purpose, procedures, and their rights, including the option to withdraw at any stage. Anonymity and confidentiality were maintained by assigning pseudonyms and securely storing data in encrypted formats.

The study adhered to ethical guidelines as outlined in the Declaration of Helsinki and local regulations (Shi dkk., 2021). Efforts were made to ensure that participants felt respected and valued throughout the research process, with their well-being prioritized at every stage.

RESULTS AND DISCUSSION

Aspirations and Expectations Toward Regenerative Technology

Participants expressed high hopes for stem cell therapy as a potential solution to their degenerative conditions. For many, the therapy symbolized a "last chance" to regain a semblance of their prior health and independence. One participant shared, "I feel like this is my only hope to live a normal life again." These aspirations were often intertwined with a sense of urgency and desperation, particularly among individuals who had exhausted conventional medical treatments.

The therapy was perceived as a groundbreaking advancement, fueling optimism among patients. However, this optimism was tempered by uncertainty. Some patients expressed doubt about the feasibility of their expectations: “I know it’s a new technology, but what if it doesn’t work? I don’t know if I can handle another disappointment.” These narratives highlighted the duality of hope and apprehension, a central theme in understanding the subjective experiences of patients pursuing stem cell therapy.

Procedural and Financial Uncertainty

Uncertainty surrounding the procedural aspects and financial burden of stem cell therapy was a recurring concern among participants. Many reported feeling overwhelmed by the lack of transparent information about the therapeutic process, including risks, expected outcomes, and post-therapy care. One participant stated, “No one explains what happens step by step. I feel like I’m signing up for something I don’t fully understand.”

Financial considerations were equally pressing, with many participants highlighting the prohibitive costs as a source of anxiety. This tension often manifested during consultations, where patients sought clarity but were met with vague or technical responses. Observations further revealed visible discomfort and hesitation during discussions of therapy costs. A participant remarked, “It’s not just the money—it’s the uncertainty of whether it’s worth the investment.”

Emotional and Social Dynamics

The emotional and social dimensions of pursuing stem cell therapy were profound and multifaceted. Emotional support from family emerged as a critical factor in helping participants navigate their therapeutic journey. One participant emphasized, “Without my family’s encouragement, I wouldn’t have been brave enough to try this.” The presence of loved ones during consultations often alleviated stress, creating a sense of shared responsibility and decision-making.

Conversely, some participants reported feelings of isolation, particularly when faced with societal stigma or skepticism regarding stem cell therapy. “People don’t understand. They think I’m wasting money on something experimental,” shared one participant. This lack of understanding often compounded the psychological burden, leaving patients feeling alienated and unsupported outside their immediate family circle.

The findings underscore the deeply personal and often complex experiences of patients considering or undergoing stem cell therapy. Aspirations for recovery coexist with significant procedural and financial uncertainties, while emotional and social contexts play a pivotal role in shaping the therapeutic journey. These insights highlight the need for patient-centered communication, transparency in procedural and financial aspects, and broader societal education to reduce stigma and foster a supportive environment.

Summary of Key Findings

This study revealed that patients undergoing or considering stem cell therapy for degenerative diseases navigate a complex interplay of hope, uncertainty, and emotional resilience (Perna dkk., 2023). Central to their experiences are aspirations for recovery, fears of procedural and financial barriers, and the critical role of social and emotional support in shaping their therapeutic journeys. These findings address the primary research question by illuminating the subjective realities of patients, offering a deeper understanding of their perspectives.

Contribution to Research Questions

The findings provide substantive answers to the overarching research questions about patients' experiences with stem cell therapy. The hope associated with regenerative technology emerged as a pivotal theme, signifying patients’ reliance on the therapy as a potential last resort. However, this hope is tempered by significant procedural and financial uncertainties, which create emotional stress and shape patients' perceptions of the therapy’s feasibility (Plesa dkk., 2023). Additionally, the study highlights the influence of social contexts, particularly family support, in mitigating psychological challenges and fostering resilience during the decision-making process. By focusing on the lived experiences of patients, the study contributes unique insights into the socio-emotional dimensions of stem cell therapy that are underexplored in existing literature.

Relation to Previous Literature and Theory

The study's findings align with existing research that emphasizes the dual nature of regenerative therapies—offering hope while presenting significant uncertainties (Smith & Jones, 2020). Previous studies have highlighted the efficacy and potential of stem cell therapy from a biomedical perspective (Johnson et al., 2019), but few have explored its subjective dimensions. This research fills that gap by shedding light on the deeply personal and emotional experiences of patients. The role of family support, as identified in this study, echoes findings in broader healthcare research, which underline the importance of social networks in navigating complex medical decisions (Brown et al., 2018). Furthermore, the emotional toll of financial and procedural ambiguities corroborates prior studies that examine the psychological burden associated with high-cost, experimental medical treatments (Lee & Tan, 2021). This research extends these discussions by situating them within the specific context of stem cell therapy, offering a more holistic understanding of patient experiences.

Implications of Findings

The findings of this study have significant scientific and practical implications for patient-centered care in regenerative medicine (Rehman dkk., 2020). On a social and cultural level, the results highlight the importance of addressing patients' emotional and psychological needs alongside clinical care. For healthcare providers, understanding the interplay of hope and uncertainty can inform the development of communication strategies that manage patient expectations effectively while providing empathetic support. Additionally, the pivotal role of family underscores the need for involving caregivers in the therapeutic process, potentially enhancing outcomes by fostering a collaborative and supportive environment. From a broader perspective, these insights can be applied to other high-cost, experimental treatments where similar emotional and financial dynamics are likely to be present, thus extending their relevance beyond stem cell therapy.

Limitations of the Study

This study has several limitations that may influence the generalizability of its findings. The purposive sampling approach, while suitable for phenomenological research, limits the diversity of participant demographics, potentially excluding perspectives from individuals with different cultural or socioeconomic backgrounds (Ren dkk., 2021). Furthermore, the reliance on self-reported experiences introduces the possibility of recall bias, as participants may interpret or remember events differently over time. The contextual focus on stem cell therapy means that the findings may not fully translate to other medical interventions, especially those that differ significantly in cost, availability, or societal perception. These limitations should be considered when interpreting the results, and they point to areas for further research.

Prospects for Future Research

This study opens avenues for further exploration into the subjective experiences of patients undergoing experimental medical treatments. Future research could expand on these findings by incorporating longitudinal designs to track changes in patient perceptions over time, particularly as they navigate the long-term outcomes of stem cell therapy (Ru dkk., 2020). Comparative studies across different cultural or socioeconomic contexts could deepen understanding of how these factors shape patient experiences and expectations. Additionally, integrating multidisciplinary perspectives, such as combining phenomenological analysis with economic or policy research, could provide a more comprehensive view of the challenges patients face. These efforts would not only enrich the academic discourse but also support the advancement of more inclusive and patient-centered healthcare practices.

CONCLUSION

This study explored the lived experiences of patients undergoing or considering stem cell therapy for degenerative diseases, addressing the emotional, social, and psychological dimensions often overlooked in existing literature. The findings revealed the duality of hope and uncertainty, with patients expressing high aspirations for recovery tempered by significant concerns about procedural and financial challenges. Family support emerged as a critical factor in mitigating emotional stress, highlighting the interconnectedness of individual and social dynamics in the therapeutic journey. By adopting a phenomenological approach, this study provided a nuanced understanding of patient perspectives which has important implications for refining patient care strategies in regenerative medicine.. These insights have practical implications for developing patient-centered care strategies, particularly in managing expectations and providing emotional and social support. Future research could expand on these findings by exploring diverse cultural and socioeconomic contexts or integrating longitudinal studies to examine the evolving perceptions of patients over time.

CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

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