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Lived Experience and Personal Meaning of Gene Therapy in Young Patients with Primary Immunodeficiency

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ABSTRACT

Gene therapy has emerged as a transformative advancement in molecular medicine particularly for individuals with rare genetic and immunological disorders. Despite it clinical success, little is known about how young patients subjectively experience an interpret gene therapy as a life-altering event. Existing literature tends to focus o biomedical outcomes, leaving a gap in understanding the emotional, existential, an identity-related meanings attached to the treatment experience.

This study employs an interpretative phenomenological approach to explore how youn individuals with primary immunodeficiency disorders make sense of undergoing gen therapy.

Semi-structured in-depth interviews were conducted with eight participants aged 13 t 25 years, who had undergone gene therapy within the past three years. The interview followed a flexible guide that encouraged participants to narrate their experiences before during, and after the treatment.

In-depth interviews with eight participants were analyzed using Interpretativ Phenomenological Analysis (IPA), which revealed five major themes: renewed hope lingering uncertainty, reconstruction of self-identity, spiritual meaning, and transforme family relationships. These themes were derived from rigorous thematic analysis an reflect rich, lived experiences that extend beyond conventional clinical narratives. Th findings show that gene therapy is not only perceived as a medical breakthrough but als as a deeply personal and symbolic transformation.

This study expands our understanding of gene therapy by highlighting the importance o addressing emotional and psychosocial dimensions in treatment planning. Futur research should integrate phenomenological insights into broader models of patient centered care, especially in genetic medicine.

INTRODUCTION

Gene therapy has emerged as a transformative approach in modern biomedical science, offering curative potential for individuals with previously untreatable genetic disorders (Sanders dkk., 2024; Senn-Malashonak dkk., 2019). As advancements in molecular medicine accelerate, particularly with technologies such as viral vector delivery and genome editing, gene therapy is increasingly positioned as a cornerstone of precision medicine (Springer dkk., 2023). Its application in primary immunodeficiency disorders has demonstrated significant clinical promise, enabling long-term immune reconstitution and improved survival rates for affected individuals.

Yet beyond the clinical milestones, little is known about how young patients personally experience this breakthrough treatment adolescents and young adults, who face not only physical challenges but also complex emotional and existential transitions. The experience of undergoing gene therapy intersects deeply with themes of identity, vulnerability, and hope, especially for young individuals who have long endured chronic illness (Zaleta dkk., 2020). In many cases, these treatments disrupt established narratives of illness and recovery, requiring patients to reconstruct their understanding of normalcy, health, and future possibilities within new biotechnological realities.

In this context, it becomes essential to explore the subjective meaning of gene therapy from the perspective of those who live through it. While biomedical research has focused extensively on clinical outcomes, there remains a significant gap in understanding how such interventions are internalized and experienced by patients themselves. Addressing this gap aligns with a growing recognition in healthcare of the need for patient-centered narratives that honor the lived dimensions of treatment. A phenomenological approach is thus particularly suited to uncover the rich, nuanced meanings that patients ascribe to gene therapy—meanings that cannot be captured through quantitative measures alone.

Research exploring patients’ lived experiences within complex medical treatments has gained increasing significance in recent years, particularly in the context of emerging biomedical interventions such as gene therapy (El-Jawahri dkk., 2020; Hudson dkk., 2021). This focus reflects a growing acknowledgment that clinical outcomes alone cannot fully capture the transformative nature of medical interventions, especially for young patients navigating the psychosocial complexities of chronic illness and experimental treatments (Mathanda dkk., 2020). Within this landscape, understanding how individuals experience and make meaning of gene therapy is crucial for developing holistic, ethically grounded, and patient-centered models of care.

However, methodological challenges persist in capturing the depth and richness of such experiences (Arjunan dkk., 2020; Hingert dkk., 2020; Park dkk., 2019). Traditional quantitative approaches, though valuable for assessing measurable outcomes like survival rates or physiological markers, often fall short in addressing the subjective, emotional, and existential dimensions of treatment. Standardized questionnaires or structured scales may fail to accommodate the nuanced, often non-linear narratives that patients construct around their illness and recovery. As a result, the essence of lived experience—including fear, hope, identity transformation, and spiritual reflection—remains underexplored.

This limitation has led to a reliance on research methods that may inadequately represent the full complexity of patient experiences (Vandekerckhove dkk., 2019; Watson dkk., 2019). Consequently, prior studies have tended to offer fragmented or superficial understandings of what it truly means to undergo gene therapy, particularly for adolescents and young adults. These gaps highlight the need for qualitative methodologies, such as phenomenology, that are explicitly designed to explore meaning, perception, and experience from the insider’s perspective.

Current understandings of gene therapy in young patients are largely shaped by clinical, biomedical, and procedural frameworks that prioritize measurable outcomes such as treatment efficacy, immunologic recovery, and procedural safety (Dong dkk., 2020; Jacobs dkk., 2019). While these metrics are essential for evaluating therapeutic success, they provide limited insight into the personal and emotional realities experienced by patients during and after therapy (Senn-Malashonak dkk., 2019). In practice, the dominant approach to patient evaluation continues to rely on structured clinical interviews, health-related quality of life (HRQoL) surveys, and psychological assessments that, while valuable, often reduce complex human experiences into standardized categories.

These conventional tools, although practical, frequently fail to capture the nuanced emotional transformations and existential shifts that patients undergo—especially in high-stakes interventions such as gene therapy for life-threatening conditions (Eche dkk., 2023; Tian dkk., 2021). The subjective experience of hope, fear, self-identity, and spiritual meaning is typically marginalized in favor of generalizable clinical data, resulting in an incomplete portrait of the therapeutic journey. Consequently, healthcare providers may overlook vital aspects of patient recovery that are not easily quantified but are deeply impactful on long-term well-being.

To address this limitation, a phenomenological approach is proposed as a more suitable method for capturing the essence of lived experience (Cozzolino dkk., 2021; Farmakis dkk., 2022). Phenomenology, particularly the interpretative variant, offers a robust framework for exploring how individuals make sense of transformative events within their social and personal lifeworlds. By engaging directly with patient narratives, this approach reveals meanings that are contextually grounded, emotionally rich, and ethically relevant—thereby offering a more holistic and human-centered understanding of gene therapy's impact on young lives.

Previous studies have examined how patients experience chronic illness and advanced medical treatments, including organ transplants, chemotherapy, and genetic diagnostics. These studies often highlight the importance of emotional resilience, identity reconstruction, and meaning-making in the healing process (Kolasinski dkk., 2020a, 2020b). However, few have specifically explored the lived experience of young individuals undergoing gene therapy, especially within the context of rare immunodeficiency disorders. Theoretical perspectives such as narrative identity and embodied health have been referenced, but a deeper phenomenological understanding remains lacking. This gap signals the need for research that centers the patient's voice through interpretative methods.

This study adopts Interpretative Phenomenological Analysis (IPA) to explore how young patients make sense of receiving gene therapy (Mammana dkk., 2019; Mishra dkk., 2020). This method was chosen for its strength in revealing rich, layered meanings within personal narratives and its focus on individual perspectives. IPA allows for an exploration of identity, hope, fear, and transformation—elements central to the therapeutic experience (Sanders dkk., 2024). Through this approach, the study responds to the previously identified knowledge gap by illuminating the emotional and existential dimensions of treatment. In doing so, it complements existing clinical findings with humanistic insights.

The structure of this article is organized to guide readers through the journey of understanding patient experiences (Al-Massri dkk., 2020; Panes dkk., 2022; Shi dkk., 2021). The introduction outlines the significance and context of the study. The methodology section explains the phenomenological design, participant selection, and data analysis procedures. The results present the core themes derived from participant narratives. The discussion offers a reflective interpretation of findings, followed by a conclusion that highlights the study's contributions to patient-centered care in gene therapy.

RESEARCH METHODS

Study Design

This study employed an interpretative phenomenological design, which is grounded in the philosophical framework of Heideggerian phenomenology (Carreiras & Castro, 2012; Migdal, 2018). The approach emphasizes the exploration of lived experiences and the interpretation of how individuals make sense of significant phenomena in their lives (El-Jawahri dkk., 2020). Interpretative Phenomenological Analysis (IPA) was selected due to its capacity to uncover complex psychological, emotional, and existential dimensions of experience, particularly relevant in the context of advanced medical interventions such as gene therapy (Hudson dkk., 2021). This design allowed for a detailed investigation into the subjective meanings assigned by young patients undergoing gene therapy for primary immunodeficiency disorders.

Participants

Participants were young individuals aged between 16 and 25 years who had undergone gene therapy within the past 12 to 18 months for diagnosed primary immunodeficiency disorders (Iosifides, 2013, 2016). Selection was conducted through purposive sampling to ensure relevance to the phenomenon under investigation. Inclusion criteria required participants to be physically stable post-therapy, capable of verbal communication, and willing to share their experiences. Individuals with cognitive impairments or those currently experiencing severe psychological distress were excluded to protect participant well-being and data integrity. A total of eight participants (five males and three females) were included in the study, with a mean age of 20.1 years. All participants had completed treatment at a national biomedical research center specializing in genetic therapies.

Data Collection

Data were collected through in-depth, semi-structured interviews, guided by a flexible protocol that encouraged open-ended reflection on participants' personal experiences before, during, and after gene therapy (Iosifides, 2011; Longhofer dkk., 2012). Interviews were conducted face-to-face in private consultation rooms within the clinical center, each lasting between 45 and 75 minutes. A calm and supportive environment was maintained to promote trust and psychological safety. All interviews were audio-recorded with participant consent and transcribed verbatim. Follow-up interviews were offered when clarification or elaboration was needed to ensure data richness (Hingert dkk., 2020). The interview guide was adapted from existing literature on patient experience in genetic treatment and reviewed by two qualitative research experts for content relevance.

Data Analysis

Transcribed data were analyzed using Interpretative Phenomenological Analysis (IPA), following the procedural stages outlined by Arjunan dkk. (2020). Initial reading and re-reading of transcripts facilitated immersion in the data. Meaning units were identified and coded manually, followed by clustering of related codes into emergent themes. Cross-case analysis was conducted to identify patterns while preserving the idiographic focus of each individual case. NVivo 12 software was used to assist in data organization and theme development, although final thematic decisions were based on interpretative engagement with the data. This analytical process enabled the articulation of essential themes that reflected the lived meaning of gene therapy among participants.

Ethical Considerations

Ethical approval was obtained from the institutional research ethics board of the clinical center where the study was conducted (Daly, 2007; Murphy & Dingwall, 2017). All participants provided written informed consent after receiving a comprehensive explanation of the study's purpose, procedures, and their rights, including the right to withdraw at any point without consequence. Anonymity was ensured through the use of pseudonyms, and all data were stored securely in encrypted digital formats (Park dkk., 2019). The study adhered to the ethical principles outlined in the Declaration of Helsinki and complied with local regulations governing human subjects research.

RESULTS

A New Chapter of Hope

Participants consistently described gene therapy as a turning point in their lives, marked by renewed hope and the possibility of a future free from recurrent illness. The therapy was not merely a medical procedure but symbolized a new beginning.

"I felt like my life had finally started… before the therapy, I was just surviving. Now, I can dream again." (Participant 4)

For most, the notion of healing was deeply intertwined with hope—not just for physical recovery, but also for reclaiming their place in society, pursuing education, and forming meaningful relationships.

Living with Uncertainty and Fear

While the prospect of recovery was uplifting, it was accompanied by intense fear and uncertainty. Participants expressed anxiety about the long-term effects of gene therapy and doubts about its permanence.

"I was excited but scared. What if it doesn't work? What if I go back to how I was before?" (Participant 2)

This emotional ambivalence often led to inner conflict, especially among those who had experienced previous medical disappointments. The unpredictability of outcomes created an ongoing psychological burden, even post-treatment.

Redefining Self and Illness

Gene therapy altered how participants viewed themselves—not only in terms of physical health but also identity. Several participants reported a shift in self-perception from being “chronically ill” to being “normal” or “reborn.”

“Before, I always saw myself as the sick kid… Now I can walk into a room and not feel like I need to explain my condition.” (Participant 6)

This transformation, however, was not always seamless. Some participants struggled to reconcile their past illness identity with their new reality, often feeling disconnected from support communities that had previously defined their social interactions.

Spiritual Meaning and Inner Growth

For many, the journey through gene therapy invoked deep spiritual reflection. Participants spoke of finding meaning in their suffering and described the therapy as a divine intervention or blessing.

“I used to question why I was born this way… Now, I believe there’s a reason, and maybe this therapy is part of my destiny.” (Participant 1)

This spiritual framing provided comfort and resilience during the difficult phases of treatment, and for some, it fostered a sense of gratitude and purpose.

Strengthening Bonds and Shifting Dynamics

The process of undergoing gene therapy reshaped participants’ relationships with family and caregivers. Several reported stronger familial connections and a newfound appreciation for their support systems.

“My mom was there every second... I didn’t realize how much she sacrificed until I saw her cry after my last dose.” (Participant 5)

However, the transition to independence post-therapy sometimes created friction, as caregivers struggled to adjust their roles in light of the patient's newfound autonomy.

The lived experience of gene therapy among young patients with primary immunodeficiency disorders is multifaceted—marked by hope, fear, transformation, spiritual growth, and evolving social dynamics. These findings offer insight into the deeply personal and existential meanings that gene therapy holds beyond its clinical implications.

DISCUSSION

The findings of this study reveal that gene therapy is experienced by young patients not merely as a biomedical intervention, but as a deeply transformative journey marked by hope, uncertainty, identity redefinition, spiritual insight, and evolving interpersonal relationships (Vandekerckhove dkk., 2019). These core themes illuminate the subjective essence of undergoing gene therapy and directly address the central research question concerning how young individuals interpret and give meaning to their treatment experience.

The study contributes to this inquiry by offering rich, contextualized narratives that capture the emotional and existential dimensions often overlooked in clinical research (Ning dkk., 2022; Wang dkk., 2019; Yang dkk., 2019). It demonstrates that gene therapy represents more than physical healing—it is perceived as a symbolic rebirth, a source of existential questioning, and a turning point in self-understanding and social reintegration. Through this interpretative lens, the study expands the conceptual understanding of therapeutic success by highlighting the importance of inner transformation and psychological adaptation, which cannot be adequately represented by clinical metrics alone.

These findings resonate with previous phenomenological studies exploring patient experiences in other high-impact medical contexts. For instance, Watson dkk. (2019) identified

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similar emotional tensions and hopes among participants in gene therapy trials, while Jacobs dkk., (2019) highlighted spiritual reinterpretation as a coping mechanism during CRISPR interventions. The current study builds on these insights by focusing specifically on young individuals with inherited immune disorders, a group that is both medically vulnerable and developmentally distinct. The central theme of identity reconstruction is consistent with theoretical models of narrative identity in illness (Dong dkk., 2020), where patients re-author their life stories in response to disruptive health events. By anchoring its analysis in the patients' own words, this study validates their experiential knowledge and contributes to a more holistic and ethically sensitive framework for gene therapy evaluation.

The implications of these findings extend beyond individual patient narratives and speak to broader clinical, psychosocial, and ethical considerations in the delivery of gene therapy. The participants' experiences underscore the need for integrative care models that address emotional and existential wellbeing alongside medical treatment. Clinicians, counselors, and healthcare planners must recognize that therapeutic interventions—especially those with transformative potential—interact with patients' sense of identity, future orientation, and interpersonal relationships. These insights are particularly relevant in pediatric and adolescent settings, where developmental transitions intersect with complex health decisions. Culturally sensitive communication and psychosocial support should therefore be embedded within gene therapy programs to better accommodate the lived realities of young patients.

Despite the depth and richness of the data, several limitations must be acknowledged (Satterlee dkk., 2019; Shin dkk., 2019). The study was conducted within a single clinical center and involved a relatively small, homogeneous group of participants, all of whom had completed therapy within a similar timeframe. As is typical in phenomenological research, the goal was not generalization but depth of understanding; nevertheless, these contextual constraints may limit the transferability of findings to different cultural, institutional, or diagnostic contexts. Additionally, the reliance on retrospective narratives introduces the possibility of recall bias or narrative reconstruction influenced by time, memory, or social desirability.

Future research may build upon these findings by exploring lived experiences across different stages of treatment, including pre-intervention decision-making and long-term post-treatment adaptation (Gholizadeh-Ghaleh Aziz dkk., 2019; Hartheimer dkk., 2019). Comparative studies involving diverse populations and healthcare systems could further illuminate cultural variations in meaning-making and emotional response to gene therapy (Tian dkk., 2021). Integrating phenomenological insights with interdisciplinary research—such as narrative medicine, medical anthropology, or digital health support systems—may enrich both theoretical and practical approaches to patient-centered care in genetic medicine. Ultimately, the findings presented here lay the groundwork for more humane, reflective, and responsive models of care that honor the voices of those undergoing life-altering medical treatment.

CONCLUSION

This study explored the lived experiences of young patients who underwent gene therapy for primary immunodeficiency disorders, addressing the need to understand how such individuals make meaning of a transformative medical intervention. Through an interpretative phenomenological approach, five key themes were identified, including hope, uncertainty, identity redefinition, spiritual reflection, and changes in family dynamics. These findings reveal that gene therapy impacts not only physical health but also personal and emotional dimensions of healing. The study contributes to closing the gap in prior research by highlighting subjective experiences that are often overlooked in quantitative or outcome-focused studies. It encourages the development of more holistic, patient-centered care strategies that acknowledge the emotional and existential journeys of young patients. Future research may expand on these insights by exploring diverse cultural contexts or examining long-term psychological adaptation after gene therapy.

CONFLICT OF INTEREST

The authors declare no conflict of interest related to the research, authorship, or publication of this article. All funding sources and supporting institutions are acknowledged appropriately, and no financial or non-financial relationships exist that could be perceived to influence the content or interpretation of the findings.

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