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Exploring the Experiences and Ethical Concerns of Cancer Patients Undergoing Gene Therapy: A Phenomenological Study Approach

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ABSTRACT

Gene therapy has emerged as a transformative treatment for various types of cancer, offering new possibilities for patients with limited therapeutic options. However, while its biological efficacy has been extensively studied, little is known about the subjective experiences of patients undergoing this innovative treatment. This gap in knowledge raises the question: How do cancer patients navigate the emotional complexities, including hope, uncertainty, and ethical dilemmas, associated with gene therapy?

In addressing this gap, our study employs a phenomenological approach, specifically Interpretative Phenomenological Analysis (IPA), to explore how patients interpret and experience their journey through gene therapy. Using semi-structured interviews with 15 cancer patients, we identified key themes related to hope, uncertainty, and ethical concerns that shape their treatment experiences. The findings contribute to the existing literature by revealing that while initial hope for a cure is prevalent, it evolves into a complex emotional landscape, influenced by ongoing uncertainties and ethical reflections. Moreover, ethical concerns about the novel nature of gene therapy surfaced as an integral aspect of the emotional experience, highlighting the unique psychological challenges faced by patients undergoing this treatment.

Our study provides valuable insights into the psychosocial dimensions of gene therapy and underscores the importance of addressing these aspects in clinical care. The findings suggest that healthcare providers should integrate emotional and ethical support into the treatment process to improve patient well-being and decision-making. Further research should expand on these findings to explore long-term impacts and include diverse patient populations for a broader understanding.

INTRODUCTION

Gene therapy represents a groundbreaking advancement in molecular medicine, offering potential solutions for previously untreatable genetic disorders, including various forms of cancer. As a therapeutic approach, gene therapy seeks to modify or replace defective genes to restore normal cellular function, positioning itself as a revolutionary alternative to traditional treatments such as chemotherapy and radiation therapy. Over the past decade, research and clinical trials in gene therapy have expanded significantly, demonstrating promising outcomes in precision medicine and targeted treatment strategies. However, despite these scientific advancements, there is a notable gap in understanding the subjective experiences of patients undergoing gene therapy, particularly their psychological and emotional responses to this novel treatment. This gap raises critical questions about how patients navigate the emotional complexities and ethical dilemmas associated with gene therapy, an area that remains underexplored in the existing literature.

Within this evolving landscape, the lived experience of patients undergoing gene therapy remains a crucial yet underexplored dimension. While much of the existing research has focused on

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the biological efficacy and clinical safety of gene therapy (Ahmed, 2020), there is a significant gap in understanding how patients emotionally and cognitively process this innovative treatment. Unlike conventional cancer treatments, gene therapy presents a unique paradigm where uncertainty, hope, and ethical considerations become deeply intertwined with medical decision-making. Patients navigating this therapy often experience a profound sense of ambiguity balancing optimism about cutting-edge interventions with the anxiety of unknown long-term effects. This interplay between scientific progress and subjective human experience underscores the need for a patient-centered exploration that transcends conventional clinical assessments.

Given the transformative nature of gene therapy, it is essential to explore how patients construct meaning from their treatment journey. The phenomenological approach provides a methodological framework to investigate these subjective dimensions, allowing for an in-depth examination of how individuals articulate their hopes, fears, and ethical dilemmas in the context of gene therapy. By prioritizing patient narratives, this study aims to capture the essence of lived experiences that are often overlooked in biomedical research, thereby enriching the discourse on the psychosocial implications of novel medical interventions.

The study of patient experiences in the context of advanced medical treatments has become an essential area of inquiry in healthcare research. As gene therapy continues to gain traction as a revolutionary approach to treating cancer, there is an increasing need to understand how patients navigate the psychological and emotional complexities of undergoing such an innovative yet uncertain treatment. Patient-centered research has emphasized the importance of subjective experiences in shaping treatment outcomes, highlighting that perceptions, beliefs, and emotions play a critical role in medical decision-making, therapy adherence, and overall well-being (Bunnik dkk., 2021). However, despite this recognition, the lived experience of patients undergoing gene therapy remains underexplored, particularly in relation to how they interpret hope and uncertainty throughout their treatment journey.

One of the major methodological challenges in understanding patient experiences in gene therapy lies in the limitations of conventional research approaches. Quantitative studies, while valuable in measuring treatment efficacy and clinical outcomes, often fail to capture the depth and complexity of personal experiences. Surveys and standardized psychological assessments may provide numerical data on anxiety levels or quality of life, but they rarely delve into the nuanced ways in which patients make sense of their medical journey. Similarly, biomedical studies primarily focus on the biological mechanisms and clinical effectiveness of gene therapy, overlooking the existential and emotional dimensions that shape patient perceptions and treatment experiences (Cannon dkk., 2021)

Given these limitations, existing research methods have struggled to provide a comprehensive and holistic understanding of the patient experience. The complexity of undergoing gene therapy extends beyond physiological responses to include questions of ethics, trust in medical innovation, and the meaning of hope amid uncertainty. A phenomenological approach, therefore, offers a means to bridge this gap by centering patient narratives and uncovering the deeper meanings embedded within their experiences. By focusing on how patients construct, interpret, and navigate their journey, this study aims to provide a richer, more nuanced perspective on the psychosocial implications of gene therapy.

Existing research on gene therapy for cancer has predominantly focused on its biomedical efficacy, clinical safety, and technological advancements. While these studies provide essential insights into treatment effectiveness, they often rely on quantitative assessments and clinical trials that prioritize biological responses over patient experiences (Grassi dkk., 2019). In clinical practice, patient support frameworks are primarily designed around standardized psychosocial interventions, such as counseling and informed consent protocols, which are intended to address emotional concerns. However, these interventions often adopt generalized psychological models that do not fully capture the unique and deeply personal dimensions of undergoing gene therapy.

Despite the recognition of hope, uncertainty, and ethical concerns as critical factors in patient well-being, previous research has struggled to offer a comprehensive understanding of how patients construct meaning from their experiences. The reliance on surveys, structured interviews, and psychological scales results in fragmented insights that fail to capture the fluid, evolving, and often contradictory nature of patient emotions. Additionally, bioethical discussions surrounding gene therapy frequently adopt theoretical or policy-driven perspectives, neglecting how patients themselves negotiate the moral and existential aspects of their treatment journey (Hajj, Hachem, Khoury, Hallit, dkk., 2021)

This knowledge gap underscores the need for an alternative approach that prioritizes patients' lived experiences and subjective interpretations. Phenomenology, as a qualitative research method, offers a holistic and interpretative lens to explore the essence of patient experiences, moving beyond surface-level observations to uncover the deeply rooted psychological, social, and existential dimensions of undergoing gene therapy. By centering patient narratives, this study seeks to fill the existing gap by providing a richer, more nuanced understanding of how individuals navigate hope, uncertainty, and ethical dilemmas in the context of an emerging medical technology.

Previous studies have explored patient experiences in various medical contexts, particularly in relation to chronic illness, end-of-life care, and experimental treatments. Research on gene therapy, however, has predominantly focused on its biological mechanisms and clinical outcomes, often neglecting the lived experiences of those undergoing the treatment (Hajj, Hachem, Khoury, Nehme, dkk., 2021) While some qualitative studies have examined the emotional and ethical implications of advanced medical interventions, few have specifically addressed how cancer patients undergoing gene therapy navigate hope, uncertainty, and ethical dilemmas in their treatment journey. The absence of a deep exploration into these subjective dimensions leaves a critical gap in understanding how patients interpret and give meaning to their experiences. By adopting a phenomenological approach, this study seeks to provide insights that extend beyond statistical or clinical perspectives, offering a more comprehensive view of patient well-being.

To address this gap, the study employs Interpretative Phenomenological Analysis (IPA), a qualitative method designed to explore how individuals make sense of their lived experiences. This approach allows for an in-depth examination of the psychological and existential dimensions of gene therapy, emphasizing the personal meanings that patients attach to their treatment. By analyzing narratives of hope, fear, and ethical concerns, the study aims to uncover the core themes that shape patient perspectives. The use of semi-structured interviews ensures that participants can articulate their thoughts in a flexible manner while maintaining a structured exploration of key topics. The findings contribute to a richer understanding of how patients psychologically and emotionally engage with an emerging medical technology.

This article is structured as follows: The Introduction presents the background and significance of the study, including an overview of gene therapy and its psychosocial implications. The Methods section outlines the research design, participant selection criteria, data collection process, and analysis techniques used in the study. The Results section presents the main themes derived from participant narratives, categorized to highlight key aspects of their experiences. The Discussion contextualizes these findings within existing literature, exploring their implications for patient-centered care and bioethics. Finally, the Conclusion summarizes the key contributions of the study and suggests directions for future research in the field of gene therapy and patient experience.

RESEARCH METHODS

Study Design

This study employs an interpretative phenomenological approach (IPA) to explore the subjective experiences of cancer patients undergoing gene therapy. Phenomenology, as a qualitative research methodology, is designed to uncover the lived experiences of individuals and the meanings they ascribe to a particular phenomenon (James & Joseph, 2022). Given the study's focus on how patients navigate hope and uncertainty in gene therapy, IPA is particularly suitable as it allows for an in-depth exploration of personal narratives and psychological insights.

The interpretative nature of this approach acknowledges that experiences are not only described by participants but also shaped by their socio-emotional contexts. This aligns with Heideggerian phenomenology, which emphasizes interpretation and the researcher's role in making sense of participant narratives. Through this design, the study aims to provide a nuanced understanding of how cancer patients construct and interpret their experiences of hope, fear, and ethical dilemmas in the context of gene therapy.

Participants

Participants were selected through purposive sampling, ensuring that they had firsthand experience with gene therapy for cancer. Eligibility criteria included individuals who:

1. Had been diagnosed with cancer and received gene therapy as part of their treatment plan.
2. Had undergone therapy for at least six months to allow sufficient time for reflection on their experience.
3. Were cognitively capable of articulating their experiences and willing to participate in in-depth interviews.

Exclusion criteria included individuals who were in critical condition and unable to provide informed consent or those experiencing cognitive impairment that could hinder narrative coherence. The final sample consisted of 15 participants, with ages ranging from 35 to 68 years (mean age: 51.4 years). The sample included both male and female patients, ensuring a diverse range of perspectives. Participants were recruited from specialized oncology and gene therapy treatment centers to capture experiences from individuals with varied cancer types and treatment responses.

Data Collection

Data were collected through semi-structured, in-depth interviews to allow participants to express their experiences in a flexible yet guided manner (Protiere dkk., 2020). An interview protocol was developed to explore themes related to hope, uncertainty, ethical considerations, and psychological adaptation to gene therapy. Open-ended questions encouraged participants to elaborate on their feelings, expectations, and coping mechanisms.

Interviews were conducted in a private and comfortable setting, either in-person at the hospital's patient support rooms or through secure online video calls for participants unable to travel. Each interview lasted between 45 to 90 minutes, depending on the depth of responses. With participant consent, all interviews were audio-recorded and transcribed verbatim. Reflexive notes were taken to capture non-verbal cues and contextual details.

To enhance the credibility and depth of the data, follow-up interviews were conducted with five participants to clarify themes emerging from initial analyses. The iterative nature of data collection ensured that the study remained responsive to emerging insights.

Data Analysis

Data were analyzed using the Interpretative Phenomenological Analysis (IPA) framework, which involves a systematic, multi-step process to uncover patterns of meaning within participant narratives. The analysis followed these stages:

1. Familiarization with Data – Transcripts were read multiple times to gain an in-depth understanding of participant experiences.
2. Initial Coding and Meaning Unit Identification – Key phrases and expressions that encapsulated significant experiences were highlighted.
3. Theme Development – Identified meaning units were grouped into preliminary themes, focusing on shared experiences of hope, uncertainty, and ethical dilemmas.
4. Interpretation and Thematic Refinement – Themes were refined by identifying deeper connections and patterns across participant narratives.
5. Finalization of Core Themes – Thematic structures were validated through discussion with an external qualitative research expert to ensure consistency and minimize researcher bias. To ensure depth, we also performed member checks with participants,

validating the themes with them in follow-up interviews to ensure their narratives were accurately reflected.

Data were managed and coded using NVivo software to facilitate organization and retrieval of emergent themes. The interpretative nature of IPA ensured that findings not only reflected participants' direct experiences but also provided deeper insights into their personal and emotional responses to gene therapy.

Ethical Considerations

Ethical approval for this study was obtained from the Institutional Research Ethics Committee, ensuring compliance with ethical guidelines for research involving human participants. Written informed consent was obtained from all participants before data collection, emphasizing their right to withdraw at any stage without consequences.

To maintain confidentiality, pseudonyms were assigned to participants, and identifying details were removed from transcripts. All data were stored in encrypted digital files, accessible only to authorized researchers. The study adhered to the ethical principles outlined in the Declaration of Lindgren dkk. (2019), ensuring that participants were treated with respect, dignity, and care throughout the research process.

RESULTS

Navigating the Uncertainty of Gene Therapy

The experience of uncertainty was a dominant theme among participants who underwent gene therapy for cancer treatment. Many patients expressed a duality of emotions—hope and anxiety—while navigating the unknown outcomes of the therapy. The uncertainty was primarily linked to the novelty of the treatment, the potential for long-term efficacy, and the fear of unexpected side effects.

One participant shared their concern:

"Every day, I ask myself—what if it doesn't work? I trust my doctors, but this is something completely new. There's no one I can talk to who has been through this before." (P3)

Another patient emphasized the emotional toll of uncertainty, stating:

"It's a strange feeling to have hope in something that even the doctors are still trying to fully understand. I want to believe in this therapy, but there's always this voice in my head reminding me that it might not work." (P7)

One participant, P2, further expressed this anxiety, stating:

"It's the unknown that gets to me the most. Every day, I wonder if I'm making the right choice. I'm scared of the side effects, and I'm scared of what might happen if it doesn't work. But there's no turning back once you start."

Family members also played a significant role in managing this uncertainty, often acting as a source of emotional support. However, they too experienced anxiety, as reflected in one caregiver's statement:

"We try to be strong for them, but in reality, we are just as scared. The uncertainty makes it difficult to plan anything." (P12)

Figure 1. How to navigate the uncertainty of gene therapy for cancer?.

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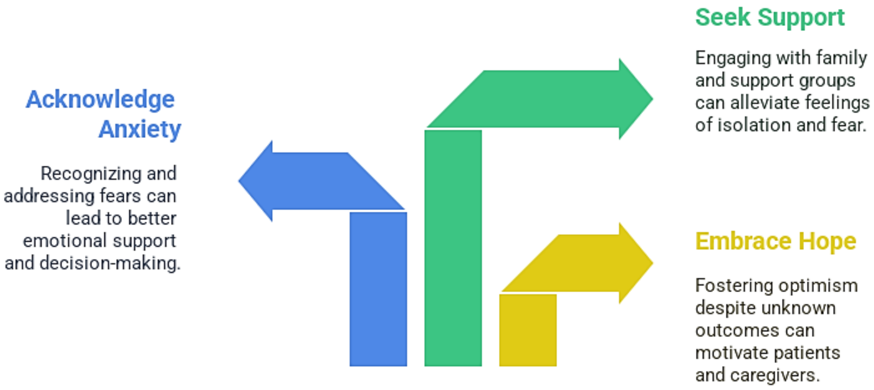


The Psychological Burden of Waiting

Patients described the waiting period—both before and after receiving gene therapy—as one of the most emotionally challenging aspects of the treatment. This waiting period involved pre-therapy assessments, eligibility screenings, and post-treatment monitoring, all of which contributed to heightened stress levels.

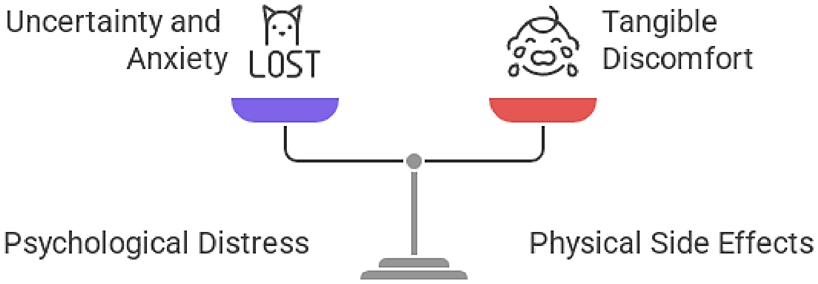
A participant reflected on this emotional burden:

"The waiting was the worst part. It felt like time had stopped, yet I was still moving through it, carrying this invisible weight of 'what ifs'." (P4)

For some, the psychological distress of waiting was more difficult to endure than the physical side effects of the therapy itself. One patient explained:

"When you feel sick, at least you know what’s happening to your body. But when you're just waiting—waiting for test results, waiting for your body to respond—it’s like you are trapped in a void." (P9)

Figure 2. Balancing Emotional and Physical Challenges in Gene Therapy



Reconceptualizing Hope through Gene Therapy

Hope emerged as a complex and evolving experience for participants. At the beginning of their treatment journey, hope was often grounded in scientific advancements and the possibility of remission. However, as they progressed through therapy, hope became more nuanced—shifting from a focus on cure to an appreciation of extended quality of life.

One participant described this shift:

"At first, I hoped for a complete cure. Now, I just hope for more good days than bad ones, for time to spend with my family, for small victories." (P6)

For others, hope was deeply tied to spirituality and faith. A patient reflected:

"This therapy gave me hope not just in medicine, but in something greater. It made me believe that science and faith can coexist." (P10)

Figure 3. Evolution of Hope in Gene Therapy Patients

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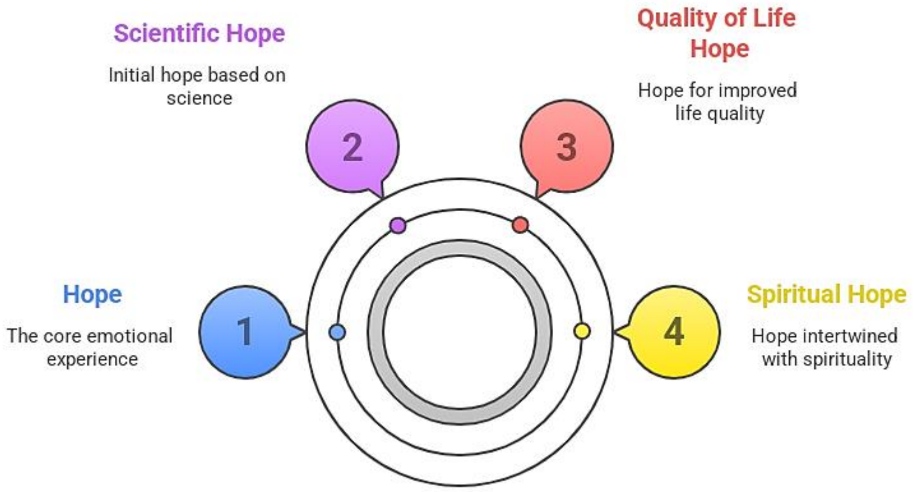

Ethical Dilemmas and the Burden of Informed Consent

Several participants voiced concerns over the ethical complexities surrounding gene therapy, particularly regarding the informed consent process. Some patients felt they were not fully aware of the potential risks due to the medical jargon used in explanations. Others expressed feeling pressured to participate in the therapy due to a lack of viable alternatives.

One participant shared:

"I signed the papers because I felt like I had no choice. When you're faced with death, you don't really read the fine print. You just say yes and hope for the best." (P2)

Another patient highlighted the difficulty of making an informed decision:

"They explained everything, but honestly, I didn't understand half of it. I just nodded and trusted them." (P8)

This theme underscores the need for a more patient-centered approach to ethical discussions surrounding experimental therapies.

The collective narratives of participants suggest that undergoing gene therapy for cancer is an emotionally layered experience characterized by uncertainty, psychological burden, evolving hope, and ethical concerns. The findings emphasize the importance of providing holistic support systems for patients—addressing not only the medical aspects of the therapy but also the psychosocial and ethical dimensions. These results will be further examined in the Discussion section, where they will be analyzed within the broader context of psychological resilience, bioethics, and the role of medical communication in shaping patient experiences.**DISCUSSION**

Summary of Main Findings

This study explored the subjective experiences of cancer patients undergoing gene therapy, focusing on their feelings of hope, uncertainty, and ethical concerns (Pratumkaew dkk., 2021). The analysis revealed that while patients displayed initial optimism about the potential of gene therapy, they also experienced deep uncertainty, particularly about the long-term effectiveness and possible side effects. These emotional complexities were further exacerbated by ethical dilemmas surrounding the treatment, highlighting the need for a deeper understanding of the psychological aspects of gene therapy beyond clinical outcomes.

Contribution to the Research Question

The findings contribute to answering the research question regarding how cancer patients experience hope and uncertainty during gene therapy. The study provides a nuanced understanding of how these patients navigate the tension between hope for a cure and the uncertainty of treatment outcomes. Patients expressed hope, initially driven by the promise of gene therapy, but this hope evolved over time as they confronted the realities of the therapy's risks and unknowns. The ethical concerns surrounding participation in an experimental treatment were another key aspect of their experience, suggesting that the patients' emotional responses were not solely shaped by medical factors but were also influenced by their moral reflections and perceived autonomy in making decisions about their health. This holistic view of patient experiences underscores the complexity of integrating gene therapy into clinical care and highlights the importance of addressing emotional and ethical dimensions in treatment planning.

Relation to Literature and Previous Theories

The findings align with and expand upon existing research on patient experiences with experimental treatments. Previous studies (Liskova dkk., 2020) have highlighted the psychological impact of undergoing novel therapies, showing that hope is often accompanied by significant anxiety and uncertainty. However, this study goes beyond previous work by incorporating the ethical dimensions of gene therapy, an area that has received limited attention in the context of patient experiences. The results also resonate with the concept of uncertainty as discussed by Matrana & Campbell,(2020), where patients undergoing new treatments often experience an ambivalent sense of hope. This study adds depth to that conversation by demonstrating how patients' sense of hope evolves from a simplistic belief in a cure to a more complex, existential understanding of what it means to live with an uncertain future. Furthermore, the integration of bioethical considerations aligns with the work of Mehta dkk.,(2020), who highlighted how ethical challenges in medical decision-making can deeply influence patients' psychological well-being. The findings suggest that the patients' experiences cannot be fully understood without considering these ethical concerns, making it essential to explore not only the biological efficacy of gene therapy but also the ethical and emotional dimensions that shape patient outcomes.

Implications of Findings

The findings of this study provide significant insights into the complex emotional and ethical experiences of cancer patients undergoing gene therapy. The study emphasizes that addressing hope and uncertainty is essential for improving patient care in gene therapy. Healthcare providers should integrate psychological support into the treatment process, ensuring that patients feel heard and understood in their emotional and ethical concerns. The study highlights that healthcare professionals must recognize the emotional burden of uncertainty and the evolving nature of hope in treatment decision-making. By enhancing communication strategies, such as providing more comprehensive explanations about the potential risks and benefits of gene therapy, healthcare providers can improve informed consent processes and reduce patient anxiety.

Furthermore, this study contributes to the broader discourse on bioethics and patient autonomy, illustrating how patients actively engage with complex medical treatments, particularly those involving high levels of uncertainty. The results suggest a need for healthcare policies that emphasize the ethical dimensions of treatment options, ensuring that patients are fully informed, feel supported in their decision-making, and are not coerced into experimental therapies due to a lack of alternatives. In a cultural context, these findings highlight the importance of providing culturally sensitive care, as ethical concerns and emotional responses may vary significantly across different socio-cultural backgrounds. Policy frameworks in healthcare systems should be adapted to include cultural considerations in the provision of care, ensuring that diverse patient populations are supported in ways that align with their values and beliefs.

Limitations of the Study

While the findings of this study offer valuable insights, several limitations must be acknowledged. First, the sample size was relatively small, consisting of 15 participants, which may limit the generalizability of the results to a broader population. Additionally, the study focused on a specific group of patients—those undergoing gene therapy for cancer—meaning that the experiences captured here may not be directly applicable to patients undergoing other types of advanced treatments or those from different healthcare systems (Oberkampf dkk., 2023). The qualitative nature of the research also means that the findings are deeply contextual and may not be replicated in different cultural or institutional settings. Moreover, while the use of semi-structured interviews allowed for rich, detailed responses, it may have introduced some interview bias, as participants' perceptions could have been shaped by their understanding of the interviewer's expectations. Finally, the study's reliance on self-reported data means that participants' responses may reflect social desirability bias or selective memory, further limiting the scope of interpretation. Future research could expand on this study by incorporating longitudinal data, exploring how patients' experiences evolve over time, and using larger, more diverse samples to enhance the transferability of the findings.

Prospective Statement for Future Research

Building upon the findings of this study, future research could explore how the emotional and ethical challenges observed in this context extend to other forms of personalized medicine or experimental treatments. Expanding the research to include a more diverse range of patients—such as those with chronic conditions undergoing gene therapy, or individuals from different socio-cultural backgrounds—could provide a broader understanding of how hope and uncertainty are experienced across various populations. Additionally, exploring the role of family dynamics and caregiver experiences in supporting patients through experimental treatments could further enrich our understanding of the interpersonal aspects of gene therapy. Finally, longitudinal studies that track the evolving emotional and ethical perspectives of patients over time would be valuable in understanding how long-term outcomes—both medical and psychological—shape patient experiences. By broadening the scope and incorporating additional dimensions, this research can contribute to the development of more comprehensive care models that account for both the clinical and psychosocial needs of patients undergoing cutting-edge medical treatments.

CONCLUSION

This study explored the subjective experiences of cancer patients undergoing gene therapy, focusing on their emotional and ethical responses. The research revealed that while patients initially experienced hope for a cure, they were also confronted by significant uncertainty and ethical dilemmas about participating in experimental treatments. These findings address a critical gap in existing literature, offering a deeper understanding of how hope, uncertainty, and ethical concerns shape the patient experience in the context of novel medical technologies. Based on these insights, healthcare providers should adapt their care models to incorporate a more comprehensive, patient-centered approach that addresses not only the clinical aspects of treatment but also the emotional and ethical dimensions. By integrating psychosocial support into the care process, such as providing counseling services, addressing patients' concerns about the potential risks and benefits of gene therapy, and facilitating informed decision-making, healthcare providers can improve the overall well-being of patients undergoing gene therapy.

The findings suggest that healthcare professionals need to be proactive in discussing the uncertainties and ethical implications of gene therapy with patients, ensuring that they feel supported throughout the treatment journey. This can include creating opportunities for patients to express their concerns and exploring the moral aspects of their treatment options. Furthermore, the study emphasizes the importance of ensuring that informed consent processes are clear, comprehensive, and empathetic, allowing patients to make fully informed decisions about their participation. Incorporating these considerations into clinical care models can help mitigate patient anxiety, enhance trust in the healthcare system, and improve therapeutic outcomes. The findings contribute to the broader conversation on bioethics and patient autonomy, offering new perspectives for improving patient care. Future research could expand on these findings by exploring the long-term emotional trajectories of patients and incorporating a more diverse sample to enhance the generalizability of the results.

CONFLICT OF INTEREST

The authors declare that there is no conflict of interest regarding the publication of this article. No financial or personal relationships have influenced the research process or outcomes presented in this study.

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