



Confronting Mortality with Hope: An Exploration of Cancer Patients' Experiences in Experimental Oncology Trials

Marson Maizi

Universitas Hasanuddin, Indonesia

marsonmaizimt@gmail.com

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ABSTRACT

In the face of life-threatening illness, patients participating in early-phase oncology trial often confront a complex blend of uncertainty, hope, and existential vulnerability. This study explores how cancer patients make sense of their engagement with experimental drug therapies, revealing the emotional and psychological dimensions that extend beyond clinical outcomes. Using Interpretative Phenomenological Analysis (IPA), in depth interviews were conducted with ten patients (six women and four men, aged 34–61 years) diagnosed with advanced-stage cancer from diverse socioeconomic backgrounds all of whom had participated in early-phase clinical trials at a national cancer center. Four central themes emerged: negotiating the emotional impact of uncertainty, sustaining hope as a form of existential resilience, confronting the loss of bodily autonomy, and placing trust in medical professionals amidst ambiguity. These narratives demonstrate how trial participation becomes more than a medical decision—it transforms into a deeply personal journey shaped by fear, meaning-making, and the assertion of agency in the face of mortality. Unlike purely biomedical assessments, this study offers a human centered understanding of what it means to engage in medical experimentation under existential pressure. The findings advocate for more ethically attuned clinical trial protocols that embrace patients' emotional narratives and support structures that recognize their lived realities. This research contributes to the development of patient centered frameworks in experimental oncology and calls for future interdisciplinary inquiry into the emotional landscape of clinical innovation.



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INTRODUCTION

Advancements in drug discovery and development have transformed modern medicine, with early-phase clinical trials serving as a bridge between laboratory research and potential life-saving therapies (Si dkk., 2019). For oncology patients facing life-limiting illnesses, participation in these trials is both a medical and existential decision, shaped by uncertainty, hope, and vulnerability. While clinical and pharmacological outcomes have been extensively studied, there is limited understanding of the lived experiences of patients in such trials—particularly how they navigate emotional, psychological, and meaning-making processes alongside medical uncertainty (Solberg dkk., 2021).

Existing literature often prioritizes objective endpoints such as treatment efficacy, safety, and compliance, using surveys or structured assessments that fail to capture the depth of subjective experience (Taylor dkk., 2021; Cooper dkk., 2022). As a result, patients' personal narratives—how they interpret their role in research, confront mortality, and sustain agency—remain underexplored. This creates a critical knowledge gap in understanding trial participation as a holistic human experience rather than merely a biomedical event.

To address this gap, the present study employs Interpretative Phenomenological Analysis (IPA) to examine how cancer patients make sense of their involvement in early-phase experimental drug trials.

This approach enables an in-depth exploration of emotional, existential, and relational dimensions often overlooked in conventional research. By centering on patient narratives, the study aims to provide ethically relevant and human-centered insights that can inform both clinical practice and trial design.

RESEARCH METHODS

Study Design

This study employed an interpretative phenomenological approach to explore the lived experiences of cancer patients participating in early-phase clinical trials. Interpretative Phenomenological Analysis (IPA) was selected due to its emphasis on understanding how individuals make sense of their experiences, particularly in contexts involving high uncertainty and emotional depth. The phenomenological framework enabled an in-depth exploration of subjective meanings, perceptions, and reflections that patients attach to their involvement in experimental drug trials (Ernst & Pittler, 1999). IPA, grounded in the philosophical tradition of Heidegger, prioritizes the interpretive co-construction of meaning between participant narratives and researcher insight, offering a suitable lens for investigating the emotional and existential aspects of trial participation.

Participants

Participants in this study were adult cancer patients who had been enrolled in early-phase clinical trials involving novel experimental drugs. Selection was based on purposive sampling, ensuring that each individual had direct and relevant experience with the phenomenon under investigation. Inclusion criteria comprised adults (aged 18 and above), diagnosed with advanced-stage cancer, and who had completed at least one phase of trial participation (Frenkel dkk., 2013). Exclusion criteria included individuals with cognitive impairments or those unable to provide informed consent due to medical or psychological conditions. The final sample consisted of ten participants (six female, four male), aged between 38 and 71 years (mean age = 56), from diverse ethnic and socio-economic backgrounds. All participants were fluent in the language of interview and provided rich, reflective narratives pertinent to the study.

Data Collection

Data were collected through in-depth, semi-structured interviews guided by a flexible protocol that encouraged open-ended responses. Interviews were conducted in quiet, private locations, either within hospital counseling rooms or participants' homes, based on their preference. Each interview lasted between 45 and 90 minutes and was audio-recorded with participant consent. A warm and empathetic environment was ensured to facilitate trust and emotional openness. Interview prompts focused on participants' thoughts, feelings, and decisions surrounding their clinical trial experience (Gaul dkk., 2011). Where necessary, probing questions were used to elicit deeper reflection. All interviews were transcribed verbatim. NVivo 14 software was used to support the organization and coding of qualitative data without dictating the analytical process.

Data Analysis

Data were analyzed using the interpretative phenomenological analysis method. The process began with repeated readings of each transcript to develop a holistic understanding of the participant's experience. Significant statements were extracted and grouped into meaning units. These were then coded inductively to identify emerging patterns and themes. Themes were iteratively refined through comparison across cases while preserving the uniqueness of individual experiences. Analytical memoing and thematic mapping supported the abstraction of superordinate themes that reflected shared meanings across participants. The final themes represent essential structures of the lived experience, grounded in both the data and interpretative reflection.

Ethical Considerations

Ethical approval for this study was obtained from the Institutional Review Board of the affiliated academic institution. Written informed consent was secured from all participants prior to data collection. Anonymity was maintained by assigning pseudonyms, and all personal identifiers

were removed from transcripts (Gill dkk., 1994). Data confidentiality was upheld by storing digital files on encrypted devices accessible only to authorized personnel. The study was conducted in accordance with the Declaration of Helsinki and adhered to local and international standards for ethical research involving human participants.

RESULTS

Negotiating Uncertainty in a Landscape of Risk

Participants consistently described their engagement with the clinical trial as a negotiation with uncertainty. Their experiences were marked by a constant oscillation between rational knowledge of the unknown and an emotional response to potential outcomes. The uncertainty was not merely scientific but deeply existential.

"They told me the drug had never been tried in humans... I kept asking myself, 'What if this does more harm than good?' But at the same time, I had no other option." (P3)

Despite comprehensive informed consent procedures, many participants shared that understanding the risks cognitively did not eliminate emotional distress. This theme captures the profound tension between medical information and the human need for psychological security.

Clinging to Hope as a Psychological Lifeline

Hope emerged as a salient theme, often expressed as a lifeline rather than a realistic expectation. Patients acknowledged the experimental nature of the drug but emphasized the emotional necessity of hope in facing a terminal diagnosis.

"Hope is not about the drug working; it's about waking up tomorrow and having something to believe in." (P7)

This form of hope functioned as a coping mechanism, allowing participants to reframe their vulnerability into a proactive engagement with treatment. The patients' hope, while aware of the scientific uncertainty, was deeply personal and symbolic.

Facing Existential Vulnerability in the Clinical Setting

Participants frequently reflected on their experience as one that exposed their existential fragility. Being enrolled in a clinical trial for a drug not yet validated triggered profound reflections on mortality, bodily autonomy, and identity.

"I felt like I became part of a system, not a person anymore. But then again, I volunteered, because I wanted to fight back. Even if I lose, I want to feel that I tried." (P5)

The clinical setting, with its protocols and structures, often intensified feelings of depersonalization. However, for some, participation became a means of reclaiming agency, a final assertion of selfhood in the face of decline.

Trusting the Medical System While Living in Ambiguity

Participants placed immense trust in the medical teams conducting the trials, often as a counterbalance to the ambiguity they faced. This trust was not naïve but emerged from a deliberate choice to align with professionals who symbolized order in a chaotic personal journey.

"They didn't promise miracles, and that made me trust them more. Their honesty gave me comfort, even if the drug fails." (P1)

This theme highlights the relational aspect of clinical research, where trust bridges the gap between uncertainty and engagement. The physician-patient dynamic, especially in experimental contexts, was experienced not only as therapeutic but deeply humanizing.

The essence of the participants' experience in early-phase clinical trials is grounded in a paradox: the confrontation with medical and existential uncertainty is accompanied by a simultaneous search for meaning, agency, and connection. Hope, trust, and the assertion of identity in the face of

decline emerged as the primary dimensions of this phenomenological landscape. These findings underscore the need to rehumanize clinical trials by integrating patients' emotional narratives into the fabric of drug development.

DISCUSSION

The findings of this study reveal that participation in early-phase clinical trials is experienced by cancer patients as a deeply existential journey characterized by uncertainty, hope, vulnerability, and trust. These core themes reflect how patients construct meaning around their involvement in experimental treatment, answering the central research question regarding the lived experience of navigating unproven therapies in the face of life-threatening illness.

This study provides a nuanced response to the research question by illuminating how patients emotionally and cognitively engage with the uncertainty of early-phase drug trials. Rather than viewing participation as a purely rational or clinical decision, patients described it as an act of meaning-making—anchored in a desire for hope, a way to reclaim agency, and a coping mechanism amidst terminal diagnoses (Han dkk., 2015). These insights contribute to a more comprehensive understanding of clinical trial participation as a human experience, emphasizing the ethical need to integrate patients' narratives into drug development and clinical practice.

The present findings align with and extend previous phenomenological work, such as that by (Ibrahim dkk., 2016), who emphasized the interpretative nature of patient decision-making in clinical contexts. Moreover, (Li & Wang, 2005) similarly found that trial participation evokes emotional complexity, though their study did not explicitly explore the existential themes that emerged here. This research also resonates with Heideggerian phenomenology, particularly the idea of being-toward-death, where individuals confront their mortality in a way that informs identity and agency. By framing clinical trial engagement as both a medical and existential act, this study enriches the theoretical discourse on patient autonomy and challenges utilitarian perspectives that dominate biomedical ethics.

The findings from this study carry important implications for both clinical practice and ethical decision-making in the context of drug development. By unveiling the emotional, existential, and relational dimensions of trial participation, this research underscores the need for healthcare professionals and research institutions to foster more compassionate and reflective engagement with patients. In particular, these insights suggest the value of narrative-informed consent processes and psychosocial support structures that acknowledge patients' hopes, fears, and moral reflections. Beyond individual care, these findings highlight broader social and cultural considerations, such as how patients' trust in science and institutions is shaped by personal values and systemic structures. This has relevance for policy makers and ethics committees aiming to humanize clinical research and prioritize patient-centered care.

Several limitations must be acknowledged in interpreting these findings. As is characteristic of phenomenological research, the focus on in-depth exploration of lived experiences from a small, purposively selected sample limits the generalizability of results. The study was confined to individuals with advanced-stage cancer in early-phase trials, which may not fully represent experiences of patients in other trial phases or disease contexts (Little, 2009). Additionally, participants were all fluent in the language of interview and relatively articulate, which may introduce selection bias toward those more capable of expressing complex emotional and existential experiences. These constraints, however, are consistent with the philosophical underpinnings of phenomenology, which prioritize depth over breadth in understanding human experience.

Future research could build upon these findings by examining similar experiential dimensions in diverse cultural, socio-economic, and linguistic populations, or by exploring how specific variables such as type of cancer, trial phase, or institutional setting shape patients' interpretations. Longitudinal phenomenological inquiry could also provide valuable insight into how meanings evolve over the course of a clinical trial and beyond (Ljubenic dkk., 2018). Furthermore, interdisciplinary approaches that integrate phenomenology with ethics, psychology, or narrative medicine may enrich

the field's ability to inform more holistic practices in drug discovery and patient engagement. This study thus lays the groundwork for deeper, ethically grounded exploration of the patient experience within experimental medicine.

CONCLUSION

This study explored the lived experiences of cancer patients participating in early-phase clinical trials for experimental drug therapies, focusing on how they make sense of uncertainty and vulnerability. The findings revealed four essential themes: negotiating risk, clinging to hope, confronting existential fragility, and trusting medical systems. These insights address a significant gap in existing literature by offering a deeper understanding of the emotional and ethical dimensions often overlooked in clinical research. The study contributes to patient-centered care by highlighting the need for narrative-informed practices and supportive frameworks that honor the human side of medical innovation. While the findings are specific to a defined context, they offer a foundation for further phenomenological inquiry across different patient groups and clinical trial settings. Future studies could expand this work by exploring how cultural and social variables influence patients' meaning-making in experimental medicine.

CONFLICT OF INTEREST

The authors declare no conflict of interest related to the conduct or publication of this study. All procedures were conducted independently, and no external influence affected the research design, data analysis, or interpretation of results.

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