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Clinical Experience of Patients in Participating in Medical Research: A Phenomenological Exploration of Emotional Dimensions in the Process, Benefits, and Challenges of Clinical-Based Medical Research

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ABSTRACT

In recent years, the integration of digital health technologies in healthcare systems has emerged as a critical area of research, particularly in understanding the experiences of both healthcare practitioners and patients. Despite significant advancements in telemedicine and digital health platforms, the subjective experiences and underlying meanings of these technologies remain underexplored. This study addresses the gap by investigating the lived experiences of healthcare practitioners and patients in using telemedicine platforms for healthcare communication. Using a phenomenological approach, we explore how these individuals interpret and engage with digital health tools in their daily practices. Data were collected through in-depth interviews with 25 participants, including healthcare professionals and patients, and analyzed thematically to identify core themes. The findings emphasize key themes such as emotional challenges faced by patients during remote consultations, concerns about the lack of personal connection, and the anxiety stemming from technological barriers. Simultaneously, positive themes such as improved accessibility and convenience were also identified. These insights offer valuable implications for improving user-centered design in telemedicine systems and inform future research on digital health adoption in various healthcare contexts.

INTRODUCTION

Clinical medical research plays a crucial role in advancing medical knowledge and developing new treatments (Bacigalupe dkk., 2020). It involves patients participating in clinical trials where they are exposed to experimental therapies or interventions with the aim of assessing their safety, efficacy, and potential benefits. These trials are essential in the development of new medications, devices, and treatment protocols, yet the experiences of patients who participate in such research remain an underexplored aspect of the clinical research process While clinical trials are often framed within scientific contexts, patients' subjective experiences—such as perceptions, emotions, and sense of involvement—are critical to understanding the broader impact of these trials.

One key factor influencing patient participation in clinical trials is the increasing use of advanced medical technologies and treatments, such as personalized medicine and experimental therapies (Ciaccio dkk., 2021). These innovations, though promising, come with uncertainties regarding their safety and effectiveness, which may contribute to patients' hesitations or anxieties. For example, patients may feel apprehensive about the unknown risks associated with new treatments, especially when the potential long-term effects are unclear. Additionally, the informed consent process, although necessary, can sometimes overwhelm patients due to its complexity, leaving them uncertain about the exact nature of the research and their role in it.

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Previous studies have largely focused on the practical or medical outcomes of clinical trials, such as the success rate of interventions or the statistical analysis of results (Concannon dkk., 2024). However, few studies have delved into the lived experiences of patients, focusing on their subjective perceptions and emotional responses. Phenomenological approaches, which emphasize the exploration of lived experiences, offer a unique opportunity to gain insights into how patients understand and interpret their participation in clinical research. This perspective recognizes that the meaning patients attach to their involvement significantly influences their decisions to participate, engagement during the process, and overall satisfaction.

Given these considerations, this study aims to explore the subjective experiences of patients involved in clinical trials (de Moura dkk., 2020). By focusing on the emotional, cognitive, and social dimensions of their participation, the research seeks to shed light on the underlying factors that shape patient engagement in clinical research. This approach aligns with the increasing demand for patient-centered research, where understanding the human experience becomes as important as the scientific outcomes.

Research into the lived experiences of individuals involved in specific phenomena, such as clinical trials, has become a critical area within both medical and psychological research (Haeyen & Dimaggio, 2024). Understanding how participants experience clinical research—particularly their perceptions of risks, benefits, and emotional responses—is vital for improving patient engagement, satisfaction, and the overall efficacy of clinical trials. In the context of medical research, the subjective experiences of patients often shape their willingness to participate, their adherence to study protocols, and their overall outlook on the potential outcomes. This makes it essential to gain deeper insights into how patients perceive their role in clinical trials and how these experiences impact their participation and decision-making.

However, exploring such subjective experiences presents significant methodological challenges. Quantitative approaches, which focus on numerical data and statistical analysis, are limited in capturing the depth and complexity of human experience (Li dkk., 2022). While they can provide valuable insights into trends and patterns, they often fail to address the personal, emotional, and social aspects of patient involvement in clinical research. Furthermore, traditional survey methods may overlook the nuanced ways in which patients process and interpret their participation in clinical trials, such as the internal conflicts they may feel between the potential benefits of a new treatment and the uncertainties or risks associated with it.

The limitations of these methods underscore the need for qualitative approaches, particularly phenomenology, which is designed to uncover the essence of human experiences through in-depth exploration. By focusing on individuals' lived experiences, phenomenological research offers a more holistic understanding of how participants make sense of their involvement in clinical trials. This approach allows researchers to capture not only the cognitive aspects of decision-making but also the emotional and social dimensions that may influence patients' perceptions and actions during their participation.

Despite the growing recognition of the importance of understanding patients' subjective experiences, the field of phenomenological research in clinical trials remains underdeveloped. While some studies have explored the experiences of patients in healthcare settings, few have concentrated specifically on clinical trials and the rich, layered meanings that patients attach to their participation.

This highlights the need for research that delves deeper into the emotional and cognitive dimensions of clinical trial participation, addressing gaps in existing literature and offering actionable insights for patient-centered research. Therefore, there is a clear need for research that delves deeper into the lived experiences of clinical trial participants, highlighting the complexities and emotional nuances that influence their involvement in medical research.

While much of the existing research on clinical trials and patient participation relies on practical approaches, such as quantitative surveys and outcome-based studies, these methods have inherent limitations in capturing the rich, subjective experiences of participants. Quantitative approaches often focus on measurable outcomes, such as treatment efficacy or side effects, and fail to

explore the deeper emotional, cognitive, and social aspects of a patient's experience. While such data are valuable for assessing the success of clinical trials from a medical or statistical perspective, they do not provide a holistic understanding of how patients perceive their involvement in clinical research, how they process their emotions, or how their participation aligns with their personal values and expectations.

This gap in understanding has led to an incomplete picture of the patient experience in clinical trials. Traditional methods tend to overlook the complexity of patients' perceptions, fears, and motivations. For example, patients may feel conflicted about their participation, weighing the potential for personal benefit against the uncertainty of experimental treatments. Such nuanced experiences are difficult to quantify but are essential for understanding the human side of clinical research. This is where phenomenology offers a more suitable alternative. Phenomenology, with its focus on exploring lived experiences and the meanings individuals attach to them, allows for a deeper, more holistic examination of the patient's perspective. By prioritizing the subjective experience, phenomenology can uncover insights that quantitative methods are ill-equipped to reveal.

Adopting a phenomenological approach to studying the experiences of clinical trial participants can provide a richer understanding of the factors that influence their decision to participate, how they engage with the process, and how they interpret the outcomes. It allows researchers to explore the essence of patient involvement, capturing not just the "what" of their experience, but the "how" and "why"—the underlying emotional and cognitive processes that shape their perceptions and actions. This shift toward phenomenology is crucial for developing more patient-centered clinical research practices and improving the overall experience of those involved in medical trials.

Research into the experiences of patients participating in clinical trials has highlighted the importance of understanding the subjective aspects of their involvement. Several studies have explored the cognitive and emotional factors that influence patient decision-making, often focusing on perceptions of risk, benefit, and trust in medical professionals. However, many of these studies rely on quantitative data, which cannot fully capture the depth of the lived experiences of participants. Theories such as the Health Belief Model and the Theory of Planned Behavior provide insights into how patients weigh risks and benefits, yet they do not fully address the emotional and psychological nuances of participation. Previous research, therefore, points to the need for a more qualitative and phenomenological approach to uncover the underlying meanings that patients attach to their participation in clinical trials.

In response to these limitations, the study adopts a phenomenological approach, which is particularly well-suited for exploring the lived experiences of individuals. By focusing on the personal, subjective experiences of patients, this methodology allows for a deeper understanding of how they perceive their involvement in clinical trials, how they make sense of potential risks and benefits, and the emotional dimensions of their participation. Phenomenology allows for a more holistic examination of the patient's perspective, moving beyond statistical outcomes to uncover the essence of the experience itself. This method is specifically chosen because it can capture the complexities and emotional layers of patients' experiences, which are often missed by traditional quantitative research.

The article is structured to first provide an introduction to the research context and the phenomenon under study. It then presents the phenomenological approach used, outlining the process of data collection through in-depth interviews with clinical trial participants and the thematic analysis that followed. The findings will be discussed in relation to the existing literature, followed by conclusions that highlight the implications of the study for clinical trial design and patient engagement. This approach allows for a comprehensive exploration of the patient experience, ensuring that the results reflect both the cognitive and emotional components of participation in clinical trials.

RESEARCH METHODS

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Study Design

This study employs a phenomenological research design to explore the subjective experiences of patients involved in clinical medical research (Liang dkk., 2021). Phenomenology is particularly suitable for this research because it focuses on understanding how individuals perceive and make sense of their lived experiences. By prioritizing participants' perspectives, this approach allows for an in-depth exploration of the meanings they attach to their involvement in clinical trials, including the benefits, challenges, and emotional responses they encounter.

Phenomenology is chosen as the guiding methodology to capture the essence of the participants' lived experiences, rather than to generalize or predict outcomes. The study is grounded in descriptive phenomenology, which seeks to provide a detailed description of the phenomenon as it is experienced by the participants, free from preconceived interpretations or theoretical assumptions. This approach allows for the extraction of rich, nuanced insights into the participants' thoughts, feelings, and perceptions about their involvement in clinical research.

Participants

The participants in this study were 15 patients who had either completed or were currently participating in clinical medical research across various hospitals and clinical research centers in Indonesia. A purposive sampling strategy was employed to select participants who had experienced medical research for at least six months and were able to provide insightful perspectives on their experiences.

Inclusion criteria were: (1) patients who had participated in clinical trials for over six months, (2) patients able to provide informed consent and articulate their experiences verbally, and (3) individuals willing to share personal reflections on the clinical research process. Exclusion criteria included: (1) patients who were unable to provide informed consent due to medical conditions or cognitive impairments, and (2) those who had participated in research for less than six months.

The sample included a diverse group of participants in terms of age, gender, and medical condition, which is essential for understanding the broad range of experiences encountered during clinical trials. A sample size of 15 participants was deemed sufficient for this phenomenological study, as it aligns with the methodological emphasis on depth rather than breadth of data. Phenomenological studies prioritize rich, detailed accounts over large-scale representation, and data saturation was reached when no new themes emerged during analysis. The participants were aged between 30 and 75 years, with a fairly even distribution between male and female participants. Most participants had a chronic condition for which they were seeking experimental treatments, and they were recruited from a variety of therapeutic areas including oncology, cardiology, and neurology.

While the sample was intentionally diverse, potential biases in participant selection were acknowledged. For instance, recruitment from specific hospitals and research centers may limit the generalizability of findings to broader clinical trial populations. Efforts were made to mitigate this by including participants from varied therapeutic areas and ensuring a balance in demographic factors such as age and gender. Additionally, the reliance on self-reported experiences may introduce recall bias, which was addressed by probing participants’ recent and specific memories during interviews.

Data Collection

Data were collected through semi-structured interviews and observational methods to capture both verbal and non-verbal aspects of participants' experiences (Mejia dkk., 2024). Interviews were conducted in person, with each session lasting between 45 to 90 minutes, depending on the participant's availability and willingness to share. Interviews were carried out in private rooms at the research hospitals and clinics to ensure a comfortable and confidential environment for the participants.

A semi-structured interview guide was used to direct the conversation, with open-ended questions designed to elicit detailed responses about the patients’ experiences, emotional reactions, and perceptions of the clinical trial process. The guide included questions such as, "Can you describe

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your feelings when you first heard about the clinical trial?" and "What concerns did you have, if any, about participating in the study?"

In addition to interviews, observations were conducted during the research visits to capture the dynamics between participants and research staff. Observational data helped contextualize the interview responses by providing insight into the interaction patterns and emotional states of participants in real-world clinical settings. All interviews were audio-recorded with the participants' consent and transcribed verbatim for subsequent analysis.

Data Analysis

The data were analyzed using thematic analysis, a widely used technique in phenomenological research. Thematic analysis involves identifying, analyzing, and reporting patterns (or themes) within the data. The analysis was conducted through a systematic process, beginning with the immersion in the data by reading and re-reading the transcripts.

The next step involved coding the data, where key phrases and sentences that reflected the participants' lived experiences were highlighted and categorized. Following the initial coding, patterns and themes were identified across the data set. Each theme was then analyzed to uncover its meaning and relevance to the research question. The analysis was performed manually, with the assistance of qualitative data analysis software (NVivo) to facilitate the organization of codes and themes.

Data saturation was achieved when no new themes emerged during the later interviews, indicating that sufficient data had been collected to address the research question.

Ethics

Ethical approval for this study was obtained from the relevant ethics committee at each participating institution. Informed consent was acquired from all participants prior to their involvement in the research. The consent process ensured that participants were fully aware of the study’s objectives, procedures, potential risks, and their right to withdraw at any time without penalty.

All participants were assured of the confidentiality of their responses, and any identifiable information was anonymized to protect their privacy. The data were securely stored and only accessible to authorized personnel. This study adhered to international ethical standards for research involving human participants, ensuring that participants' rights, well-being, and dignity were safeguarded throughout the research process.

RESULTS

Confusion and Uncertainty About the Research Process

One of the primary themes emerging from the data is the confusion and uncertainty that patients often experience regarding the clinical research process. Many patients expressed difficulty in understanding the research protocols and the specific role they were expected to play in the study. This lack of clarity led to feelings of anxiety and hesitance about their participation.

For instance, one patient a 45-year-old male,shared, "At first, I didn’t really understand what was happening. They gave me some papers to sign, but I still wasn’t sure about what I was signing up for. The doctors explained it, but it still felt confusing." Another participant a 62-year-old female, noted, "There were many things I didn’t know about, like the risks involved. I didn’t fully grasp what I was getting myself into."

This uncertainty was exacerbated by the complex medical terminology used by researchers, which contributed to a sense of alienation among the participants. Many patients reported feeling overwhelmed by the technical language used during the consent process and in the communication with research staff.

Anxiety About Potential Side Effects and Risks

Anxiety regarding the potential side effects of experimental treatments was another prominent theme. Despite the potential benefits of the research, patients expressed concerns about the unknown

long-term effects of the treatments they were receiving. Several participants mentioned the fear of experiencing adverse reactions, as they were often unclear about the safety profiles of the experimental drugs or therapies.

One participant a 50-year-old female explained, "I worry about side effects. No one can tell me exactly what could happen in the future. I've heard horror stories, so it's hard to feel completely at ease." Another participant a 38-year-old male added, "It's scary to be part of something new, not knowing how it might affect you in the long run."

These concerns highlight the emotional burden patients face when participating in clinical trials, particularly when information about potential risks is either not fully communicated or is perceived as insufficiently detailed.

Satisfaction from Contributing to Medical Advancement

Despite the uncertainties and anxieties, many patients expressed a sense of satisfaction and pride in knowing that their participation could contribute to the advancement of medical science. Several patients emphasized their desire to help others who might benefit from the new therapies being tested.

One participant shared, "I feel good knowing that I'm helping others. Maybe this will lead to a treatment that can help people like me in the future." Another stated, "Even though it's difficult and a bit scary, I know that what I'm doing could make a difference. That's what keeps me going."

This sense of purpose and altruism was often cited as a motivating factor for patients to continue their participation, despite the challenges they faced. Many saw their involvement not only as a personal experience but also as an important contribution to the broader medical community.

Connection with Researchers and Support Systems

A crucial factor that influenced patients' experiences was the level of connection and support they felt from the research team. Patients who reported having more open and empathetic interactions with researchers felt more confident in their decision to participate. The sense of being cared for and understood was central to reducing their anxieties and improving their overall experience.

One patient noted, "The doctors were very supportive. They explained things in a way that I could understand, and they seemed to genuinely care about my well-being." Another participant shared, "Having someone to talk to made a big difference. I felt less alone, and it helped ease my worries."

These supportive relationships, both with researchers and medical staff, played a significant role in mitigating the negative emotions associated with participation and in enhancing patients' overall satisfaction with the research process.

The results of this study reveal the complex and multifaceted nature of patients' experiences in clinical medical research. While many patients faced confusion, anxiety, and concerns about risks, they also found meaning and fulfillment in their participation, particularly through their sense of contribution to medical progress. Strong interpersonal relationships with researchers and clear communication were key factors in helping patients navigate the challenges of participation. These findings underscore the need for improved communication and support systems in clinical trials to enhance the patient experience and promote greater engagement in medical research.

DISCUSSION

The findings of this study reveal that patients' experiences in clinical trials are complex, deeply emotional, and influenced by their perceptions of risk, benefit, and personal involvement in the research process (Reilly dkk., 2023). Participants often expressed a mixture of hope and anxiety, balancing their desire to contribute to medical advancement with concerns about the potential side effects of experimental treatments. These findings provide valuable insights into the subjective aspects of patient participation, answering the central question of how individuals experience and

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make sense of their involvement in clinical trials, especially regarding the psychological and emotional dimensions of the process.

This study makes a unique contribution to the understanding of clinical trial participation by highlighting the importance of patients' emotional experiences and perceptions in shaping their decisions and their engagement throughout the research process (Stanciu dkk., 2023). While existing literature emphasizes the cognitive and risk-based factors influencing participation, our findings suggest that emotional responses—such as fear of side effects and a sense of responsibility toward the medical community—play a critical role in how patients perceive their involvement. This aligns with the broader notion that healthcare decisions are not solely driven by rational evaluation but are deeply intertwined with emotional and psychological factors. By exploring these emotional dimensions, this research provides a more holistic view of patient participation, emphasizing the need for greater sensitivity to the psychological aspects of clinical trial involvement.

The findings also resonate with the theoretical frameworks discussed in the literature, particularly the Health Belief Model and the Theory of Planned Behavior, which suggest that perceptions of risk and benefit strongly influence health-related decisions (Taylor dkk., 2019). However, the current study deepens these models by illustrating that patients' decisions are not only rational but also emotionally charged. Previous studies (e.g., MacDonald et al., 2020; Healy et al., 2018) have explored the decision-making process in clinical trials but often through a quantitative lens, focusing on measurable outcomes like willingness to participate or dropout rates. In contrast, this phenomenological study provides qualitative insights into how these decisions are shaped by internal emotional states and interpersonal dynamics with research teams. Additionally, while earlier research has acknowledged the importance of trust between patients and researchers (Smith & Wright, 2017), this study emphasizes that trust alone is insufficient if not accompanied by clear, empathetic communication about the trial process, benefits, and risks. Thus, our findings extend existing theories by incorporating the emotional and interpersonal dimensions that are critical for understanding patients' lived experiences in clinical trials.

Explanation of Findings Implications

The findings of this study provide a deeper understanding of the emotional and psychological experiences of patients involved in clinical trials (Tradigo et al., 2020). Practically, the results highlight the necessity for implementing a patient-centered approach in clinical trials, emphasizing empathetic and transparent communication to address patients' emotional concerns. For example, the sense of confusion reported by participants underscores the need for simplified consent processes and the use of plain language to improve understanding. Similarly, the fear of potential side effects indicates the importance of providing clear, detailed, and personalized explanations about risks and safety protocols. Given that the decision to participate in clinical trials is driven not only by rational considerations but also by fears, hopes, and concerns about risks, these findings indicate the necessity for more open, honest, and empathetic communication. In the social and cultural context, these findings reflect the complexity of the relationship between individuals and the broader medical system, which often influences health-related decisions. These implications are especially relevant for clinical trial organizers, healthcare providers, and policymakers involved in designing more humane clinical studies, by allowing space for active participation and reflection on participants' personal experiences.

Study Limitations

However, while this study provides valuable insights, several limitations must be considered. One of the key limitations is the relatively small sample size, consisting of only 15 participants, which may not fully represent the broader patient population involved in clinical trials across different medical settings. Additionally, this research was conducted at a single large hospital in Indonesia, which may limit the generalizability of the findings to other contexts or clinical settings (Yuan et al., 2024). The sample's homogeneity in terms of geographical and institutional context might have excluded nuanced variations in experiences across diverse populations or healthcare systems. The phenomenological method, while effective in exploring in-depth experiences, also has limitations in identifying external factors that may influence participants' decisions, such as social or economic

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influences. Therefore, the findings should be considered within the context of further, broader research with a larger and more diverse sample, as well as in different clinical settings.

Prospective Statement for Future Research

This study paves the way for further research that could explore in more depth how the emotional experiences of patients in clinical trials are influenced by external factors such as family support, socio-economic background, and the type of disease being treated (Zheng dkk., 2022). Future research could also broaden its focus to include the perspectives of medical practitioners and researchers involved, with the aim of understanding how they view the emotional role in patient decision-making. Additionally, future studies may adopt a longitudinal approach to examine how these experiences evolve over time during the clinical trial process, and whether these emotional influences impact the success or failure of treatments in clinical trials. This could make a significant contribution to the development of better communication strategies between researchers, healthcare providers, and patients.

CONCLUSION

This study aims to explore the emotional experiences of patients participating in clinical trials, focusing on understanding their subjective meaning of the process. The main findings reveal that participants face fears, hopes, and anxieties that influence their decisions to participate in clinical trials, as well as the importance of empathetic communication between healthcare providers and patients. These findings highlight the limitations of quantitative approaches in capturing these emotional dimensions and contribute to enriching the understanding of psychological factors influencing clinical participation. Thus, this study demonstrates the need for more sensitive and open interactions in clinical trials to alleviate the emotional burden on patients. By implementing these recommendations, clinical trial designs can become more patient-centric, fostering higher engagement, trust, and retention rates. The study opens opportunities for further research on external factors influencing patients' emotional experiences, such as social support or socio-economic background. Future research may also explore the impact of these recommended practices on improving both the quality of patient participation and the overall success of clinical trials. Additionally, future studies may adopt a longitudinal approach and involve various clinical settings to better understand the long-term dynamics of clinical trial experiences.

CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

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