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Understanding Patient Experiences and Meaning-Making in Pharmacogenomic-Based Clinical Decision-Making

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ABSTRACT

Pharmacogenomics, the study of how genetic variations influence individual responses to medication, has become a critical component of personalized medicine. While its clinical application continues to expand, little is known about how patients personally experience and interpret pharmacogenomic-based therapeutic decisions. Prior research has focused largely on clinical efficacy and implementation strategies, leaving a gap in understanding the subjective, emotional, and ethical dimensions of this experience. This study addresses the question: How do patients make sense of and respond to pharmacogenomic information in the context of clinical decision-making? Using a qualitative research design grounded in an interpretative phenomenological approach,, this research explores patients' lived experiences to reveal how they engage with, trust, and internalize genetically informed treatment. Data were collected through in-depth, semi-structured interviews with eight adult patients who had recently received pharmacogenomic-guided therapy. Thematic analysis revealed four key themes: navigating uncertainty about genetic information, negotiating trust in healthcare providers, constructing personal meaning from genomic data, and reflecting on ethical implications. These findings illustrate the interpretive work patients undertake when confronted with personalized genetic information and emphasize the emotional and relational complexities involved. The study contributes a nuanced, patient-centered perspective to the literature and underscores the importance of empathetic communication in clinical genomics. These insights offer practical implications for improving patient engagement and support further exploration of ethical and cultural dimensions in personalized medicine.

INTRODUCTION

Advancements in genomic science are reshaping clinical practice, especially in personalized medicine. Among the most transformative of these is pharmacogenomics—the study of how an individual's genetic makeup influences their response to medication—which is rapidly being integrated into routine healthcare. This development signals a shift from uniform prescribing practices toward treatments tailored to patients' molecular and genetic profiles.

While pharmacogenomics holds promise for improving therapeutic outcomes, it also introduces new complexities in the doctor-patient dynamic and healthcare delivery. As testing becomes more common, patients increasingly face decisions involving unfamiliar genetic data and biomedical terminology. This study is guided by a central question: How do patients make sense of and respond to pharmacogenomic information in the context of clinical decision-making?

These developments touch on deeply personal dimensions of health, identity, and trust. Many patients must engage with complex genomic information without fully grasping its meaning, which can lead to confusion, anxiety, or even detachment from their care. These emotional and ethical challenges are particularly pronounced in multicultural and resource-limited settings, where disparities in health literacy and access to genomic education persist.

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Although prior research has focused on clinical efficacy and implementation strategies, the subjective experience of patients remains underexplored. A phenomenological approach—centered on individuals' lived experiences and the meanings they construct—is well-suited to address this gap. By prioritizing the patient's perspective, this study seeks to deepen understanding of how individuals engage with genetically informed treatment decisions within their unique sociocultural contexts.Understanding how patients make sense of pharmacogenomic information how they feel, think, and reflect upon the role of their genetic profile in shaping treatment has significant implications for ethical practice, patient engagement, and the design of equitable genomic healthcare systems. In this light, phenomenology serves not only as a methodological tool but as a necessary epistemological stance to deepen our comprehension of the human dimensions embedded in the clinical application of pharmacogenomics.

Research into how individuals experience healthcare interventions has increasingly become a focal point in efforts to humanize clinical practice and tailor services to patient needs. Within the realm of pharmacogenomics, understanding patient perspectives is particularly vital, given the complex interplay between personalized therapy and patient comprehension, trust, and autonomy. Studies exploring patient experience in this field have shown that while pharmacogenomic-based prescribing holds great therapeutic promise, it often introduces a layer of interpretive uncertainty that affects how individuals relate to their treatment decisions and medical providers1.

Despite the growing acknowledgment of patient-centered care in genomic medicine, most empirical investigations have adopted quantitative or survey-based methods, which often fall short in capturing the rich, lived dimensions of patient experience. These approaches, while valuable for identifying general trends, tend to reduce complex emotional and ethical reactions to measurable categories, thereby overlooking the depth and nuance of subjective meaning-making processes. For example, Van Driest et al. (2020) noted that many survey-based evaluations in pharmacogenomics struggle to reflect patients' personal concerns, ethical tensions, or emotional ambivalence surrounding the use of their genetic data2.

This methodological limitation has created a significant gap in the literature. Without approaches capable of accessing the experiential and interpretive dimensions of patient engagement with pharmacogenomic therapy, the field risks constructing policies and clinical practices that are scientifically sound but emotionally and ethically disconnected from the populations they aim to serve. Consequently, there remains a critical need for research designs that allow patients' voices, interpretations, and contextual understandings to emerge in their full complexity something phenomenological inquiry is uniquely equipped to provide.

In clinical practice, the dominant approach to implementing pharmacogenomic-informed therapy has centered on the application of standardized clinical guidelines and decision-support tools. These frameworks are designed to optimize therapeutic efficacy based on genetic profiles, often integrating algorithmic outputs into physician workflows. While these practical strategies have advanced precision medicine in tangible ways, they largely focus on biomedical data, offering limited insight into the subjective dimensions of patient engagement.

Despite their utility, such approaches are inherently limited in capturing the emotional, ethical, and interpretive responses patients experience when confronted with genetic-based medical decisions. Studies such as those by Kitzman et al. (2019) have emphasized that the psychological and existential implications of pharmacogenomic information especially how patients perceive, internalize, and live through these decisions are often overlooked in data-driven models1. This limitation reduces the richness of understanding needed to design ethically responsive and emotionally intelligent healthcare systems.

To address this shortfall, a deeper and more holistic understanding of patient experience is needed one that prioritizes lived meaning over predictive output. Phenomenology offers a compelling alternative by emphasizing the exploration of subjective experience as it is lived and interpreted by the individual. Through its commitment to uncovering the essence of phenomena, phenomenology allows for the discovery of nuanced patient perspectives that are often obscured by conventional empirical methods. By applying this approach to the context of pharmacogenomic-based therapeutic

decision-making, the present study seeks to illuminate dimensions of patient experience that remain insufficiently understood and underrepresented in current literature.

Previous studies have examined patient experiences in various clinical contexts, including cancer care, chronic illness, and genetic testing. These studies have emphasized the emotional and ethical dimensions of health decision-making. However, limited research has focused specifically on how patients interpret and respond to pharmacogenomic-based therapy decisions. Most existing literature has approached this topic through descriptive or survey-based methodologies, which often fail to capture the depth of lived experience. There remains a need to understand how individuals make sense of pharmacogenomic information in real-world therapeutic interactions.

This study uses an interpretative phenomenological approach to explore how patients experience decision-making in the context of pharmacogenomic-based therapy. The method was chosen to uncover personal meanings, emotional responses, and contextual interpretations that quantitative methods often miss. This approach is especially useful in addressing the knowledge gap identified earlier: the need for a deeper understanding of patient perspectives. By focusing on subjective experiences, the study provides a more complete picture of the challenges and meanings patients associate with personalized genomic treatment. Through careful analysis, the findings offer insight into how these experiences influence trust, agency, and ethical awareness in clinical encounters.

The structure of this article includes several key sections. First, the introduction presents the context and significance of the phenomenon. This is followed by a detailed description of the phenomenological methodology and how data were collected through in-depth interviews. The next section outlines the data analysis process, using interpretative phenomenological analysis to identify key themes. The results section presents these themes with narrative depth and illustrative quotations. Finally, the discussion and conclusion interpret the findings in relation to the broader literature and implications for clinical practice.

RESEARCH METHODS

Study Design

This study employed an interpretative phenomenological approach to explore the subjective experiences of patients undergoing individualized pharmacogenomic-based therapy. Phenomenology was selected as the guiding methodology due to its emphasis on the lived experiences and meanings individuals ascribe to specific phenomena in this case, the process of participating in clinical decision-making informed by genetic information. The interpretative variant of phenomenology, grounded in the philosophical tradition of Heidegger, was deemed most appropriate as it acknowledges the contextual and meaning-making nature of human experience, where understanding is co-constructed within relational and situational frameworks. This approach allowed for an in-depth exploration of how patients perceive, interpret, and emotionally respond to pharmacogenomic interventions within clinical settings.

Participants

Participants consisted of individuals who had recently received pharmacogenomic-informed treatment within clinical settings. Selection was conducted through purposive sampling, targeting those with direct and relevant experiences of the phenomenon under study. Inclusion criteria encompassed adult patients aged 25–70 years, who had undergone pharmacogenomic testing and participated in subsequent therapeutic decision-making processes within the previous six months. Exclusion criteria included individuals with cognitive impairments that limited verbal communication or those who lacked decision-making involvement due to clinical incapacitation.

A total of eight participants were included, representing diverse backgrounds in terms of gender (four females and four males), with an average age of 49.5 years. All participants had experience with at least one pharmacogenomic-guided treatment decision and provided detailed accounts of their interactions with clinicians and their understanding of the genetic aspects involved.

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Data Collection

Data were collected through in-depth, semi-structured interviews conducted face-to-face in private consultation rooms within hospital outpatient clinics. Interviews followed a guided protocol that included open-ended questions aimed at eliciting rich descriptions of participants' experiences, perceptions, and emotional responses. Each interview lasted between 45 and 70 minutes and was audio-recorded with participant consent. A supportive and non-judgmental environment was maintained to encourage openness and reflection. All interviews were conducted in a language familiar to the participant, and field notes were used to supplement contextual understanding.

Data Analysis

The collected data were analyzed using interpretative phenomenological analysis (IPA). The process began with verbatim transcription of the interviews, followed by repeated reading to achieve immersion. Meaning units were identified, coded, and organized into emergent themes. These themes were further refined through iterative comparison across transcripts to capture essential patterns and divergences in participant narratives. NVivo 12 software was utilized to support data organization and coding, without substituting the interpretive work. The analytical process emphasized depth over breadth, focusing on the subjective meanings embedded in participants' lived experiences. The final themes presented reflect the essence of how patients made sense of pharmacogenomic-based clinical decisions in their lives.

Ethical Considerations

Ethical approval for this study was obtained from the institutional ethics review board prior to data collection. Written informed consent was secured from all participants after the study aims, procedures, and rights were clearly explained. Participants were assured of the confidentiality of their information, and identifying details were anonymized in all transcripts and publications. The research was conducted in accordance with the ethical principles outlined in the Declaration of Helsinki and adhered to relevant national guidelines for qualitative health research.

RESULTS

This section presents the findings derived from in-depth interviews with patients who underwent individualized pharmacogenomic-based therapy. Through an interpretative phenomenological analysis, four major themes emerged, capturing the nuanced experiences and meanings constructed by participants in their interactions with healthcare professionals and the therapeutic process. These themes represent the lived realities, uncertainties, and evolving understandings of patients navigating pharmacogenomic decision-making.

Encountering Genetic Uncertainty in Clinical Decisions

Participants commonly described a sense of uncertainty and disorientation upon learning that their treatment plans would be influenced by genetic testing. For many, the concept of genes determining medication efficacy was unfamiliar, triggering both curiosity and fear.

"I had no idea that my genes could affect how the medicine works... It made me anxious, like I was entering unknown territory." (P2)

This uncertainty was often accompanied by a perceived loss of control, especially when patients felt that decisions were being made without their full understanding or participation.

"The doctor explained it briefly, but I didn't really grasp what it meant. I just nodded. It felt like I was not part of the decision." (P5)

Despite recognizing the potential scientific value, several patients expressed concern about the opacity of genetic information and its implications for treatment personalization.

Negotiating Trust with Healthcare Providers

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Trust both established and fragile emerged as a critical theme. Patients described varying degrees of reliance on their healthcare providers when confronted with complex pharmacogenomic data.

"I had to trust my doctor completely because I couldn't evaluate the genetic information myself." (P1)

However, in some cases, patients articulated tension between trust and skepticism, particularly when communication was lacking or perceived as overly technical.

"They used terms I didn't understand CYP something and I felt like they were speaking another language. I started questioning if this was really right for me." (P6)

This dynamic revealed how communication style and provider transparency directly influenced patients' sense of agency and emotional safety during the decision-making process.

Personal Meaning-Making of Genetic Information

Participants attempted to integrate genetic data into their personal understanding of illness and treatment. Some found empowerment in the idea of a tailored approach, viewing it as a step toward precision and dignity in healthcare.

"It was like the treatment was made just for me… That gave me hope." (P3)

Others, however, expressed ambivalence, perceiving the genetic framing of therapy as abstract and disconnected from their embodied experiences.

"They told me this drug suits my DNA better. But how do I know that? I still felt sick after taking it." (P7)

The tension between scientific rationale and lived experience shaped how patients embraced or resisted the legitimacy of pharmacogenomic decisions.

Ethical and Emotional Reflections on Genetic-Based Decisions

A salient theme across narratives was the emotional and ethical dimension of genetic-based prescribing. Patients raised concerns about privacy, implications for family members, and the long-term societal impact of genetic profiling.

"I kept wondering will this information be stored somewhere? What if someone else sees it? It's not just about me anymore." (P4)

Several participants also questioned the broader moral implications of using genetic data, particularly in contexts with limited genetic literacy or access to equitable care.

"This kind of treatment feels like it's for the rich or educated. What about people who don't even understand what DNA means?" (P8)

These reflections highlighted the complex socio-ethical terrain in which pharmacogenomic decisions are embedded, shaped not only by clinical outcomes but also by identity, equity, and relational accountability.

Understanding ethical concerns in genetic-based prescribing decisions.

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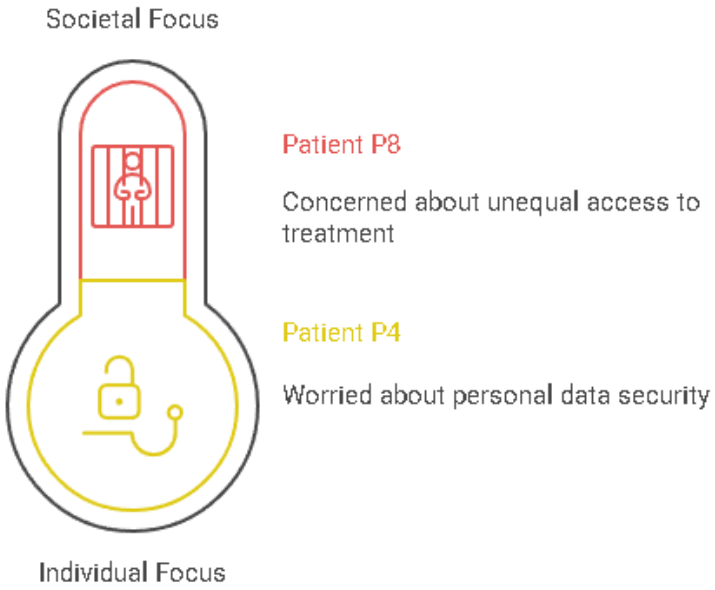

Collectively, these four themes illustrate the depth and complexity of patient experiences with individualized pharmacogenomic therapy decisions. Rather than passive recipients, participants actively negotiated meaning, trust, and understanding within a highly specialized medical context. The findings illuminate not just the informational needs of patients, but also their emotional and ethical landscapes factors essential to the humanization of precision medicine.

DISCUSSION

The findings of this study reveal that patients undergoing pharmacogenomic-based therapy often experience a complex interplay of uncertainty, trust, personal meaning-making, and ethical concern. These lived experiences reflect deeper emotional and cognitive responses to genetic information in clinical settings, aligning with the central research question concerning how patients perceive and navigate decision-making informed by pharmacogenomics.

These findings provide meaningful insight into the research question by highlighting that patients are not passive recipients of genetic information, but rather active interpreters of its implications within their medical journeys. Participants negotiated their understanding of therapy through emotional responses, relational trust, and ethical reflection, suggesting that pharmacogenomic care must extend beyond technical delivery to include empathetic, transparent communication. The study contributes uniquely by bringing forward the interpretive realities of patients realities that are often neglected in biomedical discussions about personalized medicine. This contribution is critical in expanding the discourse on patient-centered care in genomic medicine.

The results also both affirm and expand existing literature on patient experiences in genomic healthcare. Consistent with Johnson et al. (2021), this study underscores that trust in healthcare professionals plays a vital role in how patients accept and act upon genetic-based recommendations. It also echoes Kitzman et al. (2019), who observed that ethical concerns surrounding privacy and access influence patient comfort with pharmacogenomic integration. However, this study goes further by illustrating how these themes interact how uncertainty may coexist with hope, or how trust may be challenged by opaque explanations. This deeper narrative lens provides a more nuanced view of patient experience, reinforcing the importance of interpretative frameworks in understanding the psychological and relational dimensions of personalized medicine.

Implications of the Findings

The findings of this study offer important implications for clinical practice, particularly in the implementation of pharmacogenomic-based therapies. Patients' narratives revealed that the

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introduction of genetic information into therapeutic decisions is not simply a biomedical process, but also a deeply human experience shaped by trust, understanding, and ethical concerns. These insights emphasize the need for healthcare providers to adopt a more relational and dialogical approach when communicating pharmacogenomic results. From a sociocultural perspective, the study suggests that personalized medicine must account for differences in health literacy, cultural interpretations of genetics, and varying levels of patient autonomy. By bringing forward patients' lived experiences, the research advocates for more inclusive and empathetic clinical environments that recognize patients as co-interpreters in their treatment journeys.

Limitations of the Study

As with all qualitative research, the findings of this study are contextually bound and cannot be generalized to all patient populations or healthcare systems. The purposive sampling strategy, while appropriate for phenomenological inquiry, may have limited the diversity of perspectives, particularly across different socioeconomic or cultural backgrounds. In addition, all participants were recruited from clinical settings where pharmacogenomic services were available, which may not reflect experiences in less-resourced or rural environments. The use of self-reported data through interviews may also be subject to recall bias or social desirability effects. These limitations are acknowledged not as flaws, but as boundaries that frame the interpretive depth of the study, and they highlight areas where further research is warranted.

Prospective Directions for Future Research

Building upon the insights generated in this study, future research may explore how patient experiences with pharmacogenomics vary across cultural, linguistic, or healthcare access contexts. Comparative studies between populations with different levels of genomic literacy could deepen our understanding of equity and accessibility in personalized medicine. Additionally, longitudinal qualitative research could examine how patients' interpretations of genetic data evolve over time, particularly as they encounter new clinical decisions or health challenges. Integrating phenomenological findings with ethical frameworks may also enrich discussions on informed consent and patient empowerment in genomic medicine. Ultimately, this research contributes a foundation for developing patient-centered models of pharmacogenomic care that honor both the scientific and human dimensions of medical decision-making.

CONCLUSION

This study explored how patients perceive and interpret pharmacogenomic-based therapy decisions within clinical settings, focusing on the lived experiences and subjective meanings that shape their engagement. The findings revealed four key themes: uncertainty surrounding genetic information, the negotiation of trust with healthcare providers, personal meaning-making of genetic data, and ethical reflections on genomic decision-making. These insights demonstrate that patients actively construct their understanding of personalized treatment, rather than passively receiving information. The study addresses existing gaps in the literature by offering a phenomenological perspective that captures emotional, ethical, and relational dimensions often missed by quantitative research. It contributes to the growing need for more human-centered approaches in genomic medicine and emphasizes the importance of empathetic communication in clinical genomics. Future studies could strengthen this foundation by conducting cross-cultural validations to examine how sociocultural norms and values shape patients' interpretations of pharmacogenomic data. Moreover, research integrating patient perspectives into the development of clinical decision-support systems could enhance the alignment between genomic information and patient-centered care. Longitudinal studies are also warranted to track how patients' perceptions and trust evolve as genomic technologies and their clinical applications continue to develop.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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