



Exploring Patients' Lived Experiences of Trust and Privacy in AI-Driven Health Chatbots for Chronic Illness Care

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ABSTRACT

Artificial intelligence (AI) has become integral to digital healthcare, with AI-based chatbots increasingly supporting chronic disease management. Despite proven functional advantages, little is known about how patients perceive trust, privacy, and emotional connection in these non-human interactions. Previous research has emphasized usability and efficiency, leaving unexplored the emotional and relational dimensions of AI-mediated care. This study examines how patients with chronic conditions experience trust and privacy when interacting with AI-driven health chatbots, employing an interpretative phenomenological approach. Semi-structured interviews with 12 long-term chatbot users were thematically analyzed. Four key themes emerged: ambivalent trust, emotional distance in algorithmic care, negotiated privacy, and the tension between being heard and understood. Findings highlight the paradox of digital care—patients value accessibility but seek relational depth often missing in AI interfaces. This study reveals that trust in AI health tools is fluid, context-dependent, and emotionally nuanced, offering insights for more human-centered and ethically transparent AI design.



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INTRODUCTION

In recent years, the integration of artificial intelligence (AI) into healthcare systems has reshaped how patients access, perceive, and experience medical care (Pandey & Sharma, 2023). Among these advancements, AI-driven health chatbots have emerged as digital interfaces capable of providing symptom assessments, medication reminders, mental health support, and lifestyle guidance, especially for individuals managing chronic conditions (Fournier-Tombs & McHardy, 2023). This innovation aligns with a broader societal shift toward digital health transformation, where technology plays a central role in extending care beyond traditional clinical settings. As healthcare delivery becomes increasingly automated and decentralized, the interaction between patients and non-human agents introduces new dynamics into the therapeutic landscape.

The use of health chatbots is especially relevant in chronic disease management, where continuous monitoring, behavioral adherence, and timely communication are critical (Kurniawan et al., 2024). While these tools offer convenience, efficiency, and scalability, their adoption also evokes complex emotional and ethical considerations. For patients, engaging with AI-based systems entails not only exchanging information but also navigating trust, intimacy, vulnerability, and perceived safety in spaces once reserved for human clinicians (Nadarzynski et al., 2020). These interactions are embedded within broader cultural and societal narratives about privacy, data security, and the humanization of care in the digital age. As such, the experience of using health chatbots extends beyond functional utility and enters the realm of personal meaning-making.

Despite the technological sophistication of AI in healthcare, there remains limited understanding of how patients interpret their experiences with these systems (Rezaeikhonakdar, 2023). Most existing studies emphasize clinical outcomes, user satisfaction scores, or system

performance metrics, often neglecting the nuanced and deeply personal dimensions of patient interaction (Au Yeung et al., 2023). Yet, in the context of chronic illness—where long-term engagement and psychological resilience are paramount—the subjective meanings attributed to care technologies may significantly influence their acceptance and impact. This gap signals a pressing need to explore the inner world of patients' lived experiences, beyond the surface-level usability or technical adequacy.

Phenomenology, as a philosophical and methodological approach, offers a valuable lens to examine how individuals make sense of their encounters with AI health tools (Wang et al., 2022). It emphasizes the importance of first-person accounts and lived realities, providing a pathway to uncover the emotional textures, moral tensions, and relational nuances often absent from quantitative assessments (Görtz et al., 2023). By foregrounding patient voice and experiential depth, a phenomenological exploration of AI-chatbot interaction can contribute to a more holistic and humane understanding of digital healthcare.

Understanding the subjective experience of individuals interacting with AI-based healthcare technologies has become an increasingly important area of inquiry within medical informatics and digital health (Bays et al., 2023). As AI-driven chatbots are integrated into chronic disease management, they do not merely serve as informational tools but also engage users in emotionally and ethically significant ways (Jungwirth & Haluza, 2023). The lived experiences of patients—how they perceive trust, navigate privacy concerns, and interpret the emotional tone of machine-mediated care—demand methodological approaches that honor the complexity and depth of human meaning-making.

Despite this emerging significance, many existing studies in this domain continue to rely heavily on quantitative or hybrid methodologies that prioritize functionality, usability metrics, or behavioral outcomes (Boucher et al., 2021). While such data offer valuable insights into system efficiency and user acceptance, they often fail to illuminate the subtle, evolving, and sometimes contradictory ways patients experience AI in their daily lives (Siglen et al., 2022). These approaches tend to overlook the nuanced affective responses and ethical considerations that arise in non-human care interactions, particularly in long-term health conditions where psychological comfort and interpersonal trust are central to sustained engagement.

This methodological gap limits our capacity to fully understand how digital health tools are embodied, interpreted, and emotionally integrated into patients' health journeys (Pan et al., 2023). Traditional research frameworks often reduce patient experience to static variables or generalizable patterns, missing the dynamic and contextualized meanings that emerge through direct, prolonged interaction with AI-based systems (Nadarzynski et al., 2021). Consequently, previous methods, while informative, have proven insufficient in capturing the essence of patient experiences—especially in areas where relationality, vulnerability, and self-reflection intersect with technology use.

Phenomenology, with its emphasis on depth, context, and subjectivity, presents a suitable and necessary alternative (Lee et al., 2023). It allows for the exploration of not just what is experienced, but how it is experienced—making it particularly well-suited for examining the personal dimensions of trust, autonomy, and emotional engagement in AI-supported healthcare settings.

In the current landscape of AI-integrated healthcare, most efforts to evaluate patient interaction with health chatbots have relied on pre-established practical frameworks such as usability testing, satisfaction surveys, or technology acceptance models (Rouhi et al., 2024). While these approaches offer measurable indicators of system performance and general user attitudes, they fall short in capturing the richness and depth of individual experiences, particularly those involving emotional, ethical, and relational complexities (Imran et al., 2023). For instance, concerns around trust, privacy, and perceived empathy—critical elements in long-term digital care—are often reduced to checklist items or rating scales that obscure the layered realities of patient engagement.

This tendency toward functional reductionism limits the ability to understand how patients internalize, interpret, and emotionally respond to AI-based care technologies (C. Blease & Torous, 2023). The subtle tensions between feeling supported and feeling surveilled, between being heard and

being understood, remain largely unexamined in studies that privilege statistical generalizability over personal meaning (Temsah et al., 2023). Furthermore, little is known about how patients construct or lose trust in algorithm-driven systems, or how the absence of human touch shapes their experience of care over time—especially in managing chronic illnesses that demand ongoing, emotionally resonant support.

Given these limitations, there is a clear need for an alternative methodological approach that foregrounds the lived experiences of patients and allows their voices to shape our understanding of digital health interactions (Dergaa et al., 2023). Phenomenology, particularly in its interpretative form, offers such a framework by emphasizing meaning, context, and subjective depth. Rather than treating patient input as data points to be quantified, it seeks to uncover the essence of human experience as it unfolds within specific socio-technological contexts (Hirosawa et al., 2023). This study responds to that need by adopting a phenomenological lens to explore how individuals with chronic conditions experience trust and privacy when interacting with AI-based health chatbots—an area still underrepresented in current research yet deeply relevant in the evolution of digital healthcare.

Recent studies have explored patient experiences with digital health tools, but most focus on technical efficiency or general user satisfaction. For example, Ghanem et al. (2024) investigated patient interactions with AI chatbots in primary care but emphasized functional trust rather than emotional meaning. Similarly, Liu et al (2022) examined digital companionship, yet did not explore how patients internalize feelings of vulnerability or relational disconnection. These studies highlight the growing relevance of AI in healthcare but leave open questions about how patients truly experience trust, privacy, and emotional presence in these interactions. A deeper, more subjective approach is needed to address these gaps.

This study adopts an interpretative phenomenological approach to explore how patients with chronic illnesses experience trust and privacy when interacting with AI-based health chatbots (Barnett et al., 2021). This method is chosen for its ability to access personal meaning, emotional depth, and context-bound perceptions. It moves beyond surface-level evaluations and aims to uncover how individuals make sense of their digital healthcare encounters (Hua et al., 2023). The approach offers an appropriate response to the knowledge gap by focusing on lived experience, not just functionality or usability. The study provides insights that are both human-centered and technologically relevant.

The structure of this article follows a clear progression. The introduction outlines the general and specific background of the phenomenon and defines the knowledge gap. The methodology section presents the interpretative phenomenological design, participant selection, data collection, and data analysis procedures. The results section organizes the findings into themes grounded in participants' narratives. The discussion connects these findings to existing literature and explores their broader implications. Finally, the conclusion highlights the essential meanings and potential contributions of the study to digital health practice.

RESEARCH METHODS

Study Design

This research adopted an interpretative phenomenological design to examine the lived experiences of patients interacting with AI-based health chatbots for chronic disease management. Phenomenology, as a qualitative inquiry, centers on understanding how individuals perceive and make meaning of their lived experiences (Johnson, 2014). It provides a methodological foundation for accessing the essence of a phenomenon through the detailed narratives of those who have experienced it firsthand. The interpretative (hermeneutic) variant of phenomenology, influenced by Heidegger's philosophical framework, was employed to allow for a deeper exploration of the relational and contextual meanings embedded in patients' interactions with AI technologies (Wilhelm et al., 2023). This approach enabled the uncovering of nuanced emotional, ethical, and existential dimensions of trust and privacy as experienced in digital health environments, offering insights beyond what can be captured through purely descriptive or technical perspectives.

Participants

Participants were individuals diagnosed with chronic health conditions—such as type 2 diabetes, hypertension, or heart failure—who had consistently used AI-powered health chatbots as part of their self-care routines for at least three months. A purposive sampling strategy was applied to identify participants who possessed rich and relevant experiential knowledge of the phenomenon under investigation. Inclusion criteria comprised: adults aged 21 years and older, sufficient digital literacy to engage meaningfully with chatbot platforms, and the capacity to provide informed consent and articulate personal reflections. Exclusion criteria included individuals with acute cognitive impairments or those without any direct experience using AI-based chatbot applications for healthcare (Chen et al., 2024). A total of 12 participants were included in the study, comprising 7 women and 5 men, with ages ranging from 29 to 67 years (mean age: 48.3). Participants came from both urban and rural regions, and represented diverse levels of comfort and familiarity with digital health technologies, enriching the dataset with a variety of lived perspectives.

Data Collection

Data were collected through in-depth, semi-structured interviews guided by an open-ended interview protocol. Interviews were conducted remotely via encrypted Zoom video calls to ensure accessibility and accommodate geographic limitations. Each session lasted between 45 and 70 minutes and was audio-recorded with the consent of participants. The interview environment was intentionally designed to be non-intrusive, with participants given the autonomy to choose the timing and setting in which they felt most comfortable sharing. The interview guide was iteratively refined after the initial sessions to better align with the emerging themes. All interviews were transcribed verbatim and anonymized to preserve confidentiality. The protocol was informed by existing qualitative frameworks in phenomenological research and adapted to focus on key dimensions of trust, privacy, relational engagement, and digital interaction with AI-based health tools.

Data Analysis

Data were analyzed using Interpretative Phenomenological Analysis (IPA), a methodology that emphasizes the co-construction of meaning between participant narratives and researcher interpretation. The analysis involved several iterative stages. First, transcripts were read multiple times to grasp the overall sense of each narrative. Meaningful segments of text were identified as initial codes, which were then grouped into clusters reflecting common experiential patterns (Andrew, 2024). These clusters were synthesized into broader thematic structures that captured both shared and divergent meanings. Thematic development was supported by the use of ATLAS.ti software, facilitating systematic organization of codes and linking of emergent ideas. The analytic process remained grounded in participants' own language and expressions, with selected quotations used to illustrate the essential structures of meaning. This method allowed for the identification of interpretive insights into how trust and privacy are negotiated, embodied, and challenged through encounters with AI-driven health chatbots.

Ethical Considerations

Ethical approval for the study was obtained from the institutional review board of the affiliated university. Informed consent was obtained in writing from all participants after they were provided with a comprehensive explanation of the study's aims, procedures, and their rights as voluntary contributors. Anonymity was maintained by assigning pseudonyms and removing identifiable information from the transcripts. All data were securely stored in password-protected digital files, accessible only to authorized personnel. The study was conducted in accordance with the ethical guidelines outlined in the Declaration of Helsinki and complied with local regulations on the protection of human subjects in health-related research.

RESULTS

The Lived Experiences of Patients Navigating Trust and Privacy in AI-Based Health Chatbots for Chronic Disease Management

Conditional Trust in Non-Human Care

Participants expressed a conditional and context-dependent trust in AI-driven health chatbots, appreciating their accessibility yet questioning their reliability and emotional authenticity. For some, the chatbot's instant responsiveness created a sense of safety during moments of vulnerability. However, this confidence often dissolved when emotional understanding or ethical reassurance was lacking.

“It was comforting to know someone—or something—was there at 2 a.m. when I had symptoms. But I also kept thinking, can this thing really understand what I’m feeling?” (P4)

Others hesitated to disclose sensitive health information, citing the chatbot's inability to convey empathy or safeguard emotional privacy.

“You can ask me how I feel, but if you don’t feel it back, how can I really trust that my data is safe or that you even care?” (P7)

This theme highlights trust as situational—anchored in convenience but undermined by the absence of emotional reciprocity and perceived data insecurity.

Emotional Distance and Simulated Intimacy

Participants described a paradoxical experience of “algorithmic intimacy”—a sense of digital proximity coupled with emotional detachment. While chatbots offered consistent interaction, the emotional tone was experienced as mechanical rather than relational, creating a subtle feeling of alienation.

“It keeps reminding me to take my meds, and it tracks everything. But there's no warmth in it... it's like being cared for by a machine, not a person.” (P2)

This feigned closeness often blurred the line between care and surveillance, leaving users uncertain whether they were being supported or monitored.

“I sometimes feel more like a data point than a patient. It's helpful, yes, but also kind of lonely.” (P9)

This theme distinguishes emotional distance from trust by focusing on affective disconnection rather than functional reliability. It captures how chatbots simulate attentiveness without offering genuine human engagement.

Negotiating Privacy and Control in Automated Care

Participants consistently voiced concerns about data privacy and control. While many accepted data collection as necessary for personalization, ambiguity about data ownership and secondary use triggered apprehension.

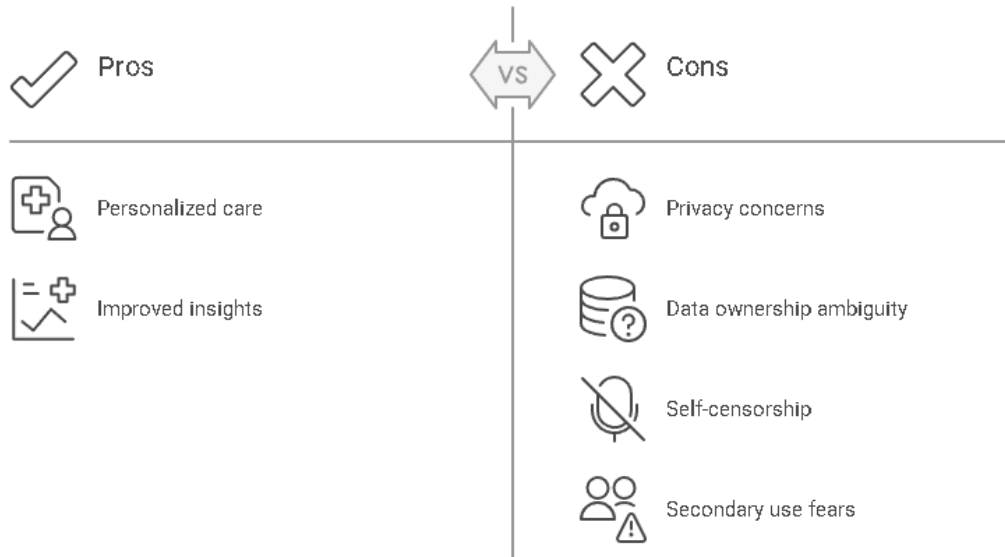
“It listens, but I don’t know who else is listening. I keep wondering where my health info goes and who sees it.” (P1)

Some developed self-censorship strategies, intentionally filtering or altering inputs to maintain a sense of autonomy.

“There were things I didn’t tell it. I wasn’t sure how it would interpret what I said—or if my insurance company would find out.” (P6)

This theme isolates privacy as an active process of negotiation, emphasizing how users balance the benefits of tailored care against fears of exposure and loss of agency.

Data collection for personalization



Being Heard Without Being Understood

Many participants felt that chatbots could process information but failed to grasp personal meaning or context. This led to perceptions of being “heard” in a technical sense but not “understood” in a human sense.

“I can type my symptoms, and it gives me suggestions. But it doesn’t get why I’m worried, or the bigger picture of my life.” (P3)

“With my doctor, she knows my past, my fears. The chatbot doesn’t. It gives good advice, but it lacks context.” (P10)

This theme is reframed to emphasize cognitive rather than emotional limits, distinguishing it from Emotional Distance. It highlights the absence of contextual intelligence in AI-mediated communication.

Integrative Synthesis: Balancing Functionality and Humanity

Across all themes, participants demonstrated a dual consciousness of empowerment and vulnerability. They recognized the efficiency of AI-based care yet grappled with its emotional and ethical constraints. Trust, intimacy, privacy, and understanding emerged as interlinked but distinct dimensions, each revealing different tensions between human expectation and machine mediation.

This synthesis underscores that patients’ engagement with AI chatbots is not a binary of acceptance or rejection but a continual negotiation between usability, empathy, and ethical clarity.

DISCUSSION

The findings of this study reveal that patients with chronic illnesses experience a complex and often ambivalent relationship with AI-based health chatbots, particularly regarding trust, emotional presence, and privacy (Li et al., 2024). These experiences, deeply shaped by both the perceived capabilities and limitations of the chatbot, provide meaningful insights into how individuals navigate care within digital and non-human frameworks—offering direct answers to the central research question concerning the subjective meaning of trust and privacy in AI-supported healthcare.

The results contribute significantly to the understanding of how patients interpret their engagement with digital health technologies beyond functional outcomes (Abbasian et al., 2024). Rather than passively receiving information, participants actively constructed meaning in their interactions with the chatbot—grappling with contradictions between emotional needs and algorithmic responses (C. R. Blease et al., 2024). This research uniquely shows that patients’ trust is contingent not only on informational accuracy but also on their perception of relational authenticity, a

dimension rarely captured in previous assessments of AI-based systems. It highlights the emotional labor patients undergo in digital spaces and foregrounds the role of perceived empathy and contextual understanding in sustaining trust over time.

These insights align with and expand upon prior research. For example, Almalki & Azeez (2020) discussed early patient trust in AI chatbots but focused primarily on structural and functional trust factors; this study deepens that understanding by exploring how trust is formed, fractured, and repaired on a personal level. Similarly, the emotional distance identified by Musheyev et al. (2024) as a characteristic of digital companionship is echoed in the theme of “feeling heard, but not understood,” reinforcing the notion that simulated empathy may fall short in fostering meaningful digital relationships. This study, therefore, contributes to a growing body of literature that critiques the over-reliance on quantitative indicators of satisfaction, proposing instead that the emotional and interpretive dimensions of digital care must be more intentionally integrated into AI healthcare design and evaluation frameworks.

The findings of this study carry significant implications for both the development of AI health technologies and the delivery of patient-centered care (Zhu et al., 2022). From a practical standpoint, the results suggest that chatbot designers must go beyond improving informational accuracy and prioritize relational features that foster emotional connection and perceived empathy. This includes designing AI interactions that reflect not only user preferences but also contextual and affective cues (Levkovich & Elyoseph, 2023). On a broader social level, the study highlights how the digitalization of care is reshaping patient expectations and perceptions of trust, particularly in marginalized or resource-limited settings where human interaction may be limited. These insights may inform health policymakers, digital health developers, and clinicians about the need for more ethically responsive and culturally sensitive digital tools.

As with all qualitative inquiries, this study has inherent limitations. The sample size, though appropriate for phenomenological research, limits the transferability of findings to broader populations. Participants were selected based on their ability to reflect on and articulate their experiences, which may not represent all users of AI-based health chatbots (Vandelanotte et al., 2023). Additionally, the remote nature of data collection may have influenced the depth or openness of some responses. These contextual and methodological factors should be considered when interpreting the results, particularly in relation to different demographic or cultural groups (Choudhury & Shamszare, 2023). Despite these limitations, the study offers rich, contextually grounded insights into an underexplored phenomenon.

Future research may build upon these findings by exploring patient experiences in different cultural, linguistic, or clinical contexts to identify how sociocultural norms influence perceptions of AI-based care (Vilaza & McCashin, 2021). Longitudinal studies could examine how trust in AI evolves over time, especially as patients transition between acute and chronic care phases (Qiu et al., 2023). Further investigation is also needed into how algorithmic design choices—such as tone, pacing, or responsiveness—shape patient perceptions of empathy and privacy. By expanding the phenomenological lens to different settings and populations, future studies can help guide the ethical and human-centered integration of AI into healthcare systems.

CONCLUSION

This study explored how patients with chronic conditions experience trust and privacy when engaging with AI-based health chatbots. The findings revealed that while these technologies offer accessibility and informational support, they also evoke emotional ambivalence, feelings of disconnection, and concerns over data security. Participants valued responsiveness but questioned the chatbot’s ability to convey empathy and understand personal context. These insights contribute to a deeper understanding of patient-AI interaction, addressing gaps left by prior studies that overlooked emotional and relational aspects. The study underscores the importance of integrating patient-centered values into the design of digital health tools.

To translate these insights into practice, developers and healthcare institutions should prioritize the co-design of AI systems with patients, ensuring emotional responsiveness, transparent data governance, and ethical clarity are embedded from the outset. Policymakers should establish regulatory frameworks that define standards for data transparency, consent, and accountability in AI-driven healthcare. Moreover, clinical practitioners can leverage chatbots as complementary—not substitutive—tools that extend, rather than replace, human care relationships. Future research should not only examine cross-cultural variations and the long-term evolution of trust but also test intervention models that operationalize empathy and privacy assurance within AI-mediated care. Such approaches can bridge the gap between technological efficiency and the humanistic foundations of healthcare.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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