primary and hospital care

MDPI

Article

Healthcare Memory: Patient and Provider-Side Perspectives on Preserving Care Context and AI-Supported Continuity in Discordant Chronic Comorbidities

Peiran Yu, Yanbing Jin, Zoe Sadowski and Tom Ongwere *

Department of Computer Science, University of Dayton, 300 College Park, Dayton, OH 45469, USA; yup003@udayton.edu (P.Y.); jiny10@udayton.edu (Y.J.); sadowskiz2@udayton.edu (Z.S.)
* Correspondence: tongwere1@udayton.edu

Abstract

Patients living with multiple chronic conditions may face challenges maintaining continuity of healthcare information across conditions, providers, organizations, and encounters. These challenges may be particularly complex in the context of discordant chronic comorbidities (DCCs), where treatment and self-management demands can differ across conditions. This study explored how patients and provider-side participants understood these information-continuity challenges and perceived the potential role of AI-supported patient technologies. We conducted semi-structured qualitative interviews with 16 participants, including six patients and 10 provider-side participants. Patient interviews emphasized lived experiences managing multiple chronic conditions and reactions to a patient-facing application concept, whereas provider-side interviews explored AI-supported medication information and decision-aid scenarios, clinical workflow, trust, accuracy, and human oversight. Four researchers independently coded the interview transcripts and developed themes through iterative comparison and discussion. Four themes emerged: (1) healthcare memory breaks down across care settings; (2) healthcare memory preserves context rather than records; (3) healthcare memory supports patient representation during vulnerable moments; and (4) AI may augment healthcare memory rather than clinical decision-making. We conceptualize healthcare memory as the ongoing work of preserving, reconstructing, and mobilizing clinically meaningful context across time and care settings. This study contributes a conceptual lens for understanding continuity of context and identifies design considerations for AI-supported systems, including source traceability, contextual preservation, patient control, privacy, and human oversight. The findings represent participant experiences and anticipated design opportunities rather than evidence of improved clinical outcomes.

Keywords: healthcare memory; discordant chronic comorbidities; continuity of care; patient-generated health data; patient-facing health technologies; artificial intelligence

Check for updates

Academic Editor: Shanthi Mendis

Received: 29 September 2026
Revised: 10 November 2026
Accepted: 13 November 2026
Published: 24 November 2026

Copyright: © 2026 by the authors. Licensee MDPI, Basel, Switzerland. This article is an open access article distributed under the terms and conditions of the Creative Commons Attribution (CC BY) license.

1. Introduction

Patients living with multiple chronic conditions routinely navigate care distributed across providers, appointments, medications, laboratory results, and treatment plans. This challenge becomes particularly complex in the context of *Discordant Chronic Comorbidities (DCCs)*, where patients manage chronic conditions with different, and sometimes competing, treatment priorities. Successfully managing DCCs therefore requires more than following individual treatment plans; patients must reconcile competing or discordant

treatment demands [1–3] while also managing and communicating health information across providers and care settings [4].

This coordination work extends beyond the clinical encounter. Patients routinely manage medications, monitor symptoms, prepare for appointments, interpret test results, and carry information between providers and healthcare organizations [4–6]. Patient portals, personal health records (PHRs), and patient-centered digital health records have improved access to health information and created new opportunities for patient engagement and chronic disease self-management [7–9]. Yet access to information does not necessarily ensure continuity. Patients may still need to remember why a medication was changed, reconstruct the sequence of prior treatments, recall what was discussed during an earlier appointment, or explain their history to a provider who cannot access information generated elsewhere.

These challenges are particularly consequential for patients with DCCs because clinically relevant information is distributed across multiple conditions, providers, organizations, and episodes of care. Patient-generated health data (PGHD) provide opportunities to capture information beyond the formal medical record [10,11], while emerging AI-supported health technologies offer possibilities for organizing, retrieving, and summarizing complex health information [12–14]. However, capturing more information does not necessarily preserve the relationships that make that information meaningful. A medication list may show what a patient currently takes without preserving why a medication was started or discontinued. A laboratory result may be available without showing how it relates to a treatment change. An appointment summary may document a visit without helping the patient reconstruct what was discussed, decided, or left unresolved.

Recent literature reinforces the distinction between access to health information and the ability to use it meaningfully over time. A systematic review of patient access to electronic health records found that access can support engagement, self-management, communication, and adherence, while also identifying persistent usability and implementation challenges [15]. A separate systematic review found that the effects of personal health records on patient activation are heterogeneous, suggesting that access alone does not consistently translate into greater activation [16]. These findings motivate closer attention to how information is organized and connected across encounters, rather than treating availability as sufficient for continuity.

These observations point to a broader problem of *healthcare memory*. We use this term to describe the ongoing work of preserving, reconstructing, and mobilizing clinically meaningful context across time, care settings, providers, organizations, and episodes of care. Healthcare memory is therefore not synonymous with storing medical records. Rather, it concerns whether the relationships among symptoms, treatments, appointments, laboratory results, decisions, and lived experiences remain available and understandable when they become relevant again. This distinction is especially important during moments when patients may have difficulty representing themselves, such as emergencies, postoperative recovery, or cognitively and emotionally demanding clinical encounters.

To investigate this problem, we conducted a qualitative interview study with patients living with DCCs and a provider-side interview strand recruited to contribute healthcare-side perspectives. Participants discussed experiences relevant to managing and communicating complex care and reflected on patient-facing or AI-supported design concepts. We examined not only participants' perceptions of AI, but also the information work they described as necessary to maintain continuity across care trajectories.

Our findings show that participants sought more than a repository of medical records. They wanted technologies that could preserve the context surrounding healthcare events: why treatments changed, how symptoms evolved, what occurred during appointments,

and what information needed to remain available when they could not easily explain their own history. Participants also viewed AI most favorably when it could reduce the burden of this work through summarization, organization, retrieval, and contextual explanation, rather than when it was positioned as an autonomous decision maker.

Although prior research has examined access to patient health information, patient-generated health data, and AI-supported summarization, less attention has been given to how clinically meaningful context is preserved and reconstructed across time, particularly for patients managing discordant chronic comorbidities. This study addresses that gap by examining how patients and provider-side participants describe the information work required to maintain continuity and by developing healthcare memory as a conceptual lens for that work.

This paper makes three contributions:

- First, we extend research on patient portals, personal health records, and patient-generated health data by reframing continuity as a problem of preserving and mobilizing healthcare context, rather than providing access to individual records alone.
- Second, we show how DCCs make this problem particularly visible because patients must reconcile multiple treatment trajectories across conditions, providers, and care settings.
- Third, we derive design implications for patient-facing technologies that support longitudinal care context, patient representation during vulnerable moments, distributed remembering with trusted others, and bounded uses of AI for healthcare-memory support.

Together, these contributions position *healthcare memory* as a lens for understanding an often-overlooked dimension of chronic care: the work required to carry the meaning of past healthcare experiences into future encounters.

2. Related Work

2.1. Patient-Facing Digital Health Records and Personal Health Records

Patient portals, personal health records (PHRs), and patient-centered digital health records have expanded patients' access to information generated through healthcare encounters. These systems provide patients with access to medications, laboratory results, appointment information, clinical summaries, and communication with providers, and have been associated with increased patient engagement and participation in chronic disease management [7–9]. By making clinical information available beyond the point of care, patient-facing records can support patients' ability to review their health information and participate more actively in their care.

Recent evidence provides a more qualified account of these benefits. Alomar et al. [15] synthesized research on patient access to electronic health records and reported potential benefits for engagement, self-management, communication, and adherence, alongside challenges related to usability and implementation. Similarly, a systematic review by Osovskaya et al. [16] found that the relationship between PHR use and patient activation varied across studies. Taken together, these reviews suggest that making information accessible is important but may not, by itself, ensure that patients can interpret, organize, and apply it in the context of ongoing care. Healthcare memory builds on this distinction by focusing on the relationships among information and events that patients need to recover over time.

However, access to information does not necessarily resolve the continuity challenges associated with complex chronic care. Patients may still need to interpret, organize, and reconcile information across encounters and providers [4,17,18]. Existing patient-facing

systems also tend to organize information around records, documents, or individual encounters. Such organization can facilitate retrieval of specific information, but may provide less support for understanding how healthcare events relate to one another across time.

This distinction is particularly important for patients with discordant chronic comorbidities (DCCs), whose care may involve multiple providers, specialties, and organizations. A medication list can indicate what a patient currently takes without explaining why a medication was initiated, changed, or discontinued. A laboratory result may be available without showing how it relates to a preceding treatment decision. Similarly, an appointment summary may document what occurred during a visit without preserving the questions, concerns, or unresolved issues that shaped subsequent care.

Continuity-of-care research provides an important point of comparison. Haggerty et al. distinguish *informational continuity*—the use of information about past events and personal circumstances to make current care appropriate—from management and relational continuity [19]. Healthcare memory builds on this concern with longitudinal information but shifts attention toward the patient-facing work required when continuity is incomplete: preserving, reconstructing, and mobilizing the context that links healthcare events across fragmented records, lived experiences, and moments of reduced self-representation.

2.2. Patient Work, Care Coordination, and Continuity in Multimorbidity

Managing chronic illness involves substantial work that occurs outside formal clinical encounters. Patients routinely manage medications, monitor symptoms, prepare for appointments, interpret health information, coordinate among providers, and maintain personal records of their care [3–5]. This work has been characterized as an often invisible component of healthcare in which patients assume responsibility for coordinating information and activities distributed across fragmented systems.

The burden of this work increases when patients live with multiple chronic conditions. Different conditions may require different treatment priorities, treatments may interact or compete, and recommendations from different clinical contexts may not always align [1–3,6]. Patients consequently become important coordinators of their own care, carrying information between providers and reconciling recommendations across clinical contexts [3,4].

Recent qualitative work has examined multimorbidity from the perspectives of patients, family caregivers, and healthcare professionals. Peeler et al. [20] describe shared but not identical experiences of managing symptoms and coordinating care, highlighting the importance of relationships, communication, caregiver support, access to resources, and coordination. A systematic review of co-designed care for multimorbidity likewise emphasizes the value of involving multiple stakeholders in shaping care approaches [21]. This literature supports the importance of considering patient, caregiver, and healthcare-side perspectives while recognizing that these perspectives may foreground different needs. The present study contributes to this discussion by examining complementary interview strands: patient accounts of lived care-management experiences and provider-side accounts of information use, workflow, and trust. The strands were not designed as a standardized comparison, but together illuminate different dimensions of continuity work.

An important but less visible dimension of this coordination work is remembering. Patients may need to recall when a medication was started, why it was changed, what symptoms occurred afterward, what a previous provider recommended, or what happened during an earlier encounter. This information may become especially important when patients encounter a new provider or seek care in an unfamiliar setting. Although prior work has documented the informational and organizational work performed by patients, less attention has been given to the role of maintaining a longitudinal memory of care itself.

Our findings extend this literature by conceptualizing healthcare memory as a component of continuity work. Healthcare memory encompasses the effort required to preserve what happened, why it happened, how it affected subsequent care, and what information needs to be carried forward into future encounters. DCCs make this work particularly visible because patients must maintain continuity across multiple treatment trajectories rather than within a single disease pathway.

2.3. Patient-Generated Health Data and Contextual Health Information

Patient-generated health data (PGHD) includes information that patients create, collect, or record outside conventional clinical documentation. Examples include symptoms, medication use, side effects, mood, activity, self-monitoring measurements, and personal observations about everyday health experiences. PGHD has been increasingly examined as a resource for self-management, personalized care, and communication between patients and healthcare providers [10,11,22].

The potential value of PGHD, however, depends on more than the quantity of information captured. Prior research has identified challenges involving data quality, provenance, interpretation, privacy, governance, and integration into clinical workflows [10,11]. For patients managing chronic conditions, attitudes toward sharing patient-generated information may also vary with illness trajectory, health status, privacy concerns, and the context in which sharing occurs [22].

Together, these concerns highlight that the value and use of PGHD are context-dependent. They also motivate a distinction between *data capture* and *context preservation*. A symptom recorded without information about when it began, what was happening at the time, or whether a medication had recently changed may have limited meaning when revisited later. Similarly, a medication log may identify a drug and dosage without preserving why it was prescribed, how the patient responded, or why it was eventually discontinued. Future work is required to explore how patient-facing systems should support *context-preserving linkage*: maintaining meaningful relationships between patient-generated information and the healthcare events surrounding it.

2.4. AI-Supported Sensemaking, Summarization, and Patient-Facing Health Assistants

Recent advances in artificial intelligence have created new possibilities for helping patients and clinicians navigate increasingly complex health information. Prior work has explored question answering over electronic health records [12]. Emerging research has also examined large language models for automated summarization, conversational sensemaking of patient-generated health information, and personalized interaction with personal health records [13,14].

One potential use of AI is to transform large amounts of health information into concise and understandable representations. AI systems may assist with organizing information chronologically, identifying relevant events, summarizing encounters, and retrieving information through conversational interaction. Such capabilities may be particularly useful for patients whose health histories span multiple providers, conditions, and years of care.

Recent empirical work illustrates both the promise and the constraints of clinical text summarization. Van Veen et al. [23] evaluated adapted large language models across several clinical text summarization tasks and reported that model-generated summaries could perform competitively with medical experts in their evaluation. However, broader evaluations of healthcare applications of large language models identify substantial limitations in the evidence base, including inconsistent use of real-world patient-care data and gaps in the assessment of safety, bias, and clinical utility [24]. More recent work has proposed explicit frameworks for evaluating clinical safety and hallucinations in medical

text summarization, underscoring the need to assess omissions and unsupported content as well as fluency [25]. These studies suggest that AI-supported healthcare memory should not treat generated summaries as authoritative histories. Instead, summaries should remain traceable to source information, temporally accurate, open to correction, and subject to appropriate human review.

At the same time, AI-supported health information systems introduce important risks. Recent work has identified concerns involving hallucination or confabulation, temporal errors, privacy, transparency, over-reliance, and failures to integrate or correctly attribute clinically important information [13,14]. These concerns are particularly consequential when AI is positioned as an autonomous source of diagnosis or treatment recommendations.

3. Method

3.1. Study Design

We conducted an exploratory qualitative interview study to examine how patients and healthcare provider-side participants experience and reason about information, continuity, and decision-making in the context of discordant chronic comorbidities (DCCs). This study brought together two complementary perspectives: patients' experiences managing multiple chronic conditions and healthcare personnel's perspectives on reconstructing, interpreting, and using patient information during clinical encounters.

Patient interviews focused on participants' lived experiences of managing multiple chronic conditions and their reactions to a patient-facing application concept designed to support treatment management, information organization, and communication across routine and emergency care. Provider-side interviews explored perspectives on AI-supported medication information and decision-aid concepts, including patient preparation, clinical workflow, trust, accuracy, communication, and human oversight.

Across both interview groups, we explored three overarching areas: (1) challenges in managing and coordinating care across multiple chronic conditions; (2) the information and contextual knowledge needed across clinical encounters; and (3) opportunities and concerns associated with AI-supported technologies for organizing, retrieving, summarizing, explaining, and communicating healthcare information. This design enabled us to examine DCC care from the perspective of patients who must remember and communicate their health histories and from the perspective of healthcare personnel who must reconstruct patient context during clinical encounters.

3.2. Participants and Recruitment

We recruited 16 participants ($N = 16$), comprising six patient participants (PP1–PP6) and 10 provider-side participants (HP1–HP10). The two groups were recruited using different eligibility criteria and interview emphases, as summarized in Table 1.

Patient participants were eligible if they were adults reporting two or more chronic conditions that they experienced difficulty managing. They were recruited to discuss their experiences coordinating care, managing treatment, and communicating health information, as well as to provide feedback on a patient-facing application concept.

Provider-side recruitment targeted individuals with professional, clinical, or clinical-training perspectives relevant to the care of patients with type 2 diabetes and at least one additional chronic condition, including arthritis, chronic lung disease, or depression. The group included physicians, a pharmacist, a medical student, and other provider-side participants. We included the medical student to capture a clinical-training perspective on patient information, medication-related decision support, and the anticipated use of AI-supported tools in healthcare. The student was not treated as an independently practicing

clinician; their contribution was interpreted as a trainee perspective rather than as evidence of independent clinical practice.

Table 1. Summary of study participants (Healthcare Providers).

Participant	Medical Position	Medical Specialty	Knowledge About DCCs
HP1	Pharmacist	Family Medicine	Very knowledgeable
HP2	Medical doctor	Internal Medicine	Very Knowledgeable
HP3	Medical doctor	Family Medicine	Very knowledgeable
HP4	Medical doctor	Pediatrician	Very Knowledgeable
HP5	Medical doctor	Internal medicine	Knowledgeable
HP6	Medical doctor	Family Medicine	Very knowledgeable
HP7	Physician assistant	Internal medicine	Very knowledgeable
HP8	Physician assistant	Acute-care	Knowledgeable
HP9	Physician assistant	Family Medicine	Very knowledgeable
HP10	Physician assistant	Internal medicine	Knowledgeable

Each participant self-reported having worked with, helped, or supported a patient with DCCs and is knowledgeable about and comfortable using emerging technologies. Very Knowledgeable participants include those who manage DCC cases daily and have over ten years of experience. Knowledgeable participants have experience with DCC patients, though it is not their primary role.

All participants received information about this study before participation and provided written informed consent by signing a consent form. Participation was voluntary, and participants were informed that they could withdraw from this study or decline to answer individual questions at any time without penalty. Patient participants received a USD 10 gift card, and provider-side participants received a USD 25 gift card as compensation. This study was reviewed and approved by the Institutional Review Board (IRB).

3.3. Interview Procedure

We conducted semi-structured interviews in person and remotely using Zoom. Interview guides were tailored to the two participant groups while retaining a shared set of topics to support comparison across perspectives. The semi-structured format allowed participants to describe their experiences in their own terms while enabling interviewers to ask follow-up questions to clarify responses and explore issues raised during individual sessions.

Interviews were conducted by three (N = 3) researchers. Patient interviews focused on experiences managing multiple chronic conditions, coordinating information across providers and care settings, preparing for healthcare encounters, and communicating health histories. Participants also reviewed a patient-facing mobile application concept designed to support treatment management, medication adherence, health-information organization, and communication during healthcare encounters, including emergency situations.

Provider-side interviews focused on AI-supported medication information and decision-aid scenarios. Discussions addressed the perceived usefulness and limitations of AI-generated information, patient preparation, clinical workflow, communication, trust, accuracy, interoperability, empathy, and the appropriate role of human oversight.

In addition to the questions in the interview guides, interviewers used follow-up questions to clarify participants' statements and explore topics that emerged during the discussion. These questions addressed, as relevant to the participant's responses, (1) how health information was remembered, retrieved, and communicated; (2) challenges maintaining continuity across providers and care settings; (3) the consequences of incomplete, outdated, or difficult-to-access information; (4) expectations and concerns regarding the accuracy, transparency, and trustworthiness of AI-supported information; and (5) the perceived fit of technology concepts within patient and clinical workflows.

Follow-up questions were asked when a participant raised an experience, concern, or interpretation that required clarification or further exploration, rather than being admin-

istered as a fixed set of questions to every participant. Their use therefore varied across interviews. The underlying topics were relevant to both groups, but the specific questions reflected each group's experiences and interview materials. For example, patient follow-ups emphasized personal experiences of remembering and communicating health histories, whereas provider-side follow-ups emphasized clinical information needs, workflow implications, and human oversight. This approach allowed us to pursue emerging issues while retaining the shared focus of this study.

With participant permission, interviews were audio-recorded and subsequently transcribed for analysis. Participants were reminded that they could stop the interview or decline to answer any question at any time. Recordings and transcripts were handled confidentially and were accessible only to members of the research team.

3.4. Study Materials

The interview materials differed by participant group to reflect participants' respective experiences and areas of expertise. For patient interviews, we used a patient-facing mobile application concept designed to support DCC treatment management, medication adherence, health-information organization, and communication across healthcare encounters. Particular attention was given to situations in which patients may need to communicate their health histories during urgent or emergency care.

For provider-side interviews, we used DCC medication scenarios and examples representing DCCs, as well as an earUSD stage medication decision-aid prototype from our broader research program. Example scenarios incorporated combinations of type 2 diabetes, arthritis, and depression and included concerns such as drug interactions, medication-related weight changes, and medication cost.

These materials functioned as *elicitation probes* rather than standardized experimental conditions. Participants were not asked to evaluate the diagnostic or prescribing accuracy of the systems. Instead, the materials provided concrete representations through which participants could discuss perceived usefulness, limitations, trust, workflow fit, communication, and design requirements. Because follow-up questions were adapted to participants' responses, not every provider-side interview included identical probes or follow-up questions.

3.5. Data Analysis

We used an iterative qualitative coding and thematic analysis approach to analyze the interview transcripts. This approach was selected because this study was exploratory and sought to understand how participants described and interpreted continuity, contextual information, and AI-supported care. The construct of *healthcare memory* emerged during the analysis rather than being imposed as a predetermined coding category. Dedoose was used to support transcript management, coding, memo writing, and organization of the analysis [26,27].

The analysis proceeded through three iterative stages. First, four researchers independently reviewed and coded the interview transcripts to identify concepts, experiences, and patterns relevant to the study questions. Initial codes included medication histories, appointment recall, emergency information access, care coordination, patient–provider communication, privacy, and trust in AI. Independent coding allowed each researcher to interpret the interview material and identify relevant concepts before the research team compared their interpretations.

Second, the three researchers compared their coding and interpretations through discussion. Differences were examined by returning to the relevant transcript passages and considering the context in which participants described their experiences. Through

this process, the researchers discussed alternative interpretations, clarified code definitions, consolidated overlapping codes, and introduced additional codes when new concepts emerged from the data. These discussions informed the iterative refinement of the coding framework and helped establish a shared understanding of the concepts represented by the codes.

Third, related codes were grouped into higher-level analytic categories, and relationships among these categories were examined within and across the patient and provider-side interview groups. Throughout the analysis, researchers used analytic memos to document emerging interpretations, examine relationships among categories, and consider similarities and differences across participant groups and care scenarios.

In particular, patient accounts frequently described the burden of remembering, reconstructing, and communicating personal health histories, whereas provider-side accounts emphasized the need for complete and current patient context, efficient preparation for time-limited encounters, workflow integration, and maintaining human clinical judgment when using AI-supported tools. Comparing these perspectives helped the researchers examine how the challenges of healthcare memory were experienced differently by patients and provider-side participants.

The analysis resulted in four themes characterizing how participants described continuity and contextual information in DCC care:

1. Healthcare memory breaks down across care settings;
2. Healthcare memory preserves context rather than records;
3. Healthcare memory supports patient representation during vulnerable moments;
4. AI augments healthcare memory rather than clinical decision-making.

These themes were developed through iterative examination of recurring patterns across the interview data and consideration of how patient and provider-side perspectives complemented or differed from one another. They represent an analytic interpretation of participants' accounts rather than a measure of the effectiveness or clinical accuracy of an AI system.

4. Findings

Our analysis identified four themes that we interpret through the analytic lens of healthcare memory in the context of discordant chronic comorbidities (DCCs): (i) healthcare memory breaks down across care settings, (ii) healthcare memory preserves context rather than records, (iii) healthcare memory supports patient representation during vulnerable moments, and (iv) AI augments healthcare memory rather than clinical decision-making. Patient interviews supplied the most direct accounts of remembering and reconstructing care, while provider-side interviews added healthcare-side perspectives on information transfer, whole-patient context, patient preparation, workflow, and the boundaries of AI-supported care. Because the interview strands used different elicitation materials, we organize the findings around convergent design problems rather than treating the two groups as directly comparable experimental conditions.

4.1. Healthcare Memory Breaks Down Across Care Settings

Participants described healthcare information as fragmented across providers, institutions, appointments, and moments of acute care. Importantly, participants did not describe the problem simply as missing records. Rather, information often existed but was difficult to access, connect, or carry forward when patients moved between care settings. This fragmentation shifted responsibility for maintaining continuity onto patients, who frequently had to

remember treatment histories, reconstruct prior encounters, and repeatedly communicate information that had already been documented elsewhere.

4.1.1. Information Existed, but Did Not Reliably Travel with the Patient

Participants described receiving laboratory tests and other forms of care from multiple institutions, resulting in information being distributed across systems. PP1 explained:

> *"Sometimes I have to get my lab work done here, sometimes it's at home [...] there are like 5 different companies that do it, and so the reports, they're all in different spots."* —PP1

The participant emphasized that this fragmentation could affect subsequent care:

> *"For long-term care, though, the doctors would not have access to my previous lab results and all of that. So there's definitely some gaps in the coverage."* —PP1

Similarly, PP6 described situations in which information from another hospital was unavailable because it remained within that institution:

> *"Because it's from a different hospital."* —PP6

Provider-side participants highlighted a complementary workflow constraint: patient-held information may not be the first source clinicians consult. HP1 described emergency staff identifying a patient and retrieving the institutional chart rather than searching the patient's phone:

> *"Typically, what happens is you find ... their license, so then you have their name and date of birth, and then you pull it up on, like, your computer ... Typically, we don't really look at the patient's phone to get any of that kind of information."* —HP1

HP8 similarly emphasized that continuity often depended on direct communication between clinicians rather than on the existence of a referral or record alone:

> *"Those direct conversations with our consultants are what drive a lot of the quality of care ... because the communication seems much clearer than if it were just a referral with minimal communication."*– HP8

These accounts illustrate a distinction between information being *stored* and information being *usable*. Records could exist within healthcare infrastructures while remaining inaccessible at the point when patients or providers needed them. The provider perspective further suggests that continuity technologies must fit established clinical retrieval practices rather than assume that clinicians will search a patient's personal device.

4.1.2. Patients Became Custodians of Continuity

When information did not move reliably across systems, participants often became responsible for maintaining continuity themselves. This involved remembering medications, reconstructing treatment histories, recalling previous conversations, and keeping track of multiple appointments.

PP4 described the cumulative burden associated with managing many chronic conditions:

> *"I do think this is really a good idea, because it gives you [...] you're not like, wait, what did they say? Especially, you know, when you have a lot of chronic conditions, you go to a lot of appointments, and it's like [...] how do you keep all of that information straight?"* —PP4

Participants also described difficulty recalling the precise dates associated with previous procedures and medications. PP2 explained:

> *"I've had surgery before on my MCL [...] because they'll ask you the date, and I'm like, I have no idea."* —PP2

They similarly recalled difficulty providing precise medication histories:

"When did you start taking this medication? No, I don't know, like, three years ago. Yeah, I don't remember the day." —PP2

These experiences suggest that patients often retained a general memory of their healthcare experiences while lacking the chronological precision required during clinical encounters. Continuity consequently became dependent on the patient's ability to reconstruct details on demand.

4.1.3. Continuity Needed to Persist Across Everyday Care

Participants also wanted healthcare information to remain connected to the temporal structures through which they organized their lives. Rather than treating appointments, summaries, and follow-up information as independent records, they wanted to revisit information through the appointments and dates to which it belonged.

PP5 described this preference:

"Not only have the summary, but be able to link it to the appointment in your calendar." —PP5

They further explained:

"If you need to go and revisit a past appointment, you can just go in your calendar, click on the appointment, and it would have the summary right there." —PP5

PP6 similarly emphasized integration with tools already used to manage everyday activities:

"Just making sure there's a way to put it on a GCal or something like that would be helpful, because... a calendar on the app versus GCal is kind of different." —PP6

Together, these accounts indicate that participants did not view healthcare memory as a separate archive. They wanted information to remain connected to the appointments, dates, reminders, and routines through which care unfolded.

4.2. Healthcare Memory Preserves Context Rather than Records

Participants' accounts indicate that simply bringing records together would not fully address their needs. What mattered was preserving the context surrounding healthcare events: why a treatment was initiated or changed, how symptoms evolved, what occurred during an appointment, and how one event related to another. Participants therefore described healthcare memory as longitudinal and relational rather than as a static collection of records.

4.2.1. Medication Histories Needed to Capture Change and Experience

Participants viewed medication information as more than a list of current prescriptions. They wanted to know why medications were prescribed, when they changed, why they were discontinued, and what effects they experienced.

PP1 explained:

"I'd like to know what the medication is for, like why I'm taking it... and if something changed, like if the dosage changed, I'd want to know that too." —PP1

PP2 similarly emphasized the importance of preserving discontinued medications:

"If I stopped taking something, I'd want to know when I stopped taking it, and why." —PP2

Participants also wanted medication histories to capture their own experiences. PP4 described the value of connecting a medication with subsequent effects:

> *"It would be nice if I could see, okay, I started this then, and then this is when I had that side effect, or this is when I noticed it was helping."* —PP4

Provider-side feedback added a reliability requirement to this longitudinal view. HP1 emphasized that a patient-facing medication record could be clinically useful only if it remained current:

> *"If the app was up to date with the current medications, then it would be very helpful for me to make sure there's no duplicate therapy..."* —HP1

These accounts show that medications were understood as part of an evolving treatment trajectory. The meaningful unit was not simply the medication itself, but the relationship among the medication, the reason for its use, changes in treatment, and the patient's subsequent experience. HP1's concern also shows that healthcare memory must preserve not only history but also the currency and reliability of information presented for clinical use.

4.2.2. Symptoms, Laboratory Results, and Treatments Needed to Remain Connected

Participants similarly wanted information from different parts of their care to remain connected over time. PP1 described the value of viewing laboratory results as trends rather than isolated measurements:

> *"I think seeing trends would be helpful, because sometimes you just get the numbers, but you don't really know, like, is this better than before? Is this worse than before?"* —PP1

PP5 described the importance of reconstructing sequences among symptoms, treatments, and events:

> *"This is when this happened, and then this is when I started feeling this way, and then this is when the medication changed—that would be helpful."* —PP5

These accounts suggest that participants wanted to reconstruct relationships rather than retrieve isolated facts. A laboratory result became more meaningful when viewed in relation to earlier results and treatment changes. A symptom became more informative when associated with when it began and what happened afterward. Healthcare memory therefore depended on preserving the temporal relationships among events.

Provider interviews reinforced this need for whole-patient context. HP7 argued that an integrated AI system would need to understand the patient's medication list and broader health history rather than optimize around a single diagnosis:

> *"It really makes a huge difference if the integration is there so that the AI model can understand ... the medications that the patient is taking, all of the health problems that the patient has, and not focus on one disease process at the exclusion of understanding the patient as a whole."* —HP7

This provider perspective extends the patient accounts by showing that contextual linkage is not only valuable for recall; it also shapes whether information can be interpreted safely and usefully in clinical decision-making.

4.2.3. Appointments Needed to Preserve Decisions and Unresolved Questions

Participants also described appointments as information-rich events whose meaning could be lost after the encounter. They wanted summaries to preserve what clinicians said, what decisions were made, what actions were expected, and what questions remained unresolved.

PP5's earlier description of linking appointment summaries directly to calendar entries illustrates this need to revisit an encounter in its original temporal context. For participants managing multiple chronic conditions, that capability also addressed the cumulative burden of repeated appointments, a concern already visible in PP4's account of trying to keep information straight across many visits.

The challenge was therefore not simply remembering that an appointment occurred. Participants wanted to preserve the substantive context of the encounter so that its recommendations and decisions remained available when needed later.

4.2.4. Lived Experience Was Part of Healthcare Context

Participants also wanted healthcare memory to preserve information that may not appear in formal clinical records. This included symptoms described in their own words, treatment experiences, and observations that occurred between appointments.

PP6 explained:

> *"I think it would be nice to be able to put in notes, because there are things I notice in the moment, but if no one asks me right then, I'm probably not going to remember them later."* —PP6

PP2 similarly described difficulty translating a prior experience into words during a later encounter:

> *"I know something was wrong, but by the time I'm there, I can't always explain it the way I was feeling it at the time."* —PP2

These accounts demonstrate that participants viewed lived experience as part of the context of care rather than as information separate from clinical records. Preserving patients' own observations could help maintain details that might otherwise disappear between encounters.

4.2.5. Healthcare Memory Depended on Relationships Among Events

Across these accounts, participants consistently described value in linking information rather than simply accumulating it. Medications were meaningful when connected to symptoms and side effects; laboratory results were meaningful when connected to treatment changes; and appointments were more useful when connected to summaries and follow-up actions.

Healthcare memory therefore involved preserving relationships among events. The central concern was not simply whether information could be retrieved, but whether patients could reconstruct what happened, what changed, and how different events were related.

4.3. Healthcare Memory Supports Patient Representation During Vulnerable Moments

Participants described healthcare memory as particularly important when they were unable to fully represent themselves. Emergencies, postoperative recovery, lengthy appointments, and emotionally or cognitively demanding encounters could reduce patients' ability to remember and communicate critical information. In these situations, participants wanted healthcare memory to provide a persistent representation of their health histories that could support communication with clinicians, caregivers, or family members.

4.3.1. Emergencies Exposed the Limits of Patient Recall

Participants described emergencies as situations in which they were repeatedly asked to provide medication names, dosages, and treatment histories while simultaneously experiencing pain, illness, or cognitive overload.

PP4 described an adverse medication reaction that resulted in ambulance transport and hospitalization:

> *"Two weeks ago, I had an adverse reaction to medication, and I ended up in an ambulance, being transported to the hospital, and then I got admitted. But I mean, like, the number of times I was asked, like, what did you take again? What were the milligrams? Like, and I'm just, like, I'm so [...] sick. Yeah. Just do something."* —PP4

The significance of this account lies in the mismatch between the demands of the encounter and the participant's ability to respond. The patient was expected to reconstruct precise medication information at the moment when their capacity to do so was most compromised.

Similarly, PP1 described difficulty processing information immediately after surgery:

> *"As an adult, going into surgery... I woke up, and, like, two minutes later, the doctor's right there telling me, and I'm supposed to remember..."* —PP1

These experiences demonstrate why healthcare memory becomes particularly consequential during vulnerable moments: the patient may remain the expected source of information even when their ability to recall or communicate that information is temporarily limited.

4.3.2. Critical Information Needed to Remain Immediately Accessible

Participants identified medications, dosages, diagnoses, allergies, and recent treatment information as examples of information that could become particularly important during urgent care. The value of such information was not simply that it was stored, but that it could be accessed quickly and understood by someone other than the patient.

PP4's earlier emergency account illustrates the problem: clinically important medication details had to be reconstructed repeatedly while the participant was acutely ill. Participants therefore envisioned healthcare memory as a mechanism that could reduce the need to reconstruct critical information under stress. In this sense, a persistent health history could function as a form of patient representation when direct communication became difficult.

4.3.3. Vulnerability Extended Beyond Emergencies

Participants did not restrict vulnerability to acute medical crises. Long appointments, complex discussions, postoperative conversations, and encounters involving multiple chronic conditions could also create situations in which patients struggled to retain information.

PP6 described this need for post-encounter memory support:

> *"That would be nice... to have a write-up of what happened."* —PP6

Together with earlier accounts of long appointments and repeated visits, this suggests that vulnerability could emerge through cumulative cognitive burden rather than a single emergency. Healthcare memory could reduce that burden by preserving information that patients might otherwise have to reconstruct repeatedly.

Provider-side participants also connected preparation with more meaningful patient–clinician communication. HP9 explained that a patient who arrived with usable information could participate more effectively in the encounter:

> *"They'll have working information that makes their understanding and the doctor's understanding more meaningful."* —HP9

This suggests that patient representation begins before the encounter itself: preserving and organizing relevant context can help patients enter time-limited visits better prepared to ask questions and understand decisions.

4.3.4. Family Members Functioned as Co-Representatives

For some participants, healthcare memory was distributed across family relationships. Family members helped remember symptoms, manage appointments, and communicate health histories when patients had difficulty doing so themselves.

PP6 described the importance of having their mother present during difficult appointments:

> *"If it's a super long meeting, or if my mom can't go... it could be hard to remember all details."* —PP6

PP2 similarly described relying on their mother for healthcare-related tasks:

> *"I still make her make my doctor appointments for me."* —PP2

These accounts suggest that patient representation is sometimes inherently relational. Healthcare memory may be distributed among patients, family members, caregivers, and clinicians. A patient-facing system that supports continuity should therefore consider not only individual access, but also appropriate mechanisms for sharing relevant information with trusted others.

4.4. AI Augments Healthcare Memory Rather than Clinical Decision-Making

Participants generally responded positively to the potential use of AI, but their expectations were bounded. They did not primarily envision AI as replacing clinicians or making autonomous treatment decisions. Instead, participants valued AI for helping them capture, organize, summarize, retrieve, and interpret information that was difficult to manage across time.

4.4.1. AI Could Organize and Retrieve Fragmented Information

Participants described accumulating medications, laboratory results, notes, and appointment information that could be difficult to organize. AI was appealing when it could reduce the effort required to locate and consolidate relevant information.

PP1 described this potential:

> *"I think if it could kind of pull it together for me, like summarize what happened or what changed, that would be really helpful."* —PP1

PP6 similarly emphasized the value of extracting important information from a larger encounter:

> *"If there was a way for it to, like, take what happened and give me the important parts back, that would be really helpful."* —PP6

HP6 described a parallel clinical use: AI could help a clinician digest a large longitudinal record and surface the few issues that most needed attention in the current encounter:

> *"It serves a huge role in being able to digest huge amounts of information and then get me to the point where I can say, these three things need to be addressed today."* —HP6

These accounts position AI primarily as an information-organizing layer. Participants wanted help consolidating information and identifying what had changed rather than having AI independently determine what their health condition meant.

4.4.2. AI Could Preserve Appointment Information

Participants were particularly interested in AI-supported summaries of healthcare encounters. As described in the preceding theme, lengthy and information-dense appointments created substantial memory demands, and PP6 valued having a written account of what happened after an encounter. Provider-side participants identified the same opportunity from a clinical perspective. HP1 explained:

> *"Being able to give a full summary of the visit would definitely be beneficial for patients."* —HP1

In this context, AI-supported summarization could serve as a mechanism for preserving healthcare memory. Its value would come from reducing the likelihood that important information, decisions, and follow-up instructions would be lost after the encounter, while keeping the summary available for later patient review.

4.4.3. AI Could Improve Interpretation Without Becoming the Authority

Participants also described opportunities for AI to make complex information easier to understand. PP1's earlier interest in viewing laboratory results as trends rather than isolated values illustrates this broader desire for interpretive support.

Participants therefore saw AI as potentially useful for organizing and presenting information in ways that supported their understanding and conversations with clinicians. The preferred role was interpretive support rather than autonomous clinical authority. Provider-side interviews reinforced this orientation: the strongest use cases were those that helped patients and clinicians understand, prepare, and review information without presenting generated output as final clinical truth.

4.4.4. Trust Depended on Keeping Clinicians Central

Participants drew a clear boundary between AI-supported information management and clinical decision-making. They were more receptive to AI organizing information, generating summaries, or supporting appointment preparation than to AI independently determining diagnoses or treatments.

PP1 expressed this distinction:

> *"I think it's helpful if it can organize things or explain them better, but I wouldn't want it to be making decisions instead of my doctor."* —PP1

Provider-side participants repeatedly drew the same boundary. HP5 described AI as a tool for efficiency while keeping decision authority with people:

> *"It's very important to still have that humane aspect ... still have humans ... making decisions with the help of AI to make our work more efficient."* —HP5

HP4 similarly emphasized that algorithmic recommendations could not replace the clinical relationship or the need to depart from an algorithm when an individual case required it:

> *"I don't think that AI will ever replace the relationship that you have with your primary care provider ... the algorithms work a lot of the times, but sometimes they don't. And you have to go off of the algorithm and make a different decision."* —HP4

This boundary is central to understanding participants' acceptance of AI. Across patient and provider-side interviews, AI was valued when it reduced information and memory burdens while preserving the clinician's role in diagnosis, treatment, and clinical judgment.

4.4.5. AI Was Most Valuable When It Reduced Rather than Redistributed Patient Work

Finally, participants' accounts suggest that the value of AI depended on whether it actually reduced the work required to maintain healthcare memory. Participants were already responsible for remembering dates, tracking medications, taking notes, organizing reports, and preparing for appointments. A system that simply created another place for patients to enter information would not necessarily address this burden.

Instead, participants were most interested in AI that could work with information already generated through care, identify relevant changes, generate summaries, and return important information when needed.

Taken together, these findings position AI as an augmentation of healthcare memory. Participants valued AI not because they wanted it to replace clinicians, but because they wanted assistance with the persistent information and memory work required to maintain continuity across complex care trajectories.

5. Discussion

Our findings suggest that continuity in complex chronic care is not only a problem of information access. It is also a problem of remembering, reconstructing, and communicating the relationships among healthcare events over time. Patient participants described fragmented information, difficulty recalling treatment histories and appointment details, and heightened challenges when illness or cognitive burden made self-representation difficult. Provider-side participants added a complementary clinical concern: information becomes useful only when it is current, connected to the whole patient, compatible with workflow, and presented in a way that supports rather than replaces human judgment. Across both groups, AI was most compelling as a means of organizing, retrieving, summarizing, and explaining information while keeping clinical decision-making within the patient–provider relationship.

Building on these findings, we develop *healthcare memory* as a conceptual lens for understanding continuity in patient-facing health technologies. Healthcare memory extends beyond the storage of medical records to encompass the preservation and mobilization of contextual relationships among symptoms, treatments, appointments, decisions, and lived experiences. We discuss this contribution in relation to existing work on patient-facing records, patient work, patient-generated health data, and AI-supported health information systems.

5.1. From Fragmented Records to Healthcare Memory

Patient portals and personal health records have substantially improved patients' access to clinical information. However, our findings suggest that access alone does not guarantee continuity. Participants frequently described situations in which information existed somewhere within the healthcare system but was unavailable, difficult to locate, or disconnected from information generated during other encounters.

This distinction suggests two related but different problems: *information availability* and *information continuity*. Information availability concerns whether a record exists and can be accessed. Information continuity concerns whether the information remains connected to the broader history of care in a way that allows it to be understood and used during subsequent encounters.

This distinction is consistent with recent reviews of patient access to electronic health records and personal health records, which report potential benefits but also variation in engagement and activation outcomes [15,16]. Our findings add a contextual dimension to this literature: participants' concerns were not limited to whether information could be opened or viewed, but included whether they could recover why an event occurred, how

it related to other events, and what should be carried forward. In this respect, healthcare memory is concerned with the continuity of meaning, not simply continuity of access.

For patients with DCCs, this distinction is particularly important. Their healthcare trajectories are distributed across multiple conditions and treatment plans, making it difficult to interpret individual pieces of information without understanding their relationships to other events. A medication change may only make sense in relation to a symptom that occurred previously. A laboratory result may become meaningful when viewed alongside a treatment adjustment. A provider recommendation may depend on a decision made during an earlier encounter.

Healthcare memory therefore reframes continuity as a relational problem. The objective is not simply to create a more comprehensive repository of patient information, but to preserve the relationships that allow patients and care partners to reconstruct their healthcare histories. In this sense, healthcare memory complements rather than replaces existing health records.

This perspective also extends research on patient work. Existing work has shown that patients perform substantial coordination and information-management activities across fragmented healthcare systems [3–5]. Our findings suggest that remembering is one component of this work. Patients are not simply coordinating current information; they are continually reconstructing the history that makes current information interpretable.

5.2. Healthcare Memory Is Contextual and Relational

A central finding was that participants did not want healthcare information merely collected in one location. They wanted information to remain connected to the context in which it was generated.

This distinction is important for the design of patient-facing systems. Traditional record structures tend to treat medications, laboratory results, appointments, and notes as individual information objects. Although these structures support retrieval, they may not adequately represent the temporal and causal relationships through which patients experience their care.

Participants' descriptions of medication histories illustrate this problem. A medication list can identify a medication, dosage, and status, but participants also wanted to know when a medication was started, why it was prescribed, whether the dosage changed, what symptoms or side effects followed, and why it was discontinued. Similarly, participants wanted laboratory results represented as trends and appointments represented as events containing decisions, questions, and follow-up actions.

We therefore characterize healthcare memory as *relational* rather than merely archival. Its fundamental unit is not an isolated record but a relationship among events.

For example:

- A medication can be connected to the condition for which it was prescribed;
- A medication change can be connected to a symptom or side effect;
- A laboratory result can be connected to a treatment decision;
- An appointment can be connected to its summary and follow-up actions;
- A patient observation can be connected to the encounter or treatment episode in which it became relevant.

Such relationships allow patients to reconstruct not only *what* happened, but also *when*, *why*, and *what happened afterward*. This is particularly important in DCC care because treatment decisions for one condition can affect the management of another.

Healthcare memory therefore provides a useful conceptual bridge between longitudinal health records and patient-generated health information. PGHD can capture information that may not appear in formal clinical documentation, but its long-term value depends

partly on whether that information remains interpretable within the patient's broader care trajectory. Context-preserving linkage can help maintain this interpretability.

5.3. Healthcare Memory as Patient Representation

Our findings further show that healthcare memory becomes especially important when patients are vulnerable or unable to fully represent themselves. Participants described emergency situations, postoperative recovery, and cognitively demanding appointments in which they were expected to recall medications, dosages, diagnoses, and prior treatments while simultaneously coping with illness or stress.

This finding extends the notion of patient-centered health information beyond empowerment and access. A patient-facing record can support patient participation when the patient is able to review and communicate information. Healthcare memory, however, also has value when the patient's ability to communicate is temporarily constrained.

In these circumstances, healthcare memory can function as a form of *patient representation*. The system does not replace the patient. Instead, it preserves information that can help represent the patient's history when direct recall is difficult.

This distinction is important because vulnerability is not limited to emergency departments. Participants described long appointments, complex treatment discussions, postoperative conversations, and situations in which family members could not attend as circumstances that made remembering difficult. Healthcare memory can therefore support continuity across a broader range of vulnerable moments.

The concept also helps explain why family members and caregivers emerged in participants' accounts. Healthcare memory is not always individually maintained. Family members may remember appointments, medications, symptoms, and treatment histories on behalf of patients. This suggests that continuity technologies should consider healthcare memory as potentially *distributed* across patients and trusted care partners.

A patient-centered system could therefore provide controlled mechanisms through which patients designate trusted individuals who can access relevant portions of their healthcare memory. Such sharing would need to preserve patient autonomy and privacy while supporting situations in which another person may need to communicate on the patient's behalf.

Recognizing healthcare memory as distributed also changes the design responsibility of patient-facing systems. They should support selective sharing with trusted others without requiring patients to surrender control over their complete records, and they should complement institutional information exchange rather than create another repository that patients must manually populate and curate. Where possible, capture and organization should be automated while patients retain the ability to validate, correct, annotate, and control what is shared.

5.4. AI as an Augmentation of Healthcare Memory

Participants' perspectives suggest a bounded role for AI in addressing these challenges. Rather than positioning AI as an autonomous clinical decision-maker, participants valued AI for organizing information, summarizing encounters, retrieving prior information, and helping make longitudinal histories understandable.

This distinction is important in light of concerns surrounding AI-supported healthcare systems, including hallucination or confabulation, context omission, privacy, temporal errors, and over-reliance [13,14]. The more consequential the clinical decision, the greater the potential harm when an AI system produces an inaccurate or incomplete representation of a patient's history.

Healthcare memory therefore provides a useful boundary for AI-supported functionality. AI can assist with the *information work* surrounding care while leaving diagnosis, treatment selection, and clinical judgment to patients and healthcare professionals.

Several AI-supported functions follow directly from participants' accounts:

- **Longitudinal summarization:** Generate concise summaries of changes across appointments, medications, symptoms, and laboratory results.
- **Contextual retrieval:** Retrieve relevant prior information in response to a patient's or provider's question while preserving its temporal context.
- **Change detection:** Identify meaningful changes in medication regimens, symptoms, laboratory trends, or treatment plans.
- **Appointment preparation:** Surface relevant prior events and unresolved questions before a clinical encounter.
- **Post-visit memory support:** Transform complex discussions into understandable summaries and follow-up actions.
- **Emergency information support:** Present critical medication, allergy, diagnosis, and treatment information when patients may be unable to communicate effectively.

These functions should not be interpreted as evidence that AI will necessarily improve clinical outcomes. Rather, they represent design opportunities derived from participants' perceived information and memory needs.

Importantly, AI-generated healthcare memory should also be *traceable*. Patients and providers should be able to determine where summarized information originated, distinguish documented information from generated interpretation, and correct errors. A healthcare-memory system should therefore prioritize transparency, provenance, user control, and the ability to inspect the underlying records supporting a summary.

Recent evaluations of clinical summarization reinforce the need for this bounded role. Although adapted language models have shown promise on clinical summarization tasks [23], systematic evaluation has identified gaps in the evidence supporting healthcare LLM applications, including safety and real-world evaluation [24]. Work specifically focused on clinical safety and hallucination assessment further highlights the importance of detecting omissions and unsupported statements in generated medical summaries [25]. Accordingly, our design implications emphasize source traceability, temporal context, correction, and human oversight. These safeguards are not optional additions to an otherwise complete AI feature; they are central requirements if generated content is to become part of a patient's longitudinal healthcare memory.

5.5. Design Implications for Healthcare-Memory Systems

Our findings suggest several design principles for patient-facing systems intended to support healthcare memory.

5.5.1. Design for Relationships, Not Only Records

Systems should represent meaningful relationships among medications, symptoms, laboratory results, appointments, decisions, and follow-up actions. Rather than displaying information exclusively as isolated lists, interfaces could provide timelines or linked views that allow patients to understand how events evolved.

5.5.2. Preserve "Why," Not Only "What"

Healthcare records frequently preserve what occurred without fully supporting later reconstruction of why a decision was made. Patient-facing systems should therefore preserve decision context when available, including treatment rationale, patient concerns, medication changes, and follow-up plans.

5.5.3. Support Memory Before, During, and After Encounters

Healthcare memory should not be designed only as an archive for retrospective review. It can support preparation before appointments, information access during encounters, and recall after visits. These three moments correspond to different memory demands and different opportunities for system support.

5.5.4. Design Explicitly for Vulnerable Moments

Emergency and high-burden situations should be treated as first-class design contexts. Systems should provide rapid access to high-value information without requiring patients to navigate complex interfaces or reconstruct their history manually.

5.5.5. Support Distributed Healthcare Memory

Patients should be able to selectively share relevant information with trusted family members, caregivers, and healthcare professionals. Sharing mechanisms should provide patients with control over who can access which information and for what purpose.

5.5.6. Minimize the Curation Burden

A healthcare-memory system should not simply shift documentation work from clinicians to patients. Wherever possible, information should be captured from existing records, patient-generated data, and encounters and then organized automatically. Provider feedback further suggests that memory-support tools should complement established clinical records rather than create a parallel source that depends on patients to keep a second medication or care record manually updated. Patients should primarily validate, correct, annotate, or add information rather than repeatedly recreate their medical histories.

5.5.7. Keep AI Bounded, Transparent, and Corrigible

AI should assist with organization, retrieval, summarization, and contextualization while preserving human oversight for clinical interpretation and decision-making. AI-generated summaries should identify their sources, expose uncertainty where appropriate, and allow patients and clinicians to correct errors. When summaries combine institutional records with patient-entered information, interfaces should make those sources distinguishable so that users can assess provenance and clinicians can review consequential information.

5.6. Theoretical Contribution

The concept of healthcare memory contributes a complementary perspective to existing work on patient portals, personal health records, patient work, PGHD, AI-supported health information systems, and informational continuity [19].

Informational continuity describes how information about past events and personal circumstances supports appropriate current care. Healthcare memory is narrower in one sense and more patient-facing in another: it focuses on the work of preserving, reconstructing, and mobilizing contextual relationships when continuity is incomplete or distributed across records, people, organizations, and personal recollection. Patient portals and PHRs primarily address *access*; patient work research emphasizes the *coordination burden* experienced by patients; PGHD research focuses on *capturing patient-generated information*; and AI research increasingly addresses *retrieval, summarization, and sensemaking*. Healthcare memory connects these concerns through the problem of *continuity of context*.

The central proposition is that continuity depends not only on whether healthcare information is available, but on whether the relationships that give that information meaning remain recoverable over time.

This perspective is particularly relevant for DCCs because patients must maintain continuity across multiple concurrent treatment trajectories. Healthcare memory therefore provides a conceptual lens for examining how patient-facing technologies can help individuals carry contextual knowledge from one encounter into the next.

We do not propose healthcare memory as a replacement for clinical records or a fully developed theory of chronic care. Rather, our findings use the concept to make visible a dimension of patient work that is often distributed across records, people, encounters, and personal recollection.

5.7. Implications for Future Research

The findings also suggest several directions for future research. First, future studies should examine how healthcare-memory interfaces affect patients' ability to prepare for and communicate during clinical encounters. Second, longitudinal deployments could investigate whether such systems reduce the perceived burden of maintaining healthcare information over extended periods.

Third, future work should examine how healthcare memory can be shared across trusted individuals while preserving privacy and patient control. This is particularly relevant for patients whose care involves family caregivers or other informal support networks.

Finally, AI-supported healthcare memory requires systematic evaluation of accuracy, provenance, temporal reasoning, transparency, and user trust. Future work should investigate how AI-generated summaries compare with source records and how patients and clinicians respond when AI representations are incomplete or incorrect.

5.8. Limitations

This study has several limitations. First, the sample was relatively small, consisting of 16 participants, including 10 provider-side participants and 6 patient participants. The provider-side strand also included varied professional and training backgrounds. These interviews therefore provide heterogeneous healthcare-side perspectives rather than a statistically representative account of any single profession or specialty.

Second, this study relied on participants' self-reported experiences and perceptions. Participants' positive or negative expectations regarding AI-supported healthcare memory do not establish that such systems would improve clinical outcomes, medication adherence, or patient safety.

Third, the interviews were role-specific and used different elicitation materials. Patient interviews focused on lived care-management experiences and a patient-facing application concept, whereas provider-side interviews included AI-supported medication-information and decision-aid scenarios and varied follow-up prompts concerning workflow, trust, empathy, and human oversight. We therefore interpret convergence across the two groups at the level of broader design requirements rather than as a standardized comparison of identical tasks.

Fourth, patient eligibility was based on having two or more chronic conditions that participants experienced difficulty managing, while recruitment materials framed those experiences within DCC care. We did not apply a separate quantitative measure of treatment discordance; DCCs should therefore be understood as the clinical and design framing of recruitment rather than as an independently validated classification for each patient participant.

Fifth, this study examined anticipated use and reactions to design concepts rather than evaluating a deployed healthcare-memory system longitudinally. Participants' expectations may therefore differ from actual behavior during sustained use.

Sixth, this study focused specifically on DCCs and therefore may not capture the full range of healthcare-memory needs experienced by patients with other health conditions or populations.

Finally, AI-supported healthcare memory introduces risks involving inaccurate summaries, missing context, privacy, and inappropriate reliance. These issues require empirical investigation before such systems can be considered for real-world clinical deployment.

6. Conclusions

Patients living with discordant chronic comorbidities face a continuity problem that extends beyond access to medical records. Across our interviews, participants described the difficulty of preserving, reconstructing, and communicating healthcare context across fragmented systems, repeated appointments, medication changes, and moments when they were least able to represent themselves. We conceptualize this challenge as *healthcare memory*: the ongoing work of preserving, reconstructing, and mobilizing clinically meaningful context across time, care settings, and episodes of vulnerability.

Our findings suggest that patients need more than a repository of records. They need support for preserving the context that makes healthcare information meaningful and usable—including why treatments changed, how symptoms evolved, what occurred during appointments, and what information may become critical during an emergency. Participants also identified a bounded role for AI in this process. Rather than replacing clinicians or making autonomous clinical decisions, AI was viewed as potentially valuable for organizing information, summarizing encounters, retrieving relevant history, and helping patients make sense of longitudinal care.

This work contributes a conceptual lens for understanding continuity in complex chronic care and a design agenda for patient-facing technologies. Future healthcare-memory systems should preserve relationships among healthcare events, support patient representation during vulnerable moments, accommodate trusted care partners, and use AI to augment rather than replace human judgment. By shifting attention from information access alone toward the preservation of context across time, healthcare memory offers a direction for designing digital health technologies that better reflect the lived realities of managing complex chronic conditions.

Author Contributions: Conceptualization, P.Y., Z.S. and T.O.; methodology, P.Y., Z.S., Y.J. and T.O.; software, P.Y.; formal analysis, T.O.; investigation, P.Y., Z.S., Y.J. and T.O.; resources, P.Y., Z.S. and T.O.; data curation, Z.S. and T.O.; writing—original draft, P.Y., Y.J. and T.O.; writing—review and editing, Z.S. and T.O.; supervision, T.O. All authors have read and agreed to the published version of the manuscript.

Funding: This project did not receive any funding

Institutional Review Board Statement: The study was conducted in accordance with the Declaration of Helsinki. The study was reviewed and approved by the University of Dayton Institutional Review Board (protocol IRB-FY2026-133, approval date 12 March 2026).

Informed Consent Statement: Informed consent was obtained from all participants before their interviews.

Data Availability Statement: All necessary data is reported in the findings section

Acknowledgments: During the preparation of this manuscript, the authors used ChatGPT, version 4.5, for text editing. The graphical abstract was prepared using Canva. The authors take full responsibility for the content of this publication.

Conflicts of Interest: The authors declare no conflicts of interest.

References

1. Tinetti, M.E.; Bogardus, S.T., Jr.; Agostini, J.V. Potential pitfalls of disease-specific guidelines for patients with multiple conditions. *N. Engl. J. Med.* **2004**, *351*, 2870–2874. [CrossRef]
2. Piette, J.D.; Kerr, E.A. The impact of comorbid chronic conditions on diabetes care. *Diabetes Care* **2006**, *29*, 725–731. [CrossRef]
3. Caldeira, C.; Gui, X.; Reynolds, T.L.; Bietz, M.; Chen, Y. Managing healthcare conflicts when living with multiple chronic conditions. *Int. J.-Hum.-Comput. Stud.* **2021**, *145*, 102494. [CrossRef]
4. Ancker, J.S.; Witteman, H.O.; Hafeez, B.; Provencher, T.; Van de Graaf, M.; Wei, E. The invisible work of personal health information management among people with multiple chronic conditions: Qualitative interview study among patients and providers. *J. Med. Internet Res.* **2015**, *17*, e137. [CrossRef]
5. Ancker, J.S.; Witteman, H.O.; Hafeez, B.; Provencher, T.; Van de Graaf, M.; Wei, E. "You get reminded you're a sick person": Personal data tracking and patients with multiple chronic conditions. *J. Med. Internet Res.* **2015**, *17*, e202. [CrossRef]
6. World Health Organization. *Continuity and Coordination of Care: A Practice Brief to Support Implementation of the WHO Framework on Integrated People-Centred Health Services*; World Health Organization: Geneva, Switzerland, 2018; ISBN 978-92-4-151403-3.
7. Irizarry, T.; DeVito Dabbs, A.; Curran, C.R. Patient portals and patient engagement: A state of the science review. *J. Med. Internet Res.* **2015**, *17*, e148. [CrossRef]
8. Lyles, C.R.; Nelson, E.C.; Frampton, S.; Dykes, P.C.; Cemballi, A.G.; Sarkar, U. Using electronic health record portals to improve patient engagement: Research priorities and best practices. *Ann. Intern. Med.* **2020**, *172*, S123–S129. [CrossRef]
9. Brands, M.R.; Gouw, S.C.; Beestrum, M.; Cronin, R.M.; Fijnvandraat, K.; Badawy, S.M. Patient-centered digital health records and their effects on health outcomes: Systematic review. *J. Med. Internet Res.* **2022**, *24*, e43086. [CrossRef]
10. Kawu, A.A.; Hederman, L.; Doyle, J.; O'Sullivan, D. Patient generated health data and electronic health record integration, governance and socio-technical issues: A narrative review. *Inform. Med. Unlocked* **2023**, *37*, 101153. [CrossRef]
11. Tiase, V.L.; Hull, W.; McFarland, M.M.; Sward, K.A.; Del Fiol, G.; Staes, C.; Weir, C.; Cummins, M.R. Patient-generated health data and electronic health record integration: A scoping review. *JAMIA Open* **2020**, *3*, 619–627. [CrossRef]
12. Bardhan, J.; Roberts, K.; Wang, D.Z. Question answering for electronic health records: Scoping review of datasets and models. *J. Med. Internet Res.* **2024**, *26*, e53636. [CrossRef]
13. Pakianathan, P.V.S.; Islambouli, R.; Branco, D.; Schmidt, A.; Guerreiro, T.; Smeddinck, J.D. Exploring AI-augmented sensemaking of patient-generated health data: A mixed-method study with healthcare professionals in cardiac risk reduction. *arXiv* **2026**, arXiv:2602.05687. [CrossRef]
14. Sayres, R.; Chen, K.; Jain, A.; Thompson, M.; Richina, J.; Yin, X.; Hu, J.; Zhang, F.; Lou, B.; Sanchez, M.; et al. Evaluating the utility of personal health records in personalized health AI. *arXiv* **2026**, arXiv:2605.18937. [CrossRef]
15. Alomar, D.; Almashmoum, M.; Eleftheriou, I.; Whelan, P.; Ainsworth, J. The impact of patient access to electronic health records on health care engagement: Systematic review. *J. Med. Internet Res.* **2024**, *26*, e56473. [CrossRef]
16. Osovskaya, I.; Blandford, A.; Potts, H.W. W. A systematic review of the effect of personal health records on patient activation. *Digit. Health* **2025**, *11*, 20552076251315295. [CrossRef]
17. Damen, D.J.; Schoonman, G.G.; Maat, B.; Habibović, M.; Krahmer, E.; Pauws, S. Patients managing their medical data in personal electronic health records: Scoping review. *J. Med. Internet Res.* **2022**, *24*, e37783. [CrossRef]
18. Thompson, M.J.; Reilly, J.D.; Valdez, R.S. Work system barriers to patient, provider, and caregiver use of personal health records: A systematic review. *Appl. Ergon.* **2016**, *54*, 218–242. [CrossRef]
19. Haggerty, J.L.; Reid, R.J.; Freeman, G.K.; Starfield, B.H.; Adair, C.E.; McKendry, R. Continuity of care: A multidisciplinary review. *BMJ* **2003**, *327*, 1219–1221. [CrossRef]
20. Peeler, A.; Nelson, K.; Agrawalla, V.; Badawi, S.; Moore, R.; Li, D.; Street, L.; Hager, D.N.; Himmelfarb, C.D.; Davidson, P.M.; et al. Living with multimorbidity: A qualitative exploration of shared experiences of patients, family caregivers, and healthcare professionals in managing symptoms in the United States. *J. Adv. Nurs.* **2024**, *80*, 2525–2539. [CrossRef]
21. Sumner, J.; Ng, C.W.T.; Teo, K.E.L.; Peh, A.L.T.; Lim, Y.W. Co-designing care for multimorbidity: A systematic review. *BMC Med.* **2024**, *22*, 58. [CrossRef]
22. Simpson, E.; Brown, R.; Sillence, E.; Coventry, L.; Lloyd, K.; Gibbs, J.; Tariq, S.; Durrant, A.C. Understanding the barriers and facilitators to sharing patient-generated health data using digital technology for people living with long-term health conditions: A narrative review. *Front. Public Health* **2021**, *9*, 641424. [CrossRef]
23. Van Veen, D.; Van Uden, C.; Blankemeier, L.; Delbrouck, J.-B.; Aali, A.; Bluethgen, C.; Pareek, A.; Polacin, M.; Reis, E.P.; Seehofnerová, A.; et al. Adapted large language models can outperform medical experts in clinical text summarization. *Nat. Med.* **2024**, *30*, 1134–1142. [CrossRef]
24. Bedi, S.; Liu, Y.; Orr-Ewing, L.; Dash, D.; Koyejo, S.; Fries, J.A.; Wornow, M.; Swaminathan, A.; Lehmann, L.S.; Hong, H.J.; et al. Testing and evaluation of health care applications of large language models: A systematic review. *JAMA* **2025**, *333*, 319–328. [CrossRef]

25. Asgari, E.; Montaña-Brown, N.; Dubois, M.; Khalil, S.; Balloch, J.; Au Yeung, J.; Pimenta, D. A framework to assess clinical safety and hallucination rates of LLMs for medical text summarisation. *Npj Digit. Med.* **2025**, *8*, 274. [CrossRef]
26. Salmona, M.; Lieber, E.; Kaczynski, D. *Qualitative and Mixed Methods Data Analysis Using Dedoose: A Practical Approach for Research Across the Social Sciences*; SAGE Publications: Thousand Oaks, CA, USA, 2019.
27. Foley, G.; Timonen, V. Using grounded theory method to capture and analyze health care experiences. *Health Serv. Res.* **2015**, *50*, 1195–1210. [CrossRef]

Disclaimer/Publisher's Note: The statements, opinions and data contained in all publications are solely those of the individual author(s) and contributor(s) and not of MDPI and/or the editor(s). MDPI and/or the editor(s) disclaim responsibility for any injury to people or property resulting from any ideas, methods, instructions or products referred to in the content.