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# Narrativizing care: Exploring narrative medicine for designing AI-mediated remote patient monitoring

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**Abstract**: This paper examines how care is enacted and understood within Remote Patient Monitoring (RPM) systems, which promise efficiency and autonomy but fragment care into data flows. Drawing on ethnographic fieldwork in a Dutch hospital's RPM program for myocardial infarction patients, we analyze how stories, reassurance, and contextual interpretation unfold alongside structured data, revealing the promise and limits of AI-mediated care. Using narrative medicine's triad of attention, representation, and affiliation, we identify how extractive data models overlook patients' lived realities and relational dimensions of care. We propose three design provocations for exploring the application of AI in RPM systems: narrative layers which situate data within evolving stories, shared story construction which supports co-authored records, and temporal storytelling which captures care as an ongoing narrative. We argue narrativization is central and not supplementary to relational care, and position narrative medicine as a design lens for creating AI infrastructures that sustain human connection.

**Keywords**: RPM, Relational Care, Narrative Medicine, Artificial Intelligence (AI)

## 1. Introduction

In technology-mediated healthcare, the very systems that promise empathy and personalization often operate through extractive logics of prediction, efficiency, and control (Ruckenstein & Schüll, 2017; Neff et al., 2017). As digital systems such as Remote Patient Monitoring (RPMs) and AI tools become central to healthcare delivery, a key challenge persists: how can relationality be made tangible and sustained in everyday clinical practice?

Narrative offers a compelling entry point. Feminist and Indigenous design literatures have long invoked storytelling as a mode of inclusion and resistance (Bardzell, 2010; Lindström &

Ståhl, 2014; Tunstall, 2013), yet without treating it as a structured or designable practice in its own right.

Our exploratory study approached the embedding of AI in an RPM program by examining critical gaps and observing emerging AI initiatives aimed at system enhancement. We explored how relational care is made visible, sustained, or disrupted in practice through the everyday actions of clinicians and staff, and through the ways AI is envisioned to support or extend relationality. Contextual notes, reflections, and caregiver insights represent informal acts of narrativization through which clinicians and staff reach beyond data to maintain relational continuity with the patient's story.

Our findings show that the clinician–patient relationship is stretched thin within the current RPM system, with staff relying on fragmented solutions, system notes, phone calls, contextual reflections, and time references, to capture patient context and sustain connection. The relational dimension of care was observed to be at even greater risk as AI-mediated solutions increasingly emphasize predictive diagnosis and customized communication. Our analysis reveals a widening 'narrative gap' between the structured data driving AI and the storytelling practices through which clinicians and patients sustain relational understanding.

To explore how this gap might be bridged, we turned to narrative medicine (Charon, 2001; 2006), which advances narrative competence as the ability to recognize, absorb, and be moved by patients' stories. Narrative medicine reframes the clinical encounter as a co-authored narrative in which care is enacted through attentiveness to life stories, silence, temporality, and meaning-making. Crucially, it positions storytelling not as an ancillary "soft" dimension but as a core modality of clinical reasoning and relational care, arguing that without it, both suffering and healing risk becoming fragmented and unintelligible (Charon, 2004).

To reimagine AI systems that uphold the relational dimensions of care, we advance three design provocations: Narrative Layering, Shared Story Construction, and Temporal Storytelling. These provocations surface a new set of research questions: What forms of care labour remain unsupported in AI-mediated clinical systems? How might AI meaningfully accommodate temporality, emotion, and interpretation as dimensions integral to care? And how might narrative itself be reframed as a relational and infrastructural practice and not as a secondary concern? In posing these questions, we do not seek to resolve the tension between AI and relational care, but to argue that narrative may be central to understanding how care is being shaped in an increasingly algorithmic mediated future.

This paper offers a conceptual and ethnographically grounded contribution to the design of AI in healthcare. By centring the clinician–patient relationship as a site of design intervention, we argue for a shift from AI systems that merely extract and process data

toward those that amplify human connection through story. In doing so, we contribute to ongoing debates on AI in health and narrative care in design, offering a lens for developing clinical technologies that centre not only functionality but also presence.

## 2. Related work

### *2.1 The relational aspect of care in design and HCI*

The design of care technologies has become a central concern within HCI, especially through critical perspectives that view care not merely as a functional task but as a deeply relational, affective, and political practice (Tronto, 1993; Puig de la Bellacasa, 2011; Wilson et al., 2024). The emphasis on the relational dimensions of care, how it is sustained through networks, interactions, and shared responsibilities within communities (Light, 2014; Schorch et al., 2016; Tixier et al., 2018) is also aligned with notions of care entanglements (Helms & Fernaeus., 2021) and care ecologies (Bowlby & McKie, 2019). Designing for care therefore requires attention not only to individual needs or functional outcomes but to the relationships and infrastructures that constitute a care ecosystem.

In healthcare, as care becomes increasingly mediated through digital systems, scholars have argued that relationality itself is reconfigured by data infrastructures that redistribute attention, responsibility, and empathy (Pols, 2012; Mort et al., 2015; Oudshoorn, 2011). These shifts raise new questions about how technologies participate in the moral and affective work of care. Despite this rich body of work, the relational aspect of care in HCI and design often remains implicit, treated as a value, orientation, or ethical backdrop rather than as a concrete theoretical or practical framework. Scholarship has convincingly shown why care matters and how it destabilizes dominant epistemologies, but less attention has been given to how relational care can explicitly inform or shape design practices, methodologies, and systems.

However, scholars argue that HCI must also move beyond solutionist framings that reduce care to efficiency or problem-solving. Technologies introduced uncritically into domestic contexts can disrupt existing care relationships (Vines et al., 2013), highlighting the need for ‘counterventionist’ approaches that foreground relational complexity (Wilson et al., 2024). Responsive care actions, intentional attentiveness to relationships grounded in reciprocity and mutual concern, offer an alternative orientation for design (Tronto, 1993; Brugère, 2019; Feder Kittay, 2011; Phillips, 2007; Hsu, 2025). This perspective positions individuals as embedded within broader networks of interdependence (Gary, 2022) and frames design itself as a practice of sustaining and strengthening those connections.

### *2.2 Relational care in designing RPMs*

RPM systems are increasingly positioned as solutions to healthcare workforce shortages. Yet their design often privileges clinical functionality over the relational and human dimensions of care. This reveals a critical gap: while HCI scholarship has begun to acknowledge the

importance of relational aspects of care in RPM (e.g., Offerman, 2024), there has been little sustained inquiry into what these relational dimensions entail or how they might be integrated into design frameworks.

In nursing philosophy, Kari Martinsen distinguishes three interdependent dimensions of caring: the practical, the relational, and the moral. The practical encompasses concrete actions responsive to immediate needs; the relational involves building compassionate connections attentive to lived experience; and the moral emphasizes dignity and autonomy, situating care as an ethical partnership rather than a unidirectional service. Martinsen's thinking is grounded in Merleau-Ponty's phenomenology (1964), which frames the body as central to perception and interaction. From this view, care is not reducible to clinical procedures but is inseparable from embodied, emotional, and existential experience. Martinsen (2006) further extends this phenomenological perspective to argue that caregiving must respect the full complexity of human beings – physical, emotional, and social.

## *2.3 Narrative in design as a Form of relationality*

Narrative provides a critical lens for understanding how design can mediate relationships. Research in design increasingly frames narrative not only as communication tools but as relational infrastructures that shape how people experience and sustain connections through interactions with design artifacts and systems. Grimaldi, Fokkinga, and Ocnarescu (2013) show that narrative operates across multiple layers, from minimal event representations to full dramatic arcs, creating empathy, sparking reflection, and connecting users, designers, and artifacts. Building on this, Grimaldi's (2020) *Narratives in Design Toolkit* makes these relational qualities tangible, helping designers articulate not only what a product does but what it is about, its meanings, relationships, and temporal trajectories.

More recent scholarship situates narrative within feminist and relational ontologies, viewing it as a social practice of meaning-making that organizes how designers and users live with technologies and one another (Helms, 2023). In this framing, narrative not only describes but *performs* care, intimacy, and responsibility, surfacing the affective and situated dimensions of design and aligning with anthropological and STS approaches that treat care as a mode of world-making.

## *2.4 Narrative medicine as a design lens for relational care*

Narrative medicine emerged as a corrective to biomedicine's fragmentation of illness into organs and data, re-centring practice on stories, how patients and clinicians make meaning of suffering, care, and recovery (Charon, 2001; 2004; 2006). Its premise is that narrative competence, the ability to recognize, interpret, and be moved by patients' stories – constitutes a clinical skill as essential as diagnosis or treatment.

At its core, narrative medicine is structured around the triad of attention, representation, and affiliation. Attention entails disciplined presence and attunement to what is said and unsaid; representation translates perception into reflection or text, making meaning available for shared understanding; and affiliation names the relational outcome, a durable connection grounded in recognition and non-abandonment (Charon et al., 2016). These interdependent movements reveal care as interpretive, embodied, and sustained through acts of mutual recognition.

Although most applications of narrative medicine remain pedagogical, cultivating empathy and interpretive skill through reading, writing, and dialogue, its conceptual grounding offers fertile parallels for design. Narrative medicine models how structured interpretive practices can sustain relationality under pressure and how storytelling operates as infrastructure for connection. Reframed through design, the triad suggests modes of designing that attend, represent, and affiliate: technologies that listen before intervening, render experience visible without reduction, and foster continuity rather than fragmentation. Thus, narrative medicine provides a relational framework for reimagining AI-mediated systems of care as sites of shared meaning-making rather than data exchange.

## 3. Research context

This study was conducted as an exploratory, ethnographically informed investigation of an existing Remote Patient Management (RPM) system within a hospital in the Netherlands, where a universal public health system positions RPM programs as part of state-supported care. It examined how the ongoing integration of AI technologies reshapes relationships and responsibilities evolve as care becomes increasingly mediated by digital infrastructures and predictive logics. The study ultimately aimed to explore conditions for designing future AI-mediated clinical systems that can preserve relational care.

### *3.1 Research setting*

Our empirical focus was on the hospital's RPM program, introduced during the COVID-19 pandemic to support remote follow-up for cardiovascular and other chronic conditions. It has since expanded to more than twenty care tracks and is now fully integrated into the Electronic Health Record (EHR) system. Patients receive connected devices – such as blood pressure monitors, ECG patches, smart scales, and step counters – that continuously transmit data to the hospital's digital platform.

The RPM operates through both physical and digital infrastructures: a staffed office for device logistics, onboarding, and in-person visits, and a digital ecosystem consisting of a clinician-facing dashboard and a patient app. The dashboard extends the EHR, consolidating patient data into color-coded tables that allow clinicians to track trends, add notes, and initiate follow-up.

Fieldwork took place mainly in the RPM and cardiology offices, with occasional access to clinical spaces, while patient perspectives were examined indirectly through anonymized data logs, documentation, and staff narratives.

### *3.2 Data collection*

Over six months of ethnographic fieldwork, the first author engaged closely with the RPM system through *in-situ* and participant observations, informal conversations, and 14 semi-structured interviews with eight participants across clinical, technical, and administrative roles, most of whom were interviewed multiple times. Participants included a cardiologist (P1) and a psychologist involved in the system's design (P2), two medical students (P3, P4), the RPM office lead (P5), and three system designers developing AI-driven features (P6, P7, P8). They also supported the study by sharing data reports, dashboard walkthroughs, and internal documents.

### *3.3 Data analysis*

The ethnographically informed design research approach allowed our study to engage closely with the everyday practices surrounding the RPM system. A thematic analysis (Braun & Clarke, 2006) was conducted by the first author on interview transcripts and field observation notes, identifying recurring patterns and underlying tensions in how the system operates and how emerging AI integrations reshape the relational aspect of care. These tensions emerged as the first author compared interview accounts with observed practices, revisiting and refining codes while documenting analytic notes throughout the process. The analysis was complemented by a review of existing care-path journey maps, workflow and protocol documents, and a descriptive examination of staff-generated contextual data logs, which helped triangulate the findings. The main findings were then synthesized through the lens of narrative medicine's core pillars, which informed three design provocations later discussed with P1, P5, and P6.

## 4. Findings: Tensions between system design and lived practice

We have organized the findings around three key tensions that emerge between the design of the RPM system, both in its current and envisioned states, and the lived realities of those engaging with it. These tensions reveal discrepancies between the system's underlying mental model and the everyday practices and experiences of clinicians, staff, and patients. The tensions reveal how AI initiatives aim to streamline communication and boost patient engagement, how the ambition of promoting self-management takes shape within the system, and how efficiency mechanisms, such as predictive columns, can ultimately strain interpersonal continuity.

### *4.1 Tension 1: Communication - connection*

The RPM system was originally modelled on the workflow of a senior head nurse, whose relational sensibility continues to anchor the care pathway. While the ambition to streamline compassionate communication promises greater engagement, the evidence shows that staff and clinicians' efforts extend far beyond information exchange to sustain the connection.

The current priority is to develop active, personalized, and engaging messaging within the app – intended to ease clinicians' workload by handling non-medical conversations while improving patient engagement.

> "You talk to the patient, you explain... 'Is it normal? Is it not normal? What can you do as a patient?' And these elements might also be done by AI. That would really unburden me... because my inbox is filled with emails from patients. If many of these questions are already answered by AI, that would help me a lot? — P1

Relational care in the RPM system depends less on technical expertise than on human presence and attentiveness, as practitioners bridge the emotional gaps left by the data-driven system through informal acts of understanding, reading between data points, tracing relationships, and following up with empathy.

The RPM device kit and app are introduced to patients through an onboarding process designed and continually refined by the RPM office staff. Despite regular communication, patients often report feeling disconnected once their care transitions to the system. Office staff work to maintain relationships within institutional protocols, yet many of their interactions extend beyond official workflows. In doing so, they have become the primary holders of relational care.

> "A major part of our communication involves calming patients and providing reassurance, especially when they panic about missing measurements or device malfunctions." — P5

Several ongoing projects aim to integrate AI-assisted empathic communication – using nudges and tailored messages based on patient personas to enhance engagement. Yet, as field observations reveal, many of the most distressing moments in the patient journey stem from emotional rather than informational needs.

> "A major transition from hospital to home in the first instance is quite intense... patients call it the black hole because it can feel quite lonely and quite scary." — P2

## *4.2 Tension 2: Autonomy - recognition*

Designed to promote independence, the RPM risks translating care into compliance. Developing a healthy lifestyle and autonomy in health management, requires foundational behavioral change in patients, particularly for those recovering from surgeries such as heart procedures.

> "So, in five years, I hope lifestyle medicine will be seamlessly supported by the RPM system. With its measurements, patients will be able to see the impact of their actions, what they're doing right or what they need to adjust. But it's not just about the data. The presence of a medical service center, or coaching center, will be equally important. Patients will receive guidance on their behavior, their choices, their lifestyle. And this, in turn, will lead to better lives. A better quality of life, less disease, more health… that's the ultimate goal."— P1

The app and office area, not resembling a medical environment, also reinforce the idea that the RPM is less clinical and more lifestyle. Equipped with tools like blood pressure monitors

and step counters, the RPM system encourages patients to actively monitor their health as they transition from hospital to home. The reality based on our findings shows the complexities in patient behavior that cannot be captured through their medical data.

While some patients take initiative and seek help when they notice abnormal readings, others may disregard these signs as insignificant, potentially delaying necessary medical intervention. To mitigate this, the system includes periodic reviews, where patient data is assessed every three weeks. While this approach offers a layer of oversight, it also raises questions about the potential for delays in addressing urgent health concerns. The RPM system's success ultimately relies on patients' willingness to actively engage with the resources provided.

> "A lot of people don't like feeling like a patient, and using the RPM can be confronting when it comes to that. And their adherence is such a personal story, it's hard to summarize why it happens." — P1

Systems like the RPM promote the narrative that, despite having had a heart attack, patients can regain control over their disease through the lifestyle choices they make. However, for individuals with chronic diseases or those in vulnerable situations, the idea of "lifestyle management" becomes more complicated.

### *4.3 Tension 3: Efficiency – continuity*

The fieldwork revealed a continuous negotiation between two coexisting logics within the remote RPM system: the logic of efficiency, which structures and justifies its technological design through optimization of workforce and clinical effort, and the logic of relational continuity, enacted in the daily, often improvised practices of clinicians and staff.

Efficiency manifests through structured processes, predictive columns, automated alerts, and tri-weekly data reviews intended to enhance oversight and enable early intervention. Clinicians described efficiency as a practical necessity within a healthcare system under pressure. The division of labour between the RPM office and the Medical Service Centre (MSC) institutionalizes this model: the office, staffed by non-medical personnel, manages onboarding, troubleshooting, and technical support, while the MSC handles clinical inquiries. Clinicians and staff explained this separation as "the right skill set at the right spot," explicitly designed to maximize resources and reduce clinical burden.

During a series of data walkthroughs with the RPM team, longitudinal patient dashboards were analyzed to trace behavioural and emotional patterns over time. One case, shared by P3, involved a 58-year-old woman recovering from a myocardial infarction who remained in the program for more than two years, well beyond the average duration. Her data trail reflected strong initial adherence to the prescribed routine: daily blood-pressure readings, ECG measurements, and step counts. The early months displayed stability and consistent feedback loops with staff. The patient data showed how she followed the protocol as a "safety net" that provided reassurance and structure. Over time, however, her data revealed

escalating anxiety: multiple consecutive measurements taken within minutes, frequent spikes in blood pressure, and repeated messages requesting confirmation that the readings were normal. Technical disruptions, battery failures, login errors, and delayed support coincided with a visible decline in her measurement frequency. As attention decreased and feedback loops thinned, her once-dense data pattern turned sparse.

Across the dataset, tri-weekly or monthly review cycles are protocol-based solutions for continuous monitoring of patients' data, which might create a gap between patients' contextual realities and institutional responses. The staff informally use an add-on to the dashboard called "sticky notes" as micro-narratives to preserve continuity in a patient's journey.

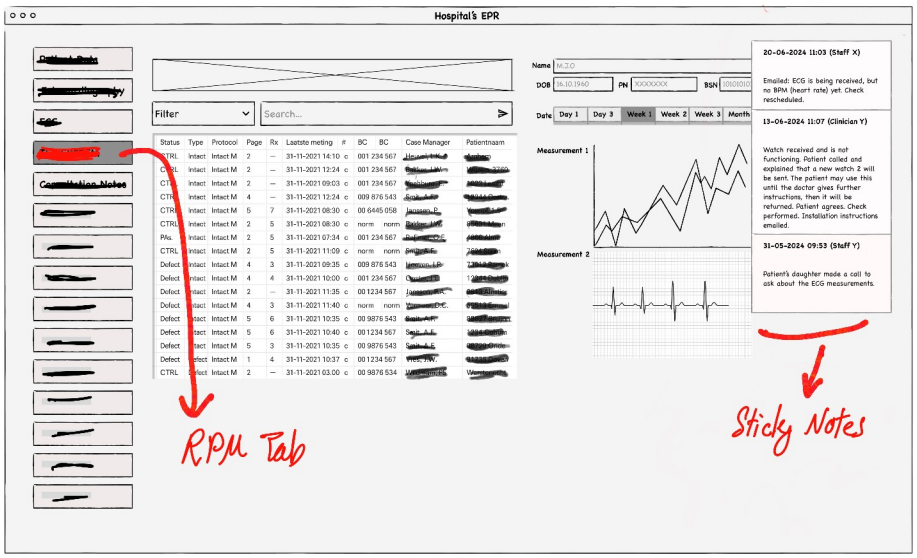


*Figure 1.* An anonymized reconstruction of the RPM dashboard view, highlighting the sticky notes used by staff to capture contextual and relational details beyond structured data.

## 5. Design provocations: Responding to the narrative gap

Digital health systems such as RPM platforms are increasingly organized around optimization to streamline communication, automate empathy, and promote self-management. However, our findings reveal how these same logics fragment the relational fabric of care, producing what we call a narrative gap between structured data and the lived, storied realities of illness. This echoes critiques within HCI and design that digital infrastructures redistribute attention and responsibility in ways that risk eroding empathy and continuity (Pols 2012; Mort et al. 2015; Wilson et al. 2024).

The three tensions identified in our analysis between connection and communication, autonomy and recognition, and efficiency and continuation, each reveal how relational care is stretched within data-driven infrastructures. As clinicians and patients grapple with sustaining coherence and connection across these digital interfaces, narrative medicine offers a lens to reimagine how relational care might be enacted through attention, representation, and affiliation (Charon, 2006). Drawing on these principles, we propose three design provocations: Narrative Layers, Shared Story Construction, and Temporal Storytelling, to explore how AI might be designed to uphold rather than erode the relational dimensions of care within RPM systems.

## *5.1 Design provocation 1: Narrative layers*

The first tension, between connection and communication, revealed how relational care is sustained through informal acts of reassurance and attentiveness that remain invisible within the RPM system. Clinicians and staff filled the gaps left by digital workflows and asynchronous communication, reading between data points, calming fears, and sustaining connection through discretionary labour. Narrative medicine's principle of attention reframes these gestures as clinical skill: the ability to listen, notice and remain attuned to the patient as a whole person (Charon, 2006).

This echoes design research that treats care as affective infrastructure – distributed and often unseen work that keeps systems functioning (Helms & Fernaeus, 2021, Hsu et al., 2025). Narrative layers respond by proposing infrastructures that integrate structured data with the contextual and emotional fragments of patient life. Rather than relegating sticky notes, calls, or reflections to the margins, such systems would treat them as essential elements of the patient's evolving story. A system designed with narrative layers would not only chart blood pressure trends but also acknowledge the anxieties that lead to over-measurement, the reassurance that calms panic, or the contextual struggles (like family involvement or technical barriers) that shape adherence.

Drawing on examples where shared data fosters relational care (Kaziunas et al., 2017), annotated symptom logs make data dialogic, and narrative interfaces frame data around meaningful episodes (Raj et al., 2023), Large Language Models (LLMs) could act as connective agents, weaving together physiological measures, clinician and staff notes, and patient reflections into short, contextualised summaries. In this way, narrative layers hold together fragments that currently fall through the cracks of digital monitoring to support communication as an ongoing act of attentive presence while providing a sense of being heard.

## *5.2 Design provocation 2: Shared story construction*

The second tension, between autonomy and recognition, highlighted how patients are encouraged toward self-management and lifestyle change but can often feel reduced to data points. Within this system, autonomy risks becoming synonymous with compliance. Narrative medicine's principle of representation offers a counterpoint to turn symptoms, emotions and contexts into stories that can be shared and acted upon (Charon, 2006).

Within the RPM system, clinicians' notes perform this interpretive work but are rarely co-authored with patients. Drawing on design research that frames narratives as relational infrastructures (Grimaldi, 2020; Grimaldi et al., 2013) and on work advocating for collaborative documentation (Tixier et al., 2018), shared story construction reimagines documents as a shared narrative process.

LLMs could support this by generating plain-language summaries that merge metrics with reflections and enable patients to annotate or respond, turning medical records into living artifacts of care. This reframes autonomy not as self-monitoring but as authorship, enabling patients the ability to participate in how their illness is represented. Shared story construction could balance autonomy with recognition, preserving individuality and strengthening collaborative sense-making between clinicians and patients.

## *5.3 Design provocation 3: Temporal storytelling*

The final tension, between efficiency and continuation, revealed how optimization logics compress care into episodic tasks that interrupt relational continuity. Narrative medicine's principle of affiliation reminds us that care is not only about intervention but companionship and sustained trust over time (Charon, 2001; 2006).

Building on design research that frames narratives as temporal infrastructures connecting lived experience, technology and meaning (Lindstrom & Ståhl, 2014; Grimaldi, 2020), temporal storytelling reimagines communication in RPM systems as a narrative unfolding over time. It proposes infrastructure that accumulate, revisit and evolve patients' stories as continuous wholes, bringing the distinct temporalities of patients, clinicians and institutions (Martinsen, 2006; Pols, 2012).

LLMs could sustain longitudinal coherence by linking past experiences, present conditions, and future possibilities to help situate daily data within broader arcs of meaning. Instead of issuing isolated nudges, AI could sustain narrative continuity that affirms the relational work of care. In this way, temporal storytelling reframes efficiency as the capacity to preserve affiliation and to keep the story of care alive.

## *5.4 LLMs as Narrative Mediators: Potential and Limitations*

Across these provocations, LLMs emerge as narrative mediators that could hold, connect and reframe the fragments through which relational care unfolds. Their generative capacities enable designers to explore new ways to weave structured and unstructured data into living records that sustain attention, representation and affiliation. However, their potential is not without limitations. As Ruckenstein and Schüll (2017) note, the datafication of health risks substituting responsiveness with simulation. LLMs may mimic empathy without understanding, producing the illusion of relation while obscuring the absence of genuine presence. They also raise ethical questions related to authorship, privacy and bias.

Designing AI for narrative care therefore requires caution. LLMs should not replace clinical listening but help scaffold it in a way that makes relational labour visible, supports reflection, and sustains coherence across time. Narrative competence cannot be automated, but it

could potentially be supported through systems designed to centre narratives as central to the practice of relational care.

## 5. Conclusions and future work

This paper argues that narrative is not ancillary to clinical work but constitutive of it, reframing narrative medicine as a design lens for AI in RPM systems. Everyday fragments – sticky notes, reassurance calls, informal reflections – show that narrative competence has a design analogue: noticing, interpreting, and holding stories across shifting tempos of care. Our three provocations explore how AI might support this work not as a surrogate clinician but as a narrative mediator.

Future research could prototype and evaluate the three provocations in collaboration with clinicians, staff, and patients — testing narrative layers, co-authored documentation, and temporal story views against measures of workload, interpretive quality, and perceived continuity. The provocations may also offer transferable guidance for technical designers and developers working on patient data-driven systems in adjacent domains.

Narrative medicine carries practical and ethical constraints - time, confidentiality, and authorship among them - yet as health systems accelerate and continuity is attenuated, narrative practices become increasingly essential for staying connected to patients and honoring what they share.

The findings of this study suggest that relational care was never absent from the RPM system but consistently enacted at its margins — through informal documentation, reassurance practices, and the interpretive labour of clinicians and staff working beyond the boundaries of structured data. The design provocations offered a means of interrogating how such labour might be structurally supported rather than incidentally performed. As AI becomes increasingly embedded in clinical infrastructures, the critical question shifts from whether algorithmic systems can approximate empathy to whether they can be designed to sustain the narrative conditions under which relational care becomes possible.

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