

Sharing the Care: Investigating How Conversational AI Might Facilitate Coordination Among Home Care Workers and Family Caregivers

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ABSTRACT

This paper presents a qualitative study with 17 participants that uses video elicitations to investigate how conversational AI agents driven by large language models might support “*shared care*,” or coordination of home-based care among family caregivers (FCs) and home care workers (HCWs) who care for the same care recipient (CR). Participants saw conversational AI as a promising tool that might help streamline communication, coordinate shift handovers, bridge language gaps, and support onboarding of new or substitute caregivers. That said, caregivers assumed AI agents would inevitably make mistakes and should thus be designed to signal uncertainty and make it easy to report errors. More broadly, participants discussed how AI agents designed for sensitive home care contexts will need to explicitly preserve the human essence of care, minimize extra data work that might distract from caregiving, and always complement—not replace—human judgment.

CCS CONCEPTS

• **Human-centered computing** → **Empirical studies in HCI**.

KEYWORDS

artificial intelligence, AI, large language models, LLMs, chatbots, conversational AI, AI agents, home health care, older adults, well-being, home care workers, family caregivers, care coordination, shared care.

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1 INTRODUCTION

The global population is aging, with many countries experiencing substantial growth in the number of older adults [91, 132]. In the United States (U.S.), where our work is situated, the number of adults over the age of 65 is projected to almost double by 2050 [120]. As people age, most would prefer to remain at home and “*age in place*” [110, 125], which often requires support from caregivers¹ to manage health needs and functional limitations. While it was previously assumed that most older adults are cared for by *either* family caregivers (FCs) or paid home care workers (HCWs), evidence suggests a growing proportion of care recipients (CRs) receive support from *both* [100]. Prior work calls this “*shared care*” [104], with surveys of U.S. households suggesting that a third of CRs have this caregiving arrangement [104].

Sharing the burdens of caregiving may provide many benefits. Research suggests that offloading personal or medical care tasks to HCWs may reduce FCs’ workload and stress [94]. For their part, HCWs have reported greater job satisfaction and a stronger sense of meaning in their work when they are empowered to perform a broader scope of care [106]. However, despite the prevalence and importance of shared care, most research on caregivers has focused on *either* FCs [15, 43, 127] or HCWs [64, 74, 116], with rare exceptions (e.g., [17]). Little work has examined coordination among these different types of caregivers as they care for the same CR.

Coordinating quality care delivery to CRs in their homes is immensely challenging [55, 69]. FCs and HCWs must facilitate the day-to-day management of CRs’ personal care, monitor and treat complex medical conditions, perform household maintenance, manage out-of-home healthcare logistics (e.g., medical and other appointments), and more [9, 35, 45]. These responsibilities often need to be coordinated across several FCs and HCWs (i.e., night shifts, weekends) [94, 105]. This can make it difficult to determine who is responsible for specific tasks and how care will be delivered or communicated back to the medical team [17, 112].

We present a qualitative study with 17 participants (nine FCs and eight HCWs) that examines how LLM-driven conversational AI agents (hereafter, agents) might support coordination among

¹Throughout the paper, we use the term “*caregivers*” to encompass both family caregivers and home care workers, unless otherwise specified.

FCs and HCWs who care for the same CR. Recent advances in LLM-based technologies [57] suggest that these tools' natural language interfaces and ability to capture, synthesize, and communicate information may make them well-suited to supporting flexible task management and communication across home care teams [98]. However, understanding stakeholders' perspectives and exploring potential concerns is essential if we want to create agents that are appropriate for this sensitive and high-stakes context, where the people expected to use these AI systems are neither clinical nor AI experts. To ground our explorations in everyday care coordination tasks, we created video elicitations [72] depicting hypothetical roles for agents to help caregivers track care tasks, summarize care delivered, manage changes in the CRs' health, and assist with shift handover.

Our findings suggest both HCWs and FCs believe that agents could make shared care more organized, connected, and trustworthy. Participants wanted care plans to act as living, shared documents—a single source of truth accessible to all. They saw AI as a way to streamline communication and bridge language gaps to reduce errors. To facilitate smooth care transitions, agents might help by onboarding new or substitute caregivers with key CR information. For monitoring and follow-up, participants emphasized the importance of real-time documentation, reminders, and assistance dealing with unexpected health changes. Finally, participants assumed agents would inevitably make mistakes and should thus be designed to signal uncertainty, make it easy to report errors, and always complement—not replace—human judgment.

Building on our findings, we provide a roadmap for designing agents that facilitate shared care in sensitive home care contexts. For example, agents might be designed to adapt the information and support they provide based on different caregivers' roles and familiarity with the CR, potentially reducing burdens on more experienced HCWs and FCs while supporting newer caregivers in building confidence and gradually assuming more complex responsibilities. Designing such agents will require careful attention to the data work needed to maintain and use these systems, which could be implemented in ways that help alleviate the already heavy documentation burdens caregivers face. Across all interactions, agents should preserve the human essence of care and expressly facilitate more (not fewer) human connections. Finally, any integration of agents into complex home care ecosystems should be accompanied by appropriate training, resources, and policies that ensure human oversight and establish clear accountability. Taken together, our findings make three contributions to the HCI community:

- (1) Empirical data that captures the perspectives of *both* HCWs and FCs around coordinating the delivery of shared care in CRs' homes;
- (2) Insights into the potential for agents to help facilitate coordination in home care, where the FCs and HCWs who would need to interact with the agent are neither AI nor clinical experts;
- (3) Implications and design recommendations to inform the responsible development of agents that augment human capabilities, bridge gaps between stakeholders, and enable caregivers to focus on delivering attentive and humanistic care.

2 BACKGROUND AND RELATED WORK

2.1 Research Context: Home Health Care

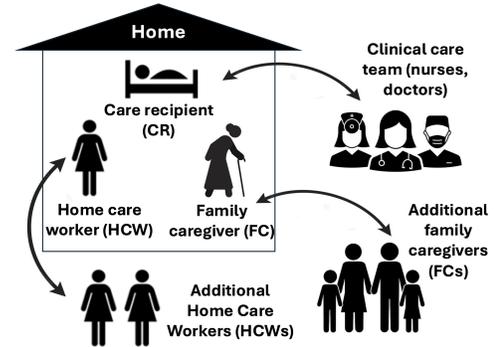


Figure 1: The stakeholders who deliver shared care [104].

Our work is situated in home health care for older adults, a sensitive, multi-stakeholder context (Figure 1). As they age, most older adults prefer to remain at home and age in place [110, 125]; to do so, they often require support and assistance from FCs [95, 113]. Some FCs reside with the CR (e.g., a spouse, who may also be aging); others live separately and provide periodic care (e.g., adult children). CRs often receive care from multiple FCs, with shifting duties as the CR's needs and caregivers' capacities evolve [89, 112, 127].

In addition, as CRs' care needs become more medically complex and they require more support, care often extends beyond FCs to include paid HCWs [76, 104]. In our context, HCWs are low-wage shift workers who provide personal and medical care in CRs' homes [56, 109]. HCWs may be employed privately (e.g., via personal referrals or online platforms like Care.com [23]) or by licensed home care agencies. Depending on the CR's needs, it is common to receive care from several HCWs (e.g., day/night shifts). FCs must liaise with HCWs and other providers to arrange care shifts, manage billing and insurance, monitor care delivery, and more.

Coordinating home care among HCWs and FCs caring for the same CR may involve scheduling (e.g., arranging HCW arrival times to relieve an FC), medication- and task-related communication (e.g., notifying an FC to refill prescriptions), health status updates (e.g., changes in symptoms), emotional and behavioral support (e.g., strategies for responding to a CR's emotional needs), logistical planning (e.g., coordinating transportation to medical appointments), onboarding new or substitute caregivers (e.g., sharing information about the CR's needs and preferences), and more [17, 90, 112, 124]. Coordinating these activities among different caregivers with precision and consistency—including task distribution and shift handovers—is a significant source of stress for caregivers [89, 112].

In parallel, caregivers must manage CRs' moods and preferences while also building trust, maintaining positive relationships, and communicating effectively with other stakeholders [101, 112]. This relational work is foundational to effective care coordination [46, 73, 77, 107, 112, 122]. Emotional attunement to CRs is

not only about providing humanistic care (e.g., tailoring interaction strategies to support CRs experiencing acute emotional distress [77]), but is also essential for maintaining shared care goals, supporting communication, enabling information sharing, addressing emerging issues, and ultimately ensuring high-quality care outcomes. To address care coordination challenges, prior research provides frameworks that aim to help caregivers manage coordination effectively, as we now discuss.

2.2 Frameworks of Care Coordination

Care coordination refers to the complex process of organizing and managing a CR's healthcare activities across multiple providers, settings, and time frames [26]. It occurs across diverse environments, including clinical settings [32, 81, 115], transitional and community-based medical sites [130], and non-clinical environments such as CRs' homes [85].

Research has long recognized the value of high quality care coordination, with prior work showing that effective care coordination may reduce hospitalizations [75, 76], improve medication and treatment adherence [32, 102, 114], enhance care quality [32, 75], increase CR satisfaction [32], and improve quality of life [115, 119]. On the other hand, poor coordination can result in adverse effects; Sterling et al. [102] showed that the need for CRs to rely on multiple providers across health systems increased the likelihood of CRs experiencing preventable adverse events (e.g., drug interactions), which they attributed to communication and coordination challenges.

Given the importance of effective care coordination, prior research has provided practical frameworks that conceptualize core aspects of care coordination [4, 6, 25, 121]. For example, working in the context of clinical cancer care, Walsh et al. [121] identified seven key aspects of care coordination: organization of care, healthcare system navigation, assignment of a "key contact", effective multidisciplinary communication, timely and complementary service delivery, sufficient and timely information for CRs, and needs assessment. Similarly, Carter [25] proposed six core activities that lie at the heart of care coordination: access to care, communication, care planning, care transitions, community resources, and CR follow-up. We utilize these theoretical frameworks in our study; specifically, we investigate how agents may help to facilitate coordination among multiple types of caregivers who care for the same CR, focusing our findings on key aspects of care coordination identified via these frameworks.

2.3 Digital Technologies and Care Coordination

HCI and CSCW research has long been interested in how digital technologies might support the coordination of care in a wide range of settings [2, 53, 66], including clinical care for children with complex conditions [7, 78], across hospital teams [1, 16, 92, 108], and within rehabilitative services [18]. A large body of work focuses specifically on coordination among informal or FCs [21, 31, 96, 112, 128]. For instance, Schurgin et al. [90] surveyed informal caregivers to understand the challenges they face when coordinating care with others, finding substantial overlap in challenges around communication, task management, and scheduling. They suggest that future sociotechnical systems should account for the interpersonal

nature of caregiving and provide scaffolding for task management. Schorch et al. [89] studied FCs' experiences in home care, finding that FCs may hesitate to involve others due to concerns about insufficient CR knowledge or a desire to shield family members from the emotional demands of care. They call for care coordination platforms that proactively share information among informal and formal caregivers, surface contingencies, and provide support for unexpected changes [89]. Tang et al. [112] uncover difficulties FCs face in maintaining awareness of CR information, managing hand-offs, and navigating interpersonal tensions, proposing a mobile application to support communication, task tracking, and more.

Separately, a growing body of work has focused *exclusively* on HCWs. Dean et al. [36] analyzed data from a pilot study where HCWs completed a telephone-based clock-in/clock-out protocol, with the intention of enabling home care agency administrators to monitor changes and escalate care as needed. This pilot informed the development of Electronic Visit Verification (EVV), now a federally mandated system for Medicaid-funded home health services [27]. While intended to improve coordination, reduce fraud, and enhance CR protections, EVV has drawn significant criticism from scholars who describe it as an intrusive technology that undermines flexibility in CR–HCW relationships [47] and that is punitive and devaluing of the home care workforce [70].

Most of these prior studies examine existing care practices and surface care coordination challenges among *either* FCs or HCWs. By contrast, little is known about the challenges that arise when FCs and HCWs need to coordinate *with each other* to manage CR care. This gap is particularly concerning given that FCs and HCWs play unique and interdependent roles in caregiving, and the quality and continuity of home-based care can hinge on how well they coordinate with each other. Only a few studies have examined coordination across both groups, typically in narrow or specialized contexts. For instance, Currin et al. [33] documented communication gaps between FCs and respite caregivers and suggested that technology could help build trust and support information exchange. Bossen et al. [17] analyzed cooperative work between HCWs and FCs and developed a tablet-based prototype for task scheduling, tracking, and messaging that relies on structured inputs.

Our study advances this literature by providing valuable empirical data that illuminates the complex challenges around coordinating shared care and examining how emerging LLM-based agents might support shared care. Unlike earlier coordination tools that relied on fixed workflows or structured inputs, LLM-based agents can interpret unstructured updates, translate between the communication styles of FCs and HCWs, and offer context-sensitive guidance. These capabilities open a qualitatively different design space for supporting FC–HCW coordination, which we study in depth.

2.4 AI and Care Coordination

A cluster of studies has examined potential roles for AI in care coordination. For example, in clinical settings, Chen et al. [29] suggested that AI's capacity to extract information and infer actionable insights from data may enable more effective information exchange. In pediatric cancer care, Seo et al. [93] explored how an AI-driven chatbot might bridge communication gaps among children, parents,

and clinicians, finding that the dynamic, context-adaptive capabilities of the chatbot enabled it to accommodate stakeholders' diverse needs.

In residential care facilities, Carros et al. [24] examined care workers' perceptions of a humanoid robot used to support physical activity and cognitive training for older adults, finding that successful integration depended on embedding the robot into existing routines. Moore et al. [77] showed that person-centered dementia care requires time, emotional energy, and deep contextual knowledge, pointing out that few interventions exist to support communication and relationship-building between formal caregivers and family members, a gap our work also aims to fill.

In home care contexts, which is closest to our work, research has studied how AI tools might facilitate communication between CRs and FCs, often with the goal of enabling CRs to independently age in place with remote support from FCs [38, 82, 118, 131]. For example, several works have proposed AI-enabled systems to support CRs and FCs via risk assessment, with predictions shared through web-based dashboards that visualize health-related data [61, 62]. Bartle et al. [11] investigated how interactive voice assistants (IVAs) might support HCWs' day-to-day activities, finding that HCWs perceived IVAs might help to ensure care plans remain up to date and accessible, provide step-by-step instructions, and ease hand off challenges. Solano-Kamaiko et al. [98] explored potential roles for AI in paid home care work and agency operations, pointing out discrepancies in stakeholders' understanding of AI.

Our research expands this literature by exploring how agents might facilitate the coordination of shared care among FCs and HCWs. We focus on LLM-driven conversational AI agents because prior research has identified the growing adoption of AI in home care workflows [98], and the rapid uptake of LLM-based chatbots (e.g., ChatGPT) [57] makes it urgent to investigate how these systems might be designed and deployed responsibly in home care. Moreover, LLM-based agents' natural language interfaces and ability to capture, synthesize, and communicate information may make them well suited to the flexible task management and communication that prior work identifies as essential to effective care coordination [77]. Understanding how these agents can responsibly support shared care is critical as families and home care workers increasingly turn to AI to meet rising care demands.

3 METHODS

We conducted an exploratory qualitative study with eight HCWs and nine FCs that used video elicitations to investigate caregivers' past care coordination experiences and perspectives on potential future roles for agents. All procedures were IRB-approved. Given the exploratory nature of our study, we followed best practices for safe research with vulnerable communities [14] by first seeking the perspectives of less-vulnerable caregivers, which will inform future research that engages with more vulnerable CRs (see Section 3.4).

3.1 Recruitment and Participants

To recruit HCWs, we reached out via email to organizations that employ HCWs and with whom we have sustained multi-year collaborative partnerships. To recruit FCs, we sent emails to institutional and community-based listservs advertising the study. In both cases,

the recruitment emails used a standardized format that described the study's objectives, time commitment, compensation, and invited participants to respond. The first author screened participants for eligibility before scheduling a study session. Eligible participants were English-speaking adults aged 18+ years who were employed as a HCW or had experience caring for a family member. Although we sought participants' perspectives on shared care, we chose *not* to recruit HCWs and FCs who care for the same CR to account for well-documented power dynamics between these groups [10, 44]. This ensured participants might freely share their perspectives without worrying how it might impact their relationships with CRs or other caregivers.

We recruited 17 participants: eight HCWs and nine FCs (see Table 1). Participants were mostly women (n=14) with diverse racial and ethnic backgrounds: nine participants identified as Black or African American and four as Hispanic or Latinx. On average, HCWs reported 13 years of home care experience, whereas FCs reported 5.6 years of caregiving experience. Most FCs resided either in the same home as CRs (n=4) or nearby (n=4). Regarding prior AI use, eight FCs reported occasional or greater use of AI tools, compared with three HCWs.

3.2 Study Procedure

We conducted 60-minute one-on-one participant sessions. Before each session, participants signed an IRB-approved consent form. All study sessions utilized a common script, with minor wording adjustments to reflect participants' roles (i.e., HCW or FC) and were facilitated via Zoom video conferencing to accommodate participants' varied schedules and geographic locations. The session began with a brief overview of the study's goals, after which we answered participants' questions, and reconfirmed their consent.

The session then proceeded in three phases. First, we inquired about participants' prior use and knowledge of technology, including AI. Second, we presented three video elicitations [72] (discussed in detail below). The researcher paused the videos at key moments (e.g., just before the agent responded to a caregiver query) and at the end of each video for discussion. We asked participants to reflect on their impressions of each scenario and on their own care coordination processes, focusing on four themes: (1) current practices and challenges, including documentation and information sharing; (2) differing information needs of HCWs and FCs; (3) expectations and concerns about AI, including errors, accountability, privacy, and agency; and (4) feasibility, challenges, and willingness to adopt such a system. Third, we engaged the participant in a broader discussion around their caregiving experiences, including communication with other care team members, documentation processes, invisible work, and cultural influences on care. Sessions were audio recorded with participants' consent for future analysis. All participants received a \$25 (USD) gift card for their time.

Video elicitations. To ground our discussions with HCWs and FCs—who have varied backgrounds and experiences—in realistic depictions of how an agent might support care coordination, we used scenario-based video elicitations. Video elicitation is a form of visual elicitation in which a stimulus (in our case, a video) is used to elicit different kinds of knowledge than might be obtained via verbal interactions alone [72]. Our video elicitations enabled participants

Table 1: Demographic details of study participants (n=17). Experience is rounded to the nearest year. For FCs who cared for multiple CRs, experience is reported as the mean across CRs. FC location is sometimes represented by more than one category, as some participants cared for CRs in different settings. AI usage indicates frequency of use: *none* refers to caregivers with no experience using AI tools (e.g., not at all); *occasional* refers to sporadic use (e.g., less than once per week or for specific tasks); *frequent* refers to regular or sustained use (e.g., several times per week or integrated into weekly workflows).

Home care workers								
ID	Age	Gender	Race or Ethnicity	Education	Experience (years)	Location	AI Usage	
HCW1	33	Female	Black or African American	Some College	8	In-home	Occasional	
HCW2	30	Female	Black or African American	Bachelor's Degree	5	In-home	Occasional	
HCW3	59	Female	Black or African American	Bachelor's Degree	17	In-home	None	
HCW4	66	Female	Hispanic or Latinx	Associate's Degree	23	In-home	None	
HCW5	53	Female	Hispanic or Latinx	Master's Degree	6	In-home	None	
HCW6	69	Female	Black or African American	Some College	17	In-home	None	
HCW7	51	Female	Black or African American	Some College	8	In-home	Occasional	
HCW8	62	Female	Black or African American	Bachelor's Degree	20	In-home	None	

Family caregivers								
ID	Age	Gender	Race or Ethnicity	Education	Experience (years)	Location	AI Usage	
FC1	41	Female	Hispanic or Latinx	Master's Degree	6	Nearby	None	
FC2	72	Male	Black or African American	Master's Degree	10	Nearby	Occasional	
FC3	51	Female	White	Bachelor's Degree	3	Remote	Occasional	
FC4	68	Female	White	Doctoral Degree	8	Nearby, Remote	Occasional	
FC5	43	Female	Black or African American	Bachelor's Degree	<1	In-home, Remote	Occasional	
FC6	40	Male	Black or African American	Bachelor's Degree	7	In-home	Frequent	
FC7	52	Male	White	Master's Degree	3	In-home	Frequent	
FC8	44	Female	White and Asian	Associate's Degree	5	In-home	Frequent	
FC9	40	Female	Hispanic or Latinx	Bachelor's Degree	8	Nearby	Occasional	

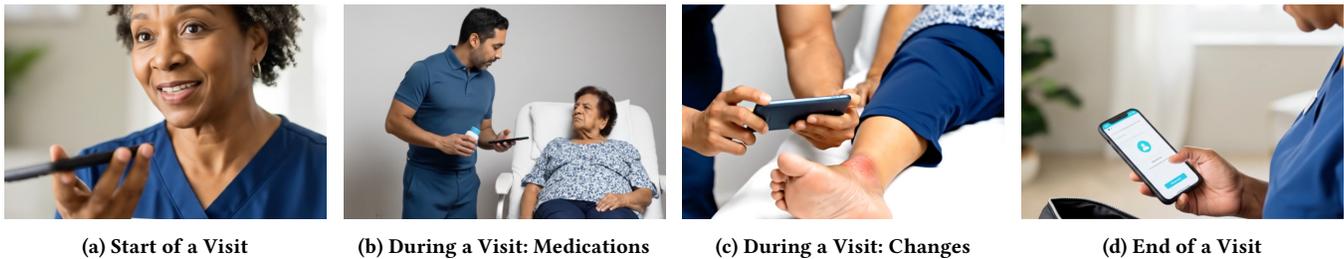


Figure 2: Example of video elicitation care coordination scenarios using an agent: (a) HCW using voice interaction to request a status update; (b) FC instructing the agent to note that he administered the CR's medication; (c) FC photographing a bedsore to upload to the agent; (d) HCW receiving a push notification from the agent asking her if she is ready to wrap up her work.

to more concretely envision practical roles that conversational AI might play in coordinating home care.

We constructed three video elicitations, each approximately 80 seconds long. Figure 2 provides example screenshots while Table 2 provides a textual summary of each elicitation; the full videos are provided as supplementary material. Each video centers on key moments for care coordination: (1) the moment a HCW arrives to begin a shift, wants to know how their CR is faring, and understand the status of care tasks; (2) the moment a FC administers the CR's medication and notices a concerning change in their health (e.g.,

a bedsore); (3) the moment a HCW is departing for the day, needs to record completed tasks, and wants to leave notes for the FC. We selected these moments because prior work identifies them as critical inflection points in care coordination, providing a realistic foundation for the scenarios [17, 36, 76, 102, 112]. Together, they span the full arc of a home care visit: beginning, middle, and end.

To construct the videos, the first author created a detailed script for each scenario that showed hypothetical interactions between caregivers and an agent, depicted as a mobile application. To encourage reflection on care coordination from different perspectives,

our videos center on three personas: *Ms. Diaz*, the CR; *Jason*, her adult son and FC; and *Mary*, *Ms. Diaz*'s paid HCW. These personas represent a diversity of ages, genders, ethnicities, and sociocultural dynamics common in home care: literature suggests that HCWs are primarily women of color who often care for CRs from different cultural backgrounds [80, 99], while FCs are often adult children supporting aging parents [95, 113].

Given the novelty of exploring agents for care coordination, we intentionally created straightforward interactions in which the agent generally behaved as intended [51]. This allowed us to communicate the core use cases of an agent clearly and succinctly, reducing participants' cognitive load and preserving time for deeper discussion during the interview. However, we acknowledge that this approach may depict idealized or seamless interactions. Therefore, after presenting the videos, we explicitly invited participants to interrogate these assumptions by discussing ambiguities, potential errors and edge cases, accessibility considerations, limitations of AI support, potential burdens, and more.

The first author produced the videos using a multi-step AI-assisted workflow. First, three static persona images were generated with Google's Imagen 4 model [49]. These images were incorporated into prompts for Google's Veo 2 and 3 video generation models [50] to create short clips. Audio dialogue was generated using Gemini 2.5 Pro [48], and iMovie video editing software [8] was used to integrate the clips and synchronize the audio. The videos were intentionally stylized to appear artificial, with slowed and exaggerated audio to ensure clarity. In particular, we generated the agent's voice to be robotic and monotone, with visual cues added to clearly signal when caregivers engaged with the agent.

3.3 Data Analysis

Our dataset consisted of approximately 17 hours of audio recordings. The recordings were transcribed using NoScribe [40], an open-source, locally run AI-based tool. After transcription, we reviewed the transcripts with the original audio to correct errors and redact potentially identifying information.

After cleaning the transcripts, we followed a structured process for qualitative data analysis [63] that involved: (1) structural coding via high-level topics, followed by (2) thematic analysis within these topics. Structural coding is a first round qualitative coding method where data is coded deductively based on key topics [37]. We used structural coding to organize our data around five key care coordination topics synthesized from established frameworks [4, 6, 25] (discussed in Section 2.2): (1) care planning and linking to community resources; (2) communication and information exchange; (3) facilitating transitions; (4) monitoring, following-up, and responding to change; and (5) establishing accountability.

After organizing the data into these topics, we conducted inductive thematic analysis [20] within each topic. We performed multiple passes over the data, developing an initial codebook and iteratively refining it through subsequent transcripts, reconciling and merging codes as needed. This process produced 167 codes in total. Finally, we performed affinity diagramming to synthesize codes, which resulted in 16 relevant themes (see Table 3).

Table 2: Summary of the three video elicitation scenarios we crafted for our study. In these scenarios, Ms. Diaz is the CR receiving care, Jason is her adult son and FC, and Mary is a paid HCW.

1. Start of a visit: understanding the CR's current status

Mary, a HCW, is about to begin a shift caring for Ms. Diaz. She uses voice interaction on her phone to ask the care coordination agent for a status update on Ms. Diaz. The agent summarizes how Ms. Diaz's is doing that day and tells Mary what tasks were completed during the previous shift. Mary then asks care tasks she should prioritize, and the agent responds with ideas and guidance. Later that day, Mary uses voice interaction to document the tasks she has completed. She also asks the agent to leave a note for Jason, Ms. Diaz's son and FC, telling him that she was unable to complete one task and asking that he take care of it later in the day.

2. During a visit: tracking medications and health changes

Jason, Ms. Diaz's son, is spending the afternoon taking care of his mother. Noting that it's time for Ms. Diaz to receive her medication, he tells the agent to make a note that he has given Ms. Diaz her medication. The agent confirms the medication details and tells Jason that it will request a refill from the pharmacy, since Ms. Diaz's prescription is running low. While checking on his mother, Jason notices what appears to be a bedsore on his mother's leg. He decided to make a note of this to make sure the HCW checks on it later in the day and to let the nurse on Ms. Diaz's care team know. Jason attempts to describe the condition to the agent but forgets the English word for bedsore, saying the Spanish word instead. The agent helps Jason with the English translation, enabling him to record his observation. Jason also uploads a photo of the bedsore to track how it changes over time and record information for clinical follow-up.

3. End of a visit: task reporting and leaving notes for other caregivers

Nearing the end of her shift, Mary, Ms. Diaz's HCW, receives a push notification from the care coordination agent asking if she is ready to wrap up her work. Using voice interaction, Mary reviews a summary of completed tasks and notes recorded during her shift. The agent then asks if there are any additional activities that were missed that she would like to add. Mary remembers that when she took out Ms. Diaz's trash, she discovered that Ms. Diaz needed more trash bags. The agent records this update and says it will notify Jason, the FC, about the need for more supplies.

3.4 Limitations

Our study has several limitations. First, we only engage with caregivers, not CRs. Given the exploratory nature of our study, existing guidelines for research with vulnerable populations [14] suggest it is safer to first engage less-vulnerable participants (i.e., caregivers) using pilot studies or participant proxies. This approach will enable future studies with more vulnerable participants (i.e., CRs) to be safer and more informed. Moreover, we explored care coordination processes via video elicitations in which agents operate as intended, with successful outcomes. Additional challenges may arise in research involving a broader set of scenarios (i.e., edge cases, errors, etc.) or deployments with real agents. Finally, we conducted a qualitative study in an urban U.S. city. Further research is needed to understand how the needs and priorities of caregivers in other locales might differ, including rural and non-U.S. settings.

3.5 Author Positionality

We acknowledge that our research is shaped by our experiences, identities, and motivations [39, 68, 88]. Our team is motivated by a desire to explore ways to develop safe and equitable technologies that support HCWs and FCs and we view agents as a promising avenue to help facilitate home care coordination. We are all U.S.-based academic researchers, including three men and two women with backgrounds in computer and information science, labor relations, healthcare, and medicine. We hold diverse and multicultural identities, including Latinx, Asian, and white backgrounds. Collectively, we possess decades of experience conducting community-engaged research with HCWs and FCs. While several team members have lived experience as FCs, none have worked as HCWs.

4 FINDINGS

Our findings illuminate opportunities and challenges for an agent to facilitate shared care among FCs and HCWs. While our study centered on care coordination among HCWs and FCs, participants naturally described dynamics across other caregiver combinations, including FC-FC and HCW-HCW interactions. We integrate these perspectives into our findings to provide a more holistic account of care coordination complexities. Using established frameworks [4, 25], we organize our findings around five key pillars of care coordination (see Table 3): care planning and linking to community resources (Section 4.1); communication and information exchange (Section 4.2); facilitating transitions (Section 4.3); monitoring, following-up, and responding to change (Section 4.4); and establishing accountability (Section 4.5).

4.1 Care Planning and Linking to Community Resources

Establishing and following a plan of care for the CR is recognized as a cornerstone of effective care coordination [4, 25]. Both HCWs and FCs emphasized how digitizing these plans and embedding them within agents could help streamline documentation, track progress, and connect caregivers to reliable resources. At the same time, they cautioned against designs that might add to caregivers' data work or replace valuable human contact with technological mediation.

4.1.1 Leveraging care plans as a roadmap for care delivery. A core component of care coordination is tracking tasks that are upcoming, in progress, or completed, and documenting a CR's needs, preferences, and clinical instructions. These care instructions and task lists are frequently recorded in paper-based care plans, which are typically written documents—developed collaboratively with CRs, FCs, and clinicians—that outline the CRs' health needs, goals, and the services required to address them. Our participants described care plans as both a roadmap for delivering consistent, CR-centered care and, for HCWs, as a reliable point of reference when entering a new CR's home. HCW7 explained:

“Sometimes when the [agency] coordinator assigns you to a particular client, they barely talk to you about the CR... So the day you start working with them, you enter the apartment. The first thing you are to look for is the care plan. Most of the time it is on the refrigerator.”

However, because this information is often stored in paper-based care plans in the CR's home, it is generally inaccessible to other caregivers who are not physically present and can easily be removed or misplaced. As a result, caregivers often independently maintain their own priority lists, reminders, and ad hoc communication practices to keep the task list current. Given the structured information that care plans already provide, participants suggested that agents might easily incorporate them as a data source, which would provide a centralized repository of CR information and care tasks. As FC6 proposed: *“When the HCW comes in, they have a plan of care. It says exactly what they need to help with. So the [agent] should probably have a plan of care.”* This information could then be used by the agent to keep track of tasks completed, aid documentation, send reminders, and more. Participants further discussed how having the care plan available as digital information accessible to any caregiver would help HCWs and FCs:

“I feel like it makes for an easier life for everybody... You don't have to rely on pieces of paper everywhere or a notebook or whatever the case may be. And this is something that you can use to collaborate with other members of the family.” (FC1)

Another advantage of incorporating the care plan into a digital format, such as an agent, is that it might prevent the care plan from being lost, removed, or hidden. For example, participants described how, in some cases, CRs actively hid their care plans to force HCWs to perform their preferred tasks (e.g., household work) regardless of clinical recommendations, a phenomenon also documented in prior work [12]. As HCW6 recalled: *“Sometimes CRs, they hide the care plan... they want you to do what they want done, not what was recommended by the nurse.”*

4.1.2 Prioritizing CR inclusion and human contact. Balancing the perceived benefits of integrating the care plan into an AI system, participants also raised potential trade-offs. Caregiving is an intensely human process that requires time, attention, and physical and emotional engagement. However, for agents to function effectively and support care coordination, they may require substantial data inputs from caregivers. Both HCWs and FCs expressed concern that agents might increase the amount of “data work” [19] for caregivers, diverting attention away from hands-on care and toward the technology. FC1 described the potential risks of this shift:

“I think it's realistic. But... it can take your focus or the caretaker's focus from the CR. How about if you're busy texting information and the CR slips and falls or something?”

Others worried that technological mediation might replace valuable interpersonal contact. For example, rather than calling or visiting the CR, family members might instead choose to receive updates from the agent, which would reduce CRs' opportunities for valuable social contact. As HCW5 explained:

“You lose this relationship, this contact with people... it's like giving all the activity to the system and not giving space to something important for [the CR], which is the connection with their family.”

Table 3: Summary of our main findings highlighting opportunities and challenges for agents to facilitate shared care.

Topic	Themes
4.1 Care Planning and Linking to Community Resources	Leveraging care plans as a roadmap for care delivery. Prioritizing CR inclusion and human contact. Linking to community resources.
4.2 Communication and Information Exchange	Easing communication challenges. Respecting caregiver boundaries. Mediating care team communication. Providing translation and language support.
4.3 Facilitating Transitions	Coordinating shift handover. Easing onboarding of new caregivers.
4.4 Monitoring, Following-Up, and Responding to Change	Documenting tasks completed. Using multimedia to facilitate routine tracking and symptom monitoring. Facilitating reminders. Responding to unexpected changes.
4.5 Establishing Accountability	Understanding the fallibility of AI assistance. Designing agents around the potential for errors. Adapting social processes to account for AI errors.

On the other hand, several participants pointed out how these tools might provide opportunities to strengthen CR involvement. For example, FC8 suggested that in-situ documentation using conversational voice interaction could increase transparency and help CRs feel included in their own care, a suggestion corroborated by prior work [12]:

“I like the fact that [the FC is] able to do that in front of his mom so that she’s sort of included in that care. As opposed to him having to go into a home office somewhere on a desktop and to do it. So it’s nice that she feels included in that. So it’s transparent for the CR.”

4.1.3 Links to community resources. Caregivers provide care within the home, often an isolated environment with little contact from the broader care team and with limited (e.g., HCW) or no (e.g., FC) formal training. As a result, participants emphasized that, beyond accessing and documenting information from the CR’s care plan, an agent might also connect caregivers to a broader set of resources and care-related information. For example, several participants, particularly FCs familiar with conversational AI, expressed interest in these systems providing validated medical information and resources. FC8 speculated about agents delivering case-specific guidance by referencing authoritative sources, saying: *“[the agent] could cite medical books, the medical journal, those sorts of things.”* FC3 elaborated on the limitations of current Internet searches, noting that online information can be overwhelming and difficult to parse. They described the potential for agents to distill medically validated facts from trusted sources, saying:

“Having information that could be more than just an article in Google would be helpful. For example, if there was a way to know some basic facts that have been

validated. I mean, I go to the Mayo Clinic website but there’s such a wide spectrum that I don’t know.”

FC9 expanded on this idea, envisioning that an agent might provide visual references for medical symptoms or CR progress to guide caregivers: *“If [the agent] could just send me an update—like, ‘this is what it should look like, and this is the stage you’re in, this is what you have’—it would save me the extra step of Googling.”*

4.2 Communication and Information Exchange

Another core component of effective care coordination is facilitating communication and information exchange among caregivers. Participants described how communication breakdowns often created stress, inefficiencies, and even safety risks in CR care. At the same time, they saw opportunities for agents to ease these challenges by improving information exchange, respecting role boundaries, and offering translation and multimodal support.

4.2.1 Easing communication challenges. Our participants were quick to point out challenges with their current methods for communicating with one another. We heard how, often, one or more FCs assume primary responsibility for overseeing care, organizing coverage, and ensuring tasks are carried out during shifts. This required frequent communication with HCWs and other FCs to monitor completed activities and relay information across visits:

“It’s not always the same HCW. So we get one that comes during the week, Monday to Thursday. We have a different one Friday. We have a different one on the weekends. Every other weekend is a different one. So it’ll be hard to coordinate for all of them to say: ‘hey, shoot a text to this number when she’s eating.’” (FC6)

As this quote illustrates, FCs and HCWs often used text-based chat messages (e.g., WhatsApp) to communicate. However, these communication channels were ill-suited for facilitating long-term care coordination across multiple caregivers. FC2 described how care-related text threads among FCs often became disorganized:

“We had set up one where both [the CR’s] sisters and her brothers-in-law were on a thread. And that thread was pretty clean for a while. So you could go back for a long time, two, three months. And then it started getting used for social things. So that turned into a problem.” (FC2)

Moreover, verbal communication can be error-prone, which can be problematic in complex and high-stakes aspects of care coordination like medication management. For example, FCs described instances of missed or incorrect doses stemming from communication breakdowns and inaccurate information when communicating with other caregivers:

“My dad had to have fentanyl patches but he had to have the right dosage because anything over a certain [amount] would fly him off the edge. So we had to be super careful with that. One time ... I gave him a little bit too much and he was spiraling off the walls. And my sister said: ‘oh, how much did you give him?’ And then I said: ‘what you told me!’ There was miscommunication because it wasn’t in text. It was verbal.” (FC9)

Responding to these challenges, participants saw potential for an agent to provide a dedicated space for caregivers to share and access important information when they need it. As HCW3 noted: *“So it’s teamwork right there ... it’s like the machine is a go between the family member and the HCW. A communication link.”* The ability for such a tool to share relevant information automatically or on demand, without the caregiver needing to make a phone call or send a text message, may help to reduce communication burdens on caregivers. As FC3 described:

“If I can alleviate the need for [the HCW] to text me, and instead I can get an automatic update, that would be helpful. Because you know, it’s not a small thing. I’m very hesitant to even ask her how my mom is doing, because basically it’s a 24 hour type of job. And so once she puts my mom to bed, that’s her only time to rest. I don’t want to bother her when she only has a few hours to herself.”

Participants also described how an agent could help coordinate communication among multiple caregivers, particularly when coverage is needed for a care shift. As FC8 explained:

“It takes a village. So like, there’s a care team and everybody gets the message. And not like shaming the person for not doing the job, because maybe they’re sick. But [the agent] calls out [tasks] so that if we need coverage, now everybody is looped in and we understand that this is maybe a ticket that needs to be forwarded to the next person.”

4.2.2 Respecting caregiver boundaries. Both HCWs and FCs emphasized the importance of being sensitive to communication timing

and boundaries when interacting with one another. HCWs highlighted the need to consider when and how care information should be conveyed to FCs, recognizing that family members often had work or other obligations that could affect how messages were received. As HCW2 explained: *“Sometimes the family members also are at work or on a trip. So you will want to be in control of the timing to text them.”* In turn, FCs described efforts to respect HCWs’ time and personal boundaries, recognizing the physically and emotionally demanding nature of home care work. For example, FC4 described only contacting HCWs when absolutely necessary:

“I never called the [HCWs]. They didn’t want you to call. That was sort of the boundary. Do not call me unless it’s like something super serious. That was their personal space. So I only texted them when it was a serious issue. Like my mom fell. They should know not to come over. She’s in the hospital.”

Participants thought that an AI tool might help to respect caregivers’ boundaries by enabling them to capture relevant data in real-time, which in turn could be shared asynchronously or on-demand with others at appropriate times.

4.2.3 Mediating care team communication. Participants also discussed how conversational AI tools might help by mediating communication in ways that support caregivers and respect their different roles. For example, both HCWs and FCs saw value in a tool that provides all caregivers with access to CR care information, but recognized that certain information, such as the CR’s finances, falls outside HCWs’ scope of work and should not be shared with them. Beyond scope of work, participants also explained that different care tasks may require different levels of emotional sensitivity and privacy, emphasizing that agents would need to be attuned to these distinctions. For example, CRs often preferred HCWs to manage intimate or physically invasive activities, while relying on FCs for emotional and social support:

“We don’t like to ask family members to do things like shower her and clean her up. If there’s an accident, we sort of have that line of respect that even my mom would not ever let me deal with her in the bathroom ... She thought [family] were there for things like social contact.” (FC4)

Along these lines, FC1 described how her mother, the CR, sometimes intentionally withheld details about her illness to protect her daughter emotionally: *“I would rely on what she [the CR] would tell me, even though sometimes I’d be like: ‘I think she’s lying.’ But ... it was more for me ... [her illness] had an emotional toll on everyone.”*

By contrast, participants discussed how communication with clinical providers (e.g., nurses) sometimes felt sterile or lacking in empathy, with clinicians *“just doing their job”* (FC9). They suggested that an agent might play a role in helping to communicate clinical information provided by nurses in ways that use *“softer”* or more empathetic language.

Interestingly, although participants discussed how certain kinds of information may need to be kept private from either FCs or HCWs, most (n=15) were not concerned about the potential privacy implications of sharing information with the AI system itself.

As FC8 said, *“All of our information is out there, like path of least resistance ... I would be fine with putting it all in a system somewhere.”*

4.2.4 Providing translation and language support. One big area where participants saw significant potential for AI was in mediating communication between FCs and HCWs who may not speak the same language. Both FCs and HCWs described how language differences create persistent problems. FC2 explained:

“I’m not aware that any of [the CR’s] HCWs have English as a first language. I’m aware that at least some of them don’t have English at all. And so, we’re getting nothing [CR information] from them.”

Even partial language overlap was described as a source of friction. For instance, FCs noted that when caregivers spoke related but different languages (e.g., Russian and Ukrainian), communication often became inefficient and error-prone. This is particularly concerning in high-stakes home care contexts where mistakes can have serious consequences. FC3 explained one such situation: *“It’s very inefficient ... it’s two of us in one language and the other is in a different language. There’s plenty of opportunity for mistakes.”*

HCWs expressed similar concerns, noting that language differences often made it challenging to convey care information clearly to other caregivers. They saw potential for agents to mitigate these challenges by translating information between languages as needed. As HCW7 said:

“We are not native English [speakers]. Sometimes it’s hard to make clear about everything. So when you enter information to the AI, it [can translate] to make it straight, understandable, and smooth for people.”

Beyond translation, participants emphasized the need for multiple modes of interaction, both voice- and text-based, so that agents could accommodate diverse caregiver abilities and contexts.

4.3 Facilitating Transitions

Facilitating handover between different caregivers is a notorious challenge [112]. Participants highlighted persistent challenges in coordinating shift handovers, noting that existing ad hoc practices were often unreliable and error-prone. They emphasized that effective handover requires tailoring information to each caregiver’s familiarity with the CR, a gap they believed agents could help address.

4.3.1 Coordinating shift handover. Participants described a lack of standardized and reliable methods for coordinating care across caregiver shifts. FCs indicated that there was no consistent way to access information from prior shifts, while some HCWs explained that the only way to learn what had happened previously was often through the CR’s own account. Participants reported relying on CRs to recap care activities and to communicate reminders for upcoming shifts, but acknowledged that this strategy was flawed: CRs who were sick or fatigued frequently forgot or misrepresented important details. As one caregiver reflected, some form of written notes or reminders would provide a far more reliable method of coordination: *“Yeah, [communicating with the CR] just face-to-face ... is silly, honestly, because when you’re sick, you don’t remember things. So notes would be better or some sort of reminders.”*

When caregivers did manage to communicate directly with others, the effectiveness of information sharing and handover often depended on the communication styles and thoroughness of the individual. For example, FC9 explained that the efficacy of shift coordination relied heavily on the family member responsible for relaying details:

“I’ll take care of her whenever they ask me to or like once every two months. But it’s a little bit chaotic because I’m depending on other people to provide the details. My cousin, luckily she’s very detailed when she texts messages ... But when my male cousins deliver the information they’re very lackadaisical with it ... So communication styles play a role.”

How often the particular caregiver visited the CR also influenced the information that was required for effective handover, with caregivers who visited more often requiring less information and/or fewer reminders since they were already familiar with the CR’s condition, preferences, and routines. As FC3 described:

“One [HCW] lives with [the CR] and then there is a weekend [HCW]. So when the weekend person comes in, it would be actually helpful if there were some kind of more subtle changes, like, the weekend person who is not with her all the time is reminded to give her x, y, and z. If anything happens call this doctor or this relative. Be mindful of the fact that maybe she was a little wobbly.”

As this quote illustrates, participants discussed how an agent designed to facilitate shift handover should tailor the information and reminders it provides based on the caregiver’s familiarity with the CR. This is particularly important if the caregiver is new, as we discuss next.

4.3.2 Easing onboarding of new caregivers. Participants felt that assistance from an agent might be especially helpful in cases where new or substitute caregivers, who may have very little information about the CR, are visiting for the first time. We heard how, when home care agencies send substitute HCWs, they sometimes fail to notify the CR, and these substitutes are often unfamiliar with the CR’s routines and care needs. As a result, CRs often have to repeat instructions and re-explain their needs to every new HCW. FC4 described this experience:

“There were problems ... [the agency] is supposed to substitute somebody, but sometimes they didn’t call [the CR] to say that she was getting a substitution. Sometimes she didn’t hear the phone call and sometimes the people were not very good. She didn’t want to have to re-explain her life to everyone new coming in.”

For the caregivers in these situations, figuring out how to care for the CR frequently required calling the FCs or other caregivers to clarify the CR’s care needs and priorities, a time consuming and burdensome task. Participants felt that an agent might help streamline these exchanges and reduce burdens for both CRs and caregivers by providing a readily available source of information about how to proceed. As HCW1 reflected: *“With this [AI] system ... if you come to the CR’s home, you [don’t have to] take your time*

guessing or calling. You just grab the phone and the AI tells you everything.”

4.4 Monitoring, Following-Up, and Responding to Change

One way to improve caregiver coordination and handovers may be through the tracking and sharing of information regarding care tasks. Participants suggested that agents might ease the burden of documentation, support symptom tracking through photos and videos, provide timely reminders, and offer reassurance during unexpected changes.

4.4.1 Documenting tasks completed. Participants, and especially HCWs, shared how they already operate within a system of documentation and reporting practices, reinforced both by agency requirements and by their own need to safeguard against liability and false accusations. For the most part, HCW participants reported documenting care interactions in personal notebooks, agency mobile applications, or phone calls with agency coordinators. In addition, since electronic visit verification (EVV) is a federally mandated requirement for Medicaid-funded home health services [27], many HCWs discussed how they are required to follow a strict clock-in/clock-out protocol. As part of this process, HCWs document care tasks completed, often by checking off a lengthy list at the end of each shift. This can be burdensome, as HCW2 explained:

“Sometimes it takes longer to do some tasks with the CR and you have to clock out . . . the clocking out takes time and you’re like ‘I’m trying to leave’ . . . I’m trying to get out the door and now I’m going to go through this like long list of things.”

In addition, waiting until the end of a care visit to recall tasks introduces errors, with HCWs sometimes forgetting to report specific tasks. Moreover, details about the tasks performed, despite being documented for EVV and billing purposes, are currently not routinely shared with FCs or other HCWs as part of shift handover. In light of these challenges, many participants saw opportunities for an agent to facilitate improved documentation and sharing, potentially reducing the burden of documentation that HCWs currently face. HCW7 explained:

“Sometimes to sit and write down everything, it can take time. So it’s better if something happens right away, take the phone and record everything you need to say . . . sometimes [HCWs] say: ‘I need to finish what I’m doing and later I will write up everything.’ Then you forget some parts of what you did. But if you record everything at the time [it happens], that’s better.”

Participants also hypothesized that agents might proactively nudge caregivers to maintain documentation best practices and keep CR data up to date. FC5 suggested that, by leveraging existing CR information, agents could detect when caregivers were falling behind in tracking or recording essential details:

“If information starts to not be shared as often and . . . [the agent] should be getting more or equal information as it was before, I think it would be good if it knew to follow up with the caregiver like: ‘okay, what are these data points? Let’s try and track these again.’”

4.4.2 Using multimedia to facilitate routine tracking and symptom monitoring. Beyond routine documentation, caregivers emphasized the value of multimedia information, including photos and videos, to monitor evolving symptoms and support follow-ups. Several participants described already using photos to confirm with clinicians whether escalation was needed, which “*worked...a lot*”, as FC9 noted. Others described using photos to capture acute scenarios or track changes over time, especially in relation to healing processes. As FC4 shared: “*I have pictures of a dog bite on my mom’s leg. The healing process. You see if it’s healing. You have records of how it changes.*”

Both HCWs and FCs emphasized the value of incorporating multimedia into conversational AI systems to facilitate communication about CR care status and health changes. HCW1 explained that photos could make it easier to report symptoms, a task that was often challenging when relying only on verbal descriptions:

“When you call the supervisor to report something or the CR has a wound here and then they ask you to describe it. Sometimes you describe it and then the supervisor might not know exactly how it looks. But with the picture, it will help them to know.”

HCW7 noted that communicating such data to clinicians (e.g., nurses) may enable them to remotely triage the situation “*without coming to the house.*” However, participants stressed the importance of the agent facilitating communication with professionals rather than attempting to independently diagnose the CR. FC8 commented: “*I like that the AI wasn’t automatically like: ‘share the picture with me, I’ll diagnose it.’ It was like: ‘share the picture and I’ll share it with the professional.’”* Other participants, such as FC5, were open to AI systems offering preliminary interpretations, so long as the information was reviewed and confirmed by clinicians:

“I think it would be okay for the system to say: ‘it looks like X, Y, Z.’ But I do think it’s an important step to ensure that a human medical professional is seeing these things.”

4.4.3 Facilitating reminders. Participants also saw immense value in the potential for an agent to proactively provide timely reminders to support caregiving tasks. As FC3 said: “*There’s so many things that my mom needs. With all my best efforts, I cannot possibly keep track of all the things.*” Building on this, HCW7 explained how the demands of balancing work and personal responsibilities can make it difficult to stay organized and respond to CRs’ constantly changing care needs. They described how contextual reminders might help prevent oversights and improve follow-up:

“Sometimes we are overwhelmed with work, with life, with everything. So you maybe forget to check the pill box and notice that it’s almost finished. So if you enter the information into the AI on the first day you get the medication, the AI can remind you: ‘hey, the medication will be over in about one to two days.’”

FCs voiced similar needs. They highlighted how disorienting and cognitively taxing caregiving can be, given the number of tasks that must be monitored and remembered. For them, AI reminders were seen as a valuable support system that could ease the mental burden of constantly tracking care information. As FC9 reflected:

“It’s an extra layer of support ... As a caregiver your mind is definitely in a million places. So whatever it can do to alleviate a task occupying rent in your head, ‘Oh, I gotta do this, gotta do this.’ It’s alright, I know my AI, it’s going to help me. It allows you to focus on other items.”

4.4.4 Responding to unexpected changes. Participants described how they often need to respond to unexpected changes in the CR’s health condition, especially changes that might require triage (i.e., assessment to determine the urgency and type of care needed) with a clinician. As HCW1 explained: *“We are the ones who are closest to the CR ... it’s our duty to report any change that you find in the CR condition.”* Sometimes, this duty to report changes conflicted with CRs’ desires, especially if CRs did not want to alert their FCs. For example, HCW6 described how a CR might say: *“oh, don’t report that. This is just a [little] thing.”* Yet HCWs emphasized their duty to communicate important changes. Given the hierarchical working environment and pervasive power dynamics in home care [73, 98, 116], HCWs highlighted the potential for agents to help standardize adherence to reporting processes, both to maintain reliable records and to create a defensible *“paper trail”* in case of adverse events or allegations. Reflecting on this protective dimension of reporting, HCW3 explained:

“I have to cover myself. I don’t know how long it has been. I don’t know what we’re talking about. Physical [elder] abuse, things can happen. You don’t want to be the one left with the bag hanging. Whenever I’m giving care, I turn my residents over and check. Anytime I see something new, I report it. And they said: ‘oh, we got a report yesterday.’ That’s fine. But I’m not taking it for granted that somebody else reported it.”

In addition, handling changes in a CR’s condition might be frightening for caregivers, who may be alone with the CR and may not have received training on specific disease conditions, such as dementia or heart failure. Without support, caregivers may struggle to know if a change is within acceptable limits for a particular CR. In this context, participants saw agents as a potential source of real-time reassurance, offering reminders, follow-up, or escalation pathways that could help caregivers feel less isolated. For instance, FC9 imagined an agent providing *“some type of reassurance that it’s going to be okay, that it doesn’t require 911 ... [and saying] I’ll keep track of it or I’ll follow up with [the nurse].”* Beyond reducing stress, participants emphasized that such support could help prevent unnecessary hospital visits, which they described as both traumatic and disruptive for CRs [42, 126]. FC3 described their experiences and the potential value of an agent in providing both technical and emotional support:

“It’s very difficult to transport the CR and it could cause much more harm ... and sometimes it’s for very minor things. I wish I could take a picture and send it and ask: ‘Is this serious? Should I be worried about it?’ [HCWs] are humans too ... [the HCW] was really worried and she’s always very apologetic, but a couple of times when she’s called: ‘I think you need to take her to an emergency room’ and it actually didn’t end up being so serious

but I wish we had an opportunity to run this by ... the nurse. They could tell us if it’s something that was worth coming to the hospital. Because if people are really frail, you actually do more harm by going to the hospital.”

4.5 Establishing Accountability

Given the sensitive context of home health care, we examined participants’ perspectives on accountability and how to handle the potential for AI errors. Participants acknowledged mistakes as inevitable, discussed design strategies to mitigate them, and emphasized the need to adapt social processes to ensure accountability.

4.5.1 Understanding the fallibility of AI assistance. Participants were quick to point out that AI errors were likely inevitable, but emphasized that this did not preclude agents from being useful. As HCW1 explained, *“There can be a few mistakes. I can say that 90% it helps a lot. But the 10% left, then we have to [listen to people], not AI.”* Participants also recognized that the accuracy of an AI tool would depend on the quality of the input data. As HCW3 noted, *“what you’re putting in is what you will get out of it. So we have to be mindful to put the right thing in. Because it’s a machine, it takes what you tell it.”*

In addition, participants with prior experience using AI systems, such as FC6, mentioned that the risk of critical errors might be reduced if the agent is limited to tasks like relaying specific pieces of information between caregivers or providing scheduled reminders, rather than synthesizing general information from the Internet, a process likely more prone to *“hallucinations”* (i.e., LLMs’ tendency to generate false outputs that appear convincing) [41, 54, 87]:

“The caregivers are providing it with data to regurgitate to the other user. So I can’t really see a scenario where it would hallucinate because it’s not pulling data from anywhere, like on the Internet, where it might pull a fake website, for example, that has incorrect information. It is only pulling data from the sources providing it with data, which is only going to be within that closed loop of people.”

4.5.2 Designing agents around the potential for errors. Given the inevitability of errors, participants discussed a variety of design ideas for how agents could handle mistakes—both from a technical perspective and within the sociotechnical processes in which they would operate. From a technical standpoint, participants recommended that agents be designed to communicate their level of uncertainty to caregivers, emphasizing that these systems should adopt a conservative scope of functionality and incorporate features that promote appropriate reliance. As FC5 explained, *“it feels like no mistake is allowed but that’s not realistic ... It should be built to say: ‘I don’t know or I need more information to be able to make a recommendation for this.’”*

Similarly, FC7 referenced other AI tools they had used that conveyed transparency through confidence indicators, suggesting that such features could help caregivers better interpret system outputs: *“It tells you kind of how accurate it really is. That’s an interesting way to help tell you what level of accuracy the app is registering.”* Other participants, such as FC2, emphasized the importance of caregivers being able to review the data that led to the AI’s output: *“You’d*

want to track back and listen to the notes.” More broadly, participants familiar with LLMs suggested that the system be designed to adopt a flexible, amenable conversational style that accommodates feedback and gathers additional information when challenged. As FC8 described:

“What I like right now, just as it pertains to like ChatGPT as an example, which is probably the major tool that I use when it comes to AI, is I noticed that when I question it and call it out, it backs down pretty easily. It doesn’t double down, it hasn’t doubled down on anything or like become argumentative ... the model is programmed to take feedback. And then when you second guess, it will research further. You just have to kind of prod it ... So I think that’s important in AI models is having that capability to, when the user questions it or asks for more information, it does that action as well.”

4.5.3 Adapting social processes to account for AI errors. Beyond the technical design of the conversational agent, participants also suggested adapting the sociotechnical processes surrounding the technology in ways that might anticipate and account for potential errors. Participants generally agreed that caregivers ultimately remain responsible for managing care and an agent should function as an “assistant” (FC8) rather than something that can be fully relied upon. Given the high stakes context, participants, like FC3, felt it would be important to be clear about who would be liable for the consequences of any mistakes: *“There’s always danger with inaccurate responses and then who’s liable for this?”*

At the same time, participants questioned how feasible it would be for caregivers to remain constantly vigilant, particularly as they grow accustomed to using these tools. As FC7 explained: *“We all have a limit on how much we can really try to verify. We need to assume that some of our systems are correct.”* FC8 emphasized the importance of strong policies and training for caregivers to ensure accountability, which may be easier to implement for HCWs who are subject to agency policies than for FCs:

“Hopefully [there would be] really strong training that instills the fact that you would still be responsible. So that way they’re even more diligent about cross-checking and not relying on that information.”

Finally, participants suggested having clear processes for quickly reporting mistakes and correcting inaccuracies. For instance, FC8 highlighted Wikipedia’s community-based reporting system as an example to draw from:

“There should be a way to report it. So sort of like community-based reporting, like Wikipedia, like you can submit a correction, whether that be by voice or by sending a ticket but there should be a way to immediately report it so that it gets corrected ... the quicker you report it, the better, because who knows how rapidly it could spread.”

5 DISCUSSION

Our findings highlight numerous opportunities and challenges for agents to coordinate shared care among HCWs and FCs. For example, agents could make essential information more accessible,

mediate context-aware communication, facilitate shift handovers and personalized onboarding, and enable more flexible and timely documentation, follow-ups, and reminders. At the same time, realizing these benefits will require carefully balancing coordination efficiency with human-centered care, managing caregiver labor burdens, respecting privacy and stakeholder boundaries, and addressing AI errors and accountability. Below, we synthesize these findings into key considerations for responsibly designing agents to facilitate coordination of shared care by: reducing data work and improving FC–HCW communication (Section 5.1); complementing and encouraging human-centered care and relational work between FCs, HCWs, and CRs (Section 5.2); tailoring interactions to caregivers’ different roles (Section 5.3); and treating agents as sociotechnical interventions that require supportive resources and procedures for oversight and accountability (Section 5.4).

5.1 Managing data work

The first key design consideration involves managing and reducing the burden of data work [19]—the inputting and maintenance of information required by digital systems (and a well documented challenge in frontline care contexts [97, 98, 111]). As Section 4.4.1 highlights, participants, especially HCWs, already operate within established but cumbersome documentation and reporting systems. Because agents often require timely, accurate, and robust data to function effectively, their use might increase the amount of data work FCs and HCWs are required to perform. Thus, responsible agent design should consider how to align with the data work caregivers already perform and how any additional tasks required to support an agent might interact with or replace this work. This suggestion builds on prior work highlighting the importance of aligning new technologies with stakeholders’ existing practices and priorities [13], a critical challenge in home care settings where caregivers are often overburdened [65] and undersupported [103].

Our findings provide concrete examples of challenges and potential opportunities for agents to support caregivers’ workflows in ways that improve care coordination. Section 4.4.1 illustrates how current processes often require caregivers to manually record and recall activities throughout a visit (e.g., using notebooks) until clocking out, when the end-of-shift requirement to check off lengthy lists is burdensome and error-prone. These findings connect with prior work critiquing EVV systems, which are ostensibly designed to improve coordination, but are often intrusive technologies that increase HCWs data collection burdens, constrain caregiver flexibility, and devalue their expertise [47, 70]. Caregivers suggested that agents could streamline existing care coordination workflows by supporting real-time documentation in a more natural and seamless manner, such as through voice-based inputs in their preferred language. Furthermore, because care coordination involves heterogeneous and dynamic data, LLMs may be able to enhance information retrieval and summarization while enabling caregivers to interact with systems via more natural conversational exchanges [29].

Taken together, these findings point to the importance of input affordances that reduce data work by aligning with caregivers’ existing workflows. Providing dynamic and flexible input modalities,

such as natural voice-based inputs, language translation capabilities, and multimedia support, may reduce documentation burdens while also improving overall care. For instance, participants noted the potential for multimedia, such as photographs or videos, to lessen documentation burdens on caregivers by reducing the need to describe complex symptoms in words or enabling remote triage without needing the CR to visit a hospital or doctor's office. Participants also highlighted how language translation capabilities might reduce burdens by facilitating communication between HCWs and FCs who may not share a common language, eliminating the cognitive load of trying to communicate in another language. Participants valued these design affordances because they aligned with caregivers' existing abilities and priorities—effectively meeting caregivers where they are. These insights corroborate prior work that calls for agents to offer flexible input modalities tailored to users' needs (e.g., language support) and accept diverse input types (e.g., multimedia documentation) [12, 131].

5.2 Preserving attentive and humanistic care

Beyond being mindful of data work and aligning with existing coordination practices, participants in Section 4.1.2 raised concerns that agents designed to improve care coordination might redirect caregiver attention away from CRs and toward the technology, posing two main risks. First, participants stressed that increases in data work are not merely inconvenient but directly counter to the goals of caregiving, risking erosion of the relational bonds that sustain CRs' wellbeing as well as potentially jeopardizing their physical health. For example, in Section 4.1.2, our findings suggested that distracted caregiving might reduce caregiver vigilance around fall prevention.

Second, while agents may improve care coordination by automating communication, as participants suggested in Section 4.2.1, this could inadvertently reduce direct interpersonal connections. For example, if FCs have greater awareness of the CR's status through technological mediation—ostensibly an improvement in coordination—they may perceive less of a need to visit the CR, weakening one of the most meaningful aspects of home care: human connection. These insights build on prior work highlighting how care coordination involves more than optimizing task performance—relational work is a foundational element of coordination and essential for providing holistic, high quality care [77, 112]. For example, caregivers often coordinate to share information about CR's preferences or strategies for navigating CR's emotions [77].

To mitigate this risk, careful attention is needed to ensure that agents designed for care coordination complement rather than undermine the human essence of care. In particular, the agent might incorporate features that explicitly support physical and meaningful social connections for CRs [83]. For example, agents could keep track of when FCs visit, to identify when CRs are at risk of social isolation, and prompt caregivers to reach out to CRs they have not contacted recently. Agents could further suggest activities or plan shared meals to strengthen relational engagement.

5.3 Tailoring the agent's interactions to caregivers' roles

Building on the need to preserve the human essence of care coordination, a related design consideration involves ensuring that agents in shared care contexts interact with different caregivers in ways that are contextually appropriate, an approach supported by our findings in Section 4.2.3. Central to the concept of shared care is that CRs receive care from multiple types of caregivers (see Figure 1). At a high level, our study explored the coordination needs of FCs and HCWs, but we found numerous variations within these categories. For example, information that is appropriate for a primary FC who lives with the CR is different from a FC who visits periodically for social interaction (see Section 4.3.1). The task reminders required by a HCW who spends every day with the CR differ from one who provides temporary coverage. On top of that, our findings show that caregivers' needs change over time, with new caregivers requiring more information about the CRs' needs and preferences than someone who has cared for the CR for a long time. These findings raise the question of how an agent might appropriately tailor its interactions based on caregivers' different roles and coordination needs.

One strategy might be to utilize caregiver profiles that give the agent contextual information to guide its interactions and allow it to dynamically adjust the information and communication provided to different caregivers. For instance, a caregiver might be assigned a baseline profile (e.g., primary FC, experienced HCW, occasional FC, relief HCW) that then adapts and evolves over time. This might facilitate appropriate onboarding for new caregivers that includes essential information about the CR, their needs, and required tasks. This would reduce the need for the CR to repeat information or new caregivers to call others for assistance. In addition, new or less frequent caregivers might by default receive more reminders than experienced caregivers with deep understanding of the CR's needs.

Our findings support this approach. As described in Sections 4.3.1 and 4.3.2, participants expressed interest in using an agent to streamline handover and onboarding processes, noting that doing so could lessen the burden on CRs and other caregivers by facilitating the sharing of key information about care tasks, health status updates, preferences, and routines. These ideas also connect with and build on research that advocates for technologies and agents to offer tailored support to caregivers that is aligned with their individual needs across different phases of caregiving [89, 131], as well as work on context-aware agents [5, 30, 52, 58, 60, 71, 93], and personalization through user accounts [77, 131].

Tailoring the agent's interactions to caregiver roles may further enable it to support different needs around emotional sensitivity and privacy. In Section 4.2.3, our findings suggest that CRs may wish to regulate information sharing, for example to shield FCs from the emotional strain of their condition or preserve their privacy around intimate situations, such as bathing, where ensuring CR dignity and privacy is paramount. In addition, we heard how caregivers, especially FCs, are emotionally invested in their loved one's life and may be struggling with their physical or cognitive decline. An agent might take into account the sensitivity of particular information, the caregiver's role, and the CR's preferences to determine when,

how, and with whom sensitive, private, or potentially upsetting information might be shared.

5.4 Developing supportive sociotechnical resources and processes

Lastly, our findings raise sociotechnical considerations around deploying agents for care coordination. At an organizational level, deployment may require additional infrastructural support, including potentially augmenting existing roles or introducing new personnel. As Section 4.4.2 suggests, agencies may need clinicians (e.g., nurses) to triage communications from caregivers, or staff to provide technological oversight. Attention is also needed around device use: relying on HCWs' personal phones raises concerns about data sensitivity, privacy and security, and financial burdens, particularly given that HCWs are low-wage workers [56] and should not incur additional costs from these tools.

Privacy and security considerations may further complicate the integration of agents into care coordination workflows. While agents may streamline information sharing by drawing on data sources such as care plans, they also may introduce risks and technical challenges (also identified in prior work [60]), including data leaks and AI-generated inaccuracies. These risks are especially concerning in care coordination, where errors (e.g., in medication dosages) could have high-stakes consequences and where caregivers may have varying levels of familiarity with the CR, impacting their ability to detect and triage AI mistakes. Responsible development could ground user interactions in principles of contextual integrity [79] to assess the appropriateness of information flows, and trauma-informed approaches [28, 84, 117, 129] that consider stakeholder safety, choice, and empowerment. To accommodate diverse privacy preferences, agents might be developed with meaningful consent mechanisms and user-controlled data settings, leveraging technical approaches and protections supported by HIPAA privacy legislation [3].

In addition to privacy risks, AI fallibility represents a foreseeable technical challenge. As participants noted in Section 4.5.1, AI errors may be inevitable. Prior work shows that LLM-based agents can generate plausible but incorrect outputs (i.e., hallucinations) [41, 54, 87] or act on inaccurate user inputs [59]. Strategies for developing safe agents for shared care might mitigate these risks by grounding outputs in reliable sources [67], using one-shot or few-shot prompting to clarify tasks [34], or employing chain-of-thought prompting to improve reasoning and transparency [123].

Beyond technical mitigations, responsible deployment also requires comprehensive training and clear usage policies. As our findings in Section 4.5.3 suggest, caregivers must be equipped not only to use these systems effectively but also to understand their limitations, including the potential for errors and the escalation protocols to follow when errors occur. This finding aligns with prior work showing that practitioners were frustrated that existing agents emphasized technical design while offering little support for educating or explaining system capabilities to stakeholders [86]. Addressing this challenge will require holistic approaches, such as explainability strategies [22, 86, 97] that, as our findings suggest, account for differences in oversight and accountability among HCWs and FCs. Policies and training that ensure caregiver accountability

may be easier to implement for HCWs, who are already subject to agency oversight, than for FCs, who operate independently and on a voluntary basis. Future work should therefore explore how to design training programs and policy frameworks that address these differences and ensure equitable accountability across caregiver groups.

6 CONCLUSION

This paper investigated how agents driven by LLMs might support shared care, or coordination of home-based care among HCWs and FCs who care for the same CR. Through video elicitation sessions with participants, we provided empirical data capturing the perspectives of both HCWs and FCs, who would need to interact with agents despite being neither AI nor clinical experts. Our findings showed that FCs and HCWs view agents as a promising tool for improving care coordination. We highlighted implications and design recommendations to inform the responsible development of agents that augment human capabilities, bridge gaps between stakeholders, and enable caregivers to deliver attentive and humanistic care.

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