Orchestrated Informal Care Coordination: Designing a connected network of tools in support of collective care activities for informal caregivers

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ABSTRACT
Often, family caregivers experience difficulties in coordinating older adults' health care because it requires not only a lot of time but also a diverse set of responsibilities to coordinate care for their loved ones. While many can reduce their individual burden by sharing care tasks with other family members, there are still many challenges to overcome in maintaining the quality of care when they work together. As they increase their informal care network, it becomes more difficult for them to stay informed and coordinated. Coordination breakdowns caused by having multiple caregivers who are cooperating to care for the same care recipient result in reduced quality of care. I explored opportunities for "Internet of Things (IoT)" technologies to help informal caregivers better coordinate and communicate care with each other for their loved ones. Based on identified design opportunities, I propose the concept of CareBot, a smart home platform consisting of interactive tools in support of collective care activities of family caregivers.

Author Keywords
Caregiving; Caregiver; Connected Home; Internet of Things; Field Study; Qualitative Methods.

ACM Classification Keywords
H.5.2. Information interfaces and presentation (e.g., HCI): User-centered design

INTRODUCTION
According to the U.S. Census Bureau, about 1 in 5 U.S. residents are projected to be aged 65 and over by 2030 [4]. Already more than 65 million Americans are informal caregivers providing care for an ill, disabled or aged family member [3]. Due to the continuous growth in the elderly population and the fact that most Americans would rather keep living in their homes than move to care facilities as they get older [2], the number of informal caregivers and the importance of in-home care will continually increase.

In the face of this trend, research has been conducted from both health informatics and HCI communities on how smart home and IoT technologies can support home health care and promote senior's independent living through monitoring and sensing data of residents. However, despite the fact that family caregivers play a significant role in managing seniors' overall health care [1], little has been focused on how family caregivers can benefit from these technologies when it comes to care coordination for their loved ones in their own homes.

I investigated opportunities for IoT technologies to help informal caregivers better coordinate and communicate care with each other for their loved ones. Using a user-centered design approach, I explored various facets that make up the overall experiences of family caregivers who are involved in in-home care coordination. My design process included:

- Conducting in-depth interviews with 16 people including family caregivers, care recipients, and professional care coordinators
- Developing design concepts that address findings extracted from the exploratory research
- Speed dating as a means to validate user needs, obtain feedback and gain perspective on the concepts
- Physical form studies with various material forms and interactions as a way of further exploring design ideas.

The findings of the qualitative study have revealed three main opportunities in which IoT can play a significant role for informal caregivers' collective care coordination: (i) facilitating care works by reminding caregivers of tasks that need to be done and providing instructions on how to accomplish it, (ii) having crucial information accessible to everyone in the network of informal caregivers to stay organized and coordinated, and (iii) keeping everyone engaged and connected to avoid breakdown caused by poor communication and lack of information. Based on identified design opportunities, I suggest the concept of CareBot, a smart home platform consisting of interactive tools that help family caregivers better coordinate and communicate care with each other for their loved ones.

CONCEPT OVERVIEW
CareBot is designed to provide a new way of engaging in care and preventing potential breakdowns caused by having multiple caregivers who work together. Main features of the concept of CareBot are three fold:

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1. Remind: It triggers reminders to prompt caregivers to complete care activities that haven't been done on time. It aims to reduce the chances of forgetting and overlapping care works such as taking medication, drinking water, and simple exercise.
2. Capture: It helps caregivers capture the care activities that should be coordinated at the point of action. It provides a way to document and annotate care activities that have or haven't been done to give contextual information to other caregivers.
3. Connect: It keeps all family caregivers connected to crucial information of care as well as to each other. It makes it easier for caregivers to stay in the loop and organize support together. It also gives caregivers the opportunity to volunteer and take over care tasks.

To concretize these features of CareBot, its design should leverage the benefit of smart home and IoT technologies.

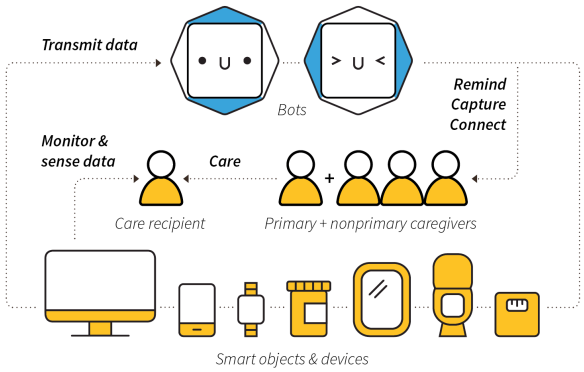

Figure 1. System map of CareBot.

First, these technologies allow caregivers to keep track of important care information by monitoring data of residents. CareBot should communicate with a range of smart objects and devices to get necessary information of care such as a schedule for must-do activities and real-time data of caregivers and care recipients' activities. Second, A connected network of physical objects would engage caregivers as more active and better-informed participants of care. CareBot has a physical tool which is directly situated in the real context of care to allow it to better trigger reminders and capture the care work at the point of action.

The physical tool of CareBot breaks mainly into two parts: the Bot and an e-ink display. The Bot is the part that signals users to take actions and that users actually interact with to get information. It is packed with multiple sensors and components including LED display, motion detector, Bluetooth, and etc. The e-ink display is the part that displays details of information that the Bot provides. The Bot lights up when there's an action to take for the care recipient. Each side of the Bot has different types of information that caregivers need to know and lights up when there's specific information to display. When users turn the Bot, the e-ink display presents details of information on the surface which correspond to the right side of the Bot.

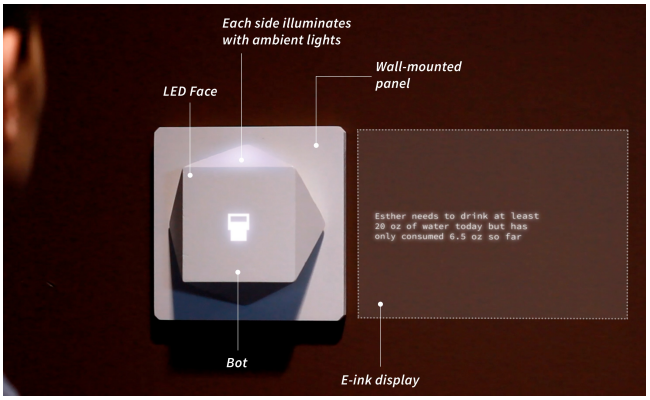

Figure 2. Physical tool of CareBot

FUTURE WORK

The caregiver role involves a wide variety of types of care, and caregivers and care recipients' social dynamics are incredibly diverse. Although I tried to ensure a various spectrum of contexts of care, this research is still limited to certain types of contexts of care. Therefore, further research should be conducted to verify and extend the resulting design to different disease and circumstances.

The concept of CareBot also requires a more robust system around it to better support family caregivers and care recipients. In the future, it can connect with a more diverse set of smart devices, such as a home medical kit, fitness kit, thermostat, and etc. The service side should be designed and verified as well in a holistic way in order to make CareBot more useful for family caregivers as a smart home platform. For example, family caregivers might want to seamlessly connect the information and data of their care activities that they gathered from CareBot to professional medical service providers for a better medical experience. Great opportunities exist for the bridge between informal care coordination and formal medical care, so further work is needed to explore these opportunities.

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