Carebit: A Privacy-Preserving "Step" Toward Remote Informal Caregiving

Arup Kumar Ghosh
University of Central Florida
Computer Science
arupkumar.ghosh@ucf.edu

Pamela Wisniewski
University of Central Florida
Computer Science
pamwis@ucf.edu

Zaina Aljallad
University of Central Florida
Computer Science
zaina.aljallad@knights.ucf.edu

Karla Badillo-Urquiola
University of Central Florida
Computer Science
kcurquiola10@knights.ucf.edu

GROUP '18, January 7–10, 2018, Sanibel Island, FL, USA

ACM ISBN 978-1-4503-5562-9/18/01.
https://doi.org/10.1145/3148330.3154520

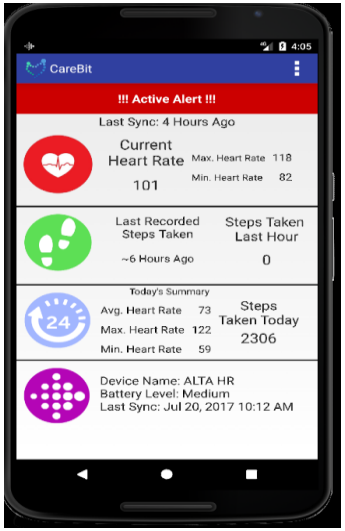
Abstract
Several tele-monitoring systems have been developed for in-home patient use. Unfortunately, many of these systems are cost prohibitive and privacy invasive to the patient. To overcome this problem, we designed a more affordable and lightweight solution called *Carebit*, an Android application that leverages the Fitbit API. We conducted two user studies to understand ways to improve our design. Overall, we found that the notifications feature is the most useful feature for users, and no concerns about privacy were mentioned. The goal of *Carebit* is improve informal caregiving.

Author Keywords
Family Caregiving; Wearable Internet of Things; Privacy

ACM Classification Keywords
K.4.1 [Public Policy Issues]: Ethics, Human safety, Privacy

Introduction
An informal caregiver is a family member, friend, or neighbor, who provides unpaid services and supervision to a loved one, someone who is ill, incapacitated, or otherwise needs help [7]. There are approximately 43.5 million informal caregivers in the United States, out of which 75% live within 20 minutes from their care recipient, and 13% live in between 20 minutes and an

Sidebar 1a. Carebit Caregiver Dashboard



Sidebar 1b. Carebit System Architecture

hour away [7]. Otherwise, informal caregivers often take care of loved ones as in-home patients, requiring constant attention that creates significant caregiver burden, especially when care requires constant supervision [6]. As a result, a number of tele-monitoring systems to help with in-home care have been developed [3]. Yet, a major concern with these monitoring systems is that they often require patients to give up their personal privacy for the sake of their health and safety [5].

To address this problem, we conceptualized and created *Carebit*, an Android application ("app") that leverages the Fitbit API, for informal caregiving relationships, where the patient is well enough to live independently but desires a lightweight means for another to check in on them on a daily basis. Our contribution to the broader SIGCHI community, including GROUP, is a remote caregiving solution that preserves privacy through a lightweight and low cost means. We conducted two pilot studies on an initial prototype for *Carebit*, and synthesize these results to discuss future design iterations of *Carebit* to improve informal caregiving.

Background

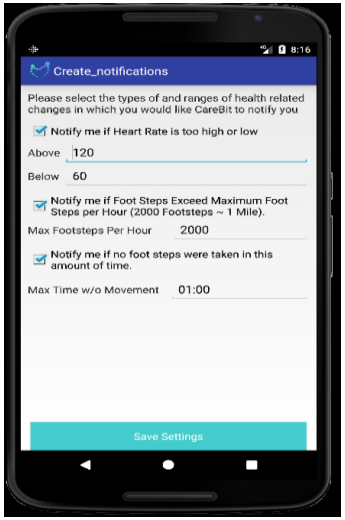
There have been numerous studies conducted on wearable technologies to assist in caregiving [1,5]. The common theme that emerged from all these studies is the trade-offs between privacy and the usefulness of the wearable technology. For example, in one study patients mentioned how they didn't want their loved ones knowing every single thing they were doing: "It's none of their business [5]." Another prohibitive factor was cost; many tele-monitoring solutions require investing in physical hardware and monthly monitoring fees [2]. In our work, we explicitly designed our solution to reduce these barriers to user acceptance.

Carebit Implementation

The Carebit dashboard and system architecture are in shown in **Sidebar 1**. *Carebit* was implemented as a mobile app using Android Studio. The app is designed to be installed on the caregiver's mobile Android smartphone. Meanwhile, the only hardware required by patients is: 1) a Fitbit equipped with a heart rate tracker and 2) a device to sync the Fitbit via the internet (e.g., smart phone or tablet). The Fitbit is a very popular wearable fitness tracker, and costs between $150-$170 [8].

The *Carebit* app uses the Fitbit application protocol interface (API) to get pertinent health data from patients. Our solution applies Nissenbaum's contextual integrity privacy framework [4] in our design and allows the patient to control the types of information shared to a given caregiver. In order for caregivers to get access to this information, the patient must login using their Fitbit credentials and provide their consent for the caregiver to access a limited amount of the Fitbit data. For example, the last time steps were taken or current heart rate, but not sharing less relevant information, such as weight or historical data. The app is designed to keep patients' privacy in mind, but still provide the information needed for the caregiver to know if they patient may need assistance. Caregivers are free to access the application at any time to check up on their loved one and are also alerted when the patient may be in danger, which is determined using pre-defined thresholds based on the patients' vital signs (i.e., last step activity and heart rate). See **Sidebar 2**.

Sidebar 2. Alert Notification Settings



Methods

We conducted two pilot studies to get solicit user feedback about our initial design and prototype.

Design Probe and Interview

We showed storyboards of our initial prototype to a convenience sample of 21 participants, primarily college students and adult acquaintances. We described the main purpose of Carebit to the participants and asked the following follow-up questions:

1) *Do you think an app like this might be useful to you now or in the future? Why or why not?*
2) *What types of notifications would you want this app to be able to give you?*
3) *If you were designing this app, what features would you include in the app?*

The results from this probe were used to inform the design of the alert notifications implemented in the later app for a one-day user simulation.

One-Day Simulated User Study

Five college student volunteers participated in a 24-hour user simulation, acting as informal caregivers. A research assistant acted as the patient, setting off alert notifications via a Fitbit throughout the day. Volunteers were instructed to send a text message every time they received an alert, as if they were checking in on their loved one. A post-survey was administered at the end of the user simulation.

Results

Design Probe Feedback

After seeing the Carebit storyboards, about 85% of participants thought that *Carebit* was useful because of the following reasons: giving the patient more independence, allowing caregivers to monitor their loved ones from afar, etc. The users also liked how the integration of technology was used to improve health. Yet, 15% did not find the app very useful as they thought the solution was very similar to existing emergency devices such as *Life Alert*. The most common alerts requested included irregular heartrate, low activity levels, goals achieved, and falls. Therefore, we incorporated heart rate and step activity alerts into our prototype prior to conducting a second user study.

Simulated User Study Results

The results from the second user study indicated that the participants responded a little over half of the time after receiving a notification. We found the average response time varied between 20 and 35 minutes. From the post-survey, we 60% of users stated the most useful feature was the notification alerts. Very few participants said that they checked the dashboard consistently through the day. Some participants felt the need for more alerts or alerts that persisted until they were cleared. Other felt the need to monitor more activity than just steps, such as the fall alerts that were also suggested in the prior user study.

Limitations and Future Work

Overall, our user studies showed promise that our solution may be useful and provided insights on how we can further improve *Carebit.* We realized that the alerts seem to be more critical for users than the dashboard itself. Yet, a major design flaw that we uncovered during the second user study was that alert notifications sometimes disappeared before participants saw them. In the future, we plan to improve this functionality and implement additional alert notifications. However, it is unlikely that Fitbit can be

used to accurately detect falls. Another limitation of our pilot studies is that most of our participants were college students. For future user studies, we will recruit participants who are actually informal caregivers, as well as the loved ones they are caring for. We believe that recruiting from the intended target audience will increase engagement, as well as provide more insightful feedback on whether *Carebit* can, indeed, provide a piece of mind for individuals who desire to live independently, but need just a little bit of care.

Acknowledgements

This work is dedicated to the last author's friend Susan Riggs, who passed away due to complications from Diabetes. After being in a coma on her kitchen floor for two days before being found by a neighbor, she suffered severe lung and kidney damage, which claimed her life. Our goal is to create a production-ready version of *Carebit* for free download for friends and loved ones, who may want to watch over one another to avoid similar tragic events. We would also like to thank Kim Chen, Richard Hyman, and Joseph Prause, undergraduate students who supported development efforts. Support for this work was provided by the National Science Foundation Research Experience for Undergraduates program under Award No. 1560302. Any opinions, findings, and conclusions and recommendations expressed in this material are those of the author(s) and do not necessarily reflect the views of the National Science Foundation.

References

1. Daniel Aranki, Gregorij Kurillo, Posu Yan, David M. Liebovitz, and Ruzena Bajcsy. 2016. Real-Time Tele-Monitoring of Patients with Chronic Heart-Failure Using a Smartphone: Lessons Learned. *IEEE Transactions on Affective Computing* 7, 3: 206–219.
2. Ghassan A. Hamad and Alyn H. Morice. 2016. Telehealth in COPD: Compiling a Tele-Monitoring Package. *Chronic Obstructive Pulmonary Disease: Open Access* 1, 2.
3. Cliodhna Ní Scanaill, Sheila Carew, Pierre Barralon, Norbert Noury, Declan Lyons, and Gerard M. Lyons. 2006. A review of approaches to mobility telemonitoring of the elderly in their living environment. *Annals of Biomedical Engineering* 34, 4: 547–563.
4. Helen Nissenbaum. 2004. PRIVACY AS CONTEXTUAL INTEGRITY. *Washington Law Review* 79, 119.
5. John Vines, Stephen Lindsay, Gary W. Pritchard, et al. 2013. Making Family Care Work: Dependence, Privacy and Remote Home Monitoring Telecare Systems. *Proceedings of the 2013 ACM International Joint Conference on Pervasive and Ubiquitous Computing*, ACM, 607–616.
6. Allison Williams, Bharati Sethi, Wendy Duggleby, et al. 2016. A Canadian qualitative study exploring the diversity of the experience of family caregivers of older adults with multiple chronic conditions using a social location perspective. *International Journal for Equity in Health* 15: 40.
7. Caregiver Statistics: Demographics | Family Caregiver Alliance. Retrieved September 17, 2017 from https://www.caregiver.org/caregiver-statistics-demographics.
8. Fitbit Official Site for Activity Trackers & More. Retrieved September 21, 2017 from https://www.fitbit.com/home.