Position Statement

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1. INTRODUCTION

The health information feedback loop, conceptualized in Figure 1, is the idea that people collect data about their health, share it with various decision maker stakeholders - most likely caregivers and healthcare professionals, and then receive personalized feedback about how to improve their health. This feedback loop relies on rich data collection, reflection, and sharing so that the decision maker stakeholders have enough information to provide actionable steps to improve an individual's health. Unfortunately, there are breakdowns in the United States health information feedback loop - namely in data collection, sharing, and administering by lay individuals. My research explores how information communication technology (ICT) can assist in each of these break-down areas.

2. IMPROVING THE FEEDBACK LOOP

We study data collection and reflection for low literacy chronically ill populations by designing, developing, and evaluating DIMA. For data sharing and reflection, we investigate how the general populace can share information with the Colorado Care Tablet (CoCare Tablet) and how health professionals use Electronic Medical Records (EMRs) in their workflows. Finally, we research how to assist caregivers improve their families' health with the Health Bridge project and identify medications with the Medication Vision Recognition project.

Rich Input Collection: For collecting rich, health-related data, my research has primarily investigated the best ways to collect and display dietary intake information to assist low literacy, chronically ill individuals manage their illness. My collaborator found that dialysis patients in the target population lacked the literacy skills necessary to adhere to their strict diet [3]. In response to this finding, we designed and iteratively developed ***DIMA*** - an application that assists dialysis patients monitor their dietary intake in relation to prescribed dietary limits [2]. We investigated how different input modalities could support dietary intake collection in participants' everyday lives [9, 10, 15]. The final DIMA prototype was used in a 6 week field study with 18 dialysis patients. From a computing and design standpoint, we found that the immediate personalized feedback motivated continued usage throughout the study [1]. From a medical standpoint, we found that DIMA did help dialysis patients who previously had difficulty managing their dietary limits. Indeed, participants who previously went over their prescribed fluid limits only consumed 56% of their prescribed limit during the study [14].

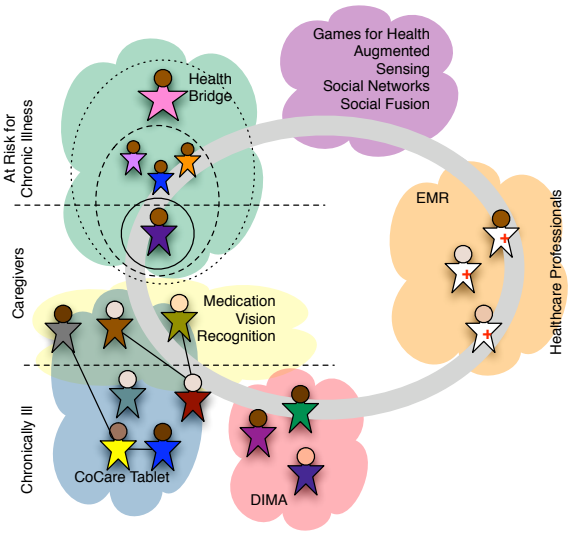

Figure 1: Overview of Research Activities to Improve the Health Information Feedback Loop

Data Sharing and Reflecting: With respect to data sharing in the Health Information Feedback loop, I study the potential for PHRs to assist with patients' overwhelming responsibilities as the data repository and conduit to share information with caregivers and healthcare providers. In the ***CoCare Tablet*** project, we explored what older adults and caregivers needed to manage and share their medication regimes. We found that older adults and caregivers sought: (1) medication information from multiple sources depending on the urgency of their informational needs; (2) autonomy of their medication regime; (3) a better way to integrate conventional and alternative medicines into their regimes; and (4) reasons for taking too many medications [4]. We iteratively designed the CoCare Tablet through six user studies. The Personal Health Application (PHA) was easily used by older adults because it borrowed heavily from older adults artifacts and workflows [5, 13]. Information from the CoCare Tablet could be easily shared with other PHAs.

Once an individual collects all of this health information data, we must consider how it will be shared with healthcare providers. Before we look at PHR sharing, however we must better understand healthcare professionals' current

workflows in relations to EMRs and how PHRs could integrate into healthcare professionals' work activities. As part of my NSF CAREER award, my lab is studying the workflows of healthcare providers and the usability of small-scale EMRs in the ***Wardenburg EMR Project (WEMR)***. We are currently shadowing healthcare professionals in a small-scale health facility. Through this study, we hope to identify how to integrate PHR data into workflows and develop design guidelines for small-scale EMRs.

Reliance on Lay Caregivers: The U.S. healthcare system relies on lay caregivers - whether it is because people do not have access to healthcare, such as in low socioeconomic status populations, or because the system does not have the resources to care for a growing demographic, such as the older adult population. We were able to identify what low socioeconomic status, lay caregivers need to improve the health of their families - personalized, actionable steps [8, 12]. In relation to improving physical activity, we found that caregivers could benefit from a persuasive technology that would encourage the caregiver to understand that busy inactivity is not effective exercise and that their health is as important as their children's health [7]. Once we better understood what caregivers said, we explored what they and their families wanted from technology through design workshops [11]. These studies laid the groundwork for my NSF CAREER award, ***Health Bridge***. We are currently analyzing data for the last part of the needs assessment - a video elicitation study to learn about what caregivers actually do in their lives.

When we worked with older adult caregivers during the CoCare Tablet project, caregivers often told us they were unsure of what medications were being taken and how to accommodate changes into medication regimes [4]. This is especially problematic because people often think of their medications by context or color. We are developing a ***Medication Vision Recognition*** system that used the shape (unique signature) and color (RGB color model) to retrieve a matching final image from a candidate group that was pre-classified by shape analysis. The current algorithm can correctly identify a medication 92% of the time. The system accuracy should improve by integrating in other color models, imprint analysis, and scoring detection [6].

3. WORKSHOP PARTICIPATION

I can contribute to the workshop by providing insight into EMRs and PHRs - specifically design, interoperability, and workflows associated with each record. In addition, I recently completed a Distinguished Visiting Fellowship from the Scottish Informatics and Computer Science Alliance to study the potential of PHRs within the Scottish population. Thus, I have some insight into personal health information needs from an international population with access to universal healthcare. During the workshop, I hope to learn more about the needs of people with disabilities in regards to health records. I discussed PHRs with people from the Coleman Institute for Cognitive Disabilities, however I must learn more about the general needs before pursuing research in this area.

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