In-Home Assessment of the Activities of Daily Living of the Elderly

Daniel H. Wilson
Robotics Institute
Carnegie Mellon University
5000 Forbes Ave, Pittsburgh, PA 15213
dwilson@cs.cmu.edu

Sunny Consolvo & Ken Fishkin & Matthai Philipose
Intel Research Seattle
1100 NE 45th Street, Seattle, WA 98105
[sunny.consolvo, ken.fishkin, matthai.philipose]@intel.com

ABSTRACT

In-home health assessment of elders is often accomplished with the help of caregivers, usually family and friends. When formal support is necessary, it is commonly provided by case managers, professionals who visit the home to assess the mental and physical status of the elder, or "client." In an effort to understand how ADLs are collected, we performed semi-structured interviews with five case managers who maintain a combined caseload of over 150 clients. In this position paper, we discuss the results of those interviews, focusing on the utility of an automatic in-home monitoring system. We discuss how some current research could be influenced by our results and describe the next phase of our study.

INTRODUCTION

People aged 65 and older are the fastest growing segment of the U.S. population (set to double in the next two decades). As people age, they depend more heavily upon outside support for health assessment and medical care. Current health-care infrastructure is inadequate to meet the needs of an increasingly older population. One solution is to enable *aging in place*, in which elders live independently and safely in their own homes for as long as possible, i.e. avoiding the transition to a care facility.

Living safely and independently requires frequent health assessment. This service is often provided by *case managers* (CMs), specially trained caregivers (not necessarily nurses) who visit elderly *clients* in order to assess their physical and mental health status. During *monitoring visits*, a CM tracks the abilities of the client and is responsible for introducing new equipment (e.g., walkers, grab bars, etc.) and services (e.g., personal care assistants, home-delivered meals, etc.) as needed. For a CM, a significant part of assessment is captured by observing the client's performance over a specific set of activities - called activities of daily living (ADLs). ADLs are chosen to represent overall cognitive function and physical abilities; they include bathing, preparing food, getting dressed, grooming, and eating meals.

The use of technology to automatically monitor ADLs has been a focus of research at Intel Research Seattle (IRS) [1,2] and elsewhere. However, there has been relatively little exploration of 1) how information about ADLs in the home is currently collected, and 2) how information about ADLs is used by caregivers. To begin such an exploration, we conducted interviews with five case managers who maintain a combined caseload of over 150 clients. Through one-on-one interviews, we investigated how CMs collect information about ADLs, in order to motivate the design of assistive technologies.

In this position paper, we describe our study in which we interviewed case managers about how they do their jobs. We report our preliminary results and describe the impact that these findings may have on several areas of research related to health assessment. Finally, we describe our plans for a follow-up study to build on these results.

STUDY

Participants. Participants in this study were 5 females who were recruited by word of mouth at the case management agency where they work (located in Oklahoma). Participants ranged in age from 32 to 52. Every participant had the job title "case manager," although two participants were also registered nurses (RNs), and one was the case management supervisor.

Questionnaire. Participants initially completed a brief questionnaire about their age, job title, job experience, and on-the-job usage of technology (e.g., cell phone, email, answering machine, etc.).

Interviews. We performed semi-structured interviews with participants (N=5) who routinely visit elderly clients in order to collect information about ADLs. Interviews were conducted separately and each lasted approximately 90 minutes. All interviews were conducted in the home office of one of the researchers. Audio data from the interviews was recorded on a digital recording device and later used to generate post-interview notes. Participants were asked questions in four main areas: 1) their general job duties, 2) visiting a client in his/her home, 3) ADL forms and the flow of information, and 4) their opinions on the idea of an automatic ADL monitoring technology. To preserve generality, we chose not to mention a specific technological approach during the interviews.

RESULTS

In this section, we discuss the participants' current practices and their initial thoughts on the benefits and drawbacks of using an automatic in-home ADL assessment technology.

- **Assessment of ADLs:** One participant aptly describes her job as "being a detective." A CM must piece together information from clients, family members, hired *personal care assistants* (PCAs), nurses, and many others in order to assess the true abilities and safety of the client. Participants expressed interest in new technology in order to quickly detect changes in normal routine, [1] and notice things that may have been missed during visits [2].

- **Auditing:** A CM must decipher conflicting information from their experience in the home and conversations with clients and PCAs. Elderly clients may exhibit reporting bias based on a desire to gain services or by a fear of losing them [3]. The majority of monitoring visits are conducted by phone, where information is difficult to verify [4]. In addition, PCAs work without direct supervision and are prone to exaggerate their hours [5]. Participants expressed interest in using the technology to *"sort out the facts,"* in order to 1) find out *why* the client isn't telling the truth, 2) to hold clients *accountable* when they are untruthful, and 3) to *verify* that PCAs are really doing their jobs.

- **Family involvement:** A majority of participants mentioned that ADL information would be useful to family members, in order to keep them involved in supporting the elder. Non-paid caregivers, called *informal support*, are often in tune with the day-to-day life of an elder, and their involvement and knowledge are very important to a CM [6]. For example, informal support may notify CMs when there is a problem (e.g., the elder has been hospitalized). On the other hand, one participant noted that informal support is sometimes less informed, because some questions are too embarrassing for family members to ask [7].

- **Improved scheduling:** The three participants that work as full-time CMs reported an average caseload of 50 clients (minimum was 45 and maximum was 60). Participants reported scheduling home visits based on hard deadlines imposed by state requirements (usually quarterly visits), and by the geographical distribution of cases (clients who live close together are easier to visit). The scheduling process was described as volatile, however, because elders' medical conditions often change suddenly [8]. Participants overwhelmingly expressed interest in using up-to-the-minute ADL information to improve scheduling [9].

- **Functional decline:** Several participants discussed how the abilities of elders decline over time [10]. Participants described ADL monitoring as the main mechanism for tracking functional decline. Specifically, the CM is responsible for ordering additional services to replace lost functionality (e.g., ordering home-delivered meals for someone who is no longer able to cook). One participant described using monitoring technology to watch clients over time, to spot those that have begun to decline (e.g., they are wandering or falling more often).

- **Acceptance issues:** Most participants did not believe that their clients would accept an automatic ADL monitoring technology in their homes. Several participants made suggestions for making a system more palatable. They stressed that the system not be seen as a "tattle-tale," but that the technology should be there to keep the client living at home independently as long as possible. Time and again, participants pointed out the negative association that elders have for the nursing home, [11] and how strongly elders are motivated to avoid it.

- **Privacy issues:** The majority of participants mentioned privacy issues as the main drawback of in-home monitoring technology. Currently, information collected by CMs is accessible to other CMs, some office staff, physicians, the government officials who oversee the program, and to individuals who are specifically indicated by the elder. Several participants suggested that "release of information" forms should be used to determine access to data. Two participants pointed out privacy issues that monitoring technology could possibly allay: 1) minimizing the number of strangers who enter the client's home, [12] and 2) side-stepping certain awkward questions [13].

- **Delivering information:** Participants had varying familiarity with technology. Although every participant routinely used a cell phone, experience with computers varied (some CMs fill out forms by hand and others use computers). Thus, some participants were comfortable with receiving information in a computer printout, while others liked the idea of a web site, and at least one was most comfortable with receiving the information via phone call.

- **Concern over job loss:** The majority of participants expressed concern that such technology would put them out of a job. However, one participant – the CM supervisor – expressed interest in using the technology to increase caseloads.

[1] *"If you saw a big change, then that would tell you that you need to get out there."*

[2] *"It would help identify the things that maybe we don't pick up on."*

[3] *"If I ask them if they've fallen, they may not tell me that they have, because they are afraid of going to a nursing home."*

[4] *"All we go on mainly, especially in phone monitors, is what our consumers are telling us – which could be total B.S."*

[5] *"Aides [i.e., PCAs] lie because we will never find out."*

[6] *"We like to visit with them [informal support] separately sometimes, okay, to get some adequate information."*

[7] *"You aren't going to ask your mother if she took a shower."*

[8] *"We're required to see them quarterly, but most often it's more than that because their needs change."*

[9] *"You might prioritize which ones [clients] you did home visits for."*

[10] *"Usually in the beginning, a consumer [i.e., client] requires less assistance, but as they are on the program three or four years, they are increasing."*

[11] *"They think it's the end of the line; going to a nursing home means you are dead."*

[12] *"...strangers are going to come into your home and all of the sudden ask you to remember things?"*

[13] *"...it is harder to ask the older gentlemen about incontinence."*

IMPLICATIONS & FUTURE WORK

The results of this study can potentially help researchers interested in developing technology for automatic health assessment, specifically monitoring ADLs. Currently, we are using the results of these interviews to design a more comprehensive, survey-based study. The survey will be sent to a large number of case managers at agencies around the United States. Survey questions will focus on job duties, home environments, home visits, phone visits, reporting bias, visit scheduling, paperwork, and care networks. In this section, we discuss some implications of our formative work on three areas of research related to health assessment.

People tracking in the home.

People tracking is a fundamental problem in ubiquitous computing and has been approached by many researchers (including the authors [3]). Location in the home can be an important indicator of social involvement, cognitive functioning, and physical ability. A key design decision is the granularity of tracking (e.g., room level vs. centimeter level). The majority of our participants reported that simply knowing whether or not a client was at home could greatly improve scheduling. As we gain more results, we hope to explore the landscape of the home environment (e.g., how many people are usually home, how often there are visitors, and whether there are pets) and better understand movement information (e.g., which places are visited the most and by whom, and which places are the most dangerous).

Automatic recognition of ADLs.

Performance of ADLs can be used to ensure that elderly clients are living safely and independently. Many research projects, including our own [2], have focused on automatic recognition of ADLs. In this study, we examined which ADLs are the most important to a CM, which are the most time consuming or awkward to collect, and which generate the most reporting bias from clients (i.e., fibbing). Additionally, we examined the standard forms used by CMs during home monitoring visits. In the future, we hope to understand ADL forms well enough to offer other researchers a quantitative breakdown of the time-savings offered to an overworked CM [14].

Delivering information to care networks.

The physical and mental well-being of an elder is intimately tied to a "care network" – the group of people involved in caring for the elder. Projects at Intel Research Seattle and elsewhere have been aimed at understanding the challenges for the care network and providing services that will connect and expand this network [1]. Our results upport a crucial design decision – determining who has access to what information. Our participants pointed out that elderly clients are not always receptive to sharing information, even with loved ones [15]. In future work, we will build on our results by collecting more detailed information about how elders and CMs interact with care networks.

[14] *Participants reported needing fifteen minutes to an hour and a half to fill out each form.*

[15] *"If [my daughter] wants to see how I'm doing then she can call me. [Note: the CM was describing a conversation]"*

CONCLUSIONS

We described a study in which we interviewed five case managers who are responsible for assessing ADLs in elderly clients. We discussed the results of the study, focusing on the findings that related most to automatic health assessment. Some implications were discussed toward three research areas related to automatic health assessment, and future work was proposed.

BIOGRAPHIES

Daniel H. Wilson is an NSF Graduate Fellow pursuing a Ph.D. in the Robotics Institute of Carnegie Mellon University. His research goal is to provide simultaneous tracking and activity recognition in the home via many simple sensors.

Sunny Consolvo is a researcher at Intel Research Seattle. Her research focus is in applying human-centered design to ubiquitous computing applications. She is currently working in the areas of privacy and human activity inferencing.

Matthai Philipose is a researcher at Intel Research Seattle. His primary areas of interest are programming languages and probabilistic reasoning. He is currently working on sensors, data modeling, and statistical reasoning techniques for recognizing human activities.

Kenneth P. Fishkin is a researcher at Intel Research Seattle and an Affiliate Professor of Computer Science at the University of Washington. His current research centers on ways that ubicomp networks can help infer and guide human activities, with a focus on novel uses and techniques for RFID technology.

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