Supporting Awareness of Functional Abilities for Older Adults, their Caregivers, and Clinicians

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Abstract

Older adults have difficulty maintaining awareness of changes in their functional abilities as they get older. Functional changes such as how well they perform instrumental activities of daily living can be important early indicators for cognitive or physical decline. Often these early signs are ignored or explained away as the individual unknowingly continues on a trajectory towards disability. They can become more prone to dangerous situations such as mismanaging finances, taking the wrong medication, or forgetting to turn off the stove. Embedded home sensors that monitor how well older adults carry out everyday tasks can collect longitudinal, continuous, and ecologically valid performance data. These data can empower older adults with the awareness to make appropriate adaptations to remain independent, inform caregivers about when to help, and provide valuable data for the clinician for earlier diagnoses and treatment of cognitive or physical conditions such as Alzheimer's or Parkinson's disease. In this proposal, I describe my research in understanding how to design and deploy home sensors that monitor how well individuals perform everyday activities. These systems collect an overwhelmingly large amount of data, and thus I will identify the information needs of stakeholders to inform the design of salient summaries of the data for elders, their family caregivers, and their doctors to become more aware of changes functional abilities. I discuss the initial field work I conducted to assess the potential usefulness of these types of embedded home sensing systems and plans for building and deploying sensors that can monitor specific instrumental activities of daily living in the homes of independently-living older adults. I conclude this paper with a discussion about the potential technical, informatics, and clinical implications of this work.

Introduction

Many older adults strive to "age in place" by remaining independent in the comfort of their own homes as long as they can before moving to a care institution such as assisted living facility or a nursing home. As they age, older adults, particularly those who are living alone, have difficulty maintaining awareness of the subtle changes in their cognitive (*e.g.*, memory, planning, execution) and physical (*e.g.*, grip strength, gait, and balance) abilities [14]. Consistent declines in cognitive or physical abilities may be early signs of progressive neurological conditions that are increasingly common among older adults such as Alzheimer's disease or Parkinson's disease.

Changes in cognitive and physical abilities usually first manifest themselves as changes in functional ability, that is, how well an individual is able to perform routine tasks that are important for independence in everyday life. These relatively complex tasks are commonly categorized as Instrumental Activities of Daily Living (IADLs) [12] and include medication taking, preparing a meal, managing finances, and using the telephone, whereas Activities of Daily Living (ADLs) comprise more basic tasks such as feeding, bathing, toileting, and transfers from bed/chair. IADLs require a higher level of cognitive ability as well as fine motor control and strength.

To complement "aging in place," embedded sensors in the home can make possible "assessment in place" (or sometimes called embedded assessment [14]). Simple sensors that can sense an individual's interactions with common objects in the home can keep track of how older adults perform routine IADLs. Monitoring for changes in functional abilities can be important as early indicators for declines in the cognitive and physical abilities these tasks demand. Based on the observed behaviors, these systems can make salient the subtle but important functional declines that older adults have trouble keeping aware of. This provides an opportunity for earlier intervention by the individual and other members of her care network to delay further declines in abilities and even prevent accidents leading to disability [1]. For example, an individual who is forgetting to take her blood pressure medication may be more prone to falling. She could benefit more from proactive feedback about poor medication adherence, than from a reactive system that simply monitors for falls and calls for help. Simple sensor technologies [7,22] can keep track of *how often* a task is performed and help older adults be more aware of how successful they are in their routines for maintaining health.

In addition to monitoring simply whether and how often a task is completed, monitoring *how well* a task is completed may be an even earlier indicator of declines in the complex cognitive or physical abilities necessary to carry out IADLs. For example, medication taking can require multiple steps, with one particularly complex step being sorting which pill to take at the right time. Knowing how well the individual is sorting their pills can give an indication for the cognitive (*e.g.*, memory) and physical (*e.g.*, eyesight) abilities required in that aspect of the subtask. Sensors can measure how well or facile a subtask is performed by looking at the converse--the amount of effort or struggle. The amount of time taken [17] to perform the subtask or the number of recovered errors encountered during the task can be ways to measure how much the individual is struggling. For example, an individual may still be taking the right pill but may be taking a longer time to select which subset of pills to take due to confusion or eyesight problems. By measuring how well a given task is performed, caregivers can provide pre-clinical indicators of disability [6]. In a pre-clinical stage of disability, individuals use compensatory strategies to maintain their functioning at a level where there is no apparent change to their ability to complete the task. In this stage, neither the individual nor members of their care network may realize, or acknowledge, that an underlying impairment exists or that the individual may be on a trajectory towards disability. For example, individuals who may be experiencing decline in executive functioning may have more difficulty preparing a meal that involves multiple concurrent steps. To compensate, they can slow down, pay more deliberate attention to their actions, and tolerate a few more mistakes. From a purely task completion view, the outcome is the same (the meal is prepared) but the underlying impairment impacts how much effort the person expends to perform the task. Thus, information about *how well* an individual performs a task is important for earlier prediction [1], for treatment of decline, and for delaying the onset of the subsequent disability as long as possible.

Compared with traditional methods for assessing of functional abilities such as self-report [16], caregiver-report [10], and performance testing [5], ubiquitous embedded sensing can provide earlier, finer-grained, and more objective ground truth about how people function in the environment that matters most everyday—their home. Yet, embedded assessment sensing systems can produce an overwhelmingly large amount of data. The challenge is thus to identify the most meaningful aspects of these data and create salient summaries that are usable and useful for elders, caregivers, and clinicians to support their health goals.

For my dissertation, I plan to address the following research questions through formative field work, design and implementation of novel sensing systems targeted at specific everyday tasks, a field deployment to collect real data, and evaluations with real users:

1. Is embedded assessment of how well people perform everyday activities *useful* for stakeholders (older adults, their caregivers, and their doctors and therapists) for maintaining wellness and providing care?

2. How can *simple sensors* be used in the home to monitor how well people perform specific everyday activities?

3. What are the *information needs* of each group of stakeholders, and how should *meaningful salient summaries* of data be produced?

4. How can embedded assessment data actually *enable stakeholders* to be more aware of changes in abilities and to provide better care?

5. Can data from embedded assessment be used clinically to *predict* cognitive, physical or functional decline?

Related Work

An augmented intelligent living space that can monitor and assist people as they age has long been a long-standing vision [14]. Prior efforts at building living laboratories such as the AwareHome [11] and house_n [9] have yielded a suite of valuable sensing techniques well-suited for sensing and reacting to the behavior of residents. However, one aspect of the vision for aging in place that has been less explored is that of prevention and maintaining wellness. Ubiquitous sensing in the home can capture longitudinal streams of data and present analyses of these data directly to individuals so that they can become more self-aware of the changes they are going through.

Researchers conducting participatory design of embedded assessment systems have worked with various stakeholders. Morris & Lundell [15] conducted focus groups with elders, caregivers, and doctors and identified an opportunity for technology to make more relevant and frequent assessments of functional abilities, which is the type of assessment provided by the sensing concepts I use as probes in my concept validation study. Steele *et al.* [21] found that elders were most concerned with cost and control of embedded assessment technology. Blythe *et al.* [3] found that elders valued not only safety but also their privacy and freedom, calling for "socially-dependable" design. Demiris *et al.* [4] installed sensors in the homes of elders and tracked how frequently they performed various IADLs. In participatory feedback sessions, elders said that the technology was unobtrusive and provided them with peace of mind. Rantz *et al.* [19] conducted focus groups with nurses who found interactive visualizations of how often residents engaged in various IADLs to be useful. Beaudin *et al*. [2] investigated which domains people wanted to track for long-term self-monitoring and short- term health goal tracking. These prior evaluations focused mainly on embedded assessment data about *how often* individuals engaged in different IADLs. There still remains the question about *whether information about how well IADLs were performed actually provides value to elders, caregivers, and clinicians as earlier indicators for changes in functional abilitie*s. And thus, my dissertation work will seek to understand how longitudinal and objective sensor data about how well individuals are carrying out everyday activities can be useful and how they should be presented to support the wellness of older adults, opportunities for help from caregivers, and better-informed diagnoses in the clinic. I will endeavor to prove the following thesis statement: salient summaries of data from embedded assessment of wellness allows for more timely awareness, assessment, and compensation of cognitive decline than traditional methods.

Initial Field Work

In the formative stages of my research, I wanted to determine the potential impact and utility of embedded assessment sensing systems to stakeholders prior to building and deploying a long-term field study. I conducted a concept validation study [13] in which I used scenario-based interviews with older adults, caregivers, and clinicians to evaluate the utility of various sensing concepts and the data they would collect. The scenario-based technique allowed the interviewees to place themselves into a future world where embedded assessment systems are a reality. Interviewees were able to reflect on how the sensors could sense their everyday abilities and also predict what they would do (or not do) with the hypothetical data collected by these sensors over the course of the past year.

The specific concepts presented were systems to monitor medication taking, telephone use, and making a pot of coffee. These concepts were selected based on both the canonical tasks of IADLs [12] and also earlier field work where I observed the routines of older adults in their homes. These tasks are important for independence and have the potential to be predictive of decline. The think-aloud concept validation interviews focused on whether and how useful the stakeholders found the sensing concepts and also the data they would produce. We also probed on different features of the data including the fact that these embedded systems can provide both long-term data as well as fine-grained details about the individual subtasks.

The results of the concept validation showed that stakeholders were able to express how they could use the sensing concepts and the data they collected to support their goals. The older adults expressed that the data would help them keep track of their ever-changing health and make the adjustments necessary to maintain independence. Family caregivers said monitoring these "mundane" tasks gave them a new window into the daily functioning of their loved one. Doctors said that the sensor data provided them with more detailed information than they can normally obtain from short interviews with patients during an office visit. Occupational therapists found the low-level details helpful for identifying the particular deficit in the task and applying the right adaptation to maintain task adequacy. Clinicians also found it helpful for tracking the effect of a change in medication or new functional adaptation. Overall, this study showed provided preliminary support for research question #1. The concepts and our approach of embedded sensing in the home were well received as being valuable for older adults to maintain awareness of health changes and providing their care network with opportunities to provide better care.

Current and Proposed Research

Having completed this initial validation of the value of our proposed sensing approach, I am currently designing and building an embedded assessment sensing system that will be deployed to collect real long-term IADL performance data from independently-living elders. With this personalized data I can further identify the information that stakeholders find useful for supporting their respective goals. Based on these information needs, I will create salient summaries of this personalized data to highlight the most important features, events, or trends for each stakeholder.

In contrast to previous research efforts that use one or two "high-level" sensors to monitor and categorize multiple activities (*e.g.*, accelerometers, motion sensors, or computer vision), I am using focused sensing for particular activities that can detect not only *how often* an individual carries out that activity but also can track the individual steps of the task to measure *how well* the task is performed, hence the term "embedded assessment of wellness." The three particular IADLs that will be sensed are medication taking, breakfast preparation, and telephone use because these are important tasks for independence, common among elders, reasonably easy to sense, and most importantly, are already used in existing scales [5] of functional abilities. These tasks can be naturally decomposed into smaller steps that can be performed well or poorly, making them amenable to the type of detailed analysis that computational systems are particularly good at when compared to a human. I am currently integrating these IADL sensing systems with a drop-in wireless infrastructure to minimize the intrusiveness of the sensors.

In the near future to address research question #2, I will continue to refine the design of the sensors through a combination of laboratory and field pilot testing to ensure accuracy and robustness for detecting the individual steps of the task. I will then deploy the sensors into the homes of ten elders who live on their own who may be already experiencing some declines in functional abilities, so that they are more likely to experience changes in functional abilities during a 12-month study.

The deployment will begin with a 1-3 month baseline period, where the older adults will carry out their routines as they normally would but with the addition of the wellness sensors that will be passively and unobtrusively monitoring their performance. During this period, we will be able to observe how individuals perform on a day-to-day basis and also adjust and customize our sensing appropriately to accommodate their specific routines.

After six months into the deployment, we will reflect back the collected data to older adults either through a one-time interview where they will be able to explore the collected data or through a continuous feedback display placed in their homes that can display both short-term and long-term summaries of how they are performing their everyday tasks. The interactions with the display will be logged as well as specific comments generated from the older adult to determine what information is most useful. In addition, I will evaluate the utility of the data with family caregivers and clinicians through a series of interviews in which I will show them salient summaries of the data and give them the ability to look through the data and draw their own conclusions. To address research question #3, I will use iterative design to develop visualizations that highlight the most salient information from the sensor data required by each stakeholder. From these summaries, I will be looking for instances of a mismatch or information gap between (correct) sensor data and the knowledge of the stakeholder. For example, an older adult may realize that her medication taking routine is not as consistent as she may have thought. A caregiver may realize that her mother is misdialing the telephone two or three times before getting through. A doctor may find that a patient who performs very poorly on standardized testing in the clinic is actually highly functional and safe at home.

In contrast to the initial concept validation fieldwork, engaging stakeholders with real data will enable us to address research question #4 by observing how the data actually impacts the practices of stakeholders, rather than having stakeholders only imagine what they would do. For example, older adults who may notice that they are making more errors when dialing the telephone may take steps to rely more on their address book for numbers rather than their memory. Caregivers who find that their loved one is taking an increasingly longer time to make coffee in the morning may decide to help rearrange the kitchen to make it more convenient. Clinicians who notice that the patient is making more errors sorting her pills may choose to combine dosages to ensure adherence.

And finally to address research question #5, the cumulative sensor data will be compared with expert assessors and standard psychometric tests for cognitive and physical decline (such as the Short Physical Performance Battery [7], Computer Aided Measure of Cognitive Impairment [20], Digit Symbol Substitution Test [23], and Functional Activities Questionnaire [18]) to determine the predictive value of task performance data.

Contributions

This research provides technical, informatics, and clinical contributions. From a technical standpoint, I will develop new sensing technology that can sense how well—instead of merely how often—a task important for independence is performed. From an informatics standpoint, I will investigate the information needs of the stakeholders of embedded assessment technology (older adults, their caregivers, and clinicians) through evaluations before, during, and after a long-term deployment. From these data, I will generate and evaluate design guidelines for making salient summaries and visualizations for long-term performance data of functional abilities. This research will also have practical clinical contributions in the form of novel, objective, ecologically-valid, timely, and salient measures of functional abilities that can help clinicians make better-informed diagnoses of physical, cognitive, or functional decline. This research can also help elders and their caregivers become more aware of changes in their abilities as they age. These sensors and summarization techniques can influence the design of future commercial home monitoring for elders, children, and smart home residents.

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