THE USER-CENTERED DESIGN OF A MOBILE APP FOR DISTANCE CAREGIVERS OF OLDER ADULTS THAT LIVE IN SMART HOME ENVIRONMENTS

By

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A DISSERTATION

Presented to the Department of Medical Informatics and Clinical Epidemiology
and the Oregon Health & Science University
School of Medicine
in partial fulfillment of
the requirements for the degree of

Doctor of Philosophy

June 2015

Department of Medical Informatics and Clinical Epidemiology

School of Medicine

Oregon Health & Science University

CERTIFICATE OF APPROVAL

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"The user-centered design of a mobile app for distance caregivers of older adults that live in smart home environments"

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To my amazing wife Kathy
and
my wonderful children Kyle, Karissa, Emmalee and Jane

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

ACKNOWLEDGMENTS

I would like to express heartfelt thanks to the many individuals who have contributed large amounts of time and effort to assist me in completing this dissertation.

Especially, I am grateful to my two wonderfully supportive and insightful PhD advisors, Dr. Holly Jimison and Dr. Paul Gorman. Holly's work with older adults provided the foundation for much of the work described here and both Paul and Holly have spent large amounts of time reviewing manuscripts, providing much-needed guidance, and extending support/friendship.

I would also like to thank the remainder of my committee, Dr. Vishnu Mohan, Dr. Paula Carder and Dr. Michelle Hribar for their teaching, mentoring and advice that have made this dissertation far better than it would have been without their input.

In addition, thank you to my fellow DMICE students, especially Dr. Dian Chase, Dr. Patty Yao and Dr. Travis Gamble each of which started the program at the same time as I and have provided wonderful friendships, helpful advice and much needed moral support (especially through all of the stats courses!)

Furthermore, I am grateful to the DMICE staff, especially to Andrea Ilg, Diane Doctor and Lynne Schwabe for their support and guidance as I have progressed through the PhD program.

Lastly, I express my gratitude to my loving parents Joe and Leslie Williamson who instilled in me a love for both engineering and medicine, and my beautiful wife, Kathy Williamson, whose loving encouragement, selfless sacrifice and ever-ready correcting pen accompanied me at each stage of this process.

This research was supported by the National Library of Medicine of the National Institutes of Health under Award Number T15LM007088 and by the National Science Foundation under grant number 1111722. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health or National Science Foundation.

ABSTRACT

Throughout the developed world, population aging requires increasing numbers of friends and family members to serve as informal caregivers of older adults. Currently, due to factors such as reduced fertility rates, and increased numbers of women in the workforce, demand far outweighs supply. Many researchers have suggested that using information technology to bridge the caregiver -care recipient divide may be a promising means of addressing these issues. In this dissertation we discuss the user-centered design of information technology tools for informal caregivers, specifically those that do not live in the same home as their older adult loved ones.

Study 1 - Before designing any caregiver tools, we felt it was most appropriate to better understand the information needs of caregivers. As such, we conducted semi-structured needs assessment interviews via Skype with 10 remote caregivers of older adults. To facilitate the discussion, we presented basic mockup screenshots of a potential website for caregivers. Through this process we identified important functional requirements and design implications for our caregiver tool. Findings included high interest in information regarding medication regimens and adherence, calendaring, and cognitive health. Usage was estimated as at least once per week, with many subjects desiring the ability to access the information from a smartphone

Study 2 - We developed a high fidelity interactive prototype of a smartphone app for caregivers. We then took a rapid, agile approach to usability testing in which 15 users were recruited to participate in three iterative rounds of testing. Users were asked to “think aloud“ while using the app to participate in five different caregiving scenarios. At the conclusion of each round of testing, problems were classified as either ”resolve” or

“wait and see”. Solutions were developed to address any problem marker for resolution while “wait and see” items were used as special areas of focus for subsequent rounds of usability testing. Overall, usability of our caregiver application was high, with all users able to properly navigate through the app without any guidance/training. 34 unique usability problems were identified with a large majority of problems based upon poor labeling, unclear interaction styles, and inappropriately sized or placed user interface elements.

Study 3 - We used an insight based evaluation methodology to ensure that caregivers could properly interpret the graphs used in our caregiving app. We recorded 15 caregivers “thinking aloud” while they explored 10 different graphs depicting health activity data (e.g. medication adherence, sleep and exercise). Recordings were then used to identify individual insights made by each caregiver. And sets were then rated according to value and correctness. Our analysis showed that chart complexity significantly impacted both the number and quality of insights gained, with ~4 insights being elicited per minute. Lessons learned from this process included the importance of displaying longitudinal graphs when long-term problems are detected and short closely zoomed graphs when recent problems have occurred.

The findings of these 3 studies combine to provide important, user-derived findings that inform the design of more appropriate tools for caregivers around the world.

Chapter 1 - Introduction

1.1 Caring for Our Old

Since the beginning of time, civilizations have developed social systems and tools to care for their elderly. Whether shown by the ancient Egyptians' use of walking sticks, the Confucian virtue of filial piety in which adult children throughout China cared for their aging parents, or the deep reverence and respect for the wisdom of old age by the Greeks and native-Americans; older adult care systems are not new.

Today, though our approaches to older adult care have changed dramatically, we find ourselves in a time with many unprecedented challenges on the horizon.

1.2 The Challenges

1.2.1 Population Aging

Historically, bar graphs depicting population levels by age have been shaped like a pyramid. In these "population pyramids", the largest number of individuals fall within the youngest age groups with each subsequent age group decreasing in size due to mortality. More recently however, many countries around the world are experiencing a phenomenon known as population aging.

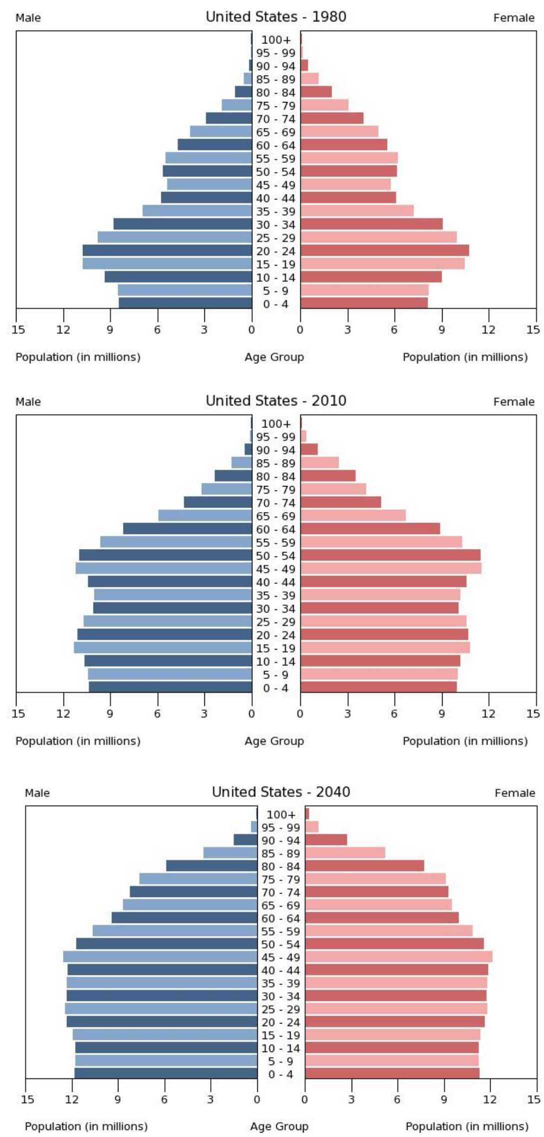

Figure 1.1 Population Pyramids for the United States. (1980 – 2040 projected) – Source: census.gov

As the name implies, population aging occurs when the median age of a population increases. This results in a greater proportion of the population falling within the latter years of life. The two primary causes of this phenomenon are increased life expectancy and declining birth rates. An example of this occurred at the end of World War II when a huge number of soldiers returned from war, ready to get married and start a family. This in turn started a spike in the number of children being born in the 1950s. These so-called baby boomers then went on to have far fewer children than their parents, creating a surge of older adults with far fewer children to support them in the present day. Other countries are also experiencing this phenomenon with China seeing the consequence of their one child policy and Europe expected to see a doubling in the percentage of the population age 65+ between 2000 and 2050.[1,2]

1.2.2 Chronic vs. Acute Care

The primary cause of prolonged life expectancy has been our ability to treat and cure acute illness. For example, vaccinations have all but eliminated dozens of life threatening diseases such as smallpox, polio and tuberculosis that historically have claimed the lives of many children and working adults. These and other advances have made it possible to add nearly 30 years of life expectancy over the last century[3]. Acute illness has instead been replaced with the chronic diseases of older adulthood (e.g. heart disease, cancer, diabetes, Alzheimer's etc.) as well as limitations in physical activity, vision, and hearing. This shift from acute to chronic disease requires the health care system to re-think the way that care is delivered. Instead of being admitted to the hospital when we are chronically ill, the majority of care is received at home. As such, a greater emphasis needs to be placed on the daily activities of older adults as they manage chronic illness[4] rather than focusing on the isolated and often fairly sporadic interactions that occur in hospitals and doctors' offices.

1.2.3 Rising Healthcare Costs

Since 1966, Medicare has served as the primary health insurer for Americans aged 65 and older. With the majority of medical care occurring in the later years of life, Medicare now funds almost half of all inpatient hospital costs in the United States[5]. Looking forward, from 2010 to 2040 the number of Medicare enrollees is expected to almost double from 47 million to 88 million. As a percentage of the United States' gross domestic product, Medicare costs are expected to rise significantly from 3.5% in 2014 to 5.5%-6% in 2040[6]. In terms of actual dollar amounts, Medicare spending is expected to nearly double over the next 10 years[7]. These shifts along with the recently implemented affordable care act, require an increasing amount of public funds to pay for American healthcare. Without large increases in gross domestic product, such growth is likely to be unsustainable. Many have suggested [8–12]the need to fundamentally re-think the manner in which we deliver healthcare in the United States, especially when caring for our older adult population.

1.3 The Overlooked Majority

While physicians, nurses and other healthcare professionals provide invaluable care to older adults in the United States, the care they provide is a small portion of the overall American healthcare system for older adults. Each year across America, almost one thirds of Americans (66 million) spend an average of 21 hours/week providing unpaid care to loved ones [13]. If we were to provide a rather meager wage of only $10 per hour to these individuals, we would need to pay them almost $450 billion annually[14]. Though sometimes forgotten, these informal caregivers form "the backbone for much of the care that is received by older adults in the United States" [15].

Though traditionally an informal caregiver is thought to provide unpaid hands on assistance, more recent definitions have been expanded to also include many of the other caregiving tasks that may not occur at the "bedside". Donelan defined an informal caregiver as "anybody who provides unpaid help, or arranges for help, to a relative or friend because they have an illness or disability that leaves them unable to do some things for themselves, or because they are simply getting older."[16]

1.3.1 Caregiver Demographics

Two thirds of all caregivers are female, with an average age of 48 years old. Interestingly, this gender gap almost disappears among 18 to 49 year-olds, with females representing only 53% of caregivers. Caregiver ethnicity is somewhat varied. Of all caregivers in the US, approximately 72% are white; 13% are African-American. 12% are Hispanic and 2% are Asian American. In most cases, caregivers are caring for a parent, stepparent, mother-in-law, or father-in-law.

1.3.2 Caregiver Burden

Caregivers face significant burden in many different forms. Not only must they cope with the emotional stress of seeing a loved one's health decline, but there are significant stressors in terms of both cost and time as well. Caregiving has been correlated with higher incidence of depression[17] and mortality[18], along with lower perceived health status[19] and immune function[20]. Not only do caregivers experience such negative health effects, but our entire society pays a significant price as well. Absenteeism due to caregiving requirements costs the US society $25 billion dollars annually[21]. Such high levels of burden may also negatively affect the quality of care that is provided to older adults[22].

1.3.3 Supply versus Demand

As we look to meet the oncoming challenges described above (population aging, increasing levels of chronic disease, and increasing healthcare costs) the role of informal caregivers becomes increasingly important. There is some concern however, that as the demand for caregivers increases the actual supply of caregivers may decline. Primary reasons for this include that individuals who are now reaching older adulthood have had fewer children than in generations past, thereby decreasing the chances that an older adult will have a suitable caregiver available. Even if an older adult has a child that could serve as a caregiver, the increasing number of women in the workforce means that many of the women that would traditionally serve as caregivers are unable to do so. Also, our shift towards a more global society has resulted in fewer adult children opting to live in close proximity to their parents. Ryan et al. highlighted this trend by projecting that from 2010 to 2030 the number of 75-year-olds that do not have a child living near them will increase six fold going from ~100,000 in 2010 to over 600,000 in 2030[23]. Reasons for this shift include the ease of travel, children are more likely to move away for educational, professional or personal interests, that some older adults choose to retire in a faraway location and that older adults may choose to remain behind in their home rather than following family members when they move[24]. Projected personnel shortages within caregiving professions[25] are likely to exacerbate the problems by requiring an even greater number of individuals to provide informal care.

With informal caregiving traditionally requiring a large amount of face-to-face interaction, the decreasing number of older adults without nearby children is also likely to magnify the overall decline in availability. This is especially concerning considering the unprecedented increase in demand. As such, the central motivation for this work is based upon our attempts to enable caregivers regardless of their proximity to older adult loved ones. It is our hope that by removing the proximity barrier, more individuals will be enabled to serve as caregivers and that existing caregivers will be better equipped to meet their caregiving challenges.

1.4 Narrowing the Distance Through Technology

In just a few decades, the Internet has grown from a small network that connected academic institutions into a pervasive network connecting billions of people from around the world[26]. This relatively recent increase in connectivity allows us to explore new ways in which individuals can act as caregivers regardless of location. In many different fields, the connectivity provided by the Internet has removed geographic separation as a significant barrier. Examples of this include telemedicine, in which physicians are able to interact with and diagnose/treat patients even though they are not in the same location and telecommuting in which an employee is able to work from anywhere they have an Internet connection. We propose a similar approach to older adult caregiving in which the Internet is able to "narrow" the distance that separates potential caregivers from their older adult loved ones. While we acknowledge that there are some "hands-on" aspects to caregiving that cannot be adequately addressed by Internet technologies, we are confident that many aspects of caregiving can be accomplished remotely. Some of these tasks include providing emotional support, helping with financial management, managing in-home care services and acting as information coordinators[27]. It could also be possible to perform many other tasks remotely if certain data streams were available. For example, there are many commercially available fitness and sleep trackers (e.g. fitBit, Nike fuelband, etc.) that are able to collect activity data and then transmit this data via the Internet. This allows for the possibility of sharing fitness and sleep data with caregivers. Caregivers can then act as monitors and motivators to assist and/or encourage older adults when necessary. These and many more types of activity data can be collected in an unobtrusive way through using smart home environments. (Smart home environments will be discussed in greater detail in the background section of this work.)

When trying to solve a problem through technology, a technology-centered approach is often taken. Unfortunately, this can often result in a solution that does not address user needs and can lead to user frustration, errors or low usage levels[28]. Instead, our approach centers on caregivers as the primary focus throughout the design process. The use of a user-centered approach allows us to engineer a solution through understanding caregiver needs, identifying problem areas with our solution and measuring the value that our solution provides. As such the three aims of the work presented here are as follows:

1.5 Specific Aims

1.5.1 Aim 1

Assess the information and technology needs of long distance caregivers of older adults

1.5.2 Aim 2

Identify usability problems by iteratively developing and usability testing a prototype smartphone app for out-of-home caregivers of older adults

1.5.3 Aim 3

Evaluate the timeliness, quality and quantity of insights that can be gained by out-of-home caregivers as they interact with 10 data representations within our prototype caregiver app.

Chapter 2 - Background

2.1 Outline

To provide a clear understanding of the work that has already been undertaken, this section will provide background information concerning five important areas.

1) A brief history of user centered design
2) Remote Interventions for Informal Caregivers
3) Long Distance Caregivers and Technology
4) Smart homes for Aging in Place as a Data Source for Informal Caregivers
5) Gaps in current knowledge and calls for further research

2.2 User Centered Design

With origins in human factors and ergonomics, many of the underlying principles of user-centered design have been used for centuries. It wasn't however until computers became more widely available that researchers such as Nickerson recognized that "the need for the future is not so much computer oriented people as for people oriented computers."[29]

Despite Nickerson's forward-thinking observation however, it wasn't until 1986, that Norman first proposed his work first describing "User centered system design"[30]. This original work was then expanded upon and repackaged in a more consumer-friendly format in the seminal book The Psychology Of Everyday Things[31] (later renamed as The Design Of Everyday Things[32]).

Since it's introduction, user-centered design has grown into a central design philosophy comprising of many different methodological approaches and strategies. Methods include requirements analysis/needs assessment, task analysis, focus groups, usability evaluation, card sorting, questionnaires, interviews and field studies. Though highly varied, each approach is connected by the common goal of optimizing a product around how users can, want or need to use a product rather than forcing users to change their own behavior. Benefits of using UCD to design usable systems include increased productivity, reduced errors, reduced training and support, improved acceptance and enhanced reputation[33].

Such diverse methods allow user centered designers to design studies that are informative yet still conform to other research constraints such as time, subject availability and cost. This flexibility has also allowed user-centered design to adapt as new interaction styles are developed (command line -> GUI -> touch screen -> gesture -> speech/brain interfaces etc.) For example, user-centered designers studying a command-line driven interface in the early 1980s required a different toolset than a modern day researcher investigating a gesture based touch interface.

In 1990, the International Organization for Standardization (ISO) published ISO 9241-210 formally describing a design as user-centered if:

- The design is based upon an explicit understanding of users, tasks and environments.
- Users are involved throughout design and development.

- The design is driven and refined by user-centered evaluation.
- The process is iterative.
- The design addresses the whole user experience.
- The design team includes multidisciplinary skills and perspectives.

Today, user-centered design is a common design philosophy used extensively across many different fields, including various branches of medical informatics[34–37]. Many of these studies involve using user-centered methodologies to design and evaluate tools for older adults and their informal caregivers[38–40]. Researchers have called for the "greater involvement of users, carers and service providers in the design, delivery and evaluation of supporting services for older people."

2.3 Remote Interventions for Informal Caregivers

Traditionally, supports systems for caregivers have focused upon using tele-health approaches. These interventions were generally phone-based programs[41,42] in which nursing staff would provide support in various forms (e.g. social, emotional support/counseling[43], informational/educational[44]). Often these programs were administered to caregivers of older adults with specific diseases such as older adults with dementia or stroke survivors[43,45,46]. In some cases a hybrid approach was used in which in person training was delivered by nurses visiting caregivers in their homes and then gradually replacing some of these in person visits with phone calls as the caregiver became more capable[44].

During the 90s, as the Internet became increasingly available some health interventions for caregivers were migrated to the Internet. As with phone-based systems, the primary goals of these programs were generally to support caregivers information needs about specific diseases or conditions[47–50] and to reduce the levels of caregiving induced stress/anxiety. As time progressed, many of the earlier systems were delivered using a mixed approach in which the internet delivered information needs and phone calls were used for helplines and counseling[51].

One notable pioneer in this area was the "computer link" system[52], which allowed family caregivers of dementia patients to participate in online discussion boards, access a caregiving knowledge base, and contact nurses via e-mail when needed. Follow-up studies of this system showed that providing caregivers with the ability to interact via discussion boards allowed them to obtain informal information, support and advice from other caregivers and increased self-confidence when making decisions[53]. Another study showed that the system also caused a reduction in caregiver strain under some conditions (e.g. highly stressed individuals, non-spouse caregivers)[54].

Since the year 2000, many researchers have looked in greater detail at the benefits of Internet delivered tools for caregivers. Wu et al. conducted a literature review[55] for communication technology interventions for caregivers of Alzheimer's patients. They found consistent trends in the literature showing that Internet based interventions are more interactive and attractive while less intrusive than telephone based approaches. Other benefits in the caregiving literature include: round the clock availability of information, social anonymity, greater access to both peers and professionals and a more diverse range of services[55–58].

Another project of note is the 15+ year Swedish caregiver and older adult support platform known as ACTION[59] (Assisting Carers using Telematics Interventions to meet Older persons' Needs). Multiple studies were conducted to evaluate the system from various perspectives.
In its infancy, the action project started by first investigating the needs of family caregivers. Key needs revolved around educational support, general advice about how to provide care, and someone to talk to in order to "let off steam"[60]. Later, the PREP (preparedness, enrichment and predictability) model of nursing was used to guide caregiver education materials and usability testing was performed to increase system usability[61]. Subsequent versions of the service grew to include a computer application, educational and support materials and even a call center. A case study[62] with five families was used to show that the system resulted in cost savings while actually providing significant benefits in comparison to traditional models of care.

In 2011, the system had grown from a research project into a mainstream service that covered most of Sweden. Overall, system users reported high levels of satisfaction, increased quality of life, and fewer feelings of isolation for both caregivers and care recipients. Many caregivers also reported increased competence security and confidence in their caregiving role[63].

It is important to note that all of the remote caregiver studies described thus far have referred to instances in which caregivers received interventions remotely but did not necessarily provide care to older adults from a distance. Historically, the investigation of remote care delivery by family caregivers is less studied in the scientific literature. More recently, however, greater emphasis has been placed on the remote delivery of informal care.

2.4 Long Distance Caregivers and Technology

Long Distance caregivers (LDCs) are generally defined as those that live more than an hour's drive from the care recipient. While there is limited research on this unique group of caregivers, some studies have provided evidence to suggest that LDCs are on average both older and more affluent than caregivers in general[64]. LDCs are also more likely to provide financial support and as expected, spend more money on travel expenses[64,65]. While LDCs are unable to provide many of the in person services generally associated with caregiving, there are many activities that can be performed to support care recipients. These activities largely center around a LDC serving as an information coordinator in which he/she manages/arranges needed in-home care, oversees any medical treatments and creates plans in case of an emergency. In addition LDCs are able to provide emotional and financial support as well as provide respite to a local primary caregiver[27]. The literature also reports many significant challenges faced by LDCs. In addition to not being able to provide physical help to care recipients, LDCs have also reported that there is a lack of adequate communication in which care recipients may sometimes withhold information from them. LDCs may also possess a limited understanding of the services available in the care recipient's neighborhood and/or face frustrations due to living in different time zones. These challenges have been shown to increase feelings of worry, helplessness, anger, stress and guilt[66,67].

2.5 Examples of IT Tools for Distance Caregiving

Recently, as computer technologies have matured, an increasing number of assistive devices and services have become available to support older adults (e.g. robotic assistants, smart homes, smart pillboxes, tele-care) [68]. While these devices and services serve as important tools, there are few examples in which similar technologies are being used to provide much-needed information to caregivers[69–71].

Though originally designed to be used directly by patients, Pagliari et al. propose[72] that the use of personal health records (PHRs) by family members could be beneficial in the care of older adults and would allow caregivers to view, add, or update information as needed. They warn however of the potential security risks that could arise from providing protected health information to individuals other than patients.

2.5.1 Directions

Multiple investigators have looked at the role that caregiver technology can play when older adults have more serious diseases such as Alzheimer's. For example, one system[73] serves as a directions application for those with cognitive disabilities and allows caregivers to track the location of older adults by using GPS and edit routes remotely as needed. Another approach uses pictures from familiar landmarks to provide directions to patients and allows caregivers to establish geo-fences that will trigger an alarm if crossed[74].

2.5.2 Virtual caregivers

Other researchers have looked at the possibility of using virtual caregivers as a way to minimize the number of tasks/interruptions that are required of human caregivers. Hossain describes an experiment[75] with seven older adults and three family caregivers in which a smart home environment is used to gather activity data and then send alerts to the caregiver when an anomaly such as falling out of bed or the entry of a stranger into the apartment was detected. Caregivers in this study reported that such a system would minimize their monitoring burden and rate the system fairly highly for ease of interaction. While the authors of this study labeled their system as a virtual caregiver, human caregivers were still required to intervene when an anomaly was detected. Another study[76] describes a much more autonomous system that, rather than simply alerting a human caregiver, would take proactive steps to remedy anomalies automatically. A computer simulation was used to test a system in various situations that required an intervention. For example, if an excessive level of natural gas was detected in the home, the virtual caregiving system would automatically open windows, shut off the natural gas and alert the care recipient. The authors note that though promising, further real world research is needed to better understand the effectiveness of such a system.

2.5.3 Caregiver Perception of Value

In 2011, the National Alliance for Caregivers conducted a study[77] in order to identify potential technologies that would be beneficial to caregivers. In the study, 1000 technology using family caregivers completed an online Likert scale survey investigating the perceived benefits and barriers of various caregiver technologies. About three fourths of survey respondents perceived the various technologies as likely to save time, make caregiving easier logistically, increase feelings of effectiveness, and reduce levels of stress. On the other hand, perceived high costs and a belief that the presented technologies would not address a pressing caregiving issue were reported as the most common perceived barriers. Personal health record tracking, a caregiving coordination system, a medication support system, caregiver training simulations, and a caregiving decision-support tool were the five technologies that were perceived to be most helpful while having the fewest number of barriers. Of all of the presented technologies, only the caregiving coordination system was more likely to be used by long distance caregivers than by in-home caregivers.

2.5.4 Caregiving Tools in Industry

Very few studies have focused exclusively on long distance caregivers and potential technological tools that could aid them in providing care. Though this is a new area of research that lacks sound scientific investigation, there are a number of commercial software applications[78–81] that have recently become available to caregivers. These tools provide features such as:

- Digital locker (for secure storage of important digital documents)

- Shared calendars (to keep caregivers informed of an older adults planned activities and to coordinate caregiving tasks between multiple caregivers)
- Medical histories and medication lists
- Financial tools
- Journal
- Social features (e.g. message boards, photo galleries etc.)

While these commercial applications should be lauded in their attempts to ease the burden faced by LDCs, there are some significant problems associated with these products. First and foremost, these tools have not been evaluated in order to determine their effectiveness in helping LDCs provide care to loved ones. Also, most of these products require the purchase of a subscription that may be prohibitive to some users.

Perhaps most problematic is that most commercial solutions require all data to be manually entered by the caregiver, which may lead to increased caregiver burden and problems with data This however, is expected to

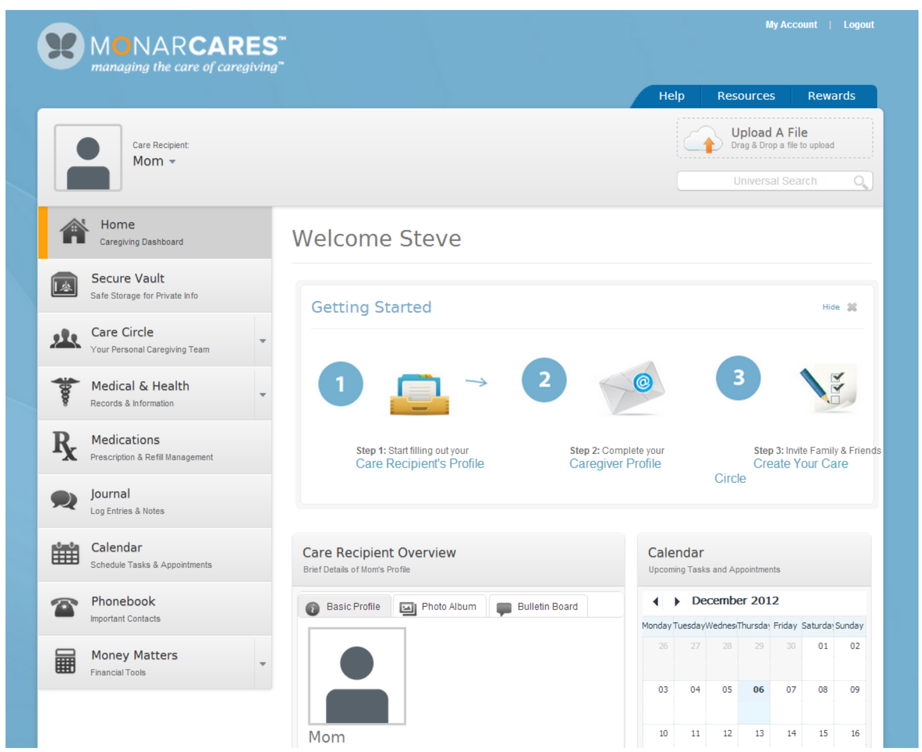

Figure 2.1: An example of a commercial website designed to support caregivers

change for both academic and commercial offerings as the rise of Internet of Things (IoT) and ubiquitous computing devices allow for data to be collected automatically in smart home environments.

2.6 Smart Homes for Aging in Place

The use of "smart homes" for older adults (know as "Ambient Assisted Living" in Europe) is a promising area of research that allows older adults to age safely in their own homes by using unobtrusive methods to monitor health and wellbeing. Many different projects in various stages of implementation/testing have demonstrated important system features such as fall detection[82,83], various forms of motion detection[84–86], activity reminding[87], health and medication monitoring[88], and emergency detection[89]. Techniques to measure activity in the home vary greatly with some studies[90,91] measuring electronic signatures on a home's electrical wiring as a proxy for various activities (i.e. turning on the TV or turning off the lights at bedtime) and other researchers providing older adults with wearable sensors that track activity and motion[92]. Another method relies on the use of various types of unobtrusive sensors[93,94] (see Table 1) to track motion and activity. One major benefit of these new approaches is that continual data streams from these sensors provide a continuous

Sensor	Measurement
Passive Infrared	Motion
Active Infrared	Motion/Identification
RFID	Object Information
Pressure	Pressure on Mat, Chair, etc.
Smart Tiles	Pressure on Floor
Magnetic Switches	Door/Cabinet Opening or Closing
Ultrasonic	Motion
Camera	Activity
Microphone	Activity
Phone Monitor	Call activity
Software monitors	Computer usage/patterns

Table 2.1: Unobtrusive sensors typically used in smart home environments. Adapted from Rashidi et al., 2013

longitudinal dataset. This dataset can then be used to develop personalized baselines and trends as reference points for each individual. Some systems[87,95,96] are then capable of using machine-learning algorithms to try to detect significant departures from an individual's baseline that might be indicative of health concerns.

2.6.1 The Life Lab

The Oregon Center for aging and technology (ORCATECH)[97] at Oregon Health & Science University (OHSU) is home to the ORCATECH life laboratory, a population of about 30 older adults who live in their own homes. Upon recruitment into the life lab cohort, each older adult agrees to participate in various research studies that investigate new aging in place techniques and technologies. In addition, each individual's home is "upgraded" to a smart home by installing sensors to monitor activities of daily living. These sensors include IR motion sensors in most rooms, phone activity monitors[98], load cells to monitor sleep[99], and Bluetooth enabled pillboxes[100]. In addition, many other important metrics are derived through the use of tracking software installed on each participant's computer to measure metrics such as typing speed[86], mouse movement[101], e-mail and Skype activity, and cognitive computer game activity[102–104]. Some life laboratory participants are also enrolled in the health coaching platform[105] in which participants meet virtually each week with a health coach that helps them to set goals and address concerns. All of the work described in this dissertation focuses upon designing and testing an application that would draw from data streams available as part of the ORCATECH life laboratory and then sharing these data with family caregivers.

2.8 Sharing Smart Home Data

Earlier research surrounding the use of smart homes to allow older adults to age in place focused almost exclusively on scientific methodologies to acquire useful data. In the last few years, as data acquisition methods become more robust, there has been some effort to investigate ways in which the data from smart homes (also known as remote monitoring technology or RMT) can be shared with others. In a systematic review of the views of clinical staff regarding the acceptability of incorporating RMT into primary care, researchers found overall positive views but also a large number of concerns such as the potential to change clinical roles and patterns of care, concerns regarding the clinical relevance of the data, compatibility and liability concerns, and insufficient staff/time to monitor and discuss RMT data with patients. Given these concerns, we propose that family caregivers can act as information stewards, providing a basic level of monitoring yet still raising any concerns with health professionals when necessary. In order to enable family caregivers in this new task, it is important that we first investigate appropriate ways in which smart home data can be shared in an effective way.

Only a few studies have been performed thus far in this new area of research. Mynatt presented[106] an early system for family members of older adults that used a digital

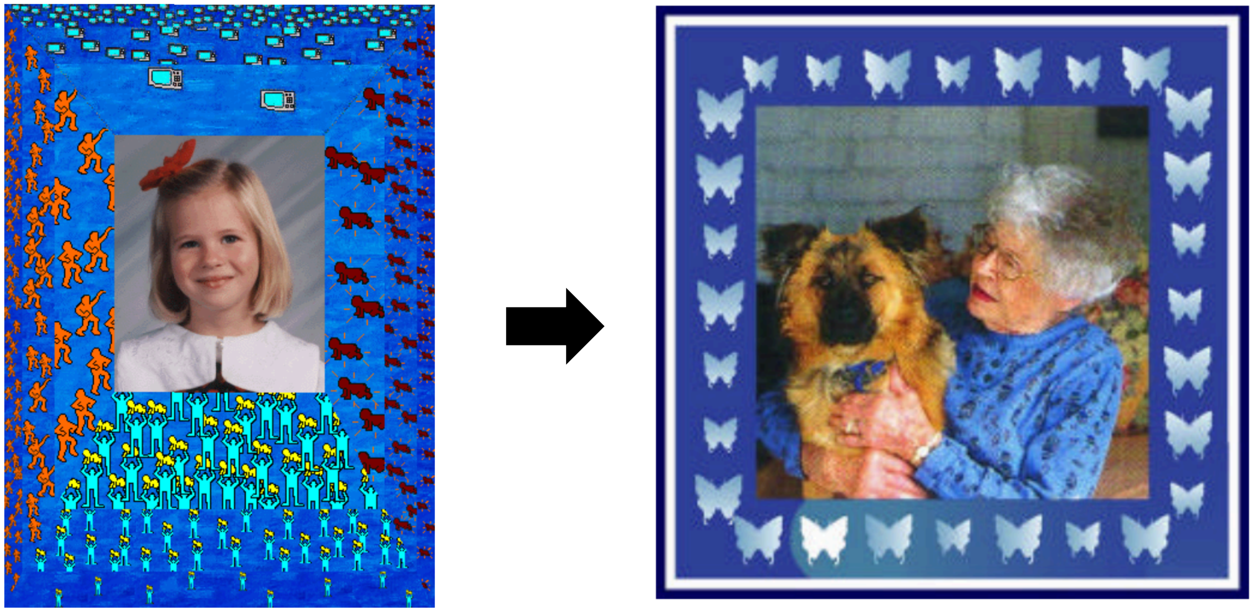

Figure 2.2: The use of a digital photo frame to convey an older adult's health status

photo frame in a caregiver's home to display qualitative data about an older adult's health status. Admirably, they first started with a basic needs analysis and later conducted a simulated field trial. The field trial was accomplished by one of the researchers calling the older adult each day to ascertain levels for health, environment, relationships and activity. These levels were then displayed pictographically around the border of a digital frame with a picture of the older adult in the middle. During the field study, the authors found this approach too busy, so opted to instead use 1 picture frame for each type on information. There was also an attempt to show days with irregularities by displaying a small series of dots along the frame border. A later field trial [107]went on to use actual sensor data with 1 caregiver-care recipient dyad, with both users finding utility in the system. While an important first step, the authors did not attempt to measure whether or not users could adequately understand and interpret the data representations in the study.

Also, since this study only focused on qualitative data types, we are not provided with a sense of what a system for displaying quantitative data might look like. Finally, while the information was displayed on a digital picture frame, the data displayed were relatively static, only updating once per day. We need more information about how to display interactive data, especially quantitative data that cannot adequately be displayed pictographically.

A more recent use of digital picture frames is described in 2010[108] in which the frame of the digital picture glowed different "aura" depending on the older adults health status. The frame also allowed caregivers to view information regarding cognition, weight and sleep. A multitude of user centered design methods were used in this study including interviews, prototype evaluation, and focus groups. Two users were also enrolled in a short field trial. While both users liked the system, the authors report that the lack of longitudinal data in the study made it difficult to properly test the value of the system. They conclude by noting "it is of interest to investigate what users infer from the awareness information, in particular from long-term trends in parameters related to well-being."

One approach has also looked at providing feedback to caregivers by machine generated narrative[109] but results of such a system were inconsistent with few participants showing high interest in purely text based information. Others have focused exclusively on [110,111] the design of interventions supporting older adults with dementia. Hwang et al. used a highly cooperative approach in which users and researchers worked hand in hand to develop the system. They note the use of interface artifacts as "triggers" to help subjects better understand the complexities of the care that they provide.

The TOPIC project[112] also aims to understand caregiver needs through the use of a diverse set of user-centered design methods. The team used ethnographic case studies[113] to understand user needs, possibilities, constraints and challenges for any kind of information or communication technology. Their approach included the use of cultural probes such as paper clock and emotion stickers so that users could convey their emotions at different times of the day. While research is ongoing, their solution, CarePortfolio, includes a social network for caregivers, sharing (multimedia) files, recommending interesting Internet sources, and establishing audio, video, and text communication channels with friends and family. CarePortfolio also includes a "Fun Corner" to browse humorous videos and images, and a Learning Corner to provide knowledge to facilitate caregiving.

Costa describes[114,115] the "UserAccess" mobile app, which provides data from the European ambient assistant living for all (AAL4ALL) project in a "human-readable form". The authors report that the app "is built according to usability guidelines, presenting succinct information about the monitored user and

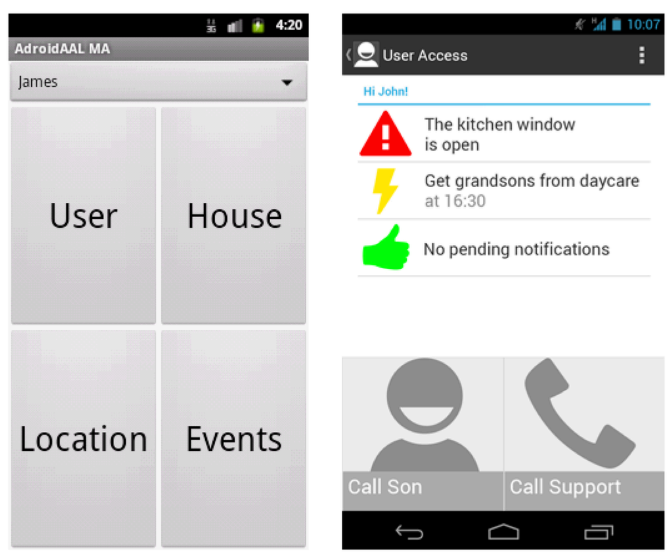

Figure 2.3: Screenshots from the UserAccess smartphone app

having simple and intuitive buttons that require less than three interactions to obtain the information". Unfortunately, rather than testing the app with caregivers to ensure it was useful and usable, the only testing of the system was to ensure the proper firing of alerts when sensor readings surpassed predefined thresholds.

2.9 Concerns About Caregiving Technologies

2.9.1 Technology Acceptance

While results from caregiving tools thus far are promising, important concerns are also discussed in the literature. In a study[116] of caregiving tools for caregivers of older adults with dementia, cluster analysis of questionnaire data revealed two distinct clusters. Those that were highly in favor of technology's role in caregiving and those that were hostile to it. This polarized reaction to technology is an important consideration for any future research.

2.9.2 Privacy Controls

There is also concern[117] that both older adults and caregivers may be unwilling to accept new technologies, with some research to show that those that are most in need of aging in place technologies are least likely to accept them[118]. One way to mitigate this may be to provide data access controls that allow older adults control of who is able to access their health data and the ability to turn the system off for a given period of time[119].

2.9.3 Communication Replacement

There is some apprehension by older adults that providing technology and communication tools to caregivers may actually have an adverse effect on caregiver-care recipient communications. Systems need to stress the importance of in-person care when possible and encourage an increase in healthy communication. Huber conducted a 6 week study and found no decrease in communication, but rather a shift in communication topics towards conversations about the system[120].

2.10 Gaps in Knowledge

While these first steps provide a valuable foundation, many important research questions remain. Questions identified thus far in the literature include:

1) **How can we facilitate effective communication between distance caregivers and care recipients?**

   Bevan suggested that "distance caregiving communication remains an uncharted research territory that we encourage caregiving scholars to explore."[67]

2) **What are the information needs of distance caregivers?[121]**

   Benefield stressed that "studies are needed that prioritize and match technological capabilities to actual caregiving needs"[24] while Bledsoe emphasized that "more research needs to be conducted to fill the gaps in knowledge regarding the needs of [distance caregivers]"[122].

3) **"What interaction modalities do caregivers prefer for their interaction with smart home systems?"[121]**

4) **How do we design visualization tools that "allow the caregiver to easily view the daily activities and health information of the older adult"?[94]**

5) **How do we design caregiver tools that will "not take them days to learn and will give them great benefit"?[123]**

   The author that posed this question then went on to suggest that "participatory design with familial caregivers should be done to include them while the interfaces are being developed."

6) **What do users infer from health activity data representations, especially when viewing long-term longitudinal data?[108]**

   "Visualization interfaces for most smart homes need to be clearer for non-researchers. They need to have metrics that make sense to the task being done."[123]

Following the counsel of the researchers that posed these questions, we propose a user-centered design process to further explore these important issues. We anticipate that our work will provide a greater understanding of caregiver information needs and new understanding regarding best practices in the design of useful and usable tools for distance caregivers of older adults.

Chapter 3 - A Mobile/Web App For Long Distance Caregivers Of Older Adults: Functional Requirements And Design Implications From A User Centered Design Process

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[Accepted at American Medical Informatics Association (AMIA) Annual Symposium 2014]

3.1 Abstract

Recent trends of population aging and globalization have required an increasing number of individuals to act as long distance caregivers (LDCs) to aging family members. Information technology solutions may ease the burden placed on LDCs by providing remote monitoring, easier access to information and enhanced communication. While some technology tools have been introduced, the information and technology needs of LDCs in particular are not well understood. Consequently, a needs assessment was performed by using video conferencing software to conduct semi-structured interviews with 10 LDCs. Interviews were enriched through the use of stimulus materials that included the demonstration of a prototype LDC health management web/mobile app. Responses were recorded, transcribed and then analyzed. Subjects indicated that information regarding medication regimens and adherence, calendaring, and cognitive health were most needed. Participants also described needs for video calling, activity data regarding sleep and physical exercise, asynchronous communication, photo sharing,

journaling, access to online health resources, real-time monitoring, an overall summary of health, and feedback/suggestions to help them improve as caregivers. In addition, all respondents estimated their usage of a LDC health management website would be at least once per week, with half indicating a desire to access the website from a smartphone. These findings are being used to inform the design of a LDC health management website to promote the meaningful involvement of distant family members in the care of older adults.

3.2 Introduction

2011 marked a critical milestone for Americans; the first set of baby boomers reached the age of retirement. For the first time in the United States' history, the number of adults age 65 and older exceeded the number of children under the age of 5. By 2014, the percentage of the population age 65 and older will reach an all-time high of 14%; double the proportion that was seen in the 1940's [124]. As this process of population aging unfolds, the problems associated with caring for unprecedented numbers of older adults become increasingly apparent. Unparalleled demand will be placed not only upon the US healthcare system, but also, upon the millions of family members, friends, and neighbors that provide unpaid care to elderly loved ones. These individuals, often referred to as informal caregivers[16], form "the backbone for much of the care that is received by older adults in the United States"[15]. In an increasingly global society, geographic separation presents a significant challenge to many as they strive to provide care from afar. Challenges such as inadequate methods of communication, living in different time zones, and lack of familiarity with a loved one's surroundings may all combine to prevent a long distance loved one from providing care[66]. Such separation often increases the burdens of time, cost, and emotional strain upon the caregiver[67]. In the last few years, it has been suggested [24,125]that internet technologies have matured insomuch that they may prove to be viable options for providing support to long distance caregivers (LDCs). Such an approach however, remains understudied.

Some early research has focused on identifying information needs of caregivers for individuals with dementia [50,126], while others have focused on providing appropriate information regarding how to care for other specific illnesses/conditions[127,128]. One promising study, conducted by the National Alliance of Caregiving and United Healthcare [77], investigated caregivers ranking of various health IT tools to support them in their care. This study, measured perceived benefits and barriers of 12 technologies for both in-home and out-of-home caregivers. Systems that allowed for personal health record tracking, caregiving coordination and medication support had high levels of perceived benefits and lower levels of perceived barriers. We suggest that these and other caregiving tools may be especially useful in the context of a smart home in which older adults are monitored using unobtrusive sensors to track various health metrics.

Recently, work[129], has been undertaken to provide a better understanding of the prevalence of technology use by out-of-home caregivers in the United States. Current estimates indicate that about one third of out-of-home caregivers use health IT in their caregiving activities. An interesting contrast is found however, in that even among "technology nonusers", over 70% of LDCs expressed an interest in using technology in their caregiving responsibilities. The incongruence between interest to use health IT tools and actual usage may be explained by barriers such as perceived cost, potential resistance by the care recipient[77], and a lack of user-centered focus in the design and implementation of current LDC systems[129].

In the interest of promoting higher levels of usage and utility, we resolved to use a user-centered-design approach to assess information needs and discern important usability principles in the design and development of health IT tools for LDCs. The research outlined below is innovative, due to the fact that no studies have specifically looked at the information needs and technology preferences of LDCs by providing caregivers an opportunity to openly discuss their needs and preferences. Furthermore, our study is unique in that we are investigating information needs in the context of a smart home, containing multiple sensors that provide important data streams about activity, cognition, and physiologic parameters. Investigating LDC needs from this perspective provides us with additional information that will enable us to better understand the emerging needs of caregivers living in an increasingly "electronic" world.

3.3 Methods

Due to the exploratory nature of this research, qualitative methods were chosen. Since our subject recruitment pool contained individuals throughout the United States, we chose to conduct semi-structured interviews via Skype as the primary method of data collection. We chose Skype over a traditional telephone as we felt that the face-to-face interaction would help subjects to feel more at ease when talking to an unfamiliar person. The use of Skype also helped us to detect any visual cues that may not have been as apparent via a phone call and allowed us to visually present questions and stimulus materials to subjects as we spoke with them. Skype also served as an ideal platform for data collection due to the fact that all communications are encrypted using robust encryption algorithms.

3.3.1 Prototype Development

In keeping with other qualitative research, [130,131] we elected to develop basic prototypes of a caregiver web (shown in Figures 1 & 2) and mobile app as stimulus materials to facilitate and further enrich our discussions. This approach was chosen due to the limited availability of remote caregiving systems and the anticipated lack of familiarity with the types of data that may be collected in a smart home environment. In an attempt to intelligently develop an initial prototype that delivered an optimal user experience, we drew upon the following four data sources for guidance:

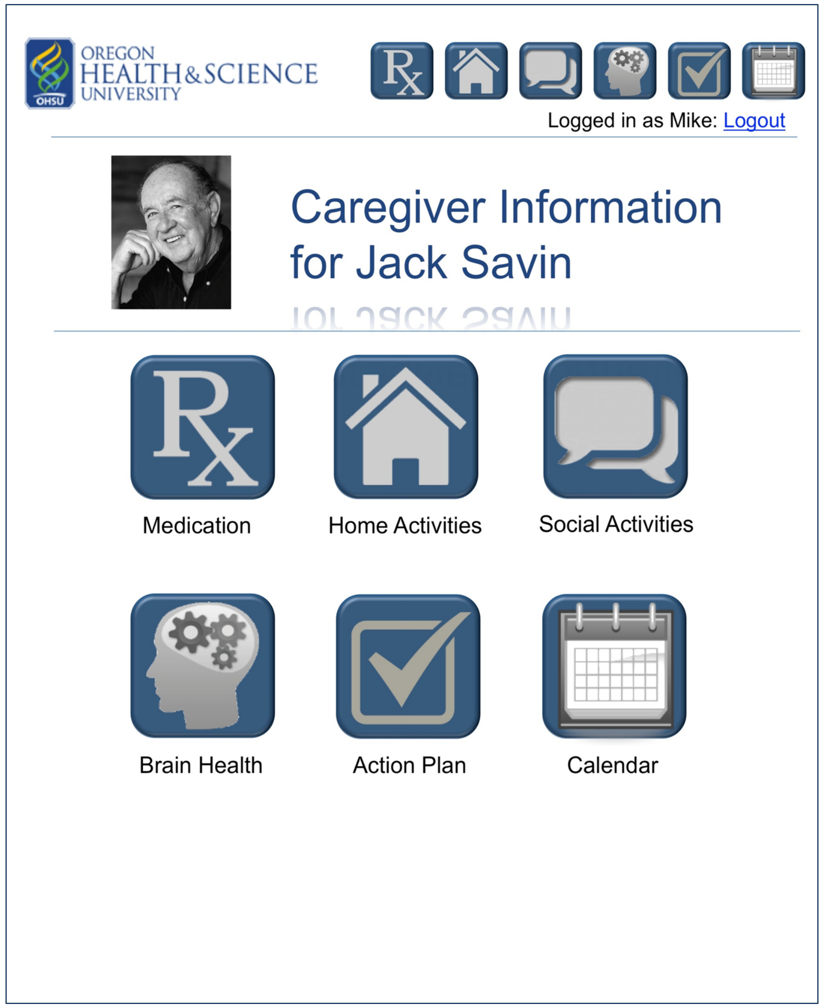

Figure 3.1: Screen shot showing the splash page from a prototype caregiver web app

1. Well established usability principles from the human computer interaction literature
2. Scientific articles that specifically described caregiving systems/prototypes

3. Existing commercial systems designed to be used by caregivers

4. Usability experts within our institution

Based upon our review of the literature and existing systems, we begun development of an initial mockup using Microsoft PowerPoint. During this process, usability experts within our institution were also consulted. To provide caregivers with a better understanding of system functions, we opted to make parts of the mockup interactive. This was accomplished using transitions and animations within the PowerPoint slideshow and allowed us to demonstrate behaviors and actions when we clicked on various elements within the user interface.

3.3.2 Interview Guide Development

Careful thought and attention was given to development of an interview guide[132]. Our guide was developed with the primary goal of facilitating open conversation with the caregivers in our study. As such, we elected to start by asking very broad, open-ended questions which were then followed up with more focused questions and probes when greater clarification was needed. Great care was taken to ensure that questions would be easily understood and would not lead study participants towards a specific idea or thought, but rather to allow them to express their own thoughts freely. Due to the fact that interviews were conducted via Skype, we also elected to display each question on the participants' screens as they were asked. This allowed each subject to both hear each question audibly as well as see the questions visually. It was our hope that doing so would help to ensure that each question was better understood and would allow respondents to re-read the question as they formulated their response.

After an initial draft of the interview guide was completed, two scholars were asked to review each question for simplicity, readability and neutrality and to suggest changes when necessary. As a final step in development, the interview guide was then used to conduct two mock interviews. This process not only allowed for minor changes to the guide but also helped the research team to practice interviewing techniques before the start of formal data collection.

3.3.3 Study Setting

A network of older adults living in smart homes throughout the Portland, Oregon region has been established as part of our existing cognitive health coaching platform[105]. Older adults that participate in this health-coaching platform are continuously monitored using various health tracking sensors. Areas of study include:

- Medication adherence and reminding - measured by a camera embedded pillbox
- Socialization - measured by phone, Skype and email monitors
- Sleep quality - measured using mattress pressure sensors
- Cognitive health - measured by cognitive computer games

Because the socialization module encourages the use of the telephone, email and Skype video calling, each older adult in the socialization intervention had previously chosen a remote partner with whom they would regularly communicate. These individuals in turn agreed to provide remote support to the older adults in our project. All remote partners lived in a location different than the older adult and were generally a close friend or family member. A group of 11 subjects was recruited from within this pool of remote partners as participants in our needs assessment.

3.3.4 Data Collection

Each participant was contacted initially via telephone and then later interviewed for approximately 45 minutes. Due to geographic separation between the subjects and the researchers and as all enrolled LDCs were familiar users of the Skype video conferencing software, interviews were conducted remotely through the use of this system. Initially, a short introduction was given in which the purpose of the study and each subject's role was clearly explained. An emphasis was placed on the fact that subjects could ask questions or make suggestions at any time. Next, subjects were asked to introduce themselves and to describe some of the challenges that they had encountered as they strived to provide care from a distance. Respondents were then asked which types of information are most important to them as caregivers. Next, subjects were asked to identify ways in

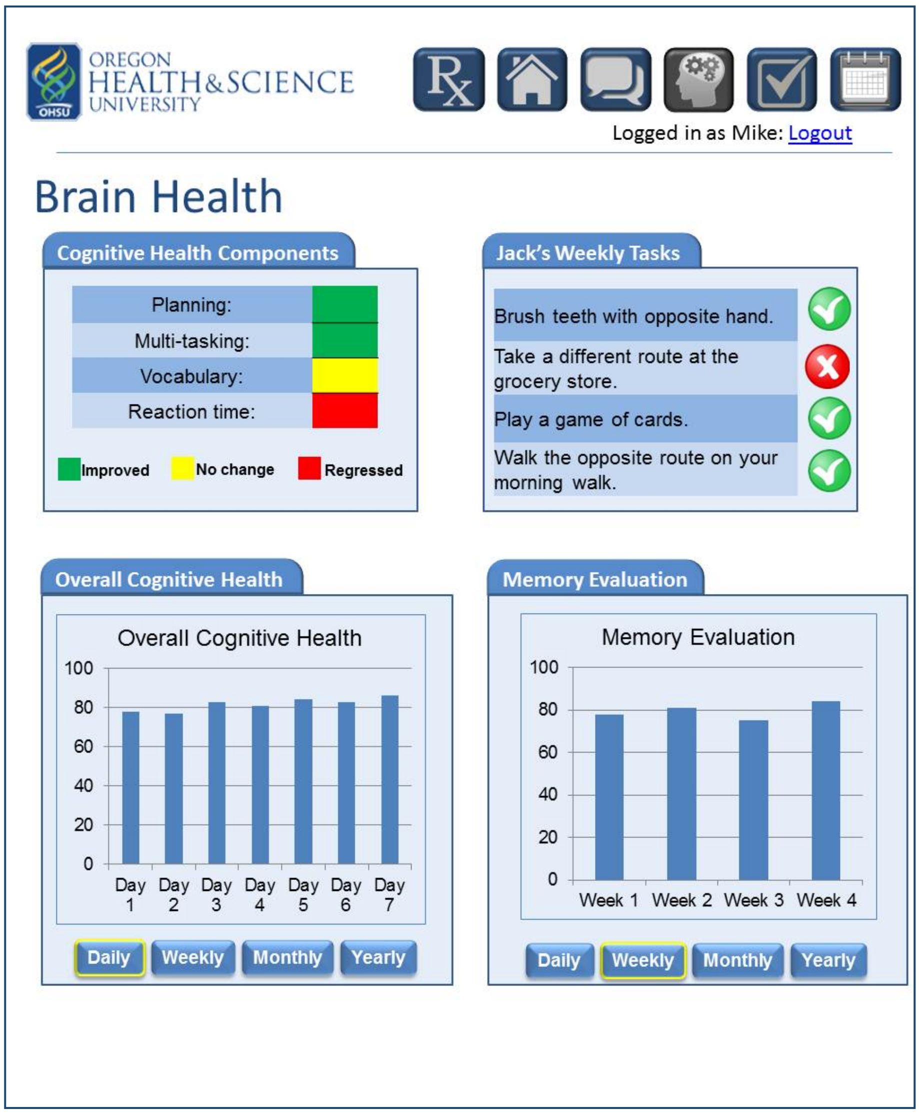

Figure 3.2: Screen shot showing the brain health page from a prototype caregiver web app

which technology might serve to ease some of the burdens encountered by LDCs.

After respondents answered these questions, stimulus materials including sample screen-shots for web and smartphone based health management were displayed using Skype's screen sharing feature. These materials enriched discussion and provided subjects with a real world example of ways in which technology could help them to provide care. In particular, subjects were shown a prototype website in which sensor data regarding medication adherence, socialization, calendaring, sleep quality, and cognitive health was presented using easily understood language and graphics. Tips and suggestions for how to help the older adult were also displayed. After presenting the prototype, discussion was facilitated by the presentation of thoughtful questions designed to promote feedback about key areas of interest (*e.g.* estimates regarding level of usage, importance of mobile devices, design recommendations). Finally, each subject was asked for any additional comments or suggestions regarding site design and types of information available. Each interview was recorded, transcribed, and subsequently analyzed by grouping similar thoughts and concepts into appropriate themes and ideas. The findings of our needs assessment will then be used to inform the development of version 2.0 of our prototype. This new and improved prototype will then be used in a usability study investigating the way that real world users interact with the proposed application.

3.4 Results

Of the 11 subjects that were initially recruited, 10 individuals were successfully contacted and interviewed, with one participant unable to proceed due to lack of a sufficiently reliable internet connection. Of these 10 individuals, 6 were female and 4 were male.

3.4.1 Desired Functionality

Subjects in our study reported that LDCs desire 14 different basic functions: video calling, calendaring, medication tracking, cognitive health tracking, sleep tracking, physical exercise tracking, access to medical records, asynchronous communication, photo sharing, journaling, online health resources, real-time monitoring, an overall summary of wellness, and guidance/feedback regarding the care they provide. These 14 functions are described in Table 1.

Table 3.1: Fourteen Basic Functions for Long Distance Caregiving	
Video Calling	Nearly all of the individuals interviewed spoke about the benefits of using videoconferencing software such as Skype to communicate with the older adult under their care. Four individuals spoke of the value of nonverbal communication that is not available over a regular telephone call. The participants' thoughts regarding this matter are well summarized by the comment "Now, instead of hearing how she's doing, I can see how she's doing. It's one thing to tell someone how you're doing but it's a little harder to look at someone and tell them that you're feeling good when you're not." In addition, one interviewee talked about the benefits of being able to show objects over video rather than simply describing them. Some frustration was expressed that this was only a valuable form of communication when there were not technological barriers such as unreliable internet connections, audio dropouts or pixelated video.
Calendaring	Six individuals indicated that a shared calendar would be useful to them in their caregiving responsibilities. Respondents were especially interested in being able to view upcoming doctors' appointments and any planned trips or outings. One person commented that "to [her] the calendar would not be at all useful because digital calendars are cumbersome". Another commented that "it might take a bit of switching going from a paper calendar to an electronic one but I think I can convince my mom to switch". The comment was also made that it would be useful for older adults to see a very high level version of the caregiver's calendar so that the older adults could be reminded of times that the LDC would not be available and the care recipient would know to contact somebody else if a concern arose. The idea that the calendar could be used to coordinate care by multiple LDCs was also mentioned. This would allow multiple individuals to share the responsibilities of caregiving rather than a single individual being expected to carry all of the burden

Medication Tracking	Four individuals indicated that information regarding medication adherence was very important to them. In addition, the importance of knowing the older adult's medication list and regimen was also mentioned. Respondents made comments such as "medications are a big concern" and "if you're not taking your medication, everything else would fall apart". One individual, however, said that medication information was the least important of all the types of information presented. He commented that this was due to the fact that using images obtained from a camera embedded inside a pillbox did not really indicate if the medication was actually taken. In his words "they could take it out of the box but then not really take it".
Cognitive Health Tracking	Four interviewees suggested that data regarding cognitive health was very important to them. Two of these individuals indicated that this information would be especially interesting to them if it could be presented over a long period of time allowing the caregiver to track any problems. In the words of one subject, "as he gets older, I especially worry about his brain and memory".
Sleep Tracking	Three respondents spoke of the importance of knowing if and when an older adult was experiencing difficulty sleeping. Each of them expressed concern that inadequate sleep can then lead a large number to other problems/concerns. One interviewee described the utility of a system that would automatically alert her after her loved one had experienced multiple consecutive nights of poor sleep so that she could call and check on the older adult and then intervene if necessary.
Physical Exercise Tracking	The importance of knowing whether or not an older adult is regularly exercising was also mentioned. Caregivers wanted to know that the older adult in their care was able to regularly exercise. Along with this information need one caregiver also mentioned the importance of knowing certain metrics of physical ability such as strength and balance.
Medical Records Access	Two LDCs asked about the possibility of being able to access the older adult's medical information and test results. They expressed a desire to be more informed and involved in the older adult's medical care because "sometimes if we don't go with him/her, then his/her story doesn't make sense".
Asynchronous Communication	Many of the LDC's interviewed spoke about the need and value that comes from asynchronous communication. Whether this communication was via e-mail, text message, instant message *etc*. seemed to be less important than the ability to communicate asynchronously. This was important to them because it allowed them to communicate with the older adults without having to worry about the time of day (*e.g.* too early, too late, while the older adult was busy). One respondent also said that this form of communication allowed the care recipient to communicate with him without worrying about disrupting him at work.
Photo Sharing	The ability to share photographs was mentioned in a few different interviews as an important form of communication. Two LDCs spoke about the value of being able to send pictures back and forth. These individuals mentioned that seeing pictures helped to bridge the gap between caregiver and care recipient and made them feel more involved in each other's lives.
Journaling	Two caregivers spoke about electronic caregiving journals that would allow for note taking and could be used to keep track of items that may not be included within the caregiving application. One suggested that journals could be tied to a calendar so that reminders could be integrated within the journaling feature.

Online Health Resources	Multiple caregivers talked about the importance of being able to access reliable health information electronically. Caregivers described medical websites as an important resource that they could use to research a specific condition or illness and then share the pertinent information with the older adult.
Real-time Monitor	The need for a real-time indication of an older adults status was described throughout our conversations with LDCs. Caregivers were especially interested to know if an older adult had fallen or was in immediate need of help. Conversely, caregivers also wanted to know when the older adult was doing well and no intervention was needed. One caregiver described a system that could not only indicate when help was needed but also "how badly [the care recipient] needed help".
Summary Metric of Overall Wellness	While many caregivers saw the value in providing data regarding individual items (*e.g.* medication, sleep, *etc*.) they also expressed a need for a summary metric that could be an overall indicator of wellness. This would allow caregivers the ability to look at a single graph and see a general trend of wellness over time.
Feedback /Guidance	Over half of the respondents talked about the importance of providing guidance and feedback. Not only is it important to provide monitoring data to caregivers, but it is essential to also provide suggestions of what they as the caregiver can do to provide better care and encourage healthy behaviors by the older adult. One caregiver also spoke about the importance of providing encouragement to caregivers when they logged into the system and tried to play a more active role.
Other Suggestions	Some respondents also suggested other types of information that would be useful to them as long distance caregivers. One caregiver suggested the inclusion of "information about hobbies and interests". He went on to suggest a page in which the older adult could share pictures and information regarding hobbies with the caregiver. Another caregiver was interested in the possibility of including information regarding diet through the use of a "smart refrigerator to track if she needs milk and that sort of thing". One final suggestion was the ability to send an alert to the older adult. He commented that "Dad hasn't been drinking enough water lately. It would be nice if there was a way to remind him with a beep or something."

Table 3.2. Design Implications for a Mobile/Web App for Long Distance Caregivers.	
Usage Patterns	Every individual interviewed expressed optimism about their usage of the proposed system and felt that they would use it on a fairly regular basis. All participants indicated that they would likely use the system at least once per week with three participants indicating that they thought they would use the system "a couple times per week" and two respondents suggesting that they would use the system on a daily basis. Two individuals indicated that they would be much more willing to use the system regularly if "the system had the ability to alert me when there was something that needed my immediate attention". Some LDCs estimated that their usage would be heavily tied to the health of the older adult under their care. They suggest that when the older adult was healthy they would be less likely to have any concerns and would not use the system as regularly. In contrast, they felt they would use the system much more frequently when the older adult's help was concerning to them. While not as valuable as actual usage data, these expected usage patterns provide valuable information regarding the overall flow and design of a caregiver website. Such high frequency of usage would suggest the need to design a dashboard that would allow the caregiver to quickly check an older adults condition without the need to click on each individual category. Also, as noted by two of our participants, an intelligent alerting system that drew the caregiver's attention to potentially worrisome data would be ideal. If alerts are to be used however, the authors urge that a great deal of care be taken so as to not inundate caregivers with false alarms as this is likely to lead to alert fatigue.
Device Preferences	Of our sample, half of the respondents indicated that they would be likely to access the LDC website from a smartphone. This closely mirrors smartphone adoption data for the US population during the time that the interviews were performed. As such, we expect an increasing proportion of caregivers to request smartphone compatibility for a caregiver website. Of those that desired smartphone compatibility, many talked of the convenience and importance of having access to the system while traveling either to/from work or while on vacation. These participants described use cases in which a smartphone would be used while on the go but a traditional PC would still be the preferred choice if available (i.e. when at home). Such usage in which both a smartphone and a traditional PC are used interchangeably requires a consistent look and feel, as well as similar functionalities and feature sets regardless of which device is used to access the site. In addition, due to respondents reporting high levels of expected usage, a mobile app is recommended in lieu of a smartphone compatible website. Such an approach allows caregivers to view historical data even when no data connection is available and allows for more sophisticated alerts to be displayed when necessary. Identified barriers to using a smartphone to access the LDC website were a small screen and relatively high costs of ownership and usage. However, we expect these concerns to fade somewhat as smartphone manufacturers/providers continue to shift towards larger screen sizes and lower cost devices/services.
Data Sharing Preferences	A few caregivers expressed concern that due to the sensitive nature of health data, their older adult may not be willing to share all of the different types of information with them. Though this was not confirmed by discussing data sharing preferences with older adults in our study, we suggest that any such system provides a way in which older adults are able to control the visibility of the data collected. It was also suggested that older adults might be more willing to share monitoring data if the system is implemented before they are facing serious health challenges. In the words of one subject "It might be better to start them when they don't need it because if you start too late then they may not want to do it. I guess it's one of those things that if they sense that they aren't doing well then they will resist that." As such, we recommend the early implementation of health monitoring systems as a possible way to mitigate this challenge. Such an approach also has the added benefit of collecting longitudinal data while an individual is still healthy so that there is a greater likelihood of early detection when problems arise.

Longitudinal Tracking	Caregivers reacted favorably to the idea that longitudinal data could be presented in a meaningful way. They recognized the value of being able to look at data over different periods of time to identify potential areas of concern. As one subject put it "looking by week or month that data is very useful. What I keep trying to get in my head is the progression …seems like this is a great tool to know their decline". While we agree that there is likely value in providing longitudinal data to caregivers, we also expressed concern about the possibility of either misinterpretation or over interpretation of these data. Contributing to this is the fact that many data streams from current smart home environments are fairly noisy. These concerns may be mitigated somewhat through the use of data smoothing algorithms and clear indications to the caregiver when specific scores are vastly different from an individual's baseline.
Caregiving Terminology	Very few individuals that we interviewed identified themselves as either a long distance caregiver or a caregiver in general. Many individuals expressed that they thought of a caregiver playing a more hands-on role that was not possible from a distance and instead viewed themselves as a helper, friend or family member. While we feel that it would be healthy to help redefine the lay definition of what constitutes a caregiver, we also recognize a need to properly frame any communication with LDCs in language that they understand and can relate to.

3.4.2 Design Implications

In addition to describing desired functions of an LDC web/mobile app, study participants also shared insights that have important design implications for those seeking to develop such a system. These design implications concern usage patterns, device preferences, data sharing preferences, and the presentation of longitudinal tracking data, described further in Table 2.

3.4.3 Overall Impressions

The overall reaction from caregivers was very positive with many making comments such as "I think this is a great idea" and "This is going to be really helpful for people like me". Though individuals suggested the improvements detailed above, none of the participants thought that building a web site/app for LDCs was a generally bad idea. In addition to the expected benefits of being able to ease the burden of providing care and improve involvement of LDCs, a few other benefits were suggested. One caregiver remarked that the system would "help [her] not feel so guilty for living so far away". It was also suggested that such a system would help older adults because "having us involved helps her to feel loved and valued". Even when an older adult already lives near family members, one individual suggested that "I can help my mom and uncle by alleviating some of their stress. If there's something going on I can let them know and have them go visit her". At the conclusion of one of the interviews, one caregiver became emotional as he spoke of the privilege of being able to care for his aging parents as they "experience this amazing process of the end of life" and suggested that a LDC website would allow him to do that more effectively.

3.5 Discussion

After conducting qualitative semi-structured interviews with 10 subjects, we identified 14 different functions that LDCs desire (video calling, calendaring, medication tracking, cognitive health tracking, sleep tracking, physical exercise tracking, access to medical records, asynchronous communication, photo sharing, journaling, online health resources, real-time monitoring, an overall summary of wellness, and guidance/feedback regarding the care they provide). We also identified 4 important design implications concerning LDC usage patterns, device preferences, data sharing preferences, and the presentation of longitudinal tracking data. Overall, we found that participants reacted very positively to the proposed system.

These results are concordant with previous studies that have investigated the role of technological solutions for caregivers. Our findings are similar to those of The National Alliance for Caregiving (NAC)[77] who also identified health record tracking, medication support tools, caregiving coordination tools, interactive systems for physical, mental and leisure activities, a symptom monitor and transmitter, a video phone system and a caregiving decision support tool as some of the most important tools for caregivers. Though described by our respondents using different terminology, many of the desired features identified in our study are functionally very similar. One feature listed in the NAC that was not reported by our study is the need for caregiver training simulations. While it is possible that this feature is also desired by LDCs, we note that the NAC study involved both long distance and in-home caregivers and this feature in particular may be more important to individuals serving as traditional "hands-on" caregivers. We also identified some desired features that have not been suggested previously and identified design implications that we believe are important for those looking to develop successful LDC systems.

During the planning of this study, there was some concern that presenting the prototype to interview participants may bias our findings. We expected that we might lead interviewees to talk about the information needs that we anticipated them to have rather than actual information needs. We were surprised to find that while some participants did not speak of some types of information until prompted, at least one participant spoke of each type of information need before the prototype was presented to them. This leads us to believe that our approach was indeed appropriate and the prototype served as a probe to elicit deeper understanding rather than serving to bias our respondents. This is reaffirmed by the high level of agreement between our study and previous work.

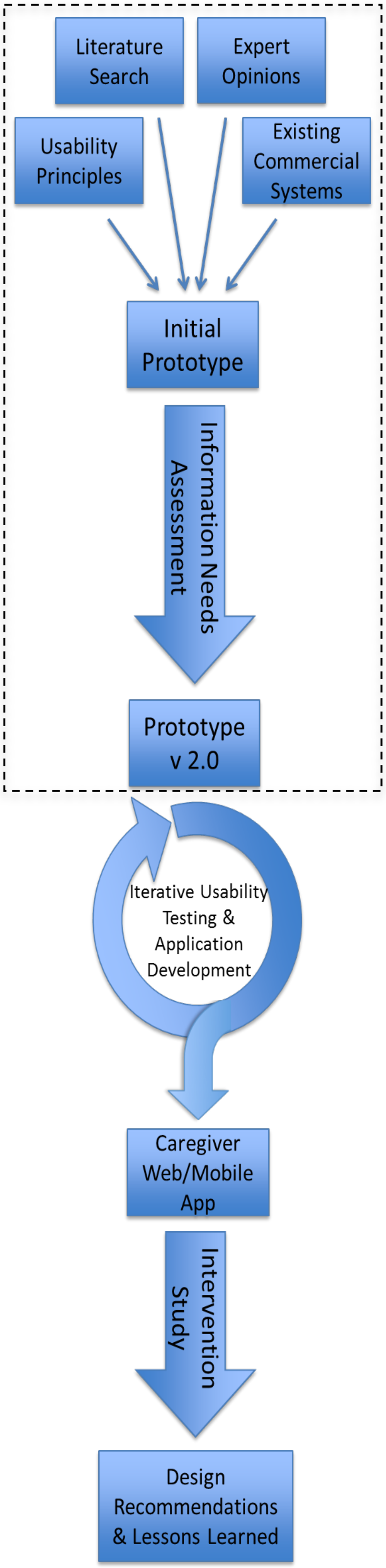

Figure 3.3: Long term research plan for development and evaluation LDC web/mobile app (dashed box designates work described in this paper)

The overwhelmingly positive reaction towards our prototype system also follows trends found by other researchers[129]. Our results however, indicate an even higher level of acceptance with 100% of subjects expressing enthusiasm for an LDC system. While somewhat explained by the limitations listed below, we also suggest that such high levels of enthusiasm are the result of high levels of caregiver burden, with many caregivers desperately looking for assistance as they struggle to provide for loved ones.

Limitations

While we feel that the findings of this study are indeed useful, our choice of methodology and sample population created some important limitations that should be considered. These include:

1) Small Sample/Lack of Diversity - Though not as important due to our use of qualitative methods, our sample size was still very small (N = 10) and had limited inclusion of ethnic minorities. Also, the LDCs in our study only provided care to older adults that had displayed little to no cognitive impairment.

2) Pro-technology - Study participants were drawn from a pool of technology using seniors and LDCs and are likely more receptive to new technologies than the general population.

3) Hesitant to criticize - Study participants may have been unwilling to provide a critical analysis of our prototype for fear of offending members of the research team.

4) Unable to Discern Needs - It is unclear if subjects are entirely aware of their own needs. As with many needs assessments, there is concern that individuals are unable to identify specific needs, choosing instead to be content with their currently available toolset. This may be especially true when discussing a new technology that subjects have not had the opportunity to use in the real world. During our interviews, this was evident when individuals responded that they were not sure whether or not they would need a particular type of information.

As such, we stress the importance of conducting future research to address these limitations by investigating what other information needs are required by other caregiving populations and by trying to answer our research questions with complementary methodologies.

Despite these limitations, many valuable themes emerged that we hope will prove useful as we strive to provide LDCs with new information technology tools. It was very encouraging to find that all 10 individuals interviewed suggested that building a LDC web/mobile app would be accepted positively. Equally encouraging were indications that the proposed application may be used on a regular basis. However, perceived usefulness and usage may not be accurate indicators of actual system usage and utility.

While this study has identified information types that are likely to be useful and valuable to individuals providing care from afar, the best methods for presenting these data to caregivers warrants further exploration. In addition, while the ability to access an older adult's medical information and test results has been suggested as a useful feature, limitations regarding privacy of medical data may prove to be substantial hurdles.

3.5.1 Future Research

The work described here is the initial step in a larger effort to better understand the role that health IT can play in assisting caregivers. Our future research will use these findings to improve our existing prototype. As shown in Figure 3, these improvements, along with making the prototype fully interactive will allow us to enter an iterative usability testing and development phase during which users will be asked to use our prototype to perform various tasks. We hope that this iterative cycle of development will allow us to create a final caregiver web/mobile app that is both useful and user-friendly. This out will then be evaluated by means of an intervention study. Both quantitative and qualitative methods will be used to determine the impact that our caregiver application makes in the real world. These data will then be synthesized into design recommendations and lessons learned for future researchers interested in the field of technology enhanced caregiving.

3.6 Conclusion

The information needs of long distance caregivers are extensive and may vary somewhat depending upon the health problems of the care recipient. LDCs described needs for video calling, calendaring, data regarding medication, sleep, physical exercise and cognitive health, asynchronous communication, photo sharing, journaling, access to online health resources, real-time monitoring, an overall summary of health, and feedback/suggestions to help them improve as caregivers. We feel confident that we have obtained sufficient preliminary data to justify the continued development of a long distance caregiver application with the final goal of conducting a field trial of such a system in the real world.

Chapter 4 - Operational Usability: Lessons Learned from Rapid Usability Testing of a Smartphone App for Out-of-Home Caregivers of Older Adults

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[Tentatively accepted to be published in the Journal of the American Medical Informatics Association (JAMIA)]

4.1 Abstract

Objective: To iteratively test and improve the usability of a prototype smartphone application for out-of-home caregivers of older adults.

Materials and Methods: 15 subjects were recruited over three rounds to participate in a think aloud protocol. Subjects were instructed to follow five caregiving scenarios while using the application. Data were collected by observation and subject comments. Debriefing interviews provided additional insight into any identified problems. After each round, all problems were classified as either "resolve" or "wait and see". Solutions were developed and implemented for "resolve" items while "wait and see" items were used as special areas of focus in subsequent rounds of testing.

Results: General usability was high with all subjects intuitively completing all basic navigational tasks. Overall, 34 unique usability problems were identified, 22 in the initial round of testing. Problems centered around themes of poor labeling/wording, hidden functionality, anticipated functionality of static UI elements, and graph comprehension. The original medications section was found to be especially confusing due to high cognitive load from comparing multiple complex images. This prompted a complete redesign that greatly simplified the task.

Discussion: Key lessons include: (1) the importance of maintaining an operational approach while also ensuring high prototype fidelity, (2) a recommendation that regardless of previous testing, two additional rounds of usability testing are performed whenever significant changes are made to the application.

Conclusion: Our approach to usability testing was an effective and efficient way to identify and resolve many of the usability problems in our caregiver smartphone application.

4.2 Introduction

4.2.1 Background

Though often overlooked, informal caregivers have long been an integral part of our efforts to manage chronic disease among older adults. As we strive to accommodate the growing needs of our older adult population, the role of caregivers is likely to become increasingly important. Traditionally, the term "caregiver" has been reserved for individuals that lived with and provided hands-on care. More recently however, many have recognized the numerous caregiving tasks that can be performed when caregivers and care recipients live separately. In fact, some estimates [13,16] suggest that out-of-home caregiving, in which caregivers and care recipient do not live in the same home, is the most common model of care in the U.S. As households continue to shrink in size[133], out-of-home caregiving is likely to become increasingly prevalent[134].

While the burden associated with all types of caregiving is significant, out-of-home caregiving brings its own set of unique challenges. These include lack of effective communication, the inability to easily provide physical hands-on help and a limited understanding of the services available in the care recipient's vicinity[66].

Some have looked to technology to mitigate these challenges suggesting that PCs, tablets and smartphones could enhance communication and provide accurate and timely information [24]. Caregivers have also looked to technology to ease their burden with 76% expressing desire to use technology in their caregiving. Despite their willingness, actual usage remains fairly low (~30%). Reasons for this mismatch include:

1) Difficulty gaining access to a loved one's medical records.
2) Unfamiliarity with the many websites/apps tailored to caregivers[129].
3) A lack of user centered research and design in current caregiving solutions.

While data restrictions and unfamiliarity with existing tools are important issues that deserve significant time and attention, in this paper we focus on the importance of user-centered methodologies in the design of any caregiving application.

4.2.2 Technology-centered Versus User-centered Design

The rapid growth of tablet/smartphone app stores has created a high stakes environment in which some consumer health applications have been rushed to market. Often times, young, tech-savvy developers take a very technology centered focus to design, forgetting that their guiding principles should be based on end users[28]. Such a tech-centric approach can increase user burden and frustration resulting in users abandoning a particular technology. Instead, many scholars have suggested a user-centered approach to design[30,33,34].

As the name suggests, user-centered design places a user's needs, goals, abilities and limitations as the central focus throughout the design process. This focus allows designers to first, design solutions around people rather than technology, and second, to test their designs with end users to ensure congruence between product design and user requirements.

One way to evaluate congruence is through user focused usability testing. Such an approach generally involves study subjects using a prototype application in a simulated environment as researchers collect quantitative (e.g. time taken to complete a given task, error/success rates) and/or qualitative (impressions, suggestions, thoughts) data about the user or prototype. These data are then used to make informed changes to the application in an iterative fashion[135].

Over the last two decades, many researchers within and outside the informatics community [136–142] have documented the value and importance of usability testing in the design and development process. Despite these recommendations however, usability testing is often still overlooked for many consumer health applications. Reasons for this disconnect include lack of buy-in from upper management, the perception that usability testing is costly or takes an extended period of time, and a belief that usability testing will not provide an adequate return on investment.

To address these concerns, we present our experience with a rapid, low cost approach to usability testing a smartphone application for out-of-home caregivers. It is our hope that both our approach and findings will be beneficial to not only those building caregiver solutions, but to the wider consumer health informatics community as we strive to empower patients in their healthcare.

4.2.3 Prototype Application

Understanding Caregiver Needs

As a starting point for our usability study, we looked to our previous work[143] investigating the information and technology needs of distance caregivers. Using semi-structured interviews with 10 caregivers, we collected user feedback and perceptions about the role that a computing device could play in their care. We then used this data to generate a list of functional requirements and design recommendations.

Device Selection

Our previous work also informed our device choice for the prototype. Caregivers reported a desire to use a smartphone application when mobile but a desktop version at home. This is congruent with recent estimates showing that smartphone adoption by middle aged individuals is now quite high (74% for ages 30-49[144] and 51% for ages 55+[145]). This shift in adoption by older demographics is significant because the large majority of caregivers come from this group, suggesting that smartphone use by caregivers may be similar.

Another important theme from our needs assessment was the importance of time sensitive information such as reminders, alerts and activity data. To deliver these types of information promptly, requires a portable device that could remain with the caregiver throughout the day. For these reasons, we elected to design our prototype application as a smartphone app with the intention of creating tablet and desktop versions at a later date.

Prototype Development

Initially, functional requirements from our previous study were rated by importance, feasibility, and difficulty of implementation. This allowed us to systematically identify any requirements that were outside of the scope of the application or that were not feasible given our time and resource constraints. Requirements were then mapped to a list of primary "views" that would be necessary for our application. Paper-based sketches were developed for each screen and informal feedback was requested from the rest of the team. This information was then used to design a high fidelity, interactive prototype application.

Rather than build a basic wireframe to test general items such as application navigation and button placement, we elected to build a high fidelity prototype that, to the end user, appeared fully functional. This provided more authentic interactions for test subjects and allowed subjects to focus on using an app that felt familiar to them. This approach also allowed us to better understand subjects' opinions regarding important design considerations such as colors, fonts, icons, animations, transitions and the use of gestures.

To construct the prototype, we selected JustInMind v5.2, a drag and drop application built specifically for the rapid development of rich interactive user interface prototypes. JustInMind also allowed us to export our prototype to HTML/JavaScript and run it directly on a smartphone, further enhancing the authenticity of user tests.

4.3 Methods

4.3.1 Sample Size & Recruitment

We recruited five subjects in three rounds of testing (15 users total). Though in the early 90's Nielsen and Virzi both suggested [146,147] that 80-85% of all usability problems will emerge from the first 4-5 subjects, many have since disputed their claims[148–150]. More recently, Nielsen[151] suggests an updated approach in which researchers use an iterative methodology to test 15 users in 3 rounds of 5 subjects. In this manner, any identified usability problems can be resolved at the end of round 1. Rounds 2 and 3 then serve to confirm that previously identified problems have been remedied and to identify any remaining issues.

For our study, round 1 subjects were recruited from among informatics students who had taken at least 1 graduate class in usability. Round 2 subjects were drawn from usability experts at OHSU. Similar to other studies[129], out-of-home caregivers in round 3 were required to meet the following inclusion criteria:

1) Have an older adult family member or friend (age 65+) with a chronic health condition.
2) Live apart from the care recipient for more than half of the year.
3) Report a high willingness to help the care recipient with his/her health.
4) Communicate at least once/week with care recipient.

Using graduate students and usability experts allowed for simplified recruitment and allowed us to resolve any "low-hanging fruit" usability problems quickly. This left the most authentic version of the prototype for our most representative subjects in round 3. Also, given the short amount of time spent with each subject, individuals with usability training may uncover issues more quickly than untrained caregivers.

4.3.2 Scenario Based Testing

We anticipated that the most common use cases within the application would be:

1) Receive alert
2) Review graphical data

3) Review textual data

4) Update/modify data

Each use case served as the basis for a scenario in which subjects were asked to use the app as if they were caring for a hypothetical loved one.

Data were collected during 30-45 minute sessions with individual subjects. Subjects were provided with a short description of the app and the smart-home environment used to collect care recipient data. Next, subjects were provided with an Apple iPhone 4S and a sheet of paper that described each scenario as they followed a "think aloud" protocol[152]. During each session, subjects' interactions with the prototype were carefully observed and any usability problems or insightful comments were documented using a customized data collection form. To minimize the time spent recording observations while subjects were actively using the prototype, short verbal cues were initially recorded, with additional information being added during brief pauses between scenarios. This was possible due to the short duration of each scenario (generally 3 minutes or less). Upon completion of the scenarios, debriefing interviews elicited further insight about identified usability problems. Subjects were not compensated for their participation.

4.3.3 Data analysis

At the conclusion of each round of testing, a list of usability problems was compiled. Due to concerns that using traditional usability problem schema[153–155] would require additional training and increased time/cost, we continued our pattern of operational usability by taking a more streamlined approach. Rather than classifying problems according to underlying cognitive processes, problems were organized by method of resolution as either:

1) **Wait & See** - Collect more data in an effort to better understand the problem
2) **Resolve** - Propose and implement a solution

Categorization was based on problem severity and frequency, depth of problem understanding, and difficulty of resolution. Using subject observation/feedback and standard usability principles, we then developed and implemented solutions for all "resolve" items. After all rounds of testing were completed, we grouped usability problems by similar ideas and identified the lessons learned from our testing process.

4.4 Results

4.4.1 Participant Characteristics

15 participants were enrolled during 3 rounds of 5 subjects each. For the first two rounds of testing, we chose not to record demographic information, focusing solely upon skill sets in informatics and usability. In round 3 however, we collected demographic information (table 4.1) to ensure that our subjects' demographics were similar to caregivers nationally.

Subject #	Age	Gende r	Highest Education	Smartphone User
11	39	F	High School	Yes
12	53	F	Master's	No
13	41	F	Bachelor's	Yes
14	38	M	Bachelor's	Yes
15	54	M	Master's	No

Table 4.1: Demographics of round 3 caregiver subjects

4.4.2 Usability problems

A total of 34 usability issues were identified (table 4.2). As testing progressed, both the total number of usability problems and the number of newly identified problems decreased substantially with each round (see figure 4.1). These issues were then categorized according to established usability heuristics[156,157].

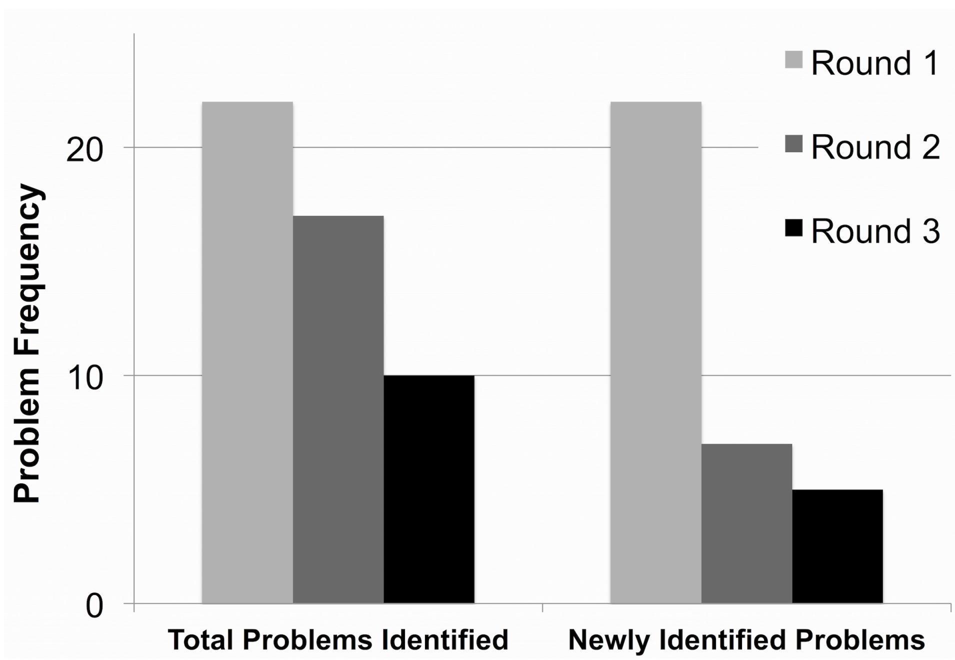


Figure 4.1: Total and newly identified usability problems for rounds 1, 2, and 3

Courses of action:

- Yellow: Wait until next round to better understand problem
- Light green: Implement proposed solution
- Dark green: Solution confirmed appropriate via additional testing

Usability Problem	Round 1	Round 2	Round 3	Solution
Round 1				
Inadequate descriptions for data on charts	light green	light green		Add description on help screen for each category
Items in list of goals look to be buttons but are not	light green	dark green		Add ability to click on items for more info
Unable to go back to an alert once dismissed	light green	dark green		Store all alerts as part of news feed
News feed scroll is too fast	light green	dark green		Slow scrolling speed to allow more time to read
News feed should scroll left to right, not top to bottom	light green	dark green		Change scroll from vertical to horizontal
Series lines in legend unclear, look like minus symbols	light green	dark green		Change symbols from a line to a square
Abbreviation of 1 month as 1m is unclear	light green	dark green		Change to 1mo, 6mo, 1yr etc.
Brain health label not very descriptive/appropriate	light green	dark green		Change label to "Cognition"
Date format on graphs is difficult to read (e.g. 13.May)	light green	dark green		Replace period with a space
Zoom label incorrectly assumed to be a button	light green	dark green		Functionality obvious without label - remove
No direction for how to use the data in my caregiving	light green	light green	dark green	Add "How to Help" text throughout app
Zoom buttons too small to tap	light green	light green	dark green	Increase button height by ~33%
No indicator of current date on medication images	yellow	light green	dark green	Add labels (e.g. today, yesterday etc.)
Week view on graphs important	yellow	light green	dark green	Add week views to graphs with daily values
Typing speed shouldn't be under "motion" category	yellow	light green	dark green	Rename category to "movement"
Confusion from graphs with 2 different units/scales	yellow	light green	dark green	Don't plot on same axis - use 2 different y-axes
Allow swipe navigation on news feed	yellow	light green	dark green	Initially changed to swipe, then changed to tap
Medication images hard to interpret	yellow	light green	light green	Multiple changes - see "medications" section
Viewing all longitudinal data on a chart is confusing	yellow	light green	light green	Use data grouping algorithm to reduce noise
Unclear that legend entries are interactive	yellow	yellow	light green	Train new users via brief tutorial
Pinch to zoom feature difficult to discover	yellow	yellow	light green	Train new users via brief tutorial
Difficult to discern between no data or value of 0	yellow	yellow	light green	Train users to tap line and view value on tooltip
Round 2				
Language in descriptions is too advanced		light green		Reduce text complexity to 6th grade level
Use more than color to differentiate between data series		light green		Add data point markers to data series
Tick and cross marks may be confusing for badges		light green	dark green	Remove ticks. Only use badges for alerts
Duration should be first tab on sleep		light green	dark green	Change tab order for sleep screen
Zoom controls may be confused as part of graph title		yellow		Increase spacing slightly. Not a common issue
Reluctance to click on help		yellow	light green	Change from ? symbol to I symbol
Outcome of tapping on legend different than expected		yellow	light green	Train new users via brief tutorial
Round 3				
Zoomed-in view of pill photo expected when tapped			light green	Add full screen photo view for pill images
Previous/Next buttons too small on medications page			light green	Increase size of tap area. Label remains same
Incorrectly interpreted medications page			light green	Multiple changes - see "medications" section
Not enough color			light green	Assign specific color to each category
Longitudinal data ignored - mainly viewed 1st week			light green	Train new users via brief tutorial
Difficult to read vertical y axis labels			yellow	Conduct additional testing

Table 4.2: Identified usability problems, courses of action for each testing round and problem solutions.

4.4.3 Error Prevention

We prevented errors by minimizing instances in which users experienced navigation difficulties in finding content or moving to the desired screen.

Inadequately Sized Controls

In 2 instances, navigation errors were due to controls that were too small for users to reliably tap with their fingers. In both cases, slightly increasing button height and creating a hot-zone by extending the "tappable" area of the buttons beyond their actual size appeared to resolve any subsequent errors.

Anticipated Interactivity

Four errors were based upon users incorrectly anticipating interactivity from a non-interactive UI element. All but one of these instances were resolved by adding the expected interactivity. The fourth (a label next to a button) was resolved by removing the element altogether after users indicated that the functionality of the buttons was intuitive.

Unexpected Behavior

We encountered one occurrence of unexpected behavior when a user tapped the legend in a graph expecting it to show more detailed information about the graph's data. Instead, tapping on items in the legend acts as a show/hide toggle for each data series on the graph. We anticipate that training new users via a short tutorial will avoid this issue.

4.4.4 Recognition Rather Than Recall

Graphs

Many interactive graph features (e.g. pinch to zoom, toggle data series on/off, display numerical values for a selected data point) were not easily discovered by users. After testing, users reported that these features were easy to use but were difficult to discover independently. As such, we changed the appearance of some elements to better indicate their functionality. We also anticipate that users will quickly learn to use these additional functions through an easily accessible new user tutorial.

4.4.5 Help and Documentation

The help section of the application (signified by a question mark inside of a circle) was largely undiscovered. Only 3 of the 15 users tapped on help with most users reporting that their "pride got in the way" and [they] wanted to figure it out on [their] own." When asked if we should change the icon and label to "More Info" answers from different subjects in rounds 1 and 2 were inconsistent. In round 3 however, all caregiver subjects were in favor of the name change.

4.4.6 Match between System and the Real World

Category Labels

Multiple subjects in round 1 suggested that labeling one of the categories as "Brain health" could be confusing. Subjects suggested titling this category "Cognition". We then confirmed that users approved of the change in subsequent rounds of testing.

Abbreviations

Round 1 users were confused by the abbreviations used in the range selector for graphs. The initial prototype signified 1 month, 6 months and 1 year time periods as "1m", "6m" and "1y" respectively. 3 users found this confusing and thought that 1m signified 1 meter etc. After round 1, the abbreviations were changed to "1mo", "6mo" and "1yr" (figure 4.2). After the change, all further subjects interpreted the abbreviations correctly.

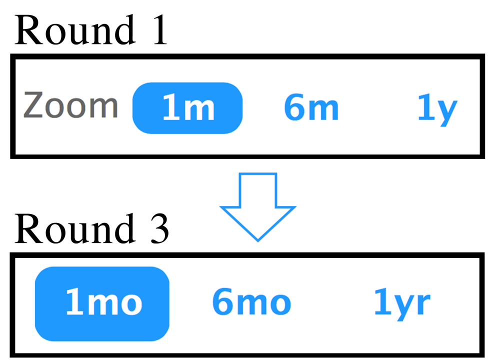


Figure 4.2: Before and after view of the abbreviations used for the range selector controls within the application

Reading levels

Multiple usability experts in round 2 felt that the reading level of the help pages was too advanced for our target audience. After round 2, all help pages were reviewed and edited to simplify content, vocabulary, and structure. Caregivers in round 3 did not express concern with the edited content, but more rigorous testing is required to ensure that the language within the app is suitable.

4.4.7 Aesthetic and Minimalist Design

Aesthetics

Subjects were generally positive about the app's "look and feel" with many expressing that they liked the color scheme and "clean" interface. Two caregiver subjects suggested that the app was too monochromatic and proposed that we assign a different color to each of the 6 main categories in the app.

Icons + Symbols

Users in all 3 rounds reported that the icons and symbols used in the app were generally easy to understand and helpful. One area that caused confusion was the use of a badge with a checkmark. This badge was originally designed to indicate that everything was in order for a particular category. Users felt that a badge was not necessary in this case as the absence of a badge correctly conveyed that there were no concerns for that category. We found that this is consistent with platform conventions on both Android and iOS in which badges are only displayed when user action is required.

4.4.8 Specific Problem Areas

Graphs

<u>Data grouping</u>

70% of subjects in the first two rounds expressed concern that the 1-year and "all" views on the graphs displayed large amounts of longitudinal data on a very small screen. This was especially evident for bar charts in which the width of individual bars became very narrow. As such, we applied a data-grouping algorithm that reduced the number of individual data points. Despite these efforts, 2 caregiver subjects still expressed concern that viewing so much data on a single graph was overwhelming.

<u>Legend</u>

A suggestion by three different subjects prompted us to change the legends for the line graphs. They commented that using the same line thickness in the legend as in the actual graph made it difficult to discern between the different colors. To remedy this we used boxes instead of lines, greatly increasing the visibility of each color (figure 4.3).

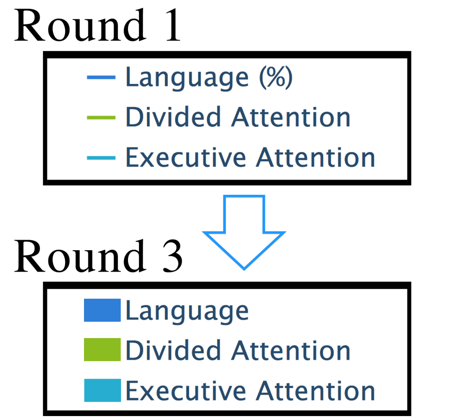
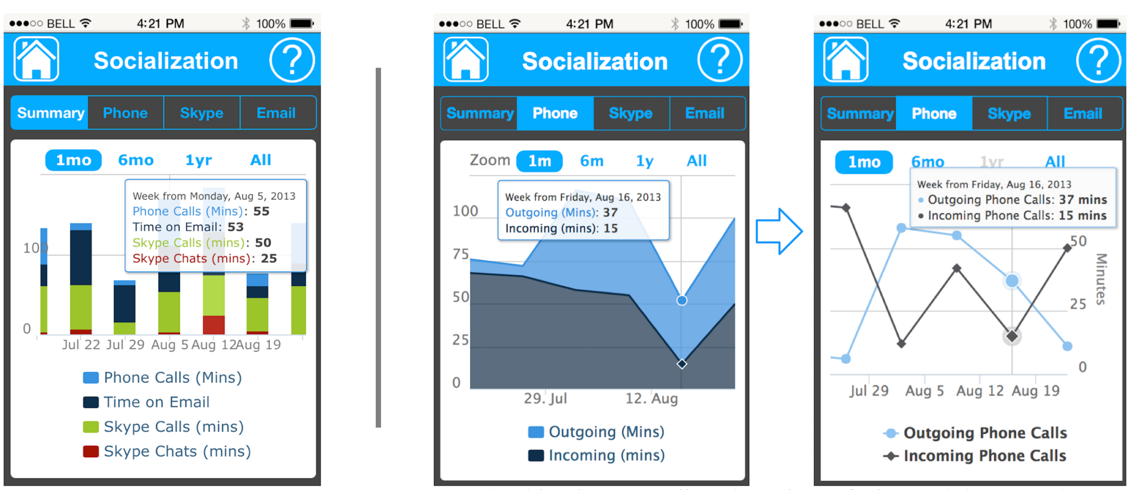


Figure 4.3: Before and after view of the graph legends within the prototype

<u>Stacking Column Versus Area</u>

Many subjects in rounds 1 and 2 were confused by our use of "stacking" area charts in which multiple series are stacked one on top of another. This approach allows viewers to look at the top line on the graph to see the sum of each of the individual series combined. During testing however, many subjects misunderstood that the series were stacked, instead thinking that each series started at the x-axis. Interestingly, a similar trend was not observed for bar charts that used a similar stacking technique, with all users interpreting them correctly. Confusing graphs were simplified by changing them to non-stacking line graphs (figure 4.4).



Stacking in column charts is easily understood

Stacking in area or line charts is confusing and these graphs were changed to non-stacking line charts.

Figure 4.4: The improper use of stacking in graphs can lead to confusion

Medications

The medications section of the app underwent the most significant design changes (figure 4.5). Based upon the confusion expressed by 1st and 2nd round subjects, we decided to completely redesign this section of the application for round 3. In round 1, users were shown two images depicting the pillbox at two different time points ("Yesterday" and "Today"). Users found the task of comparing the two images to determine medication adherence highly confusing. The addition of a yellow box in round 2 did little to help with most subjects still misunderstanding the task. Consequently, this section was redesigned to split images for each day into separate screens. While this appeared to reduce cognitive load, poor labeling caused caregivers in round 3 to assume that the two images shown to them represented 2 different pill box compartments rather than the same compartment at different times of the day. Subjects helped to remedy these labels and explained that having an image from early in the morning and then a live view of the same compartment would be most beneficial. Caregivers also requested that we consider medication regimens that require multiple doses per day. While we feel that we have now achieved a fairly usable design for medications, additional rounds of usability testing are required to confirm this.

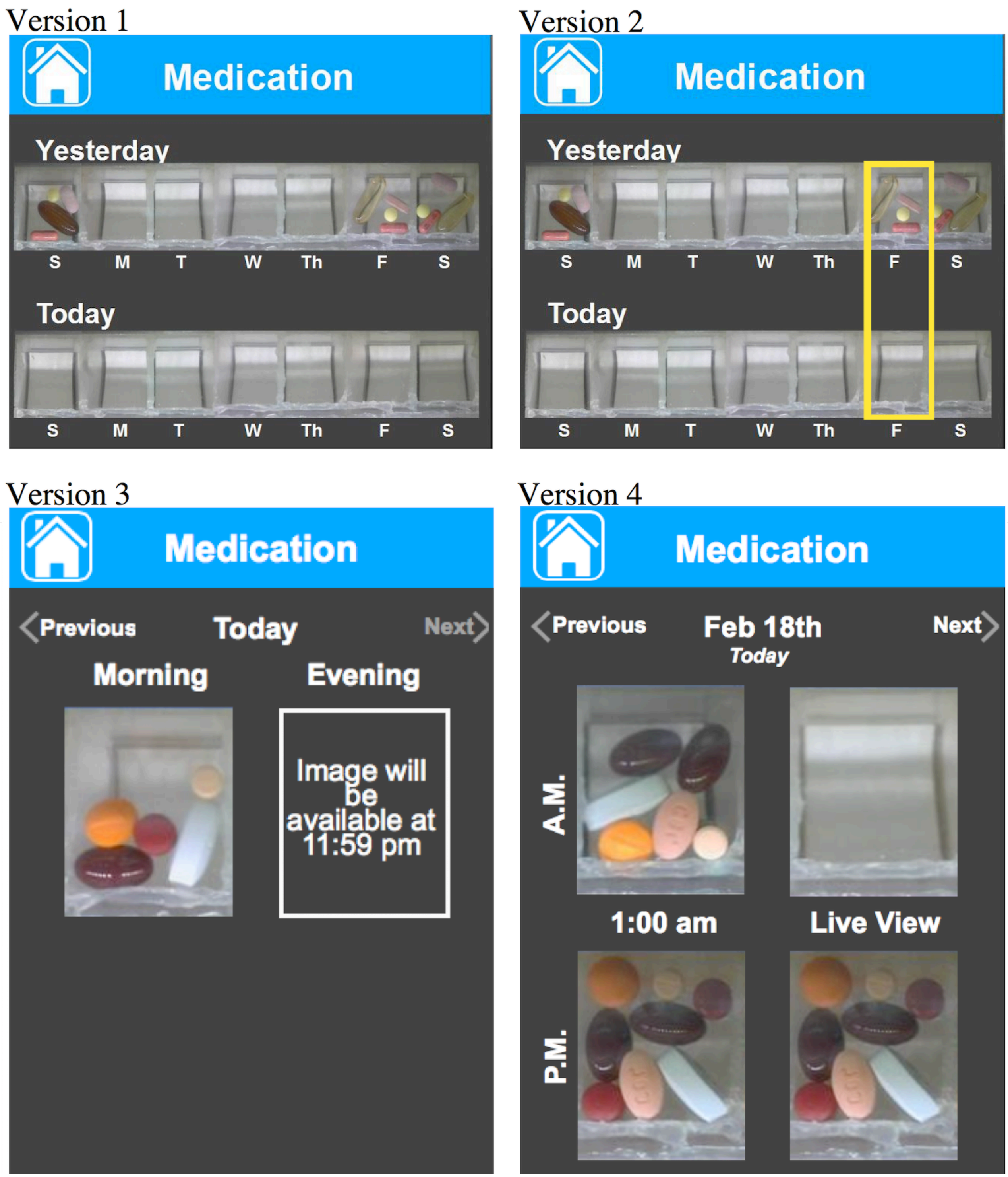


Figure 4.5: The evolution of the medications section of the application based on user error and feedback

4.5 Discussion

4.5.1 Lessons Learned

Our operational approach to usability testing provided some insightful lessons that are likely to apply to other usability researchers.

Prototype fidelity

We struggled to find the correct balance between building a prototype that felt authentic and the need to operate at a rapid pace and on a small budget. In general, users were forgiving when they uncovered non-functional areas or small inconsistencies in the prototype (e.g. the alert badges didn't disappear properly after a category had been tapped). Also, while users were impressed with the richness of the prototype, its slower responsiveness compared to a native application was sometimes a source of frustration for both users and the research team. Despite these shortcomings however, we strongly encourage researchers to use prototyping software such as Axure or JustInMind as they allow for much quicker design, development and modification without the need to hire a developer.

How Many Rounds of Testing are Necessary

After completing three rounds of testing, the majority of usability problems identified were either addressed or significantly minimized. As a general rule, we agree with Nielsen and others that 3 rounds of testing are sufficient. There were however, a few exceptions to this rule. For example, three rounds were not sufficient to test the medication aspects of the app. This was mostly due to the major redesign that took place between rounds 2 and 3. Also, though 3 rounds of testing were sufficient to help us identify important features to highlight in our tutorial, we were unable to test if our tutorial was effective in educating novice users. As such, we recommend a modified approach in which any significant changes to an application are specifically evaluated in 2 additional rounds of testing.

Managing Conflicting Opinions

We encountered a few instances in which users made comments/suggestions that were in direct contradiction with one another. We tried to look for a broader consensus amongst all of our subjects regarding each issue and asked detailed questions in future rounds of testing. Most importantly, we focused on ways that we could optimize successful task completion rather than cater to the preferences of individual subjects.

Animations Convey Information About Interaction Styles

Our use of animation allowed us to provide visual feedback to a user when a tap/gesture was detected. We identified issues however, when the use of an animation was inconsistent with the interaction style that we had designed for a given element. For example, the news feed scrolled at regular intervals from left to right. This allowed the user to see each of the items in the feed without any action on their part. Unfortunately, this animation also incorrectly conveyed to the user that he/she could scroll through news feed items by the use of a swipe gesture. On a broader scale, we remind designers and researchers to ensure that animations are congruent with an element's intended interaction style.

Problem Severity and Frequency

While we did record the frequency with which a usability problem arose during testing, we were careful to remember that the most frequent problems were not necessarily the most severe. This is based on work by Lewis that showed no correlation between problem severity and rate of discovery [158]. With this in mind, we felt it was important to carefully review each problem and identify an appropriate solution.

Small Screen Challenges

We repeatedly struggled with the compromise between maximizing the amount of screen real estate devoted to content while still maintaining an intuitive user interface. In some cases we were able to effectively combine content and UI controls into a single element (e.g. the legend in a graph is informational content but also acts as a toggle for turning each data series on/off). This resulted in a cleaner solution, but as discussed above is more difficult to discover. We also used "hot zones" in which a small UI element is used to preserve room for content but the interactive area around the UI element expands out somewhat over the content area. This allows for visually small UI elements that are still easy to target reliably using a finger.

4.5.2 Limitations

Our approach has many limitations that are important to acknowledge.

1) Heterogeneity Between Groups & Sampling Methodology

Our use of a convenience sample and involvement of usability students/experts limits how representative these results are of the wider caregiver population. Overall, this didn't appear to be a significant problem with most of the issues uncovered by caregivers in round 3 relating to design changes we had made rather than finding new problems that the previous 2 rounds had failed to uncover.

2) Manual Data Capture

The difficulties of simultaneously recording data and observing subjects as they interacted with the prototype were sometimes challenging. This may have been mitigated somewhat by capturing audio and/or video feeds during usability testing sessions. Our concern with this approach however, is the tendency to then use video and audio data to conduct a costly and timely analysis, which is not consistent with our operational approach. A more robust method may be to collect data manually, but then use audio/video data as a secondary source that researchers could use for the sole purpose of validating manually collected data. Such an approach would increase scientific rigor without significantly increasing time and cost requirements.

3) Evaluator Effect

Previous work has shown the large amount of variability in study findings based upon the skills of the research team[159]. While every effort was made to capture all relevant data and treat every interaction with subjects in a similar fashion, the effectiveness of our chosen methodology was highly dependent upon our data collection skills. This effect may be reduced through adequate training and by conducting mock data collection sessions before data collection officially begins.

4) Graph Comprehension

Though we identified important design recommendations and usability issues as caregivers graphically viewed health activity data, our methodology was insufficient to measure the utility that this may have provided to them. Additional work is needed to quantitatively assess the extent to which the graphical representations are easy to understand/interpret and the degree to which these data representations are useful to them in their caregiving responsibilities.

We anticipate that this methodology may be useful for other research teams that seek to rapidly test and improve the usability of medical informatics applications. Our approach is especially useful for situations in which usability is a concern, yet budgetary or time constraints do not allow for a full-scale investigation. In our case, this important step in the design process of our caregiver app has taught us important lessons and allowed us to rectify many unforeseen yet significant design flaws. The most concerning of these is that in its original form, the app was causing users to incorrectly interpret when and if loved ones had taken their medications. Now that this and other issues have been detected, we anticipate that future caregivers will be able to use it as an effective tool in the care for their loved ones.

4.6 Conclusion

An operational approach to user based usability testing was effective in identifying 34 usability issues for our out-of-home caregiver smartphone application. In particular, we identified the significance of reducing cognitive load when comparing medication imagery, the importance of effective labels/wording and the care that must be taken when displaying graphical representations of health information. Though there are some significant challenges, researchers and developers of consumer health applications should consider a similar approach in which useful, actionable usability information can be obtained in a relatively quick and inexpensive fashion.

Chapter 5 - Insight Analysis: A Method for Evaluating Visualizations of Health Activity Data with Family Caregivers of Older Adults

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5.1 Abstract

Objective: To measure the quantity, quality and timeliness of insights elicited by graphs within a smartphone application for caregivers of older adults.

Materials and Methods: 15 caregivers were recruited to participate in an insight analysis protocol. Subjects viewed 10 health activity graphs while "thinking aloud". Card sort activities, debriefing interviews and instruments measuring graph literacy, perceived ease of use and usefulness provided additional understanding. Insights were transcribed from recordings, and then graded according to correctness and value. Timestamps were used to calculate the number of insights gained per minute.

Results: We found significant differences in the number and value of insights elicited based upon chart complexity. We also found a significantly higher number of errors associated with complex charts. Insight rates ranged from approximately 3 to 5 insights/min depending upon chart complexity. Perceived ease of use and usefulness scores were also high.

Discussion: Key lessons include: (1) the importance of helping users zoom to the correct time span in order to identify different types of problems, (2) the importance of conducting user testing whenever nontraditional graphs are used.

Conclusion: An insight-based methodology is a valuable way to understand the utility of graphs with subjects who are not scientifically trained.

5.2 Introduction

The recent explosion of patient generated health and wellness data[160] presents both exciting opportunities and serious challenges for the future. On the one hand, ubiquitous sensors in smart phones, smart watches/wearables, medical devices and smart homes provide rich data streams that allow us to monitor and understand the health trends of individuals and whole populations with unprecedented clarity. On the other hand however, these longitudinal and often multifaceted data streams introduce increased complexity and necessitate further investigation into the ways in which they impact medical practitioners, patients, and health systems.

While concerns about the implications of "big data" on the future of medical practice by clinicians demand additional exploration, we must also be concerned with the consequences of providing these data streams to both patients and their family members. Providing this data to individuals that are not scientifically trained brings its own set of challenges that warrant further investigation.

One common way of sharing these data are through the use of various data representations (e.g. charts, graphs and data visualizations) that display large amounts of data in order to communicate patterns, trends and behaviors of interest.

Perhaps alarmingly however, a large part of the US population is graphically illiterate (41% by some estimates[161]) and may not gain much utility from graphical representations of data. Additional concerns include the misinterpretation of data[162] (both under-interpretation and over-interpretation), confusion, increased anxiety[163], and increased cognitive burden[164].

A large number of high-profile publications [165–170] have documented essential design considerations and techniques for the optimal visual communication of information.

Most of these works, however, refer to static, printed visuals rather than interactive visuals displayed on computers or mobile devices. There is also concern that some of these works are not empirically based[169]. A significant amount of research has focused specifically on the communication of health related data by using graphical representations to assist in treatment decisions or to convey information (e.g. risk) [171–175]. Other noteworthy approaches have aimed to address the challenges of displaying complex data by using machine learning techniques that provide guidance to users in their graph interpretation efforts (e.g. alerts when predefined thresholds are crossed[75] and machine-generated narratives designed to describe the data verbally[176]).

While these efforts are valuable, limited research has been conducted to investigate the extent to which patients and their family caregivers are able to understand graphical representations of health activity data. And the implementation of a machine learning approach is often costly, time consuming, and introduces additional liability when interpretation algorithms err. As such, there is also great value in identifying design considerations that allow for effective graphical communication of data to non-scientists. This study describes our approach to evaluating visual representations of health activity data and identifies design recommendations based on user-feedback, observation and the analysis of insight.

5.3 Background

Our previous work employed user-centered design methodologies to develop a smartphone app for informal caregivers of older adults[143,177]. Within the app, streams of health activity data are used to display data representations depicting various events and activities of daily living such as sleep habits, medication adherence, socialization, physical exercise, and cognitive computer game performance. The app is designed based upon feedback from a needs assessment to identify functional requirements and a usability study to ensure ease of use. Our motivation for this work is based upon findings from our usability tests that indicated that usability testing alone did not provide sufficient depth to adequately evaluate graph interpretation/utility and inform future design recommendations.

Instead, we needed tools/methodologies that would allow us to evaluate and compare various data representations. Most approaches involve designing benchmark tasks in which a graph and corresponding question are used to measure comprehension[178]. Such a focused approach provides quantitative results regarding a very specific task and is highly dependent upon scenario design. Also, asking users a specific question about a data representation focuses their attention on finding a specific answer, and is not representative of how a user would explore data in "the wild". Also, a benchmark-based approach would not allow us to measure the value/utility that each representation provides to users.

A newer, less common approach to evaluating data representations focuses on identifying and evaluating insights gained by users as they openly explore data. This methodology, originally described by Saraiya et al[179], uses data collection sessions in which scientifically-trained users are asked to "think-aloud" as they explore data and find meaningful insights. This open-ended approach to data collection allows for a more authentic interaction between study subjects and the data representation in which subjects are not focused on answering a pre-defined question, instead formulating their own questions, hypotheses and conclusions. After data collection, each insight is transcribed and graded according to accuracy, value and timeliness, which provides researchers with valuable information regarding ease of interpretation and utility. Given that our study focused on the use of data representations in a smartphone app, an insight-based approach was an ideal choice as it allowed us to understand the number and value of insights gained by users over time. For mobile users accustomed to just-in-time, simple and rapid interactions with technology, the ability to convey complex information rapidly was especially important.

Here, we present our experience with adapting Saraiya's original methodology so that it could be used with informal caregivers and discuss the lessons learned about the visual display of activity data in order to elicit more valuable and timely insights.

5.4 Methods

5.4.1 Scenario development

We followed a user centered design process (e.g. an assessment of user needs, iterative usability testing) to develop 10 representations of health activity data. To generate authentic insights from study participants, we used either completely untouched data, or when necessary to create “talking points” for a particular graph, multiple pieces of real data that were spliced together. Chart type and feature selection was based on specific chart types that we wanted to further explore and user feedback from previous studies.

Figure 5.1: Different levels of complexity for the graphs in our study

Charts were classified according to complexity as either simple (1-2 graphical features), moderate (3-4 graphical features), or complex (5+ graphical features) (see Figure 5.1).

5.4.2 Recruitment

We used a snowball sampling method to recruit 15 out-of-home family caregivers of older adults aged 65 or older. Because 2 out of 3 caregivers are women we purposely sampled more women than men and tried to recruit individuals from a diverse set of educational backgrounds. As with previous work by ourselves and others, our inclusion criteria required that our subjects:

5) Have an older adult family member or friend (age 65+) with a chronic health condition.
6) Live apart from the care recipient for more than half of the year.
7) Report a high willingness to help the care recipient with his/her health.
8) Communicate at least once/week with care recipient.

5.4.3 Data Collection

Data were collected using a mixed methods approach during individual sessions with each participant that typically lasted 60 to 90 min. Subjects were asked to provide basic demographic information and then complete the graphical literacy assessment (a 13 item validated instrument designed to measure literacy of health related graphs).

Each subject received two trainings, each about 5 min. in length. The first focused on how to use the interactive features of each graph (how to zoom in/out/turn data series on/off, etc.), while the second training taught them how to think aloud and describe the insights received from each graph. After indicating that they understood the task, each subject was then shown the series of 10 data representations discussed previously. During this time, subjects were free to explore and describe each chart as they saw fit. Once subjects indicated that they had described all of the insights received from a particular graph, they were instructed to proceed to the next.

Insight identification was followed by a debriefing interview in which subjects were asked questions regarding their comments from the previous step (e.g. if a subject had misinterpreted a particular graph, they were then asked what had led them to arrive at their incorrect conclusion). Subjects were then provided with laminated printouts showing each of the 10 charts from the insight gathering stage and asked to arrange them in order of usefulness. Finally, subjects were asked to complete validated surveys regarding perceived ease of use and perceived usefulness.

5.4.4 Insight Classification Rubric

We developed an insight classification rubric based upon the three tiers of graph literacy described by Gaelic and Garcia-Retamero[161], recommendations from Saraiya et al[179] and the specific goals of our study.

Read the data - Value Score = 1

The most basic type of insight described by Gaelic describes the ability to accurately read a specific value from a chart. Due to the fact that users were able to tap on any data point within the chart in order to display its value, we required participants to also show at least a rudimentary understanding of the implications of a specific value (e.g. simply tapping a data point and reading "Jack walked for 5 min. today" would not be counted as an insight, whereas a subject commenting that "Jack *only* walked 5 min. today" would be counted).

Read between the data - Value Score = 2

Insights were classified as "reading between the data" when subjects correctly identified patterns and trends within the data but did not state any implications of what the trend means to them.

Read beyond data – Value Score = 3

In order for an insight to be classified as "reading beyond the data", subjects were required to show that they not only understood a pattern/trend but also its meaning or implications.

Read beyond the graph - Value Score = 4

We added a new classification when users were able to correctly relate information from previous graphs into the findings of the graphs they were currently looking at (e.g. "Jack was having a hard time with his games during the month of June, which makes sense because that is when he was having trouble sleeping in the other graph").

Generate Hypotheses from the Data - Value Score = 5

Based upon suggestions from Saraiya, special emphasis was given to insights that led users to generate hypotheses or ask specific questions based on the data presented to them. Hypothesis generating insights were scored highly because they indicate questions that arise from looking at the data and encourage caregivers to further investigate potential problem areas.

Act on the Data - Value Score = 6

Because the ultimate goal of our caregiver app is to allow caregivers to know when and how to intervene when problems arise, comments that used the data to correctly generate “plans of action” on the part of the caregiver were assigned the highest insight score.

5.4.5 Data Analysis

Audio recordings from each session were first transcribed, after which each insight was separated into individual data points. Recordings were also used to attach timestamps to each insight.

Insights were classified as either correct or incorrect, with all correct insights then being rated for value based upon the insight classification rubric described previously. Once coded, insight scores were then compared with other data such as card sort rank, graph literacy, perceived ease of use and usefulness etc. We were also able to use timestamps to indicate the "insight curve" for each data representation.

5.5 Results

A total of 15 family caregivers were recruited to participate in our study. See Table 5.1 for overall demographic information and Table 5.2 for our key findings.

5.5.1 Demographics

Subject Demographics	(N=15)
Sex	
Male	6 (40%)
Female	9 (60%)
Education Level	
High school	2 (13%)
Some college	8 (53%)
Bachelors	2 (13%)
Masters	3 (20%)
Age	
35 – 49	3 (20%)
50 – 64	10 (67%)
65+	2 (13%)
Smartphone User	
Yes	12 (80%)
No	3 (20%)

Table 5.1: Subject Demographics

5.5.2 Education and Graph Literacy

Study participants were more graphically literate than the national average for the United States. Our subjects answered an average of 10.7 (95%CI 9.3 – 12.0) questions correctly out of 13, while the national average is 9.3 out of 13. This may be due in part to the higher educational attainment of our sample, with a much larger percentage of our participants attending at least some college (86.6%) compared to the general US population (58.6%)[180]. Our findings, however, align more closely with estimates of educational attainment amongst caregivers specifically[181].

5.5.3 Perceived Ease of Use and Usefulness

The graphs used in our study scored highly in both perceived ease of use and perceived usefulness. With both measures being coded using a 7 point scale (7 = extremely likely and 1 = extremely unlikely), the graphs received an average score of 5.8 (95% CI 5.5 –

6.2) for perceived ease of use and 6.0 (95% CI 5.4 – 6.5) for perceived usefulness. These results compare very favorably to other caregiving interventions that have used the same instrument[182,183] and indicate high levels for both ease of use and usefulness.

We also discovered significant correlations between perceived usefulness and insight score (p-value=0.01) and value (p-value=0.02), suggesting that charts that elicited more/better quality insights were perceived as more useful. Similar correlations were not found between insight score/value and perceived ease of use.

Measures (average counts unless otherwise stated)	**Graph Complexity** Simple	Moderate	Complex
Duration (seconds)	85.4	86.6	93.2
Number of Insights	4.6 *	6.4	6.6
Insight Value (cumulative)	13.6	17.5	19.5 S
Number of Insights/min	3.6	4.8 S	4.4
Number of Errors	0.24 Δ	0.11	0.55 *
Number of Uncorrected Errors	0.17	0.067	0.39
Number of Hypotheses	0.76	0.71	0.75
Number of Calls to Action	0.16	0.22 Δ	0.48 *
Average Cord Sort Rank	5.1	5.3	6.4

Table 5.2: Key Findings

* *result is significantly different than both of the other categories (p-value < 0.01 unless noted)*

S *result is significantly different than the "simple" category (p-value < 0.01 unless noted)*

Δ *p-value < 0.05*

5.5.4 Time

There was no significant difference in the amount of time that subjects spent viewing each chart based upon chart complexity. Overall subjects viewed each chart for an average of 83 seconds, with viewing trends showing a large amount of variation, ranging from as little as 9 seconds to as much as 263 seconds.

5.5.5 Insight

Number and Value of Insights

Overall, users stated an average of 5.75 insights per chart, with significantly fewer insights being gleaned from simple charts than from moderate and complex charts. We also found a significant difference in insight value scores when comparing simple versus complex charts.

Insight by Education Level

We found that individuals that had attended at least some college were able to identify significantly more and higher quality insights than those with only a high school education. However, continuing on to earn college degrees (i.e. Bachelors/Masters) did not show significant differences versus those with only some college.

Insight Rate

We calculated the number of insights per minute and found that overall, subjects identified an average of 4.2 insights/min with simple graphs eliciting significantly fewer insights per minute than moderately complex graphs. We were surprised to find that our most complex graphs actually elicited few insights per minute than our moderate graphs (see Figure 5.2). This however, may be due to the larger amount of time to initially understand a complex graph that a user has not seen before. Additional testing is needed to determine if this trend would continue as users became more familiar with each of the charts. It is also important to note that insight rate is not constant but varies over time as users interact with the chart. Our graphs of insight rate clearly showed three main stages that seem to align with the visual information seeking mantra[168]:

1) Overview first - A short initial period (~ 10 sec.) of very few insights as users view the chart and process the overall measure that the graph is communicating.

2) Zoom and filter - A longer steep period of insight (~90 sec) during which the majority of insights will be identified at a fairly steady rate

3) Details on demand - A final slow-down phase in which fewer new insights are discovered as users view the details of a few items of interest.

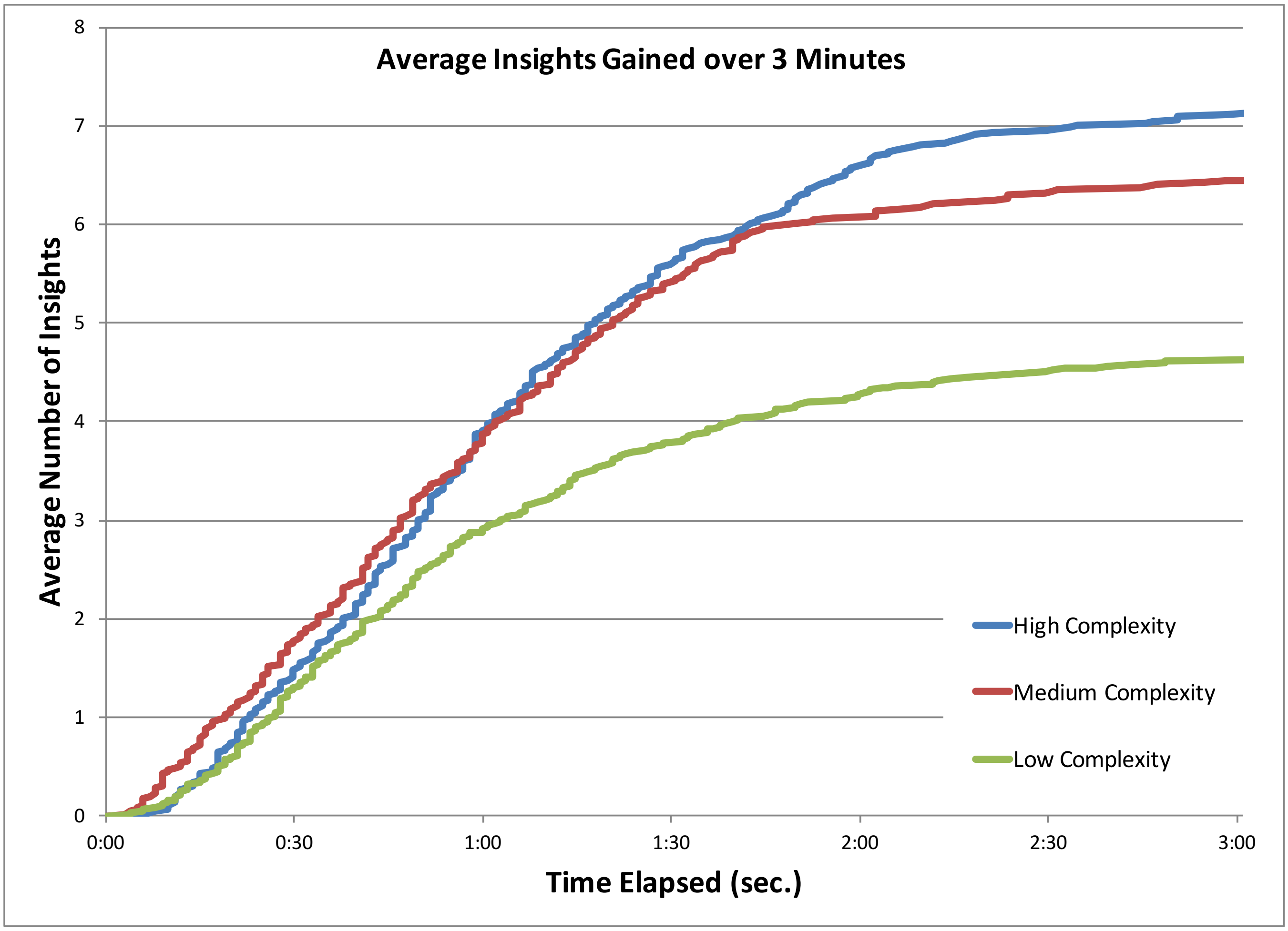

Figure 5.2: Insight rate by graph complexity

5.5.6 Errors

Users made relatively few errors with 95.2% of all statements about the charts being classified as correct. Stated another way, subjects made an average of only 0.29 errors per chart. With users later correcting themselves about one third of the time. Of note is the much higher rate of errors caused by complex charts compared to moderate or simple charts.

5.5.7 Hypotheses and Calls to Action

The number of hypotheses generated by each graph was similar across all complexity levels (mean = 0.74) whereas the most complex graphs led to significantly more calls to action than simple and moderately complex graphs. This is an important finding as it shows that more complex graphs are more likely to prompt caregivers to intervene if a problem is detected.

5.5.8 Visualization Ranking

We used the order in which users sorted the cards during the card sort activity as a way to determine rank order, from most useful to least useful. In general, complex graphs were rated more favorably (but not significantly) than simple or moderately complex graphs. Using Spearman's correlation coefficient, we detected significant correlations between a card sort ranking for each graph and the number (p-value= 0.010) and value of insights (p-value=0.012) elicited. We also noted a strongly unfavorable ranking for one chart in particular (Gantt style chart showing falls, hospitalizations and doctor visits). This correlated with our insight rate graphs, with this same chart showed the lowest insight curve of all.

In talking to users during debriefing interviews, we found that though there is a significant correlation, users don't necessarily like a chart simply because it is insightful.

Subjects noted other considerations such as color, the type and relevance of information displayed, and chart complexity.

5.6 Discussion

5.6.1 Lessons Learned

We learned some very important lessons about the design and display of health activity data that likely extends beyond our target user group.

Dashboard Incongruence

Our final scenario involved a dashboard view (see Figure 5.3) that listed the older adult's goal completion for the previous week and showed a line graph of goal completion underneath. In general, users found this graph to be very insightful due to the combination of a list and a line graph. It is interesting to note however, that only 1 of our 15 users detected that there was incongruence between the high goal completion shown by the list of goals and the very low goal completion shown on the graph. Given our users unlikeliness to detect

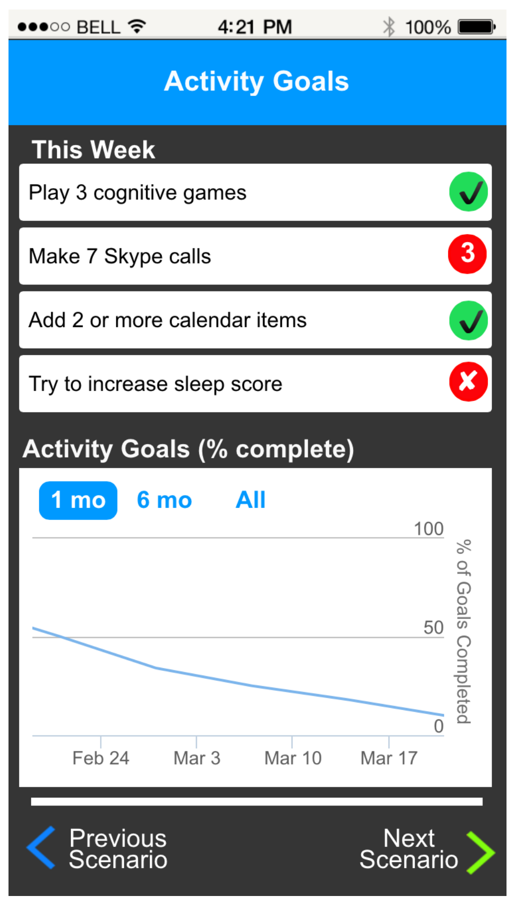

Figure 5.3: Incongruence between the list above and the line graph below

incongruence, we recommend that system designers use data testing algorithms to ensure that all parts of a dashboard view correspond with one another.

The importance of zoom

When designing the charts used in our study, we chose to always show the one-week view by default. We elected to do so as we assumed that the most recent data would be most pertinent to caregivers. When we graphed insights over time for each individual chart, we noticed that charts that displayed problems in the 1-week view generally had the steepest insight rates. There were also multiple instances, however, in which caregivers missed problems because they were required to zoom out to view an overall pattern or trend. We suggest that, in the future, artificial intelligence algorithms could intelligently choose which zoom level to initially display based upon the nature of any potential problems detected (i.e. 1 week view for short term irregularities and 1 month/6 month view for medium/long term trends). We found that, so long as users tapped on an appropriate zoom level, they were generally good at detecting and understanding problems.

Label everything

We assumed that certain elements (e.g. a dotted red line to signify a goal or a slash followed by a number to signify a fraction) would be intuitively understood by users. While this assumption was generally correct, multiple users stumbled when trying to understand graphs that contained unlabeled elements. While it may be tempting to save precious real estate on a relatively small smart phone screen, we reiterate the importance of using labels to provide clarification and direction. When possible, applying labels directly to an element rather than in a legend reduces cognitive load.

Complexity level

Overall, our findings showed that as graph complexity increased, the total number and value of insights also increased. When we looked more closely however, we noticed that the medium and high complexity graphs both elicited similar numbers of insights during the first ~100 seconds that a graph was viewed by a user, with the medium complexity graphs actually eliciting more insights than the high complexity graphs in the first 60 seconds. In addition, given that the mean number of errors was significantly lower for medium complexity than high complexity graphs, we recommend the use of medium complexity graphs, especially if users are not expected to spend extended periods of time examining the graph.

Traditional versus Nontraditional Charts

We decided to include both traditional charts (e.g. bar charts, line graphs, scatterplots etc.) and nontraditional charts (e.g. dashboard views, Gantt style charts). Nontraditional charts elicited more and higher value insights compared to traditional charts, though these increases were not significant. Interestingly, comments from subjects and cards sort data showed a trend in which subjects either loved or hated the nontraditional charts (see Figure 5.4), with very few subjects ranking them in the middle of the group. Such varied reactions to nontraditional charts underline the importance of conducting user testing, especially when users are presented with something to which they are not accustomed.

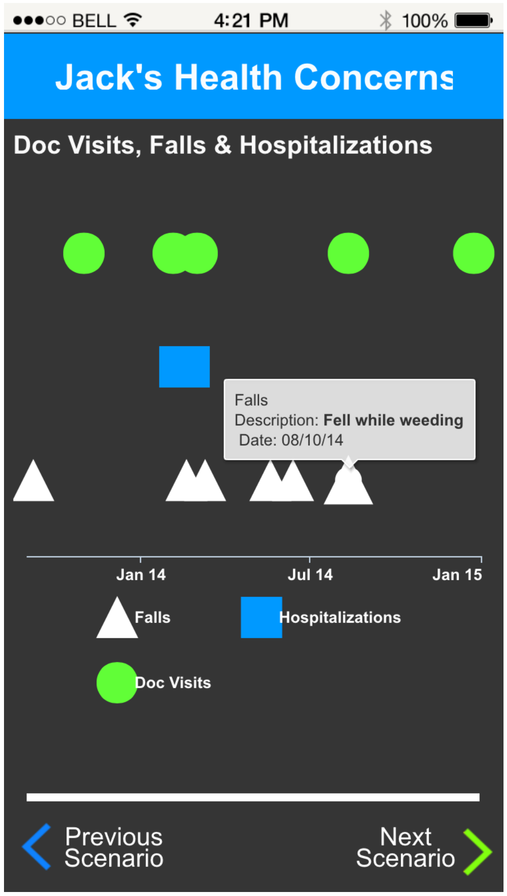

Figure 5.4: Polar reactions to non-traditional charts.

Focused Message

Our work also emphasizes the importance of having a clear, focused message that can be displayed to users quickly. While we acknowledge that there is a time delay associated with the think aloud process used in our study, our results show that it is only possible to communicate 2 to 3 main ideas in the first 30 seconds that a user is viewing a graph. As such it is important to ensure that we are directing users to the most important/telling insights. This guidance can be achieved through intelligent design, robust testing, and adherence to established data visualization principles. It may also be possible to use artificial intelligence to guide users to important charts, without requiring computer systems to also be capable of the more difficult task of reliably interpreting the graph.

5.6.2 Limitations

It is also important to consider the limitations of this work that may affect how our findings extend to other user groups and populations.

1) Order bias

Though we did provide a tutorial to educate users about how to use the charts, we did not control for any bias associated with the order in which graphs were displayed to users. This may have impacted the number/value of insights for each graph because users may have become more familiar with how to use the graphs as testing progressed. As such, we recommend that researchers following a similar "insight based" methodology randomize the order in which charts are displayed.

2) Sample Education Level/Diversity

Our sample of caregivers was surprisingly well educated when compared with other studies that have measured caregiver education level. This is important because education level was shown to have an effect upon the number of insights gained by an individual. Our sample also suffered from lack of diversity, with limited representation of ethnic minorities. We were however pleased with the broad spectrum of ages represented in this work. Future work is needed to investigate the number and value of insights elicited by individuals with limited schooling/racially diverse backgrounds to ensure that our caregiving app is beneficial to a large spectrum of users.

3) Technique Learning Effect

Though no significant correlations were found through regression analysis, it is possible that the differences in number and value of insights may be related to users becoming more familiar with the think aloud technique rather than any actual differences in the graphs. This affect was mitigated through our use of a tutorial that helped familiarize subjects with our protocol. In a similar vein, subjects may have become increasingly anxious to finish the study and may have rushed through the later scenarios. As recommended above, future work could randomize the order in which charts were displayed to mitigate these concerns.

5.7 Conclusion

We successfully adapted previous insight-based methods in order to evaluate data visualizations with caregivers of older adults who were not necessarily scientifically trained. Subjects were generally good at identifying correct and important insights, with a relatively low error rate. We detected important trends and correlations between our outcome measures of number and quality of insights and factors such as education, graph literacy, perceived usefulness. Our findings regarding insight rates and error lead us to recommend the use of moderately complex graphs for caregiver populations. Lessons learned include the importance of delivering a clear message of 2-3 main insights, the significance of using the correct zoom level to portray short versus long term trends. We encourage designers and researchers alike to apply these findings as we continue the quest to better understand how to share complex health activity data with the general public.

Chapter 6 – Discussion and Conclusions

6.1 Lessons Learned From Our User Centered Design Process

6.1.1 Value from Each Step

Each step in our user centered design process provided important information that was then used in subsequent stages of design. We stress the importance of each step, whether literature review of user centered research by others, exploratory research such as our needs assessment or confirmatory research to validate previous findings. We remind user-centered researchers that there are lessons to be learned from every step in the process. Often this requires a great deal of thought and effort as we strive to understand the different perspectives of different users. Though challenging, taking such a mindset will lead to deeper understanding and ultimately better solutions for our users.

6.1.2 Paradigm versus Process

User centered design is often thought of as either an event or process. Approaching it from either of these mindsets however suggests that its duration is finite. Instead, we suggest that user centered design is in fact a paradigm, a way of thinking and a way of conducting ongoing research. Even though we conducted a needs assessment of caregivers, we still have much to learn regarding caregiver information needs. Similarly, additional usability testing and insight analysis are needed. As such and iterative, ongoing approach to design, development and research allows for deeper understanding and better design.

6.1.3 Measured Effectiveness

In chapter 5, we measured the perceived ease of use and perceived usefulness of our caregiver app and its accompanying graphs. High scores were recorded for both measures. This suggests that our needs assessment informed us how to design a system that was of great use to caregivers. In a similar vein, our usability testing allowed us to correct a large number of usability problems which ultimately led to an app that was easy to use. These results showcase the value of our decision to involve users at each stage of the design process.

6.2 Review of Key Findings

Throughout this dissertation, we have discussed our user-centered approach to the design of a smart phone app for out of home caregivers of older adults.

6.2.1 Key Findings from our Needs Assessment

In chapter 3, we outlined a needs assessment process that took a broad approach to understanding caregiver needs by asking them simple questions such as "what information needs do you have as a caregiver?" And "how could a technology tool help you in your caregiving responsibilities?" In addition to open-ended interview questions, we also showed subjects various screenshots from a proposed caregiver website. Using these screenshots as stimulus materials allowed caregivers to give further feedback and provide greater direction regarding their needs and the functional requirements for our caregiver tool. Key findings from our needs assessment include:

1) Medication data regarding medication regimens and medication adherence are vitally important to caregivers.

2) Health activity data such as sleep duration and quality, cognitive performance, physical exercise and socialization are also important data types that caregivers feel are important. Caregivers stressed that sharing these types of data would especially be beneficial if activity reminders and alerts could notify them of irregularities and their loved ones activity levels.
3) Calendaring was mentioned by many caregivers as an important element in a caregiving tool. The reasons described for its importance were twofold. On one hand the calendar served as a vital information source that let caregivers better understand the care recipient schedule (i.e. if the care recipient would be away from home on vacation or had a doctors appointment that the caregiver could then ask questions about). On the other hand, calendars also served as a collaboration tool which would allow multiple caregivers to work with one another and ease the burden associated with being a single caregiver.
4) Anticipated usage patterns and device preferences suggested that caregivers would generally check the app at least a few times each week and wanted the ability to use the app on the go (i.e. as a smartphone app) but also would like a desktop version available to them when they were at home.

6.2.2 Key Findings from Usability Testing

Chapter 4 described our operational approach to prototype development and usability testing. Taking the findings of our needs assessment, we initially created a high fidelity prototype smart phone app for caregivers. We then used a rapid, agile approach to usability testing by following Nielsen's recommendation that we conduct three rounds of usability testing with five users per round. Then, at the end of each round of testing, any usability problems identified were either classified as either, "wait and see" if additional testing was necessary to fully understand the problem or as "fix" in which a solution was proposed and implemented to address the problem. We were then able to test the implemented solutions and subsequent rounds of testing. Over the three rounds of testing, a total of 34 usability problems were identified, 22 of which were identified in the first round of testing. Findings were grouped according to established usability heuristics with the majority of usability problems having to do with error prevention and ensuring a match between the system and the real world. Specific problem areas included:

1) The use of stacking area charts which users found highly confusing, as it was unclear that the values of multiple data series were stacked one on top of another. These charts were either changed to stacking bar charts, which were shown to be well understood, or simplified by changing them to non-stacking line graphs
2) The medication section of the app that initially caused some users to incorrectly conclude when and if a loved one had taken their medication. We found this was primarily due to the difficulty of showing two pictures of the same pill compartment at different times of the day. Even after a redesign, users incorrectly interpreted the images due to poor labeling.

We also discussed the importance of maintaining a proper balance between using high fidelity prototypes to create the most authentic experiences possible for users while still maintaining a rapid, operational approach to design. We also propose a slight modification to Nielsen's recommendation of always using three rounds of testing, instead suggesting that two additional rounds of usability testing are always performed after any significant changes are made to an application. As testing progressed, we also recognize that while valuable, usability testing did not adequately allow us to test a caregivers ability to properly understand and interpret the charts and graphs used in our application. Overall, significant changes were implemented that greatly improved usability of our smart phone app for caregivers.

6.2.3 Key Findings from Insight Analysis

Chapter 5 discusses our efforts to better understand the extent to which caregivers gain meaningful insight from the charts and graphs in our caregiver app. Rather than using a benchmark-based approach in which users were shown a graph and then asked specific questions about the graph, we used a less common in site-based approach. Our methodology required users to freely explore the data while following a "think aloud" protocol in which they described the information that was being conveyed to them by the chart. At the conclusion of testing, subjects were asked to rank each graph by level of usefulness participating in a card sort activity. Each insight identified was then judged for correctness and rated according to a grading rubric designed to measure insight value. We found significant differences in both the number and value of insights elicited between simple, moderate and complex charts. We also found a significantly higher number of errors associated with complex charts. As such we recommend that graphs with moderate complexity be used as they offer a good balance between high numbers of insights and low numbers of errors. We also found significant correlations between education level or graph literacy scores and the number and value of insights identified by users. Key lessons learned include:

1) The importance of helping users zoom to the correct time span in order to identify different types of problems. We suggest the use of artificial intelligence to automatically zoom to the correct view based upon the type of problem (1 week view for short-term problems and a 6 month view for longer-term problems).
2) Paying special attention to what a graph communicates in the first 30 seconds. In general, only 2-3 main ideas will be communicated during this time. As such it is vitally important to follow the design recommendations and employ user testing to ensure that the desired messages are communicated.
3) The importance of conducting user testing whenever unfamiliar or nontraditional graphs are used. We saw a few instances in which users were fairly concerned over our use of a nontraditional chart, whereas other users told us that the same charts were some of their favorites. As such it is important to understand the concerns of users and to take steps to mitigate any problems.

6.3 Scientific Contribution

This work contributes to scientific knowledge in many unique and important ways. Our work in chapter 3 is novel in its use of stimulus materials over Skype to better understand the information needs of caregivers. Many of the information needs found, support the findings of other studies that have also investigated caregiver needs. Anticipated usage patterns and behaviors provided critical insight into how we should design caregiving systems to be used in both mobile and desktop environments.

To conduct usability testing of our caregiver app, we adapted existing usability methodologies to develop our operational usability approach. This modified approach provides future researchers with guidance regarding how to best conduct valuable usability tests when faced with either budgetary or schedule constraints. Conducting operational usability testing with our caregiving app led to important findings about the display of health activity data and appropriate interaction styles for caregivers.

To the best of our knowledge, our insight analysis study was the first time that an insight-based analysis of data visualizations was conducted with nonscientists. We showed the value of taking an insight-based approach and discovered multiple correlations of interest. Temporal analysis of the insights gained from each chart provided better understanding of the rates at which different types of chart are able to convey quantitative information.

6.3.1 Gaps in Knowledge

1) How can we facilitate effective communication between distance caregivers and care recipients?[67]
2) What are the information needs of distance caregivers? [122]
3) "What interaction modalities do caregivers prefer for their interaction with smart home systems?"[121]
4) How do we design visualization tools that "allow the caregiver to easily view the daily activities and health information of the older adult"?[94]
5) How do we design caregiver tools that will "not take them days to learn and will give them great benefit"?[123]

6) What do users infer from health activity data representations, especially when viewing long-term longitudinal data?[108]

The questions above are repetitions of the six gaps in knowledge identified in the background section of this dissertation. We are confident that our work described here is a significant first step in providing answers to each of these important questions. We are confident that the contribution of these new methodologies, lessons learned, and design implications will assist future researchers aiming to provide tools to informal caregivers and ultimately provide better care to older adults around the globe.

6.4 Future Research

Many important research questions have arisen as we have conducted this work. Especially important, is the need to use these findings and our existing interactive prototype to build a caregiving app, which could be field-tested with caregiver-older adult dyads. This would allow us to better understand actual usage patterns over time, discover any remaining usability issues, and may uncover new caregiver information needs. Doing so would also give us a better sense of the actual value our app could provide to caregivers. Following a field trial, a larger study investigating caregiver effectiveness and health outcomes of older adults is needed to formally evaluate the role that our app can play in the caregiving process.

Another natural extension of this work would allow us to complete a similar process in order to build tools for older adults themselves. Ideally, any caregiving platform would also include a care recipient component that would provide valuable health activity data, feedback, and privacy controls to older adults. It is important to note, however, that many of the lessons learned in this work may not transfer to the older adult population, which has many unique needs and design constraints.

We are also interested in using our operational usability and graph insight analysis methodologies in other healthcare domains. Other areas of study such as the design and evaluation of electronic health records, patient portals, and other health centered smartphone apps would likely benefit from these methodologies and design processes. We would also like to refine these new methodologies and then go on to evaluate and compare them to alternate methods of study.

6.5 Conclusion

In this work, we started with a simple question; how can we use technology to augment family caregivers of older adults? To answer this question, we worked with over 40 different research subjects to conduct needs assessments, perform usability testing and analyze graphical insights. This process has shown the tremendous value of a user-centered approach to design. Our needs assessment showcased the wide assortment of information needs of family caregivers, and emphasized that needs are highly dependent upon the health problems of the older adult. Our usability study highlighted the importance of using good design to minimize cognitive load, prevent misunderstanding and reduce errors. Our graph insight analysis identified a good compromise between graphs that elicit high rates of insight yet are still simple enough as to not cause confusion and errors. As such, we recommend the use of graphs with 3 to 4 graphical features.

We present this work to the scientific community as one piece of a large and complex puzzle. We hope that it adds value and understanding to our peers that work so hard to provide real solutions to the millions of people throughout the world that have devoted their lives to the care of those they love.

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APPENDICIES

APPENDIX A - Scenarios Used For Usability Testing Our Prototype App With Caregivers

Scenarios

You are Jack's child/grandchild and 6 months ago, Jack started participating in the Living Lab study. You have just been given a new app that allows you to see how well he is doing. Use the app to complete the following tasks.

1) In your recent discussions with Jack, he seems to have been more tired. Look to see if Jack has been getting a good night's rest. Has he been getting up at night?

2) You know that if an older adult's movement slows down, they might be developing early stage Alzheimer's disease. Check Jack's typing speed to see if anything has changed

3) Sometimes in the past Jack has forgotten to take his pills. What about today?

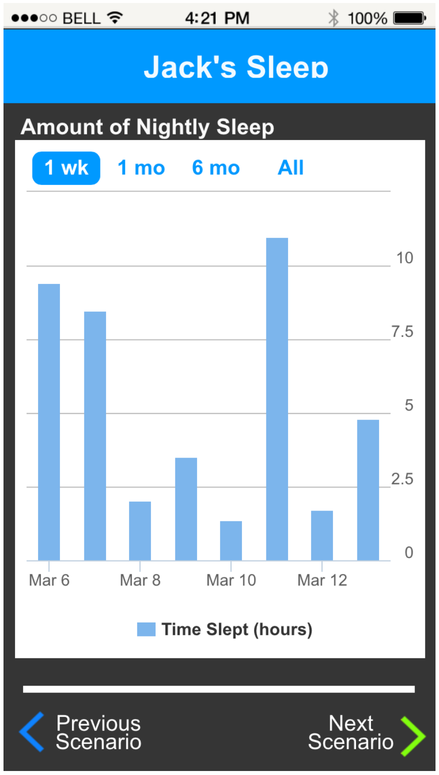
4) Look to see if Jack is meeting his goals. Is he getting better or worse at completing goals?

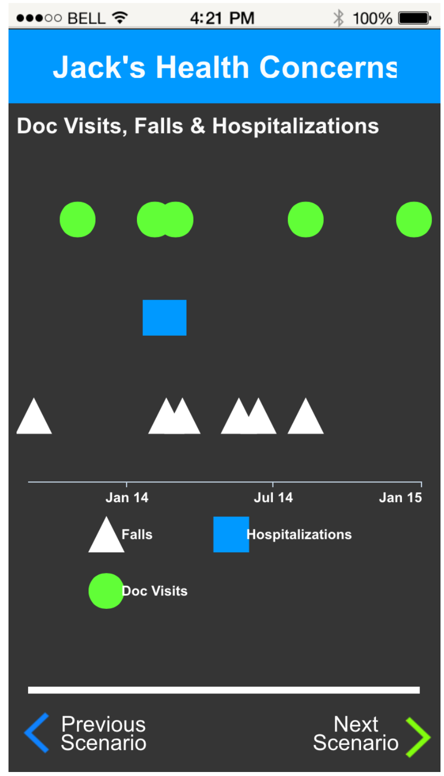
5) Feel free to explore other areas of the app. What do you like? What is confusing?

Follow-up Questions

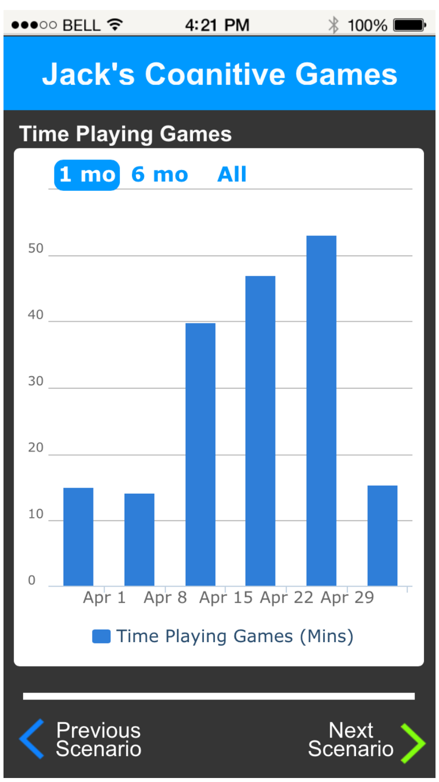
Chart tooltip? Y/N
General layout and workflow
Color scheme?
Icon?
Anything else that you would suggest?

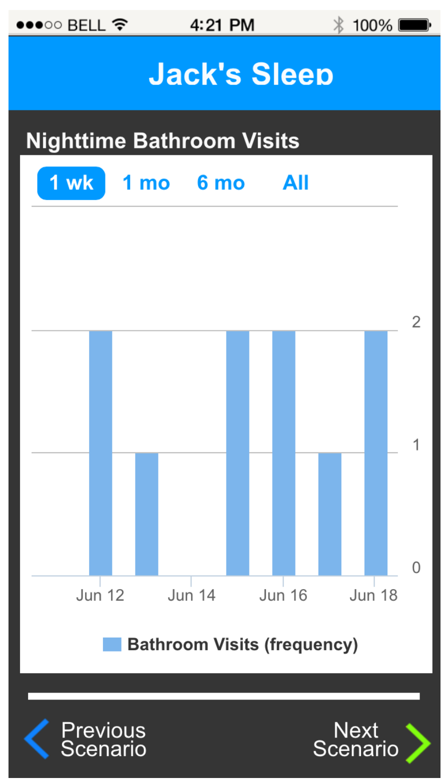
APPENXIX B – Graphs Used for Insight Analysis



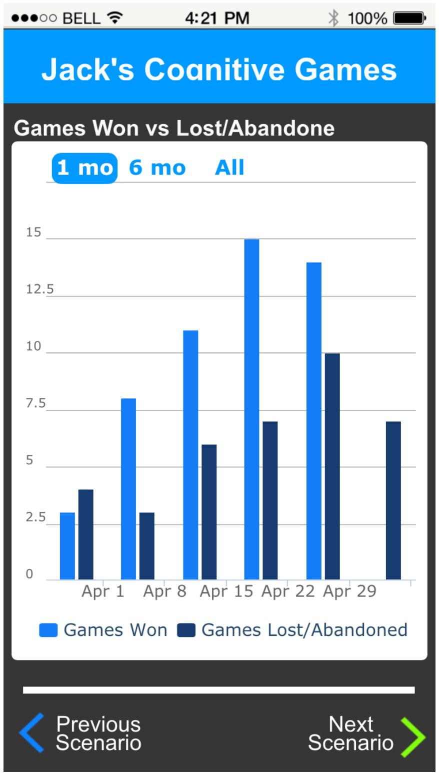


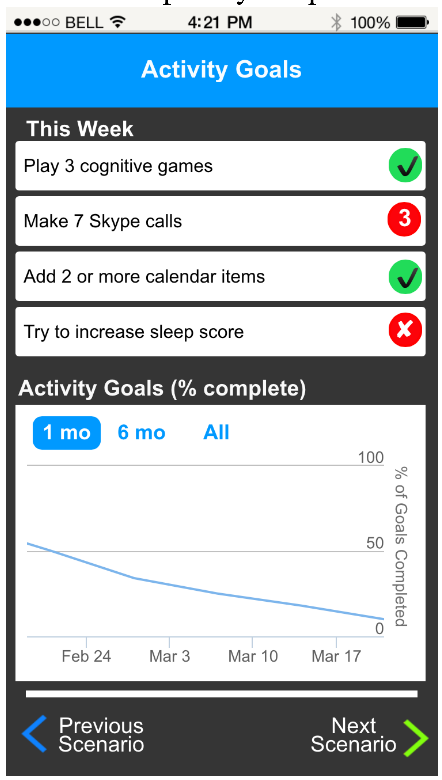
Simple Graphs

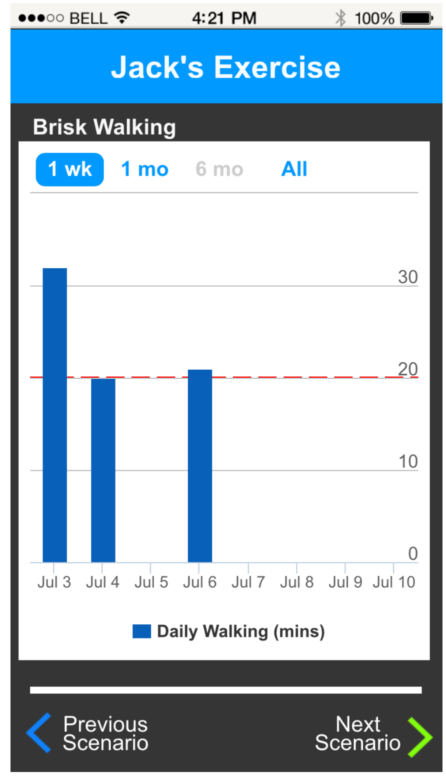




Moderate Complexity Graphs







High Complexity Graphs