Ubiquitous Computing for Cognitive Decline: Findings from Intel's Proactive Health Research

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Abstract

This paper summarizes findings from the first phase of Intel's Proactive Health research: uncovering needs brought on by cognitive impairment that can be addressed through home computing technologies. This project was motivated by the demographic shift of our aging population, the consequent health care crisis, and the particular obstacles that cognitive impairment poses to independent living. Although it is clear that the general needs of elders with cognitive impairments—for invisible, intuitive support and assessment—are well suited to innovative computing solutions, there are many unanswered questions about how these solutions can fit into everyday environments and routines. The ethnographic needs inquiry included expert interviews, focus groups, and contextualized interviews with cognitively impaired individuals and their informal care networks in 44 households in five U.S. regions. Emerging themes from this ethnographic research fall into four major categories: prevention and detection, managing everyday life, social connectedness, and identity affirmation. Technology opportunities that map onto these categories include embedded assessment, contextual prompting, social synchronization, remote wellness checking, and life span mapping. Concepts and demos that embody these solution capabilities are also described, along with directions for future research.

INTRODUCTION

"A friend of mine called the other day . . . he had a good day because he bought a car. I said I had a good day, too, because Betty made coffee on her own."
—Jim, husband of an Alzheimer patient

"This is our computer. Gerry always used a computer, but he has a difficult time using it now."
—Alice, wife of a dementia patient

When cognitive decline robs people of their abilities to use everything from a coffee maker to a computer, they are forced to adapt their everyday priorities and assumptions about how they will interact with the world. Jim's situation is typical of millions of households as elders, their families, and friends grapple with declining capabilities and changes in lifestyle that often accompany aging. And like Gerry, who cannot remember how to operate a computer, countless households are faced with the challenge of no longer being able to interact with previously familiar household devices, such as phones and remote controls. The loss of some abilities may lead to social isolation, a decreased sense of purpose, and increasing dependence on loved ones for assistance in routine activities.

The scope of this problem is expected to increase dramatically over the next two decades. As the American baby boomer moves past retirement age, the resulting increase in the number of people with cognitive decline will place severe demands on families, health care systems, and the economy. In addition to simple growth in the population at risk, there is an accompanying diversification of the aging population. The inability of current health care programs to address these demographic shifts has prompted calls for new paradigms of care [1, 2]. One promising approach lies in advanced technologies for consumer-driven, home-based everyday care [3]. Home health and monitoring technologies have the potential to reduce costs while providing those affected by cognitive decline to live more independent and satisfying lives.

Prevention, early detection, and assistance for cognitive decline may be a very useful application for the "third wave" of computing technologies. The first wave was mainframe computers and the second wave personal computers. This third wave is often referred to as "ubiquitous computing" and is defined as a method of enhancing computer use by making many computers available throughout the physical environment, while making them effectively invisible to the user [4]. Ubiquitous computing solutions typically involve multiple devices embedded in the environment, all connected together to respond in appropriate and transparent ways to the user in the context of everyday actions and events. This vision may match the needs of some cognitively impaired elders—for familiar interfaces, pervasive support throughout the home, and adaptable levels of support.

Intel is exploring location and activity tracking technologies to support elders' independence and safety monitoring by caregivers. We are also researching technologies that could enhance quality of life by facilitating social connectedness and continuation of meaningful activities. It is recognized that in order to adapt technologies for

assistance to older people, it is necessary to understand their values, beliefs, and perspectives as well as the particular relational dynamics within a given household. Culture, ethnicity, and socioeconomic status will undoubtedly influence the acceptance of technologies as a modality for or adjunct to human care. Not all segments of the current (or future) aging population will have access to some common household devices (i.e., home computers, cell phones) or feel comfortable with their use. However, the relationship between contextual factors, such as socioeconomic status, and technology adoption can be surprising. For example, we sometimes encountered more enthusiasm for hi-tech solutions among extremely low income caregivers with very little previous exposure to computing than we did among those with significant financial resources. We expect that, in the early stages of decline, technology solutions can be geared to elders themselves to help them maintain independence and enhance the quality of life. In moderate to severe impairment, solutions would be more appropriately directed to caregivers, who may be eager for information and tools that could enhance their contact with the patient and alleviate the burden of caregiving.

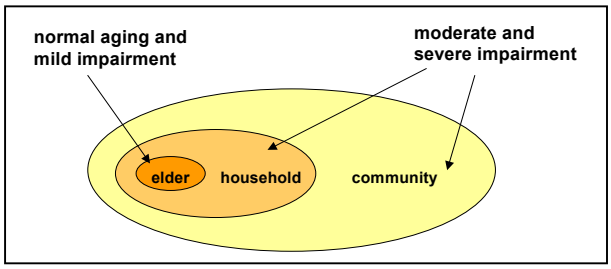

Fig. 1 *As cognitive impairment becomes more severe, the audience for technologies extends from the elder to caregivers in the household and community.*

To uncover the needs of households coping with cognitive decline, and to develop a computing paradigm that will support these needs, we have been conducting in-depth ethnographic fieldwork with households and health care professionals. This paper describes our initial findings and concept prototypes, and their implications for ongoing research, as we attempt to build, test, and iterate upon aging-in-place technologies to meet the needs of the imminent age wave. In the pages that follow, we will summarize the findings of our research and describe some of the types of technological solutions that might address the needs of elders. We will list some of the important research questions and propose a framework for conducting research in this area.

METHODS

We have taken an ethnographic approach, immersing ourselves in elders' routines and environments, with the belief that "aging in place" solutions will require a deep understanding of elders' everyday behavior and relationship to the home. Below is a sketch of our research plan.

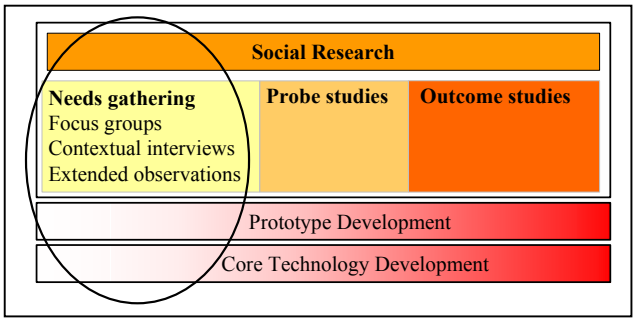

Fig. 2. *Ethnographic needs gathering is the first phase of the Social Research track, which develops concurrently with Technology and Prototype Development. Future in-home Probe studies will drive concept iteration [5] and Outcome evaluations will assess the livability and effectiveness of prototypes.*

Procedures

The ethnographic needs inquiry, situated in the research plan shown above, was designed to illuminate topics that might be hard for elders to self report—their values for successful aging, everyday struggles and rituals, and resources for coping with the challenges of cognitive decline. The tiered data gathering approach began with focus groups that surfaced a breadth of themes, and was followed by contextualized household interviews and intensive observations to explore particular themes in greater depth. Data collection was conducted by social scientists on Intel's Proactive Health team in collaboration with university researchers.

Focus groups—structured conversations with specific target groups—were conducted with elders and spouses, family caregivers, and medical caregivers. Topics of inquiry included values for successful aging, challenges of everyday life, strategies for remembering and organizing, variability in cognitive functioning, life changes since the onset of cognitive decline, coping resources, interests and valued activities, and attitudes about "aging in place." Family and medical caregivers were also asked how they detect decline and day-to-day variability and how they adjust care accordingly. The focus groups not only surfaced valuable themes but were also a mechanism to select participants for home interviews. For our interviews, we sought out individuals and couples who were able and eager to articulate their struggles. Focus groups were audiotaped for further analysis.

Contextualized interviews were conducted in the home with all available members of a household; they lasted between two and three hours. Interviews began with a discussion of lifestyle, history of illness, resources, and concerns. Interviews included tours of the home and a review of daily routines. We observed as participants demonstrated their use of high and low technology tools. Collaboratively, we mapped out participants' social networks and timelines of precipitous events leading to health and lifestyle changes. Interviews were documented with videotape and digital photos.

Several extended observations ("shadows") were also conducted. One researcher spent several days living with an Alzheimer patient and another day following a home health care nurse who treats dementia patients. These observations were documented with extensive notes and digital photographs.

Participants

Participants were selected from five regions: New York, Florida, Oregon, Washington, and California. Interviews and focus groups were conducted with cognitively impaired elders, caregiver spouses, family members, and professional caregivers. We recruited participants through collaboration with university researchers. Participants' involvement in other clinical trials afforded some diagnostic information.

In total, we conducted 45 household interviews and seven focus groups. Of the household interviewees, 10 were healthy aging elders, seven suffered from mild cognitive impairment, 25 were in various stages of dementia (ranging from mild to severe), and three were family caregivers of deceased dementia patients. Elders and their spouses and/or other family members participated in the household interviews. Of the focus groups, one was with healthy elders, two were with mild cognitive impairment elders and spouses, two were with dementia patients and their spouses, and two were with professional caregivers. Approximately ten individuals participated in each focus group, including some couples and some individuals. Our participants (not including children-caregivers) ranged in age from 56 to 97. The majority of our interview participants lived with a spouse or partner who provided care, but some participants lived alone. Households ranged from urban to suburban to rural locations and varied broadly with regard to technology exposure. Nontraditional households (siblings, friends, unmarried couples) and elders living in senior living environments were also represented. The participants ranged in socioeconomic status from low income households who relied on government and community programs for meals and assistance to those who lived in upscale neighborhoods.

RESULTS AND DISCUSSION

Part I: High Level Principles to Guide Ubiquitous Computing Solutions for Cognitive Decline

Our qualitative analysis suggests several overarching principles to guide ubiquitous computing solutions for cognitive decline. These principles—assessing while helping, adapting assistance to variability in cognitive abilities, catalyzing rather than replacing social interactions, and leveraging familiar interfaces—are elaborated below. These principles address the needs that emerged from our research and are embodied in the concept solutions we propose.

Assessing while helping

Technologies that offer assistance in any life domain can simultaneously track and trend the amount and quality of assistance that an elder requires. For example, "embedded assessment"—personalized analogues of standardized cognitive tests that are embedded in elders' everyday routines and environments—could enhance recall of items such as medications or, as explored in a prototype below, recognition of names and faces.

Adapting to variability

Adaptive technologies must accommodate not only to the differences across individuals but also to the fluctuations in any particular elder's functioning. In the short term, caregivers may have to place a support system into different modes that are appropriate given the shifting needs of the person suffering from dementia. Longer term, reliable inferences about an elders' current functional state might allow ubiquitous computing systems to automatically adjust the level of support. Such inferences would be based on data from sensors and cognitive tests embedded into everyday activities such as puzzles, games, or manipulation of home interfaces. When appropriate, feedback about functional variability could be shared with elders and their caregivers. Such feedback could increase mindfulness about patterns of lucidity and vulnerability—awareness that enable elders to leverage periods of greatest clarity and caregivers to strategize around triggers related to vulnerability.

Fig. 3 *Continuum of assistance. By tracking and adjusting to variability in functioning, the system can offer elders the optimal amount of assistance, allowing them to do as much as they can. Support should escalate from simply guiding attention to subtle suggestions, to explicit instructions, and to ultimately acting on behalf of the elder.*

Catalyzing social relationships
Technology systems should aspire to catalyze rather than replace human interactions. One avenue is to help people share information with others in their social network in a way that invites timely communication. As explored in a prototype below, ambient displays illustrating physical and social activity levels and other health related information may motivate friends and relatives to call upon each other for exercise, companionship and other forms of socializing and support. Ubiquitous systems that offer the possibility of new forms of connectedness may become as important to health as medical diagnostic and biosensor devices.

Leveraging familiar interfaces
The effectiveness of the proactive health offerings suggested in this paper will depend on familiar, over-learned interfaces. Computing needs to draw on the devices elders currently use in their everyday routines. Our research suggests a number of everyday surfaces and tools for interactive computing, such as bureau tops, refrigerator doors, mirrors, watches, hearing aids, TVs, and remote controls. Research with tangible user interfaces—especially with radio frequency identification (RFID) tagged objects like photos or everyday objects—may allow elders with dementia to interact with computing systems much longer and more effectively than they could with screen-based systems.

Fig. 4 *Potential computing interfaces*

Part II: Needs and Concepts
From our analysis emerged not only a picture of the challenges faced by the cognitively impaired but also exemplars and dimensions of successful aging. By successful aging we mean the ability we observed among many elders, despite cognitive impairment and other health problems, to fully engage with their lives and their loved ones and to have optimism about the future. The difficulties associated with cognitive impairment unfortunately lead many to restrict their experiences and disengage with the surrounding world. In particular, the problems remembering, tracking, orienting, and processing seriously challenge engagement with the outside world. Technology solutions will ideally help elders overcome these barriers and thereby bridge the gap between struggled and successful aging. Following are some key markers of successful aging and the barriers to those markers experienced by elders in our research:

A. Detecting and Preventing
Successful aging involves a balance between realistic awareness and optimistic denial about the possibility of cognitive impairment and other health problems. This balance is delicate and varies considerably from person to person. Most people endorse the concepts of early detection and prevention. The advantages of early detection for aggressive treatment are understood by the lay and medical communities. However, when it comes to their own health, most are conflicted about seeking out detection. And as has been shown in psychological research, optimism, which can drive denial, is tied to improved health and mood [6]. Elders who believe that they will always be healthy may, as a result of this hopefulness, live out healthier futures than those who anticipate and prematurely worry over the possibilities of illness.

This balance between awareness and denial was rarely articulated by research participants but surfaced as an unconscious tension in almost every story we heard. On one hand, people told us that they wish they had had more advanced warning of a loved one's illness. They felt this forecasting would have allowed them to make better decisions, prevent some of the crises that resulted from inadequate assistance, prolong periods of relative independ-ence, and seek treatment while it could still have some benefit. These same caregivers tended to take what they believe to be preventative measures for themselves, especially mental stimulation in the form of crossword puzzles.

On the other hand, they showed some awareness of having "looked over" or trivialized many early signs that something was seriously wrong. The words of one caregiver—"I did not want to believe that this was happening"—were paraphrased in almost every interview. In contrast, we observed some households that seemed to lack this optimism and as a result surrendered independence pre-

maturely. Sometimes extreme moves to assisted living environments were made based on only the worry of something bad happening. Such premature acceptance of unnecessary limitations and assistance can lead to a form of learned helplessness [6] and consequent decline.

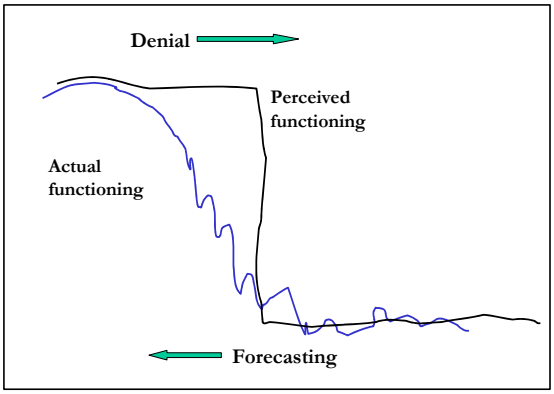

Fig. 5. *Denial often delays awareness of cognitive decline and leads to reactive rather than proactive health care choices. Functioning is overestimated until a catastrophic event, such as getting lost, after which it is underestimated. Technologies to assist with early detection need to address factors driving denial, such as optimism, fears, and uncertainty. The above diagram extends the model developed by Hirsch et al [7].*

Opportunity: Embedded assessment
Current modes of detecting cognitive decline are limited in terms of the frequency and ecological validity of clinical assessments. Embedding assessment into the homes of elders can allow for the detection of subtle changes indicative of decline. Embedded assessment can take a number of forms including:

- personalized analogues of standardized tests that have everyday relevance and a strong value proposition other than early detection (e.g., recognition aids that enhance social performance, mentally stimulating exercises)
- real time usability testing on familiar interfaces for detection of changes that are associated with cognitive impairment (i.e., gait, organization, reaction time, manual dexterity)

Concept: Name-face recognition exercise
A stage-dependent prototype to address these needs is an embedded assessment and recognition aid that would allow healthy or mildly impaired individuals to practice name and face recognition. The goals of this tool are two-fold: (1) to ease social anxiety by aiding person recognition and (2) to obtain timely and ecologically valid assessment data that could help facilitate prompt detection of further decline. This concept invites the elder to collaborate with a spouse, co-worker, or friend in developing a digital timeline and rich media database of important people, places, and events. The database can include photos, video clips, and voice recordings. To practice, the elder selects tangible photos which link up with the database. Questions about the person in the photo are presented on a TV screen or other interface. If unable to recognize the person in the photo, the elder would be presented with helpful cues (such as a voice clip or a reminder of how the individual fits into the user's family tree or social network).

This prototype includes RFID tags in objects (such as photographs) that represent social contacts for name and face recognition. The objects are read using an RFID reader, and the RFID data is used to access a media database. The information from the database is displayed on a contextually appropriate output device, i.e., the television located in the same room as the elder. The application progressively reveals hints and related information from the media database according to the user's needs during a particular session. Data from each session, such as the number of hints required and the response time, are stored and trended over time.

B. Managing Everyday Life
Need: Activities of daily living
Completing the basic activities of daily living requires recent recall, prospective memory (remembering to remember), working memory (the ability to retain and manipulate recently acquired information), and orientation to time and place—any or all of which may be compromised in an individual with cognitive decline. Additional impairments of dementia, such as motor and perceptual decline, make ADLs even more challenging. We observed elders' rather elaborate strategies to remind themselves of basic daily activities (such as medications to take after breakfast), social engagements, and locating items such as clothing and glasses. The most compelling type of reminders we observed were contextually appropriate notes (e.g., reminders on stove to turn off burners; medication reminders in the various rooms in which medications are taken—bedroom, kitchen, bathroom, etc.; notes on the door about locking it at night). Other systems include auditory reminders such as timers, photos, and objects that contain the reminder (canes placed by the bedroom door as a reminder that they should be used upon exit), to do lists, and notes on how to prepare already prepared food.

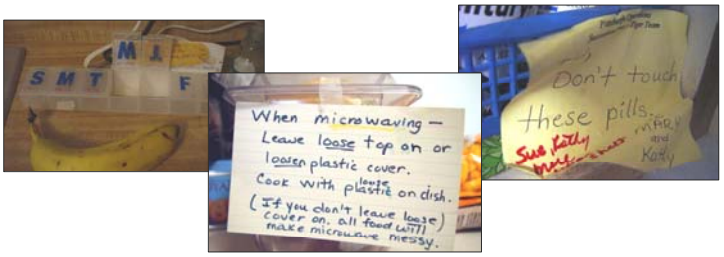

Fig. 6. *Many households depend on extensive pen and paper reminding systems.*

Need: Navigating the home

The ability to move about and manipulate the home environment is crucial for activities of daily living and for a sense of control and security. The home is laden with familiar cues and artifacts that ground, orient, and remind. Unfortunately, the home becomes drastically restricted for many elders. In early stages of impairment, this restriction may take the form of eliminating outdoor spaces that previously felt familiar and homelike. In later stages, the home itself becomes restricted to certain pathways and zones. Often, physical impairment initiates this process: stairwells and other features often become too difficult to manage. In later stages of impairment, a narrowing of attention, focus and interest can lead elders to drastically reduce their usage of the home. Most of the elders in our study, impaired or not, avoided their designated "computer rooms" and instead used favorite spots—"command centers" (a kitchen table, a favorite chair in the living room, or for the severely impaired, a bed)—as a base for entertainment, eating, work, and socializing. Unless technologies were in easy reach of these command centers, they generally were not used. With decline in physical or cognitive health came a reduction in the number of such command centers used by a particular elder.

Another type of restriction is the avoidance of relatively novel interfaces in the home, such as modern phones or microwaves. With most types of cognitive impairment, devices that were introduced later in life are more easily forgotten and for that reason rejected. For example, most cognitively impaired individuals struggled to use computers, even if they had some experience with them. In contrast, some interfaces learned in the very distant past, such as a piano in several cases, were used with comparative ease. Our general observations were that elders with cognitive impairment abandoned common devices in the following order: computers, answering machines, phones, stereos, microwaves, and televisions. Although remote controls typically remained in usage to some degree, they were often radically simplified (often with tape and markers). Often there is a gap in exposure to technologies as elders are moved from one environment to another, and afterwards the elder is not able to use technologies such as answering machines, televisions, cars, etc. that were previously familiar. For example, one woman in our study had an answering machine which she used daily, but after six months of transitions between her daughter's home and different assisted living environments, she no longer remembered how to operate the device.

Need: Negotiating independence

Successful aging requires the elder to reach a balance between self-confidence on one hand and comfort with increasing reliance on others on the other. As physical abilities decline and more help is needed with activities of daily living, the boundaries between elders, their friends,

Fig. 7. *Remote controls and other devices are often radically simplified*

and relatives begin to fade. The most content participants in our study actively negotiated reliance on others. They deliberately sought out friendships with people who could help them and thought about ways that these relationships could nonetheless be reciprocal. One couple joked that a criteria for new friends is that they "be willing and able to drive us to the hospital." To varying degrees though, all elders that we encountered expressed concerns about losing control and independence. For some people, the physical home was a stand-in for independence. They felt that as long as they could live in their homes, they would feel independent and as a result could tolerate other concessions of dependence on others. For others, independence was tied more to internal psychological issues such as flexibility and adaptability to change. Many of these people mentioned that being part of a diverse community would help them develop flexibility and strength that would be the basis for their independence. Others framed independence in terms of not relying on people other than a spouse for practical or financial help. In all cases, elders seemed wary of technologies that would lessen their perception of control. The flipside of this negotiation is the stress experienced by many caregivers, which generally increases with the severity of dementia. Many of these caregivers have significant health issues of their own that are put on the back burner. This predicament was expressed by one such caregiver—a 79 year old woman with diabetes and other severe health problems who provides 24-hour care for her 97 year old mother with Alzheimer's: "When I wake up, Mom's calling for me, the cat is calling for me. I come last."

Opportunity: Contextual prompting for elders and caregivers

Everyday life management of elders and their caregivers can be greatly eased through prompting, but to be effective, reminders and alerts must be situated in users' behavioral, environmental, and temporal contexts. Medica-

tion reminders, for example, need to be given in the place the medication is typically taken, at the time they are taken, with an awareness of what other activities (including eating and ingesting other medications and supplements) the elder is likely to be doing at that time. Given the avoidance of novel devices, prompts need to be delivered on familiar interfaces. Contextual prompts can allow caregivers reassurance and freedom through sensors and alerts that follow the caregiver as well as the elder.

Concept: Helpful hinter

Our prototype addresses the need for help completing sequential routines. It focuses on tasks related to hydration—a need that is commonly neglected among the cognitively impaired. The system detects the location of the elder and delivers contextually appropriate prompts that escalate from abstract suggestions to explicit directions to get a drink. Through RFID and motion detecting, the system follows the user into the kitchen and provides prompts if he or she loses track of tea preparation steps. Prompts, only given when a step is missed, appear on the kitchen TV.

This prototype consists of multiple types of sensors, an activity inference engine, and prompting devices. Infrared sensors track general location and orientation within the house. RFID sensors placed on shoes detect movement through doorways or steps on specific surfaces. Data collected from simple switch sensors flow into an inference engine that determines what activity is being performed and where the elder is in the process. The system must also determine if the elder has been interrupted and identify appropriate times to intervene. Prompting devices are everyday objects such as TVs, radios, lights, etc.

C. Social connectedness

Social connectedness has been shown to protect against dementia [8] and most certainly ameliorates the pain of cognitive decline for both afflicted elders and their caregivers. In addition to its intrinsic value, socializing is a strong motivation for participation in other healthy behaviors, especially exercise. Our research underlined these findings: the socially isolated elders in our research appeared less satisfied with their lives, less optimistic, and generally in a poorer state of health than those with rich social networks.

Cognitive impairment and the associated difficulties remembering names and following conversation make conversation and other aspects of social engagement challenging. One participant, a small business owner, can no longer remember names and faces of his long-standing friends and clients—this loss threatens his social relationships as well as his professional identity and livelihood. Regarding difficulty following conversations, another participant explained that he doesn't talk much in social gatherings anymore; instead he waits until the end of the evening for his wife to relay the conversation. Yet another described the pain of asking for directions when he is lost: he knows that they will be given too quickly and that he will forget even what he was able to absorb. As difficult as the inability to keep up is the impatience he feels from others. We heard from many elders that anxiety and shame about the cognitive impairment aggravates both the symptoms and sense of alienation. For caregivers too, stigma associated with dementia can cause withdrawal from friends and possible sources of help. Those households that adopted a more open coping style were sometimes able to retain the advantages of a rich social network.

Opportunity: Social synchronization through presence technologies

Presence technologies—for example ambient displays that indicate basic wellness related information—can help connect elders with one another and with their remote caregivers. These displays can tune elders in to opportune moments to reach out to family and friends. Although the concept below is focused on connecting elders who already know one another, there is also great potential for such technologies to connect elders from very different backgrounds.

Example concept

This prototype is intended to facilitate and synchronize socializing, particularly exercise companions. It is designed to support either two people or a network of people who enjoy each others' company for a particular activity, such as walking, but do not have a strict routine or commitment to join each other. The system searches for opportune moments for the friends/exercise companions to join each other and signals them in a way that suggests "no pressure, but this might be a good time to join X." In the example of walking partners, the system could, after recognizing that X has put on his walking shoes, signal Y (via a visual or auditory message) that X is about to go for a walk. Y could either contact X so they could meet up or ignore the signal if she is otherwise engaged. This prototype is also intended to find other types of moments (such as periods of low activity) that are opportune for joint exercise or other socializing. Through activity monitoring, the system trends individuals' movement inside and outside their homes and could signal two exercise companions if neither has had much movement for a while. The trending and prompting information would appear anywhere that is appropriate and desirable—the TV screen, a clock radio, or even a chime. This same "opportunity hunting" technology principle could be used to facilitate other forms of socializing, by helping people know a good time to call someone for a phone conversation or to invite a friend for an impromptu dinner.

This prototype consists of activity tracking sensors that detect and log activity in the household, an inference en-

gine for detecting activities and deciding on appropriate responses, and an intelligent network of household objects and appliances for interacting with elders. Sensors are connected with motes—small, relatively inexpensive wireless processors that can be positioned nearly anywhere and automatically configure themselves into an ad hoc network [26]. 3D tracking is implemented via infrared cameras that detect an infrared beacon worn by the elder. Multiple cameras triangulate on the infrared beacon to determine location within the household. Movement throughout the house is logged into an activity database. When the elder goes out for a walk, a pedometer logs the steps upon return home, syncs up with the activity tracking system (this part of the system has not yet been implemented). The inference engine monitors the activity of the elders and signals them at opportune moments to contact each other. In the current prototype, a chime is used to signal the partner's availability for exercise, but any interface could be used.

D. Identity Affirmation

Need: Engagement and meaning

Cognitive impairment often directly or indirectly threatens the very activities that are most crucial to core identity. Intellectual and social pursuits are directly challenged, while physical and outdoor activities are often indirectly challenged because of the safety risks introduced by inattention and disorientation. In either case, elders often need to stop the very same activities that make them feel most engaged and grounded. As examples, take Adam, Clark, and Merl, all of whom suffer from worsening dementia. Adam enjoyed teaching tremendously and thought of himself as someone who shaped the minds of younger people. Since being asked to stop teaching due to his dementia, Adam has faced a terrible loss. Clark's situation is somewhat similar. Until recently, he had a "dad's jar" full of requested projects from his wife and children. This jar defined his role in the family and leveraged his expertise and enjoyment in woodworking. For Clark and many others with cognitive impairment, there are tough trade-offs to be made between the benefits of continuing these activities and the risks they now pose. Due to his general cognitive slowing, shortened attention, and difficulty with multistep tasks, Clark now has trouble seeing even very simple tasks to completion, and the saws in his workshop cause his wife to worry about his safety. A similar issue surfaced with Merl and his wife. Once an extremely talented designer and builder, Merl is now very slowed down due to frontotemporal dementia and can no longer complete even the minor repairs on the home he designed and built. Due to these changes and his inability to acknowledge them, his wife needs to take over the burden of home management in a covert style. These scenarios and countless similar ones beg difficult questions of how technology can help people continue the activities that affirm identity and often help cognitive functioning. Because of the role changes that are brought about by dementia, they also raise questions about who will be using technologies.

Need: Seeing oneself in the broader landscape

The breadth of one's horizons seems to correlate with overall wellness and to mitigate the pain of cognitive or physical impairment. Those elders with a deep connection to the larger social and political landscape seemed less worried about their health and less bothered by their current impairments. By continuing to learn and care about new places, their lives expanded despite the restrictions imposed by illness. Cognitive impairment almost always threatens orientation to the larger world, and many types of dementia prevent the ability to learn new information. Furthermore, the ways that many people maintain a connection to the larger world and continue to incorporate distant places into their mental schemas, such as traveling, become significantly more difficult with cognitive decline. Many of our mild cognitive impairment participants are limiting or changing the way they travel. Paul, who until recently made frequent international trips, now finds himself far behind his travel companions. He is physically slowed down and struggles tremendously with things that were previously effortless, such as taking out and putting away his ID, and taking off his shoes and jacket in security checks. He used to travel in a spontaneous fashion for leisure travel, making hotel reservations and plans after he arrived. On a recent trip to visit his daughter, he used a travel agent and planned out every-

Fig. 8. *Connection with the outside world, crucial for stimulation and a sense of belonging, is often restricted for those with cognitive decline.*

thing in advance. Many of our participants expressed cognitive and other health benefits from the outside—hiking or spending time in their urban neighborhood—echoing research findings that connection with the outside world provides mental stimulation. Unfortunately, experiences or fears of getting lost have led many to restrict their outside activities.

Need: Seeing oneself throughout time
A continuous sense of self relies on the ability to stay in touch with the distant past. Following a temporal gradient, older memories of both personal and public events are more well-preserved than recent memories [9]. As dementia progresses though, even older memories deteriorate. Our research suggests that elders who actively use cues in their environment to recall people and places from the past generally have more success with recall and less distress over forgetting than those who do not. Most of the households in our study were filled with references to the past, spanning from artifacts that contain memories such as furniture made by relatives or furniture made from materials that reference a certain experience to references such as photos, scrapbooks, videos, plaques, refrigerator memorabilia, and past journals and calendars. Dementia care centers vary in their use of artifacts from the past to elicit memories from the past.

The most organic use of artifacts that we encountered was in Villa Cederschiold, a day care and residence for dementia patients in Stockholm. Dresses, jewelry, and furniture that would be very familiar to today's elders were assembled throughout the center in configurations that invited interaction, play, storytelling, and other activities like song and dance. Another way that people see themselves over time is through hard copy calendars. We were surprised to see how many people save their calendars as a reference of the past and the innovative ways that some people use calendars to map out possibilities or compare actual to intended activities.

Fig. 9 *Future computing technologies should connect with meaningful, memory laden artifacts.*

Need: Looking to the future
The denial, optimism, and fear that prevent people from confronting the realistic possibilities of serious illness also prevent them from thinking about less ominous aspects of aging: what types of communities they want to be part of, where they want to live, and what activities they always want to do. This type of projecting is daunting for most and as a result they don't do it. It is intimidating to set achievement, relational, and financial goals that may not be accomplishable and unpleasant to think about obstacles to those goals. The lack of tools to conjecture about the future add to the problem. Calendars, to do lists, and reminders work sufficiently for short term planning but not for the ambiguity of speculating about the future. Planning for the future is even more hindered among cognitively impaired elders who have reduced capacity to plan goals and contingencies. As is further explored in a concept section below, there is a need for engaging, unintimidating interfaces to help people visualize and plan the way they want to live out their lives.

Need: Self-Awareness
Awareness of one's own variability across time, place, and situation (another marker of successful aging that emerged from our observations and echoes previous research [10]), seems to mitigate the impact of negative events, enhance enjoyment in even everyday experiences, and allow people to monitor their own cognitive, emotional, and physical health more effectively. A general finding in our research that echoes anecdotal reports but runs somewhat contrary to diagnostic guidelines is the considerable variability in any given individual's cognitive functioning over the course of a day, a month, or the longer phases of illness. For example, in the course of a day, one Alzheimer patient we shadowed was able to navigate complex hiking trails with ease and speed but then became completely disoriented in his neighborhood supermarket. We encountered other reports of individuals in the advanced stages of dementia having sporadic hours of great lucidity. Those elders and caregivers who were able to recognize such variability were more likely to leverage periods of lucidity to accomplish tasks or have conversations that would be difficult at other times. The impairment brought about with Alzheimer's and other forms of dementia unfortunately extends to self-awareness: as dementia worsens, insight into one's own impairments and their impact on others diminishes significantly [9].

Opportunity: Life-span mapping
Home computing systems can connect with the needs to remain connected to the past without disconnecting from the present and future. We've begun exploring this area of life-span mapping in a number of "life capture" and rich calendaring concepts.

The Wishing Well concept, illustrated below, responds to the need for more engaging interfaces to invite ideation about the later phases of life. This concept asks users to select images that correspond to the spirit or mood of a particular goal or aspiration. The point of this concept is to motivate enjoyable speculation about topics that are typically associated with fear. This interface could be used to help people think about the social communities that will be important and desirable to them in old age. Images of friends and family, collected for purposes such as the name recognition concept described above, could be used to help elders plan their ideal communities and social networks. For a review of this need and concept, see Brooke and Morris [11].

Fig. 10 *Wishing Well concept*

CONCLUSION

This report summarizes our initial exploration of households coping with cognitive decline and our attempts to develop technology solutions that correspond to the struggles we observed. We have purposely taken a broad approach, examining not only basic physical and safety concerns but also needs of these people to feel a sense of purpose and maintain connectedness with their communities. The technology concepts that have been described are very preliminary examples of ubiquitous computing solutions. We intend to use these prototypes in homes of cognitively impaired patients as exploratory probes to learn more about what solutions might be useful and to inform the development of the underlying technology.

Below is a list of some technology areas that invite further research. These are more fully outlined by Dishman [12].

Technology Research Areas

Wireless broadband
Wireless broadband can be used to connect all devices in the home—remote controls, TVs, microwave ovens, refrigerators, washing machines, etc. This is the infrastructure that will allow communication between these devices and provide the delivery of health information in rich media formats.

Biosensors and bodily diagnostics
The emerging field of biosensor technology will provide non-intrusive real-time monitoring of biochemical functions and allow an in-home system to detect subtle changes in a patient's medical state, allowing for much more timely and effective intervention strategies.

Activity sensors and behavioral diagnostics
The ability for an in-home system to correctly infer location and activity is critical to delivering the support needed to aid the cognitively impaired. Activity sensors need to be unobtrusive, embedded seamlessly into the environment and must be designed to protect the privacy and dignity of the individual.

Information fusion and inference engines
The data collected from sensors in the environment will likely be real-time stochastic information streams from tens to hundreds of sources. That is, the data will be inherently noisy and non-deterministic. Data flowing in must be managed to prevent collision and interference, and statistical inference methods must ferret out the inherent noise and correctly infer high level behaviors from low-level probabilistic sensor data.

Ambient displays and actuator networks
Communication between the elder and the system must occur at the appropriate touch point and in a congruent modality. Sometimes, the system may need to capture the immediate attention of the recipient, while other times the system may need to send a gentle, unobtrusive reminder. The types and modalities of ambient displays need to be defined in relation to the type of intervention that is required. These methods can also be used to communicate "OK-ness" checking to a distant loved one or friend [12].

Agents, assistants, coaches, and companions
It remains to be seen how technology can and should attempt to mimic human behavior and companionship. Regardless of the answers, technology will need to model human activities, infer needs and provide those needs in a method that is sensitive to the capabilities of the recipient. Thus there is a need to research the artificial intelligence techniques required to provide agent-based support, and to research the best methods of developing this capability, whether through an anthropomorphic "coach" that utilizes a familiar voice, through computer-generated speech and graphics, or through well-placed environmental cues.

Natural interfaces
Much research needs to be conducted to understand the best methods of providing interaction between the elder and the support system. Certainly it is advantageous to utilize familiar device interfaces that elders can operate as input and output points to the system. However, more fundamental natural interfaces such as handwriting recog-

nition, gesture, and natural language may be required, especially for more advanced cases of dementia.

Social Research Areas

A host of social science questions also invite further study. For example, we need to know more about how factors such as culture, ethnicity and socioeconomic status will influence technology acceptance. At the level of individual differences, it would be helpful to develop a segmentation of elders and boomers based on attitudes and behaviors regarding issues such as early detection, prevention, privacy and independence. We also need a better understanding of what interfaces and devices are accessible to elders in different stages of cognitive decline.

This does not constitute a complete list of areas for research, but provide a glimpse of interesting and potentially fruitful areas. Although many of the required technology components are well-understood and relatively simple, no one has yet developed the comprehensive system infrastructure to support these multiple interacting sensors and consumer devices, much less developed the software that makes them work in an effective, intelligent and seamless manner. In all areas, the technology that is developed must be modular and flexible, must anticipate extensions and improvements, and must interoperate with other assistive medical technologies while providing reliable and livable solutions. This is a systems integration problem that requires much cooperation between researchers in the medical and computer industries.

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