

New Perspectives on Ubiquitous Computing from Ethnographic Study of Elders with Cognitive Decline

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Abstract. A rapidly growing elder population is placing unprecedented demands on health care systems around the world. Cognitive decline is one of the most taxing health problems in terms of both its relation to elders' overall functioning and the cost of care. The needs of elders with cognitive decline - for invisible, intuitive support and assessment - invite a reconsideration of the assumptions behind and specifications for ubiquitous computing solutions. This paper describes findings and implications of ethnographic research conducted with cognitively impaired individuals and their informal care networks in 45 households in 5 U.S. regions. Key themes regarding needs and barriers to successful aging are addressed through a set of design principles which apply across the stages of cognitive decline. To convey stage-specific findings and associated challenges for ubiquitous computing, case studies of four representative households and example concept solutions are presented. The design principles and technology challenges outlined in this paper may generalize to other contexts for ubiquitous computing.

1 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."

- Bill, husband of an Alzheimer's patient

"Gerry always used a computer, but he has a difficult time using it now."

- Alice, wife of a dementia patient

When robbed of the ability to use tools as basic as a coffee maker due to a disease such as Alzheimer's, people are forced to rethink their everyday priorities and assumptions about how they will interact with the world. Bill's struggle is unfortunately typical of those faced by the millions who care for elders with declining capabilities and consequent lifestyle changes. And like Gerry, who cannot remember what he has learned late in life, many can no longer interact with relatively recently acquired and novel home devices, such as computers and remote controls.

Cognitive decline may well invite reconsideration not only among sufferers but also the ubiquitous computing community. In particular, concepts such as ubiquity, adaptivity, contextual awareness, location-based services, and usability may take on new meaning. What might be learned about general ubiquitous computing principles

from extreme cases such as advanced Alzheimer's households? And how might ubiquitous and proactive systems improve prevention, early detection, and caregiving for people dealing with cognitive decline?

The two examples above are far from unusual, as the incidence of cognitive impairment is rising along with the dramatically increasing lifespan. Cognitive decline is part of old age to varying degrees – in fact, it is estimated that 50% of those over age 85 meet criteria for Alzheimer's Disease. Over the next five decades, the incidence of Alzheimer's alone is expected to rise from 4 to 14 million in the U.S [1]. From mild decline to severe dementia, cognitive impairment is one of the biggest threats to independence and quality of life [2]. Cognitive decline is one of many health care problems faced by the growing elderly population that invite novel paradigms of care [3, 4, 5]. Ubiquitous computing for home based health care may help reduce the unprecedented strains these health problems are placing on medical resources, and hopefully also allow elders to live with greater independence and enjoyment.

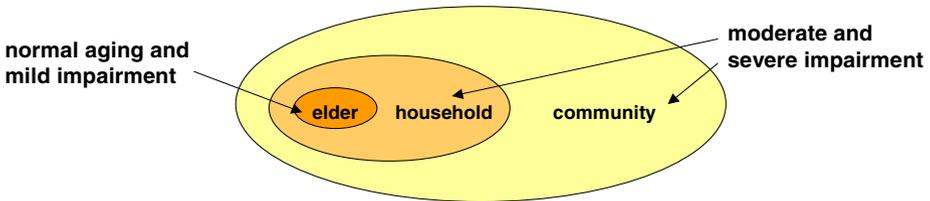


Fig. 1. Audiences for technologies. As cognitive impairment becomes more severe, the audience for technologies extends from the elder to caregivers in the household and community.

To understand the needs brought about by cognitive decline and to begin developing a computing paradigm that will support sufferers and their caregivers, Intel's Proactive Health Research team conducted in-depth ethnographic fieldwork with households coping with cognitive decline and healthcare professionals specializing in dementia. A common set of needs emerged across the stages of cognitive impairment. These needs and their implications for technology solutions are outlined in four design principles. Concept solutions geared towards specific stages of impairment are presented as illustrations of these principles. The solutions proposed range from those geared towards improving the quality of life for elders with mild impairment to those aimed at alleviating the burden experienced by caregivers of elders with moderate to severe dementia. All concept solutions were designed with the goal of prolonging independence, giving elders the option of "aging in place."

2 Related Work

Following is a discussion of several projects of direct relevance to the current study. For the sake of brevity, we have not included a comprehensive review of technology aids for the elderly.

A number of "Smart Home" platforms have been developed to implement and assess ubiquitous technologies. Several prominent examples include MIT's house_n

project [6], the Georgia Tech Aware Home [7], and the Center for Future Health at the University of Rochester [8], which features an intelligent medical advisor and early detection capabilities, such as gait assessment. The Gloucester Smart House [9], is specifically targeted to support people with dementia with relatively simple solutions, such as a bath and basin monitor to prevent overflows, and a locator for finding lost items such as keys and glasses. Rather than observing people in a lab home, Honeywell has deployed its Independent Lifestyle Assistant (ILSA) system in actual homes to test their activity detection and messaging system [10].

Other researchers have developed specific devices to provide broad based health assistance to elders. Pollack [11] has developed and tested a cognitive orthotic – the “Nursebot” – that prompts elders through activities of daily living and guides them through their environment. At the International Center on Technology for Successful Aging (ITCA), the cell phone is a focal tool for location-tracking and contextual prompting of elders and their caregivers [12]. In a more specific application area, Tran and Mynatt [13] have developed a memory aid for cooking in which cameras record events and display snapshots to show elders where they are in the cooking process.

Oatfield Estates, a residential care facility in Oregon, monitors and tracks residents via infrared badges and sensors throughout the living facilities [14]. This facility is unique in that it can easily incorporate and assess new technology in a real living environment. Intel is working with Oatfield to identify new opportunities as well as barriers to utilization of technologies. In addition, two of Intel’s collaborators, Misha Pavel at Oregon Health Sciences University and Henry Kautz at the University of Washington, are using sensor data from this site to test statistical inferencing about behavior.

3 Extending Previous Research

Like the projects above, Intel is exploring location and activity tracking technologies to support elders’ independence and support safety monitoring. Our objectives extend, however, to enhancing quality of life through technologies that will facilitate social connectedness and continuation of meaningful activities. Significant differences also lie in our needs gathering and prototyping approaches. We take 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. Additionally, the solutions we develop are “experience prototypes” designed to swiftly probe the user experience in the home environment.

3.1 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 house-

hold 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.

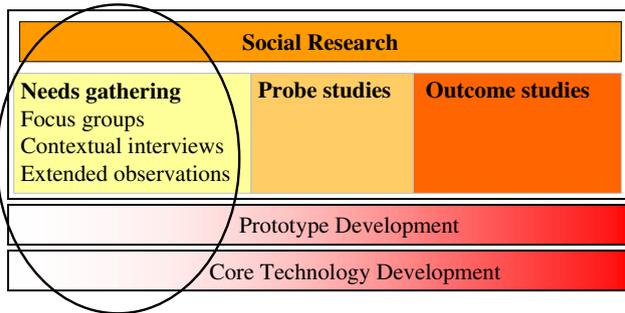


Fig. 2. Ethnographic needs' gathering is the first phase of the Social Research track, which develops concurrently with Technology and Prototype Development. Future in-home Probe studies will drive concept iteration [15] and Outcome evaluations will assess the livability and effectiveness of prototypes.

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 important themes, but were also a mechanism to select participants for home interviews. 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's patient and another day following a home health care nurse who treats dementia patients. These observations were documented with extensive notes and digital photographs.

3.2 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 interviews¹, and seven focus groups. Of the household interviewees, ten were healthy aging elders, seven suffered from mild cognitive impairment, twenty-five 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 romantic caregiver, but some lived alone. Households ranged from urban, to suburban, to rural, with a mix of socioeconomic status; nontraditional households (siblings, friends, unmarried couples) and elders living in senior living environments were also represented.

4 Principles to Guide Ubiquitous Computing for Cognitive Decline

From our qualitative analysis, key themes emerged regarding unmet needs that could be addressed through ubiquitous computing. These needs – for early detection, assistance that adapts to functional variability, and social connectedness, all through comfortable interactions with familiar devices – are addressed in the four principles below.

4.1 Supporting Early Detection with an Awareness of Denial as an Obstacle: Embedded Assessment with a Strong Value Proposition for Everyday Living

Research finding: Across all stages of impairment, we observed elders and caregivers struggling with a tension between a desire for early detection on the one hand and strong denial on the other. This tension was rarely explicitly expressed, but consistently emerged in participants' narratives. All wished they had received forecasting (diagnosis and prognosis) that could have guided healthcare choices and helped them avoid crises and extend periods of relative independence. In retrospect, though, almost all acknowledged having overlooked initial symptoms, sometimes for years. This denial was driven by uncertainties and fears about dementia, as well as optimism regarding the possibilities of illness. This is a delicate issue since optimistic denial regarding the prospects of future illness can be helpful. Indeed, households without this optimism seemed to surrender independence prematurely with a kind of learned helplessness [16]. Nonetheless, in most cases denial leads to a reactive, crisis-driven style of caregiving that negates opportunities for early detection and treatment.

¹ This includes several caregiver interviews conducted in Stockholm, Sweden.

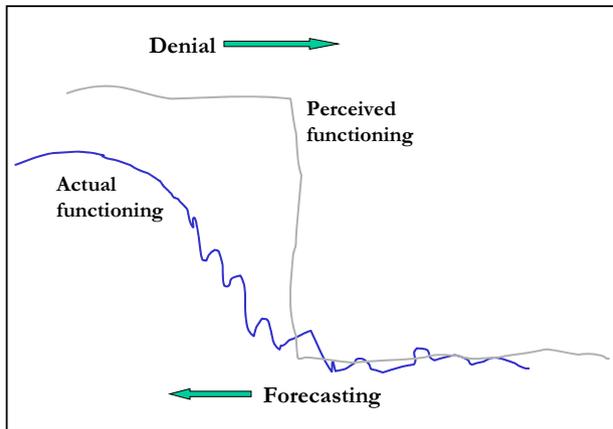


Fig. 3. Denial often delays awareness of cognitive decline and leads to reactive rather than proactive health care choices. Elders tend to overestimate their cognitive functioning up until a catastrophic event and afterwards underestimate functioning. Technologies to assist with early detection, such as embedded assessment tools, need to also address factors driving denial and offer clear value propositions for everyday functioning. The model above extends a diagram adapted by Hirsch et al. [17] to describe elders' self-perception of general health functioning.

Implication: Technologies to assist with early detection and monitoring of performance over time will need to address the factors driving denial, such as fears and uncertainties, as well as optimism. Such technologies will generally be most effective if put in place before or shortly after the onset of impairment. In order to overcome resistance, these technologies will have to have practical value in everyday life. An example is “embedded assessment” – personalized analogues of standardized cognitive tests that are embedded in elders' everyday routines and environments. Such tools could enhance recall of items such as tasks and medications or, as explored in a prototype below, recognition of names and faces.

4.2 Adapting to Variability in Functioning to Offer the Optimal Level of Assistance

Research finding: There is tremendous individual variability in the course of cognitive decline. Furthermore, for many individuals, there is considerable variability in the degree of impairment over the course of a day, a week, and the longer phases of illness. For example, one Alzheimer's patient we shadowed [18] was able to navigate complex hiking trails with ease and speed, but 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.

Implication: Adaptable technologies are needed to accommodate the lifestyles and struggles of different individuals. Even more challenging, technologies should adapt 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 ubicomp 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.

Feedback about functional variability could also help individuals gain mindfulness about their patterns of mental lucidity. The benefits of mindfulness are well demonstrated for a wide range of health problems [19] and they should extend to cognitive impairment. Ideally ubiquitous computing systems would encourage individuals to leverage their periods of greatest lucidity to accomplish tasks such as planning and organizing that may not be possible during moments of lower functioning. For the severely impaired, variability information could be valuable to caregivers – alerting them to when the patient is typically at greatest risk and perhaps even identifying contextual triggers related to lucidity and confusion.

By tracking and adjusting to variability in functioning the system can offer elders the optimal amount of assistance. In general, it is best to enable users to do as much as possible in the home – exercising control over the environment is stimulating and fosters confidence and optimism [16]. Excessive or premature assistance can invite passivity and functional decline. An example from our fieldwork is a woman who preemptively moved into an assisted living environment, began receiving help with basic skills such as bathing and now lacks the drive to do these tasks on her own. For the cognitively impaired elder the benefits of controlling one's own environment need to be carefully balanced against the risks of injury.

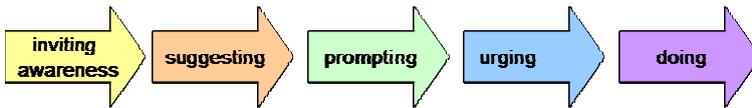


Fig. 4. Continuum of assistance. Support should escalate from simply guiding attention, to subtle suggestions, to explicit instructions, to ultimately acting on behalf of the elder.

4.3 Catalyzing Social Relationships

Research finding: Social connectedness has been shown to protect against dementia and most certainly ameliorates the pain of cognitive decline for both afflicted elders and their caregivers [20]. In our research, socially isolated elders appeared less well on a host of dimensions relating to cognitive, emotional and physical health. In addition to its intrinsic value, socializing is a strong motivation for participation in other healthy behaviors, especially exercise. Regarding the nature of social connectedness, most elders want to feel that they are having an impact on others rather seeing themselves as passive recipients of help.

Implication: 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 sys-

tems that offer the possibility of new forms of connectedness which become as important to health as medical diagnostic and biosensor devices.

4.4 Leveraging Familiar Interfaces

Research finding: We observed that elders tended to avoid designated “computer rooms” and instead used “command centers” (a kitchen table, a favorite chair in the living room, or for the severely impaired, a bed). Unless technologies were in easy reach of these command centers, they generally were not used. Most cognitively impaired individuals struggled to use computers, even if they had significant experience with them in the past. Future elders may have more sustained usage of PCs than today’s elders, given their longer exposure to them. But even for this cohort, the complexities of computer usage may eventually pose problems. Familiar and highly tangible interfaces, particularly those that draw on procedural rather than declarative knowledge, will probably have the longest usability. Research reviewed by Lezak [21] has shown that, despite many deficits, Alzheimer’s patients can often still learn simple motor skills and sometimes hold onto the ability to perform enjoyable activities they learned in the past. Indeed, several elders in our study with severe limitations in language, attention, and memory were still able to play piano or interact with some tangible interface, such as a photo album.



Fig. 5. Potential computing interfaces.

Implication: The effectiveness of the proactive health offerings suggested in this paper – early detection, adaptive support, and social facilitation – will depend on familiar, unthreatening 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 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.

5 Case Studies and Corresponding Technology Prototypes

Following are four case studies that illustrate the struggles associated with different stages of cognitive decline². For each case, we describe a component of an experience prototype system that could address the problems faced by these elders.

² The names have been changed to preserve confidentiality.

5.1 Healthy Aging

Aging is associated with some cognitive decline, most notably slowed information processing and deficits in working memory [22]. When these cognitive changes are added to the commonly experienced declines in sensory and motor functions, independence and quality of life can be compromised. These challenges are exacerbated by the social isolation that typically accompanies aging.

Stimulation – social, mental and physical – has demonstrated value in preventing cognitive decline [20, 23, 24]. Technologies that enable elders to continue the activities that make them feel most engaged and most connected with their social networks could have powerful health benefits.

A Case Study: Heidi. At 75, Heidi is physically fit and socially active. Like many of today’s elders, she takes her health seriously and assertively explores treatment options. She receives a variety of health research newsletters that keep her up to date on issues such as the role of vitamins and hormones in preventing dementia. In recent years she has been troubled by memory concerns, occasionally forgetting names, appointment dates or directions.

Heidi used to be an avid hiker and would frequently enjoy daylong explorations by herself. On a couple of occasions she lost her way and ended up in a dangerous situation. She now feels safer sticking to well known routes and always going with a particular woman she met through a hiking group. This companionship allows her to get more exercise than she otherwise would and she enjoys the conversation. She also feels that she is helping her new friend stay in shape. However, Heidi is sometimes hesitant to call her new hiking partner because she doesn’t like to burden people. She wishes she knew when it was a good time to call.

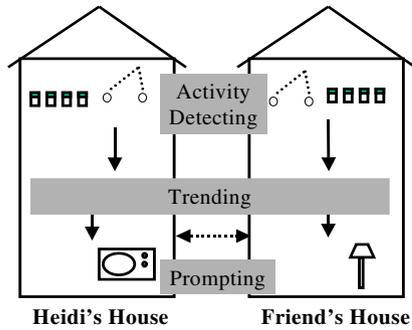
Experience Prototype to Support Healthy Aging: Facilitating Social Connectedness. A prototype to address Heidi’s needs monitors physical activity and facilitates communication between exercise partners. The monitor tracks both partners’ movement inside and outside the home, trends it over time, and signals opportune moments for joint activity to both partners. The trending and prompting information would appear anywhere that is appropriate – the TV screen, a clock radio or even a wind chime. This same “opportunity hunting” technology principle could be used to facilitate other forms of social connectedness, such as helping people know when it might be a good time to ask someone else out for coffee, a meal, or to engage in a phone conversation.

Technology Ingredients. This prototype consists of activity tracking sensors that detect and log activity in the household, an inference engine for detecting activities and deciding on appropriate responses, and an intelligent network of household objects and appliances for interacting with elders. In our current prototype, 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 and 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 wind chime is used to signal the elder’s need and availability for exercise, but any interface could be used.



Need: Heidi relies on companionship to motivate her exercise.



Experience prototype: Activity tracking and ambient displays that connect exercise companions.

Fig. 6. Need and experience prototype for healthy aging.

We connect the sensors with motes – small, relatively inexpensive wireless processors that can be positioned nearly anywhere and automatically configure themselves into an ad hoc network [25]. They can be placed in a home without having to run wires or carefully place the devices in accessible locations. Motes can easily be connected to different types of sensors and programmed to respond in a variety of ways to input. One drawback of motes is that they run on batteries, which must be replaced regularly. Current research is focused on making them smaller and less power intensive.

5.2 Mild Cognitive Impairment

Individuals with Mild Cognitive Impairment have significant memory decline but do not meet clinical criteria for dementia. A percentage of these individuals go on to develop dementia; others improve or remain stable [26].

A Case Study: Ben. Ben, a 76 year old man who lives with his wife, Lee, was diagnosed with Mild Cognitive Impairment one year ago. Of his current problems, he is most distressed by his inability to recognize business clients. Ben painfully described the day when he could not recognize a long-time friend and client who walked into his office. Ben has few outside interests – his life has always revolved around his work and his close relationships with his clients, many of whom are also his friends. He lives in fear of the day when he will have to give up the business that has provided him with his core identity.

Experience Prototype for Mild Cognitive Impairment – Easing Name and Face Recognition. A prototype to address Ben’s needs is an embedded assessment and

rehearsal tool that would allow mildly impaired individuals to practice name and face recognition³. The primary goal of this tool is to ease social anxiety, and as a consequence social connectedness, by aiding person recognition. A second goal is for timely and ecologically valid assessment data that could facilitate early detection of further decline. This assessment would be presented through actionable feedback about variability in performance (e.g., that Ben's recognition tends to be better in the morning, and therefore mornings might be a good time to make social visits) or suggestions of strategies for recognizing people that compensate for memory decline. In its current form, this concept would not be appropriate for elders with dementias that prevent learning of new material, such as Alzheimer's, or for those with severe short-term memory impairment.

This concept invites the elder with mild impairment 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 social network).



Need: Ben struggles to remember the names of his friends and clients.

Experience prototype: Embedded assessment and name-face rehearsal tool.

Fig. 7. Need and experience prototype for mild cognitive impairment.

Technology Ingredients. This prototype includes RFID tags in photos 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.

³ This is currently a partially working demo, not a prototype.

5.3 Moderate Cognitive Impairment

Moderate dementia is characterized by severe memory loss and significant functional impairment. The functional impairment often makes it impossible for these elders to live alone. Due to profound trouble with language, fine motor control, and performance of sequential behaviors, they struggle with routine tasks such as cooking, and may leave out critical steps, such as turning off the burner.

A Case Study: Betty. Betty is a 59-year-old woman with early onset and rapidly advancing Alzheimer's. According to her husband Bill, Betty was previously very bright and had a remarkably broad vocabulary. After a series of stressful events in Betty's life, her family began to notice changes: She was forgetful, less articulate and had difficulty with simple computations. When shopping one day, her daughter was alarmed to see Betty unable to count change. Bill took Betty to a psychologist, and after a series of tests and re-tests, she was diagnosed with Alzheimer's disease. That was three years ago.

Today, Betty has profound difficulty with memory, language, and perception. She often struggles to remember the name of her two-month-old granddaughter, and is unable to read a clock face or piano sheet music. One of Betty's most notable challenges is in carrying out routine sequential tasks. In our interview she demonstrated her struggle to prepare a cup of coffee. With palpable anxiety, she tentatively retrieved her cup from the cupboard, opened the coffee can, put in the coffee filter, and spooned in the coffee. She turned on the coffee machine, and nothing happened. She had forgotten to pour the water into the machine.

Experience Prototype for Moderate Cognitive Impairment – Adaptive Coaching through Sequential Routines. Our prototype addresses Betty's 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. Adaptive prompts, given only when a step is missed, appear on the kitchen TV or another familiar interface.

Technology Ingredients. This prototype consists of multiple types of sensors, an activity inference engine, and prompting devices. The infrared system described in the healthy aging case is used to track general location and orientation within the house. RFID tags in the shoes of the elder are detected when the elder passes through doorways or steps on rugs that contain RFID readers. Simple switch sensors can determine when cupboard doors have been opened, and sensors in cups and containers in the kitchen determine what the elder is doing. All of the sensor data flows into an inference engine that determines what activity is being performed, and where the elder is in the process. It 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. An important aspect of this system is that it allows the elder to be in control whenever possible. It does this by tracking the elder's general abilities and



Need: Betty forgets the next step as she tries to prepare coffee.

Experience prototype: An instrumented kitchen that tracks activity and prompts as necessary.

Fig. 8. Need and experience prototype for moderate cognitive impairment.

their current level of functioning. For example, if the elder usually requires prompting to make tea, but is having a particularly good day, the prompts might be delayed.

5.4 Severe Cognitive Impairment

Severe cognitive impairment is characterized by decline in everyday functioning that renders the elder heavily dependent on caregivers. In addition to cognitive decline that drastically limits communication abilities, coordination and perceptual difficulties necessitate help with activities of daily living (such as eating, bathing and dressing).

A Case Study: Stan. Stan is a 67-year-old man with late stage dementia. He lives with his wife Nancy (age 63) of 40 years. Nancy first started to notice that something was wrong with Stan about ten years ago. He seemed forgetful and had difficulty finding the right words to express himself. To Nancy, this was very unusual, particularly since Stan had always been highly verbal. She ignored these signs initially, partly because she was dealing with her own father's Alzheimer's disease at the time.

Stan eventually saw a doctor, but the tests were inconclusive. It was clear he had memory loss, but not whether it was permanent or a result of depression. Eventually, Stan was diagnosed with Lewy Body dementia, a disease with different cognitive and motor characteristics than Alzheimer's. Stan has now lost most of his ability to talk; his speech is mostly limited to playful babbling. Every morning, Nancy wakes him, showers and dresses him, feeds him breakfast, brushes his teeth, and gets him ready for the day. Stan likes to sit in front of the TV and watch videos. Nancy still works at home as a free-lance writer. As Stan's condition has worsened, he is at greater risk of falling and Nancy hesitates to leave his side.

An Experience Prototype for Severe Cognitive Impairment – Ensuring Safety.

Our prototype addresses the need for the elder’s safety and the caregiver’s freedom through a pervasive sensor and activity tracking system, coupled with contextualized, adaptive reminders. This system detects when Stan is up and at risk of falling, where to alert Nancy, and with what degree of urgency.



Need: Nancy is afraid to leave Stan alone for fear he will wander and fall.

Experience prototype: Chair sensors and location trackers can detect when Stan is in danger and notify Nancy.

Fig. 9. Need and experience prototype for severe cognitive decline.

Technology Ingredients. The prototype system for severe cognitive impairment consists of a sensor network, an inference engine, and a prompting system similar to the one above. Pressure sensors in the household chairs determine when someone is sitting in them, and RFID tags in the elders’ shoes combined with an RFID reader in the rug in front of the chair identify the specific person. The inference engine detects activities, and determines when a prompt is appropriate. In this case the caregiver, not the elder, is prompted when there is a potentially dangerous situation. The system needs to track both the elder and the caregiver, and to determine when it is necessary to intervene. For example, it might not intervene if the elder stands up from his chair when the caregiver is in the same room, but would send a notice to an output device if the caregiver is in another room.

6 Conclusion

Through ethnographic research, we have learned about the lifestyles, aspirations, and unmet needs of a rapidly growing population. Their primary unmet needs – for early detection that is empowering and actionable, adaptable and enabling support, and facilitation of social connectedness, all via comfortable, overlearned interaction with familiar devices – can drive design of innovative solutions for cognitive impairment, other health issues, and conceivably a much broader array of problems. The findings

from this study also broaden our expectations of ubiquitous computing. For example, ubiquity in these households will require a wide palette of networked touchpoints, not only of typical computing devices (e.g., PCs, laptops, PDAs, and tablets) but also of everyday devices (e.g., alarm clocks, radios, and televisions). Adaptive systems, will have to adjust not only to differences among individuals, but to the variability in each person's functioning, over short and longer periods of time. To be contextually aware, systems must identify not only the elder's location within the home, but also the proximity and positioning with regard to potential touchpoints, the amount of physical, social and mental activity in and outside the home, and even the quality of that activity. Finally, usability should be conceived of as livability; it is not enough that elders can use a system – they must want to do so routinely. If necessary, the elder's network of caregivers will also need to interact with the system through private, secure channels. An ongoing challenge is to design experience platforms that meet these requirements and function in the context of real lives and real homes.

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