
Design Research Techniques for Elders with Cognitive Decline: Examples from Intel's Digital Health Group

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Introduction

There are many challenges in developing usable, useful, and livable technology for normal healthy adults, as evidenced by the boom in conferences, books, consulting agencies, and design firms that specialize in "designing for usability". These challenges are exacerbated in designing for people with impairments. People with impairments often have requirements and desires that may be foreign to most people, and the common practices that have evolved to support routine activities may not apply or be counterproductive. Designers and technology developers may fail to even consider elements that might be crucial to users with impairments. Thus, the process of designing technology for people with impairments must be particularly capable of capturing unique and unforeseen requirements. We describe a few of the approaches we have used and some examples we have developed in designing technology for elders with cognitive impairment.

A Range of techniques

The Digital Health group at Intel has used a wide variety of techniques to inform design for people with cognitive impairment. These range from very open ended qualitative discovery methods to more tightly controlled experimental designs. We can describe how these approaches are used by placing them in reference to the breadth of functionality investigated and to the developmental stage of the technology design. For example, an ethnographic approach might be applied when a particular user segment has been identified, but little else is known about the needs, the environment, or the functions that might be supported or enhanced. On the other hand, usability testing might be conducted when a technology has been developed for a specific set of functions.

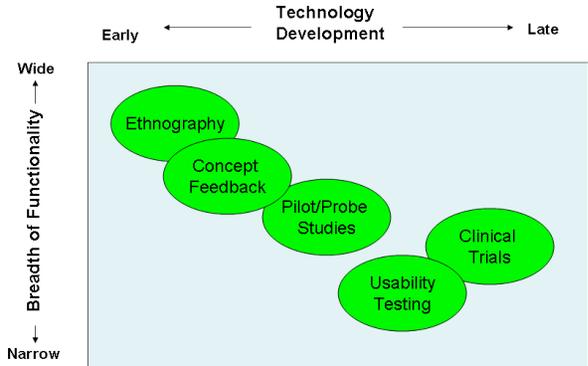


figure 1. Techniques are applied depending on the breadth of functionality under consideration and the stage of technology development.

Living with Cognitive Decline – An Ethnographic Study

Our initial work in this area began with an extensive ethnographic study of elders, spouses, and family caregivers coping with age related cognitive decline. This included people in various stages of Alzheimer’s Disease, Lewy Body Disease, and Mild Cognitive Impairment. We conducted in-depth interviews in 45 households across five different U.S. regions. Our focus was on understanding the lifestyle changes and challenges to the patient and the family as a result of cognitive decline and to develop concepts that might address these needs. In household interviews we interviewed elders and caregivers about their key challenges and examined their coping strategies, including technologies. The data from this study revealed a rich set of themes, issues, and needs that continues to provide our group with concepts and prototypes that are being developed [5].

Concept Feedback - Focus Troupes

At the conclusion of the ethnographic study, we had a wealth of data on the social and environmental challenges, and had a number of technology concepts for addressing the needs of both elders and those who care for them. We wanted to obtain validation on these concepts before moving forward with development, but of course there is a particular challenge with this group. Many of those with cognitive decline have difficulty understanding new concepts, and many, if not most of our participants were not tech savvy. We decided that the concepts needed a method of description that incorporated the social, emotional, and environmental contexts we discovered in our ethnography, and an easily understood method for explaining how the

technology might affect their lives. We decided to use focus troupes for this purpose.

A focus troupe is a method of depicting a technology concept via dramatic scenarios [7, 2]. In this method, actors demonstrate the concept by dramatizing its use in a staged context. The audience consists of target users, and a facilitator leads a discussion after each scenario about the concept and how it might be used (or not used) by the audience. Like a focus group, this method is qualitative – data is collected on people’s reactions and comments.

The value of a focus troupe is that the emphasis is on the context of use and the social interactions among the actors, as opposed to the technology or device. In fact, we conducted the dramatizations with no technology props at all. For example, when an actor was interacting with a display, she simply mimed the act of touching a screen and revealed through her comments and actions what was being displayed.

Improving Social Health – a pilot study of ubiquitous sensing and display of social interaction

One area that arose from our ethnographic studies and the focus troupes was the issue of maintaining social health [4]. We designed a sensor system for tracking the social activities of elders and developed a prototype system that could be deployed into the homes of elders. In a three and a half month pilot study, we installed the sensor system into the homes of six dyads, each dyad being an elder and a primary family care giver. We had two hypotheses. 1. A sensor network can adequately track the social health of elders (as compared with self-reports of social activity by the

elder and the care giver). 2. A social health display that reflects back the amount and quality of social activity to the elder and care giver will improve social health. Our reasoning was that a real-time display that shows how much social activity a person is getting will encourage strategies to improve social contact [see 3 for more details].

The trial provided valuable lessons not only in the efficacy of our technology (which, in many cases, demonstrated substantial improvement in social activities), but also provided insights into conducting effective home trials with elders with cognitive impairments. As an example, we found that it was very useful to recruit a family care giver who was both enthusiastic about the study and somewhat technology oriented. This helped greatly in maintaining the elder’s engagement in the study over time.

Context Aware Medication Prompting

Another area that we are conducting pilot trials is in the area of medication reminding. Medication adherence is a well recognized health problem [6], and our research has indicated that it is often considered a primary indicator of the ability to live independently. If people with cognitive impairments can manage essential activities such as remembering to take their medications, they have a much better chance to live independently. We are deploying a home sensor system that will track an elder’s activities and remind them to take their medications depending on where they are located, where their medications are located, in the most appropriate modality. Like the Social Health trials, our intent is to deploy the system in real homes over a lengthy period of time to assess its real value and efficacy over time.

Diagnosis and tracking of Parkinson's disease – usability testing and clinical trial deployment

Our final example demonstrates how we tested a specific set of functionality through user testing involving Parkinson's disease patients. In a project that is separate from our cognitive decline efforts, we have developed a device for assessing the progression of Parkinson's disease. The device is a specialized box with a display that leads a Parkinson's patient through a battery of motor and verbal tests. We designed the tests in conjunction with some of the leading experts in Parkinson's disease, and developed on-screen and verbal instructions intended to be easily learned by the patients. To validate the learnability of our design and to assess whether people would use it regularly, we brought Parkinson's patients and their spouses into the usability lab. From prior focus groups, we had learned that support from spouses would be essential in maintaining compliance from Parkinson's patients to use the device at least twice a week. In our usability tests, we had spouses sit with the patient as they set up the box and went through the on-line instructions. Through this "co-discovery" approach [1], we learned what needed to be modified in the instructions, and also gathered valuable information from the spouse on how the device would be used at home, and in which aspects the patient might need help.

After some revision of the device, we are beginning a clinical trial in 50 homes of Parkinson's patients. If successful, the device may lead to new understanding of the progression of Parkinson's disease and new therapies.

Conclusions

The methods we describe have in one sense been typical CHI methods for developing technology, but they have been adopted for this special group of people. Our ethnographic studies have required care and sensitivity in conducting our interviews and observations, and have required much expertise in dealing with sensitive medical issues. Our concept feedback was effective when the concepts were dramatized in a way that downplayed the technology and highlighted how the relationships and situations might be altered by the technology. Long term pilot studies in the elders' environment allowed us to assess the efficacy of the technology and its viability over time, while usability testing involving the patient and the spouse allowed us to evaluate its use in a situation where partner support was essential.

However, many more approaches need to be explored and developed, particularly for those experiencing severe cognitive impairment and whose communication capabilities are severely restricted. One question we would like addressed in this workshop are:

- How can we measure the value of and obtain feedback for technologies designed for someone who has very limited communication capabilities?

Another question arises from our observation that elders who may be most at risk for cognitive decline or who are experiencing early signs may be most resistant to assessment and remediation. They are essentially in denial of their condition, and resistant to anything that suggests they need help.

- How can we design assessment and diagnosis technologies that will be adopted by people at risk before cognitive decline is evident?

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Jay received his doctorate in cognitive psychology in 1988 from the University of Washington. There he studied decision making, expert knowledge, and computational theories of cognition. Jay's research in industry has focused on human-computer interaction for in-home consumer products. He has worked on Intel projects such as the Intel Web Tablet, the Intel museum site ArtMuseum.net, as well as working with companies such as Ticketmaster and the Home Shopping Network to develop consumer-friendly Internet commerce sites. His current interest is in the psychology of aging and human-computer interfaces to support health related applications. In the Intel Digital Health Group, he is conducting research to understand how technology might be used to help elders live independently and with a high quality of life in their homes as they experience cognitive decline and other health issues.

Margaret Morris, PhD, Senior Researcher, Digital Health Group, Intel Corporation

Margaret Morris is a clinical psychologist who identifies new ways to enhance mental and physical wellbeing with emerging technologies. Using an "embedded assessment" approach, Margie develops exploratory systems to continuously monitor health status and motivate behavioral change. She integrates ethnographic and clinical interviewing approaches to understand consumer health needs and usage models. In her past health research, Margie has evaluated numerous psychological and medical interventions. She has also examined changes in self-concepts with age and illness, and developed a novel assessment technique using network modeling to depict the influence of illness on self-schemas. Another of Margie's focus areas is the way people interact with the physical environment, broadly defined to include ecology, architecture and technology. Her dissertation examined the effect of sunlight on feelings of physical comfort and social connectedness. She has also studied personality expression in home and work environments, and behavioral adaptation to workspaces. Prior to joining Intel, Margie studied technology adoption as a member of Sapien's Experience Modeling group. Margie completed her Ph.D. in Clinical Psychology with a minor in Behavioral Neuroscience at the University of New Mexico, her clinical internship at the San Francisco VA Medical Center, and her postdoctoral fellowship at Stanford University. She has a B.A. in English from Haverford College.