

Caregivers, Cost, and Complexity: Understanding Technology Usage by Individuals with Cognitive Disabilities

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ABSTRACT

This research employs ethnographic and user-centered design methods in a multi-phase study designed to uncover usability issues and evolving user needs through the design and extended use of a handheld remote communication system for individuals with cognitive disabilities. This extended abstract focuses on the findings from the first phase of the research, an interview study exploring issues around adoption and usage of technology by individuals with cognitive disabilities.

Keywords

cognitive disabilities, user-centered design, adoption

INTRODUCTION AND PROBLEM DESCRIPTION

This research is part of a larger project called the Cognitive Levers (CLever) project at the University of Colorado. The Cognitive Levers research team is developing mobile, handheld assistive technology systems for individuals with cognitive disabilities (referred to here as “clients”) to bring increased independence and quality of life.

The purpose of this research project is to understand and anticipate the usability challenges and evolving user needs of a handheld remote communication system for individuals with cognitive disabilities. The research approach is a three-phased ethnographically-informed study that makes families designers of their own technology. The three phases are: 1) an in-home and in-classroom interview study with families and teachers; 2) an in-home interview study and diary and observation study; and 3) a design and usage study with a technological probe [3].

This extended abstract will focus on discussing findings from the Phase 1 interview study, which took place in the spring of 2004. This formative study explored the following research questions:

1) What assistive technology, and other technology, is used today by individuals with cognitive disabilities?

2) What is the process of assistive technology adoption?

3) Who is involved in the adoption process?

BACKGROUND AND OVERVIEW OF LITERATURE

The challenge of creating effective tools to assist individuals with cognitive disabilities may explain why although these individuals have greater functional disability than those with other types of impairments, they use the fewest number of technological aids [5]. Studies suggest that this is due at least in part to the absence of technology designed for this population [10]. In addition, across all types of assistive technology the abandonment rate is 35% or more [2, 6, 10]. Part of this challenge is that augmenting cognition [1] is a less well-defined problem than augmenting other types of abilities, such as mobility or vision. While we strive for universally-accessible design [7], each user will have a unique set of abilities and needs.

Developing tools for this population on a handheld platform introduces additional complexity. Recent user studies [8, 9] have begun to reveal the challenges users experience when using handheld devices for off-the-desktop activities. Still, there is a lack of research data available for predicting the major usability issues (e.g. battery life, fragility, screen size and touch sensitivity) that will arise with handheld-based tools for this population. A better understanding of the contextualized usage of handheld devices among individuals with cognitive disabilities is needed.

INTERVIEW STUDY METHODOLOGY

I conducted 20 semi-structured interviews with parents and teachers in Boulder and Denver who have a teenage or young adult student or child with cognitive disabilities. The interviews were held in the home or classroom, and lasted between 45 – 90 minutes. The interview questions focused on current and past AT usage and factors affecting successful technology adoption; “regular” technology usage such as computers, cell phones, and video games; and ideas about potential AT. The interviews were audio recorded, transcribed, coded and analyzed using techniques from grounded theory.

FINDINGS

Through these interviews the following key themes emerged:

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1) Assistive technology adoption is a process with multiple stages, involving multiple caregivers. In general, individuals with cognitive disabilities receive care from a number of individuals in the course of a day, and across their lifetime. Caregivers play different roles in the technology adoption process. Teachers and experts in the school system are often closely involved in the technology identification stage [5, 11], and parents are often more involved in incorporating the technology into the child's life and maintaining it after the child left the school system. Technology abandonment may occur when the goals and expectations among these different caregivers are not shared.

2) Caregivers are optimistic about the potential of technology to increase independence and social interaction. Respondents repeatedly stressed that technology has the potential, though often unrealized, to increase independence and social interaction for their children. In a few cases, clients use off-the-shelf cell phones for this purpose, albeit with some difficulties. A father described how using a cell phone played a key scaffolding role in his daughter's learning to ride the bus, and hold a job:

Well, when she first started going to work, I mean, she'd call from the bus stop, she'd call from the bus itself, she'd call when she got to Middletown, she'd call when she got to work. I mean, it's part of the process. Without the cell phone, she wouldn't have a job.

3) Barriers to adoption include complexity in configuration, and cost or difficulty of replacement. Respondents cited complexity in "setting up" devices, when configuration required too much time and effort, as a barrier to adoption. In fact, even though families acquired expensive AT devices, most AT actually used at home was "regular technology" appropriated for a special purpose. Devices included memo recorders and kitchen timers, used for their simplicity and, as one mother put it, "*when it breaks .. it won't be like a big, 'oh my goodness. now what do we do?'*". Respondents also emphasized the need for replaceability, referring to both replacing the hardware if the device is lost, and replacing customizations if the software crashes or is upgraded.

Design Implications

These findings suggest that among caregivers, independence and increased social interaction are high priorities for new AT. AT should provide usefulness out-of-the-box without requiring extensive configuration. AT systems should be designed with replaceability in mind, so that customizations are backed up and can be easily restored or exported to a new device.

FUTURE WORK AND EXPECTED ACHIEVEMENTS

This formative study has led me to focus in Phase 2 and Phase 3 of my research on remote communication, which

has been shown to have potential in increasing independence and social connectedness. In Phase 2 I will study existing remote communication patterns between caregivers and clients. In Phase 3 I will conduct a longitudinal usage study with a technology probe [3] that provides remote communication functionality, in order to identify real-world usage issues and evolving user needs.

At the end of this project, the data can be analyzed in a variety of ways: 1) as platform-level usage data to predict usability issues for handheld assistive technology systems; 2) as a longitudinal analysis of the adoption process, from the decision-making stage into the incorporation stage; and 3) as real-world data of evolving usage and appropriate customization support for such systems.

REFERENCES

1. Engelbart, D.C. Augmenting human intellect: A conceptual framework, SRI Project No. 3578 (October 1962), 1962.
2. Goette, T., Factors leading to the successful use of voice recognition technology. in *Proceedings of the third international ACM conference on Assistive technologies*, (1998).
3. Hutchinson, H., Mackay, W., Westerlund, B., Bederson, B.B., Druin, A., Plaisant, C., Beaudouin-Lafon, M., Conversy, S., Evans, H., Hansen, H., Roussel, N., and Eiderbäck, B., Domesticated design: Technology probes: inspiring design for and with families. CHI 2003, 17-24 .
4. Kintsch, A., and DePaula, R., A Framework for the Adoption and Abandonment of Assistive Technology. in *BVSD SWAAAC Conference*, (Winter Park, Colorado, 2002).
5. Mann, W.C., Hurren, D., and Tomita, M. Comparison of assistive device use and needs of home-based older persons with different impairments. *The American Journal of Occupational Therapy*, 47 (11). 980-987.
6. Martin, B., and McCormack, L., Issues surrounding Assistive Technology use and abandonment in an emerging technological culture. in *Proceedings of Association for the Advancement of Assistive Technology in Europe (AAATE) Conference*, (1999).
7. Norman, D.A. *Things that make us smart*. Addison-Wesley Publishing Company, Reading, MA, 1993.
8. Pascoe, C., Ryan, N., and Morse, D. Using while moving: HCI issues in fieldwork environments. *ACM Transactions on Computer-Human Interaction*, 7 (3). 417-437.
9. Perry, M., O'Hara, K., Sellen, A., Brown, B., and Harper, R. Dealing with mobility: Understanding access anytime, anywhere. *ACM Transactions on Computer-Human Interaction*, 8 (4). 323 - 347.
10. Riemer-Reiss, M., Wacker, R. Factors associated with assistive technology discontinuance among individuals with disabilities. *Journal of Rehabilitation*, 66 (3).
11. Rogers, E. M. 1995. Diffusion of innovations (4th ed.). NY: The Free Press.

