Original Paper

User-Centered Design of a Digital Knowledge Medium to Support Family Caregivers of Brain Injury Survivors

Teresa Chiu[1,2], PhD (Cand.); Michael Massimi[3], MSc (Cand.)

[1]COTA Health, Toronto, ON, Canada
[2]Occupational Science and Occupational Therapy Department; Health Policy, Management, and Evaluation Department; University of Toronto, Toronto, ON, Canada
[3]Department of Computer Science, University of Toronto, Toronto, ON, Canada

Corresponding Author
Teresa Chiu
COTA Health, 700 Lawrence Avenue West, Suite 362
Toronto, ON, M6A 3B4 Canada
Phone: +1 416 785 9230 ext 1109
Fax: +1 416 785 9358
Email: chiu_t@cotahealth.ca

Abstract

Background: When caring for a family member who suffers a brain injury, family members often need to share the care. While the family is learning to cope with the injury, each member must rearrange his or her own schedule as well. We envision a computer system that can aid in this transition period, and continue to support family members in managing care amongst themselves in the years to come. Designing a computer system for use in the context of healthcare requires knowledge from the health and computer science fields. **Objective:** This paper describes our experiences of integrating the knowledge in both fields to design and evaluate a digital knowledge medium that aims to ameliorate the burden of managing care schedules for families with a member who has brain injury. A digital knowledge medium is an electronic device that supports thought, coordination, and planning. **Method:** Computer system interface and system design involve iterative design to ensure that the device supports the user. Because caregivers are stressed mentally, physically, and financially, it is paramount that design choices are well-executed. This paper illustrates the strong need for lockstep design, where each design choice is validated with the family and specifically targeted for their circumstances. The design progressed in three stages. First, we conducted needs assessments with three families using stakeholder interviews, artifact assessment, and environment assessment. Second, the needs assessment data were analyzed using stakeholder, artifact, task, scenarios and requirement analysis techniques. We used the analysis results to develop a design concept. Finally, two caregivers and two case managers validated the design concept in interviews. They performed representative tasks using two prototypes. Their performance and difficulties with the tasks were observed. **Results:** The results showed that primary caregivers who were busy had to perform complex tasks to schedule and coordinate helpers. The nature of coordination and the network of helpers frequently changed. The results surprised us with new user needs. In the artifact analysis, we learned the importance of translating traditional artifacts like calendar and white board into the new digital counterparts: caregivers thought the new design useful and easy to use because familiar metaphors were chosen. In the usability study, we learned why caregivers had difficulties using some functions by carefully examining conceptual similarities and differences between the designers and caregivers. We added three new functions to enhance the design. The validation study showed that the new design was perceived as useful, easy to use and consisted of important functions. **Conclusions:** Our experience shows that eHealth technologies can be integrated into the caregiving cycle through user-centered design techniques. This project also demonstrates how a collaborative study can promote cross-germination of design and evaluation methodologies between the fields of human-computer interaction and occupational therapy.

Keywords

User-centered design; information systems; internet; family caregivers; user issues; brain injuries

Introduction

When caring for a family member who suffers a brain injury, family members often need to share the care. While the family is learning to cope with the injury, each member must rearrange his or her own schedule as well. We envision a computer system that can aid in this transition period, and continue to support family members in managing care amongst themselves in the years to come.

A Digital Knowledge Medium is an electronic device that supports thought, coordination, and planning. Designing a Digital Knowledge Medium for use in the context of healthcare requires knowledge from the health and computer science fields. In the field of human-computer interaction, user-centered design [1] is a well-established methodology employed to ensure that computer systems address real needs faced by actual people. Digital Knowledge Media applies user-centered design to involve users throughout the development stages [2]. In the health field, occupational therapists enable people affected by health problems to use technology in naturalistic environments to enhance their daily function. Occupational therapists assess the clients' functioning, home environment, use of equipment or assistive devices, and participation in life roles. A client-centered approach of care is a core principle of occupational therapy.

This paper describes our experiences of integrating the knowledge in both fields to design and evaluate a digital knowledge medium that aims to ameliorate the burden of managing care schedules for families with a member who has brain injury. This paper focuses on the design methodology used to assess the users' needs, interaction design, and validation of the design concept. Specific features of the resultant system are reported elsewhere [3].

Methods

Computer system interface and system design involves iterative design to ensure that the device supports the user. Because caregivers are stressed mentally, physically, and financially, it is paramount that design choices are well-executed. This paper illustrates the strong need for lockstep design, where each design choice is validated with the family and specifically targeted for their circumstances. There are three design processes in designing a Digital Knowledge Medium: (1) to understand the needs of users, (2) to create a design concept that can support their needs, and (3) to validate the design concept by users.

Understand user needs

The needs assessment process allows us to enter the world of the family caregivers to understand their perspectives, tasks, and environments. We used three approaches to involve the caregivers and to collect context-rich and in-depth data.

First, we identified the stakeholders who would be affected by the introduction of a new computerized caregiving management system. We selected three families and interviewed the caregivers and the brain injury survivors. We asked the caregivers what they needed to plan and organize in daily care, how they did it, who was available to help, how they communicated to coordinate the care, and their competence in using the computer and the internet. We interviewed them in their homes. The interviews lasted for approximately one hour and were audio-taped.

Second, while there we asked the caregivers to show us artifacts they used to coordinate and organize caregiving activities. These were items that stored or conveyed caregiving-related knowledge. They ranged from the sophisticated (desktop computers, cell phones) to the mundane (medicine cabinets, notepads). We took photographs of the artifacts (eg Figure 1). We asked questions about how they use the artifacts, when they use them, and what they liked and disliked about them.

Third, we observed the environments in which the caregivers and care-recipients set the schedules and communicated with each other. We assessed who was in the circle of care, their roles, and their means of communication with the primary caregiver (human environment). We identified the place where the caregivers set the schedules (non-human environment).

Figure 1.
A central calendar on the refrigerator.

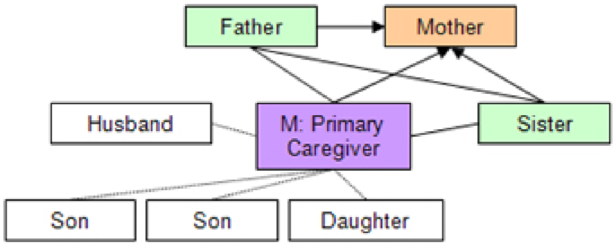

Figure 2
Family 2's caregiving diagram
Purple: Primary Caregiver
Green: Secondary Caregiver
Orange: Care Recipient

Develop the design concept

Design is a creative activity grounded on rigorous analyses of the users' needs. We used four analysis techniques to identify important elements to conceptualize the design.

First, we conducted Stakeholder Analysis to identify salient themes from the interviews that describe the characteristics of the caregivers, their tasks, the environments, and how these elements interrelated to each other. We created caregiving network mappings (Figure 2) and identified problems and strengths in communication.

Second, Artifact Analysis critically examined household items, creating an understanding of when it is used, for what, and how. We examined whether the look, functions, and properties of the artifacts can be translated into a digital knowledge medium. Doing so can promote knowledge transfer and assist stakeholders in learning to use the new Knowledge Medium.

Third, Task Analysis involves taking a task (such as setting a caregiving appointment) and breaking it down into its component subtasks. We gained a better understanding of the task and ensured all cases are appropriately handled.

Fourth, Scenario Analysis is the creation of short narratives describing the context of the interaction with a fictitious cast of characters. We created a scenario that described how a caregiver plans the tasks when she has to go away for a week. The scenario was translated into pictures of events and mock-up of the system. The graphical presentation forms the storyboard.

Finally, Requirement Analysis integrates the above analyses and sets the rules of what a design must or must not do, behave and look like. We followed five types of requirements: functional, user, data, environmental, and usability requirements [1]. Using the requirements list, we generated two scenarios, two storyboards, and two task analyses of the scenarios. We invited an expert in human-computer interaction and a case manager who is experienced in working with families of brain injury survivors to scrutinize the scenarios, storyboards, and task analyses. We modified the design on the basis of their feedback and finalized our initial design concept.

Validate design decisions with users

The validation process brings the users back into the design process. They validate the design by actively experiencing, exploring and critiquing the concept. To allow the users to fully participate in this process, the design concept is translated into prototypes. We coded two low-fidelity prototypes. One prototype was completed in HTML, and one was completed in Microsoft PowerPoint. Each one showcased a different usage scenario; in one, the user was asked to create a new appointment, while in the other they were asked to make caregiving decisions based on a calendar.

We revisited two caregivers in their home and invited two case managers to validate the design in separate meetings. We used a laptop to present the prototypes. The participants used a pencil as a “stylus” to interact with the prototype. Each meeting lasted for approximately one hour and was audio-taped. There were three parts in the validation meeting.

First, we explained to them the purpose of the design. We asked them questions such as “What would you expect this system to do? Where in the home would it be placed?” This step helps to validate our understanding of their needs.

Second, they used the prototypes to complete a set of representative tasks in a usability test. The participants were encouraged to think aloud as they performed the tasks. We noted where they had difficulties with the system and asked them to comment on how they expected the system to behave. The goal was to validate conceptual similarities and differences between the designers and the participants.

Third, after exploring the prototypes, we gave the participants a list of all proposed functions in the system, including those that were not shown on the prototypes. They were asked to check off which functions were important and which functions seemed to be missing.

Results

The primary stakeholder persona was a middle-aged female who provided part or most of the direct care herself. The care-recipient had a brain injury that resulted in physical disabilities, memory problems, and cognitive impairments. She had to manage the medical appointments, out-patient rehabilitation, and home-based services of the care-recipient. She provided care for

12 to 47 hours per week, had other life roles, and was stressed. Because the progress of the brain injury survivors was slow and long-term, the caregivers had to continuously adjust the care over a span of three to six years. The results surprised us with new user needs. When brain injury survivors gradually recovered, they were able to slowly relearn how to manage their own schedule. The primary caregiver took on yet another new challenge; she needs to educate the care-recipient and assist him/her to manage the schedule. She had experience with computers and the internet but would not spend much time to learn a new tool.

In the artifact analysis, we learned the importance of translating traditional artifacts like calendar and white board into the new digital counterparts. The caregivers used several artifacts. The calendar (Figure 1), used by all three families, was located in the kitchen with large print that makes it easy for the brain injury survivors to read. The most common use was for checking appointments for the brain injury survivor. A whiteboard often was placed close to the calendar to record appointments, reminders, or other messages for communication. The caregivers also used a telephone book/programmable telephone to record the phone numbers of health professionals, community programs, family and friends. They used the computer/internet to send emails to friends and families. The telephone was used by all families for communication.

The primary caregivers relied on a network of family members and health care providers to help. The size of the network can expand to involve more than ten people at one time. The large network offered a lot of assistance. Yet, the primary caregiver needed to coordinate the care and communicate among the members in the network. She also needed to “supervise” the caregivers who may not have the implicit caregiving knowledge the primary caregiver had. The other family members might include their partners, in-laws, spouse, children, siblings, and so on. The type of care and the number of caregivers needed were constantly changing. The primary caregivers had to skillfully handle the family dynamics in this trying time.

The non-human environment of care was unstructured and interwoven with other family activities. The central place of communication and scheduling was the wall-mounted calendar located in the kitchen. Anybody can record/check on the calendar: primary caregivers, secondary caregivers, or the brain injury survivor. Direct communication happened on the phone, during meal time in the dining room, or when the caregivers are preparing meals in the kitchen. The computers often were located in the bedroom or a room on another floor of the house, preventing them from using email as a primary communication medium.

The requirements analysis supported a design concept that simulated the display and functions of a wall-mounted calendar and whiteboard placed in the kitchen. In addition to supporting the functions of these traditional artifacts, the digital knowledge medium included three new functions: (1) the capacity to visualize potential scheduling opportunities to improve the speed and ease of decision making, (2) the support of digital communication by other users via heterogeneous communication tools such as desktop personal computers, personal digital assistants, cell phones, etc., and (3) the provision of dynamic profiles to support the varying and changing functional and interaction needs of diverse end users.

The validation meeting results showed that the participants found the two prototypes as easy to use (Mean: 5.8 out of 7; higher score more positive) and useful (Mean: 6.1). Most functions of the prototypes were perceived as important by the users, and they were able to perform most pre-determined tasks without difficulties. The results confirmed that our initial design decisions were perceived as helpful to improve their caregiving situations. The findings also illuminated ways to improve the design, such as enhancing the functions to highlight outstanding confirmations and mark urgent messages, refining the interaction sequence of the set appointment button.

Conclusions

The major contribution of this paper is its methodology employed in a case study for designing an in-home support system for family caregivers to plan and coordinate the care of a brain injury survivor. This is a pilot project and will require more work to fully understand the users' needs and validate the design concepts. Our experience shows that a Digital Knowledge Medium can be integrated into the caregiving cycle through user-centered design techniques. This project also demonstrates how a collaborative study can promote cross-germination of design and evaluation methodologies and practices between the fields of human-computer interaction and occupational therapy.

Acknowledgments

We would like to thank Victor Chung, Colin Furness, and Dr. Ronald Baecker for their contributions and tutelage. We are grateful to brain injury survivors, their family caregivers, and COTA Health case managers who participated in the design process.

Conflicts of interest

None declared

References

1. Preece J, Rogers Y, Sharp H. Interaction Design: Beyond Human-Computer Interaction. New York, NY: John Wiley & Son; 2002.
2. Baecker RM. The Web of Knowledge Media Design, Transcript of Speech Given at the University of Toronto on 23 January 1997, unpublished; 1997.
3. Chiu T, Massimi M. A digital support device designed to help family caregivers coordinate, communicate and plan the care of people with brain injury. AMIA 2006 Annual Symposium, Washington, DC, 2006 Nov 11-15 (in press).