ENSURE: support for parents in managing their children’s health

Sun Young Park - School of Design, Carnegie Mellon University, Pittsburgh, U.S.A, (412) 5266786, sunyoung@cmu.edu
Hee Young Jeong - School of Design, Carnegie Mellon University, Pittsburgh, U.S.A, (412) 7805935, hyj@cmu.edu
John Zimmerman – HCII and School of Design, Carnegie Mellon University, Pittsburgh, U.S.A, (412) 2681313, johnz@cs.cmu.edu

Abstract

Parents find themselves experiencing breakdowns when attempting to record, retrieve, or transfer health related information for their children in the many different contexts where it is needed. While the activities of caring for their children take place in diverse locations, there is currently no appropriate tool for helping parents record, retrieve, and transfer the right medical information at the right time. We see in this situation an opportunity for ubiquitous computing technology to support parents’ management of their children’s health information. Based on our user research with dual-income families, we believe the ENSURE Healthcare System that automates the collection of children’s medical/health information in order to improve the communication between parents and healthcare providers will allow for better management of children’s health. The ENSURE system will help parents collect their children’s health information easily and provide it to their health care providers, facilitating their interactions.

Conference theme: Usage and Interaction

Keywords: Smart home, family, health, human-centered design, control

Introduction

Sartre’s three states of existence as a framework – having, doing, and being – parents are parents literally because they have children. Parents come to understand who they are as parents (being) from their own experience of being a child and having parents; from their observations of other parents; from their imaginings of who they might be as a parent; and through their interactions (doing) with their children and reflection on their child’s reaction and the reaction of others to
those interactions\(^1\). Through their actions and reflection on actions, parents develop a *social identity* that is their understanding of who they are in the role of parent, and they develop an *ideal identity* of who they desire to be in this role. In our research we want to operationalize the consumer behavior research on product attachment that shows how people feel attached to things that help them discover, invent, and refine themselves in a role. With respect to parents, we have tried to make products that help parents feel they are moving towards their idealized sense of their self in the role of parent through product interactions. We call this research direction *Designing for the Self* [Ozenc et al. 2007].

One of the basic desires parents have is to take care of their children and part of this desire manifests itself as a set of responsibilities around the management of a child’s healthcare. On the surface this seemed a rich space to investigate from the perspective of Designing for the Self; therefore, taking a research through design approach [Zimmerman et al. 2007], we conducted a user-centered design project exploring how parents manage their children’s healthcare information, with a focus on searching for opportunities for smart home systems to support parents in this goal. Our fieldwork with dual-income families with healthy children revealed breakdowns when parents attempted to record, retrieve, or transfer health related information for their children in the many different contexts where it is needed. Breakdowns can lead to reduced quality of medical care due to under and overdosing of medications, and inadequate or inaccurate information provided to healthcare practitioner leading to inappropriate medical interventions.

To address this situation, and to help parents feel more in control of their children’s health, we designed the ENSURE Healthcare System, which provides (i) tools to automate recording of temperature and medication; (ii) easy retrieval of medical information at home, at a childcare providers, and at the doctor’s office or hospital; and (iii) feedback and reminders for medication. This paper provides a brief overview of related work; details of our design process; a description of the Ensure system; and a discussion of how the system helps.

**Related Work**

Dual-income families are an important and growing population. These parents live in a constant rush-hour state due to complex and conflicting schedules for work, school, children’s activities and family [Frissen et al. 2000]. As a result, they are frequently stressed and often feel like bad parents [Beech et al. 2004, Darrah et al. 2001]. They desire more flexibility to address constant

\(^1\) This application of Sartre’s states of existence comes from Russell Belk’s application of this same framework to help understand how people extend their self to their possessions including the people they interact with, the places they inhabit, and their material possessions [cite Belk: Possessions and the Extended Self].
changes to their chaotic situations [Darrah et al. 2001]. Previous smart home research shows that these parents want to *feel in control over their lives* and that they are interested in smart home technologies that help them gain this sense of control [Davidoff et al. 2006].

In terms of the smart home healthcare system, researchers have investigated monitoring technology, telemedicine systems, medication reminders and an ambient health display for an elder outside of the home in the form of a picture frame [Tabar et al. 2006, Noury et al. 2003, Miller et al. 2004, Mynatt et al. 2001]. The majority of this work has focused on the needs of elders in decline. In terms of children, researchers have investigated monitoring systems to help detect signs of Autism [Kientz et al. 2007]. In all the cases, the research has focused on the medical needs of people in decline or a focus on detecting that decline is taking place. No work has focused on helping people in good health to track their medical history.

Our research is motivated by the consumer behavior research on product attachment. This research shows that people develop attachments to products that play a role in the identity construction process [Belk, 1988; Kleine et al. 2005]. This research has shown the importance of role in the development of attachments [Ahuvia, 2005], as well as the importance of the idealized self in a role as a motivator for bringing new possessions into ones life [Kleine et al. 1993]. In our research to Design for the Self, we attempt to make products that help people become who it is they desire to be in a role [Ozenc et al. 2007].

**Design Process**

Our research followed a user-centered design process including:

1. Contextual interviews in the homes of seven dual-income families
2. Cultural probes exploring children’s medical information at home
3. Interviews with two pediatricians
4. Participatory design work session to investigate medical information sources
5. Concept generation
6. Needs validation
7. Final design

**Interviews with parents**

Interviews with parents included directed storytelling about how they manage their children’s health. During the interview we focused on how they gave medication (both pain and cold medicine and well as prescription medication); how, when and where they kept records of their children’s health; how they passed and received health information with their children’s other care providers including each other; and how they interacted with the doctor. We also asked
them to share specific stories of when they encountered problems such as forgetting to give a child medication. During the interviews, participants gave us a tour of their home, showing us where different medical related activities took place and where information, tools, and medication were stored.

**Interviews with doctors**
In our phone interviews with two pediatricians, we asked about patient visits to understand the difference between regular check-ups and sickness visits, what questions they ask parents, and how parents handle those questions. We also conducted directed storytelling to understand difficult experiences with parents and asked what expectations they have of parents: what information regarding their children should parents remember or keep and what kinds of information parents often miss. Through this interview process, we wanted to see the problems that arise in parent visits and the differing expectations between doctors and parents.

**Participatory design**
In order to better understand parents’ communication with other people and medical information resources, we asked our interviewees to participate in a simple diagramming activity. They organized post-it notes indicating various information resources according to the frequency of interaction and level of their trust. We wanted to understand the hierarchy of medical information resources and to see if the parents had different feelings about these resources from one another.

**Findings**
We categorized the data from the interviews based on theme. Through this activity, we found that parents have three major problems in managing their children’s health. First, do not use or know of tool to the capture and retrieval of their child’s medical information. Second, there are often breakdowns in communication of important medical information when a child moves from one care provider to another including moving from one parent to the other parent. Third, it is easy for parents to miss giving medicine or overdose their children, and the chances increase as their schedules get busier and as they deviate from their normal routines.

Major findings:
(i) Parents expressed a desire to take care of their children’s health and they use many different strategies for managing this. Parents take notes and keep activity diaries; however, these are easily lost or unavailable when the information is needed.
(ii) There is a disconnect in expectations between doctors and parents in terms of record keeping. Pediatricians consider it the parents’ job to keep accurate records of medical events...
such as vaccinations, while most parents consider this kind of record keeping to be the job of the pediatrician. This becomes particularly important when parents take a child to see a specialist who does not have access to the pediatrician’s records and asks parents for information they often do not have.

(iii) There are breakdowns in communication of medical information when a child moves from one care provider to another, including a transfer between parents. Examples include one parent taking over care and learning that a child has recently had fever reducer, but not getting accurate information about the time the medication was given; pickup of children from daycare where there is a general announcement that another child has a streptococcus infection, but the parent picking up has no way to capture this information; and grandparents returning a child the parents but failing to tell them that the child had a stomach ache earlier in the day.

(iv) It is difficult to keep a consolidated record of medical information and activities such as measurements of temperature, taking of medication, throwing up, stomach ache, etc., because the activities take place in many different contexts and many different times of day. Therefore, parents often have several different paper systems that are not integrated, or they have no system at all. For example, when a child is in the bath, parents may witness a rash but it is hard to record immediately. In addition, even though parents want to record their children’s medicine time, it is difficult when they are out of home or when the other caregiver is taking an action.

(v) Parents have trouble in retrieving information because it was either not recorded or because it is not available when it is needed. For example, the doctor may ask about the last time a child had medication during a visit, but this information is written on paper near a bottle in a cabinet in the home.

Design Implications

Based on the interview results and our understanding about parents’ contexts, we explored design opportunities to support their needs. Finally, we came up with four main design opportunities: record, retrieve, transfer, and remind.

1. Reduce parents’ burden to record children’s healthcare information

“I always make a note for questions I want to ask later.”

“When my daughter had a headache, a doctor asked me to write headache diary. However, I didn’t because of my busy schedule. I still feel guilty.”

One of the common strategies for managing children’s medical information is the documentation of medical records. Parents often use notes for recording something such as food
diary, headache diary, and breastfeeding diary. However, since healthcare activities such as measuring body temperature and giving medicine to kids take place everywhere in the home as well as out of the home, it is hard to record those actions.

For example, when children are on the medication, it is easy to get where the medicine bottle is, but medicines can be in different places. Fever reducer is often in the upstairs bathroom but antibiotics for children are usually the refrigerator in the kitchen.

2. Support parents to retrieve children’s healthcare information anytime, without confusion

“I often forget to bring the notes I have taken about my kids’ medical information to the doctor’s office.”

“I want to access my children’s medical information whenever I want.”

Although parents keep and record children’s health information such as symptoms of illness, medication information, recent diets, or messages from doctor’s office and school, it is a challenge to retrieve these records whenever they need. For example, when parents are at the doctor’s office and they are asked about the information on the last time of using the fever reducer, they might have the information written on the paper next to the medicine bottle on the kitchen counter. In addition, particularly during an emergency situation such as a night call to nurse or at an emergency room, parents are asked about their children’s recent diet, recent illnesses, symptoms, and medication; however, they rarely have this information available even if it is recorded.

3. Help parents feel confident to transfer children’s healthcare information to others

“I gave the medicine bottle for sure to our baby sitter directly when my kids are sick.”

“In order for my husband to give medicine to my child in the middle of night, I put a sticky note with the next medication time on the baby bottle before I go to bed.”

Dual-income parents need to interact with each other and other caregivers such as babysitters, nannies, and grandparents and let them know the exact information especially when their children are on medication. There are often communication problems between parents and these caregivers as they trade roles in caring for the children. Addition to the communication with caregivers, there happens communication issues in communicating with healthcare providers. Therefore, parents need an effective way to communicate with each other, other caregivers and healthcare providers.

4. Reminder for safe and accurate medication for the children with reliability

“We use a post-it on the kitchen counter as a reminder for everything.”
Parents need to remember important things such as giving medicine to their children, remembering how medicine is supposed to be given (before eating, after eating, etc.), and possibly even preparing to modify the child’s diet such as eliminating wheat or dairy. Parents are busy with many tasks and use routines to help them get through the day. And changes in the routine can be both hard to manage and easy to forget. For example, doctors might prescribe a ten-day cycle of antibiotics to treat an ear infection, at first, the sick child works as a reminder to give the medication twice a day, but when they begin to feel better, the natural reminder goes away, and it can be easy for parents to forget to give the medication, especially since the bottle is usually out of sight in the fridge.

**Concept Generation, Storyboards, and Needs Validation**

In generating concepts, we looked at all possible situations and contexts following the user research and actions that families have taken. We generated 60 concepts based on contexts, situations, actions, and needs to cover our four main implications: Record / Retrieve / Transfer / Remind. Then we tried to narrow down the 60 concepts to 20 storyboards for the validation session based on how much the concept can cover four implications and how much it has a realistic possibility to be implemented. We finally clustered these into five application areas: A thermometer, medicine bottle, sticky notes, cell phone, and a display (controller of the system).

We conducted individual needs validation [Davidoff et al. 2007] sessions with six families who participated in the interviews. We presented thirteen storyboards to participants and asked for their feedback on if we had understood their underlying need and if they felt an individual concept would both be beneficial and fit into their lives. As a part of the needs validation, we also used a modified version of the user enactments from the Speed Dating method [Davidoff et al. 2007], which asks participants to enact typical routines in a simulated context and then react to conceptual technology interventions (Figure 1). In this case, instead of simulating the context, we had participants perform the enactments in their homes, giving them props such as a thermometer, medicine bottle, sticky note, cell phone, and a prototype of a display.
Findings from Needs Validation

Throughout the session, we found that parents preferred physical interactions such as writing over voice recorder or a touch screens when trying to record information. We also discovered that while many healthcare related activities happen in the kitchen, parents wanted to be able to perform these actions in multiple places such as the bathroom or the child’s room. Finally, we concluded that having an appropriate tool for this is a significant part in managing the children’s health for the parents because healthcare behaviors happens in multiple places and contexts, and recording, retrieving, transferring, and reminding of information are all interrelated.

Based on findings from our needs validation, we set four directions for the final design concepts of the healthcare system as follows:

1. design a suite of home ubiquitous devices connected to central system that captures various healthcare activities in multiple contexts in order to automate the collection of children’s health information.
2. design an integrated information management system, which is organized by events about the children’s healthcare in order to support parents’ retrieving this information.
3. design an information sharing system in order to help parents transfer their children’s health information to healthcare providers or other caregivers.
4. design a reminder system to help remind parents of their children’s medication time so prevent overdosing and skipping medication.

Figure 1. Our performed healthcare system for Speed Dating. The parents are shown interacting with the display in the kitchen.
ENSURE Healthcare System

The ENSURE Healthcare System consists of five parts: the main ENSURE display, smart medicine cap, thermometer, mobile application, and a doctor’s application. Figure 2 shows the components of the ENSURE System for children’s healthcare information.

First, the ENSURE display is the main controller for the system including input and output. Basically, it has two main features: pre-visit and post-visit to doctor’s office. Pre-visit is for daily use, and it provides what parents do and record, what parents should know and prepare before they go to see a doctor. After visiting a doctor, parents can review or take actions by using the post-visit feature of the ENSURE System. Parents can also take notes easily using its pen on the display and they can carry it everywhere inside home.

Second, the smart cap connected to the system automatically records the exact time and date of taking medicine. When parents get a new prescription and bring a new medicine bottle home, they simply switch the original medicine cap to the smart cap and set up the medicine information through the display to the system. Once it is activated, the number of lights indicates how many times a child has taken. Also an alarm sound reminds parents of their
children’s medication time through the display and cell phone connected with the system. This smart bottle allows parents to keep track of the exact times and dates, and it records the medication information to the system. This will prevent overdose or missed medication of antibiotic and improve the situations when a child is on several medication.

Third, by using a thermometer that is connected to the system, parents can record their children’s medical details automatically. We have seen parents having difficulty in keeping accurate records of home measurements even though they desire to record things such as their child’s temperature, headaches or sicknesses.

Forth, an application on mobile phone transfers the information to parents and doctor from the system. When parents are out of home or doctor’s office, they access the system through their mobile phones and they can review their notes or share information with doctor. In addition, as we have seen above, it has a function of reminder for the children’s medicine time.

Fifth, an application on the doctor’s computer is directly connected with the ENSURE System and it allows the doctor to see the detail information of the child. When the doctor gives parents directions or prescriptions, the information is automatically sent to the ENSURE System. This reduces the stress of parents from memorizing or remembering their children’s medical information and prevents doctors from giving wrong medical care by having accurate information.

Help Parents Feel in Control

Based on major functions of the ENSURE healthcare system, we developed scenarios to illustrate how it works and helps parents feel in control of managing their children’s health.

Figure 3. Scenarios about an automatic recording by using a thermometer related the ENSURE system.
Through a thermometer connected to the ENSURE system, a child’s body temperature is automatically recorded in the ENSURE system. This allows parents to keep a child’s body temperature history, without needing to manually take notes. It helps parents easily answer questions about their child’s healthcare information and communicate that to healthcare providers with confidence. In addition, since the ENSURE system provides integrated storage of children’s health information, parents can be reminded of important information when communicating with other healthcare providers (Figure 3).

Figure 4. Scenarios about sharing children’s healthcare information with other caregivers

There are lots of opportunities to interact with other caregivers such as babysitters and grandparents. By using ENSURE system, parents can transfer important notes about their children’s healthcare information quickly and accurately to other caregivers. It helps parents feel in control of managing children’s healthcare even though they are out of home (Figure 4).

Figure 5. Scenarios about reminder for children’s medication time

The ENSURE system is connected to a smart medicine cap that lets parents know when it is time for their child to take their medication. This reminder system helps parents feel an increased sense of control and security when managing their children’s health (Figure 5).
Conclusion

We have presented the healthcare system and service for a healthy family that addresses four design opportunities identified in our fieldwork. Through our user research process, we designed the ENSURE system:

i) An automated system that allows parents to keep their children’s medical records and accesses them whenever they want

ii) A reminder system that helps parents remember when to give their child their medication, to help prevent over- or under-medicating.

iii) A system that supports parenting with better medical care and helps parents feel confident when communicating with healthcare providers or caregivers

iv) A system that supports parents feel secure and more in control of managing their children’s health.

v) A system that understands the family’s dynamic contexts of healthcare activities and encourages parents to form an emotional attachment to the product.

We hope our research project supports parents’ efforts to become the parents they desire to be through the system that helps them better manage their children’s health.

Reference


