Supporting Data-Based Decision-Making for Caregivers through Embedded Capture and Access

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Abstract. The care of individuals with concerns about development, health, and wellness is often a difficult, complicated task and may rely on a team of diverse caregivers. There are many decisions that caregivers must make to ensure the best care and health monitoring are administered. For my dissertation work, I am exploring the use of *embedded capture and access* to support decision-making for caregivers. Embedded capture and access integrates simple and effective capture and useful access, including trending information and rich data, into existing work practices. I hypothesize that this type of technology encourages more frequent access of evidence, increases collaboration amongst caregivers, and increases confidence with which care decisions are made. I am exploring this work through real world deployments of new embedded capture and access applications in the domains of caring for individuals with autism and tracking the development of newborn children.

1 Introduction

The care of individuals with concerns about development, health, and wellness, such as the elderly, children with special needs, or individuals with chronic conditions, is often a difficult process. There are many aspects of care that need to be considered, and in extreme cases, the person receiving care cannot take part in the care process or even give input as to how their condition is progressing. Most caregivers seek the best treatment possible for those for which they care, but often it is difficult to know which treatment is best for a particular person. Accurate and frequent record-keeping may help caregivers to make decisions about progress, but it may be cumbersome to sort through masses of information to use it in decision-making.

Caregivers often must regularly make decisions, both big and small, such as:

- Is the current treatment effective?
- Is the benefit of the current treatment worth the costs associated with it?
- Is everything progressing normally, or should we begin new treatment?
- Can we make a decision now, or do we need more data?
- Should we bring a new person into the decision-making process?

These decisions are often made with the aid of data identifying the current and past status of the person receiving care. Current practices range from no data collection, where caregivers may base decisions solely on their impressions or recollections, to large amounts of medical or behavioral data logged continuously. Depending on the type of data collected, it can be difficult for the caregiver to both keep long-term, useful data records and simultaneously provide adequate care. Computing technology has the opportunity to simplify data collection and analysis, thus assisting caregivers in the decision-making process. For example, automating some of the data collection process can ease some of the burden on caregivers, and digitized records are often easier to search, share, and distribute. It is also easier to create varying levels of detail, such as an overall graph of a trend in progress or a more detailed, day-to-day record. Most importantly, computing technology appropriately designed and ubiquitously integrated into everyday work practices can ease the burden on the caregiver with regards to data collection and processing.

To address these particular needs of caregivers, I am exploring the design, development, and evaluation of a class of applications I call *embedded capture and access*. Embedded capture and access provides simple and effective means for capturing data through automated data recording and indexing and affords easy access to data through trending and integration into existing practices. In my thesis work, I will explore the effectiveness of embedded capture and access to assist in decision-making for caregivers in two different domains: the evaluation of treatments for children already diagnosed with autism and the evaluation of the development of young children. These domains present several interesting challenges for technology design and evaluation, due to the complex and diverse nature of treatment types, wide range of caregivers, the types of decisions caregivers must make, and differences in the level of knowledge about the care process by the caregivers.

My experimental design is to first determine a need and the design requirements for embedded capture and access through formative studies of interviews with caregivers in each of these two domains. I am then iteratively developing functional prototypes of embedded capture and access systems in these domains and will study these technologies through long-term deployments with real users. These studies are exploring the usability of these systems, but more importantly, they will evaluate the usefulness and effectiveness in supporting decision-making.

2 Embedded Capture and Access

Embedded capture and access technologies should be able assist with decision-making in several key areas. The first is that they need to enable better and more frequent access to data. Decisions often are made without sufficient data, and they can be made better if more data is collected. Richer data, such as audio or video, can also provide more clues into how well care is progressing, that memory or just numerical data alone cannot provide. However, the collection of data should not interfere with the caregiver's ability to provide appropriate care. Additionally, just data collection alone is not enough to improve decision-making, as caregivers may become so overwhelmed in data that they do not have time to analyze or review it.

Thus, this data must be organized and easily accessed to help with information overload. By embedding the capture and access into the existing work practices, caregivers may be able to capture more data and visit the data more frequently.

Computing technology can also improve the decision-making process for a team of caregivers by allowing for better collaboration and coordination. Because many caregivers may work independently from one another, computing technology can help in sharing and coordinating data, so that all members of the care team have access to the same data. This can also reduce the amount of redundancy in the data. Computing technology must provide caregivers with the ability to make better decisions. However, because it may not be possible to determine if "better" decisions are made, technology can at least allow caregivers to make decisions with higher confidence. This can potentially lead to timelier decision-making and better care for the individual.

Embedded capture and access can assist in decision-making in several key areas:

- *Enable more frequent access to data.* Data, both quantitative and qualitative, can help make better decisions. However, the collection of data should not interfere with the caregiver's ability to provide care and accessing it should not take a significant amount of time or effort.
- *Increase collaboration and coordination.* Because caregivers may work independently from one another, technology can help share data and coordinate decisions, which can reduce data redundancy and improve communication.
- *Allow caregivers to make decisions with higher confidence.* This can potentially lead to decisions being made sooner, which means timelier treatments can be administered.

3 Two Case Studies in Early Childhood Development

I am exploring two specific domains in this research: the support for therapy for children with special needs and supporting record-keeping for the development of young children with the specific goal of early detection of developmental delays (both relatively new domains for HCI and Ubicomp research). These domains provide an interesting test bed for embedded capture and access, due to the complex and diverse nature of treatment types and the wide range of caregiver expertise and influence. Additionally, they represent domains with a great need for assisted decision-making.

3.1 Abaris: Supporting Teams of Caregivers Assessing the Progress of Children with Autism

Decisions about the care of children with autism can often be a difficult process, as much of the data collected is subjective in nature and often is collected independently by multiple caregivers. One particular treatment for children with autism is called Discrete Trial Training (DTT), a form of Applied Behavior Analysis, which is a popular method of teaching children with special needs a variety of low-level skills in a highly structured, data-intensive process. In this process, teams of caregivers work

individually with a child and meet regularly to discuss progress, review data, and make decisions about whether the current method of treatment is sufficient or if changes must be made.

I have designed and developed an embedded capture and access system, called Abaris, to help caregivers collect and analyze data for DTT therapy. Abaris uses digital pen and paper (see Figure 1) and a camera to help therapists automatically record videos of therapy sessions and capture data points. It also provides an interface that automatically creates graphs and provides easy access to additional session data, such as individual prompts for therapy trials and relevant moments in the video stream (see Figure 2). The access interface was designed to be used by therapists during team meetings as a tool to enable easy access to various artifacts showing evidence of the child's progress during individual therapy sessions. The full details of the technology design and development are found in Kientz *et al.* [7].

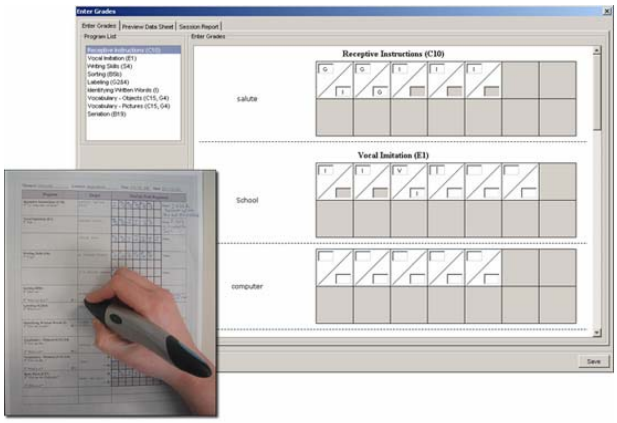

Figure 1: Abaris uses a digital pen and paper to record scores and timestamps of grades as therapists write them during therapy sessions.

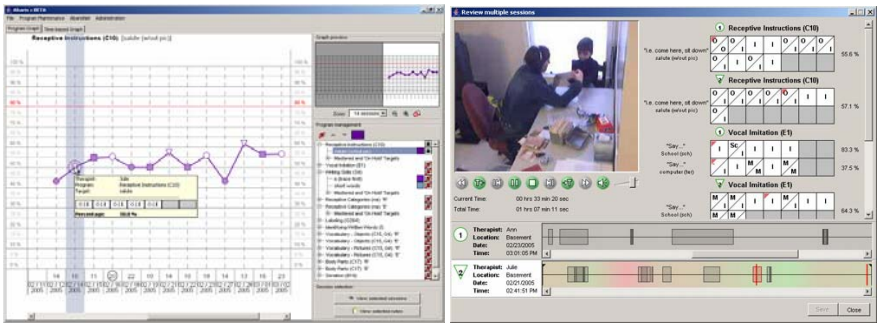

Figure 2: Screen shots from Abaris access technology that was designed to support discussion in team meetings by embedding access technologies into meeting agenda items (*e.g.*, the graphs). Left shows data analysis graphs of child's progress, right shows video preview screen.

I analyzed the use of Abaris over a four-month period in the home of one child with autism and his team of DTT therapists. Results show that therapists were able to quickly adopt the system and used it for all of the 52 therapy sessions we studied. Therapy teams used the graphing and video interface in six team meetings to enrich discussion and help make decisions about the child's progress in therapy. A detailed analysis of team meetings showed that Abaris helped increase the level of collaboration amongst caregivers and increased the use of more objective evidence (such as videos and data sheets) in the decision making process. The full details of this study and analysis can be found in Kientz *et al.* [8]. I am continuing to study Abaris in a school setting with multiple teachers working simultaneously with multiple children. I am studying its ability to encourage more frequent review of Discrete Trial Training data for teachers who are not in the habit of compiling or reviewing data. By integrating data review into the form creation process, I am encouraging participants to view data while doing something they must do before beginning their sessions with students. I am currently deploying this technology with a team of 9 teachers in a special needs classroom for a 6 week real-use study.

3.2 Grow and Know: Assisting New Parents in the Early Detection of Developmental Delay

Many developmental delays, learning disabilities, and emotional disorders in children are not apparent from birth. These disorders can manifest anywhere between the ages of 2 and 6, or even later. Many advocates argue that early detection is the key to improving the livelihood of these children [10]. One way of improving the chances of early detection is through regular visits to the pediatrician and detailed record-keeping of when children meet different developmental milestones. Not meeting specific milestones by a certain age may be an early warning sign of any of these disorders.

Capture and access technologies embedded in the tasks that parents already want to be doing can prompt them to look for specific milestones at key times and alert them if there are any signs of developmental delay. I have conducted an extensive formative evaluation of the design requirements for this domain [6], and I am currently developing an application that allows parents to enter information about their child's development. The system will automatically prompt them to enter developmental milestones as their children achieve them (see Figure 3). Because parents are already motivated to take pictures and share them with others, the system will encourage uploading of pictures or videos as evidence for milestone completion. If there are any health concerns, parents can send their child's data, pictures, or videos to their pediatrician via email to help answer questions or address concerns. The system integrates the data recording and review into a digital "baby book", which is something many parents already use. Additionally, the system will allow parents to share video clips with friends and family or create keepsakes – something parents already do. To help with data recording, I am also developing a "smart" baby monitor. The baby monitor uses a handtop computer with an integrated camera that constantly maintains a temporary buffer of the last 15 minutes of video data (see Figure 4). When parents or caregivers observe important events, they can trigger it to save video clips of events that just happened.

Figure 3: Screen shot of the digital baby book, where parents may check off completed milestones and add evidence for completion, such as video recordings.

Figure 4: Left shows screen shot of smart baby monitor interface, which allows parents to save clips of recently experienced events. Right shows prototype developed on a Sony Vaio-U™

I plan to evaluate this system through a long-term deployment with four sets of parents with a child between the ages of 1 year and 18 months and compare it with four different sets of parents using a basic version of the system without the embedded capture and access features, which will serve as a control. Parents in both groups will use the basic data recording system to capture their child's developmental milestones and evidence for completing milestones. The experimental group will have access to the smart baby monitor, proactive reminders through email, sharing of videos with friends, and family, and the creation of keepsakes. For each milestone recorded, I will have parents record their confidence level in each decision and provide a list of any supporting evidence they may have that their child has completed

a milestone. Parents will work with their pediatrician to make decisions about whether their child is on track developmentally as they would normally, but I will observe parent-pediatrician interaction and administer surveys rating the satisfaction level of the quality of communication to see whether those using the system have a better experience. Additionally, I will interview parents and pediatricians on the effectiveness and usefulness of the system and their confidence in the decisions they are making about the child's development and analyze logs of the system's use to determine frequency and amount of data collected.

4 Related Work

This work extends previous research in automated capture and access, defined by Abowd & Mynatt [1], by applying it to new domains and working to make both the capture and access activities more of an integral part of everyday practices, as opposed to supporting recall of specific events should the need arise. It aims to take advantage of existing technologies in ubiquitous computing, such as recognition technologies, natural interaction techniques, and embedded sensors, to make the data recording and reviewing activities as seamless and unobtrusive as possible. By applying seamless capture and access of data to healthcare and early childhood development, it also expands research area first proposed by Morris *et al.*'s embedded assessment [9].

The use of computers in the collection of health data has become a very broadly studied topic in computer science. Many commercial and research efforts have sought to collect and track health records electronically to ease the burden of analysis and to allow for easy transfer and backup of records. Research projects, such as those of Intel's Proactive Health group, have looked at the effects of long-term tracking of data in order to look at ways of identifying decline or other age-related or chronic disorders as soon as possible [4]. Consolvo *et al.* have focused on how caregivers for the elderly can view health records to determine a family member's overall wellbeing [3]. The UbiHealth Workshop has been a highly attended workshop at Ubicomp for the past three years and has concentrated on efforts in which ubiquitous computing can help to collect and analyze health-related data [2]. Other efforts focused on how people can use technology for self-monitoring of health records, such as wearable glucose monitors for people with diabetes (http://www.glucowatch.com). The research I am conducting is similar to these in that it will help in the automatic collection of health and developmental records, as well as look for ways of sharing relevant information with professionals for recommendations. The main difference between my research and these applications is that it seeks to give a holistic approach to the problem of record-keeping and analysis with ways of collecting, monitoring, and reporting developmental data while still providing an ulterior motivation for video collection.

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