Designing and Developing Technology for Caregivers of Individuals with Autism

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Abstract
Computing technology can assist caregivers in meeting health and educational needs of children with autism. This paper presents our work over the past several years involving the design of computing technology to support caregivers and individuals with autism. The technologies include those designed to help in record collection, record analysis, decision-making, and communication. We reflect upon how these technologies worked in practice and the lessons learned in the process of developing technology for this domain.

Introduction
The care of children and individuals with autism is often a complex, lifelong challenge. Families and care networks of children with autism face many choices on types of care, including various therapies, doctors' visits, and drug or diet regimens. The unique nature of each child makes it difficult to predict which treatments will work and time is often critical in administering treatments. For these reasons, parents may choose to try several treatments simultaneously, which increases the difficulty in determining which treatments work and which do not. Further complications result when effects of treatments may not be seen immediately or may make minor, imperceptible changes.

Often, many caregivers work together to administer care and determine if the child is currently receiving the best treatments possible. The sheer amount of data that caregivers must collect can often cause difficulty in making the best choices for the child receiving the care. Additionally, individuals with autism often cannot communicate their internal states, and thus caregivers must rely on externally perceivable characteristics to determine the individual's needs. Many of these challenges also extend to the continual care of other individuals, such the elderly, and treatment plans for diabetes or cancer.

Technology has the potential to make the care process associated with children with autism more efficient or hide some of its complexities. Data capture and analysis is an important part of making decisions about whether a treatment is working. Pervasive technology can help increase the amount of data collected, make it easier to collect, and help caregivers quickly scan through data to make better decisions about care. Additionally, technology can help teams of caregivers who must work together communicate more effectively and efficiently.

What is Autism?

Pervasive Development Disorder (PDD), also known as Autism Spectrum Disorder (ASD), is a cognitive impairment that characterized by deficiencies in communication, social interaction, and creative or imaginative play [1]. This spectrum includes Autistic Disorder (Autism), Asperger's Syndrome, Pervasive Development Disorder Not Otherwise Specified, and Rett's Disorder. Individuals on this spectrum often exhibit stereotypical, self-stimulatory behaviors, such as rocking, hand flapping, or vocalizations. Autism is the most common on the spectrum, affecting an estimated 1.5 million Americans today, and growing at the astonishingly rapid rate of 10 to 17 percent annually. Autism is typically diagnosed between the ages of two and six, although other variations on the ASD spectrum can sometimes be diagnosed earlier or later. The disorder has recently been a popular topic of discussion in the mainstream media, which is likely because it is being diagnosed at a much higher rate than ever before. Current estimates from the Autism Society of America are that 1 in 150 children will be diagnosed with some form of autism.

Although autism typically presents itself in individuals in some known ways, it is a highly variable and individual disorder, making each case unique. Individuals diagnosed on the spectrum can have large variations in their degrees of functioning. Higher functioning individuals may be able to achieve high levels of independence. The disorder manifests itself differently within each person, and in fact, may even present itself differently in the same person over time. This extreme variation among children has led to the anecdotal comment spoken by practitioners and family members alike: "If you've seen one child with autism, you've seen one child with autism."

Evidence in the behavioral, educational, and social sciences indicates that early diagnosis and intervention can be essential to achieving greater independence, an ultimate goal of these care activities [2]. As with other language acquisition disorders, such as deafness, children who do not achieve functional language by school age can be severely limited in their future abilities to interact with other people in the world [3]. Thus, caregivers can be in a race against time to try to

Figure 1: Paper data sheet and digital pen

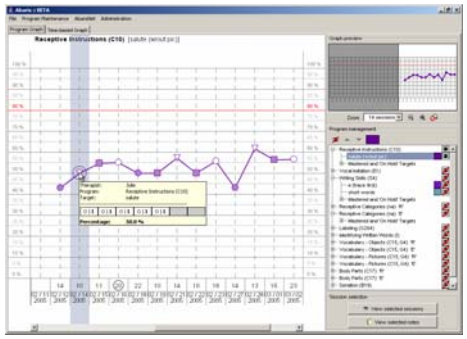

Figure 2: Graph view of Abaris access interface

Figure 3: Video review screen for Abaris access interface

find a treatment that will work for their children. However, many interventions may or may not work for any particular child, and these interventions are often applied simultaneously. These treatments include pharmacological interventions, special diets, holistic approaches such as occupational therapy and sensory integration, behavioral therapies such as applied behavior analysis or functional behavior analysis, and symptom-specific treatments such as speech or language therapy.

Two Technologies to Support Caregivers

The support of individuals with autism and their caregivers with computing technology has been a focus of work at Georgia Tech over the last three years. We have explored several dimensions of the care cycle and network, and we present two of these projects below.

Abaris – Supporting Collaborative Decision-Making

Discrete Trial Training (DTT) therapy is a current best practice intervention for children with autism in which teams of therapists administer intensive, one-on-one teaching of basic skills. In this practice, therapists assign a grade for the level of independence with which the child was able to complete the skill. After each therapy session, the therapists calculate the percentage correct for each skill and then plot the data points on hand drawn graphs. Every 1 to 2 weeks, all the therapists meet to discuss the progress of the child and how they might change the therapy practice to make the child more successful. During these meetings, common discussion points are the skills the child can accomplish and clarifications on the grading of particular skills. DTT is a practice that involves rigorous data collection and analysis to be effective. Unfortunately, it is also subject to inconsistencies and inaccuracies, as all therapists have different skills and different interpretations about the progress of therapy.

We developed a system to support teams of DTT therapists, which we call Abaris [4]. Abaris supports this practice by using a digital Anoto pen and phoneme spotting voice recognition to provide indices into videos of therapy sessions (Figure 1). Therapists access videos via an interface that they can use together for discussions during meetings (Figure 2). By allowing for easy indexing into videos, teams of therapists can use video evidence to review progress, find inaccuracies in grading, and easily show problem areas to other therapists. Abaris also allows therapists to automatically generate graphs and easily associate them with data sheets they used during therapy (Figure 3). We deployed Abaris for four months with one particular home-based DTT team and found that the system enabled therapists to use objective evidence more frequently in the decision-making process. Therapists used videos, graphs, and data sheets more frequently than they did without Abaris. Prior to Abaris, they would rely on their own recollections of what happened during therapy and only consult written data sheets if there was a high need. We also determined that the use of Abaris during team meetings increased the collaboration amongst the therapists [5].

CareLog – Capturing and Analyzing Behavioral Data

Children with autism and other developmental delays often exhibit behaviors that are inappropriate and may be disruptive or dangerous. Severe behavior often includes hurting themselves or others. To address these behaviors, teachers, specialists and parents often attempt to understand the cause of these behaviors.

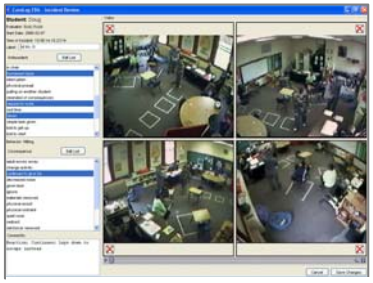

Figure 4: CareLog allows teachers to view behavioral data from 4 different angles in a classroom

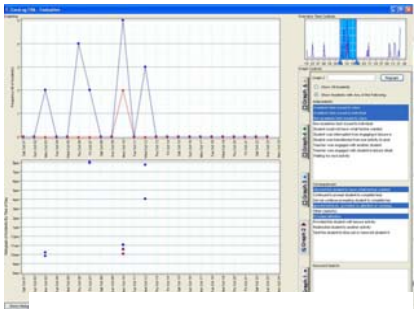

Figure 5: CareLog graphs showing overall frequency and occurrence of behavioral incidents

One best practice for making these determinations is known as Functional Behavior Assessment (FBA). When done in the natural environment, FBA includes a portion of time of direct observation. Caregivers observe a child and after a behavioral incident, they note the context of the incident and what happened directly before (antecedent) and after it (consequence). Once a point of data saturation is reached (usually 20 to 30 incidents over a period of a few weeks), the data is analyzed to determine the function of the child's behavior (*e.g.,* he is screaming to gain the attention of the teacher). In classrooms and homes, it can be very difficult to observe these behaviors in a rigorous enough manner to have confidence in the results of the assessment. Incidents may occur at unexpected times and unexpected places, and caregivers may not be able to write down what happened before or after while simultaneously managing the behavior itself.

CareLog is a prototype system designed to assist caregivers of children with autism in documenting and analyzing specific, unplanned incidents of interest as part of a FBA. CareLog uses audio and video buffering [6] to allow selective archiving of these media after events occur. Caregivers use a wireless button to trigger archiving. They then use a standard desktop computer to watch and tag the videos with meta-data (Figure 4). Finally, CareLog provides graphs and other analytic tools for the assessment of function (Figure 5). CareLog was deployed in four classrooms at a special education school in the Atlanta area as part of a semi-controlled study of its effectiveness. Each teacher conducted a FBA for two children, one using the traditional pen and paper method and one using our technology-augmented process. The ordering was counter-balanced and groups randomly assigned.

Overall, we observed increases in both the accuracy and the efficiency of the process [7]. Furthermore, the teachers reported enjoying the process more while feeling less burdened and more confident in the results of their assessments using CareLog.

Design Considerations and Challenges

Understand the domain - In the year before developing any technology and throughout our design cycles, we spent time conducting in-depth contextual inquires of the domain of autism [8]. These explorations included interviews with parents, caregivers, therapists, and teachers who interact with these children on a daily basis. We were also trained to become therapists and participated in therapy sessions and team meetings with therapists. We spent extensive time observing classrooms, home settings, therapy sessions of varied types, support groups, and other domain specific activities. Our design team also included individuals with expert knowledge of our user population, including parents of children with autism, autism researchers, and behavioral specialists. Having first hand knowledge of children with autism allowed us to be more attuned to how well technologies would be adopted.

Make changes invisible - Getting groups of users to change their practices to adopt any new software is always difficult, but trying to change rituals with children with autism can almost be disastrous. Many children rely on strict regimens and have difficulty adjusting to deviations. Pervasive computing can seamlessly blend into the environment and thus has a distinct advantage over other technological solutions in this domain. In the case of Abaris, we believe we were successful with capture because we kept the paper forms and the child was unlikely to notice a change.

The one change we did make (having the therapist use a headset microphone for the voice recognition), actually distracted the child, as he often wanted to touch it. For CareLog, we chose camera locations in the classrooms (in the corners near the ceiling) to reduce distraction. Despite these efforts, in one classroom, a set of higher functioning students noticed the classrooms. Also, in all classrooms, students clearly recognized changes when we were present for data collection in addition to the installed cameras.

The easier, the better - Teams of caregivers and educators are often diverse, coming from different backgrounds and computing expertise. Additionally, they are rarely co-located and do not see each other on a regular basis, if at all. In our studies, it was not uncommon for a child to see a behavior therapist, an occupational therapist, and a speech therapist all on the same day, where none of them had access to each other's records despite the fact that doing so would be beneficial. Low-tech solutions have included passing paper records with the child or parent, however, these records often do not capture the appropriate data needed by each of the individuals and can be a burden. Technologies that can automatically collect and share data can help support these types of interactions. Secondary caregivers, such as therapists or behavioral specialists, may have limited interaction with a child, see multiple children, and look at significant amounts of data. Keeping technology simple and straightforward can assist in keeping track of all data from all caregivers.

Customizability is critical - Children with autism are very unique in their behaviors, needs, and treatments. What works for one child may not work at all for another child with similar abilities. As a result, therapies and treatments often have to be highly tailored to the needs of a specific child. Any technology developed to support therapies or care must be able to reflect this uniqueness through customization. In the case of Abaris, the skills tested changed almost daily, and thus our system had to be designed to support these changes. With CareLog and behavior management, each behavior and the context surrounding it can be incredibly different even for the same child. In all of these cases, the basic underlying process is relatively standardized, but technology must support variable instantiation of that process for variable children and conditions.

Difficulties in relying on input from child - Autism inherently creates difficulties with communication, and even those who can communicate may know little about the processes invoked by caregivers. Thus, it is often difficult to rely on their input when designing technology. Most children in our studies were unable to consent to the research process, let alone provide us with insights into what would work and what would not. Instead, we generally relied on parents and caregivers to provide methods for working with these children. While most caregivers have the child's best interests at heart, it is sometimes difficult for even the experienced caregivers to know the child's needs.

Ethical and privacy considerations - Because children cannot often express their needs, it is crucial to ensure we meet the child's best interests. At the same time, caregivers, teachers, and other professionals, have direct concerns regarding data collection that might affect their jobs or have legal repercussions, especially if videos are taken out of context. For example, a child

might feel comfort being restrained, but to uninformed outside viewers, it may look like abuse. With all of the data recording needs, some technologies might violate the child's or caregivers' privacy if not carefully considered. In addition to these challenges, coordination between individuals inherently includes issues regarding privacy, security, and legislative control. The design of applications that can follow these laws will also help address any concerns raised by the individuals receiving the care or caregivers close to that individual. The CareLog system used selective archiving of camera recordings in the environment to balance the desire to catch relevant behavioral episodes retroactively against privacy and information overload concerns of continual recording.

Conclusions

Pervasive computing has many advantages when it comes to designing for the care of children with autism. Our previous work on the Abaris and CareLog prototypes has uncovered many design considerations and challenges for this domain. These considerations include understanding the domain, keeping things similar to existing practices, making simple to use systems, supporting customization, unpredictable subjects, and privacy and ethical considerations.

The lessons learned from these projects may be of benefit to other researchers in the mental health domain, as well as developers of technologies to support continual healthcare. Many of the design issues we have encountered extend beyond the domain of autism and into the management of care for other chronic conditions. Caring for individuals with autism has many similarities to caring for the elderly or individuals with chronic conditions, such as diabetes or cancer. Additionally, there are many coordination issues amongst caregivers that share a common theme with that of Computer-Supported Cooperative Care [9]. We believe the promise of computing can help begin to address these common challenges.

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