
Collective Remembering in Evidence-Based Care

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Abstract

This paper describes how technology can be used to support groups using memories of past events to provide evidence-based care to individuals with special needs.

Keywords

Collective remembering, automated capture and access, evidence-based care, design

Introduction

When individuals in a group try to remember the past, it can often be a joyous time where friends recollect on pleasant experiences they enjoyed together. This can often include looking at photos, videos, or other artifacts from the event. However, collective remembering can also involve trying to recall a more serious event. For example, adult children seeing each other over the holidays may try to recall instances demonstrating the decline in health of their aging parents. These memories may be of their mother forgetting to turn on the oven for dinner, or their father calling someone by the wrong name. These kids may use these memories to make important decisions about that parent's future, such as whether it is time to put them into an assistive living community.

Due to the emotional nature and seriousness of these types of memories, it is important that they be accurate. Technology can help to make these types of memories more accurate by recording unbiased events using video, audio, or other types of rich media collection. Since collective memories are often used to make subjective analyses of progress of individuals, or diagnose certain disorders or diseases, technology appropriately designed for use by a group of caregivers or medical practitioners is especially useful.

In this paper, we discuss the importance of collective remembering for evidence-based care, relevant work in this area, a case study of one system for assessing the effectiveness of a specific type of therapy for children with

autism, and discuss future work in collective remembering as it relates to evidence-based care.

Related Work in Collective Remembering

While several researchers have addressed the concept of using computing technology for remembering thoughts and actions in the past, it has mainly been for preserving the memories of individuals, or for memories of group interactions accessed individually. Much of the technology research in this area relates to the automated capture and access of live experiences.

For technologies supporting the record of individual memories, the MyLifeBits [4] project from Microsoft Research is an excellent example. Inspired by Vannevar Bush's historical paper [2], this ambitious project aims at supporting the archival of and access to any records from one individual's life, including pictures, sound bites, scanned documents, etc. Other devices for supporting memory include MIT's audio-based memory prosthesis [13], the Personal Audio Loop [7], and Forget-me-not [9].

Other capture and access applications have focused on specific types of events in people's lives, such as classroom lectures [1] or team meetings [12],[11]. These applications have focused on how individuals can go back and later access rich data from a shared experience. The NotePals system [3] has allowed users to share individual memories in the form of written notes.

The value of capturing memories for later retrieval in the health domain is just starting to be realized, including work in developing capture and access applications for surgeons [5] and supporting caregivers of children with autism [6]. One particular application we have worked on is Abaris [8]. In this application, groups of caregivers use a capture and access application to view videos in order to make evidence-based decisions on the progress of a child's skill acquisition. In the next section, we will give details on how this application supports collective remembering to help caregivers make decisions about the progress of a child with special needs.

Case Study: Abaris

Abaris is a technology application designed to record therapy sessions for one particular intervention for children with autism. In this intervention, multiple therapists working one-on-one with a child will teach rudimentary tasks using a structured, repetitive method and write down data about that child's progress. Every 1 to 2 weeks, all of the therapists working with a particular child will meet to go over the data and make decisions about how to proceed with the rest of the therapy.

Abaris is a result of a significant ethnographic study looking at the needs of therapists doing a particular style of therapy with children with autism. While acting as observing participants in this type of therapy and attending all team meetings, we discovered that a lot of what takes place at the meetings is speculative. Therapists will look at data and rely on their memories to make judgments on the reasons for or against the progress of the child.

Design of the Abaris System - Abaris is designed to capture video of all therapy sessions conducted by therapists and use natural input techniques to index into these videos. Since the therapy itself is structured in nature, we chose to obtain timestamps for the video indices using voice recognition on the therapist's voice and Anoto™ digital pen technology on the therapist's written grades.



Figure 1: Left shows data for a particular skill. Right shows more detailed information and video of day's session.

For the access interface, we provided the capability of showing graphs of all of the data provided by the therapists. If the therapist wants more information on a

particular day, she can click on that day's data point and bring up an interface for viewing all of the grades for that day, the video for that session, and a timeline. Clicking on grades or on marks on the timeline will jump the video to the desired time based on the timestamps provided by the voice recognition and the digital pen. Figure 1 shows the an example of the graphed data and the video viewing window.

Deployment of Abaris in Team Meetings - We deployed Abaris in the home of one child for use by his therapy team for four months. During that time, we observed the use of its data and video access interface during team meetings, where the team would be co-located and view the access interface projected against a wall.

In our deployment, we found that video viewing accounted for approximately 24% of the time in an average meeting. The users found the video useful for gaining further information about how a child was performing for a particular skill, and use the video to show others what was difficult to remember or explain. Many therapists reported afterwards that they felt the videos helped to enrich the discussion and had an overall favorable view of the access interface used in the meetings.

We also found that the access interface helped provide a structure for the discussion. Because of the way we designed it, it allowed for switching between graphs in a very systematic fashion and the access interface drove the meetings. Another useful feature was that members of the team could use the videos of therapists who were not in attendance to see what happened in their sessions, to help ensure that all therapists were doing things consistently.

While we are still validating this observation, we believe that while using Abaris, the therapists made fewer speculations about the cause of progress or lack of progress because they could use the videos to see for themselves. While viewing the videos, therapists would often notice things about a situation that did not occur to them when it was happening, such as the child being distracted by another stimulus, thus adding more information to the discussion than would ever be possible

with the memory alone. Lastly, and most importantly, we found therapists using videos to resolve disagreements or inconsistencies to ensure that the type of therapy was done consistently and that everyone could see visual examples of what they should be doing.

Design Implications for Collective Remembering

Our observations on the use of Abaris to recall events from separately experienced, similar events leads us to several implications for the design of similar types of systems.

Allow for sharing of multiple people's memories – For those participating, it helped that no single person was put on the spot by solely making his or herself vulnerable and being the only one sharing video of his or her session. Watching video or hearing audio of yourself can often be an uncomfortable experience, and it helps when you do not have to do it alone.

Who gets control? - For Abaris, the access interface was only designed for control by one person at a time. That person usually couldn't do other things simultaneously, such as take notes, but yet had the power to choose to start when and what videos to start viewing, and thus others had to request that that person show their session's video, which could be distracting. By designing an interface that easily allows all involved individuals to be on equal grounds control-wise, this can reduce the bias in deciding which moments to share.

Allow for multiple levels of detail – Depending on the question that is being asked, we found that therapists often would use different levels of detail. If the question was quick and simple to answer, they might rely on solely their memories to answer it. If it had greater importance, they may rely on just the graphed data at hand. If they were really at a loss for an explanation, they would pull up the video. Because the therapists had a variety of questions they wanted to answer, allowing them options on how much they wanted to explore meant that not a lot of time was wasted going through data that wasn't needed.

Keep the context of the memories – Because Abaris indexed into videos of entire sessions rather than saving individual segments, therapists would often see segments of video they did not intend to bring up initially, but were useful to the conversation. This is especially important for evidence based care, as often what happens immediately preceding or following the event of interest can have a big impact on that particular memory.

Future Work in Collective Remembering for Evidence-Based Care

While Abaris was not the perfect system for the type of collective remembering we were supporting, we feel it was an effective means for sharing separately experienced memories with one another for the common goal of assessing a child's progress. However, the scope of Abaris is limited in that we designed it to work very well for one specific type of structured activity, which makes it fairly inflexible. We believe this type of system can benefit others who rely on memories to make important decisions on care to use more evidence to back up memories to ensure their accuracy. We need to determine which parts are generalizable to other domains, especially as it results to other types of evidence-based care.

We believe these types of capture and access systems can be used in other domains and are exploring the potential for its use in patients expressing memories to their doctor at a medical checkup, or in situations described earlier where adult children may use home videos to assess the condition of their aging parents. However, the types of memories that will be discussed in these situations rely on more spontaneous, less-structured events, unplanned events such as a family gatherings. We are looking into how to use systems such as the ContextCam [10] to automatically capture these events and provide a collaborative interface for sharing and discussing events.

There is a strong motivation for technology to support collective remembering in evidence-based care. By using rich data to supplement people's memories, we can

improve the accuracy of important decisions being made for and reduce hastily made decisions based on emotions rather than real evidence.

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