

Tensions in Designing Capture Technologies for an Evidence-Based Care Community

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ABSTRACT

Evidence-based care is an increasingly popular process for long term diagnosis and monitoring of education and healthcare disabilities. Because this evidence must also be collected in everyday life, it is a technique that can greatly benefit from automated capture technologies. These solutions, however, can raise significant concerns about privacy, control, and surveillance. In this paper, we present an analysis of these concerns with regard to evidence-based care. This analysis underscores the need to consider community-based risk and reward analyses in addition to the traditionally used analyses for individual users when designing socially appropriate technologies.

Author Keywords

Ubicomp, ethnography, evidence-based care, capture and access, privacy, surveillance.

ACM Classification Keywords

H.5.2 [Information Interfaces and Presentation]: User Interfaces—Theory and methods, Style guides, Evaluation/methodology; K.4.1 [Public Policy Issues] – Privacy

INTRODUCTION

Automated capture technologies, a strong theme in ubiquitous computing, often evoke Orwellian fears of compromised privacy, despite the potential benefit in a wide variety of domains. When viewed from the perspective of the individual, a cost/benefit analysis often favors the rights of the individual, particularly for those who reap little benefit. In this paper, we present an argument for the examination of the effects of capture technologies on the community of stakeholders, as opposed to on an individual, for certain domains, most notably healthcare and education.

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There is a trend toward evidence-based practices to guide decision-making in healthcare and education. Simply stated, evidence-based care (EBC) emphasizes the use of empirically grounded procedures. When dealing with behavioral concerns (e.g., social disorders of school-aged children) or highly individualized conditions (e.g., autism), the best evidence often includes episodes from real life. There is a strong argument in favor of recording snippets of daily life and analyzing them to formulate a plan to improve the life of one individual, but that recording is both expensive to obtain manually and threatening to obtain surreptitiously.

We focus in this paper on the specific challenges of EBC in support of school-aged children with special needs. We hope to reveal how responsible technologists can identify an opportunity for capture technologies while still maintaining respect for the variety of stakeholders who both benefit from and may be threatened by these technologies. We discuss the background and motivation for work in EBC and the elements of it that make it a particularly interesting domain for investigation of socially appropriate design of capture technologies. We describe the current thinking in privacy and design for ubiquitous computing, outlining the opportunities for investigation of community-based risk and reward analysis. After defining the general stakeholder categories relevant to EBC, we will provide a detailed justification for automated capture applied to the specific challenges of EBC for special needs education.

The contribution of this paper is a systematic study of the variety of stakeholder perspectives balanced against potential technological solutions. Our analysis, based on a series of focus group and open-ended interviews, reveals three major tensions across stakeholders:

- Fear of surveillance can interfere with the benefits derived from evidence collection.
- Conflicts exist between a collaborative effort of a network of caregivers and individual autonomy and respect.
- A mismatch can be present between legal and societal norms and direct benefits and practicality.

We conclude with a discussion of how evaluation of potential technologies through the lens of the entire community can be used to design potentially adoptable and beneficial technologies despite the risks that may be imposed by them.

BACKGROUND AND RELATED WORK

Hayes *et al.* conducted an ethnographic study of caregivers of children with special needs from January 2003 to August 2004 [9]. One of the significant findings of that study was that the diagnosis and monitoring of children with special needs can be greatly enhanced through the collection of evidence about the child, including empirical data, narratives, and rich media like video. Recording of evidence to be included in educational and medical records is a common practice and one that has significant implications for both diagnostic and monitoring processes.

Although it has many similar definitions, for the purposes of this paper, we define evidence-based care (EBC) as the process by which caregivers in education and in healthcare make diagnostic and treatment decisions using the best available research evidence, their clinical expertise, externally observable characteristics or behaviors of patients/students, and patient/student preferences. EBC is an increasingly popular method for in- and out-patient health services as well as education [18]. Evidence-based nursing (EBN) and other disciplines have also developed from this foundation.

Because EBC often requires collecting evidence in everyday life, this domain problem correlates well to ideas about ubiquitous computing and its intersections with healthcare and education as well as its treatment of social concerns, such as privacy. Researchers have explored how individuals and certain societies and legal systems respond to ideas about privacy, awareness, and surveillance in various environments and how computing researchers should design applications to account for these concerns.

Many computing researchers have taken a technological approach to protecting people and objects from being unknowingly or unwontedly recorded by creating new technological solutions such as filters, automatic blurring of individuals, or active blocking of capture technologies [3, 24, 25, 26, 27]. While relevant in terms of what can be done to provide protections and social affordances to data capture, a comprehensive review of these technologies is outside the scope of this paper.

Instead of this technological approach, other researchers have focused on developing guidelines and frameworks for systematically designing technologies such that the benefit far outweighs the risk for an individual user [2, 4, 12, 13, 15, 16, 17, 21]. In fact, recent laws regarding privacy of information in an increasingly public and technology rich world would support this view [1, 6, 8, 11].

As opposed to these individual views of privacy, Etzioni argues that a “communitarian” view is required when

analyzing the costs and benefits of potentially invasive practices and technologies benefiting a subset of a group [7]. Although we do not subscribe to the entirety of the communitarian philosophy, we agree that there are particular domains for which design work must include a group centric rather than personal exploration of both risks and benefits.

In contrast to Hong *et al.*'s presentation of *personal privacy risk models* [12], we here focus on uncovering community-based risks and rewards. This work derives from an analysis of previous work, including both ubiquitous computing technologies and design models and processes. We also conducted an in-depth analysis of a specific domain problem, evidence-based care (EBC) that requires the collection of large amounts of potentially personal information in an arguably sensitive domain for the protection of vulnerable individuals (students and patients).

In the case of EBC, individuals who will likely receive no direct benefit themselves may need to be recorded for the best possible diagnosis and monitoring of others. Any protection afforded them, whether through restriction of recording all together or reduction of recording to simply blur or not include those individuals, will reduce the benefit to the individual(s) receiving care. Thus, when developing tools for EBC, researchers and designers must examine what level of privacy is necessary and compatible for an individual with consideration for the particular needs of this domain and its collective stakeholders.

STAKEHOLDER GROUPS IN EBC

We identify four primary stakeholder groups in any system designed for EBC. Membership in each group is well-defined but not necessarily mutually exclusive and complete. These stakeholders all incur some level of risk in terms of disclosure of potentially personal information. However, not all of them will benefit directly from such systems, nor will all of them be able to consent to the risk incurred. These groups are:

- *The individual for whom the care is offered*

In many cases, whether in a medical or educational setting, this individual may have little direct influence over the capture or subsequent use of the data captured about him/her. For example, the patient in question may be unconscious or a child who is unable to vocalize concerns or to consent. Because the records primarily pertain to these individuals, the largest number and most severe risks are incurred by them.

- *Caregivers who serve as data capturers*

These individuals currently employ record keeping of some sort (usually with pen and paper) in their care practices. These records will sometimes include details about the care they are providing, primarily as it pertains to diagnostic and monitoring purposes, but the

risks can include use of this information for employee evaluations or legal disputes.

- *Caregivers who view, analyze, or otherwise use data*

These individuals already work as consumers of the data that is currently manually collected by the caregivers of the previous category. They tend to include supervisors, family members, and sometimes external specialists and consultants. They rarely capture data themselves, although this can overlap in some cases with the data capturers group.

- *Bystanders to the recording of data about care*

Individuals belonging to this stakeholder group can be but are not necessarily caregivers, family members, nor even acquaintances of the individual for whom the care is offered. They are people who are near to or who interact with individual under care during an incident significant to either the diagnosis or the monitoring of the patient/student. For example, if a child with developmental delays approaches a shopper in a store, that interaction, including the shopper's reaction, might be important to understanding the child's particular needs. However, the shopper may otherwise have no other connection to the child.

The large quantities of data to be collected and shared amongst researchers and practitioners in fields that use some form of EBC bring about interesting and unique challenges. Naturally, one of the major considerations is about notions of awareness that evidence is being collected and concerns about privacy, control and surveillance. These concerns involve the collection and sharing of this evidence amongst individuals belonging to each of these stakeholder groups and between the groups. Thus, when considering the requirements for EBC, we needed to analyze all of these stakeholder perspectives collectively.

THE NEED FOR SUPPORT FOR GATHERING RICH EVIDENCE

There is little argument amongst behavior analysts and educators that analyzing data about children with special needs would help design interventions for both educational and behavioral goals. Furthermore, the use of health diaries to monitor and to diagnose dietetic or physical abnormalities is common in medical practice. Observing and communicating about progress made by a student or patient through records can be extremely encouraging and motivating to caregivers, as well.

“It’s also just encouraging, at least for me, to see any improvement... it’s just plain encouraging, even if it’s not going to change his life that he does X, I love to hear that.”

- *mother of a child with special needs*

A: He can’t tell us who his best friend is. He can’t tell us whether he ate his lunch. He can’t tell us any of those things that other kids come home

from school and can tell their parents... so [record keeping] is an essential part of this communication that we wouldn’t get otherwise

B: And those are the things that we want the parents to see [visually or first hand].

- mother of a child with special needs, with response from a para-professional in the school

Given these positive potential outcomes from record keeping, particularly when it involves rich evidence, it might seem surprising that we encountered so many situations in which the individual caregivers charged with caring for a child with special needs and recording data about that child either did not capture data at all or did so poorly. The problem, however, is unlikely one of lack of motivation to record so much as inability within the constraints of the caregiving environment.

Challenges to Data Collection

Teachers are primarily employed to teach, and they rarely take time away from that primary purpose to record data. A county level special education director reported that simultaneous data gathering is a “strain of resources” and that it is too “overwhelming to try to meet all needs” of caring for a particular child. Patient compliance with self-reported medical records (or with those collected by informal caregivers, such as a family member) is consistently a source of concern for the medical profession. Furthermore, one behavior analyst who worked directly with teachers on behavioral issues noted “data tends to be what people remember.” Although unlikely to be malicious in intent, teachers can often make mistakes when recording data about a child, particularly as the time between the occurrence of an incident of note and time to record information about that incident grows. Just as healthy adults rarely discuss their physical condition with physicians unless there exists a set of negative symptoms, anecdotal data in education tends to be negative.

Throughout this work, we have seen tension between the desire for caregivers to witness first-hand behaviors and other symptoms of interest and the need for caregivers and others nearby or involved in the care to maintain some level of autonomy and privacy. Everyone we interviewed, however, expressed at least some desire to record and to share rich media including video.

Available Options for Collecting Evidence

Five options for capturing evidence for EBC of a child with special needs were chosen for further exploration from the options available currently and those being researched. These options were intentionally designed to span the variety of privacy protecting solutions with a particular emphasis on using video, because participants throughout Hayes *et al.*'s study of caregivers [9] had consistently commented on the value of video. These options include:



Figure 1: In this video clip, interactions around a toy box are of interest to the caregivers. In the frame on the left, the child of interest (center) can be seen playing with the toy box in an appropriate way. For the child to the right's protection, he was only to be recorded when close to the toybox. In the frame on the right, the interaction between the children is blurred. This video clip mimics a camera fixed in an environment recording only interactions in a defined space.



Figure 2: In this video, the caregiver is only clearly visible when she is close to the child. Otherwise, she is blurred, and the areas around him are clear. At times, the child also goes off camera, making virtually the entire image blurred. This behavior mimics a fixed camera in an environment configured only to show the child of interest.

1. **Manual annotation, no video.** The arguably least invasive and most common form of data collection is requiring one of the primary caregivers, the patient/student, or a third party trained only to observe to manually annotate experiences. The results of this annotation are narrative notes or completed structured forms which can then be shared or further annotated.
2. **Fully automated capture,** in which digital video is recorded and archived at all times without intervention from the caregivers. Indexing into video is then available from manually or automatically generated triggers.
3. **Fully automated capture with a location-based filter,** in which all but one three dimensional space (*e.g.*, a work table or a toybox) of interest is blurred. Video captured within that space would be clearly viewed. Again, indexing into the recorded video in this model is made available using manually generated or time-based triggers (see Figure 1).
4. **Fully automated capture with a child-based filter,** in which space around the child of interest remains clear,

while everything else is blurred. The same index and access model applies (see Figure 2).

5. **Selective archiving of captured video,** in which capture devices are on and recording at all times, but archiving of those recordings requires manual intervention. If the recordings are never archived, they expire and are deleted after a certain amount of time. This time value is based on a custom heuristic applied based on the setting and the child of interest.

METHODOLOGICAL APPROACH

The goal of this study was to understand ways in which technology could help or hinder the practice of EBC through development of new applications for data collection and augmentation of these applications with the ability to capture “rich” media, *e.g.*, audio and video streams and sensor readings. One domain of EBC practice, behavioral assessment of children with special needs, lends itself well to explorations of these issues. We wanted to understand how the social and logistical processes inherent to these practices affects the current methods of evidence

collection and how these might affect adoption of technologies into this space.

Participants in this research were relatively diverse, including professional caregivers from both within and outside of the school settings, informal caregivers (friends and family), adults who had as children themselves been subjects of EBC (some of whom continue to be currently), and what we refer to as bystanders. Due to the goals of obtaining varied feedback brought on by both individual reflection and group discussion as well as the particular concerns of some of the subjects (*e.g.* comfort level with group interactions for individuals with disabilities), we used semi-structured interviews, participant observation, artifact collection, and focus groups.

We then completed a more focused study using a combination of methods, from January to August 2005, concentrating on uses and concerns of video capture in classroom settings for EBC. Interview participants in this study included four adults with Asperger's syndrome diagnosis [5] four special education professionals, and five bystanders. Focus group participants included:

- fourteen professional caregivers from school systems and consultancies in three counties and two states
- fourteen familial caregivers who were primarily parents but also two siblings and one aunt

The semi-structured interviews varied depending on the individual participant but focused on the costs and benefits of recording video for EBC in classrooms. A secondary focus included how these recordings could be uses as communication tools and the ways in which technology might be used to augment existing community practices.

The group interviews focused first on recording of evidence for EBC as it is done now and ways in which technology might improve the experience of capturing notes about an incident. We then presented five models for capturing rich data and prototype video snippets of those models which include video recording. We asked the participants to consider with each model of recording how comfortable they would be with recording and the details of their specific concerns. We also asked them how valuable these recordings would be and for what they would be used. We then asked them how much they would need to navigate and/or trim to find the appropriate piece of video, and with whom they might be willing to share these snippets. We varied the order in which each model was presented across the different group and individual interviews.

THREE TENSIONS INHERENT TO COLLECTING RICH EVIDENCE FOR EBC

Despite the large need for collection of rich evidence, caregivers, analysts, and researchers in EBC, continue to struggle with collecting the required evidence in a socially acceptable way. The difficulties are great, in part due to the disparate requirements generated when considering each

stakeholder group individually. When considered collectively, these requirements often conflict, creating tensions that can be designed around but only after careful analysis of the system and its stakeholders as a collective. In the following sections, we detail three primary tensions uncovered during our exploration of an EBC environment and describe the ways in which the five potential models for gathering evidence interact with these tensions. This discussion serves not only to provide design guidelines to others hoping to design technologies for EBC but also as an example of the type of analysis that must be completed for those domain problems for which personal and individual analyses would result in intractable solutions.

Fear of Surveillance can Interfere with Benefit of Evidence

It is commonly accepted that people don't like to be surveilled, whether by other people or by technology (cameras, etc). The perceptions of others about these attitudes can be as varied as the attitudes themselves. The following exchange between an external consultant and an in-school specialist is a good example of two contrasting sentiments expressed at every focus group:

"I also kind of feel like the people who are going to be comfortable being video-taped are the people who are doing what they are supposed to be doing."

– Behavioral specialist and consultant

"I wouldn't have that reaction at all, being in a classroom setting... I think it is more of a personality thing as far as feeling comfortable... for me its based on the times I was raised in that being video taped all the time was looked upon as a very scary thing, an invasive thing."

–Para- professional, in school caregiver

Regardless of the reasoning for being uncomfortable with recording, there are two ways in which organizations have tended to reduce concerns about surveillance: providing direct control of it to those who will be surveilled and/or providing visibility and awareness about the surveillance.

Controlling Data Capture

Providing control of recording to the subjects of that recording can often reduce concerns over surveillance. Current practice in public schools in the United States gives teachers almost complete control of video recording in their classrooms, thereby providing for them protection against unwanted recording for any reason, although this control then of course does not extend to the children in that classroom. If teachers want to record something to show to another teacher, an administrator, or even a parent, they usually can. Occasionally, a parent or an administrator will request evidence of a particular inappropriate behavior or of a new skill. In these cases, the teacher is still often in charge of deciding when the video recording will be made and then turns over the evidence to the requesting party. In

a rare case, an individual from within the school system may come and record a teacher's classroom, but in those cases, the teacher is nearly always alerted to the recording substantially beforehand. Once a recording is made and is part of the official educational record, FERPA guidelines indicate that guardians of a particular child have the right to access this information at any point, but the data cannot be accessed by anyone else outside the school system [8].

From the standpoint of the teachers, this approach has both positive and negative elements. Complete control of recording reduces the concern about recording anything the teacher would not want saved, and potentially more importantly shared. It also, however, increases the task load for recording a video snippet for sharing. One special education teacher we interviewed described how she liked to record skill acquisition to show to parents:

"I usually try to record the first time I ask a kid to do something and then again after I know he learned it. That way I can put it in the end of the year report...and parents can see the improvement... But sometimes, I realize after a couple of weeks that I forgot to record it the first time and now it's too late."

The possibility of missing important recordings was an important concern, repeated with all participants. Handing over the control to a third party observer (either machine or human) can reduce this concern of missing important moments, but it introduces its own difficulties. These challenges can include but are not limited to logistical details such as the resource constraints of observing classrooms all day, the potentially disruptive interactions of an observer with the children, and the potential negative feelings of intrusion by this third party observer.

Visibility and Awareness over the Lifetime of the Recording
Healthcare and education both have a tradition of surveilling trainees using human experts to document occurrences in a classroom or hospital. This level of visibility reduces some concerns over surveillance, but introduces new difficulties.

"...here's the scary thing. We go in to observe, and observation cures. Nothing happens... because we're a novelty and they [children] are curious, even though I never make eye contact with the kids..."

-behavior specialist, education trainer

Although bringing in a third party observer allows an individual trained in diagnosis and intervention for the particular problem to witness the symptoms first hand, it is also fraught with its own difficulties. One professional caregiver noted "everyone's behavior changes when people come to observe," a particularly large problem when dealing with socially inappropriate behavior. Thus, when attempting to diagnose inappropriate behavior of a student at a public school, the behavior of that student, which may

be set off by any combination of other external factors including the behavior of the teacher and of other students, cannot be accurately diagnosed nor monitored when an observer's presence alters those external factors.

Another large issue with using a professional external observer is one of being with the patient or student at all times that the behavior may occur. Caregivers reported that the majority of families find home visits by professionals to be "too invasive" but at the same time will say "If you could just see them at home" when describing particular behaviors. Thus, providing complete visibility of observation may still be considered socially unacceptable.

For individuals who are the subject of EBC, this tension may be particularly acute. The desire to be able to review previous recordings later in life and the desire to receive the best care possible can directly conflict with comfort levels of recording as noted by a 30 year old man with an Asperger's syndrome diagnosis (ASD) [5], to whom we will refer as Adam. As a child, Adam's behavior seemed "odd" to his parents and teachers. He was extremely uncomfortable in large groups of people and expressed terror at the idea of meeting anyone new or traveling to a new place. Academically, Adam excelled, but socially, he was greatly diminished. It was not until Adam was diagnosed as an adult with ASD that things began to improve for him. Armed with information and new coping strategies, he has been able to integrate somewhat into society and attend college, although he still struggles regularly. Adam noted that he wishes "he could see video of [himself] as a kid, so [he] could know what other people were talking about." He also describes himself as "camera shy," however and noted that he would not have liked to know that the camera was on as a child and would have preferred something "hidden up in the ceiling like a security camera... kids should have recording about them even if they don't like it... [caregivers] might need it, and [the children themselves] might want it later." Thus, when designing socially appropriate technologies to support collection of evidence we must consider not only the risks and benefits of the stakeholders currently but how these might change over the course of a lifetime or longer.

Tension between Community Work and Autonomy

In each of three group interview sessions, at least one individual expressed the viewpoint that caregivers who did not want to be recorded may not be as competent or at least as confident in their performance as those who did. One individual in a supervisory role even went as far to note that "intermittent .. unpredictable video taping can be one of the greatest protections for non-verbal children," a comment that was quickly followed up by a specialist in the session who noted "people that object either are not confident or *know* they are not doing a good job."

Although these sentiments may appear to be cynical in nature, they exemplify a theme that occurred throughout the study, one of using video to uncover difficulties in both the

caregivers and the subjects of care being recorded. A number of concerns of individual caregivers tend to prevent widespread use of capture technologies in EBC environments. Fear of being reprimanded for mistakes in treatment and instruction is rampant even among caregivers recognized to excel at their jobs. One education specialist commented that “teachers should see themselves on video... ‘cause I don’t think you have to say a word” for them to learn from the clips, but at the same time, she noted that “they dread it. They hate it. They don’t want to see themselves on video. Nobody likes it. You don’t realize how many times you blink your eyes or how often you do this [makes an example hand gesture]...” indicating a repulsion to video recording that has little or nothing to do with traditionally considered concerns about privacy.

Using Recordings to Build Communities

Despite the fears of caregivers, the people most often noted as being potential critics (e.g. parents in the school setting) almost unanimously reported wanting to support them.

“When [my child] was little bitty, he was in a daycare situation that was just getting this web camera put in place... and it never occurred to me that the teachers in the daycare felt this was very much an invasion, that we must want this because we didn’t trust them, and we were like ‘oh gosh, we don’t actually want to see you. We just want to see our kids.’ ... and when I found this out about the daycare teachers, it was like ‘Whoa, okay [gestures stop with both hands], it’s not worth it to me to make you feel uncomfortable.’

- mother of two children with special needs

Rare malicious individuals aside, all of the potential stakeholders in a system designed to capture information for EBC are likely to have as a goal at some level to provide (or at least not to impede provision of) the best care possible for individuals in need. Recognition of this shared goal, coupled with appropriate use of video can break down these barriers to communication and group problem solving and allow people on all sides of the issue to understand one another’s views. A school director pointed out that recording and sharing recordings may in fact be one of the best ways to build a “culture of trust.”

“[Recording and sharing of video] goes a long way to create a culture of trust.”

- Director of a behavioral education center

“You have to build teams, and I can see this as building teams.”

- Behavior specialist at the same center

His plan was to use video recordings to have group discussions and teacher training sessions in addition to using them as diagnostic and monitoring tools. In other sessions, similar sentiments were expressed, with one teacher excitedly commenting “I love trouble shooting with

a bunch of minds” and with video, you can share this “better quality of information.”

Concerns about recording can center on how the recordings would be used within an organizational or social structure that can include power differentials. Fear of negative repercussions, whether justified or not, can be enough to convince a caregiver not to use video recording. Within some communities, however, video and evidence could be used as positive trust building communication tools as well as tools for self-reflection. Use of evidence among team members can open new lines of communication and build trust as well as protect those being cared for.

Protecting Members of the Community who Might Object

Even in communities in which trust is being built and common goals are shared, individual caregivers and bystanders can still lose their senses of autonomy, their freedom to choose whether or not to be recorded, and hence some level of their privacy. When asked about what events in particular should be recorded about a child with ASD, one of the participants, an adult with ASD himself, responded, “all events that take place with other people,” a sentiment echoed by nearly every caregiver we interviewed. Recording any time a child interacts with another person necessarily requires recording a large array of people, some of whom would be fully sympathetic and others who may not. When designing for this need, we must consider then what the policies of these individuals might be.

One potential solution to recording all the time but still providing individuals to opt in or out of the recording is to apply filters to the video, essentially to blur people out, or to avoid recording when individuals who object are present. Particularly of interest is the idea of blurring an individual’s face or other identifiable features, thereby ensuring anonymity for that individual. These solutions, however, have serious repercussions for the evidence being collected.

“I don’t like that. You can’t see what that other child is doing. If I don’t know that... [no diagnosis can be made.]”

- Behavior specialist after being presented with examples in which most people other than the child of interest are blurred most of the time

Caregivers noted that with children with special needs, particularly social disorders, observations of the larger context of and the other actors in the environment are a necessity. Without being able to see these other bystanders and their behaviors, it is impossible to make an accurate diagnosis. Thus, a piece of video blurred to protect the privacy and anonymity of the other people nearby would be useless to those practicing EBC in this domain.

When presented with the idea of selective archiving, however, the response was overwhelmingly positive. Parents noted that this type of control would give them an option to record a behavior of particular concern and send it to a specialist without having that specialist in their homes

to observe. They also noted that being able to share identical copies of recordings of interesting incidents might encourage caregivers to work together. Teachers noted that they would be able to ask specialists questions about behaviors and about their own responses, again without requiring the costly endeavor of an on-site evaluation. They also expressed that with selective archiving they could use their own discretion to choose when and when not to record, giving them a sense of being in charge of the video recordings but without the fear of missing important moments as discussed in the previous section. Specialists commented that they appreciate not having to look through hours of video to find the incidents of note. They also expressed that they sometimes need the context of interactions that may be hours or even days before an incident to diagnose a particularly complex problem.

“My immediate reaction [to the idea of selective archiving] is ‘oh that’s kind of neat’ because we don’t know when the behavior might occur, but ‘oh gosh it just happened’ and now we can go back and see what happened twenty minutes previously to see if there are any triggers we missed. .. I would be more willing to [look through the video] because I know something happened.”

- Lead behavior specialist

They commented that giving teachers too much control might result in some of the same problems with recording as they witness currently, but that selective archiving was a compromise with which they were willing to work. They would be able to witness incidents free from teacher interpretation or analyze the data coupled with teacher commentary depending on the needs of the given situation.

The Effects of Legal and Societal Norms Paired with Benefits and Practicality

Parents of children with special needs in the United States are sometimes asked to consent to recording pictures and video of their children at the beginning of each year. Parents of neuro-typical children, however, are rarely asked for the same level of consent. In hospitals, private clinics, and special housing institutions for physical and mental health, again the caregivers and patients are often asked to consent to recording. Significantly, those recordings are then covered under laws designed to protect medically sensitive data. Visitors to these institutions, however, who are neither patients nor employees, are unlikely to be given the opportunity to consent to recording. Because caregivers have so rarely asked for such permission, we can only hypothesize as to the reactions based on their prospective considerations and philosophical arguments.

“From a school’s standpoint, it always comes back to a confidentiality issue... they have security cameras on that [record] all the time, so I don’t know if [it could become] kind of a standard, you’re on camera whenever you’re in a school building.”

- Special education director at a public school

Societal norms and standards with regard to recording in public institutions are moving targets. Even now, in Europe, the CCTV initiatives [20, 22, 23] demonstrate that communities will accept large scale ubiquitous recording if they believe the recording will be used for safety and emergency purposes and only those purposes. For these particular concerns, the collective community is generally considered to be more important than an individual’s concerns about surveillance, privacy, or consent. Similarly, health and education records, usually protected, are often shared during times of crisis or in situations when the health or safety of a large group of people is in jeopardy (e.g., during a disease epidemic).

Practical difficulties and logistic hurdles make getting the consent of every individual to share this personally identifiable information in these situations a nearly impossible task. Furthermore, practically speaking it may be excessive. Due its application to medical and educational domains, EBC results in records that are usually protected under the Family Educational Rights and Privacy Act (FERPA) [8] and the Health Insurance Portability and Accountability Act (HIPAA) [11] in the United States. Similar laws exist in other countries, but for the purposes of this paper, we will discuss primarily the implications of FERPA and HIPAA on EBC. These laws would protect the personally identifiable information not only of the primary individual receiving care but also of any bystanders or caregivers present in the recordings.

Under FERPA rulings, parents or eligible students can review any records stored for the student at any time and can then request updates to any records believed to be inaccurate. Schools must also have written permission from the parent or student to release any information from a student’s education record, with some notable exceptions, such as to other school officials, to organizations who are conducting studies on behalf of the school, to legal entities or in conjunction with health and safety emergencies. Many school officials expressed concerns about including rich media in the official student record primarily for fear of needing to release the records to these parties, as in a lawsuit or other contentious situation.

“[In a school] you can’t even take a still photo of a child without parental consent... you’re not supposed to do it even if its not going to be published... you’re not supposed to do it even if it’s just going to be published in a school newsletter.”

- Para-professional from a public school

This quote exemplifies the challenges encountered by school officials imposed primarily by the current social and legal climate. As these norms change over time, so will the confidentiality concerns in these settings.

BALANCING NEEDS AND RESOLVING TENSIONS

By evaluating not only personal risk and reward models for potentially invasive technologies but also by analyzing risk

and reward for the larger community of stakeholders, we can design more appropriate solutions for a set of domain problems that are particularly important to groups of individuals. These problems are prevalent in education and healthcare. Our analysis of EBC as an example of such a domain problem, uncovered three significant points of tension for four disparate stakeholder groups. Without having completed this analysis, we would not have been able to uncover the tensions present and their affects on the stakeholder groups. An appropriate design that both satisfies the requirements of collecting much needed evidence and addresses these tensions was then developed from this analysis. We here present one solution for balancing the risk and rewards inherent to this domain problem. We recognize that the techniques of this analysis may uncover different tensions and result in different solutions when applied to a different domain problem.

In the case of EBC as it is used for diagnosis and monitoring of children with special needs, there is usually one adult caregiver who serves as the primary data capturer in any particular environment at a particular time. This adult is most often a parent in the home or a teacher in the classroom. The model of evidence collection that employs selective archiving of captured video allows for a balance of the benefits of use of video in EBC with the tensions and challenges uncovered through our stakeholder analysis. This primary caregiver can act as a real-time negotiator of privacy policies for a variety of stakeholders. For example, she can verbally request consent from a bystander who interacts with the child for a period of time or she can determine at that time that consent would be unrealistic and potentially unnecessary. She can also make decisions for members of the community who are unable to consent because they cannot make those decisions or they cannot verbalize that choice (*e.g.*, other children in a classroom or friends or siblings in a home). Although acting as a real-time negotiator of privacy policies can be an added burden to this caregiver, reduction in the data recording requirements (*e.g.* by moving from manual to automatic recording) significantly offsets this added burden. Furthermore, these caregivers are primarily in similar situations on a day to day basis from which they can develop patterns of use (or avoidance) of recording.

Using this model, we can reduce the visibility of the recording for the majority of participants, because the caregiver and primary data capturer will be aware of the recording. In fact, this caregiver will be controlling archiving of anything that was recorded. Reducing the visibility is important in EBC for children with special needs, because it will disrupt the environment less and thus increase the quality of the evidence being collected.

When presented with the selective archiving model, all of the caregivers and EBC subjects we interviewed recognized that there were still issues to be considered, but at the same time, they were unanimously positive. One school official commented on both the ease of use of a selective archiving

solution and the reduction of privacy and confidentiality concerns: “I think anyone [could do it], and I don’t think you’d have any problems with confidentiality or anything [because] the teacher controls it.” Bystanders were most positive in response to models that either did not record identifiable information about them at all or recorded it in such a way that they remained anonymous (*e.g.* blurring). When presented with information about the relative utility of such models opposed to a constant recording or a selective archiving model, however, all but one conceded that they would accept the selective archiving model if approached by a human data capturer, such as a caregiver.

An open question in designing for EBC, then, is how to alert bystanders to the presence of recording. In the particular case of caring for children with special needs, caregivers are most likely to want to archive video snippets involving bystanders when the child has interacted with the bystander. Thus, some level of entrée has already been established allowing a primary caregiver to approach this individual with a verbal request. In other scenarios, one could easily implement notification events such as lights or sounds to indicate the saving of a recording, and couple these indicators with other notifications posted in an environment about the potential for recording.

CONCLUSIONS

Other researchers have suggested personal models for assessing risk. We agree that these models are useful for designing applications and recommend that when assessing the risks and rewards for any individual stakeholder, these models be considered. In some cases, however, these analyses must then be considered together as an evaluation of the cost and benefits to the community as a whole.

Social processes present in education and in healthcare settings allow for dynamic negotiation with or on behalf of all of the stakeholders *if* the primary capturer is given control of the capture and *if* the primary capturer can be considered trustworthy enough by the other stakeholders to take into account their concerns. Teachers, doctors, and other caregivers have traditionally been given this level of trust in Western societies, with notable exceptions, and thus it is reasonable to assume that they can act in these roles for technological advances as well.

In this paper, we argue for using a community based approach to privacy analysis for certain domain problems, notably those prevalent to healthcare and education. We presented an example of one such analysis for the purposes of designing socially appropriate tools for evidence-based care (EBC). Using the information uncovered in a long term qualitative study of caregivers of children with special needs and the latest research in privacy sensitive video recording, we identified four stakeholder groups and five solutions to recording for those groups. Using group structured and individual semi-structured interviews and prototype artifacts of those recording models, we were able to conduct an analysis of the technological options based on

a community of stakeholders rather than individual users. From this analysis, we determined an adoptable and appropriate design for supporting the practice of EBC.

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