Parent-Driven Use of Wearable Cameras for Autism Support: A Field Study with Families

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ABSTRACT
Recorded images of children’s activities can be useful to caregivers and clinicians who need behavioral evidence to support children with autism. However, image capture systems for autism are typically complex and provide only a top-down, outsider’s view. In this work, we assessed the use of cameras worn by children to record the context of their activities and interactions from their perspective. We used a technology probe to explore how this simple, parent-driven system could be designed for families to adopt in their homes. We present the results of a five-week field study with five families. The system helped parents to (1) see the world from their child’s eyes, (2) increase their understanding of their child’s needs when their child is uncommunicative, and (3) help them encourage their child’s social engagement. We discuss how these systems can be designed and used to their full potential.

Author Keywords
Augmentative communication, children, life-logging.

ACM Classification Keywords
H.m. Information Systems: Miscellaneous.

General Terms
Design, Human Factors

INTRODUCTION
Capture and access tools enable caregivers of children with autism to capture children’s behaviors over time. Behavioral data recorded via images and videos are useful to caregivers. The long-lasting nature of autism and other developmental disabilities, and the untested nature of many interventions, means that caregivers must often document diagnostic and evaluative information over decades [8]. Also, a major struggle for caregivers is keeping in touch with one another about changes in their children’s behavior and alterations to treatment [8, 14]. Capturing behaviors in still images and video can be a powerful tool for enabling caregiver communication and collaboration [7, 9].

For image-based capture and access tools to support communication between children and parents, enable documentation of behavior, and improve caregiver collaboration, parents should be able to capture their children’s daily activities. Capture and access systems have typically been designed for use in educational or therapeutic settings. Here, we build on prior work in automated capture and access for autism in educational settings but redesign them for use in daily family life. To make these systems accessible for families, we use a small camera worn by the child that takes pictures automatically. Automatic capture reduces the burden of daily use. A wearable camera—by nature of its mobility—follows a child through his or her activities in different locations.

The wearable camera captures images from the child’s perspective, documenting activities in the child’s life. The images are useful visual supports. Visual supports are “those things we see that enhance the communication process” [10]. They augment communication, in much the same way that sign language serves as a visual representation of language for someone with a hearing impairment. Many non-verbal children communicate with visual supports [2]. Picture-based communication supports enable the sharing of information about needs, preferences, and other everyday concerns (e.g., the Picture Exchange Communication System [1]). Others are used to teach complex concepts (e.g., Social Stories [6]).

In addition to enabling and encouraging communication, use of visual artifacts has been shown to reduce the symptoms associated with autism and other disabilities [3]. Of interest here particularly is the support camera images provide for children who may have trouble interpreting naturally occurring visual cues. When images are captured and reviewed later, parents can help their children reflect on their experiences at their own pace. As such, talking about the images can improve communication, and sharing the images can enhance social engagement [15].

In this work, we study the use of wearable cameras in daily family life through a parent-driven technology probe study. We explore the design of these cameras to ensure caregiver engagement and ease, which are fundamental to the adoption of assistive technology [4]. In a five-week field study, we uncovered how families used their technology probes, and involved parents in participatory design [17] of
wearable camera systems and interventions that would incorporate them into daily family life. We found that enabling capture from the child’s perspective held value for parents, particularly if their child was nonverbal.

TECHNOLOGY PROBES
Drawing from Hutchinson et al.’s [12] use of technology probes with families in the home, we used two different technologies as probes to explore the use of an automatic camera worn by children with autism: the SenseCam developed by Microsoft Research, and the Apple iPod Touch running a lifeloggng app, LifeLapse.

SenseCam
SenseCam is a novel recording technology developed by Microsoft Research [11]. SenseCam is a wearable digital camera designed to take photographs of everyday life without user intervention, while it is being worn (see Figure 1, left). It does not have a viewfinder or display. To ensure that relevant images are captured, it has a wide-angle (fish-eye) lens that maximizes its field-of-view (see Figure 1, right). The frequency of capture is at least once per minute, and several times per minute when changes are detected. Images are transferred to a computer and reviewed at various speeds using SenseCam’s viewing interface.

iPod Touch + Lifelapse App
The iPod Touch is the first generation of the Apple iPod to have a camera. We modified the iPod Touch to resemble the SenseCam by outfitting it with a lanyard and installing Lifelapse (http://lifelapse.com/), a simple lifeloggng app (see Figure 2). The iPod Touch is similar in overall volume and weight to the SenseCam, but has a wider surface area on the wearer’s chest. Lifelapse takes a photograph once every 30 seconds. Unlike SenseCam images, Lifelapse images can be reviewed on the iPod itself without having to download them onto a computer.

METHOD
Parents of children with autism were recruited by word of mouth through our ongoing research with the autism community. Professionals made referrals of parents who would be willing to participate in this research and whose children would be likely to tolerate wearing a device around their neck. We recruited five families with a child diagnosed on the autism spectrum. The primary parent participant in all the families was the child’s mother. The mothers were responsible for determining how and when to use the technology probe. Participants lived in suburban areas of three different U.S. states.

A first visit to each participant home served as a training session on the technology probe, as well as the start of observation. The primary parent participant was introduced to the technology probe and received training to turn automatic image recording on and off, download the images onto their computer, and review and organize the downloaded images. All participants used their own computers for the study. Those using SenseCam installed its accompanying software on their computers.

Each week, a researcher visited the families at their home for an interview along with observation of their home life and family interactions. One family (Tyler’s family, see Table 1) was an exception due to the distance of their home – after one home visit, that primary parent participant was interviewed over the phone each week.

Participation in the study was approximately 5 weeks. Several parents still wanted to use the camera at the end of the 5 weeks. One family (Daniels’ family, see Table 1) did not find the camera very useful for them and chose to end their participation after 3 weeks.

The five children participating in our study varied widely in their communication, interaction, motor skills, and day-to-day functioning. Each child on the autism spectrum has unique needs, and no one tool or intervention works equally for all children. Caregivers exhibit considerable creativity in finding the most effective appropriation of tools available to meet each child’s needs as closely as possible. In this study, we examined the unique differences in each of the children participating, and encouraged their parents to use the system creatively, so we could understand how different families appropriated it to fit their unique needs.

Due to the limited communication and social skills of the children participating, we did not interview children. All mothers were the primary caregivers, and as such, they knew their child’s personality and preferences best and were most qualified to speak on his or her behalf. Most of
the results presented in this paper are based on the mothers’
reports, but wherever possible, children’s direct reactions
and opinions are included.

RESULTS
In this section, we first describe how the families adopted
their probe, and what questions parents wanted to answer
with the probe. We then discuss our findings on how the
probe helped parents see the world from their child’s eyes,
understand their child’s needs, and encourage their child’s
social engagement. Finally, we discuss some tensions that
arose during use among the parent, child, and third parties.

Technology Probe Adoption
Four of the five participating families used a SenseCam. At
the start of the study, some of the parents expressed
discomfort with conventional digital cameras and
technology in general. All of the participants used
cameras, digital cameras, and other devices in their
homes; nonetheless, their uncertainty seemed to stem from
a lack of confidence in using an unfamiliar device.
Participants were not sure they would learn to use
SenseCam and were skeptical about its ease of use but after
a short explanation, they all learned to use SenseCam on
their own without any major problems.

Noticing these attitudes led us to consider a device with a
different form factor, the iPod Touch. We learned that the
iPod Touch was comfortable for both parents and children.
Parents spoke with excitement about the popular iPods,
iphones, and iPads. Some of our parent participants had
iphones or other smart phones, and would give them to
their children to entertain them with games and other apps.
For example, Zach was a frequent user of Talking Tom Cat,
an avatar that “repeats everything you say with a funny
voice”\(^1\). Our fifth participant, Tyler, used an iPod with the
lifelogging app Lifeslap. We therefore asked whether
familiarity and comfort would affect the way wearable
cameras are adopted and used.

We found that form factor had no effect on two issues the
probes raised: social acceptability of the device when it is

\(^1\) http://outfit7.com/apps/talking-tom-cat-1/

being worn around the neck, and the ease with which
images are reviewed and shared.

Social Acceptability
The problem of appearance of technology is a sensitive
issue because many children with autism are visibly
different or awkward, and also have challenges with social
engagement. They do not need something to make it even
closer to fit in.

We expected the iPod to be a more socially acceptable
device to wear than the SenseCam, due to its recognition
and popularity. However, parent participants expressed
similar concerns about both devices. Raquel’s mother
explained that her daughter is immediately perceived as
different by people who see her in public, due to her
awkward movements and lack of social interaction. Raquel’s
mother compared the SenseCam to her large and
bulky speech-generating device in explaining how assistive
technology made her look even more strange. Although
SenseCam’s form factor is much smaller than the speech-
generating device, and has a sleek black design, it still had
the ability to make Raquel stand out because it made her
even more different from others.

Although the iPod is more socially acceptable to use than a
device that looks like assistive technology, it is not typically
worn around the neck like our probe. Tyler’s mother was
not comforted by the iPod’s form factor because wearing it
around his neck would make Tyler stand out:

"He feels so out of sorts as a human being, and the
camera just makes him feel like a dork".

Echoing the concerns expressed by Raquel’s mother, she
felt that any atypically used device would only make her
son stand out more. Parents’ concerns about the form factor
of their technology probes led to suggestions about smaller
cameras that could be worn on hats, eyeglasses, or other
less “conspicuous” areas. Parents said they would have
preferred a hidden camera, although they also said that a
hidden camera would threaten privacy of others. They were
unsure how to find a compromise between their child’s
comfort and that of the people being captured in the images.

<table>
<thead>
<tr>
<th>Name</th>
<th>Age and Gender</th>
<th>Communication</th>
<th>Household</th>
</tr>
</thead>
<tbody>
<tr>
<td>Juliet</td>
<td>14 year old female</td>
<td>Nonverbal; limited communication using speech generating device</td>
<td>Lives with mother and brother; has a nanny; parents are divorced and she spends some weekends with her father</td>
</tr>
<tr>
<td>Tyler*</td>
<td>10 year old male</td>
<td>Verbal and high functioning, but has a difficult time with new things</td>
<td>Lives with mother, father, and sister</td>
</tr>
<tr>
<td>Daniel</td>
<td>12 year old male</td>
<td>Verbal and high functioning</td>
<td>Lives with mother, father, and sister</td>
</tr>
<tr>
<td>Raquel</td>
<td>15 year old female</td>
<td>Nonverbal; limited communication using speech generating device</td>
<td>Lives with mother; parents are divorced and she spends some weekends with her father</td>
</tr>
<tr>
<td>Zach</td>
<td>10 year old male</td>
<td>Verbal, but limited communication; social and outgoing</td>
<td>Lives with mother, father, and brother</td>
</tr>
</tbody>
</table>

Table 1. Descriptions of the five children who participated in the field study, including their age, communication skills, and who lives in their household. All names have been changed.

*Tyler used the iPod Touch probe.
Simplifying this process would significantly increase ease of use. Users need to understand where images are stored, and how to access and organize them for easy review.

The SenseCam requires images to be transferred onto a computer and reviewed from within the SenseCam software. The process of opening the software in order to view the images, rather than accessing the images from folders, was confusing to some participants. These participants would hesitate during interviews and take some time to remember how to access and view their images. Simplifying this process would significantly increase ease of use. Users need to understand where images are stored, and how to access and organize them for easy review.

The LifeLapse app enabled Tyler’s mother to create and share videos with one click. This feature is even available directly from the iPod, requiring no transfer of the images onto a computer. Tyler’s mother made a video out of their images each week. She uploaded it to the video sharing site Vimeo and emailed the interviewer a link to the video before each telephone interview. In contrast, the SenseCam limits review to only the user’s computer, and using SenseCam’s software. Due to these limitations, the SenseCam participants were not able to share their images outside the household, despite the desire they expressed in sharing them with therapists, educators, and other family members. The ability to make a video with one click, then upload and share the video, would have been useful to these users. Tyler’s mother quickly adopted this functionality, enabling her to more easily review and share the images with the interviewer. Her experience suggests that the ability to easily create and share videos is critical to improving feasibility and usefulness for parents.

Parents Asking Questions
Children with autism have impaired communication and social skills, and often exhibit repetitive behaviors. In our weekly visits to participant homes, we observed a variety of challenges with communication, which were representative of children across the autism spectrum. Some children are nonverbal, and even those who do speak may not be highly communicative, requiring repeated prompting in order to respond to basic questions. Sometimes parents receive no answer to their question no matter how hard they try. The same child may also vary in how much he or she engages in communication and interaction. Our two nonverbal participants, Juliet and Raquel, both used speech-generating devices to communicate by typing. Both girls had motor impairments, making it an effort to type. Sometimes they would type responses to their parents’ questions, even engaging in an extended conversation as their parents asked follow up questions. At other times, their parents would receive no response at all.

As a result of challenges with communication, parents of children with autism have to exert extra effort to understand what their child is perceiving and feeling. The ways our participants were able to appropriate the probe into this process reveals the potential uses for wearable cameras by families of children with autism.

Parents appropriated the probe by asking questions about their children and then exploring what the probe could do to answer these questions. For instance,

- Does Raquel actually watch the animals at the zoo, or is she bored?
- By talking with Raquel, say, about the zoo elephant in her photos, her mother might better understand Raquel’s experience.

Below, we list examples of other questions parents posed. These questions reveal the type of information parents lack, and the kinds of interactions they struggle to have with their children due to communication challenges:

**Understanding what their children experience**

- How does Raquel’s speech pathologist work with her, and what cues does she use with her that I might be able to emulate?
- What does Juliet do when she is in the kitchen and I am in the other room? Does she ever sneak food I’m not aware of, or touch something dangerous like knives?
- What happened when Zach was at school? What was his day like?

**Helping their children engage with the world**

- If I capture images of Juliet interacting with others on the street, would looking at them help her practice social skills?
- If I capture images of Daniel’s awkward arm movements at the dinner table, would that motivate him to learn to stop?
- Can we keep a record of Tyler’s progress over time to help him stay positive on the bad days by showing him how far he’s come?

Some of these questions were successfully answered by parents through the use of the wearable camera. We examined why parents were able to answer some questions and not others. We discovered what is most meaningful and useful about being able to capture images from a child’s perspective, and what challenges parents encounter when they are driving the capture process. We discuss these findings in the following sections.
Seeing the World Through Their Child’s Eyes

This work builds on prior research [7, 8, 9, 14] by exploring the capture of images from the child’s perspective. We found evidence that seeing the world through their child’s eyes was of significant value to parents.

Raquel’s mother wanted to know what was happening in the back seat of the car as she was driving with her daughter. She found that Raquel picked up books that were placed next to her in the back seat. Raquel’s mother was reassured that Raquel was preoccupied and not bored. As a result, she determined that she should continue leaving books and other things to do in the back seat for Raquel.

Juliet’s mother also noticed her daughter reading in some of the captured images. The images showed Juliet holding sheet music in front of her for an extended period of time. When Juliet’s mother asked her about the images, Juliet explained that she had taught herself to read sheet music. This fact had not been discovered until the camera gave her mother a view from Juliet’s perspective. As a result, her mother offered to buy Juliet more sheet music and Juliet confirmed that she would like that.

Both mothers learned something new about their daughters’ preferences by looking at their activities from their daughters’ perspective. Because both girls are nonverbal and often nonresponsive, it is difficult for their mothers to learn their preferences. The mothers were present in both of the examples. Moreover, there were previous opportunities for them to learn what they did about their daughters because both incidents also had happened before the study (Raquel is often in the back seat of the car; Juliet likes to read and stated that she had already taught herself how to read sheet music). However, it was with the use of the wearable camera that the mothers learned what they did, because it allowed them to more closely examine the situation from their daughter’s perspective. Raquel’s mother was driving the car and would not have been able to watch what her daughter was doing in the back seat. Juliet’s mother was preoccupied around the house while supervising her daughter, and may not have noticed when she switched from looking at a magazine to looking at sheet music, or how long she spent looking at the sheet music. The technology probes enabled them to discover things they missed even when they were with their child.

These two examples show how the probes enabled parents to make adjustments in caring for their children on a daily basis. These adjustments, even if small, can be challenging if communication is limited. For instance, Raquel’s mother finds it difficult to gauge her daughter’s interest in activities meant for her enjoyment, such as going to the zoo, and she hoped to capture images that would help her find out:

“It’ll be interesting for me to see… like what direction does she look at? Does she actually look at the animals [in the zoo]? Is she not interested in the animals at all? … Because I don’t know if she enjoys this or not. I mean if I see that all she does is look at people’s back, like why am I gonna take her to the zoo? … So she can’t talk and I don’t know where her mind is at. It would be kind of interesting to see, what is she looking at? What is she interested in?”

Later, Raquel’s mother determined that her daughter was interested in the elephants at the zoo because the images showed her leaning on the rail in front of the elephants. However, she also noted that the camera only captured the general direction her daughter was facing, rather than her actual gaze.

In addition to gaining information for everyday decisions, a significant discovery was made by Juliet’s mother upon her reflection on images from a walk in their neighborhood. Looking at the street signs from Juliet’s perspective, her mother realized she had never taken the time to teach Juliet street skills and navigation, such as reading signs. As a special education teacher, she is accustomed to these types of lessons with her students. With her own daughter, she realized she was often in “protective mode” – too concerned with other issues to think of the skills she trains her students on. In general, Juliet’s mother appreciated getting a view of the world from her daughter’s perspective. Zach’s mother (and father) made similar comments about getting a chance to see his view of the world. While our participants gained valuable information about their children by noticing specifics in the images captured, the mere exercise of viewing the world from their child’s eyes was also meaningful to them.

Understanding Their Child’s Needs

Because parents of children with autism often have difficulty communicating with their child, a key motivation for many of our participants was the ability to find other ways of understanding their child’s experiences and preferences. With the probe, they were able to learn what happens when they are not around and increase communication with the use of visuals.

What Happens When I’m Not Around?

Many of the questions our participants raised during the study were related to understanding what takes place in their absence. One of the most successful uses of the camera was in determining what occurs in the parent’s absence, when other family members are with the child.

Two of the mothers (Juliet’s and Raquel’s) are divorced from their child’s father. Both asked their ex-husbands to have their child wear the camera when they spent time together. The fathers agreed, and no complaints or tensions were reported. (Juliet’s father and neurotypical brother joked with each other about being watched by mom while the camera was on.) For both families, there was a sense of doing what was best for the child with special needs. Likewise, respondents in Nguyen et al.’s [16] study were willing to be captured by a stranger’s SenseCam if they believed the images would be used for a medical purpose, such as a memory aide for Alzheimer’s disease.
Juliet’s and Raquel’s mothers saw things they did not like in the images captured with their ex-husbands. Juliet’s mother was concerned that her nonverbal daughter was not receiving much attention:

“And then she went to her dad’s. And then that was kind of neat because I was able to... show [her brother], and I’ll share this with her dad too, that when they first get to his place that they’re just kind of ignoring her. And then when they go out to a restaurant I noticed how much more they were looking at her and talking to her and stuff. And so just kind of like warn them not to... to think about that, to not just ignore her.”

Interestingly, Juliet’s mother did not hesitate to say that she would address the issue with her ex-husband. Though there had already been jokes about her watching their dinner through the camera, she was not concerned about making the family members feel that she was scrutinizing the situation that was captured. Raquel’s mother similarly considered saying something to her ex-husband about an incident she deemed a safety hazard:

“I know I’ve had this conversation with him before. And after I saw the picture... I decided this is serious, because I saw the pictures. I’m going to take care of the situation. Because it is serious. ... I didn’t bring [the pictures] up, but maybe I will. Let’s see what happens. Let’s see how long it takes for me to train him.”

In this situation, an existing problem was exacerbated by what a parent saw in the images. Both mothers were motivated to talk with their ex-husbands about the images because what they saw was of concern. By giving the mothers a window into the perspective of their child, the camera helped them speak up for their daughters, both of whom are nonverbal.

Increasing Communication with Visuals

For Juliet’s mother, an increase in Juliet’s communication helped to answer questions. Of all the children, Juliet was the most interested in reviewing the images with her mother. In addition, Juliet’s mother is a special education teacher, making her perhaps especially knowledgeable about her daughter’s condition and how to care for her. Juliet’s mother had the most success of all the parents with engaging her child in reviewing the images. As a result, she found that reviewing the images with her daughter, and asking Juliet questions about what was happening in the images, increased the amount of input by Juliet into her text-to-speech device. The device can print her input on paper similar to a receipt, and her mother showed the interviewer these printouts because she was impressed by how much Juliet was typing. Rather than struggling to communicate with short questions and answers, her mother found that they were able to engage in more substantive conversations:

“Sometimes... she’s really resistant to using [her text-to-speech device]. She’ll just use it like – I’ll give her a choice. ‘What do you want to do’ or ‘what do you want to eat right now’. Things like that. But she’s a little bit more talkative when she has the visual there too.”

Juliet’s mother noted that the visual point of reference enabled communication. As visual supports are a best practice for autism, this is an outcome we had anticipated. However, we were able to see how photographic images taken from the child’s perspective made more effective visual supports for Juliet’s family. Despite their prior use of typical visual supports and communication aides, and expertise of Juliet’s mother as a special education teacher, this family made several discoveries within a few weeks of using a wearable camera.

When her mother asked Juliet if she enjoyed looking at the images, Juliet’s response uncovered a memory issue previously unknown to her mother:

“She said she’s quite interested in playing [the images]. And [she said] seeing them helps her process what she sees, because her memory isn’t that good. She’s never really expressed that before, that she has any trouble remembering things.”

This discovery indicates the significance of increases in Juliet’s communication. The example reveals implications of the communication challenges between parents and their children. Knowing that her child has trouble remembering or processing information, a mother may change the way she interacts with her child, may talk with behavior analysts about possible therapies, or may seek clinical tests and intervention. Parents of children with autism are creative with caring for their child’s needs every day, in addition to seeking support with educators, clinicians (such as neurologists), and different kinds of therapists (e.g., speech, occupational, physical). However, understanding their child’s symptoms and needs, and communicating these to others, is even more challenging if they have limited communication with their children. By improving their communication, wearable cameras can provide important information and cues that parents can act on.

Enhancing Social Engagement

All of the parents wanted to use captured images to help their children interpret and engage with their world. Due to impairments in social functioning, children struggle to engage with others, including their family members.

Juliet’s mother described how she used the probe to help engage her daughter in reflections of their activities in order to help her interpret them:

“She doesn’t always feel like using [the speech generating device]. And it’s not so accessible. So like if we’re in the middle of SeaWorld that wouldn’t be a time to go ‘how do you feel right now?’ But later, [we can] talk about that [while reviewing the images
Helping Juliet process and interpret the world supports learning and development, while also enhancing her engagement with her own daughter. The probe also helped others engage with Juliet. During a dinner out with family members who were visiting, Juliet’s mother had to explain the camera Juliet was wearing. As a result, the family members paid more attention to Juliet than they normally would, even engaging with her and trying to get captured in some of the images. Juliet’s mother described the significance of this interaction:

“It gives them something to talk about with Juliet. Because generally they don’t – she doesn’t give you a lot back. And at one point they were trying to get into pictures with her so that she’d have those to look at.”

Children with autism may be nonverbal, nonresponsive, or awkward in social situations. As a result, many people, including their own family members who don’t see them regularly, have a difficult time knowing how to interact with them. Juliet’s mother was often concerned about her daughter being ignored, and appreciated the device’s ability to spark conversation and draw attention to Juliet. Because individuals were even trying to get captured in the images, those images would be a lasting memory for Juliet that her mother would be able to talk with her about later. For a child who has difficulty socializing with those around her, this kind of support may be very meaningful. For example, Juliet also enjoyed sharing images with her neurotypical brother. Their mother described how they sat down together and watched the screen:

“Even if she’s not typing back about it, she’s responding. She’s lighting up and excited that she can share through her pictures what she did.”

Juliet, who enjoyed the images most out of all the children, became an active participant in sharing her view of the world with others. Because she is nonverbal, her mother helped Juliet share her experiences by looking at the images together. Juliet’s brother was often invited to view images with them, which he did eagerly. He described his sister’s use of the device, and the resulting images, as “cool”.

The outcomes that Juliet’s family experienced were in large part due to Juliet’s interest in reviewing and discussing the images. When her mother asked whether she liked looking at the images, Juliet typed:

“Yes I like playing them and seeing where I was. … [Playing the images of me] rollerblading with the camera, it feels like I’m moving again. I love the pictures, love to play them on the computer.”

Raquel and Zach’s mothers also expected to review images with their children and experience similar benefits as Juliet’s family, but their children were not as interested in the images as Juliet. Zach would look at images for a brief time, and answer questions generally with one-word answers after repeated prompting. Unfortunately, a child’s interest and willingness to engage can be highly unpredictable. For example, Raquel’s mother expected her to like looking at the images because of an intense interest she had previously shown in any photographs in their home.

Because Tyler and Daniel are highly communicative, their mothers appropriated the camera differently. These mothers wanted to use the camera to help their child improve their social skills by understanding how the world perceives them. As a result, they tried using the camera in different ways to get a reverse perspective – for example, the mother wore the camera herself or placed the camera on the table. For instance, they wanted to capture their boys’ awkward body movements to show them how they looked, and encourage them to change their behavior. Daniel’s mother wanted him to stop his hand flapping (“stimming”) at the dinner table. Tyler’s mother described his general behavior as “jumping around and acting weird.” However, in order to see these behaviors, either frequent capture rates or video capture was required.

After this appropriation did not prove fruitful for Daniel’s family, his mother stopped seeing benefits for them. Despite her willingness to participate in the research and her initial optimism toward the probe, she opted to end their participation early because there were few perceived benefits. This family’s experience is a distinct contrast to Juliet’s in large part due to Daniel’s ability to talk. He generally answers his mother’s questions and remarks. For example, his mother is able to find out what his day was like at school. However, Daniel’s communication is sparse and inaccurate. For example, he described an incident at school, but when his mother talked to others about what happened she found that some of the students he named were not even there. Perhaps using the camera more would have alleviated this problem.

Tensions Among Parent, Child, and Third Parties

Hayes and Abowd describe tensions surrounding the needs and concerns of four stakeholder groups in evidence-based care for children with autism: the person for whom the care is offered (in our case, a child), the person(s) doing the data capture (in our case, the parent and child), the stakeholders who might review captured data (parent, child, other family), and any bystanders to the recording (e.g., people who might be captured by SenseCam but are not directly involved in the care of the child and who may not even know the child) [7]. The camera’s visibility and novelty caused tension. Like all of the other mothers, Zach’s mother wished she could have her son wear the camera to school. Although photography is not allowed at school, she was used to taking photographs as her role on the PTA. She was therefore convinced that the principal would approve of SenseCam. When the principal refused to allow the use of SenseCam, she was therefore surprised. Although to Zach’s mother SenseCam was no different from the camera she
uses to take photographs for the PTA, the principal saw it as a threat likely due to its automatic capture which makes it impossible for others to know when a photograph is being taken. After this rejection, Zach’s mother became less likely to ask for permission. When she wanted to capture Zach’s extracurricular acting class, she chose to “sneak” it in without asking, and no one said anything.

To overcome its strange appearance and enable secret recording, several parents suggested a smaller camera that might be worn on a hat or as a pin, for example. The invisibility of such a camera would protect their children from being perceived as strange or different, and organizations from banning the camera. However, when we pointed out the possible concerns of ex-husbands, schools, or passersby, these participants agreed that their concerns might worsen, and they did not know how to alleviate them.

Nguyen et al. [16] and Iachello et al. [13] found that strangers wanted to be notified of recording. In Nguyen et al.’s [16] study, respondents said that if they were notified that the recording was for medical purposes, and perhaps had even been prescribed through formal channels, they were comfortable with being captured. For our participants, however, the use of a wearable camera is more complex due to the challenges of living with a disability. The daily life of a child with autism involves contexts such as schools and clinics, where recording is not generally acceptable. Moreover, parent relations with educators and clinicians can be tense because of their role as their child’s advocate. Raquel’s mother described an already tense situation at the clinic, which caused her to avoid using SenseCam:

“I wanted to [use SenseCam] when we were going to the doctor’s. Then I felt real uncomfortable and I didn’t do it because I was going to have to ask them and… We’re trying to get him to do something he shouldn’t be doing… So I didn’t want to create any more tension than what we already had. … Yeah I just turned it off because I was like, I don’t feel like explaining.”

These existing tensions, and the tensions caused by attitudes toward recording, make it difficult to negotiate when, where, and how a wearable camera will be used. Further research could identify ways to make third parties more comfortable with use, such as providing advance disclosure and explanation, as suggested in [16].

For families of children with autism, stress can be a part of daily life. Tyler’s mother described the experience as “families are at capacity.” She described several situations in which she chose not to even try using the technology probe because either she or Tyler could not handle the addition of another variable in that moment. Adding a wearable camera to a situation can be overwhelming for both the parent and child. This finding reinforces a need for extremely simple and easy to use devices and interfaces. Smaller and more autonomous cameras would help families incorporate their use in daily life.

**DISCUSSION**

The questions parents wanted to answer using their technology probe reveal the potential of wearable cameras in daily family life. The ways parents appropriated the probe in order to answer these questions reveal how well the device served them, suggesting how we might design to the technology’s full potential. In this section, we suggest design recommendations for the device and for interventions placing it in daily family life. We make recommendations for helping parents (1) adopt the system, (2) answer questions, (3) see the world through their child’s eyes, and (4) support their child in improving their social engagement. Finally, we discuss limitations of our study.

Two factors were at play as families initially adopted the probe in their daily lives: social acceptability, and ease of use when it came to reviewing and sharing images. Parents requested smaller cameras that were less conspicuous so that their children would not stand out. A camera that could be worn on a hat or eyeglasses, for example, would make it easier for their child to wear. In addition to removing the burden of wearing something around the neck, a camera inconspicuously integrated into head gear could show the direction of a child’s gaze, which many parents wanted to know as gaze is an indicator of interest and engagement.

Although ideally parents wanted to be able to hide the camera as much as possible, they recognized the intrusiveness that would result for others. Many of our participants experienced tensions, whether with ex-husbands, school administrators, or clinicians. In order to protect those who may be captured, Nguyen et al. [16] recommend disclosure. Notifying others that they will be captured, explaining the purpose of capture, and asking for consent are all key elements to managing attitudes toward capture and protecting privacy. However, the responsibility of these disclosures may be an especially large burden for the users in our study. Parents of children with autism are often overwhelmed and "at capacity", as Tyler's mother described. In some situations, parents chose not to use the probe around a third party due to existing stress felt by either the child, the parent, the third party. To make it easier for parents to disclose and use wearable cameras in a variety of situations, branding and form factors could be designed to indicate to others what the device is and why it is being used. These messages should be nonthreatening and approachable in order to emphasize benefits to the child and encourage others to engage with and support the child through the device. In our study, once some individuals found out what the probe was, they had fun engaging with the child in a playful way around the probe. In addition, this type of design would discourage parents from sneaking cameras into places or situations in which they are unsure whether capture would be permitted. Participants were so motivated to answer questions using the probe that they sometimes snuck it in without asking first.

The iPod Touch probe provided a few features that made review and sharing of images easier. First, the graphical
interface was more comfortable when operating the device. In contrast, participants using the SenseCam probe were often confused by its lack of status information and feedback. LEDs indicate, through color coding and blinking, when recording is turned on or off, and when the device is charging or needs to be charged. Knowing with certainty whether recording is on or off, and whether the camera needs charging, were important for parents to be able to use the probe in daily life. Second, the LifeLapse app had features for quickly and easily creating videos from the images captured, and sharing them with others. While the SenseCam users were able to watch images at various speeds using the accompanying software, LifeLapse users could create videos and email them with one click. This feature made it easier to review and share images, indicating that the easy creation and sharing of video files is critical for families.

The more questions parents had, and the more ideas they had for ways to answer them, the more motivated they were to use the probe. As such, the most inquisitive and creative parents got the most out of using the probe. For parents who are less creative, or unsure of how to use a wearable camera to answer questions they may have, directions for use may help them see the potential of the tool. For example, directions may include encouraging parents to capture the activities their child likes most, suggesting how they might review and talk with their child about the images, and describing methods for sharing the images with others.

Parents saw what they could not see without reflecting on images captured from their child’s perspective – due to blind spots when the parents are distracted or not looking closely enough, and blind spots when parents are not physically present. The probe helped to remove those blind spots, improving parents’ understanding of their child’s preferences, needs, safety, and health or social issues. Parents then acted on these issues based on the information they gained, to improve their child’s care and to support their development. To help parents identify important information, viewing software should give them flexibility and control over how to look at the images. Examples of flexibility and control include watching the images together as a video at a certain speed, annotating and bookmarking images, comparing selected images side by side, and organizing images in a way that is meaningful for that particular family. Computer vision could also help identify and bring to the forefront important moments captured in the images, such as the child handling an object (see [3]) or interacting with someone.

The probe also supported the child’s engagement with the world. Parents wanted to encourage their child to engage more with others by making capture into a game-like sharing activity. By capturing what the child would find interesting, parents wanted to engage them in sharing the images and talking about them with others. In turn, others engaged with the child through the probe. The probe sparked interest, especially in family members who don’t see the child often, because it is a novel technology. Family members also wanted to be a part of the capture, and liked reviewing and talking about the images with the child. The probe enabled shared experiences that would otherwise have not been possible. These shared experiences can be fostered and enhanced through game-like features that encourage collaborative capture and analysis. For example, a display within the home could encourage family members to review, remember, reflect, and talk about experiences that were captured. Walking by a display showing the images could help them reflect and point things out to each other, even when there is no time for all of them to sit around a computer to review images together. In addition, a display would remind family members about the child’s perspective and past experiences, which is especially important if the child is nonverbal and cannot share her experiences. Such reminders and insights into the child’s world could help family members engage more with a child who can sometimes be ignored because she does not speak.

Some of the children were not interested in reviewing the images. To make children’s interest and engagement more likely, capture could be tailored to their interests. For example, Tyler’s mother suggested recording a chess game, one of Tyler’s favorite activities. Recording Tyler’s victory in a game would make it even more enjoyable to review. Tyler likes the complexity and logic of chess, so he would appreciate that a camera could capture more detail than he would be able to remember. Analyzing a game and discussing the moves he made until he won would be an enjoyable activity for Tyler. Like many children on the autism spectrum, he is very interested in highly complex logical problems that he can analyze and predict, unlike human social behavior. However, the probe could not capture this amount of detail. Video, and possibly audio, would have enabled the family to appropriate the technology for his needs. Tyler’s mother hoped that using the probe in ways that interested Tyler would help him engage more with the family, because she was concerned that he prefers to spend time alone on the computer.

Limitations of our study include our small number of participants, and our inability to capture all the experiences of the children. Each child with autism is unique and has different symptoms and needs. The variations we were able to sample among families with children having different levels of communication suggest that future research should work towards a larger representative sample of children across a spectrum of communication challenges. An additional limitation was that only one of our participants used the iPod Touch probe. Having more than one user would have provided additional data about that probe. Finally, we studied the capture of images from only one perspective, that of the child. Future studies might compare a top view perspective with the child’s perspective, especially if we could capture the child’s actual gaze.
CONCLUSION
In this paper, we explored the use of wearable cameras for children with autism in daily family life. We found that the ability to see the world through their child’s eyes was of significant value to parents. In addition we found that the camera supported parents in understanding their children’s needs and helping their children engage with the world. The cameras tended to provide greatest benefit for those children who were nonverbal or had very limited communication. Through our wearable camera probe, we identified a number of design recommendations that can increase the potential of these systems for families. Through increased usability, a balance between the child’s comfort and that of those being captured, and creative uses of the images captured, wearable cameras can be more effective for parents.

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