

Towards in-home Collection of Behavior Specimens

Within the Cultural Context of autism in Pakistan

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Abstract—Children with autism often engage in problem behaviors. The frequency and severity of these behaviors can be very detrimental to their quality of life. Direct observation of problem behaviors is the gold standard for assessment and intervention, but it can be costly and intrusive. It also introduces specific challenges, such as lack of occurrence of episodes of problem behavior during clinical observation, and behavior reactivity in the presence of an observer. We propose a smart phone based capture system that can support parents in collecting samples of their child's problem behaviors in the home for assessment and intervention purposes. Four concept exploration and concept validation studies were conducted with parents, behavior analysts and other caregivers of children with autism in Pakistan. A prototype informed by the concept exploration studies was developed and used as a probe in the concept validation studies conducted in laboratory and real world settings. In this paper we present our findings and their impact on the ecological integration within the cultural context of a developing but conservative society.

Keywords—Autism; problem behaviors; in-home behavior capture; culture

I. INTRODUCTION AND BACKGROUND

Children with developmental difficulties, including autism, have a high prevalence of problem behaviors [1, 2]. Examples of these problem behaviors include physical aggression, self-injury, and tantrums. The frequency and severity of these behaviors can be detrimental to the quality of life of children with autism. Severe problem behaviors can significantly complicate the individual's ability to integrate socially and present major barriers to social and educational opportunities [3, 4, 5].

Direct observation, either in the clinic or in the home, is considered the gold standard for problem behavior assessment and intervention. It allows for understanding the typology (characteristics) as well as function (the antecedent variables that evoke and/or the consequences that maintain) of the problem behavior [6, 7]. However, it can be costly, intrusive, and it may cause behavior reactivity. In addition, it is not uncommon for families to be placed on a waiting list, in some cases for more than a year, before treatment begins. When families come in for the in-person observation, the child may not exhibit the behavior in the short span of the appointment.

Capture and access technology can be used to alleviate some of the challenges of direct observation. We posit that giving parents' access to a capture and access system can enable them to collect video samples of their child's behaviors for retrospective analysis by behavior experts. The assessment and

course of treatment would now be based on evidence of problem behaviors captured in the home setting which is a natural environment for the child. We envision a model in which the behavioral clinic would ship the system preconfigured by the behavior analyst along with instructions for parents to collect samples of the child's problem behaviors; in lieu of always bringing the child in for observation at the clinic or sending a trained observer to the child's home. In our discussion with behavior clinics and autism centers, we found that this would be a cost effective solution, reduces the long waiting list during the intake process and potentially help the clinic reach a larger population particularly those remotely located. More importantly, this allows behavior analysts to get a more ecologically valid picture of the antecedents and consequences of the child's problem behaviors. However, an important concern to address before such technology is widely adopted is the quality of collected data from the perspective of behavior analysts. In our earlier study conducted with an autism center and 8 families each with a child with autism, it was found that without any training from behavior analysts parents were able to collect examples of problem behaviors that matched the behavior analysts' code book and were clinically relevant [17]. The next important step is to understand the design requirements of a system that can support in-home behavior capture.

We conducted two concept exploration studies to understand the needs of the relevant stakeholders. Based on the findings and design considerations derived from these two studies we developed a smartphone based research prototype, smartCapture. In order to validate our design we further conducted two concept validation studies using the smartCapture prototype as a probe. In this paper we present details of the concept exploration studies, the resulting design of the smartCapture prototype, and the concept validation studies that were conducted in Pakistan along with findings and design implications.

There are two main contributions of this paper, one relating to the specific application domain of behavioral health, and one relating to the adoption of such technologies in a developing country. From the perspective of the domain of behavioral health, we present a system that allows in-home collection of problem behaviors. We introduce the notion of a "behavior specimen" to represent a sample of problem behaviors collected by parents. Second, to the Pervasive Health research community, we present findings from a series of studies of our proposed system conducted within the cultural and religious context of the developing but conservative society (Pakistan). Capture systems for the home environment have inherent

privacy concerns and these are compounded when situated within cultural and religious sensitivities, such as those presented by the Pakistani society. In this way, this work can act as a stress test for such in-home capture technologies.

One of the authors is a Pakistani national, native to the culture and fluent in the local languages. This arrangement ensured cultural sensitivity in data collection and data analysis. This also allowed for the flexibility of interacting with the participants in the language they felt most comfortable with.

In the next section we describe various existing capture and access systems that are designed to collect behavioral data. We also discuss literature about cultural implications on technology design. Next we present the concept exploration, concept generation and concept validation sections. In section VII we discuss ecological integration within the dimensions of system design and cultural nuances. Finally, we summarize our work in the conclusion section.

II. RELATED WORK

In this section we discuss related work across three topics that include 1) Behavior and Observation capture technology 2) Validity of data collected by parents and, 3) Cultural implications on technology.

A. Behavior and Observation Capture Technologies

Technology plays an important role in collecting behavior and observation data in various settings that include behavior clinics (mostly considered artificial settings), school (considered a less structured setting) and at home (natural settings)[12,13,14,15]. Numerous off the shelf technologies are available that facilitate the process of recording. Recently smart phone applications have become readily available for behavior assessment and intervention purposes. iBAA (iPhone Behavior Assessment App) [8], Student On-Task Observation [9] and ABC data [10] are some examples of such applications designed for school professionals to observe and record behavioral data in school settings. Another commercially available technology provided by Behavior Imaging Solutions is the Behavior Imaging Tool Set [11]. It includes the Behavior Capture tool to capture and store behaviors and events recorded through a webcam on a laptop via a remote control. Data captured can be shared with remote professionals using another tool called Behavior Connect.

Other than commercial tools, work exists that has focused on data collection in less structured and natural settings. One such example is Walden Monitor (WM) which collects observation data of children with autism in educational settings [12]. It includes a wearable camera and a tablet PC as an alternative to standard traditional paper based data collection methods. Another effort in a similar direction is CareLog, whose goal was to simplify teacher's record keeping tasks [13]. CareLog stores pre- and post-trigger window of data to enable the retroactive analysis of the context around the triggering point. The selective storage of data is referred to as selective archiving. Researchers found that the use of Carelog increased the accuracy and the efficiency of behavior based record keeping at schools. Furthermore, Kientz et al. developed Abaris, a capture and access tool for recording instructional data during discrete trial training (DTT) sessions [14]. This

system enabled therapists to more frequently use objective evidence in discussions and decision-making. BabySteps is another data collection tool for the home environment designed to enable parents to keep track of their child's developmental milestones [15].

An application related to our research prototype, smartCapture, is BTP (Behavior Tracker Pro) [16] which is an application for the iPhone that is designed for behavior analysts, behavioral therapists, teachers and parents to track behaviors. A caregiver can record video of behaviors to share it with other caregivers such as parents, teachers or therapists. It also allows uploading data to a team portal for advanced online charting, team collaboration, video messaging, and document management. smartCapture is an effort in a similar direction but focused more on capturing clinically relevant examples of problem behaviors. A lot of the focus is on designing a system that can facilitate close and direct communication between parents and behavior analysts. Parents collect data through a capture application that is preconfigured by a behavior analyst with a range of behaviors that parents should capture. smartCapture allows behavior analysts to supervise quality, relevance and quantity of problem behaviors collected by parents. This model of communication and fundamental focus on clinically relevant data collection makes smartCapture different from existing behavior capture applications.

B. Validity of Data Collected by Parents

In our earlier work we conducted a study to determine the quality of parent-collected video data of their child's problem behaviors. Parents were asked to record examples of their child's problem behaviors in the home using a multi-camera system, CRAFT (Continuous Recording and Flagging Technology) [17]. CRAFT was deployed in eight households, each with a child diagnosed with a developmental disorder, for an average of 16 hours. Parents were asked to flag the onset of their child's problem behaviors with a remote clicker. At the end of deployment a team of behavior analysts reviewed the continuously-recorded videos captured through CRAFT and identified all instances of problem behaviors. These were then compared with instances that parents identified using the clicker. Results showed that without any training and prior discussion, parents were able to successfully identify examples of their child's problem behaviors that matched the coding criteria of behavior analysts. In addition, parents were able to identify at least one example of every one of their child's problem behaviors in a single day of deployment. This preliminary study suggested that if a video capture system is deployed for a longer time, there is potential to collect sufficient evidence of problem behaviors in the home environment to be used for clinical assessment. The smartCapture system builds on what was learned in this study. The goal of smartCapture is to support parents in the collection of problem behaviors over a longer time frame and ensuring that they collect relevant behaviors under a behavior analyst's supervision.

C. Cultural Implications on Technology

Autism is considered prevalent in all cultures, races, and social classes and has been identified in at least 80 countries [18, 19], yet autism is rarely studied in a cultural context [20, 21]. Expectations and perceptions of individuals with autism

vary across cultures. In earlier work, we conducted a cross-cultural study of autism in Kuwait, Pakistan, South Korea, and the United States [20]. We developed a framework, based on lifestyle, socio-technical infrastructure, monetary and informational resources to facilitate the exploration of cultural implications and opportunities for technology. This work resulted in concrete examples of how cultural variations impact the design of emerging technologies in the domain of autism. Other researchers have also explored ways in which disability studies influence the field of assistive technologies [21], and have called for research connecting culture and the use of technology.

An important motivating factor for the work presented in this paper was to understand the needs and expectations of a behavior capture system within the cultural context of a developing, but socially conservative society like Pakistan. The social, cultural and religious beliefs and sensitivities of this society make it very challenging and interesting to deploy an in-home recording system, given that in-home recording inherently raises huge privacy concerns in any society. In the next section we present an overview of the four studies conducted in Pakistan.

III. OVERVIEW

There were three key phases in this work; concept exploration, concept generation, and concept validation. The table below gives an overview of each of these phases.

TABLE I. OVERVIEW OF USER STUDIES

Phase 1: Concept Exploration
Goal: Analysis of the needs of various stakeholders
Study 1: Methods: Field observation, shadowing, and contextual interviews Participants: Special need schools (n=5), welfare trusts (n=2), autism centers (n=5), children’s hospital (n=1)
Study 2: Method: 4 Focus groups: parents only (n=5), educators only (n=5), clinicians only (n=3) and heterogeneous [parents (n=3), educators (n=3) and clinicians (n=3)]
Outcome: Findings and design considerations
Phase 2: Concept Generation
Goal: Design an interactive prototype to be used as a probe
Method: Guided by the findings of phase 1, a high-fidelity interactive prototype was developed. Heuristic evaluation was conducted.
Outcome: The smartCapture system design
Phase 3: Concept Validation
Goal: Laboratory and field (in home) testing
Study 1: Methods: Think aloud evaluation of smartCapture in a lab setting Participants: parents (n=4), grandparents (n=3), teachers (n=3)
Study 2: Method: Deployment of smartCapture in 5 households for 2-3 days
Outcome: Findings and design implications

IV. CONCEPT EXPLORATION

Our goal in this phase was to conduct a thorough user needs analysis of our proposed concept of an in-home behavior capture system.

We conducted two studies with the primary stakeholders, mainly parents and behavior analysts, as well as other stakeholders that have the possibility of direct involvement such as teachers and therapists of the child with autism. These studies were conducted in Pakistan. The first study consisted of field interviews and observation, and the second study consisted of multiple focus groups.

A. Method used in Study 1:

We conducted contextual interviews and performed observations and shadowing in schools for children with autism and related difficulties (n=5), welfare trusts (n=2), autism and learning centers (n=5), and a children’s hospital (n=1) for a month. Notes and pictures were taken during these visits. During our visits to these sites we also interacted with a number of parents and conducted unstructured interviews with parents.

This field study helped us understand the current day to day behavior capture practices of the participants in various settings like a hospital (medical settings), in schools (less structured settings) and in homes (natural settings).

B. Method used in Study 2:

We conducted four focus groups, one each with parents only [n=5(2 mothers, 3 fathers)], educators only (n=5), and clinicians only (n=3) and a fourth which was a heterogeneous focus group involving parents [n=3(1 mother, 2 fathers)], educators (n=3) and behavior analysts (n=3). Participants in the heterogeneous focus group were not the same as in the earlier three groups.

These focus groups helped us understand the needs of a behavior capture system.

C. Data Analysis

Since one of the authors is a Pakistani native, we were able to interact with the participants in the language they felt most comfortable in. This led to data collection in Urdu and English. The Urdu data was then translated, and all analysis was done in English. Notes collected from both of the above mentioned studies were analyzed by creating thematic connections using a data-driven approach. Statements of interest were extracted and grouped together by theme. With each pass through the notes, these were refined until a set of distinct themes emerged. Three separate passes through the data helped us to generate the final set of themes that we describe in the following section. Each finding is followed by the resulting design consideration that was derived from it.

D. Findings

• Current Behavior Capture Practices

We found that direct observation particularly in natural settings can play a major role in problem behavior assessment and intervention. However, in reality these observations are mostly made in the clinic or in school. There are some cases when a trained observer visits the child at home to video record the child’s behavior. The video is observed by the behavior analyst at a later time in the clinic. However, a major issue with

this approach is that the presence of an observer can alter child behavior. In our study participants' responses to our proposed concept were positive, and they particularly liked the idea of parents capturing the behavior, as this will allow the behavior analysts to get more ecologically valid occurrences of the behaviors.

One parent mentioned that *"My child is totally different when she is among strangers. She would not behave naturally you see...if an observer comes to our home for recording."*

Design Consideration: Support in-home capture of problem behavior in natural settings.

- *Communication Challenges Among Stakeholders*

Participants highlighted the lack of communication between stakeholders and indicated that it sometimes results in a lack of trust.

One parent mentioned *"I don't know but sometimes he acts differently here (autism center) but at home he would never be so quiet. He is more aggressive at home than when he is here. I just don't know if (the) analysts can really see my point."*

Similarly, one analyst mentioned that *"We do give written instructions to parents to follow at home but we don't see them following them. It would make a difference if we can see how parents do it at home or somehow we can know what's going on at home"*

Design Consideration: Support online and offline communication between parents and other caregivers.

- *Family Structure*

In Pakistan there is a tendency towards large cohabiting families. In Pakistani culture it is common practice for all male children to remain in the family home even after they are married. For these reasons, often care giving responsibilities are shared across various family members.

One father mentioned that *"My wife also works so my mother looks after my son. She lives with us. If this (behavior capture system) is something she can use it would be great but she does not know how to use computers"*.

Design Consideration: Design for everyone in the family.

- *Ease of Use*

When designing for everyone in the family, it is important to minimize complexity. In addition, since the system is designed for use with children with autism, to ensure that the already overwhelmed caregivers are not burdened, it is imperative that it be easy to use and that it be designed in a way that fits as seamlessly as possible into the users' existing routine. Most importantly the system will be used when the child is exhibiting a problem behavior, so a system that requires full attention would be hard to adopt.

One participant mentioned *"if I have to use a device that captures behaviors then it should be simple. There are others children I have to attend to."*

Design Consideration: Design for simplicity.

- *Wearable Devices*

When participants were asked their opinion about wearable cameras (which they can wear or their child can wear) they raised numerous concerns related to the child's sensory sensitiveness, child willingness to wear the device and social comfort.

One participant mother said *"my daughter will never wear any such thing. She is very sensitive. She even does not wear small pieces of jewelry. I think other people like guests will notice it too."*

Further, one participant teacher mentioned *"do you think it would be safe to do so. We have so much liability....we are answerable to parents. You know for me it is hard to trust devices."*

Design Consideration: Design for social and physical comfort and safety.

- *Cultural Markers*

Participants highlighted various privacy concerns introduced by video recording in the home. They were particularly concerned about the religious and cultural sensitivities involved.

For instance, one of the behavior analysts mentioned *"we have a child in our center whose mother wears a veil, so for such families it would not be an option to record at home as it could capture other women at home"*

Similarly, one mother mentioned *"I am OK with recording as long as in all videos my head is covered. If I could delete those portions in which my head is not covered that would be acceptable for me."*

Muslim women who choose to cover usually may not cover while at home. For this reason, veiled women would either have to remain covered in their own home while the system is in use, or be given an option to delete any instances in which they were captured by the system unveiled.

Design Consideration: Design in accordance with cultural and religious values.

V. CONCEPT GENERATION

A. *smartCapture to Collect "Behavior Specimens"*

In this phase we designed a research prototype called smartCapture to use as a probe in the concept validation phase. The design of smartCapture was informed by the findings from the studies conducted in the concept exploration phase just described. In order to improve the design of smartCapture we performed heuristic evaluation with designers (n=5) who were familiar with programming on smart phones and the web. Based on their feedback we improved the design of the smartCapture system.

We define smartCapture as a system that allows the collection and sharing of *behavior specimens*. This is analogous to specimen collection containers given to patients at a lab or a clinic. Figure 1 shows the analogy between a conventional specimen collection procedure and behavior specimen collection procedure.

smartCapture

To collect and share "problem behavior specimens"

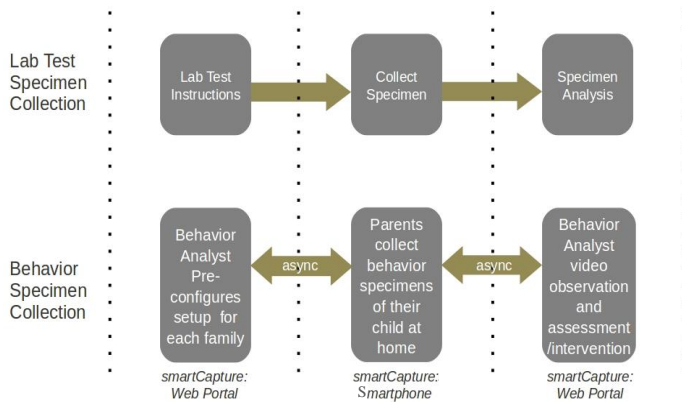


Figure 2. Behavior specimens collection procedure

The smartCapture system has two components, the smartCapture web portal and the smartCapture smartphone application. For behavior specimen collection, we envision that a behavior clinic will ship a commodity smartphone with the smartCapture application already installed to each family. The behavior analyst will use the web portal to pre-configure the smartCapture application with specific tags for behaviors they would like the parents to capture. Parents can use the application to collect specimens of their child's problem behaviors to share with experts at the clinic for assessment and intervention purposes. With respect to the smartphone, the configuration information and asynchronous instructional messages from the analyst to the parents represent the inflow of information whereas the behavior specimens (problem behavior videos) uploaded back to the data repository represents the outflow of information.

smartCapture is a telemedicine tool and thus also provides a tele-consultation platform. Behavior specimens collected through smartCapture are uploaded and shared with behavior analysts through a central online data repository. Parents can add text-based or voice-based annotations to each recording (Figure 2b). The smartCapture application on the phone also supports after-the-fact recording, so parents are able to capture a behavior even if it occurred a few minutes before the record button was pressed (Figure 2a).

Specimens are uploaded to the repository when internet connectivity is available on the phone. This means that if the smartphone is always connected to the internet then the upload begins immediately after a behavior is recorded. The user is notified when the file upload begins. Parents can stop the transfer if they do not want to share a particular video, so they have control over data collection and sharing. Parents continue to record problem behaviors until they receive an alert from the behavior analyst via smartCapture notifying them that they have captured sufficient examples of behaviors for assessment. The web portal allows behavior analysts to create definitions of problem behaviors and analyze specimens collected in the home (Figure 2c). It also allows them to asynchronously communicate with parents. The smartCapture application has a range of behaviors and contexts that are preset by the behavior analyst before the system is shipped to families. Parents can use these pre-sets to annotate the behavior specimens they collect. Parents can also create custom definitions in case they want to share some behaviors with the analyst that are not in the a-priori list of definitions created by the behavior analyst (Figure 2a). These definitions then become visible, along with specimens for those categories, to the behavior analyst through the web portal.

Once the problem behavior specimens have been collected, parents ship the smartphone back to the clinic. smartCapture aims to simplify parents' behavior capture experience. It allows for the collection of behavior specimens in natural settings, and

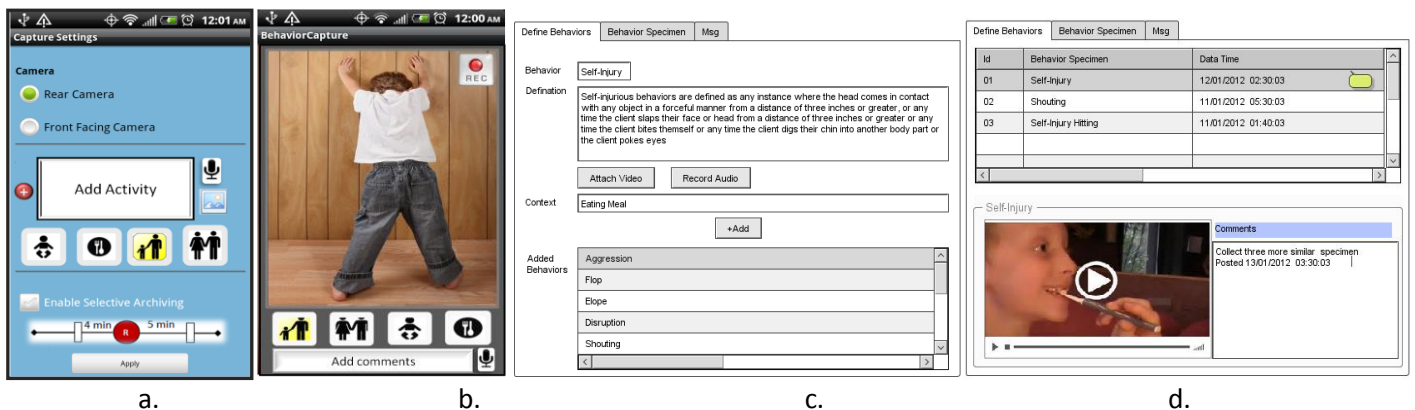


Figure 2. SmartCapture Prototype – a) Smartphone app setup dialog for parents b) Smartphone app pre-configured annotations on recording screen c) Web Portal page for behavior analyst to create behavior definitions d) Specimen Analysis using the Web portal

can ultimately broaden the number of families that can be effectively managed and improve access to care among rural and remote communities.

The smartCapture prototype was used as a probe in the concept validation study described in the next section.

VI. CONCEPT VALIDATION

A. Method used in Study 1:

The Think Aloud Protocol was employed with parents (2 mothers and 2 fathers), grandparents (2 grandfathers and 1 grandmother), and behavior analysts (n=3) of children with autism. Participants were asked to interact with the smartCapture prototype. At the end, a follow up semi-structured interview was conducted. Notes were taken during the study.

This study helped us to observe and evaluate user interactions with the smartCapture system in the controlled lab settings.

B. Method used in Study 2:

During this phase we deployed the smartCapture interactive prototype in participant's homes (n=5) for two to three days. All participants had a child with autism. Participants were asked to use smartCapture to collect specimens of their child's problem behaviors. At the end of each deployment we conducted a follow up semi-structured interview. Three of these families also helped us to arrange a meeting with their child's school/learning center to get feedback from teachers/clinicians about the utility of the videos collected in the home.

This study helped us to validate the smartCapture concept in natural settings.

C. Data Analysis

As in phase 1, the data was analyzed using an inductive thematic approach to identify various themes. Throughout this process we returned to the original field notes, to find evidence that confirmed or rejected it. This enabled us to identify the various distinct themes that are described below as findings.

D. Findings

• Support Exploration of the Collected Data

Participants wanted the system to support both high-level as well as in-depth views of the data. Participants also indicated that they found the text and voice-based annotations very useful, and wanted to have advanced search capabilities based on the annotations. In addition, due to the after-the-fact recording feature, the users were able to see events that preceded and followed the target behavior. In this way, the system enables users to uncover correlations between particular stressors and the occurrence of target behaviors.

One participant mentioned that *"At times I feel that his (the child's) behavior is getting better but other times I feel the opposite. I would really like if system can do this regression progression kind of analysis. It will give me more confidence than by just relying on my memory"*

Design Implications: Support inference and detail on demand.

• Data sharing

While all participants saw the value of sharing data, important points emerged concerning how best to facilitate this sharing. First, data ownership and control over data sharing should be given to the party that collects the data. Second, parents should be able to share the data with additional stakeholders. Third, providing a data capture system both at school and at the clinic should facilitate communication between various individuals who are working with the child. Some of the participants mentioned that they would like to share the data they collected on social network sites with other caregivers.

One grandparent mentioned *"I can imagine sharing these videos with my other family members. I would like them to see how much she is attentive now."*

Design implication: Allow adjustable data sharing policies

• Privacy and Security

Privacy is generally approached as a social consideration, whereas security is seen as a technical concern [22]. We found that privacy and security have a social origin and are deeply impacted by the social and religious practices of the culture in question. Participants raised numerous concerns with respect to privacy.

One mother mentioned that *"Cameras can make me conscious. I am fine with recording at home. I would have to make sure that my head is covered. I am Muslim and I would not want any other male outside our family to see me without hijab (head scarf). If I know for sure what is recorded and I can delete what I want... its fine"*

In such situations it is important to capture data that is relevant to the tasks being addressed and the user who captures the data should have control over its sharing. This may alleviate some privacy concerns. In addition, reducing the possibility of identification can reduce some privacy concerns.

For instance, after deployment one participant mentioned *"Can we blur faces? Sometimes there are people around like guests or other family members who would not like to be recorded. If we can blur their faces that might resolve some of the privacy issues."*

We also found that that if caregivers believe that data captured is relevant and useful, then they would be more willing to sacrifice their own privacy and agree to participate in the recording of the data. One participant mentioned *"If it can benefit my child I can do it. I will be fine with recording and sharing as long as I decide who can view it"*.

We also found that there exist physical zones within the home with varying privacy concerns. For instance, one participant family only recorded behaviors in the child's room as they considered it a less private space compared to other areas in the house. The notion of zone-based privacy was also highlighted when we asked participants about explicit and implicit capture. Explicit capture refers to recording initiated by the user, such as when the parent clicks a button on the smartCapture screen to initiate a recording of their child's

behavior. In contrast, implicit capture refers to system-initiated recording, such as recording triggered by specific behaviors such as the child shouting. We found that although participants had privacy concerns with implicit capture, some participants suggested that within certain places in the home they would allow implicit recording.

One participant mentioned *“When my child is in his play room and system starts recording by automatically detecting his problem behaviors I would like it. It’s good. I am not around but behavior is captured. But I would not be comfortable when the system does that in the living area. There are family events that we would not like to be recorded”*.

Design implication: Design for user autonomy and privacy control.

- *Managing Attention*

Participants mentioned that they would like to use the system for a longer period as the child may exhibit the target behavior only sporadically (e.g. once a month). However, they were concerned that they may forget to use the system, so a reminder that could alert them that they have not actively used the system for some time would be useful.

Participants also mentioned that some children might react even to recording using a phone. Participants suggested that the smartPhone could be covered (e.g. in a stuffed toy without affecting the camera view) so that it is less visible to the child.

In the post deployment interview one participant mentioned *“I would instead use some stuffed toy or something to hide it. When I was recording he would start looking at the camera all the time...it could change his behavior I am not sure but it can happen.”*

Design Implications: Manage the visibility of the system.

- *Overall Cost of the System*

Participants were concerned about the total cost of the system, which includes first time installation cost as well as maintenance cost. However, as our suggested model was that the clinic would own the system and would ship it to parents, the system cost would not be a burden on the parents. It was, instead, more of a concern to the behavior analysts. They were also concerned about the safety of the device.

One behavior analyst mentioned *“what will happen if a device gets broken at home or we never get it back in the shipment”*

Design Implication: Maintain low cost and have a contingency plan for damages.

- *Customization*

Participants indicated that customization features such as adding new behavioral definitions, and audio and text based annotations would be valuable. They indicated that a system that allows customization for various levels of data views will not only be fundamental to data analysis but can alleviate concerns related to information overload.

Design Implications: Allow for appropriate customizations.

VII. ECOLOGICAL INTEGRATION

We learnt many lessons through our findings with regards to “Ecological Integration”, in other words the best way to integrate such a data capture system into the routine practices of stakeholders. In this section we will explore ecological integration, as it impacts system design, and the cultural nuances that emerged from our findings.

A. *Ecological Integration within System Design*

System design plays a major role in whether or not a system achieves ecological integration when put into the real world. With respect to in-home behavior capture technology, we found that there are three major design aspects that may directly impact system adoption. These include: 1) Adaptability 2) Accessibility and, 3) Acceptability.

A system design should allow the user to adapt it according to their needs and requirements. Features like the ability to add behaviors, contextual definitions, annotations and allowing users to analyze data based on their desired level of granularity are some examples that participants mentioned. In addition to customization, another important design aspect is system accessibility. Given that caregivers of children with autism are already overburdened, it is important that a home capture system be as simple to use as possible. In addition, when it comes to designing for everyone in the family, it is important that the system be accessible to those who are not regular users of technology, like grandparents in Pakistan.

The third design aspect is the acceptability of the system. The system should be designed so that end users must see an appropriate balance between the effort they are required to put in to use the technology and the benefits they will get. However, other than utility, the system should be sensitive to the social comfort of the user. For instance, parents in our study were concerned about situations when they want to capture a behavior but there are other members of the family or guests who don’t want to be recorded. In these cases showing the user the exact field of view during recording and allowing them to delete or make edits (like blur faces) to a video can lessen some of the concerns with respect to social comfort. Another factor when it comes to acceptability is the infrastructure needs. This factor is crucial when it comes to designing technologies for developing countries. Complicated infrastructure needs or an expensive system would be less likely to be accepted given the limited resources available to parents in Pakistan. Our participants really liked the idea of the clinic or autism center owning the system and shipping it to parents on their request as it does not put a financial burden on the parents.

B. *Ecological Integration within Cultural Context*

The design of the behavior capture system must be informed by the cultural context of the individual using or being impacted by it, since culture mediates the expectations and imposes constraints on the design [19, 20, 21].

In the course of our studies we found that culture and religion play an important role when designing technology [20]. In fact religion plays an important role in defining the overall

culture and lifestyle. In the case of video capture technology, privacy becomes very crucial as it is not just a technical phenomenon but is embedded in the social, cultural and religious context. Particularly when designing capture technologies for the home, concerns are unavoidable as there is no environment in which culture plays a more critical role than the home. In Pakistan, some families may not allow video recording at all and some may allow it subject to the condition that no woman member of the family can be seen on the video. Sharing recorded videos also involves cultural and religious sensitivities. For these reasons, it is imperative that the design of capture systems is informed by the privacy practices, and general cultural values and religious obligations of the particular family by which it will be used. It is difficult to eliminate privacy concerns completely but there are ways that can help to lessen them. For instance, one model to approach privacy is known as privacy as economic rationality. The central idea of this model is that there is a tradeoff between risk and rewards, the cost and benefits associated with sharing and revealing information [22]. We found this true as some participants mentioned that although allowing video recording at home is sensitive; if they perceive value in using the system they would use it. When it comes to data sharing, giving full control and autonomy to the user can further ease their concerns. However, the challenges lies in balancing the needs and desires of the stakeholders involved in the interaction and in allowing privacy to be negotiated in a dynamic fashion.

VIII. CONCLUSION AND FUTURE DIRECTIONS

The findings of our user studies emphasize the importance of in-home behavior capture. In this paper we propose a system, smartCapture, which allows parents to capture behavior specimens and share them with clinicians and analysts for assessment and intervention purposes. This work is also the first attempt to explore the design of capture technology situated within the socio-cultural and religious context of the developing and socially conservative society of Pakistan. The concept exploration and concept validation studies we conducted allowed us to elicit the needs and expectations of various stakeholders, and our findings can enable designers to understand the nuances involved in the ecological integration of a capture system. In the future we will conduct a clinical study in which assessment of problem behaviors conferred via smartCapture will be compared against in-person assessment.

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II. REFERENCES

- [1] S. A. Borthwick-Duffy, "Evaluation and quality of life: Special considerations for persons with mental retardation", In R. L. Schalock & G. N. Siperstein (Eds.), *Quality of life. Vol. I: Conceptualization and measurement* (pp. 105–120). Washington, DC: American Association on Mental Retardation, 1996.
- [2] L. K. Koegel, R. L. Koegel and A. Surratt, "Language intervention and disruptive behavior in preschool children with autism". *Journal of Autism and Developmental Disorders*, 22, 141–153, 1992.
- [3] J. R. Sprague and V. Rian, "Support systems for students with severe problem behaviors in Indiana: A descriptive analysis of school structure

and student demographics", Unpublished manuscript, Indiana University Institute for the Study of Developmental Disabilities, Bloomington, IN. 1993.

- [4] R. H. Horner, S. M. and K.C. Brazeau, "Educational support for students with severe problem behaviors in Oregon: A descriptive analysis from the 1987–88 school year". *Journal of the Association for Persons with Severe Handicaps*, 17, 154–169. Iwata, B. A., Dorsey, 1992.
- [5] J. Reichle, "National Working Conference on Positive Approaches to the Management of Excess Behavior: Final report and recommendations". Minneapolis, MN: Institute on Community Integration, University of Minnesota. 1990.
- [6] B. A. Iwata and A. S. Worsdell, "Implications of Functional Analysis Methodology for the Design of Intervention Programs: Exceptionality" *Vol 13(1) 2005*, 25-34. 2005.
- [7] G. P. Hanley, B. A. Iwata and B.E. McCord, "Functional analysis of problem behavior: A review" *Journal of Applied Behavior Analysis Vol 36(2) Sum 2003*, 147-185, 2005.
- [8] iBAA (Behavioral Assessment Application) 2012, iPhone application, Available: <http://itunes.apple.com/us/app/ibaa/id383705019?mt=8>
- [9] SOTO(Student On-Task Observation) 2011; iPhone application, Available: <http://itunes.apple.com/us/app/soto-student-on-task-observation/id428809608?mt=8>
- [10] ABC Data Pro. 2011; iPhone application, Available: <http://itunes.apple.com/us/app/abc-data-pro/id349426906?mt=8>
- [11] CaringTechnologies. 2009; Available: <https://www.caringtechnologies.com/>
- [12] G. R. Hayes, J. A. Kientz, K. N. Truong, D. R. White and G. D. Abowd, *Designing Capture Applications to Support the Education of Children with Autism*, in *UbiComp '04.*, Springer Berlin / Heidelberg: Nottingham, England. p. 161-178. 2004.
- [13] G. R. Hayes, L. M. Gardere, G. D. Abowd and K. N. Truong, *CareLog: a selective archiving tool for behavior management in schools*, in *CHI '08.*, ACM: Florence, Italy. p. 685-694. 2008.
- [14] J. A. Kientz, S. Boring, G. D. Abowd and G. R. Hayes, *Abaris: Evaluating Automated Capture Applied to Structured Autism Interventions*. In the *Proceedings of UBIComp 2005: The 7th International Conference on Ubiquitous Computing*. September 11-14, Tokyo, Japan, 2005
- [15] J. A. Kientz, R. I. Arriaga, and G. D. Abowd, *Baby Steps: Evaluation of a System to Support Record-Keeping for Parents of Young Children*. in *CHI '09.* Boston, MA: ACM. 2009.
- [16] BTP (Behavior Tracker Pro) 2012; iPhone application, Available: <http://itunes.apple.com/us/app/behaviortrackerpro/id319708933?mt=8>
- [17] N. Nazneen, A. Rozga, M. Romero, A. Findley, N. C. Call, G. D. Abowd and R. I. Arriaga, "Supporting Parents for in-Home Capture of Problem Behaviors of Children with Developmental Disabilities." *Journal of Personal and Ubiquitous Computing*, London: Springer, 2012.
- [18] Autism Society of America. "What is autism? Advocate: The newsletter of the Autism Society of America", vol 33 pp 3, 2000.
- [19] T. C. Daley, "The Need for Cross-cultural Research on Pervasive Developmental Disorders", *Transcultural Psychiatry* 39(4): 531
- [20] F. A. Boujarwah, N. Nazneen, H. Hong, G. D. Abowd, and R. I. Arriaga, "Towards a Framework to Situate Assistive Technology Design in the Context of Culture". Presented at the 13th International ACM SIGACCESS Conference on Computers and Accessibility, 24-26 October, Dundee, Scotland. 2011.
- [21] J. Mankoff, G. R. Hayes and D. Kasnitz, "Disability Studies as a Source of Critical Inquiry for the Field of Assistive Technology". In *Proceedings of ASSETS '10*. 1-8. 2010.
- [22] P. Dourish and K. Anderson, "Collective Information Practices: Exploring Privacy and Security as Social and Cultural Phenomena", *Human computer interaction*, Volume 21, pp. 319-342. 2006.