Addressing Cognitive and Emotional Barriers in Parent-Clinician Communication through Behavioral Visualization Webtools

Ha-Kyung Kong
Seattle University & UIUC
Seattle, WA USA
hkong@seattleu.edu

Karrie Karahalios
University of Illinois at Urbana-Champaign
Champaign, IL USA
kkarahal@illinois.edu

ABSTRACT

Effective communication between clinicians and parents of young children with developmental delays can decrease parents' anxiety, help them handle bad news, and improve their adherence to proposed interventions. However, parents have reported dissatisfaction regarding their current communication with clinicians, and they face cognitive and emotional challenges when discussing their child's developmental delays. In this paper, we present visualization as a facilitator of parent-clinician communication and how it could address existing communication challenges. Parents and clinicians anticipated visualization webtools would aid their communication by helping parents gain a better understanding of their child, acting as objective evidence, and highlighting the strength of the child as well as important medical concepts. In addition, visualization can act as a longitudinal record, helping parents track, explore, and share their child's developmental progress. Finally, we propose visualization as a tool to guide parents in their transition from feeling emotional and disempowered to advocating with confidence.

Author Keywords

Visualization; developmental delays; clinical communication.

CCS Concepts

•**Human-centered computing** → **Information visualization;**

INTRODUCTION

Effective parent-clinician communication is central in establishing a positive parent-clinician relationship [10, 40], which in turn leads to an increased adherence to clinician's advice [27]. However, evidence suggests that parents are often dissatisfied with the amount or quality of information shared by clinicians during a consultation [23] or after a diagnosis [29]. Discussions that revolve around a child's developmental delays are especially challenging as parents may face cognitive and emotional barriers [39]. In this work, we present behavioral visualization as a tool for addressing these challenges in parent-clinician communication on developmental delays.

Previously, research on visualization in healthcare has mainly focused on using visualization for analysis. However, newer research findings show that visualization could also be used for parent-clinician communication [16, 30]. Clinicians suggested using visualization as a catalyst for discussions between clinicians and parents, and as a mechanism for teaching and coaching parents how to implement interventions at home [16]. This may fulfill some of the current needs of parents as they reported desiring more support with obtaining information regarding their children's disability or challenging behaviors. In another study on parent-clinician communication [20], clinicians felt that well-designed graphics could aid communication as they were less intimidating than a number rating or a spreadsheet. The reasoning was that visual information helped parents feel at ease, and thus would elicit more honest feedback and more parent participation in the conversation. However, existing research on the role of visualization in parent-clinician communication has focused on the clinicians' perception, and no research has been done on the parental perspective of the issue to our knowledge. To address this gap, we interviewed both parents and clinicians on the anticipated benefits and challenges that emerge when using timeline visualization webtools in their parent-clinician conversations. While we did not test these tools during synchronous communication, interview results revealed their potential for addressing specific communication barriers.

In this paper, we present the results from our study on how behavioral visualization webtools can address emotional and cognitive barriers in parent-clinician communication. Our contributions are three-fold. First, we add parents' voices to the discussion on visualization in parent-clinician conversations. Even if visualizations are appreciated by clinicians, their effectiveness in clinical communication will be limited if they do not meet the parents' needs as parents are one of the primary stakeholders. Our study results show that while some clinicians were skeptical of parents' interest in and comprehension of visualizations, parents in our study were enthusiastic about the use of visualization in their conversations with clinicians, and they could correctly infer information from visualizations after watching a brief introductory video. Visualization could also elicit questions from the parents and

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lead to more parent-centered conversations. Secondly, we present *how* visualization could address cognitive and emotional barriers that arise conversations about developmental delays. Parents and clinicians reported that visualization could facilitate their conversation through addressing 1) the emotional barriers by presenting children's behaviors to parents in a more supportive and objective manner and 2) the cognitive barriers by acting as an anchor for conversation and presenting important developmental concepts or patterns that are hard to convey through words or text. Thirdly, we discuss how parents' trust in visualization can be a double-edged sword in clinical communication, and propose ways that parents can benefit from visualization in their transition from feeling emotional and disempowered to advocating with confidence.

RELATED WORK

Visualization is becoming a popular form of communicating information and for analyzing data. While the clinical use of data visualization is on the rise with the increased use of electronic health records (EHR) and patient provided information, health-care professionals have focused on the *analytic* role of visualization. This traditional focus has left open the question of how visualization plays a *communicative* role in clinical contexts. The central objective of our work is to explore this communicative role of visualization, specifically in the context of parent-clinician communication. In the following section, we first navigate the current state of parent-clinician communication. Then we present current work on visualization in health-care and visualization for communication.

Parent-Clinician Communication

Effective communication is essential in clinical settings as communication is strongly correlated with patient satisfaction [43] and better patient adherence [44]. Furthermore, most of the complaints made by patients deal with communication problems rather than the competency of the clinician [25, 36], and miscommunication is a major cause of medical malpractice litigation [21]. Current challenges in medical communication include patients' anxiety, differing expectations between patients and clinicians, the lack of patient engagement, and exchanges of incomplete information [34].

Communication in pediatric consultation presents additional complexity as parents' anxiety and their need to establish the legitimacy of the consultation lead them to emphasize the seriousness of the illness [5]. Meanwhile, clinicians might misinterpret parents' emphasis on the seriousness of the illness and their request for more information as challenging their diagnosis, resulting in over prescription of drugs [4]. This shows the need of establishing an environment where the participants do not feel the need to exaggerate the situation.

In this paper, we focus on parents and caregivers of young children, who show signs of developmental delays. Although communication with clinicians can be stressful for all parents, these parents are often strained with the feeling that they have to defend their child even when the clinician is merely sharing a concern or striving to establish a mutually agreeable solution [37]. Thus, presenting information in an empathetic yet objective manner is crucial for these parents in order to promote family resilience and to build a constructive parent-clinician relationship [3].

One challenge in parent-clinician communication on developmental delays is providing an appropriate amount of information. While most parents feel underinformed, others struggle with "information overload," especially at the time of diagnosis [10]. Whether for the lack or the surplus of information, parents can find it hard to understand their child's condition and often feel disempowered [11]. Another challenge in parent-clinician communication is that parents may resist information when the information entails negative implications [9]. While temporary denial can act as a positive coping mechanism [35], continued denial may lead to problematic consequences such as refusing treatment. In Tetzlaff's study on parents of children with cancer, 97% of the parents indicated that they "wanted to know everything they could about the disease" yet 31% did not "want to hear about the bad things" [39]. These statements seem at odds against one another, but they reflect the internal struggle of a parent between their cognitive and emotional needs. With this in mind, clinicians should present information in a supportive manner to avoid increasing parents' anxiety or insecurity. Based on all these previous findings, a tool that can address parents' initial emotions as well as their informational needs would immensely benefit parent-clinician communication.

Visualization in Healthcare

Data visualization techniques improve the exploration and understanding of personal, clinical, and public health information [38]. Researchers have examined health-related visualizations for personal medical histories [33, 41], patient treatment patterns and outcomes [26], and decision making in public health [1]. Many of behavioral visualization tools were created to aid healthcare professionals in clinical analysis. Abaris, created by Kientz et al., provided an intuitive interface for inputting behavioral data during a therapy session and presented this data to clinicians and researchers for analysis [12]. Kim et al. built BEDA, a data analysis and visualization tool, for pattern analysis of children's behavior across conditions with different sensory inputs [13]. TipoVis is another behavior analysis tool, which allows users to compare two social and communicative behaviors during a screening session [8].

All of these visualization tools were built and tested with clinicians for their data analysis. However, researchers have hypothesized that visualizations in clinical settings could also improve communication [34, 38]. In their work on visualization for storytelling, Kosara and Mackinlay write that "stories naturally lead to questions, which lead to discussions, which lead to deeper analysis" [19]. This collaborative nature of storytelling through visualization lends itself to applications in clinical settings as collaboration is key for successful parent-clinician communication.

Researchers have proposed a visualization dashboard to aid communication among clinicians [7], visual representations of public health data visualization to explain risk to patients [2], and a flow diagram of similar patients to promote shared decision making in patient-clinician communication [32]. AnatOnMe uses augmented reality (AR) visualizations to facilitate

clinical communication, where the clinician projects anatomy images on a wall, model, or the patient's body using a handheld device [28]. The user study results showed that projecting on the body was more engaging than on other presentation surfaces, and thus might improve the patient's understanding. Kong et al. have explored the clinician's view on using visualization in their communication with parents [16], but they present only half the story as they have not covered the parental perspectives on the topic. Through this work, we complete the story by providing the parental perspectives on the use of data visualization in parent-clinician communication.

METHOD

We interviewed parents and clinicians to gauge the perceptions of both stakeholders regarding the use of visualization in parent-clinician communication. Through the exploration of envisioned benefits and challenges, we sought to answer the question: How can behavioral visualization webtools address cognitive and emotional barriers in parent-clinician communication surrounding developmental delays? While the key topics covered in the interviews were similar for parents and clinicians, parents participated in one more session prior to the interviews where we collected behavioral data about their child. In this section, we introduce the visualization webtools used in our study and cover the details of the parent and clinician sessions.

Visualization Webtools

As our population of interest was parents of children with development delays, we chose two visualization webtools – EnGaze [15] and Plexlines [20] – that display a child's behavior during an autism screening session. By presenting concrete examples of visualizations that cover the participants' interest (i.e., their child's behaviors), we were able to hold an active discussion about the potentials and weaknesses of these types of visualizations.

Both webtools visualized data from the Rapid Attention Back and Forth Communication Test (RABC) sessions. Instead of showing parents pre-collected RABC videos and annotations from previous studies [24], we chose to conduct RABC sessions with their children prior to the interview. This allowed us to interview parents using videos and behavioral data of their own child, increasing the ecological validity of the results. Displaying their child's data also increased parents' engagement and interest during the interview. Prior to the recruitment of parent participants, one of the researchers received training to conduct the RABC sessions from the research team that developed the RABC protocol.

The RABC was developed to screen young children for potential developmental delays [24]. In this five-minute protocol, an adult (i.e. the examiner) and a child engage in five stages of play: a greeting, rolling a ball, reading a book, wearing the book as a hat, and tickling. Each stage contains one or more examiner bids that prompt for a communicative behavior from the child. For example, an examiner bid in the book phase is saying "Look at my book!" Children's response behaviors ranged from looking at the book, pointing at the book, reaching out for the book, to not responding at all.

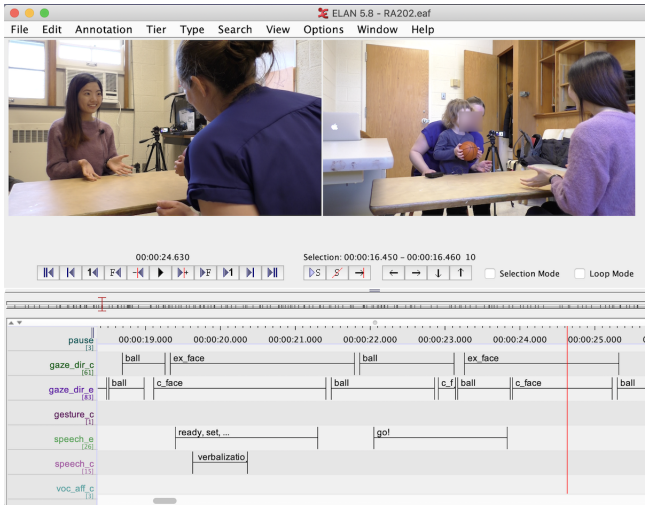

Figure 1. Child's and examiner's behaviors in each RABC session were hand-annotated in three modalities – gaze, gesture, and vocalization.

After an RABC session, the examiner's and the child's behaviors were hand annotated in three modalities: gaze, gesture, and vocalization (See Figure 1). Three members of our research lab were trained to manually annotate the videos using a protocol specifically designed for RABC sessions. This protocol had been used in previous studies of RABC sessions that involved over 100 children [6]. We tested for consistency and accuracy prior to hand-annotating the videos of our participants by coding sample videos from the larger dataset and checking with pre-established hand-annotations. We repeated the process until all coders reached an agreement of 90% or higher.

Once a session was annotated, the behavioral data was visualized as bars in EnGaze as shown in Figure 2, and as circles in Plexlines as shown in Figure 3. Each webtool consisted of a video player, an authoring tool that allows the users to filter and select data (see Figure 2a), and the visualizations. EnGaze displayed each modality on a separate line and was capable of displaying short behaviors that occurred for a fraction of a second. On the other hand, Plexlines displayed behaviors in all modalities on a single line, and the circle size was proportional to the duration of the behavior. As a result, behaviors with longer duration were emphasized on the visualization as they were represented by bigger circles. Another difference was that EnGaze gave equal weight to the child's and the examiner's behaviors while Plexlines focused on the child's behaviors by visualizing them as colored circles and examiner bids as black dots. Lastly, EnGaze displayed each modality on a separate line as shown in Figure 2d while Plexlines collapsed them onto one line. More details on the features and benefits of these webtools for clinicians can be found in Kong et al.'s comparative study of EnGaze and Plexlines [16].

Participants

The inclusion criteria for our study were parents with children (a) between the age of 0 and 5, (b) who showed signs of developmental delays but (c) were not officially diagnosed. We initially sent out recruitment flyers to multiple local schools

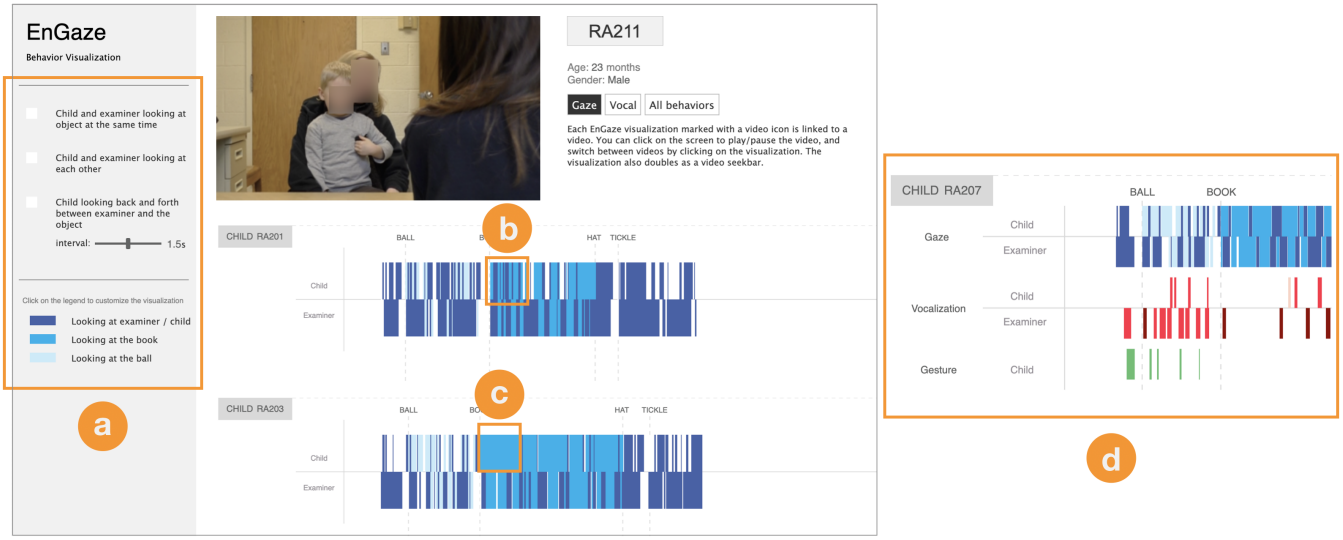

Figure 2. Examiner and child gazes are shown as blue rectangles in EnGaze. The user can choose specific moments of interest through the authoring tool (a), and the legend shows what each colored rectangle means. The visualization shows that a child's gaze alternated between the examiner and the book in (b) while another child only looked at the book in (c). All Behaviors View in EnGaze displays gaze, vocalization, and gesture as blue, red, and green rectangles respectively, as shown in (d).

and children's autism centers. However due to the strict inclusion criteria, the final recruitment was made through an active collaboration with one local laboratory school for infants, toddlers, and preschoolers. We first discussed the study goals and the population of interest with the director of the school, and the school made the judgment on who met the criteria based on developmental screenings and the school's portfolio documentation. Teachers distributed our flyers to families who met the inclusion criteria and sent us a list of parents who showed interest in the study. We recruited ten parents (7 female, 3 male) whose occupations ranged from office administrator, professor, social worker, actor, to stay-at-home parent. Children who participated in the RABC were 42.2 months on average (σ^2 = 16.9; min = 21; max = 66). Each parent received $30 for their participation.

In addition, we recruited 13 clinicians from two branches of a nonprofit health care organization that provides early intervention and autism services to young children and their families. Clinicians' occupations included Board Certified Behavior Analyst (BCBA), speech language pathologist, physical therapist, registered behavior technician, occupational therapist, and autism family navigator. Their mean years of experience working with children with developmental disorders was 17 years (σ^2 = 13.1 years; min = 2; max = 41). Their primary methods of communicating with parents were by email (N=12), phone (N=12), and face-to-face conversations (N=13).

Parent Sessions

Parents attended two sessions. The first session was conducted at the local school and began with a brief warm-up period for the child to become familiar with the examiner and the testing room. Meanwhile, the parent signed the consent form and filled out a background survey. The survey covered the parent's demographic information and their experiences communicating with clinicians. After the five-minute warm-up play, one of the researchers on our team led an RABC session with the child. Two concurrent video recordings were made during the session, one centered on the examiner's behaviors and one on the child's as shown in Figure 1.

The second session was conducted one to two weeks after the RABC session to allow time for the hand annotation of the session. At the beginning of the session, the parent saw a five-minute introductory video of one of the webtools and then explored the webtool, which contained the video and visualization of their own child's RABC session. Parents could see visualizations of other children's sessions, but the corresponding videos were unavailable for privacy reasons. The same process was repeated for the second webtool. Half of the parents started with EnGaze and the other half with Plexlines to mitigate order effects. After the exploration phase, we asked the parents to find specific moments in the visualization (e.g., where the child is looking at the examiner) to gauge their understanding of the webtools and their functions.

Then we conducted an interview starting with their thoughts on the webtools in general. Parents compared EnGaze and Plexlines and indicated their preferences between the two webtools. All the following questions referred to both of the webtools. We asked what they had noticed about their child's behaviors through the webtools. Then, the parents rated how useful the webtools would be in their communication with clinicians about their child's development, whether the tools addressed any of the current communication challenges, and how comfortable they are with clinicians using such visualization webtools to measure the child's developmental progress. We then asked the parents how well the visualizations would serve as an longitudinal record of their child's development and how comfortable they would be with sharing the visualizations with others. Lastly, parents reported any other behaviors they would like to see that currently are not captured in the

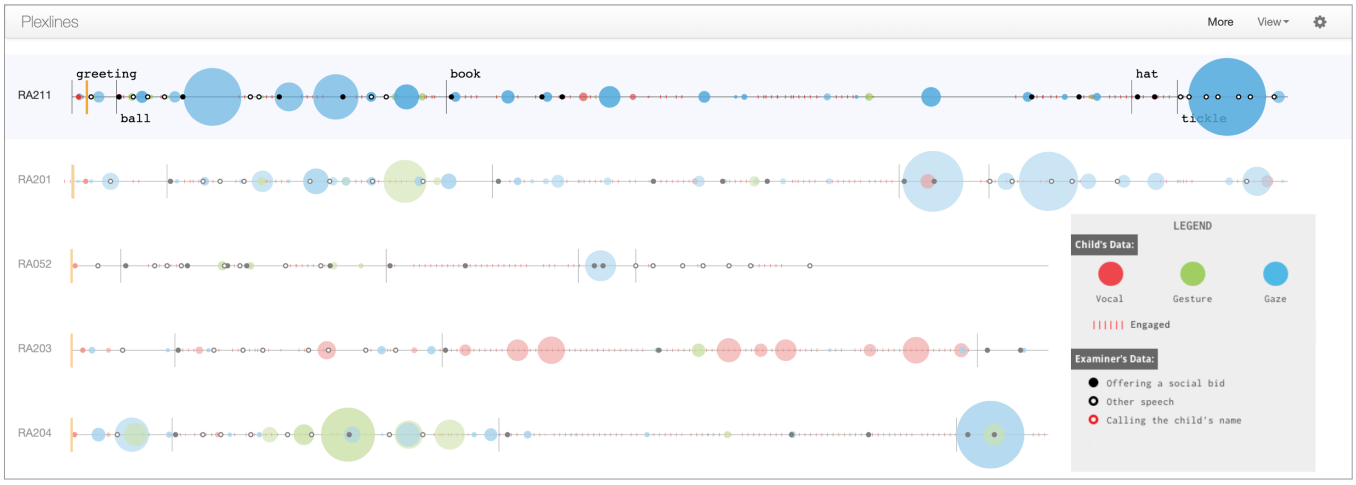

Figure 3. Multiple sessions are displayed on this screen of Plexlines. Each horizontal line represents an RABC session and each circle represents a behavior. The modality of the behavior is represented through the color of the circle - red for vocalization, green for gesture, and blue for gaze.

tools, and whether any part of the visualization was not representative of what actually occurred. After the interview, parents filled out an anonymous survey where they rated their satisfaction with the tools and indicated the strengths and the weaknesses of the tools.

For the qualitative analysis of the interview, we first transcribed the interviews and assigned codes to each response. Two researchers coded overlapping parts of the interviews. After grouping codes into overarching themes, one researcher coded all the interviews line by line. We chose axial coding over open coding due to the hierarchical nature of topics that emerged during the interviews (e.g., "denial" under "emotional barrier").

Clinician Sessions

The study procedure for the clinician sessions was similar to that of the second session for parents. Clinicians first saw an introductory video of a webtool followed by free exploration of the tool. While parents only saw videos of their own child, clinicians saw videos of all the children whose parents gave us the permission to show the videos. The webtool exploration phase was followed by a semi-structured interview. We first asked which webtool they preferred and the features they liked. Then clinicians rated how useful the webtools would be in their communication with parents and what areas in the visualization they would highlight in their conversation. Next, we asked about the current communication challenges with parents, and whether/how the webtools could address these challenges. We ended the interview with questions on whether there were any additional behaviors or features they would like to see, and the anticipated challenges in integrating this type of tool in their current workflow. Clinicians filled out an anonymous survey that was identical to the one parents filled out at the end of the session.

RESULTS

We first begin by presenting parents' evaluations of the two visualization webtools and the various roles visualizations can play to support parents. Then in the next section, we present the clinicians' evaluation of the webtools and their views on the proposed roles. Lastly, we present the envisioned benefits and challenges of using behavioral visualizations for parent-clinician communication and how visualization webtools could address cognitive and emotional barriers in communication.

Parent Interviews

Overall, parents showed positive reactions towards the webtools. On a 5-point Likert scale ranging from strongly disagree (1) to strongly agree (5), parents agreed that they were satisfied with the visualizations (μ=4.58, σ^2=0.77) and the webtools (μ=4.48, σ^2=0.9). The exact distribution of all Likert scale results can be found in the Supplementary Materials. We found that participants grasped the concept of the webtools quickly, and they were able to make interpretations from the visualizations after watching a 5-minute introductory video.

Parents' Preferred Features

After exploring both webtools, parents indicated specific EnGaze and Plexlines features that they valued. They named the dyadic display of examiner-child interaction (N=5), the ability to filter for specific moments of interest (N=5), and the detailed presentation of behaviors (N=3) as the key strengths of EnGaze. The presence of filters gave some parents the feeling of *"being in control of exactly what I was looking at, or looking for"* (P1). On Plexlines, parents appreciated the clear indication of the behavior duration (N=5) and how all the behaviors were on a single line, enabling easier detection of co-occurring behaviors (N=4). P6 commented that although Plexlines seems complex at first because there are different styles of shapes (e.g., filled and unfilled circles), Plexlines *"seems quicker to get things at a glance once you know what it is."* The compactness of the visualization made it easier to view multiple sessions in one screen as well. In summary, features parents liked the most were filtering and highlighting behaviors of interest, getting an overview of the whole session, and comparing across behaviors or sessions.

Seeing the Child from a Different View

When asked whether they saw anything unexpected from the visualization that they had not noticed during the session, eight parents answered that the visualization helped them see something new. Half of the parents (N=5) noticed the presence or the lack of a certain modality such as gaze (N=3) and gesture (N=3). *"Through the tool, I noticed that he does use a lot of eye contact. Even more so than I had realized. We think [our child] is pretty communicative for his age. He's pretty advanced in speaking and all of that. So I guess that I am not totally shocked, but it was interesting to see how tuned in he was to what you were doing"* (P10). This reflection on gaze is noteworthy since clinician participants in our previous study had indicated that parents generally have a hard time understanding or observing gaze [16].

Other parents (N=4) noticed the level of engagement through the visualization webtools. One parent was pleasantly surprised when she saw that the child was more engaged than expected. *"So the chart shows that he was very engaged, and he was really interacting with you at that time. I could see that in the chart, and I was kind of surprised by that because my view was totally different because I just saw his back [during the session]. So I didn't know if he saw you. What I knew was he just refused what you asked so that's why I thought he is really hard-headed and not like him, but I learned that he's interacting"* (P8). While our webtools contained videos of the session, subtle behaviors such as quick gaze patterns that were easy to miss in the videos were much more salient through the visualizations. Thus, visualizations helped parents notice behaviors that would be hard to observe by video alone or during live interaction. When we asked P8 "How much did you rely on the video, and how much on the visualization to understand what's going on in the session?", they answered that they relied "half and half" but used the visualization to confirm what had really happened. Another parent used the chart visualization to confirm their expectation of the child's engagement, *"It was hard to tell in the session, just how interactive he was being because I couldn't see his face. And so I'm glad to see that he is interacting a fair amount. That makes me happy because I just want him to be an empathetic, connective person"* (P6).

Interestingly, although the visualization did not show a child's affect directly, parents (N=4) inferred emotions based on the visualizations even without referring to the video. For example, one parent used the lack of vocalization and the push-away gesture as a signal of dislike and noticed *"the fact that he didn't really like the tickling. [Researcher: And you got that from the visualization?] Yeah, when we watched it through, I noticed that he kind of didn't say anything and went back towards me"* (P7). Similarly, another parent interpreted the lack of gesture as a signal of nervousness and discomfort. Although the level of engagement and the child's affect could be inferred through the video as well, parents found visualization to be a reassuring artifact. One parent explained, *"I watched the video, but I guess the fact that I could actually pick out that there was only one active [gesture]... You got a sense of it by watching the video, but with the visualization, you can actually pinpoint it"* (P3). This ability to pinpoint moments of interest makes visualization useful as a cognitive artifact for parent-clinician communication.

Visualization as a Longitudinal Record

In our previous study [16], clinicians proposed different roles of visualization in clinical settings including 1) to keep a longitudinal record and 2) to share data with others. In the next two subsections, we present parental perspectives of these roles of visualization in clinical settings.

While parents and children participated in a single session for our study, webtools could be used to display progress over time by stacking sessions of the same child vertically as shown in Figure 3. We asked parents "If you could get an updated version of your child's visualization every 6 months, do you think this would serve as an accurate longitudinal record of your child's development?" Seven parents answered that it would, and two that it would not. One parent said maybe it could for a certain age range ("one to three or four") but was uncertain.

Parents who indicated that visualization could serve as a longitudinal record often named certain behaviors they would look out for. They also reflected on their past experience or expressed future expectations. For example, P1 reflected on *"when [the child] was two and a half, we were starting to wonder a little bit about eye contact. And then it kind of 'snap' [snaps his fingers], right. And he was making it, and he was just doing great. So yeah, I think being able to document that kind of stuff would be a great little marker of his development."* Another parent mentioned that she would check for *"how well he's relating to people"* and that her expectations for future sessions was *"that he would vocally interact more"* (P7).

One parent was a social worker and remarked how longitudinal records that show signs of developmental delay could act as a social indicator: *"If you're looking at that data over time and suddenly, they are falling off for example. I know like, the kids that I've worked with that are abused, you'll sometimes see their audio, verbal outreach sort of starts to drop off. So I think it could help highlight some of those kinds of issues potentially. [...] In more severe cases, children will sometimes flinch at gestures so [if the visualization could show those behaviors,] it would have a potential for that kind of use"* (P5). Of course, visualization should not be used as a single source of information but as a flag for a closer follow up.

Some parents responded that visualization would not provide an accurate representation. Their disapproval mainly stemmed from the differing definitions of "significant" behaviors between clinicians and parents. Since the webtools were originally built for clinical purposes, they focused on communicative behaviors (e.g., responding to a bid) and did not display non-communicative behaviors. However for parents, certain non-communicative behaviors (e.g., turning a page in the book) were significant as they signaled their child's cooperation and engagement. As a result, one parent felt the visualization did not accurately reflect how engaged his child was during the session. This concern could be addressed by visualizing all annotated behaviors, even if not clinically significant. As we will further cover in the discussions section, we

should be considerate of the parents' perceptions and emotions when building a tool and strive to provide not only *accurate* but also *supportive* information.

Visualization as a Privacy Preserving Mechanism

In a previous study, clinicians anticipated using visualization webtools to educate people about autism and to communicate with other professionals [16]. However, sharing videos is often banned for privacy reasons, and even when it is allowed, parents might feel uncomfortable sharing videos of their child's RABC session. Thus, we wanted to study whether visualization could serve as an alternative representation to videos. We asked parents to rate how comfortable they would feel sharing visualizations in situations where they feel uncomfortable sharing videos (e.g., to the public or other clinicians). For clinicians, we asked how useful these types of visualization would be as an alternative to videos in circumstances where they have to preserve the patient's privacy.

Parents were generally very open to sharing visualizations in situations where they would not share the videos (1 - Very Uncomfortable to 5 - Very Comfortable; μ =4.56). Parents said visualization could work as a privacy preserving mechanism since one could not identify people from the visualization. As one parent said, *"there's no way I would be able to attach that to 'oh it's this person' or so"* (P9). She further suggested that having visualization of RABC sessions available *"for parents to see that other parents are [participating in sessions] as well, might make them more comfortable."*

Although most parents reported that they were comfortable with sharing visualizations, two parents showed concerns regarding sharing a visualization without the video. One parent mentioned that although she is comfortable with sharing the visualization, she was curious about how useful it would be without the corresponding video. Another parent said that he would be very uncomfortable with sharing the visualization without the video as it did not seem representative of the session. The reason was, once again, the differing definition of significant behaviors as previously discussed in the longitudinal record subsection.

Clinician Interviews

Clinicians rated that they were satisfied with the visualizations (μ=4.04, σ^2=0.89) and the webtools (μ=4.19, σ^2=0.9). They could vividly imagine how the webtool might address the emotional barrier in communication that arose when they made a diagnosis. One clinician provided an illustration of how a parent might respond to a diagnosis, current challenges in the communication process, and how they might benefit from visualization webtools in these circumstances:

> I think it could be beneficial, especially if you have a parent who maybe is not recognizing some of the things you have concerns for. Because you have the video, but you also have the data to show them. And when you have conversation with families and you're diagnosing the child [...], I sat on one yesterday, and as soon as you say "autism," you kind of see, you lose them. Anything you say after that ... it's hard to hear that. It's hard sometimes to be ready for that.
>
> We have a report we put together, but it takes 30 days for them to get the full diagnostic report from us. So we usually, the medical providers, the doctor tells them whether they have autism or not, and we give them recommendation for treatment. [...] We talk a lot with parents in these meetings, but I don't know how much they are absorbing. So it would be good for them to have something to look at, whether that's in writing or video, just another way of trying to communicate with them. This would be helpful because they can point out [on the visualization] 'see how he did this.' Because they don't always see that. Parents don't always know that's not typical development. So this could maybe be helpful in that way (C9).

Most clinicians agreed that visualizations would be useful as longitudinal records in healthcare. More specifically, they envisioned using visual longitudinal records of a child to display pre- and post-intervention assessments and to demonstrate the effectiveness of a treatment. P5 pointed out that compared to standardized tests, visualization could show more subtle changes over time.

> Most standardized tests are normed towards children with typically developing social skills. They are not normed for children with autism. So standardized tests often don't show as much progress. So we will see improved eye gaze and gestures, and all those good skills, but a standardized test won't pick that up. [...] I can see it being really useful tool to document progress. Like 'This is where we were before, and this is where they are now. This many more times they pointed and vocalized.'

Clinicians generally rated that the visualization would be useful for preserving privacy in situations where videos could not be shared (μ =4.56). For many of them, preserving privacy was a real concern since they had to be HIPAA (Health Insurance Portability and Accountability Act) compliant. Seven participants provided detailed scenarios where visualization would be useful for privacy. Scenarios included teaching or coaching other professionals, staff, and students; consulting other medical professionals for advice; presenting results at conferences; and dealing with children in foster care. An occupational therapist (C10) explained that in *"foster care, you're not allowed to take any video. So every once in a while, I'll see foster children at daycare. And the family's not there, but I'm not allowed to take videos to send it to the family. [...] I can only either write down or verbalize what they did. But I don't always have time to verbalize, and then to write it all down... but if I had a chart, I could say 'Oh look' you know."* This once again shows people's expectation that visualization could serve as a shared cognitive artifact during conversations.

Benefits of Using Visualizations in Communication

When asked to rate the webtools' usefulness in parent-clinician communication on a 5-point Likert scale ranging from not useful (1) to very useful (5), parents rated 4.25 on average (σ^2=0.63) and clinicians rated 3.42 (σ^2=1.15). In the following sections, we present the expected benefits and challenges of using visualization webtools in parent-clinician communication that led to these ratings.

Visualization as Objective Evidence

A key benefit of visualization webtools for parent-clinician communication envisioned by both parents (N=4) and clinicians (N=6) was the potential to serve as evidence of the child's behaviors. The following anecdote of a parent's current experience demonstrates how behavioral visualization webtools could improve parent-clinician communication.

> Sometimes in our daycare, there is an assessment, like Bayley or other things, just to see their development. Sometimes I get the report. But also because I don't have any objective cue, I was wondering what they observed. What is the base of the grade? [These reports are] just paper. They rate the child's well behavior or receptive communication skills. [...]
>
> I don't doubt their rating, but I want to see what's the evidence of that. There is a criteria, for example, my son got an emerging rating, like 14 or 15. So there is a criteria. From 13 to 15, it's an emerging area. Above 16, it's advanced. My son got 15. So there is a criteria that helps me see what it means. But also at the same time, I don't know what they observed. I mean, their rating was not surprising. That is what I expected. But also at the same time, I would more appreciate it if I could see that is what really happened and based on that, they gave him this rating. (P9)

This story reveals the current challenge parents face in interpreting development assessment outcomes, and how visualizations could improve their understanding by better illustrating how their child meets or does not meet each criteria. Parents generally envisioned visualization to meet their cognitive needs after assessments by providing a better representation of the sessions.

Clinicians especially appreciated the visualizations' capability of showing objective evidence as they often come across parents in denial. In the pre-study survey, nine out of 13 clinicians named "emotional factors" as a challenging element in their communication with parents; many of them dealt with the parents' denial of the diagnosis.

Another clinician explained that some families are referred to her by a pediatrician, and there are two components in her job for those families: 1) helping parents realize that there is a concern, and 2) helping them do something about that concern. She indicated that parents might be more receptive in receiving information as data visualization since it makes the report less subjective. *"If I say 'they don't have eye contact. They don't look at me,' that's something subjective. But this [visualization] is not. 'See how many times it didn't happen' I think parents would be more open to this, most of the time. If you take the person out of it... It's harder to argue against data than another person"* (C11).

Highlighting Moments of Interest

Both parents and clinicians appreciated how one could highlight moments of interest through the visualization webtools. Parents valued having visualization as a concrete artifact that they could refer to in their conversations with clinicians, as they often felt lost for words during these short sessions. With visualization, they could succinctlybu point at moments of interest instead of struggle to describe behaviors in words. In other words, they viewed visualization as a conversational bridge with the clinicians.

Clinicians wanted to highlight specific areas because behavioral visualizations could be overwhelming to parents at first. The problem can be alleviated by providing visual or textual cues to the important sections of the visualization. As for specific areas to highlight on EnGaze and Plexlines in their conversations with parents, clinicians most often named gaze patterns such as eye contact or joint attention. Joint attention involves a shared focus of two individuals on an object, and the lack of joint attention is considered the hallmark of autism [22]. Although joint attention is an important concept in child development, the concept is very difficult to explain to parents. Visually highlighting these rapid exchanges of eye gaze was one of the key benefits clinicians foresaw in using visualization for communication. For example, although a parent may not be able to follow quick gaze shifts in a video, they may notice alternating dark blue and light blue lines in EnGaze (in Figure 2b) or the lack thereof (Figure 2c).

Another pattern clinicians wanted to highlight was the child's response to a bid or response to name calling. Highlighting these moments could help clinicians show the parents whether or not their child seemed to understand the bids and respond in an appropriate manner. While all of gaze patterns and responses were supported on the interactive webtools, clinicians also suggested additional patterns to highlight that were currently not supported in the webtools. For example, one clinician mentioned that she would like to see "the negative values" or in other words, moments where the child was disengaged and did not look at the object or the examiner. The ability to visually represent disengagement was proposed to be useful in convincing parents to follow up with a full diagnostic assessment although one might not want to start out a session with these negative points.

In fact, clinicians generally wanted to start out a session by highlighting the strength of a child. A physical therapist (C4) said if the child *"did really well with hat and tickling, [that] would be something that carries over into treatment or intervention."* So C4 would attend to the phase and modality the child's best performance was in. Another clinician (C1) said that one of the communication challenges she faced was that parents *"find the worst case scenarios, and you're trying to explain 'well no.. that doesn't really apply here, in this case.' "* So she liked the capability of showing the strength of the child to alleviate parents' unnecessary worries.

Comparisons Across Sessions

Another suggested benefit of the visualization is providing a point of reference either across different time periods for the same child or across different children. Most parents showed interest in seeing the typical behavior for children in a similar age range as their child. In fact, several parents asked us questions during the second session such as, "So is my child doing okay?" Even after explaining that we were not BCBA's and could not give any advice on child development, they

sought reassurance that their child was on track compared to other children around the same age.

Both parents and clinicians were wary of comparing one child against another as every child reaches development milestones at a different pace. However, they were more open to seeing an aggregated or a normalized form of typically developing children as a point of reference. P3 described it as *"an articulated, measured point of reference [...] It's like a graph you get for body mass index and stuff like that for the child. When you go see a doctor, you want to know where the child is on that curve."* C1 suggested that such an aggregated comparison could also help when parents come in with an incorrect prior knowledge regarding their child's condition. She hypothesized that one could display three visualizations side by side – one of a child who is severely affected by a condition, one of a typically developing child, and one of the parent's child – to show where the child falls on the spectrum.

Challenges of Using Visualizations in Communication

While both parents and clinicians reported that the webtools would be useful in parent-clinician communication, parents were more optimistic about their usefulness. Three out of four clinicians who gave a low rating expressed concerns on parents' ability to understand the graphs. One clinician explained that the usefulness *"depends on the family. Some would look at this and have no idea. Some of the families are very data-driven. They want to see the data. They want to see the charts. So I can think of two families that would really appreciate seeing it presented this way. The rest of the families just want to see general info"* (C13). Another clinician was skeptical about the webtools due to the overhead of learning and explaining the visualization, as well as uninterested parents: *"I have a hard time explaining a simple line graph to a lot of the parents. If you add any type of language barriers, I would spend a lot of the time explaining this. And I would imagine them putting this in their bag and never looking at it again based on what I know of my parents"* (C2).

The parents in our study indicated that the webtools were easy to interpret (μ=4.11, σ^2=0.88 out of 5) and easy to use (μ=4.32, σ^2=0.75). However, their average education level is higher than that of the average population in the U.S. So future work is required to evaluate the clinicians' concern on parents' understanding of the visualization. Another challenge in using the visualization is that it could be very discouraging to parents when the behaviors visualized are sparse. Imagine the dread of staring at a nearly empty visualization that clearly conveys the lack of social interaction or the developmental delay of your child. Due to this potential challenge, C12 mentioned that she would only feel comfortable sharing the visualization if the child is doing well. This reminds us that creators and presenters of visualization should not only consider the *accuracy* or the *interpretability* of a visualization, but also its cognitive and emotional impact on the viewers.

DISCUSSION

The results show that behavioral visualization webtools could alleviate existing challenges in parent-clinician communication by addressing emotional and cognitive barriers parents face. In this section, we discuss how one of the key benefits of visualization (i.e. acting as objective evidence) could lead to misinformation and how visualizations should ideally be incorporated into the routine of parent-clinician communication. Next, we discuss how visualization could be used by parents at three different stages where they deal with the initial emotions, form a deeper understanding of their child's behaviors, and advocate for their child.

From Data Visualization to Trust

A theme that ran throughout the interviews was people's trust in data visualization. Clinicians and parents suggested that visualizations could serve as objective evidence. People's strong trust in data and visualization has been revealed through previous research [17, 31]. This trust in data visualization is a double-edged sword. On the positive side, it allows clinicians to provide a clear evidence of their diagnosis without appearing subjective, and in turn, helps parents overcome emotional and cognitive barriers. However, this trust in data visualization can also lead to the intake of visual misinformation without critical judgment. Parents and clinicians often described visualizations in the webtool as "objective," but visualizations may not be as objective as they believe. A lot of subjective design decisions are made when creating a visualization such as which behaviors to visualize and how to visualize them. Textual components such as the visualization title can also introduce subjectivity and even bias, which often goes by unnoticed by the viewer [18].

With the rise of health-related (mis)information that is spread online, blind trust in visualization can lead to the spread of incorrect medical knowledge and can hinder parent-clinician communication. One way to disclose the subjectivity in visualization is through the authoring tool, which supports a flexible representation of a single session. Allowing users to explore multiple potential visualizations of a single RABC session may show them that there is no "one objective visualization" that fully represents a session.

Next, we should develop a culture where a visualization is used as a means to an end rather than an end in itself. In other words, the mere *presence* of visualization should not be the base of parents' trust. Rather, parents should use visualization as a tool to better understand their child, which then could lead to an increased trust in the clinician as well as trust in themselves as they make decisions. Ways to assist parents to gain a better understanding from visualizations include, but are not limited to,

- highlighting and talking over the important parts of the visualization as it is presented for the first time
- giving parents a printed copy of the visualization that they can take home so that they could absorb the information at a comfortable time and location
- asking parents to annotate sections on the visualization that they have questions on and using those annotations to shape the next conversation

The first and third approaches are based on parents' and clinicians' perceptions of the use of visualization as an anchor for

conversation and highlighting material, as presented in detail in the results section. The second approach stems from clinicians' comments that some parents had a hard time digesting all the information at the time of initial diagnosis. Equipped with a comprehensible representation of a screening session, parents can examine their child's (lack of) behavior more closely and reflect on their own observations of the child's behavior. If the parent notices similar behavior patterns at home as the ones that are visualized, this knowledge could help them accept the screening results with more ease. If the child's behavior during the session seems to differ significantly from his/her regular behavior, the parent can bring it up during their next session with a clinician. One thing to note is that children's behavior at home may differ from their behavior in other settings, and further discussion with a clinician is necessary to fully understand their behavior.

From Emotions to Advocacy

In their book "From Emotions to Advocacy" [42], Peter and Pamela Wright prepare parents with a systematic approach to collect, track, and assess information about their child. Our work shows that visualization can play an integral part of this approach. First, we presented how visualization could address parents' emotions by presenting the strengths and weaknesses of a child in a more objective manner. We suggest starting a session by highlighting the child's strengths before addressing developmental delays. Showing where a child's behavior falls on a spectrum of behaviors might also help parents be more receptive to the results than showing a pass/fail style report. Thus, clinicians can use visualization to support parents' acceptance and agency after receiving a diagnosis.

Next, visualization can help parents reflect on communicative behaviors as a parent stated, *"it just makes you think about how to foster good eye contact. It's just something that I've been thinking about anyway. So it's just a tool to sort of make you think about those kinds of social interactions"* (P3). Through promoting this type of self-reflection on their child's communicative behavior and his/her social interaction with an adult, visual assistance could help parents better understand their child's behavior as well as the impact of their own behavior on their child's development. Previous work on parents' informational needs showed that "the feeling that they understood what was happening helped some respondents to cope with the illness and re-establish a sense of control" [10], and thus visualization could empower parents by providing a comprehensible representation of their child's behaviors.

Parents have also expressed openness towards using visualization as a longitudinal record of their child's developmental progress. Based on these visual resources, parents can structure questions for their next meeting with the clinician. This can lead to a more parent-centered conversation where the parent is an active contributor of the conversation rather than a passive listener. Encouraging parents' participation in the conversation is important as patient-centered communication was shown to be more effective in addressing the needs of the patient compared to clinician-centered communication [14].

Future work could complete the picture by exploring how parents can use visualization for advocacy. While our work mainly focused on visualizations that help clinicians convey their message, we believe that parents can also use visualization to convey their concerns and achievements to clinicians as well as to the public. It would be interesting to explore what types of data and visualization parent would like to show, when and how parents would present these visualizations, and for what purpose.

LIMITATIONS

The generalizability of the findings is limited due to the small sample size and the atypical education level of our participants. Our parent participants' education level was higher than that of the general U.S. population since we recruited parents from a college campus town. While parents in our study found the visualization webtools easy to use and interpret, future work with a more diverse parent population is required to determine the generalizability of our results to parents with different education levels.

This paper focused exclusively on the *anticipated* benefits of using two specific visualization webtools in parent-clinician communication. While our work contributes to the field by revealing parents' interests and concerns in using visualizations for their conversations with clinicians, realized benefits might differ from anticipated benefits. Also, the results may not generalize to other types of visualization. Additional empirical studies on the use of a variety of visualizations in actual parent-clinician communication are needed.

CONCLUSION

While effective parent-clinician communication on developmental delay is important, parents experience an emotional strain as they discuss hopes and fears, developmental concerns, and feelings of distress. In addition to the emotional strain, parents also experience a cognitive burden due to medical jargon or presentation of data that is inaccessible to them. In this paper, we presented data visualization webtools as a method of facilitating parent-clinician communication that could address these communicative challenges. Parents and clinicians responded positively to the idea of using visualizations in their conversations and suggested three ways in which they would be useful. Two additional roles of visualization in clinical settings were discussed – acting as a longitudinal record of the child's development and preserving privacy while sharing behavioral data with others. We conclude by suggesting how visualizations could be used in clinical communication while preventing misinformation, and how visualization could empower parents in their journey from dealing with emotions to actively advocating for their child.

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