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Autism and Communication: A Phenomenology of Parents' Perspectives

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Abstract

Autism spectrum disorders (ASD) are characterized by language impairments and are often treated with a variety of communication interventions. In addition to these interventions, the parents of autistic children have to learn how to care for and communicate with their children on a daily basis, especially when their children do not speak. This study made use of phenomenological investigation techniques to explore (1) what parents understand about communication with their nonspeaking autistic children and (2) what particular strategies they find to be effective. Six mothers of autistic children were interviewed, and resulting themes were divided according to parents' understandings and the formal and informal strategies they use. Implications for practice and future research are given.

Autism and Communication: A Phenomenology of Parents' Perspectives

When a mother displays the uncanny ability to understand her child or responds instinctively in parenting situations, it is often referred to as “mother’s intuition.” As parents accumulate daily shared life experiences with their children, they naturally form deep familial bonds, which leads to a sense of expertise and “intuition” within the family. These bonds may also explain how some parents and their children share an impressive ability to communicate in the face of barriers to typical communication. Although many autistic children struggle with communication, they tend to be able to communicate with their parents. In order to gain a better understanding of this interesting phenomenon, this study explored the nature of communication between children with autism¹ and their parents. This paper traces previous related research, the methods used in the present study, and the insights gained from the parents who participated. Parents discussed both the internal and external factors involved in their autistic children’s communicative abilities and the formal and informal strategies they use to communicate with their children in the context of their meaningful personal relationships.

Language Acquisition in Autism

Children with an autism spectrum disorder (ASD) exhibit many differences in their language development compared to that of typically developing children, such as lower rates of acquiring functional speech, later appearance of first words, higher

¹ In keeping with some modern research (i.e., Pellicano & Stears, 2011) and to respect the different self-identification preferences of individuals on the autism spectrum, the usage of “autistic person” and “person with autism” is alternated throughout this paper.

grammatical scatter rates, and usage of echolalia in communication (Eigsti, de Marchena, Schuh, & Kelley, 2011). These differences stem from challenges in several core branches of language including pragmatics (which is tied to social interactions), syntax, and, to a lesser degree, phonology (Eigsti et al., 2011, Ellawadi & Weismer, 2015). Many autistic children are also affected by apraxia of speech, a motor disorder that results in difficulty with pronouncing vowel and consonant sounds, especially in coarticulatory transitional environments, and with prosody (Velleman, 2011).

Some studies have investigated ways to assess autistic children's language abilities and the other variables associated with their language development, such as gesture use, non-verbal cognitive ability, joint-attention, play, and motor skills (Luyster, Kadlec, Carter, & Tager-Flusberg, 2008; Tager-Flusberg et al., 2009); unfortunately, however, there is a paucity of research on the children with ASD who have the most difficulty with spoken language. While most children with ASD acquire some level of spoken language by their early school years, around 30% are left without the ability to verbally communicate and suffer frustration and behavioral problems as a result (Tager-Flusberg & Kasari, 2013). This population, sometimes referred to as "nonverbal" or "nonspeaking" (e.g. Prizant & Fields-Meyer, 2016), has been difficult to research, in part due to the lack of clear definitions for the group. Because it can be difficult to use standardized tests in studying nonverbal autistic children, some researchers focus on using more implicit methods, such as eye tracking, neurophysiology, and magnetoencephalography, to study their language capacities. As more research is done on the unique qualities of nonspeaking children with ASD, it is possible that underlying

mechanisms will be found to explain the prevention or promotion of their language learning (Tager-Flusberg & Kasari, 2013).

Communication Interventions

Various studies and interventions have been conducted on the topic of teaching language to autistic children. In one small study, Foxx, Schreck, Garito, Smith, and Weisenberger (2004) trained two children with autism to decrease their use of echolalia by verbally identifying pictures and responding to questions about those pictures. Both children were judged successful by the end of the study in that they not only stopped echoing but answered most of the questions correctly. It is worth noting, however, that other lines of research have found echolalia to be a meaningful communication technique in some minimally verbal autistic children, suggesting that attempts to decrease echolalia usage should first consider the communicative function the echolalia is serving (Prizant & Fields-Meyer, 2016). In another study, Koegel, Koegel, Green-Hopkins, and Barnes (2010) sought to teach three children with autism to ask “Where” questions, believing that learning to ask questions will better the children’s academic and social outcomes. They found that, through repeated hour-long sessions, all three children went from never asking “Where” questions to asking “Where is it?” when appropriate, often without prompting. Using objects the children liked as part of the intervention, rather than using something like picture cards, helped promote generalization outside of the laboratory context.

Many language intervention studies, however, do not include older children who do not speak. It is important to continue research in this area, because what works for teaching language to younger, preverbal children may not work for older, nonverbal

children. Of the studies that do include nonspeaking children, many center on functional language outcomes, such as requesting, and not on spontaneous speech (Tager-Flusberg & Kasari, 2013). Some researchers also focus on “prelinguistic milieu training” in nonspeaking populations, with the assumption that a child’s increased vocalizations, eye gaze, and gestures will elicit more responsive parenting, which will in turn encourage the child to continue initiating conversation, preparing them to eventually develop spoken language (Franco, Davis, & Davis, 2013). However, these methods of focusing on vocalizations and eye contact are controversial, with some suggesting that they may actually discourage children from communicating in ways that are more natural to them (Akhtar, Jaswal, Dinishak, & Stephan, 2016; Winter, 2012). Alternatively, communication devices and other forms of augmentative alternative communication (AAC) are often used with nonspeaking children to increase their initiation of communication, although AAC does not necessarily increase spoken language (Tager-Flusberg & Kasari, 2013).

Parent Involvement

Formal interventions. Parents oftentimes take an active role in their autistic children’s education, because most interventions available to children with autism are provided through the school system. Due to this, it is particularly important that schools address parents’ concerns, especially in areas not strictly related to educational development (Lindsay, Ricketts, Peacey, Dockrell, & Charman, 2016). Occasionally, beyond voicing their concerns about the interventions their children receive, parents directly participate in the process. In one study, parents were trained to use various intervention techniques to help their children communicate, including modeling or

expanding language while playing with their child and helping increase the complexity of language used. At the end of the study, children did display increased language use and social skills, suggesting that parents' active involvement in formal interventions can yield noticeable results in their children's communicative abilities (Ingersoll & Wainer, 2011).

Personal strategies. While formal language interventions can be useful, especially when parents are involved in the process, some researchers focus on the more intuitive ways parents choose to communicate with their children. Goldman and DeNigris (2015) studied conversations between parents and children, with the children divided into three diagnostic groups: ASD, Developmental Language Disorder (DLD), and typically developing (TD). They found that parents of children with ASD and DLD used more direct questions than parents of TD children, suggesting that parents of children with language disorders take more of an active and objective role in scaffolding conversations with their children, rather than focusing on elaboration. Further, parents and children who clearly engage in reciprocal play (higher order supported joint engagement; HSJE) are more likely to see greater levels of expressive language and social communication in the children later on. HSJE is also predictive of receptive language when parents demonstrate a pattern of commenting on their child's focus, without directing them to something else, while engaging in reciprocal play (Bottema-Beutel, Yoder, Hochman, & Watson, 2014).

Parenting a Child with Autism

Many studies on treatments or therapies for autistic children focus specifically on the direct effects of the treatment. However, it is important to understand the state of the family as a whole, because families of children with autism are usually their primary caregivers. Family members' experiences can substantially impact their relationships

with the autistic child and with each other as well as the access and effectiveness of treatments (Karst & Van Hecke, 2012).

Navigating the Diagnosis

Excited about welcoming their new child into the world, many parents do not immediately notice anything different about their children with autism; even when they do notice some behavioral oddities, they may not think much of them (Desai, Divan, Wertz, & Patel, 2012; Ijalba, 2016). For some immigrant families, this could be because their home country has different perceptions of developmental milestones (Ijalba, 2016). Confused about the reasons for their children's behavior, parents may begin to question their own parenting strategies (Desai et al., 2012).

Eventually, most parents notice that something is definitely different about their child and seek a professional opinion. When they first receive a diagnosis of autism for their child, some parents do not even know what autism is (Desai et al., 2012; Ijalba, 2016), while others do and experience a mix of emotions, including joy, relief, and sadness (Carlsson, Miniscalco, Kadesjo, & Laasko, 2016). After this initial reaction, many parents seek information and understanding from experts (Carlsson et al., 2016). Some may hold onto a belief that their child will "improve" and perhaps outgrow his or her challenges (Ijalba, 2016), whereas others become concerned about their child's future (Desai et al., 2012). They may also speculate about what caused the child to have autism, possibly attributing it to emotional and/or stressful events early on in the child's development (Ijalba, 2016).

Though parents initially look to experts as the source of knowledge about autism, they ultimately challenge experts (Carlsson et al., 2016) and develop their own expertise.

They work to meet their children's basic needs and advocate for their rights (Carlsson et al., 2016; Desai et al., 2012; Foo, Yap, & Sung, 2014). Beyond their responsibility to their children, parents often feel a responsibility to their spouse (Foo et al., 2014) and to the community (Foo et al., 2014; Ijalba, 2016). This responsibility to the community can take many forms, including monitoring the child's behavior in public (Ijalba, 2016) and participating in research to benefit the autism community (Foo et al., 2014).

Predictors of Well-Being

As previously mentioned, many parents of autistic children worry about what the future may have in store, particularly after they are no longer able to care for their child (Desai et al., 2012). However, parents who demonstrate vicarious hope for their children's future were found to have better well-being overall and less stress, while those who demonstrated vicarious despair had lower well-being and more stress (Faso, Neal-Beevers, & Carlson, 2013). These findings were not associated with the autistic child's "symptom severity," indicating that having hope for one's child is an important predictor of well-being, regardless of the child's specific challenges (Faso et al., 2013, p. 294).

Additionally, family and community relationships are very important for parents' well-being. Some parents feel alone in caring for their autistic children (Carlsson et al., 2016), but mothers of children with autism experience higher levels of psychological well-being when they feel that they have the support of their family, friends, and/or partners (Ekas, Lickenbrock, & Whitman, 2010). Parents also report feeling pride from working together with their spouse to care for their child (Foo et al., 2014). In addition to the benefits that come from supportive relationships, parents can find appreciation in

their own personal development as they reflect on the positive qualities they learn through parenting a child with autism (Foo et al., 2014).

Communicating with a Nonverbal Autistic Child

Understanding Nonspeakers

Sadly, because nonspeaking autistic children have difficulty communicating, they tend to be misunderstood and labeled as “low-functioning.” This term reduces a complex individual to a stereotype and assumes that they lack the ability to think for themselves, which limits expectations of what that individual may be able to do (Sequenzia, 2012). However, when such children complete strength-informed assessments of cognitive ability, instead of standardized tests, they are more likely to score within the normal range (Courchesne, Meilleur, Poulin-Lord, Dawson, & Soulières, 2015). This suggests that strength-informed assessments provide a way to more reliably test the cognitive ability of autistic children, opening a path to understand their strengths and to help them develop their abilities. Accordingly, recent discourse in the autism field calls for “presuming competence,” or recognizing that people with autism have abilities that may not be readily evident and that they should be given opportunities to learn and grow (Biklen et al., 2005).

Partly as a result of their communicative difficulties, autistic people are also described as exhibiting social deficits, with some researchers offering that a lack of social motivation is at the core of autism (Chevallier, Kohls, Troiani, Brodtkin, & Schultz, 2012). However, struggling with language does not necessarily indicate a lack of desire to communicate. Yergeau (2011/2012), an adult on the autism spectrum, expressed that her very silence reflects her comfort with someone, while using speech can feel awkward

for her. Additionally, in a qualitative study with contributions from seven nonspeaking individuals with autism, the editor noted that, “through education, through writing, through art, through friendships, and through dialogue” (Biklen et al., 2005, p. 256), each of the contributors sought to be an active part of the world around him or her. These individuals’ communicative creativity provides evidence contrary to the common belief that autistic people are isolated in themselves and have no desire to communicate.

Practical Strategies

Communicating with a child with autism can be a challenge, requiring extra time, understanding, and creativity. For children who cannot or do not speak, it is especially important to pay attention to their nonverbal cues and respect the creative ways they find to express themselves. In autistic and typically developing children alike, nonverbal behaviors, such as gestures, serve to communicate what a child may not be able to say aloud, giving insight to inner cognitive processes (Goldin-Meadow, 2000). Additionally, due to advances in research and technology, people with autism have access to a greater variety of AAC methods than did past generations. An autistic individual may struggle to speak yet find his or her own way to communicate through pictures, written language, and/or sign language. In some cases, speech therapy may help, but it should not be prioritized to the effect of neglecting other methods of communication which may be more comfortable to the person with autism (Baggs, 2000/2012). Parents and others interacting with autistic people can help by being sensitive to their sensory issues, engaging their interests, allowing them time to process and respond, and understanding that their eye contact and body language should not automatically be interpreted the same as it would be in a person without autism (Harp, 2007/2012).

Future Directions

Even though autism science has historically been focused on finding causes or cures (e.g. Bhat, Acharya, Adeli, Bairy, & Adeli, 2014), the “neurodiversity” movement calls for a shift in perspective: rather than being viewed as “broken” through a pathology model, people with autism should be respected and valued as different, but not inferior. Proponents of this view of autism hold that there is room for more than one “correct” way of neurological functioning, and that the unique neurology of autistic individuals does not need fixing (Ne’eman, 2010/2012). Instead, in autism science, there should be more of a focus on interventions and supports that help children and adults with autism in their everyday lives. Scientists and professionals can respect these attitudes toward autism/autism science by meaningfully including autistic people in advisory groups and working to make this collaboration a personal priority (Pellicano & Stears, 2011).

Overall, the majority of developmental research has been focused on typically developing children (Jaswal, Akhtar, & Burack, 2016). However, a growing number of studies, such as the ones mentioned above, have investigated a variety of topics surrounding autism, such as predictive measures of language outcomes, the effects of parenting a child with autism, and how parents are involved in language interventions. Even so, not many studies focus specifically on nonspeaking autistic children (Tager-Flusberg & Kasari, 2013). Those studies that do focus on nonspeaking populations view nonverbal communication in autism as a precursor to language development (Ellawadi & Weismer, 2015; Rozga et al., 2011) and aim to teach functional language outcomes (Tager-Flusberg & Kasari, 2013). This narrow focus on language neglects a large number of people with autism who do not acquire speech. Nonspeaking individuals and their

caregivers must communicate with each other, even in the absence of spoken language, but very few studies have been done to investigate this phenomenon.

In the present study, parents were recognized as experts of their own experiences, uniquely qualified to shed light on the ways in which they communicate with their children with autism. This study primarily sought to investigate the following research questions:

1. What do parents understand about the effects of autism on their child's language abilities?
2. What strategies have they found to be effective in communicating with their child?

Method

To address these questions, a phenomenological qualitative approach was selected above the other types of qualitative research (Creswell, 2013). Semi-structured interviews were conducted with six parents of children with autism. This method allows for particular questions to prompt desired information, but leaves the interview open enough for participants to share what is important to them. Given that the focus of a phenomenological study is the subjective essence of participants' lived experiences (Seidman, 2013), it is important that the direction of interviews is substantially influenced by the participants themselves. In this particular case, the researcher and parents of children with autism explored the phenomenon of communicating with a nonspeaking child with autism.

Participants

The participants of this study were six mothers of autistic children from varying racial, socioeconomic, and job backgrounds. In two interviews, other members of the

family (a father and a daughter, respectively) were also present during the interview, but the mother was still the primary respondent in each case. Number of children per household ranged from one (3) to four (1). In two of the families with multiple children, the nonspeaking autistic child also had a sibling with autism, but in both cases that sibling was labeled as “higher functioning” and communicated verbally. In each family, the children with autism were all males. In most cases (5), the nonspeaking child being described in the interview lived at home with his parents, but one child had been moved to a therapeutic group home.

Procedures

Recruitment. Once Institutional Review Board approval was obtained, participants were recruited through a community organization that provides social and recreational programs for children with autism. The organization’s executive director, who acted as a gatekeeper for the study, sent parents an email detailing basic information about the study and encouraging them to contact the researcher directly. Once participants contacted the researcher, they were provided with more information about the study and offered the opportunity to schedule an interview. Those who elected to participate in the interview process were also sent an electronic copy of the informed consent form prior to being interviewed.

Data collection. Interviews were conducted in locations of the participants’ choice. Three of the participants chose to be interviewed in their homes, and one preferred to meet at a public location. The remaining two participants had moved away from the region in which most of the interviews were conducted, so they were interviewed over Skype and a telephone call. All interviews were audio-recorded and

later transcribed to facilitate the analysis process and ensure that participants' specific wording was retained. During the interviews, the researcher followed a semi-structured interview guide and restated participants' responses through prompts and follow-up questions. Additionally, although the primary emphasis of the interviews was listening to participants share about the details that were important to them, they were gently guided back to the research questions if they drifted substantially off-topic (Leech, 2002; Seidman, 2013).

Data analysis. The phenomenologist's task is not only to collect information about a phenomenon, but to consider the perception participants have about the phenomenon and what meaning they ascribe to it. This practice requires that the researcher engage in what is referred to as *epoche* or bracketing, setting aside one's own personal experiences with the phenomenon in order to understand participants' perspectives (Creswell, 2013). The researcher in this study had previously worked with autistic children and observed parent/child communication in a summer camp setting. It was necessary for the researcher to acknowledge and suspend any opinions about those interactions, and instead explore what meaning they held for the parents being interviewed, none of whom had a previous relationship with the interviewer.

In order to understand how the experience of communicating with a nonspeaking child was generally understood and practically lived out by participants, their individual descriptions were considered analytically to draw out themes (Moustakas, 1994). First, while transcribing the interviews, the researcher highlighted text that stood out as important. After these highlights were made, they were coded for words or phrases used frequently across the narratives. Those codes were categorized according to their

emerging themes, and categories were eventually combined with or divided from other categories based on frequency and similarity to other themes. Once participants' quotes were combined and organized, they were interpreted in light of each other and previous research findings. Lastly, before finalizing the manuscript, the researcher sent drafts to participants. The participants were offered the opportunity to correct misrepresentations of their perspectives and to remove information that they believed was too identifying. This process allowed for increased integrity and confidentiality of the results section (Seidman, 2013).

Results

Participant Profiles

In order to protect participants' identities, all names and other identifying information have been changed.

Amara. Amara and her husband moved from India to America before their son, Adrian, was born. Adrian was educated in the public-school system for a number of years, but Amara now teaches him herself in the home and through public outings. Prior to the interview, she sent a video of her son communicating on his letter board and said, "My aim is to educate the society about how non verbals [sic] can think and process just like us but have verbal apraxia that limits them to express."

Betsy. Betsy is mother to three: one adult son, and two younger sons with autism. Her youngest son, Blake, communicates verbally, but her middle son, Ben, does not. Currently, her primary role is to stay at home and care for her two younger sons. She is passionate about using her experiences to encourage others, and at the time of the interview was "working on a book and self-help programs for people who are stressed out

and depressed and hopeless and have gone through divorce and... the challenges of autism.”

Caroline. Caroline, like Amara and Betsy, is a stay-at-home-mom. Her youngest son, Cody meets much of the criteria for autism, although he has not been formally diagnosed. At the time of the interview, his family had recently learned that Cody has a particular genetic mutation which commonly co-occurs with autism. Caroline expressed during the interview that life with a special needs child has its challenges but is “a blessing too at the same time.” She described her son Cody as very social, saying, “He can’t carry a conversation with somebody, but he will look them eye-to-eye and [clap], because he wants them to clap.... He just likes to be around noise and excitement.” Caroline’s husband came in part of the way through the interview, but he had not been given an informed consent form, so his responses were not included in the results below.

Delilah. Delilah’s interview was conducted over Skype. Her son, Damian, is nonspeaking, but she said, “for him the social aspect of doing things is really important, and I don’t think that is always considered with autism.” She also said that she has had to change her understanding of autism as she learned about what her son was experiencing:

I definitely wanted to fix Damian... I wished that all these interventions would actually do something. And they're not useless, but what I learned by observing him in speech therapy and in occupational therapy were [sic], how he might be understanding his world...

As a result, Delilah currently strives to help Damian manage his sensory integration and communication challenges while affirming his strengths and unique personality.

Esther. Esther has four children, most of whom are grown. Her oldest son, who is in his late thirties, and her youngest son, who is an adolescent, are both autistic, so she has many years of experience raising children with autism. She also has 40 years of experience as a teacher in regular and special education settings. Edgar, her youngest, was adopted from Europe as a baby. While both sons have autism, Edgar displays different behavior patterns than Ernie and, in particular, does not speak. Esther speculated that Edgar's early childhood experiences could have contributed to his current condition, though he has made significant strides since he was first adopted:

He may not have known his mother because she gave him up at birth, but a lot of times kids will go through an Erasmus syndrome type thing and lose the will to do anything.... Once he got here and he got the love, the food, whatever it is, he became a totally different kid.

Edgar spent most of his childhood living at home with Esther but had moved to a group home by the time the interview took place. Esther's daughter, Rachel, participated in the interview, but her responses were not included because she had not signed an informed consent form.

Fiona. Fiona works as a social worker, so her husband stays home during the day with their adult son, Foster. When Foster was first diagnosed with autism as a child, autism awareness and supports were particularly rare in the rural area in which they lived. However, he has since grown to be a kind and happy man. In his mother's words, "[A]s long as Foster is happy- that's our number one goal, is his happiness.... We are so thankful and feel so fortunate because, regardless of all his challenges, he is overall ... really happy."

Research Question 1: Parents' Understandings

The first research question addressed what parents cognitively understood about their children's language abilities within the context of their autism diagnosis. A variety of themes emerged with respect to parents' beliefs about their children's language abilities, thought content, and interactions with others. Discussing their children's (1) expressive/receptive language divide and (2) inner thoughts, parents acknowledged the internal processes that preceded their children's communicative abilities. They also mentioned the external factors involved in communication as they discussed their children's connections with others, particularly (3) family connections and (4) generalizing communication with the public.

Expressive/receptive language divide. Almost all of the parents interviewed (5) expressed the belief that their child's expressive and receptive language skills were differentially affected; that is, they believed their child's capability to understand language was independent of what he was able to express verbally. Some parents gave specific examples of this, such as Betsy's explanation of Ben's ability to accurately obey spoken commands even if he would not be able to verbally respond:

Yesterday I bought him slippers for the house.... So I said, "Ben, go get your slippers, because it's cold down here." Went upstairs – it was dark – he went up there, found his slippers, and came back down, and I was like [gasp]!

Delilah expressed that it is often "a look or... a nonverbal exchange that really indicates that he understands what's going on." Other parents simply affirmed that their child understands a lot, saying "He may not be able to communicate to you, [but]... he understands what you're saying" (Esther), and "his receptive skills are way advanced

over his expressive” (Fiona). However, one mother (Caroline) expressed feeling occasional confusion when they had a “communication breakdown,” not knowing “if it’s receptive or if he’s just stubborn.... That’s a big communication problem, that we don’t know how much he really is understanding.” Overall, though, the parents recognized that their children’s expressive and receptive abilities were separate, and that receptive skills were generally higher.

Inner thoughts. Another theme that emerged with regards to the children’s communication limits was their inability to describe what they thought and felt. Amara, Betsy, and Delilah all expressed a wish for their sons to be able to clearly communicate their needs and desires, ranging from what food they wanted (e.g. Betsy: “I would love him to be able to come in the house and say, ‘Mommy, can you make me some chicken?’”) to hopes and personal boundaries:

That would be ideal, to be able to understand at any time what his thoughts and wishes and hopes are.... That he is able to let us know what those boundaries are and who he is and what he wants to do. (Delilah)

Implicit in all of these statements was the belief that the children had the cognitive and emotional capacity to form such thoughts, and that their expression was simply impeded by various communicative barriers.

Family connection. One particularly salient theme was that of a special understanding between the child and the people closest to him, especially his mother. As Betsy summarized, “There’s something about a mother and child.” Repeatedly, four of the mothers mentioned that their child communicated in a way that only they could understand. Caroline, speaking about her son Cody, told the interviewer, “You would not

understand 99 percent of what he says,” and that even his school often does not understand him, but “because we’ve done it so many times... we know now what he’s talking about.” Thus, even though their sons communicated in unconventional ways, years of shared experiences allowed the mothers to easily discern what their children were trying to express.

Generalizing communication. Although parents recognized that they had a special ability to communicate with their children, some of them (3) also expressed hope for a day in which their child could communicate reliably with the general public. Delilah, for example, said, “Multiple people need to know how to work with him. He needs to be able to move from person to person and still say what he needs to say. So that, to me, is the bigger goal: ... generalizing.” For many, this meant teaching their son to communicate through spelling, typing, or even eventually speaking. Amara in particular expressed worry about the fact that she alone could communicate with her son through his letter board, saying, “That’s what makes me sad. If I’m dead... his voice is dead too.” Because of this, and because their current mode of communication (Rapid Prompting Method; RPM) is often met with skepticism, Amara told the interviewer that she wanted to teach her son Adrian to talk:

I need to... do RPM so that my son can communicate with everyone and then they believe it. They're like, “How are you holding the board? Are you moving it? Are you putting it close to him? Are you prompting it?” Stop those questions! ... I want him to talk because ... then the whole world [will] understand him. It's so hard to teach him to talk, but still I would rather spend all my energy on my son than on the entire world. Because there is so [much] skepticism in this world. And

they would rather point mistakes in others than try to understand, “This kid [is] actually saying his heart out. Let’s believe it.”

Despite the immense challenge that communicating verbally is for Adrian and the other children included in this study, parents prioritize that mode of communication above all others because they view it as the only way their child can communicate with the world.

Research Question 2: Parents’ Strategies

While the first research question addressed parents’ beliefs about their children’s language abilities, the second sought a more practical understanding of how they lived out those beliefs: what strategies they used to communicate with their children. As parents’ narratives were analyzed, it became clear that there was an important difference between the formal interventions and techniques they used and other, more informal strategies. In fact, many of their communication strategies seemed to emerge not from a concentrated effort to use a particular communication method, but from their shared experiences with their children. Both their formal and informal strategies are summarized below.

Formal strategies. The most commonly used formal strategy in this sample was professional help: all of the moms (6) mentioned having a therapist for their son, and five of these specifically mentioned that their son was or had been in speech therapy. Two of the mothers also mentioned that their sons’ speech therapists conducted prompt therapy, “which is the type of manipulation of the lips and the tongue and helping the child ... work on the articulation” (Delilah). It was also the speech therapists who often helped in the implementation of the other formal strategies, including signed language, communication devices and iPads, and picture communication systems. Half of the

participants (3) said that their son used some signs to communicate, and two had found the Picture Exchange Communication System (PECS) to be helpful. However, nearly all (5) mentioned using a communication device and/or iPad to help their sons communicate. This practice was connected to parents' beliefs that their child would be able to communicate more easily and generally if he were to acquire spoken, or at least written, language:

Because my personal feeling is sign language is great. It really is. But I wanted to be able to use a communication device because it's going to be a lot easier. And this also can speak for him ... As he gets older I think that will be a lot better for him than trying to sign. People are not going to understand him; [with] a communication device, they will. (Esther)

Additionally, three of the mothers explained that they were working with their sons on spelling and/or typing on a keyboard. Two referenced the Rapid Prompting Method (RPM), in which they would help their son with a letter board and record his words or sentences as he spelled them out. Both believed that it had opened up the ability to communicate with their sons on more personal level than before:

[T]here are things about his personality that have come out more that are not as easily expressed except verbally.... It's not like I'm asking him a direct question about his personality, but he'll make a funny comment, or he'll have a sense of humor about something, and that really is funny and makes a difference. (Delilah)

In addition to the more common strategies, parents listed a variety of others that they found useful in communicating with their children, such as early intervention, apraxia

cards, listening therapy, whiteboards, paintings, social stories, and differing combinations of these.

Informal strategies. The informal strategies that the participants identified tended to be more intuitive than the formal strategies they used. For example, three of the mothers talked about the necessity of being understanding as they communicated with their children. The patience, tolerance, empathy, and respect they extended to their children seemed to make a noticeable difference in the quality of their communication:

[W]e've treated him more age appropriate, ... shed some stereotypes about, "Well, he's probably intellectually disabled and, you know, good luck with his future." ... And all of that... has helped him come out of his shell a little bit in that he knows that we believe in him. He knows that we are treating him with respect, and so he then puts forth more effort to communicate with us and to trust us There's better back-and-forth between us. (Delilah)

The participants (3) stated that, in order to have successful communication, paying attention to the child is of the utmost importance. Paying attention was necessary to understand their sons' communication attempts (Caroline- "You have to really actually pay attention... see what he's doing when he's saying it") and emotional needs (Delilah- "We have to be sensitive to ... how he's crying or if he wants to be left alone or if he wants us to be around, all of those cues ... that everybody has to pay attention to").

Additionally, most of the participants (4) discussed nonverbal exchanges as an important part of their communication. As Betsy explained, "Communication is being able to tell somebody something... It doesn't have to be words." The parents in the study

found that with a look, gesture, facial expression, or pointing, their sons could make themselves understood, even when a communication device was not readily accessible. The parents could likewise use those nonverbal signals to get their point across to their sons, but they did not limit themselves to nonverbal communication only. Three of the mothers emphasized that they approached communication with their son as “normal” and treated him like a regular person. Fiona, talking about her son, Foster, said “I try to talk to him just like I would talk to anyone else.” While the mothers did use a variety of formal strategies in communicating with their children, the informal strategies that came out of what felt natural to them were found to be equally important and effective.

Discussion

Given that the expressive and receptive domains of language are separate, it is not surprising that the participants in this study made a distinction between them when discussing their children’s language abilities. Their observation that their children displayed higher receptive than expressive abilities stands in contrast to some previous studies that compared the two in samples of autistic children (Weismer, Lord, & Esler, 2010); however, the children in this study were all non-speaking and had extremely limited expressive capabilities, so it is logical that their receptive skills would be higher. The fact that parents attributed to their children higher receptive language skills and cognitive abilities than what they could express verbally is also in keeping with previous research findings, which suggest that the cognitive abilities of nonspeaking autistic individuals are at risk of underestimation but that nonverbal behaviors can give an indication of internal cognitive processes (Courchesne et al., 2015; Goldin-Meadow, 2000). This emphasizes the need for parents, professionals, and researchers to presume

the competence of nonspeaking autistic individuals, even if they cannot express themselves verbally (Biklen et al., 2005).

The themes of unique family connections and the informal strategies that they promote reflect themes found in other qualitative research studies of families with autism. While parents may begin with formal strategies and seek advice from professionals in the field, they eventually develop their own expertise as a result of their lived experiences and make decisions without the need for continual professional guidance (Carlsson et al., 2016). However, the formal strategies that they use do continue to be useful. Many of the communication devices and techniques mentioned by the participants in this study have had prior research treatment, but there is surprisingly little research on the Rapid Prompting Method (RPM) used by two of the families in this study.

Finally, while many of the themes that emerged from the participants' narratives were focused on how the parents and their nonspeaking children with autism communicated with each other within the family context, parents also expressed concern about their children's abilities to communicate with the outside world. This takes some effort not only from the child, but from the general public. Other first-person accounts written by individuals with autism have had the same focus, including suggestions of various strategies for engaging people with autism and being sensitive to their communicative differences (Harp, 2007/2012).

Limitations and Future Research

Although this study offers a unique perspective into the lives of parents with autistic children, it does have some limitations. First, the sample was small and not collected through random sampling. Both of these sample characteristics limit the

generalizability of the themes presented in this study. However, although these participants' experiences may not be indicative for all parents of non-speaking children with autism, exploring their understandings of communication and the strategies they use is a useful starting point which can be strengthened through future studies. Second, because only parents of children with autism were interviewed and not a control group such as parents of typically developing children, it cannot be stated for certain that the themes revealed are unique to parents of autistic children. However, past research gives support to the unique situation of parenting a child with autism, which can be seen in the results of this study.

Future investigations can explore the themes that emerged in this study through both qualitative and quantitative means in order to gain a deeper understanding of participants' experiences and to what degree those experiences can be generalized. Additionally, the specific communication method of RPM warrants further research. Anecdotal evidence seems to indicate that it is a useful technique, but large-scale quantitative studies can offer support and indicate for whom and in what contexts it is most likely to be successful.

Implications

Despite the limitations, this study has important implications for interventions. Understanding the meaning parents of children with autism ascribe to their lived experiences will inform therapists and other professionals working with such families on how to appropriately address the concerns they have. In particular, it is important for professionals to respect the expertise that parents have. Instead of dictating the process themselves, language and other autism professionals must defer to the experiential

education of the parents and allow them to make the decisions about what particular communication strategies will be most effective for their family.

This study should also serve as a reminder to everyone who interacts with autistic individuals, not just their parents or therapists, that communication is a two-way street. Instead of placing all of the burden of communication on people with autism, everyone must recognize the effort, shared experiences, and trust that make successful communication possible.

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