

Parent Perspectives on Assisted Communication and Autism Spectrum Disorder

John Damiao, Galilee Damiao, Catherine Cavaliere, Susanna Dunscomb, Kirsten Ekelund, Renee Lago, Ashley Volpe

Importance: Parents of nonspeaking children with autism spectrum disorder (ASD) may present with complex challenges associated with communicating with their children.

Objective: To explore the firsthand experiences of parents of children with ASD who use assisted communication (AC) to communicate, which has yet to be explored in the literature.

Design: Semistructured interviews with ten parents of individuals with ASD, age 15 to 36 yr, who use AC to communicate.

Results: Analysis of the data revealed four superordinate themes, each with two subthemes: (1) Relationship (subthemes: Involving the Child, Improved Relationship), (2) Future (subthemes: Hopes and Dreams, Planning), (3) Support (subthemes: Limited Availability of Service Providers, Underestimation), and (4) Understanding (subthemes: Communication, Understanding of the Child). The themes illustrated that using AC modalities improved the parent–child relationship (Relationship) and helped parents understand their child on a deeper level (Understanding). A positive outcome of having a new means of communication with their child was that parents could better plan for a future that reflects their child’s innermost hopes and dreams (Future). Parents also reported that the lack of a consensus concerning using AC with nonspeaking children led to decreased support (Support) from professionals and educators, limiting the child’s opportunities.

Conclusions and Relevance: This study provides phenomenological qualitative evidence that use of AC provides benefits to the parent–child relationship.

Plain-Language Summary: This study investigated the lived experience of parents of children with autism spectrum disorder (ASD) and how the use of assisted communication (AC) affected their relationship with their child. Ten parents were interviewed. Four main topics emerged from the analysis of these interviews: (1) improved closeness in relationship, (2) improved ability to plan for the future, (3) wish for improved availability of service providers, and (4) improved understanding of who the child is as a person. Parents play a key role as team members in support of the child’s performance in occupations. The results of this study suggest that AC plays an important role in supporting the parent–child relationship; therefore, AC programs should be considered when implementing and planning occupational therapy treatments for individuals who have communication impairments.

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Autism spectrum disorder (ASD) is a developmental condition that can cause considerable difficulties with functional language, social–emotional reciprocity, and the intricacies of interpersonal relationships (Centers for Disease Control and Prevention, 2021). Functional language deficits affect the relationship between parents and a child with ASD in terms of a child’s ability to express their inner thoughts, dreams, and desires to their parents and the external world.

Parents of a child with ASD often report concerns regarding their child’s social participation and ability to create meaningful relationships (Strnadová et al., 2016).

Although communication may not typically be associated with occupational therapy intervention in practice settings, the *Occupational Therapy Practice Framework* (4th ed.; American Occupational Therapy Association [AOTA], 2020) validates the occupations of social participation, leisure, play, and education,

among others, as relevant areas of practice. Communication is an essential component of engagement in these occupations. Moreover, assistive technology services are commonly provided by occupational therapists and encouraged by AOTA, as described in the position paper “Occupational Therapy and Assistive Technology” (Deterding et al., 1991). These services include evaluation, intervention planning, client and caregiver training, and interprofessional collaboration and integration of technologies. This process may consist of implementing augmentative communication with high- or low-tech systems, such as augmentative and alternative communication (AAC; Cook et al. 2020), as well as others that we explored in this study.

Addressing communication early is essential for the promotion of positive social outcomes (Blackstone, 2003). If nonspeaking children with ASD cannot express themselves to their caregivers, opportunities for caregiver–child bonding may be hindered (Bontinck et al., 2018). Moreover, the importance of a meaningful relationship between a child with ASD and their caregiver cannot be understated. Research indicates that a positive bond between the child and caregiver is related to improved social functioning, adaptability, and reciprocity (Bontinck et al., 2018). Assisted communication (AC), a form of AAC, allows nonspeaking individuals with ASD to use expressive language, promoting their communication opportunities; however, these methods have also generated debate among the health care provider community (Jaswal et al., 2020).

In this study, we examined parents’ perspectives on how the relationship with their child is affected by the use of AC. In this article, AC is used to refer to the following methods of text-based communication: facilitated communication training (FCT), rapid prompting method (RPM), and spelling to communicate (S2C).

Literature Review

AC falls under the umbrella term AAC, which describes multiple ways to communicate to, supplement, or compensate for the impairment and functional patterns of people with expressive communication disorders through the use of assistive technology or communication equipment or devices (American Speech-Language-Hearing Association [ASHA], 2020).

Although the specific methodologies of AC techniques differ, they share the following basic principles:

- Text-based language provides greater opportunity for expression.
- There is a presumption of competence (the least dangerous assumption is to treat a person with complex communication disorders as if they are fully capable of learning and understanding).
- There is a perspective that communication deficits in ASD are rooted in motor and sensory challenges versus intellectual challenges (Torres & Donnellan, 2015).
- One should rely on a trained practitioner or communication partner with the eventual goal

of independence but prioritize autonomy of communication (i.e., the communicator expresses what they intend to express; see <https://www.theaacoach.com/resources>).

FCT (also known as *FC*, *typing to communicate*, or *supported typing*) is a method that originated in the 1970s whereby a trained practitioner provides emotional encouragement, communication supports, and physical supports as needed, using motor learning methods consisting of backward resistance at the arm or shoulder to slow and stabilize the person’s movement, inhibit impulsive pointing, and provide rhythm. With a goal of working toward independence, backward resistance is gradually faded as the person develops the motor skills necessary for independence (Heyworth et al., 2022; Syracuse University School of Education, Center on Disability and Inclusion, n.d.).

RPM involves the communicator pointing to letters to form words and sentences on a letter board that is held by the practitioner and eventually progresses to a keyboard. The practitioner provides questions in a scaffolded teach–ask format (“What Is RPM?”, 2020).

In S2C, a person is taught the purposeful motor skills necessary to spell, by pointing to letters. As motor skills improve through consistent practice, they progress from pointing to letters on letterboards to typing on a keyboard. Communication moves from concrete to abstract as motor skills progress (see <https://growingkidstherapy.com/>).

Although AC falls under the umbrella term ACC, opponents of AC typically target FC, RPM, and S2C because of the presence of a trained practitioner or communication partner, whereas AAC is often considered less susceptible to influence by a practitioner. In contrast to traditional AAC methods, the texts produced by AC users often present highly sophisticated language and ideas (Grayson et al., 2012).

Some AC methods, in particular FC and RPM, have been targeted and scrutinized as a “discredited technique that should not be used” according to the ASHA (2018) position statement. ASHA described these techniques as lacking scientific evidence of true authorship by the person with the disability. This statement was originally published in 1995 and was updated in 2018 with a stronger stance against FC and RPM, citing the findings from a systematic review conducted on published research spanning 2014 to 2018 (Hemsley et al., 2018). Of interest is that this review found no new articles that met the inclusion criteria and thus did not include or analyze any new research on this topic. Despite the lack of findings, however, ASHA strengthened its position on the basis of research conducted before 2014.

Although hundreds of qualitative studies on AC have emerged in the past 30 yr, opponents of AC still reference a small group of quantitative studies that were published in the 1990s by researchers who used biased and outdated methods (Heyworth et al., 2022). Parents, teachers, and health care professionals are not

traditionally taught about the various AC options. When they are informed about them, they are often portrayed by professionals as invalidated or disproven (Tostanoski et al., 2014; Travers et al., 2015). However, supporters argue that the main culprit is the lack of adequate education, training programs, and coaching in AC at the professional level for teachers and health care providers (Donato et al., 2018), as well as the lack of incorporation of lived experiences (Heyworth et al., 2022).

The perceived inconclusiveness of information, limited knowledge, and inadequate training in AC may contribute to the stigma related to its use (Jaswal et al., 2020). This stigma has inadvertently led to decreased opportunities between parents and children with ASD who may benefit from using AC to communicate, reducing overall social participation and life satisfaction (Donato et al., 2018). Although some of the research conducted in the distant past discourages the use of AC because of claims of facilitator influence, many people contend that they benefit from its use (Heyworth et al., 2022).

In her 2022 Eleanor Clarke Slagle Lecture, Patten described the urgency that the profession move further away from a reductionistic disability-centered model, rooted in ableism, and toward a paradigm-shifting, strengths-based approach consisting of inclusivity in practice, teaching, and research. Although this sentiment is not novel and is rooted in the historical call for a shift to a disability studies model, progress in the occupational therapy practice setting has been slow (Patten, 2022). What is especially interesting about this Eleanor Clarke Slagle Lecture and particularly relevant to the current study, is that Patten presented this message through the voices of self-advocates with ASD. Patten strengthened her message by using direct quotes throughout her lecture from individuals who themselves learned to communicate using an AC method.

Previous research suggests that parents of children with ASD experience elevated stress levels related to parenting. Understanding the child's needs is often challenging for parents, and a sense of helplessness may be associated with their attempts to understand their child (Del Bianco et al., 2018). Current literature suggests that parents' education-related expectations for their child often mold their parenting behaviors, influencing the parent-child relationship (Bush et al., 2017). As a result, there is a demand for interventions to improve the social opportunities and communication abilities of children with ASD (Laugeson et al., 2015).

Children with ASD experience barriers to participation in the home, classroom, community, and workplace because of limitations in verbal communication (Holyfield et al., 2017). Parents, caregivers, and professionals may have preconceived notions of an ASD diagnosis, resulting in lower emotional and cognitive expectations of their child (Arias et al., 2018; Danker et al., 2019; Gómez et al., 2020). As children approach

adulthood, their goals of social closeness and information transfer become increasingly important, replacing younger children's need for communicating perceptions and feelings (Holyfield et al., 2017).

AC has transformed the lives of many nonspeaking people by allowing them to communicate through alternative modalities, leading them to pursue opportunities such as college, writing poetry, and publishing best-selling novels (Jaswal et al., 2020). AC provides the ability for nonspeaking people with ASD to express themselves, which benefits the entire ASD community, including parents.

The purpose of the current study was to give a voice to the parents of people who use AC as a form of communication because they are an integral aspect of the support system for individuals with complex communication challenges. We seek not to validate the authenticity of what is being communicated but rather to understand the lived experience of families and how the engagement in deeper, more sophisticated communication opportunities, such as those afforded through AC, has influenced the parent-child relationship. If AC provides parents with opportunities to have a more complete understanding of, and a deepened relationship with, their child, then it must be of considerable value.

Theoretical Framework

AC allows people to communicate their opinions and feelings and enhances access to academic content in a social or learning context. By identifying personal factors, such as volition and habituation, and evaluating performance in these areas, the Model of Human Occupation frames the importance of opportunities for children with ASD to communicate their values, interests, and goals regarding their desired roles in life (Brown et al., 2019; O'Brien & Kuhaneck, 2020). Gaining information on the child's perceptions affords parents insight into their child's values in life because it validates and enhances the relationship dyad.

Method

Study Design

In this phenomenological qualitative study, we examined parents' perspectives on their nonspeaking children with ASD who use AC. The research team consisted of four graduate occupational therapy students, two occupational therapy educators experienced in research methodology, and one clinician occupational therapist who is an expert in implementation of AC. The study was approved by the institutional review board at Dominican University, in compliance with the principles of the Declaration of Helsinki. We built on previously gathered data from a previous study (Damiao et al., 2022) and integrated newly collected data to ensure saturation of content. We recruited participants known to the expert occupational therapist author in the clinical setting. Additional

participants were recruited by means of snowball sampling.

Data for this study were acquired over a 2-yr period. Results from data gathered during the first year were disseminated in a poster. Data gathered from 3 participants in the first year of the study were combined with an additional 7 participants in the second-year period for a total of 10 participants. The data we acquired demonstrated saturation of content.

Participants

Participants received an email with a consent form to confirm their participation in the study, followed by an email to schedule an interview. Inclusionary criteria consisted of (1) parent of a nonspeaking, minimally speaking, or unreliably speaking child (also referred to as having a *complex communication disorder*); (2) with a clinical diagnosis of ASD; and (3) who used either FC, RPM, or S2C to communicate expressively. More specifically, these criteria consisted of parents who described that their child's verbal communication as (1) appeared not to include expressive language, (2) was unreliably expressive and limited to having only basic needs met, and (3) struggled to use it functionally. Exclusionary criteria included parents of children who did not have an ASD diagnosis or parents of children who were capable of functionally using spoken language to communicate their expressive thoughts. Parents of children who were not part of an AC (FC, RPM, or S2C) program were also excluded.

The sample comprised 10 participants. All recruited participants agreed to take part, and therefore the study had no attrition. Participants' socioeconomic status and education levels were not recorded. English was the primary language spoken at home for all participants, and all AC occurred in English. Demographic information is provided in [Table 1](#). [Table 2](#) describes each participant's child's methods of communication.

Procedure

We created guided semistructured interview questions that addressed communication methods in the parent-child relationship, parents' perceptions of their child's intellectual abilities, parents' perceptions of their child's inner thoughts and feelings, and the quality of the parent-child relationship; these questions are listed in the Appendix. Interviews were conducted through a virtual platform and ranged between 15 and 30 min. Two of the authors conducted all interviews, which were then transcribed using an online transcription service and compiled for analysis. To reduce potential bias, journaling was conducted both during and after the interviews.

Analysis

We used an inductive approach to reflexive thematic analysis, as detailed by [Braun and Clarke \(2006\)](#), to

analyze the data. The transcripts were read through to ensure the accuracy of the transcription service. The noninterviewer coinvestigators read through the verified transcripts a second time to complete free coding, during which observations and patterns were noted. The codes were then refined by reading the transcripts a third time. Investigators verified and confirmed each other's transcripts so that all interviews received double coding. All 10 interviews were analyzed together, and 34 codes emerged. After the initial code generation phase, the focus of analysis shifted to the sorting of codes into initial themes, which involved noting how individual codes identified in the previous phase of analysis overlapped or interacted with one another ([Braun & Clarke, 2006](#)). All but the interviewing investigators collaborated through peer debriefing to identify the themes. Themes were reviewed to ensure accuracy and that the themes were reflective of the data set. Four themes, with two subthemes each, were generated.

The noninterviewing investigators journaled their feelings and assumptions to promote reflexivity during data analysis. They discussed and verified the results with the two interviewers to ascertain accuracy in the presence of participants' responses within the themes. Direct quotes were obtained during data analysis and included in this article to illustrate the meaning of the established themes. We ensured that data saturation had been reached by frequently and repeatedly discussing data during the coding and theming processes and found that the data provided a rich illustration of the research query. In addition, we conducted an audit trail to explain how data were analyzed so the process could be replicated by future researchers or reviewers. All authors were involved in discussions and reviewed the existing literature for similarities in data to achieve rigor.

Results

Most participants described AC being used with one or more parents and, on some occasions, by teachers. Most reported learning AC through a private practitioner. For some participants, the child used AC with a classroom aide, but some experienced resistance from the school districts in providing such a service. In almost all cases, participants were either provided AC services through a practitioner in a private special education setting or through private AC practitioners as recommended either by friends or people in the community or a developmental pediatrician.

All participants described communication through AC as being limited to few individuals. Most described themselves and the parents as main AC partners, including either a trained practitioner, an occupational therapist, a community habilitation worker, and, in one case, the child's special education aide.

Analysis of the data resulted in four superordinate themes, each with two subthemes: Relationship (subthemes: Involving the Child, Improved Relationship), Future (subthemes: Hopes and Dreams, Planning),

Table 1. Participants' Demographic Information

Participant Name	Child's Age, Yr	Diagnosed By	AC Modality	Experience With AC, Yr
Rosie	24	Psychiatrist	RPM	2
Nora	21	Psychologist	S2C	1
Christina	22	Diagnostic team	S2C	<1
Marie	22	Physician	S2C	14
Sonia	36	Neurologist	FCT	4
Linda	20	Neurologist	FCT	2
Paula	16	Neurologist	S2C	5
Jennifer	15	Neurologist	FCT	4
Sharon	17	Neurologist	RPM	6
Kristy	16	Neurologist	FCT	2

Note. AC = assisted communication; FC = facilitated communication; RPM = rapid prompting method; S2C = spelling to communicate.

Support (subthemes: Limited Availability of Service Providers, Underestimation), and Understanding (subthemes: Communication, Deeper Understanding of the Child). Themes and resulting subthemes are listed in the Appendix. In the sections that follow, each theme and subtheme are discussed alongside participant quotes. All names are pseudonyms.

Theme 1: Relationship

This theme represented the parents' perspective on how their relationship with their child was affected by AC.

Involving the Child

Some parents reported that they involved their child more after the child began using AC. Some parents

reported "making decisions" (Nora, Rosie) for their child before AC, but afterward they "include[d] [them] in conversations" (Sonia). Parents may have made decisions without involving their children, but after having AC as a method of communication, parents felt they involved their children more in daily decisions and activities: "Before, I was making decisions for him because it was what I thought he might want" (Nora).

Improved Relationship

A majority of the parents reported that their relationship with their child changed after the child began using AC. Some parents, said they felt they had always been "close" (Paula, Sonia), but after using AC they reported that the relationship became "closer" (Sonia, Rosie, Jennifer), "changed" (Nora), or was "different" (Paula, Jennifer) because of their child using AC to communicate. One parent revealed that "We were always close . . . but we know each other now in a different way" (Paula).

I always felt close to him, but I would say that it's definitely closer, and I know more about who he is and the way he thinks. . . . We're actually spending more time together because there's a way to interact. . . . Before it was like, conversations were so difficult that we kept them to a minimum and I didn't want to stress him out all the time, but, you know, we share so much more together now. (Sonia)

Improvements in the parent-child relationship were also noted by several parents who stated that they "know" (Sonia, Paula) their child in a different way now. Kristy expressed that AC helped her learn her son's inner thoughts, which improved their relationship:

I just learned my son now, now we have a relationship. Now he can tell me what his needs are, his opinions, his feelings, his thoughts, and he has complex thoughts. Now it's almost like . . . he feels like he has been freed from a prison. (Kristy)

Table 2. Description of Communication Methods

Participant	Primary Communication Method
Sonia	Can verbalize basic needs only. Uses AC to communicate expressively.
Nora	Minimally verbal ("yes"/"no"). Uses AC to communicate expressively.
Paula	Minimally verbal ("more"). Uses AC to communicate expressively.
Christina	Has memorized some verbal phrases. Uses AC to communicate expressively.
Marie	Can verbalize basic needs. Uses AC to communicate expressively.
Jennifer	Minimally verbal. Uses AC to communicate expressively. Verbal communication has improved since implementation of AC.
Rosie	Minimally verbal. Uses AC to communicate expressively.
Linda	Verbalizes 2- to 3-word verbal sentences. Uses AC to communicate expressively.
Kristy	Makes 1-word utterances. Uses AC to communicate expressively.

Note. AC = assisted communication.

Theme 2: Future

This theme represented how the parents' perspective on their child's future had changed as a result of AC.

Hopes and Dreams

According to the parents, they had a limited understanding of their child's hopes and dreams before using AC. However, after using AC, parents reported they may know what is "possible" (Sonia) or the "possibilities" (Linda) for their child. A majority of the parents expressed that they now know what their child "wants for their future" (Marie, Jennifer, Kristy, Sharon, Paula, Christina), such as desires for "college" (Kristy, Sharon, Marie, Christina), "friends" (Marie, Kristy), "a job" (Linda), or even "family" (Kristy) and "marriage" (Linda). With AC, parents reported understanding their child's dreams, which gave both parents and the child a sense of hope for the future: "I now know what his hopes and dreams are. . . . So, we're in a position now to pursue them, whereas before it was all too ambiguous, just too unknown" (Linda).

There's just so much hope now for the future and what she can become, after what she's accomplished and what we've helped her accomplish. I feel like the sky's the limit. . . . So, it's changed the dynamic of our whole family and how we all interact with each other. (Paula)

Planning

Parents explained that AC greatly affected their ability to plan for their child's future. Two mothers stated that they could now "plan for [their] future" (Rosie, Nora). One parent stated that their child's use of AC influenced the type of care they would seek for their child:

I would say [that] if this did not happen, we were already probably a year or two away from finding a permanent residential solution for him, which now, you know, we can't do that to him. We would know that these are so inappropriate for him . . . it's almost like . . . committing him to a life of not having the appropriate . . . communication abilities or opportunities. (Rosie)

Other parents expressed that there were limited suitable options for their children in the future because staff need to be trained in AC. One parent spoke about planning for their child's future "before I die" (Nora), such as ensuring that their child has communication partners who will be "trained" (Nora, Marie) to use AC modalities. Another parent (Rosie) spoke to the "complexity" of her child's needs. One parent expressed a fear of planning for their child's future before the child began using AC because they did not have the means to communicate with and understand their child's goals and dreams: "It feels very hopeless to know that you have a child who won't have a future, whose safety will be endangered when you die. And that's a terrifying way to live . . . really scary" (Paula).

Theme 3: Support

This theme described the parents' perspective on how the relationship with their child was influenced by the availability, or lack, of support with using AC and underestimating the child's abilities.

Limited Availability of Service Providers

Some of the participants' children were older than the individualized education program (IEP) school-age setting and thus participated in AC mostly in the home context. However, all participants, to some degree, expressed a lack of support in integrating AC into other contexts, whether it be educators (Nora, Marie, Kristy, Jennifer, Sharon), the community (Linda, Christina, Kristy), or staff (Marie, Linda, Kristy, Rosie, Sharon). Several described the impetus of these integration challenges as being directly related to the polarizing nature of AC modalities (Linda, Sonia, Kristy) and an overall lack of knowledge (Paula, Kristy). This was noted mostly in the context of children receiving services through public school districts. Although U.S. public school districts readily fund the use of AAC devices, along with the typical gamut of special needs services, AC is often met with systematically firm resistance. Sonia described her child's early experience:

We tried [AC] briefly when he was 6; it was in the '90s, and it was like the big rage at that time. And we learned it, and his teacher learned it, and his speech therapist learned it, and we did it for just a few months, and then there was all this controversy and the school pulled it.

Moreover, most parents noted the immense effort required on the educators' part to learn the AC modalities and implement them into the child's academic life. Overall, there is a lack of knowledge and trained staff to readily support the use of AC outside of the home. Kristy described the frustration she felt when advocating for AC in the classroom for her child:

My only frustration is trying to make these educators understand. There's a lot of them, I think that they are afraid to try the "new thing." Maybe because their jobs are on the line. I understand that, but these kids have to be reached, and it was very hard to get this on his IEP.

Some participants felt an overwhelming amount of "frustration" (Kristy, Sonia) and "hopelessness" (Paula) before using AC with their child. Participants discussed their feelings of "loneliness" (Linda) before using it and a general lack of direction in how to help their child:

I felt so powerless before, completely powerless to effect any sort of impact or change in her life. I couldn't get anyone to listen to me. I didn't even know what she needed, so I didn't even know what to ask for. I knew nothing was going well, so I felt totally powerless. (Paula)

Participants who expressed success in receiving support with AC were accessing these services either through private practice-trained facilitators and practitioners or through AC-trained therapists:

We tried to bring [the AC device] back home and duplicate it, but it never really happened because we didn't have the support of the school. We could never find anyone here in our town to help us; the school would not help us . . . even though we showed them videos of her doing that at the clinic. (Marie)

Linda further described the challenges she faced in receiving these services for her son:

It's quite frustrating . . . the school that he was in . . . he used to be able to go and really, you know, they were having poetry jams and it was really exciting for awhile . . . and then one administrator . . . pulled the plug on it.

Underestimation

Participants also described underestimation of their child's abilities on the part of educators and professionals before AC. Many participants believed that their child did not receive the education that appropriately represents their "true intellectual abilities" (Rosie, Kristy, Linda, Nora, Paula). The educators and professionals involved identified the child as having a much lower intellectual ability than what the child was capable of:

I always thought he was smarter, and that's why I pushed. . . . He only learned to read because I hired a tutor. [The] school didn't want to teach him to read: "Why are you wasting your time with that? He's not going to do it." That's what they said. (Nora)

Participants also felt that their child's dignity was jeopardized by those who underestimated their abilities. There is a common misconception that if nonspeaking children cannot verbally express their wants, needs, and desires then they are "not capable of having these same thoughts" (Kristy, Linda, Rosie, Marie). According to the participants, this misconception was widely rejected after AC began to be used. One participant explained, "I think, throughout their lives, they've not been taken seriously about having anything to communicate about and that [if] they had nothing to communicate, that there was nothing going on in their heads" (Linda).

Theme 4: Understanding

This theme represented the parents' perspective on how the relationship with their child was affected by using AC to establish more precise communication and a deeper understanding of their child.

Communication

Several participants reported that having a clearer, more direct line of communication that was not available before AC had allowed them to become "better parents" (Rosie, Kristy, Nora). As a result, these parents

believed they now genuinely consider their child's perspective and needs before making decisions for them. One participant described their initial experience of using AC with their child: "When I started to communicate with him through facilitated communication for the first time, I was able to penetrate into what was going on in my son's heart and mind" (Linda).

Deeper Understanding of the Child

Participants reported that AC has allowed them to "understand who their child is" (Kristy, Linda, Sharon, Nora) and get to know them in such a way that they had never had the chance to before. One participant expressed the feelings of validation she received regarding their intuitions about their child's persona:

Every new day I'm learning . . . who she is and what she's thinking. And it's very often surprising . . . some of my projections . . . guesses . . . were not right. And other things were right. . . . But she's her own person. (Sharon)

This deeper understanding provided the parents with essential insight that ultimately led to better planning for their child's future by considering their true essence. One participant described how this deeper understanding had allowed their child to become more involved in their own future: "I feel like I understand him more. And I feel like I can better plan for his future because he can now really have a voice in that" (Nora).

Other participants reported that this process has allowed them to "feel closer to their child" (Paula, Sonia, Marie, Rosie, Kristy) through the validation of their beliefs concerning their child's true interests, values, needs, and personality:

It's what I knew she was, but I didn't really know who she was. . . . She's really sassy . . . fresh . . . sweet. I had no idea how intelligent she was . . . how many words she had, but her personality is what it was. (Marie)

Discussion

In this study, we investigated the experience of parents who have a child diagnosed with ASD and the impact of AC on their relationship. The first theme, Relationship, reflects a narrative that AC modalities are intrinsic to the experience of parenting and leads to an improvement in the parent-child relationship. AC allows parents to have a communication outlet with their children in ways that work specifically for their child. The second theme, Future, reflects the difficulties participants experienced before using AC when they were planning for their child's future and the influence of AC on recognizing and supporting their child's hopes and dreams. The third theme, Support, highlights the limited availability of trained service providers, which created a barrier to communication and self-expression from the child. The fourth theme, Understanding, represents the impact of the child's

ability to use AC on establishing profound parent–child communication and enabling a deeper understanding of their child. In the following sections we discuss each theme, describing how these findings relate to and extend existing knowledge.

Relationship

This theme explores the fragility of the parent–child relationship when the child cannot verbally communicate with the parents (Del Bianco et al., 2018). This lack of communication often results in parents reporting elevated stress levels related to parenting because they rely on their instinctual understanding of their children to meet their needs (Dugdale et al., 2021). The work of Del Bianco et al. (2018) aligns with this theme in confirming that communication influences the development of a positive relationship between parents and children with ASD. Participants described the importance of involving their children in conversations, discussions, and choices to promote autonomy, a sense of independence, and freedom, which created the foundation for a positive parent–child relationship.

Children with ASD often require support to develop communication skills and access to social opportunities. When they are deprived of social opportunities they are at higher risk for lack of independence, poor mental health, social inclusion, and interpersonal relationships (Arias et al., 2018; Gómez et al., 2020; Oakley et al., 2021). Previous findings suggest that satisfaction in interpersonal relationships between the child and parent can improve self-confidence and familial relationships (Del Bianco et al., 2018). In the current study, participants initially described relying on intuition to meet their children’s needs. After using AC, however, all of them reported newly acquired insight to support their child’s needs, interests, and dreams.

Future

Parents felt that using AC modalities with their children helped them plan and prepare for their child’s future with greater self-efficacy. For many parents of a child with ASD, concerns for future planning are prominent and can cause considerable stress and anxiety (Dugdale et al., 2021; Topan et al., 2019). Participants in the current study expressed great concern about planning for their child’s future after they have died, which is consistent with contemporary research (Finke et al., 2019). Despite these concerns, the opportunity to communicate with a nonspeaking child may lighten the emotional and cognitive burden experienced by caregivers. Our findings suggest that using AC helps parents better plan for their child’s future care, such as where their child will live and future educational or vocational prospects.

Moreover, using AC helped parents understand their child’s hopes and dreams for their own future, enabling the parents to support and pursue their child’s endeavors. Participants reported that when

their child could communicate expressively using AC, their ability to plan for the future emerged. This perspective supports existing literature that proposes that the ability to plan for the future is associated with greater caregiver satisfaction (Burke & Heller, 2016).

Support

This theme emphasizes the lack of agreement concerning the implementation and education of AC in the ASD community. It also defines the participants’ underestimation of their child’s abilities before using AC. Our findings suggest that limited support while using AC, whether in the home or when speaking to educators, leads to delayed communication between the parents and their children (Babb et al., 2021; Dugdale et al., 2021). After using AC modalities, parents reported positive outcomes related to stress levels, frustration, and helplessness, all of which have been illustrated in previous research (Richardson et al., 2019; Ryan et al., 2018).

Participants felt that professionals and educators working with their children often underestimated their child’s abilities and potential. They noted a lack of understanding of their child as well as preconceived notions of AC, often leading to a misinterpretation of their child’s abilities by these experts. Previous research indicates that a limited availability of adequately trained service providers endangers the self-esteem of children with ASD, which is congruent with the current study (Dugdale et al., 2021; Sturrock et al., 2022). Moreover, participants spoke to the misconception that stereotypes nonspeaking children with ASD as incapable of expressing their needs, which has been reflected in previous studies (Dugdale et al., 2021; Leedham et al., 2020).

Understanding

This theme represents the impact of the child’s ability to use AC to establish profound parent–child communication and a deeper understanding of their child. Prior research shows that parental efforts to perceive their child’s needs generate a sense of helplessness associated with their attempts to understand their child (Del Bianco et al., 2018). However, our findings support the notion that having a more transparent line of communication between the parent and child ultimately leads parents to develop a more insightful understanding of their child.

Existing research also claims that impaired social functioning in children with ASD limits their verbal communication, affecting the evolution of meaningful relationships (Laugeson et al., 2015). The current study outlined parents’ feelings resulting from a deeper understanding of the child, which included validating their beliefs regarding their child that birthed a newfound parent–child connection. Participants concluded that this connection allowed them to be “better

parents” by allowing their children to plan for their own future.

Limitations

Socioeconomic and demographic information was not gathered beyond what is reported in Table 1. AC services can be costly; many participants sought these services through private practitioners. Thus, the experiences reported in this study reflect those who were able to obtain such services. Moreover, the participants who were willing to share their experiences may present a positively biased viewpoint regarding AC, and people with negative experiences may have stopped receiving AC services or may have been less likely to respond to the request to participate in this study.

Limitations of this study include lack of member checking in the data analysis process. Another potential limitation may be the lack of a quantitative component to support the findings with statistical measures because of the subjective nature of qualitative research. Although this study was intended to investigate both positive and negative outcomes, the interviewers could have explored more deeply the limitations and challenges associated with AC.

Implications for Occupational Therapy Practice

The varied literature and position statements from various health care communities and associations suggest that AC is a debated topic. Thus, we purposefully avoided approaching this research through the lens of validation; instead, the present findings reflect an investigation of the lived experience of parents and the impact AC has had on the relationship between parent and child users of AC. This study adds evidence that use of AC modalities strengthens the parent–child relationship and parents’ sense of well-being. Parents play a key role in an individual’s team and in their occupational areas and performance patterns; therefore, AC modalities are an important consideration for implementing rigorous client-centered, strengths-based occupational therapy services.

On the basis of the present findings, professionals who work with individuals with ASD, such as occupational therapists addressing the occupation of communication management (AOTA, 2020), can provide vital insight into how improved communication tools can enhance opportunities for children with ASD and their caregivers. This study also provides insight for key stakeholders, such as the parents of children with ASD and people in the ASD community. AC modalities offer numerous benefits in supporting and enhancing community engagement, autonomy, and social participation. Occupational therapists should explore the evidence and then assess how it relates to the needs of the individual clients and families. This can help support

the profession’s call for a paradigm shift to a strengths-based, person-centered model.

The occupational therapy lens can play an important role toward unifying the viewpoint at the level of the individual client. The occupational therapist’s holistic and systems-oriented perspective is particularly essential when collaborating with speech therapists to integrate communication throughout the various occupational contexts. Although it is important to understand the current literature on the efficacy of AC, we must also consider the individual client, context, and social dynamics, because these factors play a significant role in determining the occupational effectiveness of services. Thus, it is important for occupational therapists to collaborate with existing service providers in ensuring that communication needs are being met; they are also critical in seeking out additional supports and services to assure successful carryover across occupations.

Directions for Future Research

The lack of consensus regarding AC points to the need for improved research methodologies and intervention practices that would benefit both parties while also encouraging health care providers to take a more unified approach. Future research may benefit from involving the perspectives of adolescents and adults with ASD. Future studies should further aim to explore the challenges associated with AC use. Therefore, further investigations to evaluate the influence of AC on the parent–child relationship are needed.

Conclusion

In the current study, we explored parents’ perspectives on the relationship between their child with ASD before and after using AC. Although a growing body of research supports the legitimacy of AC, there continues to be a lack of professional agreement regarding its use. The current study offers insight into the relationship between parents and their nonspeaking children with ASD who use AC. The themes illustrated in this study included Relationship, Understanding, Future, and Support. Despite the lack of consensus surrounding AC, this study illustrates that it helped parents understand and communicate with their nonspeaking child, and felt an improvement in their relationship, and could therefore become a better advocate for their child.

The parents’ lived experience appears to be an illuminating viewpoint, which has seldom been explored in relation to AC. This perspective is paramount to obtaining appropriate services for children with ASD because it may influence the quality of the care provided and thus the quality of life experienced. Although the autistic voice is essential to the role research plays, it is also important to learn from the caregiver perspectives and experiences, as a supplement to the growing body of knowledge. 🌱

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John Damiao, PhD, MS, OTR/L, is Assistant Professor, Occupational Therapy, Pace University, Westchester Campus, Pleasantville, NY; johndamiao1@gmail.com

Galilee Damiao, MS, OTR/L, is Occupational Therapist, Chestnut Ridge, NY.

Catherine Cavaliere, PhD, MS, OTR/L, is Associate Professor, Occupational Therapy, Dominican University of New York, Orangeburg.

Susanna Dunscomb, is Occupational Therapy Student, Occupational Therapy, Dominican University of New York, Orangeburg.

Kirsten Ekelund, is Occupational Therapy Student, Occupational Therapy, Dominican University of New York, Orangeburg.

Renee Lago, is Occupational Therapy Student, Occupational Therapy, Dominican University of New York, Orangeburg.

Ashley Volpe, is Occupational Therapy Student, Occupational Therapy, Dominican University of New York, Orangeburg.

Appendix

Interview Questions

- How old is your child?
- Was your child given an autism diagnosis by a physician?
- What is the predominant language spoken at home?
- What type of AC does your child use (RPM/supported typing/other)?
- Do you consider this AC method to be your child’s primary method of communication?
- How long ago did your child start using this method?
- How did you hear about the program? Was it recommended, or did you request it?
- If you were wanting it for your child, was it difficult to find a place that could provide the program?
- Do you practice AC in the home? How often? Daily? Weekly?
- Please describe your child’s communication impairment.
- In terms of intellectual abilities, describe how your child’s AC skills have impacted your perception of their intellectual abilities compared with before they began the program.
- How has your relationship with your child been impacted by your child’s use of AC?
- How has your ability to communicate with your child changed?
- Do you feel you have a closer relationship with your child?
- How have your hopes and dreams for your child been affected?
- What is your ability to be responsive to your child’s emotional needs with use of AC compared with prior?

17. What is your perception of your child's personality/thoughts with use of AC compared with prior?
 18. Do you feel successful as a parent with AC compared with prior? What is your frustration level with parenting with AC compared with prior?
 19. What is your child's ability to be calm and regulated during their daily interactions?
 20. Does your child have maladaptive behaviors and has that been impacted by the program?
- Note.* AC = augmented communication; RPM = rapid prompting method.

Themes and Subthemes

1. Relationship
 - a. Involving the Child
 - b. Improved Relationship
2. Future
 - a. Hopes and Dreams
 - b. Planning
3. Support
 - a. Limited Availability of Service Providers
 - b. Underestimation
4. Understanding
 - a. Communication
 - b. Deeper Understanding of Child