

Communication in Autism Spectrum Disorder: A Guide for Pediatric Nurses

Amanda B. Brown and Jennifer H. Elder

Children with autism spectrum disorder (ASD) represent a large and growing group of the pediatric population in the United States (Rice, 2009). The most recent data reveal that as many as one in every 68 children in the United States has been diagnosed with ASD, a 78% increase in prevalence in six years (Centers for Disease Control and Prevention [CDC], 2014). ASD is a developmental disorder of the brain characterized by impairments in social interaction, communication, and repetitive patterns of behavior (American Psychiatric Association [APA], 2003). Providing care to patients with ASD has been described as challenging (Phillips & Phillips, 2010) and daunting (Searcy, 2001). There are case reports of patients with ASD who required prolonged sedation during hospitalization just to allow for proper treatment (Allison & Smith, 1998; Bindner, Hardin, & Berkenbosch, 2008).

Communication with patients is necessary to provide quality nursing care. Impairments in communication are a hallmark of ASD. Clinical presentations vary considerably. The portion of people with ASD who never develop functional communication has been estimated to be between 20% to 50% (Tager-Flusberg, Paul, & Lord, 2005). To provide high quality nursing care to children with ASD, nurses need to understand how communication typically develops and how this differs in children with ASD,

In the United States, one in every 68 children has autism spectrum disorder (ASD) (Centers for Disease Control and Prevention, 2014). ASD is a developmental disorder of the brain that is characterized by impairments in social interaction, communication, and repetitive patterns of behavior (American Psychiatric Association [APA], 2013). Nurses have a duty to provide high quality care to children with ASD. Effective communication is essential to providing quality care. Three main theories attempt to explain how the ASD brain functions and the implications on communication: lack of theory of mind, weak central coherence, and lack of executive function. Children with ASD have difficulties in vocalic, kinesthetic, and proxemic aspects of communication (Notbhom, 2006). Simple adaptations to environment and style can make the communication between nurses and children with ASD easier and more effective (Aylott, 2000; Green et al., 2010).

theoretical perspectives of ASD and their implications for communication, and practical applications that can improve the communication process.

Development Of Communication

Communication is the process of exchanging information in different forms with other people. It is not limited to language, but includes non-verbal communication and understanding of symbols (Heflin & Alaimo, 2007). Essentially, communication is decoding a message and being able to code a message for others. The process is complex, but it happens very rapidly (Noens & van Berckelaer-Onnes, 2005).

Typically developing (TD) children progress through three phases of communication. Intentional communication is the use of gestures or vocalizations to get attention or attempt to meet a need or a want. Symbolic communication is the use of early language to interact with others, gain attention, and meet needs. Linguistic communication is the final and most sophisticated phase. This is the ability to engage in full discourse with another using many different forms of communication (Noens & van Berckelaer-

Onnes, 2004; Prizant, Wetherby, Rubin, & Laurent, 2003). Table 1 presents an overview of typical language development.

Development of communication skills begins in infancy. Crying is the very first form of social interaction (Esposito & Venuit, 2010). Through eye gaze and observation of facial expression, typically developing infants begin to form relationships between people and objects and recognize emotion. Infants who are later diagnosed with ASD prefer to look at objects over people, notice parts of objects instead of wholes, and fixate on one item instead of gaze at multiple items (Heflin & Alaimo, 2007; Tager-Flusberg et al., 2005). At six to seven months, infants begin babbling and using vocal utterances in addition to crying to gain attention from others. Infants with ASD do not babble as much, do not seem to be as aware of language, and are often thought to have hearing impairment (Heflin & Alaimo, 2007; Tager-Flusberg et al., 2005). In the final months of infancy, TD infants begin to gesture to express needs or wants. This is a very early form of intentional communication. Infants with ASD tend to use gestures less often and in less meaningful forms of communication (Heflin &

Amanda B. Brown, PhD, RN, CPN, CNL, is an Alumna, University of Florida, Gainesville, FL and Clinical Nurse Leader, Wolfson Children's Hospital, Jacksonville, FL.

Jennifer H. Elder, PhD, RN, FAAN, is a Professor and Associate Dean for Research, University of Florida, Gainesville, FL.

Table 1.
Typical Language and Communication Development

Age	Verbal Milestone	Non-Verbal Milestone
Early Infancy	Crying.	Eye gaze; focus on people and faces.
6 to 7 months	Babbling; vocal utterances to gain attention.	Aware of language around them.
10 to 13 months	First words; begin to recognize the meaning of some words.	Begin gestures such as pointing and waving.
16 months	Using single words with intention.	Gestures become more refined, used with intention, and paired with words.
18 to 24 months	Begin to ask and answer questions, understand the reciprocity of conversation.	Motor imitation after adults and other children in complex actions; beginning of joint attention.
24 months	Uses two word phrases.	Engage in joint attention.
3 to 5 years	Continue to develop in complexity, use full sentences.	Symbolic play becomes more complex.

Sources: Helfin & Alaimo, 2007; Sowden, Perkins, & Clegg, 2008; Tager-Flusberg et al., 2005.

Table 2.
Language Characteristics of Autism Spectrum Disorder (ASD)

Term	Definition	Example
Echolalia	Children repeat what has been said to them either immediately or after some period of time.	Parent: "Do you want a drink?" Child with ASD: "Do you want a drink?" Child with ASD repeats question instead of providing an answer.
Contact gestures	Children use other people as a tool to get what they need or want. The gesture is not symbolic.	Child with ASD grabs adult's hand without making eye contact and drags to the television to get the adult to change the channel.
Pronoun reversals	Children use first (I, me) and second pronouns (you, he, she) incorrectly.	Child with ASD: "You want to go to the park." TD child: "I want to go to the park."
Neologisms	Children assign meaning to a word or phrase that is not the socially accepted meaning.	Child with ASD is given popcorn during a movie about a dog named Rebel. The next time the child wants popcorn, he/she asks for "Rebel." The word Rebel is a neologism for popcorn.

Sources: Helfin & Alaimo, 2007; Noens & van Berckelaer-Onnes, 2005; Notbohm, 2006.

Alaimo, 2007; Sowden, Perkins, & Clegg, 2008; Tager-Flusberg et al., 2005).

Toddlers and preschoolers engage in three types of behaviors that help in development of communication, social, and language skills. Participation in motor imitation, joint attention, and symbolic play are essen-

tial for skill development. Motor imitation begins before language skills. Children begin to imitate the actions they have observed in other people. In order to imitate actions correctly, precisely, or in the right context, children must be able to ascribe to the other person an intention for them to act. They have to form a concept of

the other person's mind. Children with ASD may be slow to imitate or may inaccurately imitate behaviors because they miss the meaning of symbols or behaviors or they attribute intentions inaccurately (Helfin & Alaimo, 2007; Tager-Flusberg et al., 2005).

Joint attention is the ability to engage in interaction with others. Children can see what another is interested in and gain another's attention in that action or activity. The social interaction includes sharing of emotions and reciprocal exchange of information. These continued interactions with peers and adults contribute to language development (Aylott, 2000; Bolick, 2008; Noens & van Berckelaer-Onnes, 2005; Prizant et al., 2003). The extent that children with ASD engage in joint attention play is thought to be a predictor of future communication skills (Tager-Flusberg et al., 2005). Children with ASD are less likely to request joint attention or respond to another's request for joint attention (Bolick, 2008; Chiang, 2008; Helfin & Alaimo, 2007).

Symbolic or object play in childhood helps to develop symbol representation and is critical to development of language skills. Pretend play with objects develops naturally and becomes more complex over time for TD children. The understanding of symbols contributes to the comprehension of language. Children with ASD are far less likely to participate in symbolic play (Helfin & Alaimo, 2007; Noens & van Berckelaer-Onnes, 2005; Prizant et al., 2003).

Children with ASD who develop functional communication often display atypical communication styles, such as echolalia, contact gestures, pronoun reversals, and neologisms (refer to Table 2 for definitions). It is likely that these develop because these children have a limited understanding of the meanings and intentions of symbolic forms of language (Helfin & Alaimo, 2007; Noens & van Berckelaer-Onnes, 2005). Often, these children have the vocabulary and even have memorized the syntax to pass standardized language screenings, but they struggle in real world communication settings because they lack true understanding of meaning (Paul & Wetherby, 2005; Tager-Flusberg et al., 2005).

The impairments in ASD are often described as qualitative impairments (Noens & van Berckelaer-

Onnes, 2004). Garcia-Perez, Lee, and Hobson (2007) reported that when matched for age and developmental language level to peers with mental retardation, 12 children with ASD were very comparable in objective measures of communication, such as head nodding or shaking while speaking, looks to the interviewer, and total number of smiles, but they scored significantly lower on subjective measures of communication, such as engagement and conversation flow. Children with ASD may use language to meet needs and respond to questions, but tend to make comments less often (Jones & Schwartz, 2009). They use language as a functional tool, such as for requesting items (Chiang & Lin, 2008). In fact, they may not anticipate engagement at all and tend to declare or express their needs or wants without any expectation for others to engage (Noens van Berckelaer-Onnes, 2004).

The frustration of being unable to communicate with others can lead to behavioral outbursts in some children. These behaviors have a wide range of expression and can be aggressive physical behaviors, self-harming behaviors, or loud vocalizations. These challenging behaviors are proposed to be a form of communication when there are breakdowns in the process and the children are not getting their needs met (Bronsard, Botbol, & Tordjman, 2010; Chiang, 2008; Noens & van Berckelaer-Onnes, 2004).

Theoretical Perspectives

Three main theories attempt to explain how the ASD brain functions. The *lack of theory of mind* argues that children with ASD are unable to recognize that other people have independent mental states. They may believe that everyone thinks just like they do, or they may simply not be able to comprehend that others hold their own motivations for action. Also referred to as mind-blindness, it can leave the child with ASD confused about the actions of others. This lack of theory of mind is manifested in a lack of empathy, inability to enter reciprocal relationships, or lack of desire to maintain relationships. The lack of theory of mind may explain why children with ASD have difficulty participating in natural language development activities, such as model imitation, joint attention, and symbolic play (Barnbaum, 2008; Baron-

Cohen, 2009). Theory of mind provides a rationale for many of the pragmatic issues with communication children with ASD experience (Baron-Cohen; Noens & van Berckelaer-Onnes, 2005).

The *weak central coherence theory* describes a mind that only sees information in parts and not wholes. Information is stored and retrieved separately. It is specific and not generalized to other situations. The ASD mind has a preference for processing pieces of information instead of extracting the larger meaning of the information (Happè & Frith, 2006). Communication requires many pieces of information from different sources to be quickly analyzed and contextualized; therefore, a weak central coherence can be detrimental. Noens and van Berckelaer-Onnes (2004, 2005) argue that this theory best explains all the communication deficits, both expressive and receptive, found in ASD. It can also explain delayed echolalia or the use of neologisms seen in ASD. Children with ASD do not recognize the meaning of the entire message, including its context, the first time. They instead focus on a portion of the message, possibly a phrase. Later, they may repeat that phrase, attempting to capture the meaning and context of the first message, but their recalled portion of the message is not enough to be meaningful to others.

The *weak executive function theory* holds that the ASD mind has impaired executive function. Executive function allows a person to plan, organize, multi-task, make high-level decisions, and override or inhibit automatic behaviors or impulses. It permits for flexibility in thinking and learning. Without executive function, it is difficult to change thinking after a concept has been learned (Barnbaum, 2008; Perner & Lang, 2000). Communication requires a great deal of flexibility and adapting over time as language continues to increase in complexity (Prizant et al., 2003). An example of communication impairment in ASD is pronoun reversal. After children with ASD hear "Do you want water?" and then receive water, it is difficult for them to adapt their communication when making a request. So the children repeat what they first heard "You want water" instead of stating "I want water."

Practical Applications

Children with ASD have difficulties in vocalic, kinesthetic, and proxemic aspects of communication (Notbohm, 2006). Vocalic communication is the nuances of language, including the inflection of tone, non-literal language, sarcasm, puns, and idioms. Children with ASD may be unable to understand messages in a vocalic context. Body language, facial expressions, and gesturing make up kinesthetic communication and are often not understood by children with ASD. These non-verbal aspects of communication are frequently not recognized as important signals. Proxemic communication, the concept of personal space and boundaries, also presents challenges (Helfin & Alaimo, 2007; Notbohm, 2006). Overall, children with ASD have difficulties sending and receiving messages (Helfin & Alaimo, 2007; Notbohm, 2006; Scarpinato et al., 2010).

Communication Skills History

Obtaining a thorough history of communication skills with the parent or caregiver should be given priority when caring for patients with ASD. Their input is essential to knowing the best way to communicate with their children. Table 3 includes important information to include in the history.

When assessing communication skills, it is important to remember that children with ASD may have more words in their vocabulary than they can understand (Hudry et al., 2010). It is also imperative not to assume that non-verbal children with ASD cannot understand any language; thus, the nurse should attempt to communicate, even if there is no indication that the children understand. The nurse should not presume that non-verbal children have a low IQ. Reports on the prevalence of intellectual disability in ASD vary widely, with earlier data suggesting up to 75% of people with ASD also have intellectual disability (Charman et al., 2011). More recent data suggest that the prevalence may be much lower (31%), with the majority having only a mild intellectual disability (CDC, 2014; Charman et al., 2011; Matson & Shoemaker, 2009). Case reports exist of persons who gained communication function after many years and have shared their experience of being treated as if they could not under-

Table 3.
Communication Skills History Questions

• Are there known sensory issues?
• How does the child communicate now?
• What is the child's developmental level?
• Does the child use any augmentative or assistive devices?
• Is the child able to follow directions?
• How are behavioral outbursts best handled?
• What is successful in other situations?
• What are the child's strengths in communication?

Note: Blake, 2010; Scarpinato et al., 2010; Seid, Sherman, & Seid, 1997; Souders, Perkins, & Clegg, 2008; Thorne, 2007; van der Walt & Moran, 2001; Vaz, 2010.

stand language simply because they could not express themselves (Aker, 2010; Mirenda, 2008; National Autistic Society, 2003; Schoener, Kinnealey, & Koenig, 2008).

Sensory Impairments

Sensory impairments are present in as many as 80% of persons with ASD (Heflin & Alaimo, 2007). The sensory system may be hypersensitive in some areas and hyposensitive in others. Many repetitive behaviors in ASD may actually be adaptive behaviors for the sensory differences that are being experienced. Often, children with ASD are very sensitive to smells. They usually have difficulty with auditory processing and respond best with visual communication methods. Tactile defensiveness may be present and is caused by a very low threshold for tactile stimulation. Vestibular and proprioceptive systems are also affected and may account for the clumsy behavior often described in individuals with ASD. Due to differences in their brains, they are unable to filter and prioritize sensory signals. For example, blocking out background noise may be difficult, or they may use peripheral vision to focus on people or objects because having the eyes focus directly forward provides too much sensory information at one time (Heflin & Alaimo, 2007; Notbhom, 2006).

Knowledge of sensory impairments is an important key to communicating successfully with patients with ASD. These impairments can overwhelm their systems and make it difficult for them to focus on the communication task, and may also exacerbate behavior problems that

further impede effective communication (Vaz, 2010). Reducing the total amount of stimuli that persons have to process during the communication interaction allows them to remain more focused (Aylott, 2000). Finally, one must assess the environment for possible sensory barriers (Aker, 2010). The following environmental factors may cause sensory overload or be a distraction (Aylott, 2008; Bolick, 2008; Murphy, Colwell, Pineda, & Bryan, 2011; Vaz):

- Lights: Especially bright or flashing.
- Noises: Any sound level can be distracting, call systems, monitor beeps, ringing phones, or a noisy waiting room.
- Textures: Unfamiliar sheets, bandages, paper on exam table, tongue depressor.
- Smells: Alcohol wipes, cleaning solutions, blood.
- Non-verbal behavior: Touching the patient, gesturing.

Sending and Receiving Messages

Simple adaptations to environment and style can make communication easier for children with ASD (Aylott, 2000; Green et al., 2010). The visual pathway is usually the preferred sensory pathway for children with ASD and visual adaptations can facilitate better understanding. Visuals can include pictures of objects, videos of procedures or processes, time lines, or modeling of behavior (Arthur-Kelly, Sigafos, Green, Mathisen, & Arthur-Kelly, 2009; Notbhom, 2006; Scarpinato et al., 2010; Vaz, 2010). Speakers should slow their speech and look directly at the child

using low tones (Bolick, 2008; Green et al. 2010; Scarpinato et al.). It is also important to keep the subject focused on one topic at a time and break explanations into chunks of information to allow for adequate processing (Bolick, 2008; Notbhom, 2006). The nurse should be direct, make direct requests and avoid making comments and expecting immediate responses. Although asking questions may be necessary to gain more information, the nurse should be mindful that open-ended questions are difficult for children with ASD to process (Bolick, 2008; Jones & Schwartz, 2009; National Autistic Society, 2003). Language should be concrete with simple sentence structures and without metaphors, slang, analogies, and exaggerations (Bolick, 2008; National Autistic Society, 2003; Notbhom, 2006; Scarpinato et al., 2010). Patience is required to and allow for adequate time to communicate (Aker, 2010; Blake, 2010; National Autistic Society, 2003). Table 4 describes practical applications for nurses when communicating with children with ASD.

When receiving communication from children with ASD, the most important factor is to allow them adequate time to process information and formulate a response (Aylott, 2000; Browne, 2006; Green et al., 2010). Differences in the communication style children with ASD should be considered. They may have little to no recognition of personal space, no or very little eye contact, use phrases or idioms incorrectly, and be unable to predict the type of response desired (Browne, 2006; National Autistic Society, 2003; Phillips & Phillips, 2010). Communicating requires being fully engaged during the interaction and carefully listening to words and observing for behaviors that may be attempts to communicate (Aker, 2010; Bolick, 2008; Vaz, 2010).

Some children with ASD may use Alternative or Augmentative Communication (AAC), which are strategies to help increase communication in children with impairments. Children who use AAC may experience greater gains in verbal language and there is little risk for loss of speech (Schlosser & Wendt, 2008). AAC may be aided or unaided. Aided AAC requires the use of some type of external equipment; unaided AAC does not (Mirenda, 2003). Different types of AAC include the use of sign language, visual pic-

Table 4.
Practical Applications

History	Obtain thorough history. Recognize that child may have larger vocabulary than he or she understands.
Sensory stimuli	Decrease overall sensory stimuli. Consider lights, noises, textures, smells, and your own non-verbal behavior.
Sending messages	Use visuals as much as possible. Slow your speech, look at the child, and speak in low tones. Keep the subject focused on one topic at a time. Break explanations into chunks of information to allow adequate processing. Allow the child time to process the information. Use concrete language; avoid sarcasm; metaphors, slang, and exaggerations. Check for understanding periodically. Allow the child access to AAC.
Receiving messages	Wait patiently for child to process information and formulate a response. Listen to words and watch for behaviors that may be attempts to communicate.
Handling breakdowns in communication	Be alert to breakdowns; the child may not attempt communication repair. Try to repeat, modify, or recast your message.
Outbursts	Monitor for signs of impending outbursts such as increasing agitation. Be prepared to use strategies that have worked in the past (know these from your history). During the outburst: <ul style="list-style-type: none"> • Do not physically intervene unless there is risk for harm to the patient or others. • Stop talking; use only essential words. • Use short sentences. • Use a low volume and pitch when speaking. • Make eye contact. • Slow your movements. • Be patient.

Sources: Aylott, 2010; Bolick, 2008; Blake, 2010; Green et al., 2010; Murphy et al., 2011; Scarpinato et al., 2010; Seid et al., 1997; Souders et al., 2008; Thorne, 2007; van der Walt & Moran, 2001; Vaz, 2010.

ture systems, digital voice outputs, or even computers. AAC can be as unsophisticated as a small chalkboard on which children can write (Browne, 2006; Brunner & Seung, 2009; Flippin, Reszka, & Watson, 2010; Miranda, 2001). Regardless of the type of AAC, children should have access to it at all times (Bolick, 2008).

Handling Breakdowns And Outbursts

Communication breakdowns occur when the message being sent is not properly received. Breakdowns are

usually signified by requests for clarification, ignoring of requests, or wrong response to requests. Repair strategies include repetition, modification, or recasts. Repetition is simply repeating the original message. Modification is adding to, subtracting from, simplifying, or augmenting the original message. A recast contains none of the language from the original message but is an entirely new composition. It is important to be alert during interactions with children with ASD for communication breakdowns. Children with ASD are

less likely to use repair strategies than other children, so the adult will most likely need to initiate the repair (Halle, Brady, & Drasgo, 2004; Meadan, Halle, Watkins, & Chadsey, 2006). For additional suggestions, see Table 4.

Often, behavioral outbursts in children with ASD are attributed to frustration due to inability to communicate with others. Children should be monitored during communication for signs that an outburst may be coming (Bolick, 2008; Scarpinato et al., 2010; Thorne, 2007). Knowledge of what strategies parents or caregivers have used to successfully manage outbursts can be useful in understanding how to intervene with an individual child. Practical strategies to implement during an outburst are described in Table 4.

Conclusion

Children with ASD are unique. Their communication style is different from the social norm. They experience difficulties understanding the subtleties of language including non-literal vocabulary and non-verbal components of conversation. Effective communication between a nurse and patient is essential to providing quality care. Breakdowns can leave the nurse and patient feeling frustrated and confused. Small adaptations in communication style can help facilitate a successful nurse-patient relationship. Environmental sensory stimuli should be minimized. Techniques to help accommodate understanding in children with ASD should be put into practice. Nurses should be ready for behavioral outbursts, recognize them as a sign of frustration, and know how to react. Most importantly, the nurse must remember to allow extra time and be patient throughout the process. Nurses have a responsibility to optimize communication with their patients with ASD. ■

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Goal

To provide an overview of techniques pediatric nurses may use when communicating with children with autism spectrum disorder.

Objectives

1. Define autism spectrum disorder.
2. Explain why effective communication with children with autism spectrum disorder is essential in providing quality care.
3. List three theories that attempt to explain how children with autism spectrum disorder interpret communication.
4. Describe ways pediatric nurses can adapt their surroundings to help make communication with children with autism spectrum disorder more effective.

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