

EMS Timely Tips: Autism Spectrum Disorders

Autism is one of the fastest-growing developmental disabilities in the United States, affecting approximately 1 in 54 births. For the safety of emergency medical providers and patients with developmental disabilities, it is important to understand what Autism is and how to care for pediatric patients diagnosed with it. In this segment, Children's Mercy specialists will discuss common misconceptions about Autism Spectrum Disorder, as well as share insight from a memorable EMS encounter involving a child with Autism.



Featured Speaker:

Jo-Ann Youngblood, PhD | Mary Anne Hammond

Dr. Youngblood is a Licensed Psychologist at Children's Mercy Hospitals and Clinics' Division of Developmental & Behavioral Sciences and Assistant Professor of Pediatrics, University of Missouri-Kansas City (UMKC) School of Medicine. She earned her Ph.D. from the University of Kansas. She then completed her post-doctoral experience at the University of Kansas Medical Center and Children's Mercy Hospitals and Clinics. Her practice today focuses on targeted, short term behavior management as well as challenging toileting issues for children with developmental disabilities and Autism Spectrum Disorder using the principals of Applied Behavioral Analysis.

Mary Anne Hammond has a Bachelor of Science in Communications from Iowa State University. She worked in the Pharmaceutical Industry as a Sales Representative and National Account Manager for 9 years. In 1996, she helped start the FIRE Foundation, a not-for-profit organization with the mission of helping children with special needs attend their home parish school in Kansas City/St. Joseph, Missouri. She has also worked as a certified Childbirth Educator and Doula. Since 2008, Mary Anne has been the Education Coordinator for Autism for the Division of Developmental/Behavioral Sciences at Children's Mercy Kansas City.

Transcription:

Melanie Cole (Host): Welcome to pediatrics in practice with children's mercy, Kansas City. I'm Melanie Cole. And I invite you to listen as we discuss developmental and behavioral science, EMS Timely Tips: for Autism Spectrum Disorders. Joining me in this panel are Dr. Jo-Ann Youngblood. She's a Child Psychologist in the Division of Developmental and Behavioral Sciences at Children's Mercy, Kansas City, and Mary Anne Hammond. She is the Education Coordinator for Autism at Children's Mercy, Kansas City. Ladies, thank you so much for being with us today. So, Dr. Youngblood, I'd like to start with you, tell us a little bit about autism spectrum disorders and really what you're seeing in the trends. How are these diagnosed? What are some of the clinical indications? Just give us a little summary of them.

Jo-Ann Youngblood, PhD (Guest): Sure, autism spectrum disorder refers to a broad range of conditions characterized by challenges with social interactions, communication and behavior. We know that there is not one type of autism, but many subtypes. Because autism is a spectrum disorder, each person with autism has a distinct set of strengths and challenges. Some people with ASD may require a significant

support in their daily lives, while others may need less support, and in some cases, live entirely independently. Autism is often accompanied by sensory sensitivities and medical issues such as GI disorders, seizures, or sleep disorders, as well as mental health challenges, such as anxiety, depression, and attention issues.

Diagnosing autism spectrum disorder isn't a simple process. There is no blood test that you can do to diagnose autism. The diagnosis involves experienced professionals. They gather information from a variety of people, including the parents, the child, other care providers, and they take a more in-depth look at the child's development. At Children's Mercy Hospital, all children getting an autism evaluation, will see a Clinical Psychologist. And in some cases, they will see other specialties such as a Developmental Pediatrician, Speech Therapist, or Occupational Therapist.

Host: Dr. Youngblood along those lines, what's different? What do we know now about autism and the autism spectrum disorders that we did not know 20 years ago? Tell us a little bit about what you've found, what you've learned and what's exciting as far as ASD and your work that you do.

Dr. Youngblood: So, what I've learned over the last 20 years is that the diagnostic criteria has changed. And what I like about it now is that we are identifying the level of support the individuals with autism will need. The other thing I think that we've really done is we've gotten better at the diagnosis of autism and while I am not one that diagnoses, I have colleagues that do. There are some standardized measures and kids are being diagnosed at younger ages, which we all know that early intervention is critical for children with autism. So, I think it's helped in that treatment aspect.

Host: Dr. Youngblood, I'm sticking with you for a minute, as long as we're talking about diagnostic criteria and what has changed, there's still this myth out there about vaccinations and autism. So, we've learned, and the science has taught us that there's not a correlation, but there are risk factors. Can you speak about some of those that we know about?

Dr. Youngblood: Well, that's a great question. So, I want to just stress that you're correct. The studies have shown that there's no link between receiving vaccines and developing ASD. What we do know that there are a lot of unique pathways that lead to autism and there's not one single gene. So, in most cases, we really can't say for an individual person like exactly why they have autism or don't have autism. But what we do know with all of the studies, is that if you have one person in a family with autism, it's going to increase the likelihood that other members may have autism, but it also increases the likelihood that there might be subclinical autism traits in the family members.

Host: Mary Anne, you have an interesting story to tell. So, I'd like you to share your story, your experiences, and some of the stereotypes that are commonly associated with ASD. What you've seen in both your practice and your life.

Mary Anne Hammond (Guest): You know, interestingly enough, I would say that certainly there's a white male stereotype when you think of autism spectrum disorder. Even though it does have a greater prevalence among males, autism affects all kinds of people. It also impacts females like my daughter, Kaylee, and involves a wide range of differences. You know, some people talk a lot. Some people can't speak at all. That's the situation with my daughter. And I also think that many see this as a disorder that impacts children. Well, the reality is children grow up and autism is a lifelong disorder. And finally, I

would say because of the wide range of abilities on the spectrum, you probably can't tell that someone has autism just by looking at them.

Host: So interesting and what a great answer and a great point that you made. So, if you can't tell and there is a medical emergency. So, Dr. Youngblood, I want you each to have a chance to answer this next question, but specifically for emergency medicine providers, what's your best advice for them to remember when they're caring for a pediatric patient on the spectrum? And if something emergent does happen, what are they to do? What's your advice for them?

Dr. Youngblood: Well, that's a great question. And this question really hits home for me and is a particular interest to me because my husband is a firefighter paramedic. And what I've learned is that many of his calls are medical in nature, and he's had his fair share of calls for children with ASD. So, my best advice probably for EMS providers, caring for patients with ASD is to be patient and to realize upfront that autism field responses are going to require a lot more time to resolve than others. The other thing that I really stress is that we have to communicate clearly in direct, simple and concrete language because communication deficits a core deficit for children with autism. It's really important we don't overuse language or use any slang language. So, we want to talk calmly, softly and slowly.

So, I also behaviorally in any situation, it never hurts to remember to praise and give encouragement. And this is true for all children, but particularly true for children with autism spectrum disorder. When possible, I like to offer choice to children. It gives them some control over a situation. So, for example, if somebody has to do a blood pressure, ask which arm they prefer to use. It's not really an option whether you're going to take the blood pressure, but it is an option and it gives them control over which arm to use. And for repetitive behaviors, I tell individuals, they may be very obvious, but never stop a repetitive behavior unless there is a risk of injury to yourself or others.

And I want to touch on what Mary Anne said earlier. These children with autism look like any other child, and it may not be evident unless there's a parent present that this person has autism. So, I work with all my families to have some type of identification bracelet to say I have autism, I don't talk, with the parent name, because sometimes EMS providers get there and they don't know the child has autism.

Host: What a great point. Now, Mary Anne for EMS providers, give us your take on them caring for the pediatric patient with ASD and what you'd like them to know as a parent.

Mary Anne: Like Dr. Youngblood said, I agreed with everything that she says, but I would just add that if you have access to them, ask a parent or a guardian or caregiver, what might work to calm them down. So, if it's available, silence your siren. Shut off your bright lights because people with autism have often a really heightened sensory sensitivity to things like that. And I agree with you, just know that this encounter is going to take longer and setting that expectation will help. You might show them what you are going to do, and then tell them that you're going to do it. And then do it. I would also say that if they have a sensitivity to being touched, think about working and starting distal and work to proximal. So, you know, don't go for that blood draw first thing, but take a pulse-ox, you know, do something that's less invasive. Gain some momentum on success. Less is definitely more when it comes to talking like Dr. Youngblood said, because people with autism often need time to process what you said before they can give an answer.

Dr. Youngblood: That's great Mary Anne. And the other thing is because communication is a core deficit of autism, when people ask children with autism questions, some of them respond in a scripted way and they may not accurately be answering the question or reporting accurately if they may be hurt. So, if somebody says are you hurt? And the child says no. It's really important to do a full assessment. Many children with ASD have an extremely high pain tolerance as Mary Anne's daughter Kaylee. So, they, they don't feel pain like we feel pain. And so it's really important that we evaluate them clearly.

Host: Wow. You both have so much experience in this particular topic. And this is such great advice for all providers to take heed of. Mary Anne, as a parent of a child on the spectrum who has made frequent visits to health care facilities, do you have a memorable experience with EMS that you'd be willing to share with us today?

Mary Anne: You know, I was thinking about that and unfortunately I have a few, but the one that probably sticks most in my mind is when Kaylee was about seven. I had taken her to the doctor and as I was putting her in the car, she started seizing and became unconscious. And I ran her back into the building and they called 9-1-1. And when the paramedics got there, you know, as I watched them as I watched her seizing and being put into the ambulance, they turned to my husband and me and said, you know, you cannot go with us. And I was like, what. You know. Okay. And they said, but you can follow us. And they said, and listen to us. Drive safely. We do not need you to be hurt as well. And what was so interesting is on the way down we took a serious curve in the road and I'm not exaggerating when I say our car came up on two wheels instead of four. And I was thinking, well, this is why they say that. So, I think also the, you know, we promise we'll take good care of her.

Those words are so powerful to a panicked parent. And most recently, when Kaylee was inpatient in the hospital, a nurse told me, she said, I think as long as you're here, I can get anything done that I want to get done. I can run an IV, I can get a blood draw, I can do anything. So, knowing how from the parents that you might calm them can be a real help to you, you know, as they're being transported.

Host: As final thoughts, I'd like to give you each a chance to kind of let other providers know, this is really important information. So Mary Anne, starting with you, what would you like to tell EMS providers or really anyone in the healthcare community or parents for that matter about EMS, about emergency services, children on the autism spectrum disorders and why you think it's so important that they pay attention to what you've been saying here today.

Mary Anne: Well, I would say probably going to the parents and saying, having the providers and the EMS professionals make the general public know that it's really important that if you have a kiddo like this, that you let the providers know. So, contact your police, contact your local fire station, you know, contact them. And often there is a form that families can fill out. Like for instance, we have to lock our Kaylee into her room. Otherwise she would be wandering at night. And so they know that her room is in the southeast corner of our house. So, just anything that could help them on the scene or coming to the scene that as quickly as possible help the situation. I think that's probably what I would say most.

Host: Dr. Youngblood, last word to you. What would you like to tell other providers about this particular topic and when you feel it's important they refer to the specialists at Children's Mercy, Kansas City?

Dr. Youngblood: Ooh, that's a great question, Melanie. Well, I agree completely with Mary Anne and I

want EMS providers and everyone to know especially children with autism who exhibit behavioral issues that often these are not directed toward people. These children are acting out and they're almost experiencing that fight or flight syndrome when they're in a new or a scary situation.

So, if providers can go at it, being aware that oh, they must be afraid rather than they're out to hurt me is a really good approach. Being aware of that. So, many of my children with ASD may dart into a dangerous situation or a street, or they may come at you very quickly and invade your personal space. So, if you are aware that this is out of fear rather than out of I'm going to hurt you; it's going to help you better understand and be able to help that patient.

Melanie Cole (Host): Great advice. Thank you both so much for coming on today and sharing your expertise. This has been pediatrics in practice with children's mercy, Kansas City. To refer your patient or for more information, you can visit childrensmercy.org to get connected with one of our providers. Please also remember to subscribe, rate and review this podcast and all the other children's mercy podcasts. I'm Melanie Cole.

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