The ABCs of Autism

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Abstract: With autism spectrum disorders (ASD) affecting approximately 1 in 91 children and 1.5 million Americans, the likelihood of encountering a patient with an ASD is highly likely. These development disorders affect the ability to report medical conditions, regulate behavior and communicate effectively, and may require the EMS provider to take an alternate approach at assessing and treating the patient. The "ABC's of Autism" describes fundamental concepts that guide prehospital practitioners in the management of the patient with an ASD, regardless if EMS was summoned for an illness, injury or autistic crisis.

The most recent information on the prevalence of autism spectrum disorders (ASDs) indicates that it affects approximately 1 in 91 children, ages 3-17 years old, in the United States (Kogan et al., 2009). This is a significant increase from the previous estimate of 1 in 150 children (age 8) that was released just two years ago (Center for Disease Control, 2007). While the majority of discussion about autism and its prevalence is usually related to children and adolescents, it is important to remember the disability affects persons of all ages and approximately 1.5 million Americans are estimated to be diagnosed with an ASD (Autism Society of America, 2008). For the EMS provider, these numbers mean that the probability of encountering patients with autism spectrum disorders is highly likely.

Autism spectrum disorders are developmental disorders that affect, among other things, the ability to communicate, report medical conditions, self-regulate behaviors and interact with others to get needs met. This can create serious problems for emergency responders when trying to assess and manage a patient. Common assessment techniques and traditional treatment protocols may not be appropriate for the patient with an ASD and may require modification in order to meet the needs of the patient.
While optimum training for EMS providers may be a model of "autism preparedness," which is comprised of general awareness of the disability, understanding and managing autistic escalation and meltdown and discussing assessment and treatment strategies, this approach is time consuming and the availability of such classes is limited. Therefore, there is a need for a limited, interim training model that can be expanded to include concepts of more intensive training when available. The model must be easy for practitioners to implement, applicable to a wide variety of situations that an EMS provider may encounter and should be "flexible enough" to include more detailed concepts as they are learned by the provider.

Medical professionals have historically utilized mnemonic devices to easily categorize and recall information. One of the most widely-recognized medical mnemonics is the "ABC's," most often used to represent "Airway, Breathing and Circulation," but it can also stand for "Always Be Calm" (and humorously, "Ambulate Before Carry"). This mnemonic can also be used to describe the basic actions that should be taken by EMS professionals for encounters with patients who have autism spectrum disorders, and it is applicable in almost every encounter situation, whether it is due to an autistic crisis (escalation and meltdown), a medical emergency or an injury. Used in this context, the mnemonic stands for:

Awareness
Basic
Calm and
Safe

Awareness

It is very important for EMS providers to understand that people who have an ASD will not behave or react in the same manner that most of your patients will. This is due to perceptual, social interaction and communication barriers that affect how they interact or respond in certain circumstances. Since they may not be able to adapt to the situation they are in, EMS providers will need to change their approach and strategies to meet the needs of the person with autism.

Persons with autism are susceptible to the same medical emergencies as the general population, often have co-existing medical conditions (Myers et al., 2007), such as seizure disorders and are more prone to sustaining certain types of injuries (McDermott et al., 2008), all of which increases the likelihood of an EMS response. While acute illnesses and injuries are stressful events for the majority of our patients, persons with autism have rigid routines and a very strong preference for things to be predictable and expected. Disruption is not well tolerated and the person with autism generally will lack the ability to adapt to the situation that they find themselves in.

Effective communication between the patient with an ASD and the EMS provider can be challenging. Persons with autism often have literal perception and have difficulty distinguishing patterns of speech such as humor, slang, sarcasm, or idolism from unambiguous statements. "Body language," such a gesturing and facial expression, may not be recognized either. Approximately 25-30% of persons with ASD will stop speaking, usually between 15-24 months of age (Johnson et al., 2007). About one-quarter of those will remain non-verbal at age nine (Turner, Stone, Pozdol, & Coonrod, 2006). When presented with stressful situations, even those individuals with good verbal ability may be unable to speak. Consider using a picture card system, which can help the patient express their needs and may assist you in explaining procedures and interventions to the patient. Downloadable picture card files appropriate for EMS agencies are being made available for no charge at www.autismems.net. The files can be printed out on cardstock, cut into cards and kept in your ambulances for use with patients that have difficulty communicating.

Escalation and meltdown can be described as an *involuntary* increase in tantrum-*like* behaviors that include screaming, swearing, stomping, throwing objects, hitting and/or kicking (people or objects), pushing and biting (Maryland Police & Correctional Training Commission, 2001). There are several causes of this behavior, with the most common involving sensory, emotional or cognitive overstimulation, social skills deficits, excessive demands being placed on the individual, interruption of established routines and being put in a situation that was unexpected or is unpredictable (Lipsky & Richards, 2009). If a person with an ASD is behaving aggressively or is escalated, it is rarely out of what most of us would refer to as malicious or defiant behavior. It is much more likely that the individual is reacting to extreme stress and is out of control. They often know that they are out of control, but do not have the ability to regain control effectively and may need your help to return to a calm sense of being. Simply put, they just want circumstances to change, but do not know how to implement that change (Debbaudt & Rothman, 2001)

Basic

One of the most important aspects of interacting with persons with autism is to keep things basic. There are a few ways that this concept applies:

Keep your instructions basic. Simple, clear, precise directions are easiest to follow for persons with autism. For example, say "sit down here" (pointing at chair), *not* "why don't you have a seat?" Don't be sarcastic, use figures of speech or tell jokes.

Ask basic questions. Many people with autism will do better answering short, closed-ended questions, than responding to open-ended questions. Allow extra time for the person with autism to answer even simple questions; if the person still does not answer you, they may be non-verbal, may not understand the question or may not know the answer to the question that was asked. People who have an ASD have difficulty asking for clarification when they do not understand questions or instructions.

Basic means less "stuff"! Our radios, pagers, cell phones, even things like flashlights and stethoscope covers may overstimulate the senses of a person with autism. They frequently have hyperacute responses to one or more of the five senses that a majority of people tolerate well or don't even notice. For example, they may be able to see strobe-like flickering in fluorescent lights and a gentle, reassuring touch on the shoulder may feel like they are being forcefully struck. They may also have difficulty separating loud foreground noise from faint background noise. Your radio, even turned way down, may be perceived as being as loud as you are when you speak. Sensory stimulus overload easily can act as an antecedent to escalation and meltdown. Therefore, it is important to keep as much "stuff" turned off and out of sight. When responding, if you are aware that your potential patient is autistic, it also is advisable to discontinue use of red lights and siren as you

approach the scene.

Keep your treatment basic. Since persons with autism do not adapt well to sudden changes interrupting their world, it is often best to try to minimize as many unplanned experiences as possible. In an emergency, their routines are interrupted, they are being bombarded with questions, things are being demanded of them from every direction and an injury or illness may be causing significant pain or discomfort. This results in already heightened levels of anxiety, stress and frustration being pushed to the limit. The last thing that they need is to be "attacked" by EMS providers wanting to poke them here and put stickers there. Do not withhold treatment that is absolutely necessary, but consider that it is usually best to defer treatment interventions that are done routinely as precautions or to "help" the emergency department staff. In other words, ask yourself, "*must this be done to get the patient to the hospital safely?*" before initiating specific treatments. However, it is critically important to remember that the patient with autism may not offer typical complaints, may have very high pain thresholds (thereby tolerating injuries that most patients would describe as excruciating) and may choose to engage in a pleasurable activity (such as playing with a toy or listening to music) over dealing with an obvious injury or medical condition despite the amount of discomfort it may be causing. In some cases, this may cause serious conditions to be missed; careful assessment is always needed and never withhold treatment that the patient *needs*.

Calm

When dealing with the patient who has autism, particularly if they are escalating or having a meltdown, it is imperative that you remain calm. Posturing aggressively, commanding loudly, becoming aggravated and even telling the patient to "calm down" will either be ineffective or counterproductive. Just because the individual has temporarily lost control of his/her behavior, it is no reason for you to do so (Lipsky & Richards, 2009). Remember, calm creates calm!

While a "show of force" may be an effective deterrent against aggressive behavior for many people, this strategy will likely be lost on the patient with autism. If anything, extra people add to confusion, increase frustration and heighten anxiety, all of which could cause negative behaviors to escalate. A better approach is to allow one person to make direct contact with the autistic patient, preferably accompanied by a parent, family member or caregiver.

Keep your tone of voice clear and controlled. Offer empathy and compassion; reassure them that you are there to help them and to provide support. Allow the person with autism to express their concerns and frustrations. Being calm means taking extra time – sometimes a lot of extra time. Don't force your agenda; unless their condition is immediately life – or – limb threatening, it's their emergency, and their timeline. Forcing the patient to move on before they are ready likely will result in escalation and meltdown. If they are already escalated, it may increase the intensity and duration of the event and may break all trust that has been established with them. Escalation could exacerbate medical emergencies such as asthma or heart problems. Since physical activity accompanies escalation, injuries can easily be compromised and become more serious.

Safe

Having a sense of safety and security is important to patients with autism. Often the environment that you find them in offers a sense of familiarity and security, even if it does not seem apparent to you. On the other hand, your ambulance *is* a strange and unfamiliar place; although *we* know what to expect, the ambulance represents unpredictability to the patient with autism. Therefore, it is usually best to begin patient interaction where the patient is found. Remove things from around the person that may be aggravating to them (for exam-

ple, turn off fluorescent lights) and disperse unnecessary personnel and bystanders.

While assessing the patient, consider using reverse order; in other words, do a toe-to-head exam instead of a head-to-toe exam. Move slowly and do one thing at a time, such assessing a leg or taking a blood pressure. Tell the patient *what* you are going to assess next and *how* you will assess it. Allow time for the patient to ask questions (e.g. some patients might want to know *why*) and ensure they are ready for you to complete the next part of the assessment before you do it. If the patient begins to show signs of agitation or is becoming uncomfortable, consider taking a break before continuing the assessment if their condition permits. You may need to "segment" your exam and pause several times before finishing a full assessment.

The concept of preparing the patient each step along the way is essential to establish a sense of safety. The patient needs to know what to expect next. *What* can they expect to see? *When* will it occur and *how long* will it last? Use solid, descriptive terms to explain how an intervention will feel, as persons with autism often perceive pain quite differently than how you will. For example, when describing how it feels to have a blood pressure taken, *don't* say "it won't hurt." Instead, say "this cuff is going to squeeze your arm tightly."

Allowing the patient to tell you when they are ready for you to perform interventions, procedures or treatments provides a much-needed sense of control, which translates into feeling safe and secure about what is happening to them. Let them tell you when they are ready to move to the ambulance. They may want to look around the ambulance, look in cabinets and drawers and even handle equipment before they are comfortable settling down. They may want to sit in a specific seat, such as the captain's chair, or sit in various seats before deciding where they'd prefer to sit. Involving the patient in their care by understanding and accommodating these needs will likely build trust with the patient, increasing their compliance and cooperation.

Even if the person with autism is escalated or having a meltdown, restraining the individual is frightening and terrifying. It should be avoided wherever possible and saved only as a last resort, and *only* when the person is an immanent danger of causing harm to themselves or others. If restraint is necessary, a standing restraint is preferred. This method utilizes a minimum of two individuals, one on each side, firmly grasping the upper arm and wrist of the individual's arm. A third and fourth person may be used hold his lower extremities. Avoid crossing the person's arms in front or behind them, as respiratory compromise may result from underdeveloped trunk muscles, hypotonia and restricted diaphragmatic movement (Debbaudt, 2002). Never restrain a patient in a prone position, "hog-tie" the patient or use hobble restraints, as cases of sudden death have been reported (Stratton, Rogers, & Green, 1995 and Kupas & Wydro, 2002) If prolonged manual restraint occurs, the use of a soft, mechanical restraint made of out of cravats, cloth or leather may be necessary. Four-point restraint in a supine position on the litter is acceptable; a sheet can be used to tether the chest, waist and/or legs to the litter. Sedation should be considered if the patient fights against the restraints (Kupas & Wydro, 2002). "Hard" restraints, such as handcuffs and leg irons, as well as "less-than-lethal" police force, such as peppers spray, tasers and batons should be avoided at all cost (Kupas & Wydro, 2002 and Strote & Hutson, 2006) As with any procedure in EMS, restraint and sedation of the agitated patient must be performed in accordance with your local protocols or under medical direction.

Conclusion

Using the "ABCs of Autism" can guide EMS providers in the basic approach of the patient with an autism spectrum disorder. It is imperative to remember that basic concepts of EMS always apply: scene and personal safety and the traditional "ABC's" of airway, breathing and circulation must always come first. Every person with autism is unique and will present with an individual set of challenges and features. Each encounter with autism will be different. Your actions will inevitably affect how the encounter will proceed, and whether it will be a positive or negative experience for you and the patient with autism.

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