Improving Experiences of Autistic Patients in Emergency Department Settings

Context

- Individuals with ASD are admitted to the ED **at 2.3 times the rates** of those without ASD. The most common reasons for ED visits among adults with ASD include **epilepsy, falls, schizophrenia, respiratory disorders, bipolar disorders, and depression.**
- Oftentimes, individuals with ASD can present with **acute agitation, including dangerous behaviors to self and others**, that can be exacerbated by the environment of the ED.
- **Hospital EDs have had limited success with management and de-escalation of acute agitation** in children, adolescents, and adults with ASD.
- In a 2011 survey of 3500 children, adolescents, and adults with ASD, **nearly one-third of respondents noted a negative experience and unwanted outcome in the ED.**
- It is critical that medical personnel understand the unique needs of individuals with ASD, so as to **provide effective treatment in a least-restrictive manner in crisis and ED settings**.

Strategies for managing acute agitation in autistic patients (from McGonigle et al. 2014)

1. **Rapid Assessment**
   - Quickly assess the patients' ability to follow directives, their level of cognitive abilities and input mode (visual, auditory, tactile), and their speed of processing (single vs. multistep directives).
   - Involve the parent/caregiver in the evaluation process to get accurate information around the suspected cause of agitation.
   - Assessment of etiology should consider antecedents such as environmental and interpersonal triggers, internal stressors (such as pain or acute psychiatric symptoms), psychiatric history, medication review, potential for toxic ingestion, allergies, past medical history, developmental history, and a focused social and family history.
   - Every person with ASD is unique, and treatment and interventions must be individualized to patients & their families.
2. **Environmental Adaptations**
   - If possible, direct patients with ASD to a quiet room or area of the ED with minimal stimuli.

- Lower lighting, reduce noise levels, and keep the number of staff used to care for patients to a minimum.
- During examination or treatment, move slowly and explain how and why you need to touch a patient with medical equipment.
- Using verbal or visual demonstrations with a clear explanation of what you plan to do in advance is helpful in reducing anxiety.

3. **Communication Adaptations**
   - Use verbal and nonverbal communication adaptations (pictorial, Social Stories, schedules, Picture Exchange, picture schedules, and augmentative communication systems).
   - When giving directives, present requests in a linear and sequential fashion. Avoid using metaphors or making analogies.
   - Allow plenty of time for patients to respond to questions. In many instances, it is important to repeat the questions or directives so patients can clearly understand expectations.
   - Understand that, during periods of acute agitation, individuals with ASD may not respond to directives and may not be able to express their wants, needs, or feelings including pain.
   - Be aware of body language and nonverbal signs to divert meltdowns, tantrums, and escalating behaviors related to frustration, lack of control/self-determination, and sensory overload.
4. **Behavioral Approaches**
   - Make efforts to learn from caregivers about behavioral approaches that may be effective in reducing agitation and calming patients at home, school, or in the community.
   - Applied behavior analysis and cognitive behavior therapy approaches that use incentives/rewards are considered best practice for children with ASD. EDs should have access to potential incentives, such as candy, stickers, tokens, and toys.
5. **Somatosensory interventions**
   - Relaxation using sensory intervention techniques has been effective in reducing anxiety, aggression, and self-injury in some patients with ASD.
   - Some individuals with ASD may display atypical and paradoxical responses to sensory stimuli, specifically both over-reactivity and under-reactivity.
   - Interventions in all sensory domains should be considered, including auditory (music, headphones); visual (photos, books, videos); tactile (brushing, deep pressure, weighted vests/blankets, heat wraps, cold, massage/touch); olfactory (scratch-and-sniff stickers, markers, flavored lip balm); and vestibular physical exercise or movement activity (swings, rocking chairs).

- Caregivers should be consulted on effective techniques, as individual responses may vary.

6. **Sedation and restraint**
   - Verbal de-escalation is always preferred. Sedation and restraint are warranted only if absolutely needed.
   - Always ask the patients' caregivers about a previous need for medications to reduce anxiety or agitation and the patients' previous response. The risk and benefits of using pharmacologic means to reduce agitation should be weighed and discussed carefully with parents, caregivers, and guardians.
   - Many patients with ASD have other conditions that can complicate the choice of agents used for calming (such as seizure disorder or sleep apnea). Thus, it is essential to make a thorough history and accurate medication reconciliation.
   - Honor the caregivers' guidance on how to optimally tailor the procedure, given their understanding of care sensitivities and previously effective and noneffective strategies.

Flowchart of least-restrictive treatment model for patients with ASD experiencing agitation in the ED (from McGonigle et al. 2014)

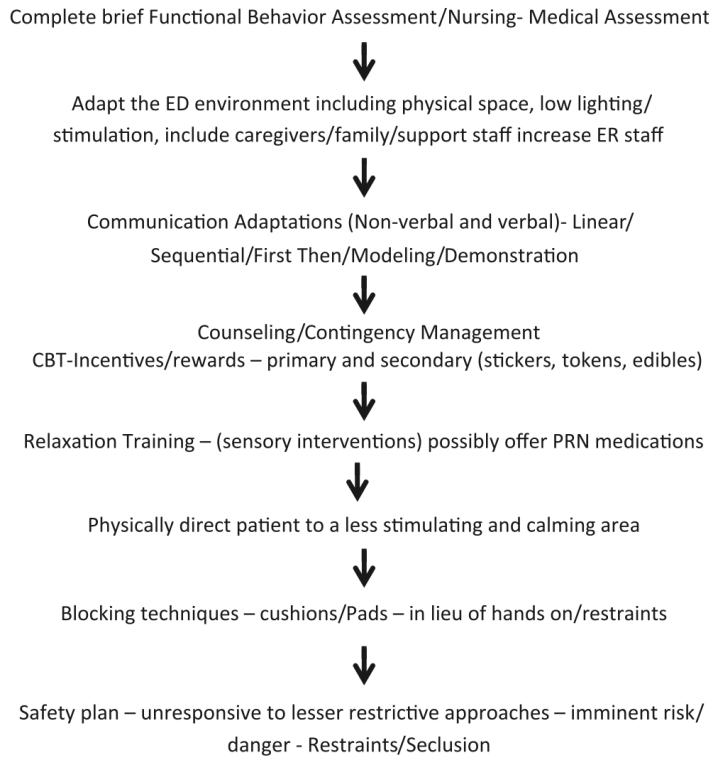

Fig. 1. Least-restrictive treatment model for ASD in EDs. CBT, cognitive behavior therapy; ER, emergency room; PRN, Pro Re Nata.

Proactive methods to combat barriers to care (from Nicolas et al. 2016)

- **ASD screening**
  - A standardized method of identifying ASD-related needs, collected in a streamlined way, is recommended as a means to collect information for care planning.
  - This may take the form of a brief standardized checklist at registration that screens for special needs, care accommodation requirements, communication style, potential triggers, and strategies to optimize care.
  - Pratt et al. implemented a hospital-wide preadmission checklist that screens for learning disability and ASD, and covers communication, sensory, and behavioral considerations for the patient. The checklist was evaluated positively by both families and health care providers.

- **Wait Time Management**
  - Patients with ASD may increasingly decompensate and emotionally struggle as unstructured waiting time in the ED ensues.
  - To proactively manage waiting, alternative quiet spaces outside common waiting areas are recommended, with distraction items (such as art supplies or computer games).

- **Capacity Building**
  - ASD capacity building is recommended through education to trainees, ongoing professional development, sharing of resources by specialized care teams, and development of toolkits.
  - Skill development is especially recommended in de-escalation and assisting caregivers during aggressive behavior and crisis.

References:

Gerson R, Malas N, Feuer V, Silver GH, Prasad R, Mroczkowski MM. Best Practices for Evaluation and Treatment of Agitated Children and Adolescents (BETA) in the Emergency Department: Consensus Statement of the American Association for Emergency Psychiatry [published correction appears in West J Emerg Med. 2019 May;20(3):537] [published correction appears in West J Emerg Med. 2019 Jul;20(4):688-689]. West J Emerg Med. 2019;20(2):409-418. doi:10.5811/westjem.2019.1.41344

McGonigle JJ, Venkat A, Beresford C, Campbell TP, Gabriels RL. Management of agitation in individuals with autism spectrum disorders in the emergency department. Child Adolesc Psychiatr Clin N Am. 2014 Jan;23(1):83-95.

Nicholas DB, Zwaigenbaum L, Muskat B, Craig WR, Newton AS, Cohen-Silver J, Sharon RF, Greenblatt A, Kilmer C. Toward Practice Advancement in Emergency Care for Children With Autism Spectrum Disorder. Pediatrics. 2016 Feb;137 Suppl 2:S205-11.

Vohra R, Madhavan S, Sambamoorthi U. Emergency Department Use Among Adults with Autism Spectrum Disorders (ASD). *J Autism Dev Disord*. 2016;46(4):1441-1454.