Autism Spectrum Disorder: Health Services & Emergency Responding

THE BINGHAMTON REGIONAL CENTER FOR AUTISM SPECTRUM DISORDERS

OVERVIEW
- What is Autism Spectrum Disorder?
- Challenges in routine & specialty healthcare
- What does someone with ASD do in distress?
- ASD and emergency medical support
- Evidence-based recommendations
- Final thoughts

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**HISTORY OF ASD**

DR. LEO KANNER
1943

AUTISTIC DISTURBANCES OF AFFECTIVE CONTACT

DR. HANS ASPERGER
1944

AUTISTIC PSYCHOPATHY

AUTISTIC DISORDER

ASPERGER'S SYNDROME

**DSM-5 (2013) – ASD CRITERIA**

- Social Communication Deficits (3 of 3 criteria)
  - Deficits in socio-emotional reciprocity
  - Deficits in nonverbal communicative behaviors used for social interaction
  - Deficits in developing and maintaining relationships appropriate to developmental level

- Restricted, Repetitive Patterns of Behaviors, Interests, and Activities (2 of 4 criteria)
  - Stereotyped or repetitive speech, motor movements, or use of objects
  - Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change
  - Highly restricted, fixated interests that are abnormal in intensity and focus
  - Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment

**WHAT IS ASD?**

- A disability across the lifespan
  - Autism does NOT only affect children.
  - There is no "cure" for ASD - We all have shared responsibility for understanding individuals with ASD.
  - Diagnosed as early as 2 years old but often not until after 5 years old; some individuals don’t get diagnosed until much later in life.
  - Invisible disability/disorder – no physical marker

**ALSO – SPECIFY PRESENCE OF LANGUAGE IMPAIRMENT AND INTELLECTUAL IMPAIRMENT, AS WELL AS ANY GENETIC OR MEDICAL CONDITION OR OTHER NEURODEVELOPMENTAL DISORDER**
BASIC STATISTICS

- Prevalence rates = 1:59 children or ~2% (CDC, 2018)
- Context - US Population in 2018 = ~326.8 million ~6.5 million individuals with ASD
- Male to female ratio is about 4:1
- Approximately 50% of individuals with ASD are nonverbal; 44% had average-above average intelligence (i.e., 56% intellectual impairment)
- 1/3 of those with ASD are also affected by epilepsy
- Sub-clinical epilepsy thought to play a role in clinical regression (Acosta & Pearl, 2004)

COMMONLY ASSOCIATED CONCERNS

- Anxiety
- Phobias
- OCD
- ADHD
- Aggression, including self-injury or self-harm
- Sleep
- Appear insensitive to pain OR overly sensitive to certain types of stimulation

INJURY & ASD

- 2-3 times more likely to experience medically attended injuries
- Significantly reduced life expectancy
- Engagement in more risk-taking behaviors than peers

CAUSES OF UNINTENTIONAL INJURY

(CDC, 2004; McDermott, et al., 2008; WHO, 2008)

<table>
<thead>
<tr>
<th>Rank</th>
<th>ASD</th>
<th>Typical</th>
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<tbody>
<tr>
<td>1</td>
<td>Falls</td>
<td>Falls</td>
</tr>
<tr>
<td>2</td>
<td>Struck By / Against</td>
<td>Struck By / Against</td>
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<td>3</td>
<td>Natural Environment</td>
<td>Cut / Pierce</td>
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<tr>
<td>4</td>
<td>Cut / Pierce</td>
<td>Car Accident</td>
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<tr>
<td>5</td>
<td>Poisoning</td>
<td>Natural Environment</td>
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<tr>
<td>6</td>
<td>Car Accident</td>
<td>Bicycle</td>
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<td>7</td>
<td>Burn</td>
<td>Burn</td>
</tr>
<tr>
<td>8</td>
<td>Bicycle</td>
<td>Poisoning</td>
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PREDICTORS OF UNINTENTIONAL INJURY

- Male
- Over the age of 5 years old
- High impulsivity
- Presence of physical or mental disability
- Impairments in attention, communication, & social interaction
- Low SES
- Exposure to hazardous environments

EFFECT OF HAVING ASD IS CURRENTLY UNCLEAR...

ASD, FEAR, AND EMOTION

- Individuals with ASD do not process facial expressions of emotions of fear, anger, or sadness as well as individuals without ASD (Farran, Branson & King, 2011).
- Body movements/postures of emotions – mixed results in research.
- Individual differences largely account for differences in fear acquisition and its impact on social interaction (South et al., 2011).

FEAR AND INJURY

- Cognitive and emotional determinants
- Awareness of impending threat for bodily or emotional harm with expectation of undesirable outcome
- Fear and accurate appraisals of injury risk
- Lack of fear associated with elevated injury risk

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PARENT VIEWS: A PILOT STUDY

- Children with ASD were perceived by caregivers as having no fear to many items
- Being afraid to hurt oneself might be a protective factor against injury in children with ASD
- Caregivers might be intervening when children show no fear to dangerous situations
  - Injury risk could be underestimated due to caregiver intervention for children with no fear
  - No one to intervene when not present

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LET ME ASK YOU…

- What are things you normally do or should do when providing care in your respective fields? Yes, take a minute and write a few items down.
- NOW – given what I have told you so far about ASD, which of those items might not be feasible?

FAMILY PERSPECTIVES

- Davignon, et al. (2014)
  - 20 children (ages 3-17) and their parents interviewed
  - First major theme
    - Productive Provider-Family Interactions
      - Providers need to learn how to communicate with individuals with ASD, use more picture cues and and other visual aids, and obtain training in behavioral strategies
      - Parents need preparatory guidance well before the procedure, including detailed accounts of what to expect during an encounter and tools parents could use to instruct their child about the visit

- Davignon, et al. (2014) continued
  - Second major theme
    - Organization of Healthcare Delivery
      - Timely care (minimal waiting), but slower pace of procedures during appointments
      - Individualizing the treatment environment as much as possible, with fewer providers entering and leaving the room and caring for child than might be typical
FAMILY PERSPECTIVES

- Interviews of 42 participants (youth with ASD, parents, and health-care providers)
- Supportive health-care providers defined as those who:
  - Acknowledged parents as experts
  - Inquired about the requirements of patients with ASD
  - Accommodated unique clinical needs of the individual patient

PATIENT HISTORY AND PREPARATION

- Assessment (Souders, et al., 2002)
  - Person’s communication, social, sensory, and behavioral skills and needs
  - Successful strategies for compliance

- Plan additional time as well as possibly additional visits to the treatment setting
- Meet the individual and have discussions with him or her (when possible) as well as caregivers involved.

SOUDERS ET AL. (2002)

- Key Components in Nursing Care Plan
  (for care of individuals with ASD undergoing complex medical procedures)
  1. Contact prior to visit.
  2. Instruct parents to bring communication mode, token system, or rewards.
  3. Prepare for behaviors – extra staff, bodily fluids.
  4. Prepare environment.
  5. Train staff,
  6. Offer pain management.
  7. Allow adequate time.

THOMPSON & TIELSCH-GODDARD (2014)

- Box 4. Presurgical checklist: Individualizing care for the patient with autism
  - Confirmation of autism spectrum disorder diagnosis
  - Parent description of patient’s abilities, response to verbal commands, behavior in new environments
  - Techniques, toys, electronic devices, or other strategies that help calm the child
  - Behaviors or cues when the patient is stressed
  - Cues before a significant emotional meltdown
  - Common behaviors the patient displays when working to cope with a stressful situation
  - Behaviors the child portrays when having difficulty coping
  - Sensitivity to touch, noise, bright lights, hospital linens/ clothing
  - Special interests of the patient
  - Will the patient be able to wait in the registration area or surgical waiting area prior to his or her appointment? If not, make special accommodations based on response
  - Encourage parents to bring a special toy, game, music, stuffed animal, blanket (regular or weighted) or other calming devices
  - Confirm the patient uses a special communication device, and if so, have the parent bring it for the visit.
ADDITIONAL SUPPORTS

Chebuhare et al. (2013) – visual schedules

EXPERIENCE OF PAIN

- Arguments of hyporeactivity and hyperreactivity, but inconsistent findings
- Review by David Moore (2015)
  - Results of wide literature search that yielded 17 articles that fit inclusion criteria
  - While self/parent report and clinical observation studies indicated hyposensitivity to pain, observations of actual medical procedures indicated normal to hypersensitive responses
- Importance of understanding the danger of assumptions – a person with ASD with tactile undersensitivity might have a normal or hyperreactive response to painful stimulation

PRACTICE MAKES...THINGS EASIER

- Individuals with ASD might require additional visits and practice completing mock treatment scenarios to be able to comply with requests and participate during scheduled procedures
- Such activities can be planned with parents and other caregivers, behavioral health providers, or others involved in case management

AN EXAMPLE
THE HIERARCHY AND STEPS/SUB- STEPS REQUIRED FOR LEARNING TO TOLERATE A ROUTINE MEDICAL EXAM (CAVALARI, ET AL., 2013)

SUMMARY POINTS

- Very important to understand that an individual with ASD receiving treatment in your facility might have weaknesses in specific areas; HOWEVER,
- Previous experience with an individual with ASD does not provide sufficient understanding of a new patient with ASD. Each person’s strengths, weaknesses, and needs are different.
- Engaging in patient-centered planning requires many of the strategies that you would need for individuals with ASD, but perhaps with more acclimation and procedure completion time added to the clinical plan.

TIME NEEDED FOR SUCCESS FOR AN INDIVIDUAL W/ SIGNIFICANT REFUSAL HISTORY

OVER 50 SESSIONS FOR ALICE TO MASTER TOLERATING A BASIC PHYSICAL EXAM

RESOURCE – PROVIDER AND PARENT PERSPECTIVE

https://asatonline.org/research-treatment/interviews/interview-with-purimahernandez/
OUR OWN PERCEPTIONS

- Imagine that you’re in the supermarket and you see a parent struggling to control their young child who is screaming and kicking violently. What would be your first thought?

- Imagine that you’re waiting at a bus stop and a young man you’ve never seen before comes up to you. He gets quite close and speaks to you very loudly in a monotone voice. He keeps asking when the bus is coming and shifting from one foot to another. What would be your first thought about this man?

WHAT DOES SOMEONE WITH ASD DO IN DISTRESS?

- Sometimes distress is not detected
- Freeze
- Upset, aggression
  - Seems out of control
  - Be empathic
- Confusion
  - Go back into a burning building: seemingly irrational action for danger
- Hiding
- Bolting/fleeing

YOU NEED TO BE AWARE THAT...

- Not responsive to sound or requests/questions but can hear
  - Appears deaf
  - Difficulty speaking (or cannot)
- Might not understand consequences of their actions (aggression)
- Difficulty with abstract or ambiguous language, words, phrases.
- Sometimes disruptive behavior is due to perceived threat or difficulty communicating to you

WANDERING AND ELOPEMENT

- Wandering: Moving/walking about from place to place.
  - Goal-oriented: to get to or away from something
  - Non-goal-oriented: no purpose, random movement
  - Due to something else: nighttime, disorientation, confusion
- Elopement: The act of running away, wandering away, walking away, escaping, or otherwise leaving a safe setting unsupervised or unnoticed.
  - Bolting/fleeing: Suddenly running away, typically from something negative/stressful
FACTS ABOUT ELOPEMENT/WANDERING

- 92% of parents reported children with ASD had a tendency to wander (2007)
- One of the most “stressful events” for parents (56%)
- Poor parenting not at root of wandering/elopement
- About 49% of children with ASD will wander/elope (2011)
- 53% gone for long enough to be concerned (41 min avg)
- 2009-2011: 91% of deaths for children with autism ages 14 and younger were due to accidental drowning following wandering/elopement
- 68% of these were in a nearby pond, lake, creek or river
- 23% at a family outing
- Death occurs within 15 min to 20 hours of disappearance

SETTING

HOME: 76%
STORES: 40%
SCHOOL: 29%

CONSIDER SPECIAL INTERESTS

- Streets/highways
- Trains
- Heavy equipment
- Fire trucks
- Roadway signs
- Bright lights
- Traffic signals
- Animals (only found at the zoo)
- Clock towers
- Mascots (Rumble Ponies)

RECENT & LOCAL – APRIL 2019

NOT ALL CASES END WELL – DEATH AFTER WANDERING/ELOPEMENT MORE COMMON THAN YOU MIGHT EXPECT

SWEATSHIRT, SWEATPANTS, ONE SNEAKER – DISAPPEARED AT NIGHT
11 HOURS MISSING BEFORE BEING FOUND
FOR SEARCH & RESCUE

- Make sure you understand the degree of Autism you are dealing with. It will make a difference in dealing with the person when located.
- Find out if there has been anything that has attracted the attention of the person within the past 24 hrs. Have they been obsessed with a location or object, at a location, within that time.
- Do not expect the person to reply if you are calling their name. You'll most likely have to make visual contact to locate them.
- On many of the searches, the person has hidden from first responders.
- Check any location that has water, such as, pools, ponds, lakes, rivers, etc. immediately. These are points of attraction for those with Autism.
- Remember that someone with ASD will, most likely, not experience fear as we do. Don't discount searching any location because you feel a reasonable person would not go there.

ASK PARENTS IMMEDIATELY

- What do they like? Something familiar to them?
- Can they swim?
- Can they respond to their name being called by a stranger? By police?
- Can they cross the street independently?
- Are they afraid of dogs? What do they do around dogs?
- Experience with police? Color of uniform?
- Loud noise – sirens – what do they typically do? (cover their ears?)
- When they are upset, how to calm down?
- What do they do when scared? Where do they go?

MORE QUESTIONS FOR PARENTS

- Where did the child last request to go? (and was denied)
- Favorite places, objects, things, people, etc.
- History of wandering/elopement
- Stranger perception
- Was the child recently upset? Engaging in high level of self-stimulatory or repetitive behavior, perseveration?
- Use of pictures/signs to communicate?
INITIATIVES

- Safe and Sound by the Autism Society
- Take Me Home – Pensacola Police Department
  - Free
- Free courses: http://www.missingkids.com/NCMECUniversity
- Think Differently – Dutchess County

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Thank you!

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