

# A Modified Autism Spectrum Disorder Care Pathway for Autistic Patients in the Pediatric Emergency Department

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### BACKGROUND

Children and adolescents with autism comprise approximately 2% of patients in the emergency room (Cohen-Silver et al., 2014). Furthermore, researchers estimated that over an 8-year period, nearly 9% of children diagnosed with autism spectrum disorder (ASD) visited the emergency department (ED) more than once, relative to 5.5% of children without such a diagnosis (Boulet et al., 2009; Mannenbach et al., 2021). Children with moderate to profound autism spectrum disorder often exhibit challenging behaviors in the emergency room such as physical aggression, self-harm, and property destruction. Children diagnosed with ASD experience significantly higher rates of physical and chemical restraint (Calabrese et al., 2024), and lower rates of parental satisfaction with emergency department healthcare (Ben Natan et al., 2024). Emergency care providers frequently report discomfort and inadequate training on unique care practices for acutely agitated children with ASD.

Kuriakose et al. (2018) initiated a specialized Autism Spectrum Disorder Care Pathway (ASD-CP) for inpatient pediatric psychiatry patients at an urban hospital in the Northeastern United States. Among other interventional components, the ASD-CP involved parent completion upon triage admission of a one-page "tip sheet," briefly surveying children's communication profiles, early warning signs and triggers for aggressive behaviors or property destruction, and most pertinently, previously effective and personalized de-escalation tactics. ASD-CP led to decreases in average length of hospital stay and use of crisis response physical holds/restraints in autistic youth receiving inpatient psychiatric care. To our knowledge, no research has yet examined whether an ASD Care Pathway has an effect on provider comfort in caring for pediatric patients with autism in the emergency department.

The current study will seek to assess the effect of a tip sheet completed by the child's parent/guardian briefly summarizing the patient's specific communication strengths and weaknesses, known triggers and calming responses for aggression/agitation, child's preferred reinforcers, and historically successful de-escalation tactics on providers' comfort when caring for autistic patients in the emergency room.

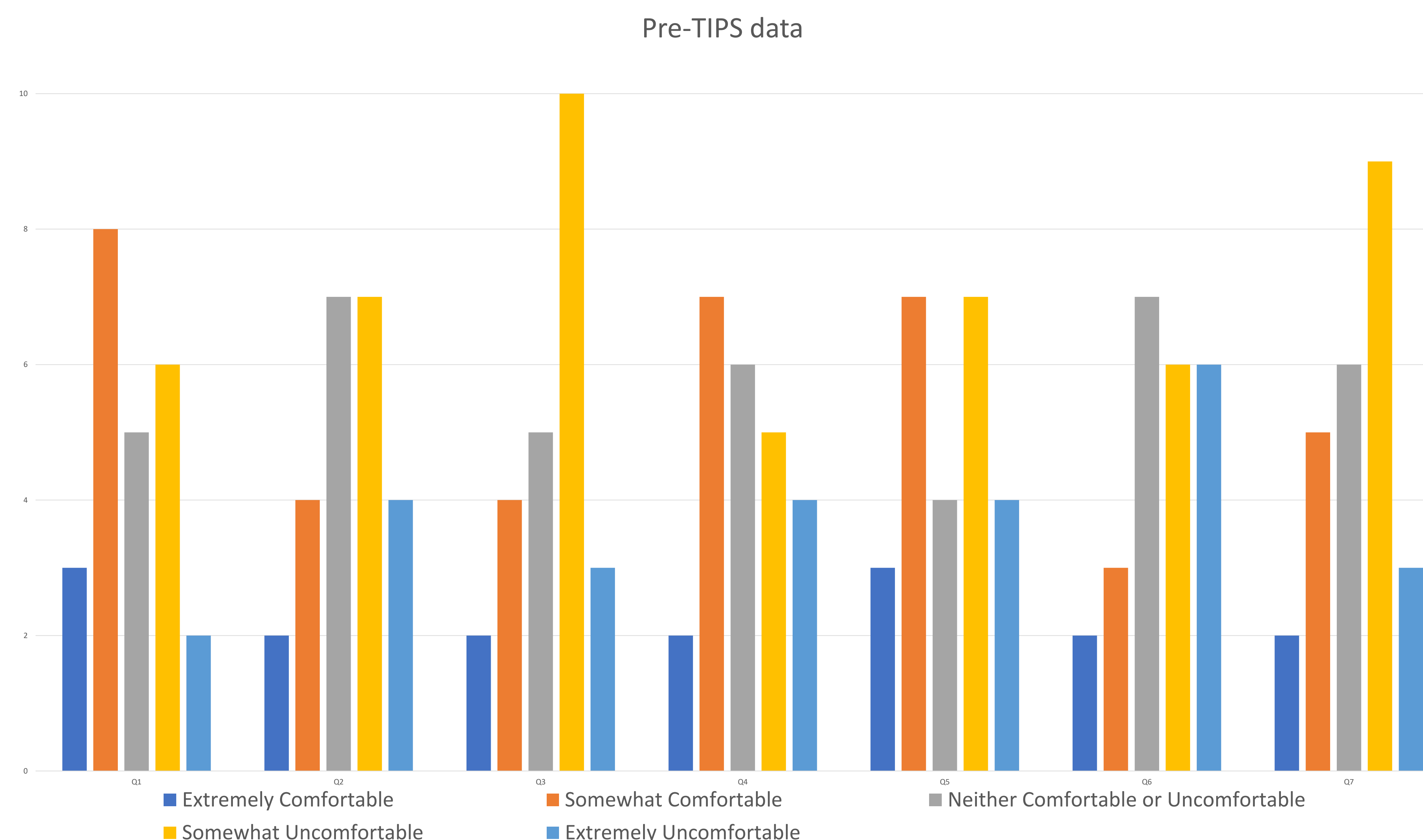
### HYPOTHESIS

Provider comfort when treating patients with moderate to profound ASD in the emergency department will improve as a result of having access to personalized de-escalation information provided on a tip sheet.

### METHODOLOGY

- Triage RN will provide a tip sheet to the parent/guardian of the child with ASD for completion.
- Upon completion, the tip sheet will be attached to the patients' charts as additional resources for provider reference.
- We will create 2 short surveys to administer to healthcare providers to examine comfort in providing care
  - Survey 1: pre-implementation of tip sheet
  - Survey 2: post- implementation of tip sheet
- Providers will be consented to complete surveys. The questionnaires will inquire about their experience and comfort level in caring for children/adolescents with ASD. Data will be de-identified.
- A consent form will detail the study purposes and privacy policy. Participation in the survey is voluntary.
- Participants will not be offered any compensation for completing surveys
- Surveys will be sent electronically to SBU employee email addresses to collect data
- Data will be analyzed using dependent T-test

### PRE-INTERVENTION RESULTS



### Survey

**Q1. How comfortable are you treating acutely agitated children with autism?**

**Q2. How comfortable are you treating acutely agitated children with autism who exhibit minimal to no functional speech abilities?**

**Q3. How comfortable are you treating acutely agitated children with autism who exhibit challenging behaviors (e.g., aggression, self-injury, property destruction)?**

**Q4. How comfortable are you with non-pharmacological de-escalation techniques for acutely agitated children with autism?**

**Q5. How comfortable are you with proper sedation selection and administration for acutely agitated children with autism?**

**Q6. How comfortable are you performing procedures on acutely agitated children with autism?**

**Q7. How comfortable are you with facilitating participation from acutely agitated autistic children in acquiring medical imaging?**



### TIP SHEET

Thank you for visiting Stony Brook Medicine's Pediatric Emergency Department. Please answer the following questions to help us optimize your child's healthcare. You may use the back of this sheet if needed. While all information is helpful, please note that due to the nature of care in the emergency department, we cannot guarantee that the information provided will impact your child's care.

Your Child's Name: \_\_\_\_\_

Your Child's Top Three Strengths:

Please check any of the below that describe your child's communication:

- No vocal speech
- Communicates through sign
- Communicates through exchanging pictures/icons/symbols (if so, can you provide staff with access?)
- Makes some vocal approximations of words
- Stronger receptive language (understanding others) than expressive (ability to state wants and needs)
- Stronger expressive than receptive language abilities
- Fluent speech

Please check any of the below that describe the amount your child communicates:

- Single words
- 2-3 word phrases
- Short sentences
- Full sentences

Does your child exhibit rigidities or strong preferences that may impact their healthcare, or have impacted healthcare in the past? If so, please describe:

Please indicate any challenging behaviors your child may exhibit that have potential to impact healthcare, and how often these behaviors occur in healthcare settings. Be sure to include instances of property destruction, verbal aggression, physical aggression, resistance to procedures:

**Behavior How often does this occur in healthcare settings?**

\_\_\_\_\_ Rarely Sometimes Always

Early warning signs that your child may engage in challenging behaviors:

Known triggers of challenging behaviors:

Activities that may help your child relax:

Preferred foods, leisure activities, and rewards:

Specific strong sensory aversions:

Does your child tolerate oral medications?

Please elaborate how your child will tolerate IV placement, if medically indicated:

### DISCUSSION

- **29% of ED residents were comfortable using non-pharmacological de-escalation techniques**
- **25% of ED residents were uncomfortable treating an agitated child with Autism**
- **41% of ED residents were uncomfortable treating an Autistic child exhibiting problem behaviors**

• **Limitations:** This study has several limitations. One is that, despite the impact provider comfort has on patient care, healthcare quality as determined by the patient and/or the patient's caregiver was not assessed. We expect to expand our study in future research by examining patient outcomes more broadly. Furthermore, provider comfort was limited to only resident physicians, and neglects the perspective of attending physicians, medical students, nurses, nursing assistants, and other emergency medical providers.

• This study is ongoing. We expect to see a marked improvement in provider comfort once adequately armed with individualized information about their patients