

Quality Story 2: Optimizing the Sedation Environment for Patients with Autism

Goals:

- To prepare patients with Autism Spectrum Disorder (ASD) prior to the appointment with the help of their families, so that they are better able to handle the stress of the visit.
- To educate health care providers about managing challenging behaviors in these patients.

Metrics:

- Survey of families to gauge impact of the preparation (goal >80% satisfied)
- Delay, cancellation, postponement or referral to anesthesia due to inability to sedate (goal < 5%)
- Staff and patient injuries or other adverse events due to patient behavior (goal 0 injuries per month)
- Pre and post tests showing improvement in the knowledge (>10% change) of health care providers in understanding the challenges for patients with ASD and strategies to prevent onset and escalation of difficult behaviors.

Project Description: Interventions and Outcomes

Patients with ASD have difficulty communicating, manifest self-stimulatory and repetitive behavior, are anxious in unfamiliar places and may have challenging behaviors and meltdowns, leading to delays or cancellations, referral to Anesthesia as well as staff and patient injuries. We developed an online educational module for health care providers (RN, MD, MA) to help them understand the core symptoms of ASD and how it impacts their abilities to communicate and interact, leading to difficulties in the medical environment. This included the One-Voice strategy to have a single person in the room communicating with patient. For patients, we developed an online visual support in the form of a social story for families (available prior to their visit online and at visit) to prepare and familiarize the child with the events that will occur during the encounter. All patients identified with developmental delays including autism spectrum disorders are contacted by Child Life Specialists in advance of their arrival to provide access to the social story and go over a list of special distraction devices from our grant-funded "Austim Tool Kit" that may help on the day of the visit. In addition, specific approaches to each patient are developed in advance with the family (i.e. security meeting family at the front door, directly bedding the patient and avoiding the waiting area, avoiding certain trigger words, identifying need for additional staff early).

Post-Trial Outcomes Metrics:

- Families have high satisfaction with preparatory materials and pre-arrival contact with Child Life. 90% highly satisfied (Likert Scale).
- Fewer same day referrals to Anesthesia/cancellations for patients unable to be adequately sedated. From 5% to less than 1%.
- Sedation team is highly satisfied with new process and has a better sense for best approach to patient before they arrive. 100% satisfied by on Likert scale.
- No staff/patient injuries in 6-months post implementation (3 staff injuries in prior year)
- Staff pre-test Autism knowledge assessment skills improved from 50% to 90% post intervention

Challenges encountered: Development took longer than expected due to the need for input from experts in ASD both at our institution and nationally.

Lessons learned: Following our lead, the institution has used the internally created module in educating providers hospital-wide. After developing this social story for sedation, other areas of the hospital have developed a similar social story for Lab draws, EEG, and clinic visits for patients with Autism (Division of Child Neurology and Laboratory Services). Successful strategies were shared with these other stakeholders involved in the development of the sedation social story.

Sedation Service Website: (<https://www.XXXchildrens.org/search-specialties/sedation-services/>)
See section on Patients with Special Needs (Blinded for Reviewer)