

Children's Hospital of Orange County
Best Evidence and Recommendations (BEaR)

*Evidenced-Based Practices for Children with Autism Spectrum Disorder When Undergoing
Medical Procedures*

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Abstract

Children with autism spectrum disorder have increased stress, anxiety, and medical trauma when undergoing medical procedures due to the core symptoms and characteristics of autism. This often leads to decreased procedural compliance and increased safety concerns. The literature was reviewed for best evidence-based practices to reduce stress, anxiety, and medical trauma in children with autism undergoing medical procedures. Additionally, outside children's hospitals were consulted on current practices and procedures. Based on a review of the literature, CHOC's current practices, and information received from other top ten Children's Hospitals, recommendations for current practice and future development with measurable outcomes were formulated. The overarching themes identified were preparation, proactive versus reactive care, addressing patient and staff safety, and standardizing care. Ways to reduce procedural stress, anxiety, and medical trauma recommended for implementation include an adaptive care program, a menu of services available, medical play kits before the procedure, an online library of resources, and increased staff and family education. Implementing ways to reduce procedural stress, anxiety, and medical trauma in patients with autism will increase scheduled procedures, increase procedural success rates, and decrease staff safety events. Ultimately, the recommendations are expandable and benefit all pediatric patients and their families.

Keywords

Autism spectrum disorder, pediatrics, medical procedures, anxiety, stress, medical trauma, desensitization, best practice, and procedural compliance

PICO(T)

For children with autism spectrum disorder, what are the best practices to reduce stress, anxiety, and medical trauma when undergoing medical procedures?

Background and Significance

The PICOT question was formulated after hearing many concerns from caregivers regarding the likelihood of their child being able to complete an ordered procedure. Caregivers expressed frustration, stress, and anxiety about letting the provider down because their child could not tolerate the procedure or having the attempted procedure lead to an emotionally traumatizing experience. As a result of these concerns, some caregivers never scheduled the recommended procedure or chose to reschedule multiple times. In addition to parents expressing concerns, clinical staff witnessed challenging behaviors from children during clinic visits that led to safety concerns for the patients, caregivers, and staff. Knowing how these behaviors interfere with medical compliance, there is an identified need to help families and staff meet the unique needs of children with autism during scheduled procedures.

The prevalence of autism is 1 in 44 nationally (CDC, 2018). Approximately 20% of all Orange County children enrolled in special education, from three to twenty-two years of age, have been diagnosed with autism (CDC, 2018). Orange County's rate is the highest in California (CDC, 2018). The 2019 Children's Hospital Orange County's community needs assessment placed mental health and autism as the number one community need (CHOC, 2019).

Studies have found that pediatric patients with autism are hospitalized at higher rates than their typically developing peers (Straus et al., 2019). Co-morbidities with autism include epilepsy, sleep disorders, GI disorders, ADHD, anxiety, depression, and feeding challenges which can lead to hospitalization and necessary medical procedures (Hyman et al., 2020). Commonly ordered procedures include, but are not limited to, LTMs, ambulatory EEGs, Sleep Studies, lab draws, MRIs, and dental procedures.

Medical procedures are anxiety-provoking for all children. Components of a medical procedure that cause stress, anxiety, and medical trauma for children include having to manage an unfamiliar environment, people, and equipment, the potential for pain, the length of the procedure, dealing with environmental stressors and sensitivities such as sounds, smells, and temperature, and past medical or emotional trauma (Drake et al., 2012; Mannenbach et al., 2021; Straus et al., 2019). The characteristics of autism that increase procedural stress, anxiety, and medical trauma include restricted and repetitive behaviors, sensory concerns, social and communication deficits, a need for sameness and routine, and difficulty with transitions (Hyman et al., 2020). Other components include impulsivity, perseveration, and self-stimulatory behaviors that can add to the difficulty of procedural completion. In addition, delayed language skills, cognitive skills, or different learning styles can make it challenging for the child with autism to understand their own emotions, possess the ability to follow directions, or communicate with staff regarding what is stressful and fearful to them. The scheduled healthcare visit and procedure may interfere with the child's daily routines, thus impacting medical and procedural compliance. These characteristics of autism, combined with the typical



anxiety from a medical procedure, exponentially increase the difficulty level of obtaining a safe, non-traumatizing medical procedure.

The Thompson Autism Center is in the initial steps of creating a desensitization program to be led by psychology and the behavioral team in which patients with a high level of desensitization needs are supported. Currently, at CHOC, there is no standardized practice to easily access predetermined information or assess patients to determine the level of support needed. In addition, the resources to implement comprehensive best practices to reduce stress, anxiety, and medical trauma for autistic patients have not been thoroughly explored.

This evidenced-based review aims to discover best practices for reducing stress, anxiety, and medical trauma in children with autism to increase procedural compliance with this patient population, decrease staff and patient safety concerns, and provide opportunities for staff education.

Framework

This EBP project utilizes the “Translating Evidence into Practice: CHOC’s Approach to EBP” model, adapted from the EBPI Model © 2007 Brown & Ecoff (Ecoff, Stichler & Davidson, 2020).

Search for the Evidence

Databases searched for this review included PubMed and CINAHL. Keywords included autism spectrum disorder, pediatrics, medical procedures, anxiety, stress, medical trauma, desensitization, best practice, and procedural compliance. The search yielded 30 articles, of which eight were found to have the applicable information. Of the articles used, levels of evidence were levels I, level III, level V, level VII, and level VIII.

Further evidence was gathered from Boston Children’s Hospital, Texas Children’s Hospital, Cincinnati Children’s Hospital Medical Center, Children’s Hospital Los Angeles, Children’s Hospital of Philadelphia, and Children’s Hospital Colorado. Professional associations consulted were the American Academy of Ambulatory Care Nursing (AAACN) and the Association of Child Life Professionals (ACLP).

Websites reviewed included Centers for Disease Control and Prevention and Children’s Hospital Orange County.

Critical Appraisal and Synthesis of the Evidence

- Best practices for procedural interventions for children with autism include employing family-centered care, advanced preparation, standardized protocols, and additional time for desensitization tactics resulting in proactive versus reactive work (See Table 1).



- Family center care allows for unique needs to be understood and addressed (Drake et al., 2012, Mannenbach et al., 2021; Zaremba et al., 2005). Individualized care plans created before procedures allow staff to be better prepared and the child to be more successful in procedural compliance.
- Site tours are conducted on applicable units and outpatient settings (Murata et al., 2020).
- Medical play kits with the option to be mailed to patients’ homes to decrease the barrier of caregivers making increased trips to the facility (Murata et al., 2020; Primeau et al., 2016; Zaremba et al., 2005).
- Systematic desensitization practices are utilized for procedural preparation involving the partnership of child life, psychology, and the behavioral team (Primeau et al., 2016).
- Sensory carts or coping kits with different items and communication tools are located in each inpatient unit and Emergency Department and are utilized for calming and coping as well as distraction (Drake et al., 2012; Zaremba et al., 2005).
- Environmental adaptation of exam rooms, including lowered lights, decreased staff members present or reduced noise, and procedure routine adaptation in which steps of the procedure are changed to accommodate the child (Murata et al., 2020; Zaremba et al., 2005).
- Increased staff, patient, and caregiver education on autism spectrum disorder, available resources for support, and procedure explanation (Murata et al., 2020; Primeau et al., 2016).
- Use of comfort holds involving parent or caregiver to assist the patient in calming and remaining still during the procedure as opposed to staff holding a patient down (Murata et al., 2020).
- Creating sub-wait rooms to place patients with autism and caregivers while waiting for a procedure (Mannenbach et al., 2021; Straus et al., 2019). Sub-wait rooms are quieter and less busy waiting rooms to decrease sensory overload. Fast-track systems in which patients with autism are not required to wait for long periods before a procedure (Mannenbach et al., 2021; Straus et al., 2019).
- Use visual cues such as social stories, pictures, and PECs cards to increase patient communication and understanding (Drake et al., 2012; Murata et al., 2020).

Table 1

Best Practices from the Literature	Source
Medical Play Kits	Murata et al., 2020; Primeau et al., 2016; Zaremba et al., 2005
Patient/caregiver/staff Education	Murata et al., 2020; Primeau et al., 2016
Visual Cues (social stories, pictures, PECS cards)	Drake et al., 2012; Murata et al., 2020,



Family Centered Care (individualized care plans)	Drake et al., 2012, Mannenbach et al., 2021; Zaremba et al., 2005
Environment/routine Adaptation	Murata et al., 2020; Zaremba et al., 2005
Distraction	Drake et al., 2012; Zaremba et al., 2005
Site Tours	Murata et al., 2020
Coping Kit (sensory/communication items)	Drake et al., 2012
Comfort Holds	Murata et al., 2020
Sub Wait Rooms & Fast-Track System	Mannenbach et al., 2021; Straus et al., 2019
Systematic Desensitization	Primeau et al., 2016

Additional Best Practices from Medical Facilities

- *Adaptative care programs* have effectively supported children with developmental, sensory, and behavioral challenges through their healthcare experiences (Doernbrack et al., 2021; Texas Children’s Hospital, 2022).
 - This program facilitates less traumatic and more productive healthcare encounters by increasing safety through alerting staff in advance of patient stressors, triggers, and positive coping strategies.
 - This provides staff with strategies to support patients with special needs by having a coping plan to help staff prepare and have resources to best support the behavioral and emotional needs of that individual child.
 - Daily reports are generated of patients in-house with a support plan for developmental disabilities and behavior concerns so that staff knows which unit these patients are on, and resources or consultation can be provided appropriately.
- Simulation Centers are being used to advance capabilities of incorporating scheduled procedures, desensitization appointments for medical play, and procedural and surgical prep, thus elevating the program from traditional simulation center practices used primarily for staff training purposes (Boston Children’s Hospital, 2022).
- The use of extended reality, including virtual and augmented reality, robots, 3-D printing, and holographic displays, are utilized to reduce stress and anxiety (Cincinnati Children’s Hospital Medical Center, 2022).
- Providing an extensive online library of resources, educational books, social stories, and procedural preparation videos accessible to families and the community (Boston Children’s Hospital, 2022).

Practice Recommendations

- Implement an adaptive care team or program to help support patients with autism seen throughout CHOC. Referrals to this team could be placed by staff or caregivers. Once



referred, an adaptive care plan will be initiated if a patient meets the criteria. A standardized set of questions is asked and added to the chart in an easily accessible place. Questions would be regarding stressors, triggers, and coping methods.

- Create an icon that would be present in the banner bar of the chart and on the unit tracker boards as a quick reference indicating that the staff member should look further into the chart for the adaptive care plan. This is essential as it promotes safety for patients and staff. CHOC can be at the forefront of establishing an icon for this purpose, as many hospitals are looking to do this but have not implemented it yet.
- Compile a complete menu of services with all practices CHOC has to offer to help reduce stress, anxiety, and medical trauma. Parents and staff can utilize this menu of services to implement what is best for that patient.
- Institute medical adaptations to care services such as providing manual blood pressure and consulting with families regarding the best time of day to schedule procedures.
- Institute environmental adaptations to include room preparation before each child's visit that incorporates the child's preferred items.
- Implement the use of medical play kits provided to families before the procedure.
- Create a sensory cart or toolbox on units accessible to all shifts for patient use.
- Utilize a fast-track patient registration system to minimize wait times for the child and their family for visits and procedures.
- Increase the use of site tours before the scheduled procedure.
- Implement the use of PECS cards downloaded on any iPads used for interaction with patients to increase communication.
- Increase care coordination between the Thompson Autism Center and other areas of CHOC to offer support, education, and patient management.
- Provide additional education and resources for staff on autism by sharing tool kits, cornerstone modules, brain bites, and presentations at ground rounds. Essential topics include: an introduction to autism, tips for working with patients with autism, including "if then and first then" methods, and positive reinforcement by utilizing a reward, token, or incentive system. Multidisciplinary collaboration on education tools with Behavior Team and Psychology is necessary.
- Create an easily accessible online library of resources with lists of educational books, social stories, virtual hospital tours, videos of procedural preparation, and PECS cards for families to use and staff to refer to.
- Increase the use of music therapy, pet therapy consults, and facility dogs.
- Increase patient use of extended reality technology for visits and procedures.

Outcome Measures

Possible outcome measures can include:

- Monitoring the number of safety reports at CHOC.
- Determining if there is an increased number of scheduled procedures.
- Implement pre- and post-intervention assessments using a pediatric anxiety scale.

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