Providing Inpatient Medical Care to Children With Autism Spectrum Disorder

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ABSTRACT Autism spectrum disorder (ASD) is a common neurodevelopmental disorder, affecting an estimated 1 in 40 children. Children with ASD have high rates of medical comorbidity and often experience high levels of distress during medical admissions, increasing the risk of agitation. Pediatric hospitalists receive minimal formal training on the inpatient care of children with ASD. In this article, we review strategies that pediatric hospitalists can use to optimize the care of children with ASD during inpatient admissions. These include gathering an ASD-related history early in the admission to understand the child’s baseline core ASD symptoms, including social and communication ability, sensory needs, and restricted or repetitive behaviors. This information can be used to tailor the hospitalist’s approach in each of these 3 domains. We conclude by reviewing procedure-related considerations, an approach to managing agitation, and quality improvement interventions.
Autism spectrum disorder (ASD) is a lifelong neurodevelopmental disorder with a heterogeneous constellation of social, communication, and behavioral symptoms. According to the Diagnostic and Statistical Manual, Fifth Edition, the 2 core symptom clusters of ASD include deficits in social communication and interaction as well as restricted, repetitive patterns of behavior, interests, or activities. Symptoms are usually apparent within the first few years of life, and individuals with ASD can exhibit a wide range of intellectual and language abilities. Over the past 2 decades, the prevalence of ASD among children in the United States has risen from 1 in 150 children in 2000 to 1 in 40 children in 2018, representing a 273% increase.

With this increase in prevalence and high rates of medical comorbidity, it has become increasingly important for health care providers and systems of care to meet the medical needs of children with ASD. In a previous study conducted at Kaiser Permanente Medical Program, researchers demonstrated that children with ASD have a higher number of medical admissions and increased total medical costs compared with children without ASD. The length of stay for inpatient admissions is >2 days longer (6.5 vs 4.2 days) for children with ASD. Total annual health care costs for children with ASD are also consistently higher when compared with the general population. Despite higher health care costs, children with ASD are more likely to report unmet access to specific health care services, delayed or foregone care, and concerns that care is not family centered. Pediatric inpatients with ASD have also been shown to be at risk for episodes of agitation during admission, placing themselves and staff caring for them at risk.

Factors contributing to limited access, increased costs, and low health care satisfaction for children with ASD are likely multifactorial and include systems-, patient-, and provider-based factors. Systems-related factors include the fast-paced and unpredictable nature of inpatient medicine, limited resources, and challenges in coordinating care between multiple health care teams. Patient-related factors that can complicate care delivery include sensory processing difficulties, communication challenges, and difficulty tolerating new experiences and transitions. These factors can manifest as boredom, overstimulation from the novel environment, and distress related to disruption of normal routines. Both parents and health care providers agree that additional training to work with children with ASD is needed. Finally, provider-related factors include typically large size and high turnover of inpatient care teams interacting with patients as well as the paucity of appropriate training for pediatric hospitalists in the management of patients with ASD, despite their desire for greater education around this issue. Researchers of one survey study of pediatricians, which reflects this desire for more guidance, highlighted the need for expert consensus practice guidelines for working with youth with ASD. Despite these challenges, there are several strategies pediatric hospitalists can use to facilitate the provision of timely and high-quality medical care while minimizing health care related distress for children with ASD. This article is a narrative review, in which we highlight some helpful approaches to providing inpatient medical care for children with ASD. The approaches we discuss include close collaboration with parents to understand each patient’s unique ASD profile, facilitating early involvement of a multidisciplinary team, advocating to modify the environment to decrease anxiety, and coordinating with consultants to streamline care and reduce peri-procedural distress. We conclude by addressing how systems-level changes and additional provider training are needed.

METHODS

A literature search was conducted using the PubMed database for articles in the English language pertaining to the medical care of children with ASD. In addition to “autism spectrum disorder,” search terms included “pediatric,” “children,” “adolescents,” “medical,” “hospital,” and “inpatient.” References from relevant articles were reviewed for additional pertinent publications.

INFORMATION TO OBTAIN ON ADMISSION

Because each child with ASD has a unique constellation of core and related symptoms of ASD, including a wide range of verbal and intellectual abilities, it is important to obtain baseline information from the child, parents, and outpatient providers to understand the patient’s ASD profile. Baseline information on the child’s intellectual ability, functional ability, preferred communication style, sensory needs, triggers, and methods to resolve behavioral escalation should be collected either before the admission or as early in the admission as possible and recorded so it is easily available to all team members. Researchers of a pilot quality improvement study demonstrated that it is feasible to obtain this information through a structured questionnaire and that 88% of parents felt it “definitely” improved their hospital experience. Parents who completed the questionnaire reported better experience of care and staff attention to their child’s ASD-specific needs than parents who did not complete the questionnaire.

The information obtained from this initial assessment aids in establishing the patient and parent as valued collaborators and informs which interdisciplinary team members are needed. When providing the history, parents can participate in a discussion about their child’s needs and strategies that can be used to minimize distress. The pediatric patient should be included in this discussion as much as possible. They should be reminded to obtain items from home that can facilitate communication, such as augmented and alternative communication devices, as well as items that can help relieve distress, such as a favorite toy or video. Several interdisciplinary team members can play unique roles to support the child, family, and health care providers during the admission. Certified child life specialists are health care professionals who help facilitate coping, decrease stress, and encourage positive development for children in medical settings. Strategies that child life specialists use to decrease child distress
include minimizing environmental stressors, using distraction tools, and providing parental support. Occupational therapists can conduct a sensory profile assessment and provide recommendations on sensory strategies that are feasible in the hospital setting. Speech and language pathologists can help devise simple communication systems to facilitate clear communication between the child and the care team. Child psychiatry should be consulted if comorbid psychiatric disorders may complicate the admission or if psychopharmacologic interventions may be helpful to manage distress. Child psychiatry can aid in obtaining collateral information from the child’s outpatient psychiatry team and helping to optimize behavioral management strategies to determine if psychopharmacologic interventions may be warranted. Finally, early involvement of case management can help to identify and address barriers to discharge.

APPROACHES TO SOCIAL AND COMMUNICATION DIFFERENCES

Although deficits in social interaction is a core symptom of ASD, children with ASD can demonstrate a wide range of social challenges. Because of this variability, it is important to determine the child’s baseline social functioning early during the admission to inform health care providers’ interactions. Social pragmatic deficits commonly seen among children with ASD include difficulty initiating conversation, poor understanding or limited use of nonverbal communication, and failure to respond to social interactions. Some general social approaches that may be helpful include limiting staff turnover, decreasing the number of providers in the room at one time, ensuring that only one provider is speaking to the child at a time, and paying close attention to the child’s nonverbal cues. The physical examination can be a stressful interaction for children with ASD, particularly because it involves physical contact. Parents of children with ASD felt that explaining each step as it occurred, allowing the children to examine the instruments, and modeling the examination on a trusted adult would improve cooperation. If a social interaction becomes overwhelming, the majority of parents felt that giving the child some space or a break would be the most helpful approach.

Children with ASD also have a wide range of communication abilities. Researchers of a survey study of children and adults with a parent-reported history of ASD (average age: 14.6 years, age range: 2–49 years) who were hospitalized demonstrated that 38% of patients expressed their needs through sign language or gestures, 31% used communication tools (including Picture Exchange Communication Systems or electronic devices), and 23% used verbal language. Only a minority of patients (19%) used spoken language to communicate the nature and location of physical pain. Twenty-seven percent of patients expressed pain through self-injury or aggression, whereas 32% of patients expressed pain through crying or screaming. Facilitating clear communication during a medical admission is of critical importance because effective communication strategies can reduce disruptive or challenging behaviors. If a child has limited verbal language abilities and their home communication devices are not available, the health care team should consider using simple visual symbols such as cue cards or storyboards to enhance understanding and ease anxiety. In a pilot study, a hospital system created 150 visual symbols representing commonly conducted physical examinations, medical investigations, and treatment procedures. Health care providers felt that use of symbols was helpful for improving cooperation and understanding. When verbal communication is used, it is helpful for the provider to use direct, literal language to avoid confusion or misinterpretation and to assess whether the child’s verbal abilities are overwhelmed.

APPROACHES TO SENSORY NEEDS

Hyper- or hyporeactivity to sensory input is one of the diagnostic criteria of ASD in the Diagnostic and Statistical Manual, Fifth Edition, and ≤80% of children with ASD exhibit sensory processing differences, often with difficulties in more than one sensory modality. The hospital environment can be sensorially overwhelming because abnormal sensory responses to nonnoxious stimuli can generate discomfort and distress. Patients with significant sensory sensitivities may also be at increased risk of experiencing agitation during inpatient admission. Health care provider understanding and flexibility around these sensory inputs can help ease a great deal of distress. The health care environment for children with ASD should attempt to limit aversive sensory stimulation wherever possible. Certain areas of the hospital, such as emergency department waiting rooms, have higher levels of sensory input. Time spent in these areas should be either avoided or limited as much as possible.

Caring for children with ASD in quiet and private settings is a helpful strategy to limit sensory-related distress. Use of natural lighting rather than hospital lighting, having access to a private room, clustering care, and closing the door to minimize sensory input are other strategies that are simple and likely feasible to implement. One tertiary pediatrics hospital developed a clinical pathway to identify patients with sensory sensitivities and implement care in the emergency department and pediatric inpatient units that was sensitive to their sensory needs. Components of the clinical pathway included staff training, provision of sensory toolkits, early collaboration with allied professionals, and continuous parental involvement. The component of the clinical pathway that families felt was most beneficial was use of sensory toolkits, which included noise-canceling headphones, fidget tools, light spinners, and weighted lap pads.

APPROACHES TO RESTRICTED AND REPETITIVE PATTERNS OF BEHAVIOR

Restricted, repetitive patterns of behavior, interests, or activities is another core symptom of ASD. Children with ASD often
have an insistence for sameness or inflexible adherence to routines. Inevitably, hospitalization is a major disruption to a child's routine that can be extremely distressing. To reduce this distress, health care providers should attempt to create routines and structure during the hospitalization and maintain as many home routines as possible. The development of a specialized psychiatric inpatient unit for children with ASD which decreased length of stay and need for readmission highlights several strategies that can be adapted to a pediatric medical unit.\(^25\) The structured environment on the specialized psychiatric unit included organizing the environment to clearly define areas for various activities such as social group, independent leisure, relaxation, and work with staff.\(^25\) This approach could be modified for a pediatric medical unit by identifying spaces within the patient's room that are for relaxation and spaces that are for medical treatment. If possible, procedures that are aversive should be performed outside of the patient’s room. Other strategies that were beneficial for the psychiatric unit included incorporating consistent daily schedules and alternating less preferred activities with preferred activities.\(^25\) To minimize distressing unpredictability, it may be helpful to incorporate routines for the medical unit, such as rounding at the same time, conducting the physical examination in the same order each time, or creating visual schedules that are similar from day to day and include time for preferred activities or breaks. Cooperation with unpleasant activities should be positively reinforced using time for preferred activities or using the child's unique interests.\(^28\) Home routines such as mealtimes, bedtimes, and bedtime routines should be maintained in the hospital. Parents can also be encouraged to bring in familiar everyday items from home such as cups, toys, soap, and toothpaste.\(^14\)

**CONSIDERATIONS FOR PROCEDURES**

Understandably, even relatively minor procedures such as laceration repair and imaging can be difficult for children with ASD to tolerate because of the aforementioned social, communication, and sensory needs of this population. Additionally, the most helpful approach will vary from child to child. Some children will find preparation through viewing a video of the procedure or social stories, a short sequence of pictures and sentences to prepare a child for a new experience, helpful. Elements of preparation that seem to be most helpful include structure, the ability to practice, and reduced fear of the unknown.\(^29\) For other children however, advanced preparation may actually increase anxiety, and there are also emergent or unexpected situations that are not possible to prepare for. More general approaches that can help decrease distress in these situations include using distraction, reducing wait times, bundling or streamlining care, providing positive reinforcement, and using anxiolytic medication.\(^30\)\(^-\)\(^32\) Distraction techniques generally consist of diverting a child's attention away from noxious stimuli to more pleasant stimuli, such as a favored toy or video. Decreased wait times can help limit the window for anticipatory anxiety. Bundling care, particularly when a child will require general anesthesia, can allow for multiple noxious procedures or examinations to be conducted efficiently. Although no conclusive studies on the most effective and safest anxiolytic medications in hospital settings have been conducted, a pilot study assessing perioperative management of children with ASD used either oral midazolam or oral ketamine or a combination of the 2 to premedicate children before insertion of an intravenous catheter and induction of anesthesia.\(^32\)

**MANAGEMENT OF AGITATION**

Pediatric hospitalists are encouraged to work to proactively reduce the risk for challenging behaviors through identifying and avoiding known triggers for agitation, ensuring adequate communication, minimizing sensory-related distress, and creating structure and routines. Identification of patients at increased risk for agitation may allow for earlier and more active efforts to prevent it. In one recent study, researchers demonstrated that the best predictor of agitation during hospitalization is a history of aggressive or self-injurious behavior; the risk increases in accordance with the severity of these past behaviors, and that patients with significant sensory sensitivities are also at increased risk of agitation in the hospital.\(^3\) It is also important to determine warning signs for impending agitation so that behavioral interventions can be implemented as early as possible to reduce the need for emergency medications and use of physical restraints.\(^33\) Researchers of a recent study demonstrated that brief applied behavioral analysis–based interventions for children with ASD displaying challenging behaviors in hospital settings is feasible and well-accepted by both hospitalists and parents,\(^14\) highlighting the importance of maximizing behavioral strategies to manage agitation. Parents should also be consulted on effective strategies for decreasing distress that can be used in the hospital setting, ideally early in the admission, particularly for children with risk factors for agitation. If the child's behaviors create an imminent safety risk for him or her and/or staff, emergency medications should be administered with the goal of calming the patient enough to use behavioral strategies and coping techniques. Details of past responses to medications should be used to guide the psychopharmacologic approach because children with ASD can exhibit sensitivity to medications and are at risk for paradoxical reactions.\(^34\) Ideally, such a contingency plan would be determined upon a child's admission to the pediatric floor to avoid any potentially dangerous delays in administering medications if they are needed. In general, benzodiazepines and anticholinergic medications should be avoided, particularly if the child has not received the medication in the past, because of elevated risk of paradoxical reactions. That said, some patients do benefit from using these medications, particularly if other agents are ineffective or contraindicated.\(^35\) Studies on the psychopharmacologic management of acute agitation in children with ASD are lacking. For mild to moderate agitation, oral medications including \(\alpha\)-2 agonists, such as clonidine and guanfacine, should be considered. If the agitation is more severe, a second-generation antipsychotic, such as...
risperidone or aripiprazole, may be considered.

It is imperative that the health care team seek to identify the cause or function of the challenging behaviors. It is essential to complete a full medical review of systems and physical examination, because physical discomfort can manifest as self-injurious or aggressive behaviors. Impaired sleep can also contribute to irritability in children with ASD. Difficulties with communication, co-occurring untreated psychiatric disorders, and maladaptive reinforcement patterns in which the challenging behavior leads to secondary gain should also be considered and addressed if present.

**SYSTEMS-BASED AND QUALITY IMPROVEMENT INTERVENTIONS**

Improving the quality of care for pediatric patients with ASD requires changes not only at the level of the individual patient, but also systemic change in the approach to treating these patients, of which pediatric hospitalists should be a critical part. One effective quality improvement intervention is the development of a care pathway that helps guide the treatment of patients with ASD according to defined best practices. Elements of such a care pathway might include online preadmission materials for families to help prepare them and the patient for admission, a streamlined preadmission process that minimizes wait times in crowded and overstimulating environments, preferential assignment to individual rooms when possible, and the use of order sets that prompt an admitting clinician to consider orders that may be helpful, such as consultation to occupational therapy and psychiatry.

Another helpful systemic intervention that has been described is the development of a parent questionnaire that can help inpatient providers gather useful information about the patient, including potential triggers for agitation and soothing strategies, and using this to develop individualized care plans for the patient that can be easily accessed through the electronic medical record.

Finally, administrators and clinical leaders must ensure that providers have access to the resources they need to provide high-quality care for patients with ASD. These resources include physical equipment such as weighted blankets, sensory toys, communication devices, and protective equipment for staff caring for severely agitated patients. They also include readily available access to information including effective treatment strategies as well as local and regional resources for children with ASD. The development of online “toolkits” containing this kind of information may be a valuable intervention.

**TRAINING AND ADDITIONAL RESOURCES FOR PEDIATRIC HOSPITALISTS**

Pediatric hospitalists are called upon to care for patients with ASD during the uniquely stressful experience of an inpatient hospital stay; however, there is little formal training provided during any stage of medical training, from medical school to pediatric residency to hospital medicine fellowship, to prepare providers for this important task. Instead, most knowledge is gained by on-the-job experience. This shortcoming is underscored by the fact that when surveyed, pediatric residents express gaps in training and knowledge related to the medical care of patients with ASD. Furthermore, although the specialty is in its infancy, Pediatric Hospital Medicine fellowship programs are not mandated to provide a formal curriculum for educating hospitalists in the care of hospitalized children with ASD. Although successful graduates of the fellowship must “demonstrate the ability to refer and/or comanage patients with common behavioral and mental health issues along with appropriate specialists when indicated,” there are not specific guidelines about how such a competency should be achieved. As such, there are opportunities to improve the education of pediatric hospitalists during their training as well as opportunities for practicing hospitalists through the development of training materials and consensus guidelines.

**CONCLUSIONS**

In summary, ASD is a highly prevalent neurodevelopmental disorder with high rates of medical comorbidity. The core features of this disorder can contribute to making inpatient medical admission a particularly stressful situation for these children and families and can present significant challenges for health care providers as well. Despite increased associated health care costs and use, patient and family satisfaction surveys clearly indicate that there is a critical need to improve the quality of care for this patient population. Through a deeper understanding of ASD and knowledge of helpful treatment strategies, pediatric hospitalists can play an essential role in this effort.

**REFERENCES**


122(6). Available at: www.pediatrics.org/cgi/content/full/122/6/e1149


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