


Medical Encounters for Youth With Autism Spectrum Disorder: A Comprehensive Review of Environmental Considerations and Interventions

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Jolie Straus¹ , Sarah Coburn¹, Stephanie Maskell¹,
Jessica Pappagianopoulos¹ and Kathryn Cantrell¹

¹Department of Child Study and Human Development, Tufts University, Medford, MA, USA

ABSTRACT: Approximately 1 in 59 youth are currently diagnosed with autism spectrum disorder (ASD), a neurodevelopmental disorder. In comparison to typically developing peers, youth with ASD encounter hospitalization at higher rates due to their heightened health care needs. While visiting the hospital is a stressor for youth with neurotypical needs, the experience contains unique challenges for those with ASD. This systematic literature review highlights research that considers the psychosocial impact of the hospital environment on the coping and adjustment of youth with ASD. Specifically, the review focuses on recommendations and interventions that may be used by health care professionals while supporting this population as they encounter the health care system. Ninety-six articles were identified as meeting inclusion and exclusion criteria. The findings suggest that practicing clinicians should implement a wide variety of interventions for youth with ASD including diversion techniques, comfort positions, and picture schedules. Although there are published evidence-based interventions for supporting youth with ASD in the hospital, most clinicians lack ASD-specific training. This article concludes with recommendations for future research.

KEYWORDS: Autism, emergency medicine, surgery

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CORRESPONDING AUTHOR: Jolie Straus, Department of Child Study and Human Development, Tufts University, 105 College Ave, Medford, MA 02155, USA.
Email: Jolie.Straus@childrens.harvard.edu

Background

Autism spectrum disorder (ASD) is estimated at affecting 1 in 59 children and this rate is on the rise.¹ In addition, ASD is a developmental disorder that affects behavior and communication.² Autism is considered a “spectrum” disorder because the severity and symptoms vary widely among individuals. Some individuals diagnosed with ASD are able to independently perform activities of daily living, while others require significant support for basic activities such as communicating and socializing.³ Core characteristics of an ASD diagnosis include communication difficulties, restricted interests, repetitive behaviors, and sensory challenges, such as sensitivities with severe lighting, noise, clothing, and temperature. Likewise, youth with ASD adjust to new environments more easily when there is a structured routine.³ Consequently, a hospital setting is especially challenging for youth with ASD considering the sensory input, social demands, and disrupted routine. A large percentage of youth with ASD have medical comorbidities that require frequent visits to the hospital.⁴ Although medical experiences can provoke anxious feelings in children who are typically-developing, youth with ASD face additional challenges, such as difficulty with sensory integration, transitions, flexibility, and communication within their medical experiences.⁵

Youth with ASD are hospitalized at higher rates in comparison to their typically developing peers.⁶ Frequent hospitalizations and medical appointments are due to the high rate of comorbidities among individuals with ASD. Common comorbidities associated with an ASD diagnosis include gastrointestinal issues, eczema, allergies, asthma, ear and respiratory

infections, seizures, and migraines.⁴ Despite the higher than average hospitalization rates, the health care system is often not adequately supporting this population’s unique sensory, behavioral, and communication needs. The aim of this comprehensive literature review is to identify research that examines the adjustment of youth with ASD in various health care settings. These settings include the emergency department (ED), surgical and procedural areas, primary care offices, waiting rooms, and inpatient settings. These settings were chosen due to the high frequency at which youth with ASD encounter these environments, which are the main components of most pediatric medical facilities. For each area, this review explores (a) common stressors and barriers to care, (b) recommendations to improve common challenges, and (c) future considerations. With more intentional and targeted interventions for youth with ASD, health care providers can support their psychosocial adjustment before, during, and after medical encounters.

Method

To identify research describing interventions aimed at supporting the adjustment of youth with ASD, a comprehensive literature review was conducted. In accordance with Cooper⁷ and Moher et al,⁸ authors followed 5 guiding steps in conducting the present comprehensive literature review (ie, problem formulation, data collection, data evaluation, analysis and interpretation, and presentation of results). For problem formulation, the team clearly defined the limits of the population, setting, and search terms. During data collection, the team created a review protocol and each team member ran searches for a



specific setting. Team members switched settings to provide colleague triangulation. Data evaluation also followed in the footsteps of Cooper (2015): team members met together to assess whether the articles met inclusion/exclusion criteria and if so, should they be included as a valuable resource in this article. To ensure strong internal validity among team members, the team met to analyze each of the articles and synthesize their main points. Finally, the team also collaboratively discussed which articles would be included in this article and which would be omitted.

Search strategy

In an effort to provide an extensive view of the range of literature chronicling psychosocial adjustment to hospitalization among youth with ASD, authors performed a comprehensive literature search of articles published between January 2006 and May 2018 across 3 databases. Authors explored all published scholarly articles including observational and experimental studies, position papers, other literature reviews, and dissertations. To cover the medical and social sciences literature, the present review conducted searches across disciplines in the following bibliographical databases: Google Scholar, PubMed (National Center for Biotechnology Information [NCBI], January 2006– May 2018), and PsycINFO (EBSCO, January 2006–May 2018). Primary search terms included autism* and ASD* (ie, the target population). Asterisks were used to ensure all variations of terms were included in the search. The 2 primary search items were individually combined with 5 secondary search terms (ie, the 5 hospital settings), emergency department*, waiting room*, surgery* and procedure*, inpatient*, and primary care*, resulting in a total of 10 search combinations and 30 distinct searches across the databases.

Inclusion/exclusion criteria

The present review explored literature on the adjustment of youth with ASD to hospital encounters. Thus, items chronicling populations across the lifespan other than youth with ASD were not included. This was operationalized as individuals aged 0–18 with an ASD diagnosis. Likewise, this review considered the youths' psychosocial adjustment to hospitalization and did not consider papers that chronicled the medical impact of hospitalization. In addition, book chapters, books, articles unavailable in English, and articles focused on diagnosis/screening of autism were omitted. Authors had a checklist of inclusion/exclusion to guide their process. Authors gathered abstracts of all studies meeting criteria before evaluating their final inclusion in the study.

Data extraction and management

When exploring across all search terms, the initial literature search produced 61 719 articles. Five researchers reviewed the

list of citations and abstracts, removing duplicates across search terms and applying the exclusionary criteria methodically to identify relevant articles. Papers were commonly excluded if the focus was on experiences outside of the psychosocial adjustment of the child to hospitalization or adult (>18), rather than pediatric populations.

On initial review by the team, 140 articles met the inclusion and exclusion criteria. Subsequently, the team reviewed, discussed, and critically appraised all studies to ensure consistency. Included in this critical appraisal was an evaluation of the studies' risk of bias, usefulness in supporting psychosocial adjustment, and methodological rigor. On triangulation among the entire research team, 96 articles remained, after correcting for duplicates across all search terms and databases. Disagreements and discrepancies regarding inclusion in the review were resolved by discussion, comparison of results, further examination of the papers, and group consensus.

Analysis

For each study, the researchers categorized the articles' disciplines, methods, and appropriate section for inclusion in this literature review. Researchers identified common themes that emerged across each setting of literature. Following these discussions, the team compiled this article.

Results

From our literature search to post triangulation of the findings, we found 96 articles meeting our inclusion criteria. Publications spanned multiple fields including child life, pediatric psychology, nursing, medicine, public health, and education. The studies ranged from original research to theory validation to position. For this literature review, we used the 96 articles to explore risk factors and prevention efforts associated with psychosocial adjustment of children with ASD to various hospital settings. Results are organized by setting and listed in Table 1.

Results by setting

Results by setting are described in Table 1. For each set of search terms, the total number of articles found across all 3 databases was recorded. Afterwards, each article found was reviewed to determine whether the article met inclusion/exclusion criteria. This number was also recorded. Finally, the number of articles remaining after team triangulation and correcting for duplicates was also recorded.

Barriers to Care, Recommendations, and Future Considerations by Setting

The aim of this comprehensive literature review is to describe how to support the psychosocial adjustment of youth with ASD in various hospital settings. This review considers both common stressors creating barriers to adjustment, as well as interventions accelerating adjustment. Our review yielded studies in the following areas of the hospital: emergency

Table 1. Results by setting.

SETTING	TOTAL ARTICLES FOUND ^a	TOTAL MEETING INCLUSION/ EXCLUSION CRITERIA	TOTAL REMAINING AFTER TRIANGULATION AND DUPLICATE OMISSION
Emergency department	10 188	29	25
Surgery/procedures	56 247	11	11
Primary care	17 460	47	25
Waiting room	4816	17	12
Inpatient	4241	36	23

^aAcross all 3 databases.

department, surgery and procedures, inpatient, waiting rooms, and primary care. Overall, 140 studies were evaluated by the team and 96 were included in this review. Many of the articles had similar suggestions. As such, we will first discuss the suggestions found across all settings of the hospital. Afterwards, each section will provide specific guidance for the setting's unique characteristics.

Across settings

Two main themes for improving adjustment in youth with ASD were discussed across all settings explored in this literature review: provider education and parent-provider communication. Risk factors for poorer care include medical teams' lack of training related to treating youth on the spectrum and infrequent communication between providers and parents.^{9–12} Articles within this literature review identify the importance of medical teams gaining a comprehensive understanding of ASD through education and professional development programs.¹¹ Likewise, large communication gaps between parents and providers resulted in lowered satisfaction ratings among parents and their children with ASD.^{13,14} Regarding communication, 6 core strategies to improve communication were discussed: (a) develop services, systems, and policies that support improved communication; (b) devote time to communication; (c) ensure adequate access to communication tools (nurse call systems and communication aids); (d) access personally held written health information; (e) collaborate effectively with care providers and caregivers; and (f) increase the communicative competence of hospital staff.¹⁴

To successfully tailor care to youth with ASD, it is crucial for all staff to receive professional development, resources, and toolkits that increase their competency and confidence in working with this population.¹⁵ Specifically, previous research found that the availability of ASD training resources (eg, brochures and videos) was related to higher levels of comfort working with this population¹⁶ and a training manual with case examples and first-person perspectives was effective in supporting staff interactions with youth with ASD.¹⁷ Consistent across studies, caregivers emphasize the importance of providing child- and family-centered care.^{18–21} Regarding staff

training, providers should be trained to consult with parents, the experts on their child.¹⁵ Finally, special training should be provided to nurses caring for patients with ASD in the inpatient setting as the nursing team is often asked to manage difficult behaviors.⁵

ED

This comprehensive literature review yielded 25 articles that considered the psychosocial impact of an ED environment on the coping and adjustment of youth with ASD. This review focuses on ED visits due to medical, rather than psychiatric, concerns. In comparison to neuro-typically developing peers, children and adolescents with ASD typically visit the ED at higher rates due to their heightened health care needs.²² Specifically, a retrospective analysis of a 2005–2013 database of ED utilization rates across the United States found that youth with ASD were 4 times more likely to visit the ED compared with peers without ASD.²³ The emergency room is a busy, unpredictable setting that is overwhelming due to its unfamiliarity, bright and fluorescent lighting, excessive noise, abundance of staff, and lengthy waiting times.^{15,24} Such challenges are worsened when emergency care staff attempt to communicate with advanced medical jargon or use medical play (eg, administering medicine to a doll), despite their patients not being able to successfully engage in pretend play.^{21,24,25}

In response, certain recommendations for enhancing the care of children with ASD while visiting the ED that consistently emerged across studies included (a) sufficient preparation prior to a visit, (b) modifications and strategies to address sensory issues, (c) communication supports, (d) sufficient staff training and resources, and (e) inclusion of parents in the care of their child. Regarding preparation, researchers recommend hospitals' implementation of a 1-page registration card, such that caregivers may identify specific accommodation requirements, potential stressors, individualized communication styles, and other methods for enhancing care.^{18,24,26} Caregivers report that placing an "alert" in the child's file removes parents' obligation to repeatedly publicly disclose their child's diagnosis to health providers in the ED.²⁰ Furthermore, researchers suggest the development of a care

plan complete with the aforementioned information that would be available for patients when they transition from pediatric services into adult care facilities.²⁴

To mitigate sensory triggers, patients may benefit from modifications to the physical environment, such as providing quiet waiting room sections and/or private patient rooms to avoid sensory overload, dimming lights, providing distraction items, and allowing for multiple breaks.^{15,19,21,24,27} In addition, researchers recommend a variety of somatosensory interventions that can be brought from home or available within the medical setting (eg, headphones, books and videos, applying deep pressure, weighted vests and blankets, offering massages, and space for vestibular physical activity).²⁷ For communication, researchers emphasize the significance of medical providers delivering concrete instructions, breaking down directions into steps, and noticing nonverbal behavior and cues.^{15,27} In addition, researchers recommend providers utilizing social stories, role-playing, or technological communicative systems when explaining procedures or preparing youth for transitions.^{18,19} In summary, results suggest that sensory and communication concerns present as barriers within this population when visiting the ED. As such, appropriate preparation, adaptation of the physical environment, sufficient training, and inclusion of parents may improve the experience of visiting the ED for youth with ASD.

Surgery and procedures

This comprehensive review yielded 11 articles that considered the psychosocial impact of a surgery environment on the coping and adjustment of youth with ASD. A surgical or procedural setting contains numerous stressors for this population and their families. Families tend to have minimal control when scheduling their child's procedure, and often, youth need to restrict their food or water intake prior to the procedure.²⁸ Likewise, the sterile, unfamiliar environment of a procedural unit provides additional sensory challenges such as harsh lighting, impersonal uniforms, and large medical equipment. Researchers described that when youth with ASD become agitated in procedural settings, it can result in challenging behaviors (eg, tantrums, aggression, and self-harm) that can interrupt the throughput and productivity of surgical settings.²⁹ Likewise, these behaviors can impact the care provided to families as clinicians not trained in managing challenging behaviors may avoid interactions with the family.²⁹

Because of these barriers, it is critical that special attention is given to youth with ASD who require surgery. Prior to surgery, when possible, a preoperative visit or phone call with the family would support the child and their family as they plan how to cope.³⁰ In turn, staff members can meet the child prior to the surgical visit and gather important information from the caregiver about their child's readiness to engage in their coping plan.³⁰ Knowledge about potential triggers (eg, routine disruption, loud noises, and unfamiliar people) and the best methods

of communication strategies can be obtained to help clinicians make appropriate accommodations.²⁸ Making sensory augmentations to the procedural environment can support youths' adjustment to the experience. Turning down the lights, providing more time for transitions, decreasing the number of people involved with the case, and decreasing loud noises are strategies to decrease sensory overload in these areas.²⁸ If youth must wait in the preoperative area for extended periods of time, medical teams would benefit from requesting the services of a child life specialist or providing families with sensory-soothing items.

In order for these interventions to be effective, the medical team should allot time and resources to youth with ASD. Potential resources include brochures or picture books that describe the surgery environment, schedules documenting the day of their procedure, and tips for coping with the long wait times. As is suggested in other settings, the medical team should acquire training on ASD to ensure plans are individualized to youths' needs. In summary, results from these studies suggest that youth with ASD would benefit from consistent medical teams, preparation before procedures, and more knowledgeable clinicians' comfortable working with youth on the spectrum.

Primary care

This comprehensive review yielded 25 articles that considered the psychosocial impact of a primary care environment on the psychosocial coping and adjustment of youth with ASD. Due to the high prevalence rates of ASD among youth, many primary care providers (PCP) treat and follow youth with ASD for well checkups and preventive visits.³¹ In most cases, youth with ASD do not receive the appropriate care from their PCPs; in fact, many youths with ASD were less likely to receive critical preventive services such as flu shots and other vaccines.³²

To provide appropriate and sufficient care for youth with ASD, PCPs should be allotted time for ASD-specific training, communicate openly and thoroughly with parents and their children, generate individualized treatment plans for each child, and engage in shared decision making with the parent and their child.^{33,34} Training of medical providers on ASD-specific needs is especially important in primary care as PCPs usually act as the medical hub that many children first encounter throughout critical points in development.^{35,36} As PCPs gain awareness and knowledge about ASD, they can begin to identify risks for ASD earlier, which thus helps with early intervention during the critical window of development, ideally before the age of 2 years.

PCPs can support youths' adjustment to primary care and hospitalization in general by providing families with valuable services and resources specific to the ASD diagnosis including child life, psychology services, and educational resources.³⁷ Other helpful strategies that PCPs can employ are recognizing parent expertise by listening to the parents, identifying and

understanding triggers to behaviors, and utilizing a resource kit such as a picture schedule to help the child visualize the sequence of the primary care visit.^{34,38} In summary, by acting as a strong resource for parents and their children with ASD, PCPs can provide specialized, individualized care and guide parents with navigation of specific health services, all the while coordinating comprehensive family-centered care for this patient population.^{34,39}

Waiting room

In all, 12 articles considered the psychosocial impact of a waiting room environment on the coping and adjustment of youth with ASD. Most of the literature focused on lengthy wait times and lack of structure in the waiting room as catalysts for agitation among youth with ASD. The 2 main barriers repeated throughout the literature include lengthy wait times and lack of developmentally appropriate toys for youth with ASD. Likewise, results of Bultas⁴⁰ study suggested that parents would like written instructions from the health care center in advance on what to expect during the patient's hospital visit. Parents often had trouble remembering verbal instructions from the medical team due to the overwhelming nature of the visit, while simultaneously managing their child.⁴⁰ Written instructions can ease this anxiety, allowing parents to focus on supporting their child through the health care experience.⁴⁰

Identifying wait times prior to arrival at the hospital or medical site can decrease the amount of time that the child and their family spend in a waiting room. Parents contacting the front desk to find out whether a child's doctor is running behind on their schedule can eliminate unnecessary wait times by allowing the family to arrive later.⁴⁰⁻⁴² Parents may experience difficulties completing paperwork in the waiting room due to numerous distractions and anxieties concerning their child; therefore, inquiring about completing paperwork prior to their arrival may lessen worries of these parents.⁴⁰ Children may also benefit from being allowed to wait with their caregiver outside or in their car until ready to be seen. A private waiting room may decrease some of these challenges for children and their caregivers.⁴¹ In addition, prioritizing patients with ASD is recommended and may shorten the length of time they spend in the waiting room.⁴² Pictorial support (eg, visual schedules and communication boards) provided by health care professionals in the waiting room has been found to ease anxiety of youth with ASD.⁴³ Of the studies that do exist, the summarized recommendations for supporting youth with ASD in waiting rooms is to decrease wait times and to make the waiting room more manageable by providing developmentally appropriate toys, visual schedules and displays, and a private or alternative waiting area.

Inpatient

A total of 23 articles considered the psychosocial impact of an inpatient environment on the coping and adjustment of youth

on the spectrum. This review considers just medical inpatient hospitalizations, not hospitalizations related to psychiatric needs. Multiple studies have found that youth with ASD are more likely than typically developing peers to encounter an inpatient medical stay.⁴⁴⁻⁴⁷ For example, Carbone et al⁴⁵ found that the percentage of hospitalizations in the ASD population was 55.9%, while the cohort without ASD only had a 22.9% rate of hospitalization.

Multiple studies suggest strategies for improving the inpatient environment to meet the unique needs of youth with ASD.^{14,48,49} Kopecky et al⁴⁹ conducted a parent survey that identified 3 areas for intervention in inpatient settings: communication, pragmatic, and sensory processing. For communication, youth with ASD express pain in various ways, and therefore, inpatient medical teams should work with parents to identify unique communication styles. For pragmatic concerns, youth would benefit from preparation prior to any physical exams or procedures; access to diversion stimuli such as music, puzzles, and videos during procedures and wait times; low lighting; schedule boards or counting aloud to communicate the passage of time; and providing distance and space should youth become agitated. These adjustments could be made by psychosocial clinicians such as certified child life specialists or consulting psychologists working in the inpatient setting. For sensory processing, parents identified that their youth with ASD are most agitated by loud noises, the feeling of hospital equipment, and food sensitivity. Again, psychosocial clinicians working or consulting in inpatient units could design interventions to meet patient needs such as augmenting the environment and advocating for adjustments to patient meals.

As youth with ASD begin to age out of pediatric services, research suggests that the number of health care encounters decrease⁵⁰; despite this, families report that youth are rarely included in the transition plan from pediatric inpatient services to adult care facilities.⁵¹ When adapting communication within inpatient setting, special care should be given to transitions at discharge and aging out of pediatric services. Overall, results from our inpatient search suggest that communication, pragmatic, and sensory concerns can lead to difficult inpatient behaviors among youth with ASD. As such, interventions designed to promote patient-provider communication, adapt the sensory experience of the inpatient environment, promote positive transition between services, and train health care providers could bolster preventive care and decrease the amount of unnecessary inpatient utilization among this population.

Conclusions

The primary goal of this comprehensive literature review was to identify research-supported practices that individuals working alongside youth with ASD can employ to better their psychosocial adjustment to medical settings. Different medical settings have unique stressors that can thwart a child's efforts to cope successfully with medical encounters. This literature review demonstrates that the hospital setting can trigger

challenging behaviors for children with ASD across 5 specific hospital settings. Considering the common stressors that can create barriers to care among individuals with ASD, as well as potential interventions to accelerate adjustment, the articles provided detailed suggestions for supporting adjustment in these areas. Across all areas, efforts should be made to decrease sensory overload (ie reducing loud noises, limiting bright lights, and reducing the amount of people present in the hospital room), improve communication between caregivers and providers, and provide training for medical professionals on ASD.

Specific strategies for youth with ASD would be more beneficial in 5 areas of the hospital: ED, surgery and procedures, primary care, waiting room, and inpatient unit. Within the ED, one of the most important ways to help youth with ASD is to modify sensory stimuli which may lead to agitated behaviors. For surgery and procedure environments, developmentally appropriate preparation for youth with ASD prior to any procedure is important for decreasing the stress of the medical experience for the patient, their family, and the medical providers. Often, a surgical setting is unlike other medical encounters that youth may have previously experienced, and appropriate preparation can help prevent surprises. For primary care, PCPs should work to increase their knowledge of ASD as PCPs are a consistent presence in the lives of youth with ASD. Within the waiting room, in an effort to decrease anxiety, it is preferred for the child and their family to spend less time waiting. Finally, appropriate diversion activities are key resources for youth with ASD who are admitted to an inpatient unit within a medical setting.

This information can be directly integrated into a clinical setting by psychosocial staff, such as child life specialists, consulting psychologists, and/or behavior specialists, charged with improving coping across pediatric environments. However, due to lack of funding or resources, many facilitates may lack psychosocial clinicians trained in improving adjustment. As such, this review can be a valuable resource to medical providers wishing to improve their care with youth with ASD. By integrating staff trainings, improving communication with caregivers, and addressing sensory barriers, medical providers can ensure they are working toward creating a more ASD-friendly environment for their families.

This review has several limitations; literature chronicling the adjustment of youth with ASD to the hospital environment is published in a number of disciplinary silos. While the 3 search engines chosen cover a broad range of disciplines and dissemination outlets, some disciplines may have been missed. Likewise, while the 5 reviewers maintained a consensus on the articles included in this review, valuable information could have been overlooked in the omission process due to human error. Finally, the literature contained in this review has a Western bias due to the inclusion criteria specifying English-only publications. As such, research chronicling the psychosocial adjustment of youth with ASD across other cultures was

not included in this article. Future research should consider methods for increasing transnational dissemination of ASD-specific research. With the high prevalence of ASD and the likelihood of a child with ASD having other medical complexities, it is important for additional research to be dedicated to this topic.

Author Contributions

JS, SC, SM, JP, and KC performed the literature review, explored all published articles, and followed inclusion and exclusion criteria. All authors discussed the results, wrote the manuscript, and participated in revision of the manuscript. All authors read and approved the final manuscript.

ORCID iD

Jolie Straus  <https://orcid.org/0000-0002-4041-0552>

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