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Children with Autism Spectrum Disorder At a Pediatric Hospital: A Systematic Review of the Literature

Norah L. Johnson, Dana Rodriguez

Four times more common in boys than girls, autism spectrum disorder (ASD) is a broad term representing a neurodevelopmental disorder of socialization, communication, and repetitive behaviors (American Psychiatric Association [APA], 2000). Symptoms of ASD range from mild speech and social skills limitations and high cognitive processing, to severe forms of ASD, with developmental delay and intellectual and developmental disabilities (APA, 2000). The prevalence of ASD is increasing and is now estimated at 110 per 10,000 (673,000) U.S. children 3 to 17 years of age (Kogan et al., 2007), and 1 in 88 people (Centers for Disease Control and Prevention [CDC], 2012). The cause of ASD is thought to be a combination of genetics and unknown environmental factors (Hallmayer et al., 2011; Rutter, 2005). No cure exists, only treatments designed to improve communication and social functioning, and to decrease challenging behaviors (Agency for Healthcare Research and Quality [AHRQ], 2009, 2011).

Co-morbidities, in addition to ASD itself, result in more health care visits, more time during these visits, and more medications prescribed than for neurotypical children (Gurney, McPheeters, & Davis, 2006; Liptak, Stuart, & Auinger, 2006). Population-based studies of children with ASD report they are also more likely to be hospitalized than typically developing peers, with longer

This review of literature describes the behaviors of hospitalized children with autism spectrum disorder (ASD) that health care providers find challenging. It also identifies strategies used to address these challenging behaviors. The systematic review of literature identified 34 articles from databases on health care of challenging behaviors of children with ASD. The review identified four categories of challenging behaviors (non-compliance, hyperactivity, sensory defensiveness, self-injury) and several strategies for reducing these behaviors. Partnering with parents to develop strategies is important for children with ASD to deliver timely and safe care.

lengths of stays and higher associated costs (Lokhandwala, Khanna, & West-Strum, 2012). A study that compared hospitalization data of 191 children with ASD and intellectual disability (mentally challenged) with that of 238,317 typically developing children, found that 64.9% ($n = 124$) of children with ASD and intellectual disability were admitted to the hospital in the first 5 years of life, compared to a 48.2% ($n = 114,819$) admission rate for typically developing children (Williams et al., 2005). Another study reported that children with ASD ($n = 1610$) were 20% more likely to be hospitalized for injuries than typically developing children ($n = 91,571$) (McDermott, Zhou, & Mann, 2008). Further, the increased rate of hospital visits for outpatient therapy translates to higher expenses for this population (Croen, Najjar, Ray, Lotspeich, & Bernal, 2006). On average, children with ASD had Medicaid expenditures 10 times greater than those of other Medicaid-eligible children (Mandell, Cao, Ittenbach, & Pinto-Martin, 2006).

Problem

Hospitalization for children with ASD may provoke challenging behaviors. Literature shows that children with ASD have more anxiety and behavioral conduct problems than children without ASD (Gurney et al., 2006). Moreover, ASD is recognized as the most severe behavioral disorder for children (Newsom & Hovanitz,

2006). Challenging behaviors are more likely in children with the severe forms of ASD, and include aggression, tantrums, property destruction, hitting, kicking, biting, punching, scratching, and throwing furniture (Hellings et al., 2005; Matson, 2009). These behaviors stress parents, families, and health care providers (HCPs) (Carbone, Farley, & Davis, 2010; Gray, 2002; Herring, Gray, Taffe, Sweeny, & Einfeld, 2006; Scarpinato et al., 2010; Woodgate, Ateah, & Secco, 2008), placing all at risk for injury (Debbaudt, 2009). Behaviors may be attributed to the child's desire for attention; alone/sensory/non-social time; a tangible item, such as food (Matson, Sipes, Horovitz, & Worley, 2011); or even more likely, frustration over the inability to express himself or herself to be understood. A better understanding of the function of an individual child's behavior during hospitalization could contribute to effective care planning and interventions for hospitalized children with ASD.

Family-centered care principles are the foundation of care planning and interventions for hospitalized children. Family-centered care relies on the collaboration with family members to develop an optimal plan of care for the child. The family and the HCP bring their respective experience and perspectives in establishing the plan. The family knows the child's likes and dislikes, as well as his or her behavior triggers, essential informa-

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tion to communicate to the HCP. Because the child's challenging behaviors stress parents (Carbone, Behl, Azor, & Murphy, 2010; Phetrasuwan & Miles, 2009; Woodgate et al., 2008), this important communication may be inhibited. Parents describe a feeling of embarrassment and stigmatization by their child's behavior (Gray, 2002) and by a vigilant style of parenting, purposefully trying not to upset the child (Woodgate et al., 2008).

Mothers are often the primary caregivers (Phetrasuwan & Miles, 2009; Woodgate et al., 2008), and the stress of dealing with the challenging behaviors puts them at risk for poor mental health outcomes (Herring et al., 2006; Phetrasuwan & Miles, 2009). For their part, HCPs with limited knowledge of a given child may be stressed by the child's overwhelmed sensory system and limited cognitive abilities (Scarpinato et al., 2010) as they strive to deliver safe and timely care. Parental mental health is important because HCPs rely on family members who know their child best to be full partners in developing a plan of care (Inglese, 2009).

Challenging behaviors are a child's way of communicating their frustration when their routine is interrupted. Parents may teach the child an acceptable behavior to use in place of the challenging behavior (Matson, 2009). With a set routine and predictable behavioral interventions, children with ASD are often able to comfortably participate in educational and community activities (Durand, Hieneman, Clarke, & Zona, 2009). Predictable schedules and forms of behavior therapy are effective strategies for preventing challenging behaviors (Burbach, Fox, & Nicholson, 2004; Durand et al., 2009; Matson, 2009). Behavioral parent training uses the principles of applied behavior analysis, an evidence-based method, to shape acceptable behaviors for children with ASD (AHRQ, 2011; Durand et al., 2009). Effectiveness of the program depends on the degree of stress and the spectrum of severity of behaviors of children. Behavior intervention includes a) consequence-based strategies using reinforcement or punishment (for example, tokens or time-outs), b) instructions that build skills (for example, using repetitive trials to build language and social skills using shaping, prompting, fading, and chaining), c) targeting the functions of behaviors (for example, some children act out to avoid a task,

such as an injection), and d) preventing behaviors by changing the antecedent to the event (for example, quieting a noisy physical environment that stresses the child's sensory system) (Durand et al., 2009).

In addition to behavior therapy, parents of children with ASD often prepare their children for non-familiar people and unusual social expectations with a strategy known as Social Stories™ (Gray, 1994). Social stories break procedures down into steps and improve social understanding, which may lead to improvements in behaviors (Kokina & Kern, 2010; Reichow & Sabornie, 2009). Some parents use technology (for example, the Proloquo2Go™ communication software for the iPod™ [<http://www.proloquo2go.com>]) or alternative communication systems (such as Picture Exchange Communication System) (Scarpinato et al., 2010) to allow their child's voice to be heard through pictures.

In health care settings, children with ASD may have trouble generalizing skills they use with people they know well to new HCPs, and they may become anxious and act out (Scarpinato et al., 2010). Strategies that work at home and school may be adapted for use in the health care setting; however, HCPs with little experience working with this population may not know the antecedents to the challenging behaviors or the strategies for communicating and relating to children with ASD (Debbaudt, 2009; Shanley & Guest, 1995). Advocacy organizations develop materials for use in hospital settings. For example, Autism Speaks (2012) posted a thorough toolkit for HCPs with strategies to use when preparing a child from a blood draw. However, access to these resources by HCPs may be limited by lack of awareness of their existence or location. Familiarization with strategies to prevent challenging behaviors of hospitalized children may lead to improved safety, decreased cost of care, and a more satisfactory experience for parents (Kogan et al., 2008).

Aims of the Systematic Review

The aims of this review are to describe the behaviors that are challenging to HCPs and identify strategies used to address challenging behaviors when children with ASD are hospitalized.

Methods

This systematic review followed the steps of Cooper, Patel, and Lindsay (2009): 1) problem formulation, 2) data collection, 3) data evaluation, 4) analysis and interpretation, and 5) presentation of results. A search was completed for health care sources in CINAHL, Proquest, PsycINFO, and Medline 1997-present. Items were excluded if they were dissertations, books, or editorials, or if the focus was on parent experience related to receiving the diagnosis of autism for their child, measurement tools, siblings, and adults with autism. Multiple words were used to search for research and clinical practice references to literature on experiences surrounding the health care/hospitalization of children with ASD. Search terms were placed in online indices individually, and then in combination with one another: *autism, autism spectrum disorder, ASD, Asperger's, child life specialist, nursing, staff, behaviors, procedure, hospital, acute care hospitalization, staff, and parent*. The inclusion criteria were a) parent or HCP and a child with ASD in acute health care or outpatient settings, such as dental visits; and b) publication in English language. All abstracts were reviewed based on their relevance to the review.

Eleven research or theory-based studies and 23 clinical practice articles covered the research questions. The selected literature was appraised to assess validity. Melnyk and Fineout-Overholt's (2005) system of seven levels of evidence from highest to lowest was used for the appraisal: (I) a systematic review or randomized controlled trials (RCT), (II) a minimum of one RCT, (III) controlled trials without randomization, (IV) case-control and cohort studies, (V) systematic reviews of qualitative and descriptive studies, (VI) single descriptive or qualitative study, and (VII) opinion of authorities or expert committees. Discerning and reporting the level of evidence was vital to the process of determining the clinical usefulness of the information on how to help children with ASD when they interface with the medical community. Level I evidence is superior to level VII evidence. However, themes across level VII can be a useful way to inform nursing strategies in lieu of higher level of evidence studies that are not available. In this review, two researchers independently discerned the categories for challenging behaviors and the strategies for dealing with these behaviors.

Results

Thirty-four articles were included in this review. The summary of the articles' findings and each article's level of evidence can be found in Table 1.

Behaviors of Children with ASD in the Health Care Setting

Four categories for behaviors of children with ASD in the health care setting emerged from the literature review. There was overlap across arti-

cles of the depicted behaviors, which was expected given the reality of the neurodevelopment disorder and the behavioral nature of the diagnosis of ASD. The behavior categories are 1) non-compliance, 2) hyperactivity, 3) self-stimulatory, and 4) self-injury.

Non-compliance. Children with ASD were reported to have difficulty with co-operation (non-compliance) in health care settings and hospitals. Although not an intentionally willful non-cooperation, non-compliance results in poor adherence to requests

of health care providers, according to the literature reviewed. For example, three research studies reported poor cooperation/compliance during dental procedures (Lalwani, Kitchin, & Lax, 2007; Loo, Graham, & Hughes, 2009; Lowe et al., 2007). Non-compliance extends to emotional outbursts (Bellando & Lopez, 2009) and temper tantrums or behavioral outbursts when children with ASD are asked to comply with instructions related to their health care and hospital care (Browne, 2006; Lowe et al. 2007;

Table 1.
Summary of Articles Included in the Systematic Review

Author/Year	Design/Sample	Level of Evidence (Melnik & Fineout-Overhold, 2005)	Conclusion
Summary of Research Studies			
Bultas (2012)	Interpretive phenomenological qualitative. Mothers ($N = 11$) of children between 36 and 72 months old.	VI	Mothers described the child's behavior during health care visits and resources and barriers for pre-school children with ASD. Two themes for mothers about the health care providers: (1) "They just don't get it," with subthemes a) acknowledging the expertise of mother...mom knows best, b) not recognizing the emotional toll of autism on the family, and c) understanding the need to seek out alternate therapies and treatment; (2) marginalized by those who should care, with subtheme barriers to care, especially environmental: waiting room set up and the lack of developmentally appropriate toys.
Carbone, Behl, Azor, & Murphy (2010)	Focus groups of mothers ($n = 4$), 1 father ($n = 1$), and pediatricians ($n = 9$).	VI	Child behaviors stress parents. Parents use complementary and alternative treatments.
Chebuhar, McCarthy, Bosch, & Baker, 2012	Feasibility/pilot study of intervention; using picture schedules in medical setting for patients with an autism spectrum disorder, health care providers ($n = 8$, nurses and a child life specialist), and parents ($n = 9$).	VI	A 5- to 6-item author-developed survey asked parents of children with ASD and health care providers to evaluate each child's distress level; based on behaviors observed during a procedure or task. Reported 87.7% of staff and 77.8% of parents that rated picture schedules decreased child anxiety. Parents indicated their own anxiety was decreased. One parent reported using own pictures for years plus using social stories for doctor's visits.
Kogan et al. (2008)	Random-digit telephone survey of parents of ASD children ($n = 2008$); emotional and behavioral problems ($n = 26,751$); other special health care needs ($n = 26,751$).	II	Children with ASD, emotional and behavioral problems, and other special health care needs have trouble accessing care and have unmet needs. They are less likely to receive family-centered care than typical children and report more problems with receiving referrals, coordinating care, and obtaining family support services.
Lalwani, Kitchin, & Lax (2007)	Retrospective dental record review general anesthesia in the OR ($n = 23$); office ($n = 114$).	VI	Many children are unable to cooperate with dental procedures in the dental office. Dental care in the operating room is on average \$4,849 more than office-based care.

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Table 1. (continued)
Summary of Articles Included in the Systematic Review

Author/Year	Design/Sample	Level of Evidence (Melnyk & Fineout-Overhold, 2005)	Conclusion
Summary of Research Studies (continued)			
Loo & Graham (2009)	Retrospective, comparative dental chart review/children with ASD (<i>n</i> = 395); unaffected (<i>n</i> = 386).	III	Children with ASD are uncooperative with dental procedures. Those with ASD and who are mentally challenged demonstrate pica and self-injurious behavior, and are uncooperative 100% of the time. Strategies used in the office included behavior guidance techniques (39%), general anesthetic (37%), protective stabilization (held by a person, a restrictive device, or combination) (20%), and conscious sedation (4%). There was an increased likelihood of general anesthesia for girls. Girls also had less protective stabilization.
Lowe et al. (2007)	Retrospective screening. Children with ASD and learning disabilities (IQ < 55) (<i>N</i> = 1770); 50% living in staffed housing, 33% personal homes, 17% hospitals.	VI	Children demonstrated noncompliance, temper tantrums, repetitive pestering, over-activity, pacing, prolonged screaming, absconding, wandering, stripping, smearing feces, unacceptable sexual behavior; self-injury (hitting head, pulling hair, pica, biting, pinching), aggression (hitting, pinching, scratching), and destructive behavior (personal property, others' property, small items, furniture, fixtures, and fittings).
Lubisch, Proskos, & Berkenbosch (2009)	Retrospective study. Children with ASD (<i>n</i> = 262); with other behavior problems (<i>n</i> = 63).	VI	Dexmedetomidine, in combination with specialized sedation teams, is useful for procedural sedation for radiology procedures or electroencephalography.
McDermott, Zhou, & Mann (2008)	Record review. Children with ASD (<i>n</i> = 1,610); unaffected (<i>n</i> = 91,571).	III	Children with ASD had head, face, and neck injuries; poisonings; and self-inflicted injuries. They had a lower rate for strains and sprains than typically developing peers.
Souders, Freeman, DePaul, & Levy (2002)	Descriptive, part of a larger study; strategies developed for IV insertion for children with ASD in the hospital. Children with ASD aged 3 to 8 years (<i>n</i> = 62).	VI	Children demonstrated aggression: biting, spitting, head butting, scratching, pinching, punching, slapping, and kicking. Tantrums: aggression, screaming, flopping to the floor, stripping, and property destruction. Recommendations: 1) consult the parent prior to the hospital visit to assess child's communication, social, sensory, behavioral skills; successful strategies for compliance; and the child's strengths; 2) use a quiet treatment room with durable furniture. Hide supplies from view. Remove unnecessary equipment. Use additional staff. Keep environmental stimuli to a minimum. Specific strategies were also used depending on the level of functioning of the child: 1) high functioning ASD: modeling, choices, distraction with conversation, and token systems; 2) mild-moderate ASD: imitation, shaping, choices, and distraction; and 3) severe ASD who are mentally challenged: high probability request paired with low-probability request (for example, touch nose, touch ear, hold out arm, blood pressure), distraction (singing and counting), and holding techniques.
Tucker, Derscheid, Odegarden, & Olson (2008)	Quasi-experimental, two-group, non-randomized, pre-test/post-test design. RNs employed on a child psychiatric unit (<i>N</i> = 27).	III	Children with behavior problems often have anger management, anxiety problems, or both. Recommend praise and incentives with children and parents, and reducing the amount of overall commands. Validating a parent's feelings of frustration and despair aids reducing defensiveness and is the first step toward discussion of strategies. There was a significant change in the number of positive behaviors and statements by nurses after the training.

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Table 1. (continued)
Summary of Articles Included in the Systematic Review

Author/Year	Focus of Article	Conclusion
Summary of Clinical Practice Literature – Level VII		
Aylott (2004)	Prevention of nursing discrimination for patients with autism.	Persons with autism have problems with information processing, sensory processing, anxiety, social interaction, communication, and special interests. They need a safe and secure environment. Duties to make reasonable adjustments for people with autism include changing practices, providing auxiliary aids and services, and providing services by alternate methods.
Baas (2006)	Behaviors of children with autism.	Very small children are irritable, may cry easily, or may not snuggle into being held. Self-injurious behaviors (head banging, hitting self in face, biting a finger leaving a callus or discoloration, hitting or biting parent or nurse, inconsistent response to pain, screaming with stethoscope but not flinching at blood draw. In older children: may not understand a joke, very literal, may wish for you to keep a distance away but if they do the approaching they may speak to you six inches from your face. Recommendations: 1) use an individual approach, and 2) rule out physical reasons for challenging behaviors, such as sleep problems, GI disorders, infections, and food sensitivities.
Beard-Pfeuffer (2008)	Nursing interventions for children with autism in the ED or pediatric unit of a hospital.	Parents are the best resource for developing individualized strategies for controlling child behaviors. When children with sensory dysfunction are over-stimulated or under-stimulated, they may find relief by self-stimulation behaviors or “stiming.” These behaviors include twisting hands, flapping arms, blinking eyes, making noises, biting objects, and making repetitive movements. Recommendations: 1) keep wait short in a private place if possible as noise may upset child and child’s behavior may disturb other patients, and 2) follow any special routines that help child feel at ease.
Bellando & Lopez (2009)	Practice suggestions for school nurses to prevent emotional outbursts in children with ASD.	Recommendations: 1) create individualized health plans, 2) give medications as prescribed, and (3) use “visual” instead of “verbal” instruction (for example, pictures for communication of important events that occur during the day that the child can hand to the teacher to express his or her needs).
Blackwell & Niederhauser (2003)	Pediatric nurse practitioner screening, diagnosis and treatment recommendations.	Behaviors: Over-active or very passive aggression, self-injury, hand flapping, rocking, inappropriate laughing. The “social story” uses scripted scenarios to help children with autism understand and follow specified social protocols.
Blake (2010)	Implications for nurses caring for children with ASD.	Talk with caretakers before working with the child with autism. Ask how the child communicates and responds to tasks and procedures. Plan ahead, customize, and limit care. Maintain routines. Expect sleep disturbances. Keep inedible objects out of reach of child. Allow extra time for everything.
Browne (2006)	Communication skills for nurses caring for ASD children.	Repetitive behaviors and adherence to rigid routines help calm children with ASD. Saying the word “no” to a child can provoke temper tantrums. Recommendations: 1) do not interrupt behaviors; 2) speak clearly and slowly, with simple, literal speech; 3) avoid saying “no;” and 4) pause to give the child time to process information. Waiting can be difficult but is effective. If child is having a tantrum, stop talking. Talking may make behavior worse. Do not insist on eye contact.
Carbone, Farley, & Davis (2010)	ASD-associated conditions.	Sleep disturbances, gastrointestinal problems, anxiety, and hyperactivity. Goal of long-term management of children with ASD is to minimize maladaptive behaviors.
Debbaudt (2009)	Behavior and communication of ASD children.	Sensory overload (beeps, flashing lights, movement, and bustling of a hospital environment) is over-whelming and may cause flight of the child. Your attempt to stop flight may escalate the child’s behavior. Be patient and calm. Allow for delayed responses to your questions. Model correct behaviors.

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**Table 1. (continued)
Summary of Articles Included in the Systematic Review**

Author/Year	Focus of Article	Conclusion
Summary of Clinical Practice Literature – Level VII (continued)		
Galinat, Barcalow, & Krivda (2008)	School nurses' recommendations for caring for children with autism.	Each child is unique. Self-stimulatory behavior, altered sensitivity to pain, and injury from self-abuse. New environments and changes in normal routines (such as a visit to the health office) can be stressful and evoke aggressive behaviors and tantrums. Use distraction, rewards, and tokens to manage behavior.
Gardner (2001)	Single case study. Child with ASD (N = 1) at school.	Request for child participation results in tantrums, kicking, yelling, and rolling on the floor. Recommendations: 1) monitor tantrum pattern to determine precipitating factors; 2) prepare child for transitions, such as leaving the classroom to visit the nurse; 3) provide structured calm approach; and 4) use concrete language. Avoid sarcasm or teasing. Explain rules clearly.
Golnik & Maccabee-Ryaboy (2010)	ASD behaviors in primary care clinic.	Hyperactivity, anxiety, aggression, impulsivity. Recommendations for treating or preventing behaviors: 1) medication, 2) provide pictures of the medical team and/or a story describing a clinic visit (pictures can facilitate behavioral management, such as toilet training or sleep), 3) use a medical care plan to document techniques to facilitate the visit, and 4) provide or ask parents to bring sensory toys (such as a spinning globe).
Inglese (2009)	Management of children with ASD.	Anxiety is related to changes in home structure schedule and leads to stress. Parents have a difficult time telling if the child is in pain. Child often cannot communicate pain. Recommendations: 1) work with parent to help with patient communication, and 2) create a routine.
Marshall (2002)	Nursing implications for caring for a child with Asperger's syndrome.	Recommendations: 1) keep to a schedule; 2) work with their interests and strengths, whatever their fixation or focused interest, and using these skills in work situations; 3) introduce changes gradually; 4) communicate clearly because words are taken literally, and nonverbal messages and communication are not understood; 5) give encouragement through feedback; 6) plan for physical activity because these children need an outlet for stress and anxiety; and 7) regard these children as unique individuals because they experience the world differently.
Raposa (2009)	Behavior management for dentists for children with ASD.	Change in behavior could indicate dental pain. Impulsiveness and a low threshold for frustration are common. May have physical or verbal cues that set them off or calm them down. May pinch or bite themselves or others, head bang, or self-induce vomiting. Recommendations: 1) interview caregiver about behavior management technique for each individual patient ahead of time and allow caregiver to be present during the exam, 2) prepare individual for dental visit through role-play, books, and pictures, 3) bring distracters for waiting room and have a short wait time, 4) schedule appointment at best time of day for individual; and 5) use consistent staff at each visit. Goal of initial appointment is to develop trust. Speak directly to the child.
Scarpinato et al. (2010)	Case examples of hospitalized children with ASD (N = 9).	Agitation of the patient is preceded by many people and the uncertainty of their roles, loud sounds, smells, and tactile encounters; communication challenges; inability to understand non-verbal cues, facial expressions, hand gestures; pain; restricted interests; instructing others to perform a ritualistic behavior (for example, the completion of a task or a specific greeting). Recommendations: 1) assign a primary nurse for consistency; 2) silent alarms, close door, do not disturb signs, minimize interventions, and spot-check vital signs instead of continuous monitoring; safe, clutter-free environment; 3) use clear, direct, simple sentences; augmentive and alternative communication systems (such as the picture exchange communication system); 4) assess and minimize pain; self-report may be possible; in preparation for blood draws or injections, use a lidocaine-based topical cream; and 5) complete ritual. Allow child to complete rituals; child who cannot control the movement of doctors and nurses may also be more at risk for acting out episode.

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Table 1. (continued)
Summary of Articles Included in the Systematic Review

Author/Year	Focus of Article	Conclusion
Summary of Clinical Practice Literature – Level VII (continued)		
Searcy (2001)	Hospital visits for children with ASD.	Inappropriate behaviors, non-compliance, and temper tantrums related to 1) difficulty coping with change, 2) trouble generalizing from one situation to another, 3) overtly literal interpretation of language, 4) difficulty recognizing reward, and 5) sensory defensiveness to textures, loud sounds, and bright lights. Recommendations: 1) make environment predictable; use visuals; 2) teach each step of task; 3) use concrete terms; 4) be aware of the desire to please others because motivation for behavior may be nonexistent; use tangible rewards; 5) write specific rules and post where the child can read them; and 6) provide occupational therapy.
Seid, Sherman, & Seid (1997)	Case examples children with autism (N = 2).	Abnormal reaction to stimuli (light, sound, touch, and pain) and attachments to unusual objects and rigidly stereotyped routine. Pre-operative anxiety high. Different peri-operative protocol from normal operative patients. Depending on the age and degree of impairment, age-appropriate teaching that precedes surgery may heighten frustration and anxiety in new social situations. Recommendations: 1) use a quiet room; 2) do not separate from familiar caretakers, objects, and set routines; 3) use pre-operative role playing, tailoring anesthetic induction and using post-operative distracters; 4) use a quiet room after surgery; 5) send home as soon as possible; and 6) treat pain.
Shellenbarger (2004)	Strategies for nurses caring for patients with Asperger's in the emergency department.	Described a patient as agitated and flinging a clipboard to the floor, attempting to flee. Strategies: 1) identify stress triggers and avoid if possible, 2) include parents in all activity, 3) use visual clues and prompts, 4) keep instructions simple, 5) try to limit the number of staff caring for patient, and 6) reduce sensory stimuli around child.
Skinner, Ng, McDonald, & Walters (2005)	Case example of 18-year-old girl with autism (N = 1).	Menstruation triggered depression and aggression. Recommendations: 1) management involved resolving complex medical, psychiatric, and ethical issues on an adolescent medical unit.
Tagon, Bryan, & Kurth (2006)	Strategies for Radiology and ASD.	Likelihood of successful completion of an MRI depends on the age and diagnosis of the child. Recommendations: 1) use anesthesia for CT, MRI, or Nuclear Medicine for child with ASD; and 2) use a caretaker or child life specialist to decrease anxiety, provide distraction, or reduce noise (use headphones).
Thorne (2007)	Strategies for a productive and less stressful health care visit.	Children with ASD may have behavioral outbursts and anxiety. Strategies: 1) always try to communicate with the child; the child may understand you; 2) use books/videos about going to the doctor; 3) use clutter-free, quiet room; 4) post-visual schedule, including vital signs, meal times, and other activities; 5) explain step by step what will happen during a procedure (rewards for each step); 6) give choices about care; 7) consult family for calming techniques; and 8) ask child if it is okay to touch him or her.
Valente (2004)	Nursing management of children with autism.	Children with autism do not adapt easily to change. Behaviors include tantrums, rigid behavior, and obsessive activities. Management recommendations include medications to treat anxiety, aggression, and hyperactivity. Behavior modification techniques: 1) positive reinforcement, and 2) setting small goals. Psychotherapy for the child with autism has limited value.

Notes: Levels of evidence: I = systemic review or meta-analysis or randomized controlled trials (RCT), II = a minimum of one RCT, III = controlled trials without randomization, IV = case-control and cohort studies, V = systematic reviews of qualitative and descriptive studies, VI = single descriptive or qualitative study, VII = opinion of authorities or expert committees (Melnik & Fineout-Overholt, 2005).

Searcy, 2001; Thorne, 2007). Children may be aggressive (Golnik, & Maccabee-Ryaboy, 2010; Lowe et al., 2007; Skinner, Ng, McDonald, & Walters, 2005), destroy property (such as small items, furniture, fittings, fixtures) (Lowe et al., 2007), and scratch, head butt, punch, and slap others (Souders, Freeman, DePaul, & Levy,

2002). Children with ASD are prone to agitation (Scarpinato et al., 2010), with kicking/yelling and rolling to/on the floor (Gardner, 2001).

Non-compliance is generally due to the child's natural high anxiety, which is a feature of ASD. Eight articles describe children with ASD as having high anxiety (Bultas, 2012;

Carbone, Farley et al., 2010; Golnik & Maccabee-Ryaboy, 2010; Inglese, 2009; Raposa, 2009; Seid, Sherman, & Seid, 1997; Thorne, 2007; Tucker, Derscheid, Odegarden, & Olson, 2008). Bultas' (2012) qualitative study captured parents' experiences when accessing health care. Negative child behaviors, in their experience, are due

to their child's anxiety, waiting, and the overwhelming nature of health care visits. Identifying and noting the child's fears, anxieties, and antecedents to challenging behaviors provide more positive health care experiences (Bultas, 2012).

Hyperactivity. Nine articles described children with ASD as overactive/hyperactive and impulsive (Blackwell & Niederhauser, 2003; Bultas, 2012; Carbone, Farley et al., 2010; Golnik & Maccabee-Ryaboy, 2010; Lowe et al., 2007; Marshall, 2002; Raposa, 2009; Shellenbarger, 2004; Valente, 2004). Children with ASD may run, and get into drawers and trash cans when bored (Bultas, 2012), and may even attempt to run out of the room (Shellenbarger, 2004). Verbal children with ASD may display their hyperactivity by pestering (Lowe et al., 2007).

Sensory defensiveness. Sensory defensiveness is the child's aversion to certain environment elements, such as sounds, textures, and odors. Six articles describe the child with ASD's "sensory defensiveness" to loud sounds, smells, and tactile encounters (Aylott, 2004; Bellando & Lopez, 2009; Debbaudt, 2009; Lowe et al., 2007; Scarpinato et al., 2010; Searcy, 2001). A child with ASD may flee a room when his or her senses are overwhelmed. Debbaudt (2009) noted children with ASD jerk away from basic care and touch. The sensory defensiveness may be the antecedent to the child's non-compliance.

Children with sensory dysfunction who are over-stimulated or under-stimulated may find relief from the discomfort with self-stimulation behaviors (Beard-Pfeuffer, 2008). Self-stimulatory behaviors include twisting hands, flapping arms, blinking eyes, making noises, biting objects, and making repetitive movements (Beard-Pfeuffer, 2008). Thus, the behaviors serve a self-calming function for the child.

Self-injury. Five articles noted children with ASD self-injury (Blackwell & Niederhauser, 2003; Loo et al., 2009; Lowe et al., 2007; McDermott et al., 2008; Raposa, 2009). Observable self-injurious behaviors included pinching self; head banging; biting self; self-induced vomiting (Lowe et al., 2007; Raposa, 2009); head, face, and neck injuries; and poisonings (Lowe et al., 2007; McDermott et al., 2008).

Strategies for Dealing With Challenging Behavior

Parents and HCPs recommended

many strategies for dealing with challenging behaviors. The majority of strategies reflect the HCP perspective.

Strategies for non-compliance. Nurses report that requesting participation of a child with ASD often provokes a tantrum (Browne, 2006; Gardner, 2001; Thorne, 2007). Children with ASD can become agitated by overstimulation from many people touching them, and from loud noises and smells in their environment. They have difficulty understanding non-verbal cues, facial expressions, and hand gestures during these encounters (Scarpinato et al., 2010; Searcy, 2001). Agitation can progress to an emotional meltdown if the child continues to be over-stimulated (Smith-Myles & Southwick, 2005). Communication recommendations to avoid over-stimulation and confusion include using calm, concrete language and avoiding sarcasm or teasing (Debbaudt, 2009). Communication with pictures or a visual schedule is effective as well (Chebuhar, McCarthy, Bosch, & Baker, 2012). HCPs need to be patient, reduce the number of commands, and use gentle praise, positive reinforcement (Tucker et al., 2008), and distraction (such as counting or singing) (Galinat, Barcalow, & Krivda, 2008; Souders et al., 2002; Tagon, Bryan, & Kurth, 2006). This settles a child, who can now focus on something familiar. Other recommendations to decrease stimulation include closing doors to limit noise, using "do not disturb signs," clustering nursing interventions, involving parent(s) whenever possible, and spot-checking vital signs instead of continuous monitoring (Inglese, 2009; Scarpinato et al., 2010; Shellenbarger, 2004).

For procedures, HCPs should use a quiet treatment room with durable furniture, hide supplies from view, remove unnecessary equipment, and keep environmental stimuli to a minimum (Souders et al., 2002; Thorne, 2007). Headphones can be used to reduce noise if the child can tolerate the tactile stimulation (Tagon et al., 2006). Other strategies for sensory defensiveness can be personalized to the child by an occupational therapist (Searcy, 2001) and with the input of the parents (Bultas, 2012; Scarpinato et al., 2010).

A second precipitating factor for a tantrum is pain. For example, children with ASD can have dental, gastrointestinal, or menstrual pain that may precipitate a behavioral outburst (Baas, 2006; Carbone, Farley et al., 2010; Gardner, 2001; Scarpinato et al.,

2010; Skinner et al., 2005). Determining if a child is in pain may be difficult (Inglese, 2009). Pain can be assessed with the picture pain scales (Golnik & Maccabee-Ryaboy, 2010) and needs to be treated to prevent outbursts.

Third, children with ASD may not cooperate because they tend to like engaging in obsessive activities and routines, and do not want to break them (Browne, 2006; Galinat et al., 2008; Scarpinato et al., 2010; Seid et al., 1997; Valente, 2004). The rituals give them comfort and should not be interrupted (Browne, 2006; Scarpinato et al., 2010). HCPs may be asked to perform a ritualistic behavior, for example, the completion of a task or a specific greeting. If the HCP does not comply, the child could become agitated. Therefore it is best to complete the ritual to prevent the behavior outburst.

Strategies for hyperactivity. Children with ASD may have co-morbid conditions that include hyperactivity (such as attention deficit hyperactivity disorder [ADHD] and ASD, anxiety and ASD, depression and ASD) (Reaven, 2009). Two strategies are identified in the literature review for hyperactivity: 1) planning for physical activity as an outlet for stress and anxiety (Marshall, 2002), and 2) treating the hyperactivity symptoms of ADHD with pharmacology treatments, such as stimulants, which may have side effects and may not be effective (Golnik & Maccabee-Ryaboy, 2010).

Strategies for sensory defensiveness behaviors. HCPs should not interrupt self-stimulatory behaviors because they serve the purpose of decreasing anxiety (Browne, 2006; Scarpinato et al., 2010). Anxiety reduction strategies were reported in several articles. Raposa (2009) recommends a consistent caregiver and allowing this caregiver to be present during medical procedures. Similarly, Tagon et al. (2006) recommend a caretaker or child life specialist to reduce anxiety and provide distraction. Parental presence generally helps calm the child with ASD. Moreover, planning ahead by consulting the parent prior to the hospital visit to assess the child's communication; social, sensory, and behavioral skills; successful strategies for compliance, and the child's strengths is recommended (Blake, 2010; Souders et al., 2002).

Knowing what to expect may reduce the child's anxiety (Bellando & Lopez, 2009; Browne, 2006; Giarelli,

Souders, Pinto-Martin, Bloch, & Levy, 2005; Raposa, 2009; Scarpinato et al., 2010; Thorne, 2007; Tucker et al., 2008). For example, the step-by-step expectations written in the format of a social story using scripted scenarios reduce anxiety, and thus, help the child cooperate and complete medical procedures (Blackwell & Niederhauser, 2003; Thorne, 2007). It is best to give these to parents to use a few days before the event to help prepare child.

Tantrums that occur at times of transition may be minimized with a system of visual cues and prompts for the child. Preparation includes alerting the child that a change is coming with the use of Now/Then pictures or whatever the parent usually does to signify a change in activity (Chebuhar et al., 2012; Gardner, 2001; Shellenbarger, 2004; Valente, 2004). Children can be prepared for change with prompts on a visual schedule. Examples of prompts include words or pictures depicting vital signs, meal times, and other activities (Chebuhar et al., 2012; Thorne, 2007). Further, HCPs should always try to communicate with the child with ASD and/or parents by asking the child if it is okay to touch him or her, and/or by giving the child choices (Thorne, 2007). For example, the HCP can ask what the child wants done first (for example, listen to heart or belly). All of these actions improve the child's ability to communicate, make decisions, and thus, have some degree of control, which also decreases anxiety (Scarpinato et al., 2010).

The use of restraint, sedation, and general anesthesia aids completion rate of procedures for dental (Lalwani et al., 2007), radiology (MRI), and electroencephalogram procedures on children with ASD, according to physicians (Loo et al., 2009; Lowe et al., 2007; Lubisch, Proskos, & Berkenbosch, 2009; Tagon et al., 2006). Use of this technology adds expense and potential harm to children, which needs to be considered. For some children it might be safer to sedate, while others can cooperate if properly prepared. The decision to use the additional measures is often something that needs to be worked out with parents, the child, and the physician. Although nurses are hesitant to use restraints (Thorne, 2007), they should refer to individual institution restraint policies to be clear about what restraint use is allowed.

Strategies for self-injury. Self-injury may be the result of the child's difficulty communicating physical pain (Inglese, 2009; Raposa, 2009;

Scarpinato et al., 2010; Seid et al., 1997) or from not understanding expectations (Blackwell & Niederhauser, 2003). Children may slap or bite a limb that hurts (Inglese, 2009). Self-injury may be decreased with improved communication methods. Communication strategies include pausing after asking a question to give the child time to process information (Browne, 2006; Debbaudt, 2009). Patience and waiting can be difficult but effective.

Discussion

According to Melnyk and Fineout-Overholt's (2005) rating system, the articles available on the behaviors of children with ASD in the health care setting and the strategies parents and HCPs use have low levels of evidence, which reflects in the lack of standardized care for hospitalized children as the state of the science. The dearth of research studies might be related to the fact that the increasing prevalence of ASD is relatively new, so it is too early to have a research base and/or that ASD is too varied in its presentation of symptoms to recommend common strategies. Only two level VI articles of the behaviors of children with ASD in the acute care hospital setting were located, while the majority of articles were level VII. Given the nature of the ASD and breadth of the autism spectrum, this finding is to be expected. These children cannot be easily categorized nor has the science progressed to begin to think about standard let alone best care. It is still very much learning about these children and how they respond to different types of interventions/strategies. The most important strategy is to learn from the parents and follow their suggestions and routines. Parents' have strategies for changing expectations/routines or introducing new behaviors.

All articles except one (Woodgate et al., 2008) were from the HCP perspective. Some articles explore the parenting experience of caring for a child with autism; however, these articles are more about general child-care and are unrelated to health care. These studies are very informative about the needs of the child and parents, and strategies used to provide daily care, school experience, and family/peer/siblinginteraction (Galinat et al., 2005; Woodgate et al., 2008).

The dental research studies highlight the cost of care for children for the methods (such as restraint, sedation, general anesthesia) used to help

children with ASD complete medical procedures. (Loo et al., 2009; Lowe et al., 2007; Lubisch et al., 2009; Tagon et al., 2006). During hospitalization, nurses hesitate to use restraints (Thorne, 2007), and boys are more likely to be restrained than girls (Loo et al., 2009). Methods in lieu of or in addition to restraint use merit discussion for their association with children's challenging behaviors.

Terms used to describe the behaviors of children with ASD from the 23 level VII articles in this review discerned four categories of behaviors that were also mentioned in the 11 research articles of behaviors that typified ASD. These four categories are non-compliance, hyperactivity, sensory defensiveness, and self-injury. Along with the research articles, the level VII articles suggest strategies to improve communication and compliance with children with ASD and without the use of restraint or sedation. Non-compliance was a term used in several articles. Behaviors of non-compliance seem to stem from the child's susceptibility to be overstimulated in the noisy hospital environment. By collaborating with family/parents, HCPs can calm the environment around hospitalized children with ASD to gain their compliance and avoid tantruming behaviors. For example, the door to the child's room can be closed, and nurses can bundle care. When approaching the child with ASD, nurses can speak slowly in a soft tone, in simple language, explaining or using pictures to inform the child what they will be doing before they do it.

There are also triggers for aggressive behaviors and non-cooperation internal to the child, such as untreated pain and anxiety. Nurses can ask family/parents to describe the child's norm and how their child expresses pain and fear. The most important strategy is to learn strategies for changing expectations/routines and introducing new behaviors from the parents. Nurses should follow parent suggestions and routines.

Daily routines for some children with ASD include an established way to cope using self-stimulatory behaviors as a way of self-calming. Restraints inhibit these self-calming mechanisms. When the environment is over-stimulating, self-stimulating behaviors can progress to self-injurious behaviors or add the destructive element to other people or property. Research is needed on interventions, such as communication methods of preventing challenging behaviors.

Goals for interventions are to minimize maladaptive behaviors (Carbone, Farley et al., 2010) and have successful outcomes for children with ASD in the health care setting. These outcomes include decreased length of a child's health care appointments or hospital stay, and reduction in the social and economic cost of care for children with ASD (Mandell et al., 2006). With the increasing prevalence of children with ASD in the acute care hospital setting, HCP collaboration with family/parents is critical to the assessment, planning, and implementation of anxiety-reducing strategies.

Although a better understanding of the behaviors of children when hospitalized is necessary and can only be realized with a higher level of evidence research, HCPs who care for children with ASD and their families can implement some of the strategies outlined here. Strategies to address non-compliance behaviors recommended in the reviewed literature match the behavior management principle of preventing behaviors by targeting the functions of behaviors and by changing the antecedent event to challenging behaviors (Durand et al., 2009).

By calming the environment, HCPs may gain the child's compliance and avoid emotional meltdowns from over-stimulation (Durand et al., 2009). Likewise, behaviors of hyperactivity and sensory defensiveness can be addressed with communication strategies reported in the literature. Additional resources to assist with communication include the Autism Speaks (2012) health care tool kit (<http://www.autismspeaks.org>), CDC's information on autism (<http://cdc.gov/autism>), and the Autism Society of America (<http://www.autism-society.org>).

Committees to research and propose policy changes in the hospital and clinic settings are recommended. One policy to consider is HCP contact with the child before an elective admission or clinic appointment. Contact with families in advance of care facilitates knowledge/understanding of the individual behavior triggers and promotes safety.

With the majority of literature representing the HCP perspective, research is needed to capture the parental perspective of the behaviors of their children with ASD in the hospital setting. Behaviors deemed disruptive by the HCP may be different from what parents consider disruptive. Parents may have established a strategy for a given behavior that

could inform interventions. To test the effectiveness of interventions, HCPs need a valid and reliable standardized behavior observation tool to accurately measure children's behavioral outcomes. The development of such a tool is difficult given all the various conditions included in the autism spectrum. Future research is needed to identify the behavior clusters and trigger events for children with ASD within the context of acute health care settings, as described by both parents and providers, to inform the development of a tool. ■

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