Guest Editorial

Autism in Critical Care

Dawn M. Turnage, PhD, DNP, APRN, FNP-BC
Brian C. Peach, PhD, RN, CCRN

Autism spectrum disorder (ASD) is a developmental disorder characterized by impaired communication and socialization and the preference for rigid routines.[1] This disorder occurs along a spectrum, meaning there are differences in the severity of the symptoms. The current *Diagnostic and Statistical Manual of Mental Disorders,* fifth edition (DSM-5) classifies severity levels as level 1,"requiring support"; level 2, "requiring substantial support"; and level 3, "requiring very substantial support."[1] Individuals with all levels of severity require support; however, those with level 3 ASD require higher levels of support because of the severe impairments in communication and socialization.[1] The *Lancet* Commission on the future of care and clinical research in autism recently highlighted the greater need for support for people with ASD, particularly those with profound autism.[2] In this editorial, the terms *severity* and *profound* are used interchangeably to denote individuals with level 3 ASD.

Autism spectrum disorder is present in all races, ethnicities, and socioeconomic backgrounds, with males having a 4 times greater risk than females.[3] In 2018, 1 in 44 people were diagnosed with ASD, compared with 1 in 200 in 2013.[3] This ongoing increase in prevalence is attributed to better assessment and diagnosis, as well as inclusion of ASD in the *Diagnostic and Statistical Manual of Mental Disorders,* fifth edition.[1] Because more people are living with ASD, more adult patients will present with this condition to hospitals, including in critical care units.

Presentation of ASD

Because ASD is a spectrum disorder, patients with this condition may exhibit 1 or more of the following symptoms[1]:

- Impaired social and emotional function
- Limited or no verbal communication
- An intense desire for repetitive behaviors or routines
- Repetitive movements and/or speech
- Hyposensitivity or hypersensitivity to sensory stimuli
- Intense focus on objects or hobbies

On the autism spectrum, patients can have challenges that are mild to profound, dependent on the severity of their diagnosis. Patients with severe ASD may be nonverbal, be unable to function independently, and require constant care and supervision.

Autism spectrum disorder often presents with other comorbidities, which can further complicate care. Common comorbidities include seizures, sleep disorders, speech and language delays, intellectual disabilities, motor problems, bowel and bladder incontinence, constipation and/or diarrhea, obesity, attention-deficit/hyperactivity disorder, anxiety,

Authers
Dawn M. Turnage is a lecturer, Nursing Systems Department, College of Nursing, University of Central Florida, Orlando, Florida.

Brian C. Peach is an assistant professor, Nursing Practice Department, College of Nursing, University of Central Florida.

Corresponding author: Dawn M. Turnage, PhD, DNP, APRN, FNP-BC, Nursing Systems Department, College of Nursing, University of Central Florida, 12201 Research Parkway, Suite 300, Orlando, FL 32826 (email: dawn. turnage@ucf.edu).

obsessive-compulsive disorder, and other mental health disorders. Additionally, individuals with ASD may have sensory-seeking or sensory-avoiding behavior and intense food preferences or intolerances, as well as a high or low pain tolerance threshold. Because of the wide variance in symptoms, comorbidities, and behavioral and sensory issues, it is difficult for nurses to give patients with ASD a one-size-fits-all plan of care, particularly in the critical care setting. Although a physical assessment and chart review can provide some important information for patient care, eliciting input from family caregivers can provide valuable information about routine, issues, sensory preferences, and pain tolerance or intolerance.

Critical Care Settings

Patients with ASD can be easily overstimulated by the critical care environment, which includes unusual visual, auditory, olfactory, gustatory, and tactile stimuli. Sounds, for example, may include those heard at home such as conversations, televisions, and toilets, but also medical equipment such as intravenous pumps, ventilators, bed alarms, unfamiliar voices, and intercom pages. Frequent visits from consulting providers can make the environment further disruptive and stressful for patients with ASD. Even for patients without autism, forming a trusting relationship and being receptive to treatment are difficult with so many unfamiliar faces. Additionally, impaired cognitive function may increase anxiety, as patients may not understand why they have been hospitalized, the hospital environment, or the treatment plan.

Long stays in critical care settings, particularly those that involve mechanical ventilation and sedative administration, predispose patients, both with and without ASD, to delirium.[4,5] It is standard of care to screen critically ill patients at least once a shift for delirium using tools such as the Confusion Assessment Method for the Intensive Care Unit and the Intensive Care Delirium Screening Checklist.[6] These tools have been validated for use in patients with numerous conditions, but they have not been tested in patients with ASD. The current delirium screening tools include points for inattention and inability to follow commands, which could result in patients with ASD falsely screening positive for agitated delirium and unnecessary treatment with agents commonly used by nurses such as haloperidol and quetiapine. Further confounding delirium assessment is the significant variation in behavior and communicative

abilities among those with ASD. To our knowledge, there are no known alternative validated tools for measuring delirium in patients with ASD, which presents an opportunity for critical care nursing researchers.

Pain assessment is a confounding factor in delirium assessment of patients with ASD. Intensive care nurses are trained to recognize nonverbal signs of pain using tools such as the Behavioral Pain Scale[7] and the Critical Care Pain Observation Tool.[8] However, to our knowledge, there are no pain assessment tools validated for use in nonverbal patients with ASD. Erratic behavior in nonverbal patients with ASD may reflect pain and be misconstrued as delirium manifestations. Pain-related behaviors in patients with ASD may vary, and it may be difficult to assess pain levels, particularly in nonverbal patients. People with ASD have been found to experience more pain, anxiety, and pain-related fear than people without ASD, which is theorized to be related to sensory differences and altered processing of painful stimuli.[9] Anxiety and fear can amplify pain. Family caregivers may be able to help nurses by providing information on how pain is recognized in their loved one with ASD.

Implications for Critical Care Nurses

Best practices for nurses caring for individuals with ASD include (1) assessing and recognizing differences in severity of ASD and needs; (2) soliciting family input on patients' signs of pain and anxiety and therapeutic approaches to helping them; and (3) frequent rounds to assess safety. Tailoring care to the needs of the individual should include taking into consideration the severity of the condition, personal preferences, and family caregiver input. Critical care nurses should enlist the assistance of interprofessional services, including child life, physical therapy, occupational therapy, and speech therapy. These interprofessional services, in addition to input from family caregivers, can be invaluable to nurses when caring for a patient with ASD.

Critical care nurses should solicit information from family members about the patient's dietary and activity preferences and strategies for medication administration. Home comfort items such as stuffed animals and blankets can help decrease signs and symptoms of anxiety that may be mistaken for indicators of delirium. Although many intensive care units (ICUs) have restricted visiting hours, allowing family members to stay at the bedside can help to decrease the anxiety of patients with ASD.

Using consistent language/images and familiar terms can help provide comfort and orient the patient to the new surroundings. Nonverbal patients may use sign language or communication devices. Sensory noise-cancelling headphones may be helpful to reduce anxiety-inducing background noises in the ICU. Caring for a patient with ASD can be stressful for critical care nurses, and it is unrealistic to expect them to be knowledgeable about the many different expressions of ASD. Therefore, it is imperative to involve family members when caring for a patient with ASD and to embrace, rather than resist, their input. It is beneficial to the patient, but also for the nurse caring for them.

Normal strategies for reduction and prevention of delirium, such as using the ICU liberation bundle (also known as the ABCDEF bundle) still apply.[10] Pain should be assessed, prevented when possible, and managed. Spontaneous awakening trials and spontaneous breathing trials are necessary to reduce the number of ventilator days. Protracted time receiving sedatives and mechanical ventilation is a known risk factor for delirium. The choice of analgesics and sedatives should be closely scrutinized, particularly considering other psychiatric medications a patient with ASD may be taking at baseline. Stopping home psychiatrics medications, as is common in ICU settings, could result in hyperactive behavior in a patient with ASD. Medications should only be stopped when there is a clear clinical justification and should be restarted as soon as possible. Delirium should be assessed, taking into consideration what is normal behavior per the patient's family or caregivers. Early mobility and exercise are important strategies to reduce delirium in all patients and may also help to decrease the anxiety of patients with ASD. Lastly, family engagement and empowerment are key to decreasing anxiety and reorientation efforts, particularly in patients with ASD.

The *Lancet* Commission on the future of care and clinical research in autism stresses the importance of providing greater support for people with ASD and their families and discusses the need for research focused on profound ASD in all settings.[2] In critical care settings, caring for a patient with ASD presents different challenges and critical care nurses have a unique opportunity to help these individuals and their families. Preparing oneself with the knowledge to meet this challenge is a good first step in being ready to meet the needs of a patient with ASD. CCN

References
1. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders.* 5th ed. American Psychiatric Association; 2013.
2. Lord C, Charman T, Havdahl A, et al. The *Lancet* Commission on the future of care and clinical research in autism. *Lancet.* 2022;399(10321):271-334. doi:10.1016/S0140-6736(21)01541-5
3. Centers for Disease Control and Prevention. Data & Statistics on Autism Spectrum Disorder. Accessed August 1, 2022. https://www.cdc.gov/ncbddd/autism/data.html
4. Ouimet S, Kavanagh BP, Gottfried SB, Skrobik Y. Incidence, risk factors, and consequences of ICU delirium. *Intensive Care Med.* 2007;33(1):66-73. doi:10.1007/s00134-006-0399-8.
5. Pisani MA, Murphy TE, Van Ness PH, Araujo KLB, Inouye SK. Characteristics associated with delirium in older patients in a medical intensive care unit. *Arch Intern Med.* 2007;167(15):1629-1634. doi:10.1001/archinte.167.15.1629
6. Gusmao-Flores D, Salluh JIF, Chalhub RA, Quarantini LC. The confusion assessment method for the intensive care unit (CAM-ICU) and intensive care delirium screening checklist (ICDSC) for the diagnosis of delirium: a systematic review and meta-analysis of clinical studies. *Crit Care.* 2012;16(4):R115. doi:10.1186/cc11407
7. Gélinas C, Joffe AM, Szumita PM, et al. A psychometric analysis update of behavioral pain assessment tools for noncommunicative, critically ill adults. *AACN Adv Crit Care.* 2019;30(4):365-387.
8. Zhai Y, Cai S, Zhang Y. The diagnostic accuracy of ritical Care Pain Observation Tool (CPOT) in ICU patients: a systematic review and meta-analysis. *J Pain Symptom Manage.* 2020;60(4):847-856.e13. doi:10.1016/j.jpainsymman.2020.06.006
9. Failla MD, Gerdes MB, Williams ZJ, Moore DJ, Cascio CJ. Increased pain sensitivity and pain-related anxiety in individuals with autism. *Pain Reports.* 2020;5(6):e861. doi:10.1097/PR9.0000000000000861
10. Ely EW. The ABCDEF bundle: science and philosophy of how ICU liberation serves patients and families. *Crit Care Med.* 2017;45(2):321-330. doi:10.1097/CCM.0000000000002175