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Caring for the Adult patient with Autism: Development of staff education and an online toolkit for Healthcare Providers

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<center>**Executive Summary**</center>

Introduction of the Problem

The American healthcare system expands practice by pushing boundaries and seeking better treatments, procedures, and patient outcomes. Unfortunately, it is also a system with vast disparities in care. One of the many groups struggling to receive adequate and appropriate healthcare are adults with autism. Autism is a lifelong condition, and those with this diagnosis struggle with social, emotional, and communication skills their entire lives. There is no cure for autism, and symptoms occur along a spectrum, ranging from extremely intelligent to extremely impaired (Centers for Disease Control [CDC], 2020). Autism is characterized by impaired social communication and restricted, repetitive behaviors. Some people with autism spectrum disorder (ASD) are nonverbal while others speak extremely well but struggle with social communication and pragmatic language. Issues with pragmatic language can include responding inappropriately in conversation, misunderstanding verbal communication, or lacking the competency to establish age-appropriate friendships. These inconsistencies in communication can impair many interactions for the adult with autism, especially when navigating the complex world of healthcare services.

A great deal of research, information, and focus has been placed on the pediatric population with autism spectrum disorder. Autism-focused researchers convey that there is a relative void in information for the adult autistic population (Corden et al., 2021). The Centers for Disease Control does not collect data on Autism in adults. The current prevalence of autism in the United States is one in forty-four children (Centers for Disease Control [CDC], 2020). As these patients age into adulthood, the increased number of patients with autism will present a significant challenge when receiving treatment in a hospital setting. Lack of knowledge about the

characteristics of this patient population and strategies to enhance their care pose a significant barrier for competent care.

Without adequate knowledge of potential behaviors exhibited by the patient with autism, the healthcare worker may be uncomfortable or stressed when caring for the patient. If the healthcare worker does not have foundational knowledge, autistic behaviors may be misconstrued as aggressive or attention-seeking. The healthcare workers' discomfort may be negatively perceived by the patient and his/her family, perhaps potentiating the atypical behavior. Healthcare workers can also leverage technology to prepare themselves and others for the effective care of this patient population. It is possible to use an online document repository or computer based-learning management system to increase knowledge and efficacy regarding caring for patients with autism. It has been suggested that the development of a toolkit for staff to access on an "as needed" basis can be crucial for enhancing patient care (Carter et al., 2017). Preparing healthcare workers to care for this patient population is necessary and overdue. An influx of adult patients with ASD will be seeking healthcare and it is imperative that training and education help prepare the healthcare workforce.

Literature Review

A search was performed to locate relevant information from electronic databases. The literature identified that stereotypical behaviors associated with ASD can influence care received in a hospital setting. It is recommended to adapt tools created for the pediatric ASD population for use with the adult population. Using adapted tools can aid caregiver efficacy when caring for this patient population. Using tools for communication will help bridge the gaps in care for adults with Autism. The research suggestions included understanding common social, behavioral, and communication impairments of patients with autism spectrum disorder

healthcare worker preparation and knowledge when working with this patient population, learning modalities, tools used for the hospital-based care of patients with autism, and identified gaps in care for adult autistic patients. A total of fifty-two references were reviewed.

The patient with ASD may have social impairment ranging from mild to severe, as the symptoms of this disorder can be expressed along a spectrum. Regardless of symptom expression, it is important to understand the unique needs of the patient. The stress of a hospital encounter may impair the otherwise strong social skills of the patient with autism. The stressful environment of the healthcare setting, however, may act as a catalyst for behavior regression. A nonverbal patient needs to have their preferred adjunct communication method used by all healthcare workers. It has been documented that between 40-50% of autistic adults do not speak to communicate. Even those who communicate verbally with spoken words, is not without issue (Poon, 2012). Persons with autism can often have rigid schedules which creates a sense of comfort. Hospitals have their own schedules, as well. Attempts should be made to regulate and organize the patient's schedule for consistency while hospitalized (Jolly, 2015).

Project Methods

Developing staff training and a patient care toolkit will help ensure patients with autism receive the care they require while in the hospital setting. "ASD patients with social and communication deficits, restricted patterns of behavior and sensitivity to sensory cues may face heightened barriers to care when hospitalized" (Carter et al., 2017, p.1510).

After receiving exempt institutional review board status from Southern Illinois University Edwardsville, the project was instituted at a community hospital in metropolitan St. Louis, Missouri. The hospital performs over six thousand outpatient surgical procedures and admits over three thousand inpatients. A module was developed and assigned to nurses and patient care

technicians via the Learning Management System (LMS). The module contained information of autism spectrum disorder (ASD), common stereotypical behaviors, communication tools, and possible triggers noted in the hospital environment. The module served to provide an overview of the disorder and discuss misconceptions. An online toolkit for healthcare worker was developed and available on the Teams platform. The toolkit contents and location were socialized to healthcare workers. Prior to the release of the LMS module on caring for the adult patient with autism, a baseline assessment of healthcare worker knowledge and stigma regarding autism was performed. A frequency analysis was applied to the survey results. The pre- and post-survey questions were the same to evaluate the educational intervention. Demographic information including age of practitioner, gender, education level, and years in healthcare was collected for comparison. Analysis of descriptive statistics and frequencies was performed with Qualtrics.

Evaluation

The purpose of this project was to increase awareness and confidence of staff at an ambulatory-based hospital setting when caring for adult patients with autism spectrum disorder (ASD). Knowledge and confidence were assessed in a pre-test and post-test format, prior to and immediately after completing the educational module using a modified version of the ASK-Q assessment (2017). Additional questions regarding confidence in identifying behaviors specific to ASD, recognition of patient triggers, and certainty in delivering proficient care to this subset of the population were asked before and after the education. Microsoft Excel was used for analyzing staff responses. There was an increase in staffs' knowledge when comparing pre and post-test scores in 10/12 statements. Staff knowledge did not improve regarding the gender most associated with ASD and erroneous beliefs about ASD being associated with intellectual

disability. A total of one hundred and ninety-two staff members completed the learning module between July 2022 and December 2022. During the same timeframe, one hundred and ninety-four staff completed the pre-test and one hundred and eighty-nine staff members completed the post-test. Improvement in post-test scores was based on summative assessments. Notably, the questions concerning provider confidence showed the most significant levels of increase.

The project did have some limitations. During project implementation, no patients with ASD were cared for in the project implementation facility. The knowledge gained nor the staff communication and assessment tools were not utilized in direct patient care. The training and development of the tools, including a survey of preferred communication strategies, tips for recognizing and reducing sensory triggers, and visual communication tools, did prompt discussion among staff members regarding the possibility of caring for a patient with a sensory processing disorder. The learning module helped staff gain additional insight into common behaviors and communication techniques when working with a patient with ASD. Discussion surrounding the need for communication with both the patient with a sensory processing disorder and his/her support person is critical to understand the unique needs of the patient. Additionally, the method of education, a learning module loaded into the computer-based learning management system (LMS) is often considered a burden by many staff members. Depending on the learning style and interest of the staff member, this method of teaching may not be the most effective. A final limitation is the high number of agency staff contracted to work at the hospital. These staff members commit for short-term contracts. Educational initiatives have less impact in this population, as they consider themselves short-term and not dedicated to the organization.

Impact on Practice

The immediate patient care impact of this project was to increase awareness of the growing adult ASD population and knowledge and confidence in caring for adult patients with the condition. No immediate change was seen in the care of patients at this facility, as this population was not cared for during the project implementation, but the opportunity to share the learning module and tools with other facilities will change practice on a broader scale. Future goals for the project team include understanding the needs of patients with developmental disabilities. Research has identified lack of knowledge regarding autism as a barrier to patient's receiving the appropriate care and resources they need (Corden et al., 2021). Working with the patient and his/her caregiver to understand triggers and sensitivities will enhance care delivery for the staff member and the patient. Increasing awareness regarding techniques and tools available will empower the staff member to understand how to competently care for their patient.

As the online ASD toolkit of aids for staff members is used, it should be examined critically for efficacy. The tools created to enhance communication and assist the staff member to identify and control triggers are intended to be a fluid document and should be curated as such. The tool should not be an inconvenience, it should meaningfully contribute to information gathered during traditional history or assessment. Patient and family input and suggestions, depending on the cognitive abilities of the patient, should be considered. The adult patient with ASD is the expert in their communication techniques and sensory triggers. Understanding the assessment piece from their unique perspective could ensure that information obtained is the necessary information. All patients deserve to receive care that is appropriate to their needs. The education and tools created will benefit both the patient and the staff member.

Conclusions

It is well documented that much of the research and information regarding autism spectrum disorder is centered around the pediatric population. Nurses and other healthcare staff who care for adults have not routinely cared for these adult ASD patients. Children with ASD are quickly growing into adults with ASD. The sensory and communication difficulties that are stereotypically seen in this disorder will act to exacerbate medical symptoms. It is pressing that healthcare workers have the knowledge and tools necessary to provide competent care for these patients. The risk of communication and sensory processing issues for patients in a hospital setting is very likely (Carter et al., 2017). An awareness of these risks is inadequate. Staff members must be cognizant of communication strategies, possible triggers, and adaptations that may need to occur to ensure appropriate care for this patient population.

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