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The Need for Change in Emergency Medical Approach When Caring for Individuals with Autism

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The Need for Change in Emergency Medical Approach When Caring for Individuals with
Autism

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Senior Honors Project

**Submitted in partial fulfillment of the graduation requirements
of the Westover Honors Program**

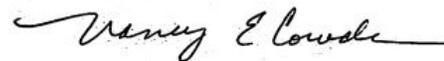
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Abstract

This paper highlights the need for policy changes and additional training related to caring for individuals with autism in emergency situations. Individuals with autism spectrum disorder are at risk of receiving inadequate care due to the challenges that come with such a complex diagnosis. Depending on the severity of autism for each individual, behavioral outbursts and aggression can often occur due to the overwhelming amount of stimulation in the emergency department environment. While medical professionals have the potential to be a great help during times of crisis, there is often very little training given to providers in regard to delivering care to patients with autism spectrum disorder. While there are individuals who see the need for change related to emergency care for patients with autism spectrum disorder, there are not nearly enough medical professionals trained to deliver such care. Providers need to receive training that prepares them for the behavioral, social, and communicative challenges they may face when caring for patients with autism spectrum disorder. Hospital systems need to prepare to treat patients with sensory and behavioral challenges, including providing quiet, private rooms to patients with autism spectrum disorder. Communication with parents and caregivers should be addressed as soon as a patient enters the emergency department; this will aid providers in assessment and treatment and avoid any unnecessary triggers that may delay care. With the correct training and policies in place in the emergency department, the hospital setting can be a safer place for patients with autism spectrum disorder.

Introduction

Despite the increased acceptance of individuals with autism spectrum disorder (ASD) in the community over the last several decades, there are still many inconsistencies that occur in providing a safe and inclusive environment. One of the biggest issues in creating a safe environment for people with ASD is the lack of knowledge and training when emergency medical care is needed. Patients with ASD who report to the emergency room with an injury or illness need a higher level of care than many other patients, and extra measures need to be taken to accommodate for their differences. Many health care professionals have not been trained to care for patients with ASD and are, therefore, unable to provide quality care and make accommodations that are so desperately required.

The need for an altered approach to medicine is crucial when caring for individuals with ASD, especially in emergency situations. High-stress environments like emergency departments can cause increased anxiety and overstimulation, which can lead to an autistic crisis in a patient with ASD. Much reform is required and policies need to change in order to keep individuals with behavioral and sensory issues safe in emergency situations. This is especially important in regard to individuals with ASD who are nonverbal, since they will be unable to articulate their need for personal space and what care they are comfortable receiving. There are many changes that need to take place in order to increase safety for people with ASD, and the changes need to begin with policy reform related to administering emergency medical care to this vulnerable population. There is not enough training given to emergency room doctors, nurses, and other staff in order to provide the high level of care that patients with ASD need.

This analysis will show the need for changes in the healthcare system in regard to patients with ASD. Emergency medical situations are stressful without the added complications

of sensory overload, altered communication, and potential violence that can occur when caring for individuals with ASD. These common characteristics of ASD often create dangerous situations in which medical personnel or the patient receiving care can be seriously injured or traumatized. These issues relating to care of patients with ASD need to be resolved in order to provide the best care possible for patients.

Background

ASD is a developmental disorder that impacts social interactions, communication, and behavioral expression (Copeland, 2018). It is a complex disorder that affects each individual differently, meaning that every encounter with a person who has ASD may need to be approached in a distinct way. Anyone interacting with an individual with ASD, especially in a professional medical capacity, needs to assess the individual in question and cater their approach to meet the needs of their specific patient. ASD has been growing in both occurrence and awareness over the last several decades (Wright, 2017). The Center for Disease Control (CDC) reports that one in 68 children in the United States were diagnosed with some form of ASD in 2018, compared to one in 150 in 2000 when the CDC began tracking the prevalence of ASD (Wright, 2017). Due to this increased diagnosis, there is a greater need for education and training for healthcare professionals who may be required to care for individuals with ASD at some point.

A survey by the National Survey of Children's Health found that parental report of medical service usage was much higher if their child was on the autism spectrum (Gurney, McPheeters & Davis, 2006). Compared to children without ASD, there was a higher prevalence of parents reporting their child's health as poor if the parent also reported that the child had an ASD diagnosis (Gurney, McPheeters & Davis, 2006). Parents of children with ASD also reported much higher rates of using medical care, mental health care, educational services, and

special therapy than parents of children not diagnosed with ASD (Copeland, 2018). One of the specific healthcare areas that is seeing an increased need for services relating to people with ASD, especially children, is emergency healthcare. Children with ASD were more likely to be treated in the Emergency Department (ED) compared to those without ASD, even if the reason for the ED visit was unrelated to the diagnosis of ASD (Copeland, 2018). The need for skilled ED care for individuals with ASD is great, and access to this care is often hard for some individuals to attain depending on their demographics.

In a study comparing the use of ED services by children with ASD in rural and urban communities, it was found that children in rural areas have less access to services and specifically adapted interventions to accommodate their special needs (Zhang et al., 2017). The amount of interventions provided to children with ASD in urban hospitals was higher than the amount of interventions provided to children who visited the ED in rural hospitals (Zhang et al., 2017). Although children with ASD in rural areas who visited the ED received fewer developmentally appropriate interventions, their rates of ED visits were far higher than children with ASD in urban areas due to the lack of resources available to them outside of the hospital environment (Zhang et al., 2017). The study revealed that one of the main reasons for this increase in services provided was the lack of care outside of the hospital environment, including in-home services, therapies, and safety interventions (Zhang et al., 2017). Due to this need for services and more children with ASD being seen in the ED, there needs to be more training and education for healthcare professionals in the ED so that they can better care for individuals with ASD.

Literature Review

The people with the most expertise in regards to individuals with ASD are the parents or caretakers of those individuals. These caregivers spend every day of their lives navigating and meeting the complicated needs of these unique people. A study surveyed the needs of hospitalized individuals with ASD from a parent perspective (Kopecky et al., 2013). The ASD diagnosis was self-reported by parents at the time of their child's hospital stay, and those parents were then asked directly by physicians to complete the survey. The survey, developed by physicians, nurses, parents, and child-life specialists, was comprised of 21 questions that covered topics related to sensory, communication, and social needs. The survey sought to identify the patients' primary needs regarding these main areas and also identified ways that the children and adults with ASD may require the physical exam or the hospital environment to be altered. The results of the survey were not scored but, instead, were used to inform the healthcare team on the best methods of assessing and treating their patients with ASD.

In total, 80 surveys were completed. Using those responses, the needs of the patients with ASD were evaluated and compared with one another to identify whether there were similarities or trends in the data that could be used to help care for other patients with ASD. The first main section of data was focused on communication. Of the 80 patients surveyed, only 23% communicated their needs verbally (Kopecky et al., 2013). Thirty-eight percent of patients communicated using sign language and gestures, and another 31% used communication tools such as picture exchange communication systems (Kopecky et al., 2013). In regards to communicating pain, 32% of patients were reported as expressing pain through crying and screaming, 27% expressed pain by showing aggression and self-harming behaviors, and 19% expressed pain by communicating verbally with spoken language (Kopecky et al., 2013). The

next main area assessed was social/pragmatic needs, mostly relating to assessments and examinations of the individuals with ASD. Parents expressed that certain aspects of the exam, including blood pressure measurements, inoculations, blood draws, genital examinations, ear examinations, and throat examinations were the most difficult for their children to tolerate. There were several methods that parents reported to be helpful for their children when they needed to be assessed or procedures needed to be performed. Thirty-five percent reported that distractions such as puzzles, videos, and music were helpful, 18% reported that a trusted escort and low lighting were helpful, and 37% reported that allowing the patient to examine the equipment first and see it used on a trusted adult were beneficial to remaining calm during the exam or procedure. There was a wide range of results in regard to best practices to help patients calm down during times of stress; 59% of parents expressed that their children calmed down best when left alone and given space, and 23% expressed that engaging with their child garnered faster results when trying to achieve tranquility. Twenty-nine percent of parents reported that their children had certain words or actions that would trigger anxiety. Fifty percent of parents expressed concerns about their child's safety in the hospital environment. These concerns included elopement, pica, pulling out IV tubing, aggression, and self-injury. The last main area that the survey covered was sensory needs. Loud noise was found to be the biggest contributor of sensory overload in patients with ASD, with 39% of parents reporting it as a trigger. Tactile and food sensory processing issues were also reported as common in the hospital setting (Kopecky et al., 2013).

The patients surveyed covered a wide range of ages, so responses were evaluated for differences in patients: 5 years old and younger and patients 5 years old and older. In regard to communication, patients under 5 years of age were found more likely to communicate using

gestures and sign language, while patients over 5 years of age were more likely to communicate using communication devices. Patients 5 years old or younger expressed pain mainly through crying or screaming, whereas patients 5 years old or older were most likely to express pain through aggression, self-injury, or spoken communication. The parent concerns for safety remained the same throughout the age differences, as did patient ability to tolerate tactile sensory stimulation such as ID bands and hospital gowns. Giving patients personal space during times of stress and anxiety remained the best way to aid in the calming process in patients of all ages (Kopecky et al., 2013).

Researchers found that the needs of hospitalized patients with ASD vary drastically, and the policies in place in the hospital setting need to reflect that. The assessment and procedural methods that work for one ASD patient are not likely to transfer to another patient with the same results. The study found that it is vital to assess patient needs and request parent/caregiver input as soon as possible when a child with ASD enters the hospital. There is a wide range of challenges when caring for a patient with ASD, and the communication, sensory, and social challenges are of utmost importance to understand in order to deliver the best care possible. The authors suggest protocols for assessing the needs of patients with ASD in any hospital setting so that care can be delivered as easily and effectively as possible (Kopecky et al., 2013).

Another perspective helpful in understanding the needs of individuals with ASD in the hospital setting is that of the providers who deliver care. Especially in an ED setting, previous experience caring for children with ASD can make a situation safer and more tolerable for a child who is likely to become overloaded with sensory input and be unable to communicate effectively. In a study that took place in two, high-acuity pediatric emergency centres, a survey was conducted that characterized the perspectives of health-care providers who delivered care to

children with ASD in the ED (Zwaigenbaum et al., 2016). Physicians and nurses were allowed to participate in the study if they had cared for a person with ASD who was under the age of 18 in the ED setting. The 22 participants were surveyed within four months of their most recent encounter with a child with ASD, and participant experience in the ED setting ranged from one year to several decades. Care providers were interviewed by a graduate-level researcher who asked open-ended questions about past experiences and suggestions for future care plans. Participants were encouraged to discuss specific situations in which they had faced challenges when caring for patients with ASD. Some participants reported caring for children with ASD in the ED often, while others reported that they rarely cared for patients with ASD. Only one child that was cared for by a provider in the ED was brought to the ED for behavioral reasons; all others were seen due to a comorbidity, and ASD was an added challenge to their care. Some of the reasons for ED visits were wound care, aggression, musculoskeletal concerns, respiratory issues, bowel issues, neurological issues, and foreign body aspiration (Zwaigenbaum et al., 2016).

The questions asked by the researchers fell under three main themes: factors contributing to challenges in the ED, factors that facilitated effective care in the ED, and suggestions to improve care of children with ASD in the ED. Participating providers revealed several main challenges when caring for children with ASD in the ED. The characteristics of the child (age, severity of symptoms, and ability to communicate) were extremely important as to whether or not care would be more or less challenging to deliver. Providers reported that older children were more difficult to assess and treat due to their larger size and strength, especially if they had a tendency to become aggressive. The more severe symptoms and inability to communicate presented increased challenges, and these challenges were also increased if the child showed

aggressive behaviors. One of the biggest contributing factors to challenges in delivering care was said to be that the ED is not an optimal environment for children with ASD. The ED is filled with sensory triggers that could easily overload a child with ASD; noise was reported to cause many issues, as was sensitivity to touch, since it made examination and assessment much more difficult. The demands of the ED, which require a provider to deliver quick and efficient care, can be hard to meet when caring for children with ASD; these children need an approach that is tailored to their own routines and familiar materials. Children also respond best to familiar environments and people, and the ED is usually an unfamiliar setting filled with new people, often many new people at one time. Providers reported that even when they knew how to effectively deliver care to their patients with ASD, it was often impossible due to lack of resources, the needs of other patients, and lack of input in patient assignments. Providers also saw a correlation between long wait times and anxiety and behaviors in their patients with ASD, and reported that ideally patients with ASD would be seen sooner rather than later to decrease anxiety before they were examined. Unfortunately, this is not often an option since ED triage is based off of acuity of an injury and presenting symptoms (Zwaigenbaum et al., 2016).

The providers involved in the study identified several ways to improve care for patients with ASD in the ED setting. Assessing communication needs was reported as one of the biggest contributors to effective care. Nurses and providers alike reported that taking the time to try several communication methods, paying attention to non-verbal cues, and assessing anxiety and stress levels all aided in creating an environment that was more conducive to delivering effective care. Including parents or other caregivers in the care of the patients and asking them questions improved care since parents and caregivers are the true experts when it comes to their children. Parents were able to identify and warn providers about potential triggers and anxieties, which

helped create a more tailored approach to assessments and procedures. Parents were also especially helpful when communicating with patients in an effective manner and were also helpful when engaged in assisting with care, such as giving medications and checking vital signs. Most healthcare providers questioned reported that their past experiences in caring for patients with ASD was most helpful in preparing them for delivering care to future patients with ASD, as opposed to training that they had received. Providers reported that encouraging and accepting input from many non-traditional team members was helpful in creating and carrying out the best care plan for their patients with ASD. Parents and child-life specialists were identified among the most valuable members of the care team; social workers and hospital volunteers were also identified as helpful. All of these team members together are needed to provide the time and high level of care that children with ASD require. Another important factor in delivering effective care and reducing stress and anxiety in patients with ASD was reported to be creating a calm environment and reducing sensory input as much as possible. Providers reported taking advantage of private rooms as often as possible when caring for children with ASD and that this contributed to decreased sensory overload and anxiety in their patients. Using distraction techniques and taking extra time for procedures also contributed to a calmer environment. Several providers mentioned that using sedation for procedures where sedation was not normally used was also helpful, due to patients' inability to interpret sensory cues and their increased pain responses (Zwaigenbaum et al., 2016).

Most of the challenges that providers caring for children with ASD in the ED identified had to do with the environment and processes and procedures in place in the hospital. Similarly, the contributing factors to effective care were often related to environmental and procedural issues. Providers involved in the study suggested many changes to improve care for children

with ASD but identified that systematic changes need to be implemented before care can be improved on a personal level (Zwaigenbaum et al., 2016).

Limitations

There are several limitations to the studies that were reviewed. In both studies, the sample sizes were small, assessing only a small percentage of the population. Without research that incorporates more hospitals and patients, there is not enough data to accurately assess the problem. While suggestions and changes can be made based on the small sample sizes reviewed in these studies, more statistics and results need to be available to make definitive claims regarding ED care of patients with ASD. Another limitation is that the studies reviewed surveyed parents and providers in high-acuity, urban hospital settings, so the results are not necessarily representative of patients receiving care in hospitals in more rural areas and lower-acuity settings. More research needs to be done in ED settings in many different areas of the country to accurately assess the needs of patients in all environments. Lastly, only one study assessed patient care in the ED, while the other was seeking information about hospital stays in general. The information conveyed in the study was still valuable, but more research needs to be done specifically on parent perspectives of care delivered in the ED to accurately assess the needs of ASD patients.

Discussion and Recommendations

Both studies reviewed identify the need for an altered medical approach when caring for individuals with ASD. Parents of children with ASD in the hospital and providers caring for children with ASD in the ED all agree that there are certain factors that contribute to the effectiveness of care that is delivered. One of the most important factors in delivering quality care is communication (Zwaigenbaum et al., 2016). Communication among team members and

with patients contributes greatly to creating a safe environment and one that is conducive to treatment and healing. Since most children with ASD in the ED are being treated for a comorbidity and not their diagnosis of ASD, it is important that both needs are met (Zwaigenbaum et al., 2016). Viewing parents as experts in the care of their children is vital to delivering the best care. Parents should be involved in the planning of care before any assessments or procedures are carried out, so that providers are aware of any words or actions that may cause an already stressful situation to escalate. There are several ways to include parents and increase communication that are both easy and would greatly improve the quality of care delivered to patients with ASD. One way to increase communication is providing parents or caregivers of patients with ASD a questionnaire that addresses topics such as communication needs/assistive devices, potential triggers for sensory overload, common characteristics of the patient's behavioral outbursts, and ways in which previous healthcare providers have successfully cared for the patient. By asking these questions on admission, healthcare providers will have a more clear understanding of patient needs and behaviors even before entering the patient's room. This can help create a better relationship between provider and patient from the very beginning interactions.

Besides communication, there are other ways in which the ED can be made safer for individuals with ASD. More training needs to be given to providers about ASD and how to treat patients with this comorbidity. Because each individual with ASD has such complex needs, no training can be sufficient to cover every need of every patient with ASD that a provider may encounter, but more training could be beneficial in raising awareness and preparedness. Simply understanding the basic needs and common triggers of an individual with ASD could aid a healthcare provider in assessment, communication, and critical thinking when caring for their

patient in the ED. Due to the fast-paced nature of ED care, a previous understanding of ASD and the additional needs a patient with ASD will have could greatly reduce the time needed to initiate care and understand what care needs to be altered to meet patient needs. This is especially important in rural areas where the rates of ED visits for ASD patients are higher than in urban areas (Zhang et al., 2017). The ED may be the only resource available to ASD patients in areas where home and school resources are lacking, so it is important that ED providers are prepared to address increased needs.

The ED environment can be altered for sensory needs by allowing patients with ASD to be placed in private rooms with dimmed lighting in quiet areas. Non-stimulating rooms will allow patients with ASD to feel more comfortable in an unfamiliar setting and could help them remain calm during assessments and procedures. Over-stimulation is likely to occur in the ED, and assigning a patient with ASD to a quiet area of the unit could greatly decrease the risk of sensory overload (Zwaigenbaum et al., 2016).

Smaller patient assignments for providers would allow for more interaction with ASD patients, creating more time for the slowed procedures and communication that is often required. Patients with ASD have more complex needs and behaviors than patients without ASD and, therefore, need more attention when receiving care due to this comorbidity. Decreasing patient assignments would allow nurses and doctors to spend time with their ASD patients and cater to their unique needs. Providers who have previous experience with ASD patients should be assigned to treat ASD patients in the ED whenever possible. Scheduling is not always flexible, but rearranging assignments to provide more experienced care for patients with ASD would be beneficial and decrease the likelihood of complications in patient care (Zwaigenbaum et al., 2016).

When patients with ASD first arrive at the ED, more can be done to decrease their wait time in busy waiting rooms so that their stress and anxiety levels are not heightened before they are seen by a provider. If parents self-disclose their child's diagnosis of ASD during registration in the ED, hospital staff will have the knowledge they need to quickly prepare a space where the patient is exposed to less stimulation while they wait to be seen by a provider. This action alone could decrease the occurrence of aggressive outbursts, and combined with a slowed approach and quiet environment, the ED can be a place where the needs of patients with ASD are met quickly and without incident.

Conclusion

Individuals with ASD receiving care in the ED are likely to experience anxiety and stress related to sensory overload, communication barriers, and social issues. The needs of patients with ASD are incredibly complex and need to be addressed as such. Since the needs of patients with ASD vary so drastically, it is important for providers in the ED to assess the needs of each patient related to their diagnosis of ASD before delivering care. The inclusion of parents as experts on the healthcare team is vital to creating a safe and effective treatment plan for patients with ASD, and their involvement in delivering care can often decrease anxiety and aggressive behavior. There needs to be a change in the system that allows for a more tailored approach for each individual with ASD who is seen in the ED. Long wait times, the needs of multiple patients assigned to providers, and an over-stimulating environment all contribute to increased stress and anxiety in patients with ASD. These challenges cannot be controlled successfully by individual providers, requiring a systemic change that involves new policies and procedures.

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