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Increased Knowledge of Autism Spectrum Disorders Reduces Stress Levels in Staff Caring Directly for Patients With Autism Spectrum Disorder.

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INCREASED KNOWLEDGE OF AUTISM SPECTRUM DISORDERS REDUCES STRESS LEVELS IN STAFF CARING DIRECTLY FOR PATIENTS WITH AUTISM SPECTRUM DISORDER

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An Abstract of the Scholarly Project by
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Autism Spectrum Disorders (ASD) is a group of disorders that affects approximately 1 in 59 children (Autism Spectrum Disorder, 2019). This group of disorders can cause deficits in communication, social relationships, and those with the diagnosis may exhibit undesirable behaviors as well as restrictive and repetitive behaviors (RRBs). There is limited education given to healthcare providers on this group of disorders, making it difficult to care for these patients. This study was conducted to determine if the stress level of staff that directly care for patients with ASD, at a pediatric behavioral health hospital, decreased following an educational presentation over ASD. This study also researched if knowledge levels increased after the implementation of an educational presentation over ASD, and if the interventions suggested in the presentation were utilized following the presentation. The results were consistent with what was believed to occur which was that the stress levels of the staff did decrease following the educational presentation, the knowledge level increased between the pre-educational survey and the post-educational survey, and the interventions were utilized multiple times during the month in which the study took place. It is believed that the increase in knowledge over ASD, resulted in a decrease of stress in the staff, when caring for patients with ASD.

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Chapter I

Introduction

Autism Spectrum Disorders (ASD) are a group of neurologic disorders that are characterized by deficits in communication and social interactions as well as increased restrictive and repetitive behaviors (RRBs), interests, or activities (Burns, et al., 2017; Hay, et al., 2016). ASD causes lifelong deficits that usually manifest themselves within the first three years of life (Burns, et al., 2017). Increasing prevalence now estimates that one in 59 children are diagnosed with ASD with a four times higher likelihood in males than females (Centers for Disease Control, n.d.). In addition to the deficits in communication and social interactions and RRBs, sensory stimulation can increase difficulties for these children. ASD persons often experience hypersensitivity to sound, touch, smell and other sensory stimuli, while having hyposensitivity to pain (Anonymous, 2009). Estimates of the prevalence of children with ASD affected by sensory difficulty are approximately 45% to 96% (Howe & Stagg, 2016; Schaaf, et al., 2014).

The *Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition (DSM-5), states that the deficits in social communication and social interactions are often manifested by social-emotional reciprocity (American Psychiatric Association, 2013). These range from the abnormal approach or lack of normal back-and-forth conversation to the reduced sharing of interest in activities, emotions, or affect. This also includes

failure to initiate or respond to social interactions (Hay, et al., 2016). Deficits in nonverbal communication include difficulty in integrating verbal and nonverbal communication such as abnormalities in eye contact, body language or understanding or using gestures; or the complete absence of facial expression or use of nonverbal communication (Hay, et al., 2016). The DSM-5 also states that deficits in social communication and social interaction can manifest as challenges developing or maintaining relationships as a result of having difficulty adjusting behaviors to fit social contexts, difficulties in participating in imaginative play or in making friends, or the total absence of interest in peers (Hay, et al., 2016). RRBs include stereotyped repetitive motor movements including lining up toys, flipping objects, rocking, spinning, or other constant motions (Hay, et al., 2016; Jolly, 2016). Insistence on sameness is another manifestation of RRBs included in the DSM-5, which manifests as strict adherence to routines, or ritualized patterns of behaviors (Hay, et al., 2016). Fixated interests include, but is not limited to, strong attachment to or obsession with unusual objects, as well as hyper- or hypo-reactivity to sensory aspects of the environment. Indifference to pain; adverse responses to tactile stimulation, sound, or smell, textures of foods; excessive smelling or touching of objects; or a visual fascination with lights or other moving objects are also included in the DSM-5 RRB criterion (Hay, et al., 2016).

There have been previous correlations made between the occurrence of RRBs and sensory stimulation, perhaps suggesting that RRBs are a response to sensory stimulation and are a compensatory mechanism to maintain homeostasis as these sensory stimulations are stressful triggers for these children (Black, et al., 2017; Howe 7 Stagg, 2016; Jolly, 2016; Lane & Heathcock, 2014; Spratt, et al., 2012; Samson, et al., 2014;

Schaaf, et al., 2014). The sensory stimulation that precede the occurrence of RRBs are often those that would evoke limited or no response from typically developed (TD) children, such as fluorescent lighting, light touch from another person (such as a teacher placing a hand on child's shoulder or back while speaking to them), background noises such as a lawn mower outside or a ceiling fan motor, and soft smells such as food, perfumes, or cleaning products. These sensory stimuli, while unharmful to TD children, caused physical pain, a decrease in concentration, or severe impairment or discomfort for the child with ASD (Howe & Stagg, 2016).

Significance

The prevalence of ASD increased approximately 78% from 2008 to 2014 (Brown & Elder, 2014). The likelihood of having to care for a person with ASD in the inpatient setting increases with the increasing prevalence of the disorder. Deficits in communication and occurrence of RRBs create limitations in caring for these patients, as well as increase stress for the provider caring for the patients and increase stress for the patient themselves. There is limited knowledge regarding ASD characteristics, features, diagnosis, and treatment methods (Brown & Elder, 2014; Giarelli, et al., 2012; Tipton & Blacher, 2014). This lack of knowledge may stem from the minimal to complete absence of requirements for undergraduate and graduate nursing programs to incorporate specific content on ASD. The need for continuing education for these nurses is crucial to providing appropriate, competent care for these patients with ASD. Nurses and other direct care staff including nurse technicians and assistants need education as to how to properly communicate with the diversity of patients in their care. According to the American Association of Colleges of Nurses (2008):

> Cultural sensitivity is experienced when neutral language, both verbal and not verbal, is used in a way that reflects sensitivity and appreciation for the diversity of another. Cultural sensitivity may be conveyed through words, phrases, and categorizations that are intentionally avoided, especially when referring to any individual who may be interpreted as impolite or offensive.

The American Association of Colleges of Nursing (AACN) emphasizes the importance of education and experience in caring for patients from diverse cultures during baccalaureate nursing programs in order to promote cultural sensitivity in the workplace post-graduation (American Association of Colleges, 2008). There is a very minimal amount of education provided to nurses on the ASD "culture" which limits the ability to provide culturally sensitive care to this group of patients. The need for autism education, for all providers participating in direct patient care, is great.

Specific Aims/Purpose

The purpose of this study was to provide education regarding ASD to nurses and direct care staff at a local pediatric behavioral hospital. The staff who received this education included registered nurses (RN), licensed practical nurses (LPN), behavioral health specialists (BHS), and therapists. The education focused on characteristics of autism and intervention strategies for recognizing and intervening appropriately to undesirable behaviors including RRBs, self-harming behaviors, and destructive behaviors.

The aim of the study was to assess the knowledge of the nurses and direct care staff related to ASD and their implementation and retention of such knowledge and the impact it had on their stress level and competence in caring for ASD patients in the

inpatient behavioral setting. The second aim of the study is to evaluate the effectiveness of such interventions on the occurrence and the de-escalation of RRBs and undesirable behaviors.

Applied Behavior Analysis (ABA) is deemed the best clinical practice guideline for treating patients with ASD (Burns, et al., 2017). This has been the most researched treatment approach, however, there are significant downfalls to utilizing ABA. ABA is at times a very time sensitive and expensive approach to addressing ASD, that sometimes, insurance companies will not cover, which limits the use of these services for many families (Burns, et al., 2017). It also requires extensive training on the part of the providers utilizing the approach. Sometimes this can be unrealistic for hospitals to provide the time, money, and effort in training their staff, as turnover rates occur and the motivation level of staff members may be limited.

This study explored the teaching strategies and information provided on ASD and the effectiveness of suggested intervention strategies in a stress-free, more affordable setting for the employees in comparison to courses and education taken to become certified in ABA. It also explores the efficacy of such strategies and interventions in limiting and de-escalating behaviors common to those patients with ASD.

Theoretical Framework

Utilizing Patricia Benner's Novice to Expert theory as a theoretical framework for this study, many theoretical assumptions are associated within the study. Figure 1 shows the major assumptions obtained from Benner (1984), and how they correlate to this study. The framework focuses on how nurses through experience, research, and increased knowledge, will go from a novice nurse to an expert (Petiprin, 2016). The goal was to

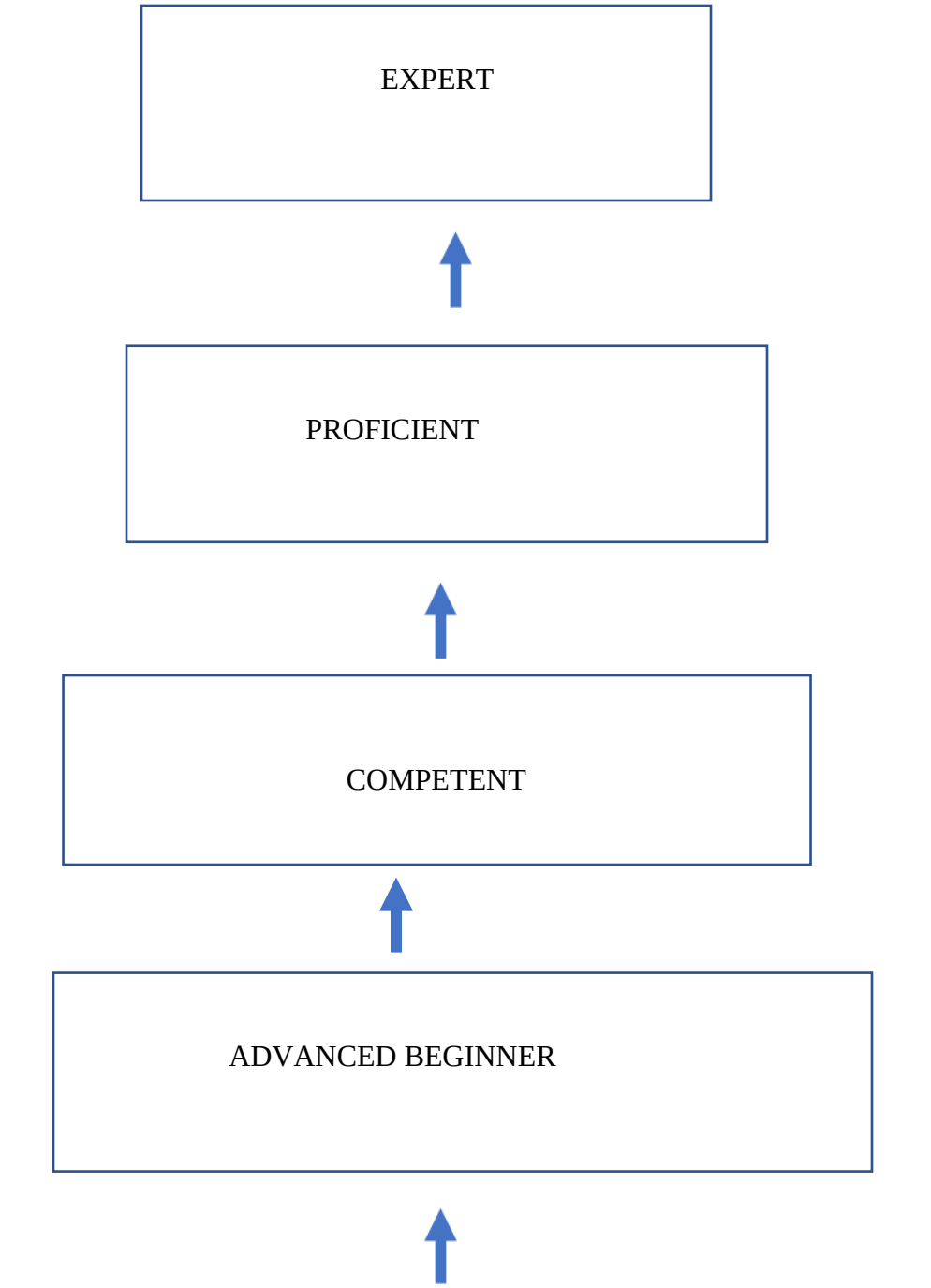
implement a teaching tool to promote the education of ASD to nurses, who may range from novice to proficient, in order to encourage the promotion to expert nurse.

Figure 1
Benner Model Assumptions

Major Assumptions	Study Aspects
Stage 1 -Novice	This would be a nursing student in his or her first year of clinical education; behavior in the clinical setting is very limited and inflexible. Novices have a very limited ability to predict what might happen in a particular patient situation. Signs and symptoms, such as change in mental status, can only be recognized after a novice nurse has had experience with patients with similar symptoms.
Stage 2 - Advanced Beginner	Those are the new grads in their first jobs; nurses have had more experiences that enable them to recognize recurrent, meaningful components of a situation. They have the knowledge and the know-how but not enough in-depth experience. The patient variables, or "client variables" as stated by Neuman, are present in all persons, however, in ASD patients, they may be defined or manifested differently than those TD patients.
Stage 3 – Competent	These nurses lack the speed and flexibility of proficient nurses, but they have some mastery and can rely on advance planning and organizational skills. Competent nurses recognize patterns and nature of clinical situations more quickly and accurately than advanced beginners.
Stage 4 – Proficient	At this level, nurses are capable to see situations as "wholes" rather than parts. Proficient nurses learn from experience what events typically occur and are able to modify plans in response to different events.
Stage 5 – Expert	Nurses who are able to recognize demands and resources in situations and attain their goals. These nurses know what needs to be done. They no longer rely solely on rules to guide their actions under certain situations. They have an intuitive grasp of the situation based on their deep knowledge and experience. Focus is on the most relevant problems and not irrelevant ones. Analytical tools are used only when they have no experience with an event, or when events don't occur as expected.

(Benner, 1984).

Figure 1-1 Stages Through Which Nurses Must Progress to Obtain Expert Status.



Transition through the stages by learning from clinical experience, research, and continuing education.

Project Hypotheses

This study hypothesizes that 1) The nurse and direct care staff knowledge of ASD characteristics and intervention methods will increase following the educational presentation; 2) The staff will be able to utilize the interventions given during the educational presentation a minimum of 5 times; and 3) The stress experienced by the nurses and direct care staff caring for those with ASD will decrease from the beginning of the study to the end of the study.

Summary

To summarize this first chapter, the assumption needs to be made that healthcare professionals lack the appropriate training and education to appropriately care for patients with ASD. This lack of knowledge may limit the likelihood that a nurse will reach the expert level whilst working with patients with ASD. The expectation that nurses provide culturally competent care need to extend to those patients with autism spectrum disorders and their unique communication, interaction, restrictive and repetitive behaviors, and sensitivity to stimuli. The effect of increased cortisol during stress responses in these patients may play a role in exaggerating responses to stressful situations. The increased sensitivity to sensory stimuli may result in the restrictive and repetitive behaviors as a compensatory mechanism for returning to their homeostasis state. However, this study is not to focus on the causes or the reasons as to why these patients exhibit behaviors the way that they do, but rather educate nurses and direct care staff on how to respond and intervene appropriately, with hopes that the results will conclude a decrease in stress for the nurses and direct care staff by increasing their knowledge of ASD.

Chapter II

Review of the Literature

In this chapter, review of the literature is discussed. The information given in this chapter has an emphasis on ASD incidence and risk factors, characteristics of ASD, current treatment guidelines, and the importance of this information to nursing and healthcare providers alike. Within the importance to healthcare providers, the difficulties that healthcare providers often face when caring for patients with ASD, due to insecurities or lack of knowledge regarding the disorder are discussed.

Incidence

Autism is the most common intellectual disorder in the diagnosis category called Autism Spectrum Disorders (Anonymous, 2009). As stated earlier, ASD is currently recognized as occurring is approximately 1 in 59 children (Centers for Disease Control, n.d.). Three diagnoses, that once were separate diagnoses, are now all considered to be part of the autism spectrum disorders. These include autistic disorder, pervasive developmental disorder not otherwise specified, and Asperger syndrome (Centers for Disease Control, n.d.). ASD is a developmental disability that can cause significant communication, social, and behavioral problems. The appearance of patients with ASD is physically unremarkable as there is no set of physical characteristics that pertain strictly to ASD. The intelligence of patients with autism can range from gifted to extremely

challenged. Lastly, some ASD patients may need extensive amount of help completing activities of daily living, while other patients may be able to live and function independently (Centers for Disease Control, n.d.). ASD occurs in all racial groups, ethnic groups, and socioeconomic statuses, but is about four times more common in boys than in girls (Centers for Disease Control, n.d.).

Risk factors. Studies have been completed to explore the possible risk factors or cause of ASD. There has been limited definitive information obtained, but due to scientific studies, there are some ideas on what could potentiate the cause of ASD, as well as studies that have disproven some factors causing autism. Prenatal factors that have been thought to influence the diagnosis of autism include advanced maternal and paternal age at birth, maternal gestational bleeding, and gestational diabetes. Perinatal risk factors include umbilical cord complications, birth trauma, fetal distress, a low 5-minute Apgar score, ABO blood group system or Rh factor incompatibility and hyperbilirubinemia (Sadock, et al., 2015).

Most evidence has concluded that there is a genetic factor involved in the diagnosis of ASD (Centers for Disease Control, n.d.). Children who have a sibling with ASD are also at greater risk for having ASD. ASD often tends to occur more in those with genetic conditions including fragile x syndrome and tuberous sclerosis (Centers for Disease Control, n.d.).

A frequently heard myth that vaccines cause autism originated from a study completed in 1998 by Wakefield and colleagues. The study found that eight of twelve parents with autism spectrum disorders (ASD) also had gastrointestinal problems and stated that the onset of their symptoms occurred after receiving the measles-mumps-

rubella (MMR) vaccination. The researchers hypothesized that the MMR vaccination possibly caused bowel dysfunction that contributed to their neurological disorder. However, the study was retracted later due to the controversy of the article and the inability to replicate the study with numerous attempts following publication of the article (Peacock & Yeargin-Allsopp, 2009). Attempts to replicate did not find any significant causal relationships between autism and the MMR vaccine.

The Center for Disease Control (CDC) reports there is no documentation that thimerosal (a component in childhood vaccinations) contributes to autism. After thimerosal was eliminated from most childhood vaccinations there was no decrease in the prevalence of autism and there would have been a significant decrease if thimerosal had been a causative factor (Vaccine Safety, 2015). There still needs to be extensive research conducted over risk factors and causal relationships leading to the diagnosis of ASD, however, at this time, there is no research that has found any definitive information regarding the cause of autism.

Characteristics of ASD

Characteristics of Autism include impaired social interaction, difficulties communicating (verbally and nonverbally), and unusual or repetitive activity or interests or severely limited activity or interests (Giarelli, et al., 2011). An article written by Nadel and Poss (2007) reviewed tools used to help with diagnosing children with ASD. There were nine characteristics found that were common characteristics in ASD patients:

> a) lack of appropriate gaze; b) lack of warm, joyful expression with gaze; c) lack of sharing enjoyment or interest; d) lack of response to name; e) lack of coordination of gaze, facial expression, gesture, and sound; f) lack of showing

(something of interest to someone); g) unusual prosody (how one says something [i.e., intonation and tone of voice]—not what one says); h) repetitive movements or posturing of body, arms, hands, or fingers; and i) repetitive movements with objects (p.410).

During infancy, autism symptoms that may be observed include the inability to focus on a person or focusing on one thing while excluding others for long periods of time (Anonymous, 2009). It is deemed alarming if a child by twelve months of age is not babbling, pointing, or making other gestures and immediate further evaluation is necessary. If by sixteen months the child is not saying single words, immediate further evaluation is necessary (Goolsby & Blackwell, 2005).

Autism can greatly affect sleep habits of school-aged children. Insomnia occurs in 44 to 83 percent of school-age children (Sadock et al., 2015). Interventions that have been found to help treat this symptom include routines performed by parents before and at bedtime. Also, pharmacological interventions have proven successful in treating insomnia in this group of children. Other symptoms for children with autism can include a heightened pain threshold and an overresponse to some stimuli while having a limited response to others. Mood instability, hyperactivity, inattentiveness, and a higher intelligence than peers that are without the diagnosis of ASD can also be characteristic of autism (Sadock, et al., 2015).

Higher rates of certain self-injurious behaviors (SIB) are often noted in people diagnosed with ASD. There is thought to be correlation between early parental involvement in counseling and reduced or absent SIB (Akram, et al., 2017). During the study participants' parents completed a standardized inventory survey of self-injurious

behavior including how often and what types of behaviors were exhibited. The most common SIBs were banging/self-beating, severe scratching, pinching, picking (scabs, other wounds), biting, hair pulling, and rubbing skin on rough surfaces. The results of the study concluded that there was a reduction in SIB when the children received early intervention compared to those that did not receive any intervention and also which did not have parental involvement in counseling services (Akram, et al., 2017).

When discussing behaviors that are commonly attributed to persons with ASD, it must also be noted that behaviors may not have a specific cause or purpose. Hanley, et al., (2003) completed a rigorous literature review that focused on behaviors and why those behaviors may have occurred. Behaviors that they observed included, but were not limited to, aggression, pica, disruption, stereotypy, self-injury, elopement, tantrums, noncompliance, and vocalization. The review showed differences in occurrence of specific behaviors based upon the child. The behaviors did not necessarily correlate with a specific reason, but rather with a multitude of reasons including to escape, for attention, automatic response for no specific reason, and for a combination of the above mentioned (Hanley, et al., 2003). This review proves that not all behaviors exhibited by children with ASD are caused by the same thing or are exhibited for the same reasons.

Contributing factors to characteristics. A study was completed to research the cortisol levels in children with autism from a first-morning void, during a stressor, and after a stressor compared with typically developing (TD) children during the same time. The study found that urinary cortisol levels at the first morning void between the two groups of patients were not significantly different ($p = 0.329$). There were significantly different cortisol levels between the two groups during the blood draw ($p = 0.014$), with

autism patients being significantly higher. Both groups displayed an increase in salivary cortisol levels 20 minutes after the blood stick, with a greater increase in autism children. The cortisol level taken 40 minutes after the blood draw in children with autism was still above baseline, while the children without autism were below baseline. Differences between males and females were not significant (Spratt, et al., 2012). This means, that during a stressor, autism children produce higher cortisol levels, which may be the cause of their RRBs.

In a study by Shabha (2006) the possible triggers for stereotypical or repetitive behaviors displayed by those with ASD were examined. The study found what appeared to be a relationship between sensory stimuli and stereotypical ASD behaviors including rocking, hand flapping, and spinning. The study hypothesized and concluded that the interrelated effect of sensory environmental stimuli significantly influences the psychological comfort of sensory impaired children and affects their behavior. During the study, questionnaires were given to teachers in a school for ASD children and they were asked to observe and note anything that seemed to trigger the stereotypical behaviors being researched. The completion of open-ended interviews also validated the questionnaire findings. Stereotypical or repetitive behavior was aggravated by intensity of light, sound echoing, and reverberation in larger spaces with all seeming to have similar effects. Low-pitch traffic sounds heard through windows, extractor fans, and personal computer fans also showed to influence behaviors. The study had found that stereotypical behaviors were intensified by stress or by boredom (Shabha, 2006). This is an example of how hypersensitivity or hyposensitivity is a major component of ASD and helps to try an explain why some of the stereotypical behaviors may occur.

Treatment Guidelines

After extensive researching, this author was unable to obtain a specific set of guidelines to use when caring for patients with ASD. Therefore, this section summarizes and incorporates multiple ideas on ways to care for those with ASD, in order to get a broad understanding of interventions to be used when caring for patients with ASD.

One article stated that the goal of treatment for patients with ASD is to target behaviors to help improve social interactions, increase strategies to participate in school, develop meaningful relationships with peers, and increase skills to maximize independent living. Individual therapies for academics, behaviors, and communication are an emphasis in the treatment of autistic persons (Sadock, et al., 2015).

An article written by Stokes (2016), suggests interventions aim to lessen the stress for ASD patients and provide a better healthcare experience for them. She reported that assessing the patient during the initial visit and assessment could be beneficial to making appropriate adjustments and interventions for the patient. During the assessment, noting the patient's ability to communicate and preference for communication (pictures, writing, sign language, stories, etc.), the patient's ability to follow directions, noting social, behavioral, and sensory skills, and discussing the patient's strengths and limitations with family members can be crucial to the care being given to the patient to enhance their comfort. Adjustments that can be made include using the patients preferred method of communication (drawing, pictures, verbal, writing, computer/typing, etc.), using positive reinforcement for procedures including a piece of candy or a kind of "treat" at the completion of the procedure or using a rewards system that is already in place at home and is familiar to them; altering flavors of medication that may be unpleasant when

available, limiting noise such as closing doors, silencing alarms, or allowing for a quiet waiting room or less time spent in the waiting room, and allowing the patient to keep personal items that they bring from home to help them stay calm and feel safe may be appropriate to decrease the stress during health visits (Stokes, 2016). Eliminating stressors as much as possible is key to keeping the patient comfortable and maintaining a feeling of safety and trust.

Applied behavior analysis (ABA) is a proven effective approach to modifying behaviors over time, by analyzing behaviors and social interactions and identifying the behaviors that require modification and tailoring treatment to each individual patient's needs (Psychology today, 2018). Since the site of this author's study is a short-term pediatric behavioral hospital, ABA is not utilized as a treatment since longer time with the patient is typically needed to produce the desired behaviors.

Importance to nursing and healthcare providers

Giarelli, et al., (2011) completed a study that discussed the issues and the limited knowledge that nurses had regarding the care to be given to ASD patients. The researchers conducted a course for further education for nurses caring for autistic patients. The study found that after taking the course, participants used something that they learned within the course at least once and that post-course surveys indicated that over ninety percent of participants shared what they learned with their employer or with a co-worker (Giarelli, et al., 2011). If providers accept that there is a knowledge deficit when it comes to autistic patients and conferences and learning opportunities are utilized to learn more, then this patient group can benefit greatly from the interventions that would be able to be provided.

In another study aimed to assess physicians' comfort levels in treating patients with ASD analyzed that, as previously mentioned from another study, physicians had limited knowledge regarding ASD due to lack of formal training regarding the disorder. Some physicians did not know that ASD included Asperger's. None of the physicians in the study had any formal training regarding the disorder (Zerbo, et al., 2015). Frustrations encountered by physicians during this study were difficulty in communicating with non-verbal patients diagnosed with ASD and establishing rapport with patients with ASD. The researchers concluded the frustrations were caused by a lack of training regarding ASD (Zerbo, et al., 2015).

At a nurse practitioner conference, primary care nurse practitioners were surveyed regarding their self-perceived competency level in providing care to children with ASD in comparison to providing care to children with complex/chronic issues. Nurse practitioners rated their desire for more education regarding ASD using a Likert scale (1=never and 7 =always); the score was 6.42. When asked about desire for education regarding complementary and alternative medicine (CAM) training for these patients they responded 6.23 (Will, et al., 2013). The top three rated barriers for providing care to ASD patients within this study were family skeptics about vaccinations, lack of care coordination, and lack of time.

One study interviewed patients with mild to moderate intellectual disabilities who were 18 to 65-years of age and the caregivers of the patients regarding their experiences with healthcare. The participants stated there were barriers to communication including they felt "talked over', procedures were not adequately explained, and diagnoses and medication information was not adequately discussed. Patients and caregivers also

explained the difficulty in receiving access to help due to limited resources or referrals and timely support (Ali et al., 2013). Suggestions for improvement of care from the caregivers and patients included: prioritizing the patient to avoid long wait times when possible and necessary, providing healthcare information in an easy to understand way, noting on electronic charting that the patient has an intellectual disability to alert staff, and being available to see the healthcare environment prior to any surgical or non-surgical procedures (Ali et al., 2013).

In a different study completed by Harrop, et al., (2016), the focus was placed on the importance of involving caregivers in research and treatment to help identify what causes caregiver stress in terms of finding effective intervention strategies. The study identified three hypotheses that explain the study well.

1. Caregiver report of child RRBs will not change significantly over the course of a short-term longitudinal study
2. Caregiver reported stress will associate concurrently with child's RRBs, with higher rates of RRBs associated with higher rates of caregiver's stress.
3. Change in caregiver stress over time will be predicted by change in RRBs, after controlling for parent socioeconomic status, ethnicity, and sex as well as child sex, overall ASD severity and developmental functioning.

Ninety-one participants completed the entirety of the study. Caregivers completed various rating scales and questionnaires about themselves and their children across 3 times periods from 12-18 months. Children's behaviors were gathered using the Repetitive Behavior Scale -Revised (RBS-R) and caregiver stress was gathered using the Parent Stress Index-Short form (PSI-SF). In the conclusion of the of study, it was found

that there was a correlation with increased RRBs and increase in caregiver stress. When caregiver stress increased, the occurrence of RRBs increased as well. This study promotes the importance of finding effective interventions, as the occurrence of RRBs directly impacted the caregiver's stress and overall wellbeing (Harrop, et al., 2016).

Understanding a background about potential causes and myths is important for healthcare providers to be aware. As stated by Vondrak and Bishop (2017), "Health care providers also play a major role in answering questions, dispelling myths and educating people about the safety and effectiveness of vaccines." Understanding the myths, safety, and effectiveness of vaccines is vital in giving accurate and complete information regarding vaccinations and their features.

Another important aspect for providers to be aware of is the stigma that autism can have and the stress for parents that stigma can create. A study was completed on the effects of stigma of autistic children and the stress it places on the parents including the lack of friends at school, isolation, rejection by peers, and exclusion. It is important for providers to understand these risks and to provide parents with the support that is needed to limit stress and care for their child to the best of their abilities to provide for the best outcomes possible (Kinnear, et al., 2015).

Summary

Knowing and understanding the incidence, risk factors, characteristics, and provider perceptions of ASD is the first step to properly caring and advocating for this patient group. Understanding that ASD is generally a genetic disorder that greatly affects communication skills, social skills, and behavior, and understanding the components of

how to appropriately address these problems, is the first step to appropriately and effectively care for patients with ASD.

As determined from the previous literature review, healthcare providers are given minimal training or education on ASD. With the incidence of ASD being 1 in 59 children, it is likely that healthcare providers will encounter at least one patient with ASD in their career. It is important that the care that is given to ASD patients is holistic and thorough, which includes providing the patient with a sense of comfort and trust and knowing how to interact with the patient to create those feelings.

Chapter III

Methods/Plan

This chapter outlines the methods and plans involved in this study. The design of this study is a quality improvement (QI) project utilizing a quasi-experimental approach due to the lack of randomization or control group within the study. For this study, an educational presentation over ASD was given to staff that work directly with pediatric patients at a local pediatric behavioral hospital, Heartland Behavioral Health Services (HBHS). The aim of the study was to provide education regarding ASD and intervention strategies to de-escalate behaviors or reduce the amount of RRBs that the patient may exhibit. The study examined the knowledge of nurses (RN), licensed practical nurses (LPN), and behavioral health specialists (BHS) and if there was an improvement in their stress level in caring for patients with ASD after the educational presentation and implementation of suggested intervention strategies.

Sample population

The sample population was the direct care staff working at HBHS. There were approximately 200 participants invited to participate in the research study. The subjects were recruited for the study when they arrived for their monthly in-service, where the educational presentation was performed. The only exclusion criteria for the study was if any staff member knew they would no longer be employed at HBHS for the following

month, as the follow-up survey was conducted one month following the educational presentation. Institutional Review Board (IRB) approval was obtained through Pittsburg State University to allow the participation of human subjects in this research study.

Instruments and procedure

A pre-educational survey (see appendices) was provided to the staff to gain a baseline measure of knowledge prior to the educational presentation. Prior to handing out that survey, this researcher introduced herself and explained the purpose of this project. It was also explained that participation was voluntary and there would be no repercussions for not completing the survey or any repercussions for their answers on their surveys. There was a number assigned to each participant that was listed on the top of each of their surveys. The numbers were assigned at random, based on the sign-in sheet that was required by HBHS. Once the surveys were handed out for the participants to complete, their surveys no longer contained any identifying factors and no identifiers were linked to the data. The survey had a few generic demographic questions such as job title and years of experience in that position. Other questions asked on the survey were Likert-Type Scale questions that were on a 0 to 10 scale. A PowerPoint presentation was the educational tool used for presenting to the direct care staff at HBHS. This encompassed all information from the literature review and then further explained interventions suggested for use when caring for patients with ASD. These interventions consisted of utilizing voice intonation, body language, and the environment appropriately. For example, if a child has a sensitivity to noise, yelling at or around that child, may not be beneficial for de-escalating the behavior, but rather have the opposite effect and escalate the behavior further. After the educational presentation, participants were asked to fill out

another survey without the demographic questions, that had the same assigned number to compare the data from the pre-test to the post-test survey. This helped to determine if their knowledge or attitudes regarding ASD had changed. Following a four week trial period where staff was encouraged to utilize what they had learned in the educational presentation, a follow-up survey, which can be seen in the appendices, was administered to determine if they had utilized the information and interventions given during the presentation and if so how many times they believe they have used it. This survey also addressed their stress level when caring for patients with ASD, and their likelihood of seeking future educational opportunities over ASD.

Resources needed. Copy paper and a printer was needed to make copies of the surveys to hand out to the participants. A computer and projection board utilized for the presentation and supplied by HBHS, as was the location for the presentation. This study was feasible without any challenges faced regarding the resources that were needed.

Participants. The participants were informed of the purpose of this study prior to beginning the study. They were also encouraged, prior to the start of the educational presentation, to closely pay attention and ask questions as they arose. The participants were also encouraged to participate in the educational presentation and back and forth conversation was allowed if they had any experiences that they wished to share. The participants were then asked to complete three surveys, at three different time intervals (pre-educational, post-educational, and one month follow up), as well as utilize interventions in their everyday workplace, where they believed it to be appropriate as explained in the educational presentation. The participants gave permission to participate

in the study when they completed their surveys. There were no repercussions for the employees who choose not to complete the surveys.

Data outcomes

Utilizing the Likert-Type scale data from the surveys completed by the participants, statistical analysis of the data was obtained. Demographics including job title and years of service were obtained for educational purposes only. Each question was analyzed to determine efficacy of the educational presentation as well as efficacy of the interventions that were implemented. Comparisons from the pre- and post-educational survey were completed, with an additional comparison of what information they utilized during practice, four-weeks after the educational intervention.

Chapter IV

Evaluation of Results

The purpose of this study was to determine if healthcare providers, directly caring for patients with ASD in the acute inpatient setting, had an increase in knowledge regarding ASD after being provided with an educational presentation. This study also examined the relationship that the healthcare worker will have a decrease in stress level following the educational presentation. The third research question being studied was if the staff would be able to utilize the interventions suggested in the educational presentation within their practice.

Participant Demographics

Participants in this study included thirty-four behavioral health specialists (BHS) which have been trained to aid in the care of adolescent patients, ages 4-18, with behavioral problems. Participants also included four licensed practical nurses (LPN), and twenty-six registered nurses (RNs). Therapists, psychiatrists, nurse practitioners, and administrators were welcome to join the study and attend the educational presentation, however, there were none that chose to participate. There were sixty-four total participants that completed the study. Their experience ranged from less than one year of experience to thirty-four years of experience. The surveys took approximately five

minutes, per survey, to complete and the participants were engaged in an hour-long PowerPoint presentation conducted by this researcher.

The follow-up survey was handed out and collected during their regular working hours, by the Psychiatric Mental Health Nurse Practitioner who is on the committee for this project. The follow up surveys were given one-month following the educational presentation. The surveys were collected over a one-week time period. Some follow-up surveys were not completed, either due to the employee no longer being employed by HBHS or the employee was not working during the week that the surveys were being completed.

Analysis of Project Question

The statistical analysis portion of this study was completed using SPSS software. The full analysis of all questions on the pre-educational survey, post-educational survey, and follow up survey are shown on Table 1 and Table 2. In consideration of the research question, *Did the educational presentation regarding knowledge of ASD decrease stress experienced by staff when caring for these patients?* - the results indicated this was definitely the case. Specifically, item four on the follow-up survey addressed this research question. The item stated, *In the past month, I found myself feeling less stress when patients began to exhibit undesirable or restrictive and repetitive behaviors*. The most frequent response rating on this item was a 10 indicating "totally agree." This finding signified that they felt less stress following the educational presentation as hypothesized. See appendices for questionnaires.

The hypothesis that their knowledge would increase was also supported by the data. The results from the knowledge-based questions (the first six items on Table 1)

were compared from pre-educational survey to post-educational survey. Significantly higher scores were found from the post-educational survey (as reflected in the differences in the medians or means, depending on the statistical test). The comparison of knowledge-based questions (the first six items on Table 1) between the pre-educational survey and the post-educational survey showed a significantly higher mean. The correct answer for these questions was 10. On the post-educational survey, more answers were 10 than on the pre-educational survey, indicating that the participants knowledge did increase following the educational presentation. In addition to the knowledge-based questions, question eleven on the post-educational survey asked the participants to identify the truth in the statement *I learned something new during the educational presentation today that I wasn't aware of before*, the median for this question was 10, indicating that the participants, on average, totally agreed that they learned something new.

In the follow-up survey, the participants responded to whether they had utilized the interventions discussed in the educational presentation. The respondent also had to designate how often they implemented to intervention. The most popular response on question one was category three, which correlated with 11-15 times. The next two most common responses were category 2 and category 4. These categories were identified as 6-10 times and more than 15 times. This indicates that the participants were in fact, able to utilize the interventions suggested, and did so multiple times in the month in between the educational presentation and the administration of the follow-up survey.

Table 1

Pre- and Post-Educational Training Survey Results

Survey	Pre		Post		*T*	*z*	*p*
	Mdn	*M*	*Mdn*	*M*			
Survey Content							
Vaccinations…	0	1.19	0	0.10	153.00	-3.71	***
Three diagnoses…	8	-	10	-	1172.00	-5.61	***
Clock ticking…	9	-	10	-	606.50	-4.82	***
Tactile stimulation…	9	-	10	-	489.50	-4.78	***
Odor reaction…	10	8.81	10	9.78	489.50	-4.78	***
Visual effects…	9	-	10	-	528.00	-4.99	***
Addressing behavior…	7	-	10	-	1232.00	-4.99	***
Comfort addressing…	8	-	9	-	778.50	-4.59	***
Stress increases…	9	-	9	-	522.00	-1.19	*n.s.*
Prior knowledge…	-	-	10	-			
New information…	-	-	10	-			
Additional courses…	-	-	10	-			

Note. Median and mean comparisons between pre-educational survey responses versus post-educational survey responses using Wilcoxon Signed-Rank tests. The last three items on survey content were items that were only addressed on the post-educational survey. {-} indicates that there was not a calculation for that variable.

***$p<.001$.

Means were not calculated for all questions, as seen on Table 1, because ordinal data was used for the questions and mean calculation is not indicated. The reason that there was a mean shown for two of the questions, was to signify that there was a difference from the pre-survey to the post-survey, as the medians were the same. However, the mean indicates that there was a difference in the answering of those questions, regardless of what the median showed.

Table 2

Follow-Up Survey Results by Question

	Mdn	*Mode*	*SD*
Survey content			
Intervention used…	3.00	3	1.354
Interventions helpful…	8.00	9	1.824
Ability to care…	9.00	9	2.438
Less Stress…	9.00	10	2.357
Potential Causes…	9.00	9	2.330
Understanding…	9.00	10	1.931
Continuing to learn…	9.00	10	2.071
Escalate behaviors…	9.00	10	1.489
De-escalate behaviors…	9.00	10	1.388

Note. This table shows the median, mode, and standard deviation from each question on the follow up survey from the participants.

Additional Statistical Analyses

Other findings, that were not directly related to the hypotheses or the research question that was asked, included the participants desire to participate in future educational opportunities. This finding was significant as the most frequent answer was a 10 indicating ‘totally agree.’ This finding was asked to see if participants were interested in learning more over ASD and to assume that they felt there was still more to learn over ASD.

Another question that was asked that did not relate specifically to the research question or hypotheses was item 10 on the post-educational survey, *I am pleased with the*

amount of knowledge and training I have received over Autism Spectrum Disorder prior to the educational presentation received today. This was asked to determine if those people that work directly with patients with ASD had already learned or participated in educational opportunities over ASD. The answer for this question was unexpected. The most popular response to this question was 10, which indicated "totally agree." This was different than expected due to the thought that participants would indicate that they were not pleased with the amount of education they have had over ASD because they lacked that education. It is unknown what kind of education they had received over ASD prior to the educational training they had received during this study. It is known, however, that the participants in this study had not received educational training over ASD provided by HBHS; however, outside of HBHS, it is unknown how much information was obtained prior to this study.

Summary

The purpose of this study address and further support the notion that healthcare providers have little training over ASD. The study also examined if the interventions discussed in the educational presentation were utilized and if so, how often the staff was able to utilize the interventions in a month's time. The third research point was if the stress level of staff decreased after being presented with information of ASD while caring for patients with ASD. The findings supported the research hypotheses and questions. The knowledge of the staff increased between the pre-educational survey and the post-educational survey. The staff reported that they were able to utilize the interventions given in the educational survey multiple times in a month, and the staff reported during

their follow-up survey that their stress level had decreased when caring for patients with ASD that displayed undesirable behaviors or RRBs.

Chapter V

Discussion

Relationship of Outcomes to Research

This study was designed to address and further support the notion that healthcare providers have little training over ASD. This study focused on three main hypotheses: 1) The nurse and direct care staff knowledge of ASD characteristics and intervention methods will increase following the educational presentation; 2) The staff will be able to utilize the interventions given during the educational presentation a minimum of 5 times; and 3) The stress experienced by the nurses and direct care staff caring for those with ASD will decrease from the beginning of the study to the end of the study.

To address the first hypothesis, data was obtained to understand a baseline of knowledge that was had from the participants, regarding ASD. It was then evaluated using knowledge-based questions after the educational presentation. It was found, that the average number of correct answers were greater on the post-educational survey than on the pre-educational survey.

The second hypothesis was addressed by utilizing the first question on the follow-up survey. The participants identified that they were in fact, able to utilize the interventions multiple times throughout the month between the educational presentation and the administration of the follow-up survey.

The third hypothesis was evaluated using question four on the follow-up survey, which stated *In the past month, I found myself feeling less stress when patients began to exhibit undesirable or restrictive and repetitive behaviors,* it was found that majority of the participants chose '10' indicating that they 'totally agree' with this statement.

This study's findings were consistent with previous research found regarding the knowledge level of staff caring directly for patients with ASD. The participants in this study demonstrated that there was enough knowledge regarding ASD to interact with patients with ASD, prior to educational presentation, but there was still much to be learned about ASD. There were not any studies found regarding the other two hypotheses researched in this study. This study was intended to build a bridge between the gap in literature that was found and to, hopefully, initiate other studies to be completed on the specific interventions that can be utilized when caring for patients with ASD, and the furthering of education for staff that give care to patients with ASD.

Previous research has concluded that staff members and healthcare providers are often unhappy with the amount of education they have received over ASD. In the case of this study, most of the participants responded that they were happy with the amount of education and information they have received over ASD. The difference between these results and the previous results may be due to the question itself and how it was worded. The participants may not have fully understood the question or thought that the question was pertaining to the educational presentation that they received during this study.

This study could impact the continuation and initiation of other studies that pertain to ASD and the lack of information that providers receive during undergraduate and graduate nursing programs. This study also could impact the importance of providing

healthcare employees with information regarding interventions and ideas on how to approach and care for patients with ASD, as to decrease stress levels for the staff and for the patients. Perhaps most importantly, the results indicate there are significant improvements that training can make in the knowledge level of ASD among health care professionals. Given the increased prevalence of individuals diagnosed with ASD, such improvements should be among our nation's top health training priorities.

Observations

During the educational presentation, many participants in the group were actively involved in the presentation and wanted to share their experiences with the group. With the involvement of the participants, this was likely to break-up the monotony that PowerPoint lectures can have. This also, provides more realistic and relatable examples that help to 'drive the point home.' It was interesting, how many participants seemed to be fully engaged in the presentation. It is unknown whether their engagement was due to their curiosity over the topic, or that it was a presentation that invited participants to talk about their experiences.

The results to the hypotheses were reassuring, as it was what was expected at the start of the study. If anything were to be changed in a future study, wording on the survey questions would be fine-tuned and re-evaluated by more people not involved in the study, to determine the legibility and clarity of the question.

Following this study, it was stated by psychiatric mental health nurse practitioner (PMHNP) Bethany Fast, that there were changes being made to sensory rooms and changes in the standards to which care is given to patients with and without ASD. Due to the change that was seen in patient care, following the educational presentation,

administration and providers have begun to make further changes to their programs to help further positively impact the lives of the children that they serve.

Evaluation of Theoretical Framework

With the implementation of the educational presentation, and the results that found that knowledge level of staff increased, following the educational presentation, it is assumed that the participants in this study have progressed in their level of nursing regarding ASD. Even though some of the RNs, BHS, and LPNs already had great knowledge of ASD, most of the participants gained something from the educational presentation, allowing them to advance their abilities as a nurse and BHS, getting them closer to the Expert level of their profession.

Limitations

Possible limitations in this study were the instruments used to receive the information from participants. As stated previously, the survey questions, in some instances, may not have been clear to the participants, making it difficult to answer honestly or appropriately. This was not relevant for all of the survey questions however, it may have been relevant for some. Another limitation was the sample size and number of participants in each category. Although there were sixty-four participants in the study, there were less nurses involved in the study than originally anticipated, therefore, the results may have differed if the proportion of nurses to BHS were higher. This, however, does not change the results of the significance of this study.

Implications for Future Research

Utilizing this study as a starting point, future research should involve the same type of study, focused in a medical hospital as opposed to a behavioral hospital. Future

research should also focus on the interventions used and the patient's response to those interventions. For this study, the patient's response to intervention was not evaluated, however, in future studies, intervention methods and patient responses and opinions should be the focus.

Implications for Health Policy

This study, as well as previous research, has concluded that there is limited education given to nurses at the undergraduate and graduate level, that covers ASD and characteristics, diagnosis, interventions, treatment options, and referral guidelines of the disorders. If multiple studies conclude that the knowledge level is lacking in those caring directly for ASD, then creating a policy to increase the requirements for such education should be pursued.

Conclusion

This study was completed to address gaps in the literature that were found including stress levels of staff that care directly for patients with ASD, the knowledge level of those staff members, and the specific interventions given during the educational presentation. Ideally, this study is the starting point for continued research regarding this topic, as well as ideas for where future research should be sought. Ultimately, the purpose of this study was to advocate for patients with ASD and help them to receive the competent care that they require and deserve.

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Appendix

Pre-Educational Survey

1. **What is your job title?**

   BHS LPN RN Therapist

2. **How many years have you been in this job title?_____**

3. **How many total years have you worked at HBHS? _____**

For the following questions, please rate your opinion based on a 0 to 10.

4. **Autism Spectrum Disorder is caused by receiving vaccinations as an infant.**

Definitely No Unsure Definitely Yes

0 1 2 3 4 5 6 7 8 9 10

5. **Three previously separate diagnostic categories are now included in the Autism Spectrum Disorders**

Definitely No Unsure Definitely Yes

0 1 2 3 4 5 6 7 8 9 10

6. **The ticking of a clock can evoke a reaction in a patient diagnosed with ASD**

Definitely No Unsure Definitely Yes

0 1 2 3 4 5 6 7 8 9 10

7. **The tactile stimulation, such as touching a piece of paper, can evoke a reaction in a patient diagnosed with ASD.**

Definitely No Unsure Definitely Yes

0 1 2 3 4 5 6 7 8 9 10

8. **An odor, good or bad, can evoke a reaction in a patient diagnosed with ASD.**

Definitely No Unsure Definitely Yes

0 1 2 3 4 5 6 7 8 9 10

9. **The visual effects of seeing three cars lined up bumper to bumper with one car turned backwards, can evoke a reaction in a patient diagnosed with ASD.**

Definitely No Unsure Definitely Yes

0 1 2 3 4 5 6 7 8 9 10

For the next set of items, please circle the degree to which you feel is appropriate.

10. **I have the ability to address restrictive and repetitive behaviors when caring for a patient with Autism Spectrum Disorder.**

Definitely No Unsure Definitely Yes

0 1 2 3 4 5 6 7 8 9 10

11. **When a patient is having behaviors on the unit, I am comfortable and confident in my ability to de-escalate that patient without using any restrictive means (restraint, PRN medication, etc.)**

Definitely No Unsure Definitely Yes

0 1 2 3 4 5 6 7 8 9 10

12. **My stress level increases when I am caring for a child that consistently exhibits behaviors on the unit I am working.**

Definitely No Unsure Definitely Yes

0 1 2 3 4 5 6 7 8 9 10

Post-educational Survey

1. **Autism Spectrum Disorder is caused by receiving vaccinations as an infant.**

Definitely No — Unsure — Definitely Yes

0 1 2 3 4 5 6 7 8 9 10

2. **Three previously separate diagnostic categories are now included in the Autism Spectrum Disorders**

Definitely No — Unsure — Definitely Yes

0 1 2 3 4 5 6 7 8 9 10

3. **The ticking of a clock can evoke a reaction in a patient diagnosed with ASD**

Definitely No — Unsure — Definitely Yes

0 1 2 3 4 5 6 7 8 9 10

4. **The tactile stimulation, such as touching a piece of paper, can evoke a reaction in a patient diagnosed with ASD.**

Definitely No — Unsure — Definitely Yes

0 1 2 3 4 5 6 7 8 9 10

5. **An odor, good or bad, can evoke a reaction in a patient diagnosed with ASD.**

Definitely No — Unsure — Definitely Yes

0 1 2 3 4 5 6 7 8 9 10

6. **The visual effects of seeing three cars lined up bumper to bumper with one car turned backwards, can evoke a reaction in a patient diagnosed with ASD.**

Definitely No — Unsure — Definitely Yes

0 1 2 3 4 5 6 7 8 9 10

For the next set of items, please circle the degree to which you feel is appropriate.

7. **I have the ability to address restrictive and repetitive behaviors when caring for a patient with Autism Spectrum Disorder.**

Definitely No Unsure Definitely Yes

0 1 2 3 4 5 6 7 8 9 10

8. **When a patient is having behaviors on the unit, I am comfortable and confident in my ability to de-escalate that patient without using any restrictive means (restraint, PRN medication, etc.)**

Definitely No Unsure Definitely Yes

0 1 2 3 4 5 6 7 8 9 10

9. **My stress level increases when I am caring for a child that consistently exhibits behaviors on the unit I am working.**

Definitely No Unsure Definitely Yes

0 1 2 3 4 5 6 7 8 9 10

10. **I am pleased with the amount of knowledge and training I have received over Autism Spectrum Disorder prior to the educational presentation received today.**

Definitely No Unsure Definitely Yes

0 1 2 3 4 5 6 7 8 9 10

11. **I learned something new during the educational presentation today that I wasn't aware of before.**

Definitely No Unsure Definitely Yes

0 1 2 3 4 5 6 7 8 9 10

12. **If given the opportunity to attend additional educational courses on autism, I would like to participate.**

Definitely No Unsure Definitely Yes

0 1 2 3 4 5 6 7 8 9 10

Follow up Survey

1. **I have utilized the interventions that were discussed in the presentation over Autism**

   0 times 1-5 times 6-10times 11-15 times More than 15 times

2. **I have found that the interventions that were suggested were helpful in de-escalating behaviors or decreasing the amount of behaviors that I saw on my unit.**

   Not At All Unsure Totally

   0 1 2 3 4 5 6 7 8 9 10

3. **In the past month, I found myself more able to care for patients with autism.**

   Not At All Unsure Totally

   0 1 2 3 4 5 6 7 8 9 10

4. **In the past month, I found myself feeling less stress when patients began to exhibit undesirable or restrictive and repetitive behaviors.**

   Not At All Unsure Totally

   0 1 2 3 4 5 6 7 8 9 10

5. **In the past month, I found myself searching more for potential causes for undesirable behaviors, rather than simply searches for ways to make them stop.**

   Not At All Unsure Totally

   0 1 2 3 4 5 6 7 8 9 10

6. **I have a better understanding of autism spectrum disorder and potential intervention strategies that can be applied when caring for patients with autism spectrum disorder.**

Not At All					Unsure					Totally
0	1	2	3	4	5	6	7	8	9	10

7. **I am interested in continuing to learn more about autism spectrum disorders in order to improve the care that is given to patients diagnosed with ASD.**

Not At All					Unsure					Totally
0	1	2	3	4	5	6	7	8	9	10

8. **I have a better understanding of how my behavior, body language, voice volume, and voice intonation can escalate a patient's behavior.**

Not At All					Unsure					Totally
0	1	2	3	4	5	6	7	8	9	10

9. **I have a better understanding of how my behavior, body language, voice volume, and voice intonation can de-escalate a patient's behavior.**

Not At All					Unsure					Totally
0	1	2	3	4	5	6	7	8	9	10