

Nursing Care of Children with Autism

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### **Abstract**

According to the Center for Disease Control (CDC), it is estimated that 1 out of 68 children are diagnosed with autism each year (CDC, 2015). This prevalence rate has doubled since 2004, when it was 1 out of 125 (Autism Society of America [ASA], 2016). Numerous studies emphasize the importance of early diagnosis and appropriate interventions. Early interventions have been shown to result in significantly improved outcomes for patients with autism (ASA, 2016).

With the increasing prevalence of autism, nurses and healthcare staff should be educated about this disorder to provide optimal healthcare. The goal of this project is to increase autism awareness among the senior nursing students at the University of Florida, as well as to provide them with the basic understanding of the disorder and the fundamentals to deliver optimal care for their patients with autism. This research project included a ten question pre-survey about autism, followed by a brief ten minute educational seminar on autism. After the presentation, a post-survey was administered. The statistical analysis from the surveys provides strong evidence that the majority of senior year nursing students at the University of Florida were unaware of essential techniques to facilitate optimal patient care for this unique patient population.

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To be diagnosed with autism, the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) has specific criteria that must be met. The diagnostic criteria are based on unremitting difficulties in the social use of verbal and nonverbal communication and restricted repetitive behaviors (Autism Speaks, 2013). Therefore, in order to effectively communicate with their patients, nurses should have an understanding of the diagnostic criteria and the three hallmarks of autism: repetitive behaviors, language disability, and social communication deficits. Understanding these hallmarks will improve the nurse-patient relationship and result in positive outcomes for both the patient and the nurse.

### **PCORI Background**

Our project is associated with the Patient-Centered Outcomes Research Initiative (PCORI). PCORI aims to identify populations of interest, including rural areas, minorities, children, and other individuals with health care needs (PCORI, 2015). PCORI is unique in that it focuses on investigating what the population is needing, and works to improve patient outcomes by providing resources, education related to health care decisions, and research that addresses questions among the population. Our mentor, Dr. Jennifer Elder, received a tier-one PCORI grant, which has provided funding to work with families of children who have autism. These

families live in rural areas of North Florida and are in need of numerous resources, including health care.

The goal of the PCORI grant is to determine the resources that these families need, build collaboration between the families and researchers, and provide the families with education about autism. The resources include Applied Behavior Analysis therapy (ABA), occupational therapy, physical therapy, primary health care, etc. As a team and support group we are working to discover which resources are in the highest demand and determine how to provide access to these resources.

Dr. Elder's long term goal is to move from a tier-one PCORI grant to a tier-three PCORI grant. A tier-three grant would allow for a substantial increase in funding to essentially provide the needed resources, including increased access to healthcare. In addition to increasing access to resources there is a need to increase affordability of these resources including health care costs. According to Harvard researchers, autism costs average more than \$17,000 per child each year in the United States. These expensive costs include health care and education required for children with autism (Lavelle et al., 2014). It is evident due to exceeding costs that the tier-three grant would be beneficial to the PCORI families.

While working on our project, we interviewed the PCORI families about their health care experiences. We found that these families travel hours to visit their primary care providers and to attend therapies. Their case studies provided first-hand evidence that there is need for improvement in the healthcare system related to autism, especially in rural areas of Florida. According to Rural Healthy People 2010, "Only about ten percent of physicians practice in rural America, despite the fact that nearly one-fourth of the population lives in these areas" (Rural Healthy People, 2010, p. 45).

After attending three PCORI meetings, actively working with these families, and reading numerous research articles, we combined our resources to create the educational seminar on the nursing care of children with autism, as well as the corresponding surveys.

### Project Description

With the increasing prevalence of autism, nurses and healthcare staff should be educated about this disorder to provide optimal healthcare. This project advances the understanding of autism in the field of nursing by providing a brief educational seminar about the basics of autism, as well as tips on nursing care for patients who have autism.

The educational seminar includes the essential guidelines for treating patients with autism by spelling out the letters in AUTISM. Each individual letter provides what is most valuable when caring for a child with autism. These guidelines are: A- awareness, U-understanding communication barriers, T- taking your time, I- individuality, S- sensory stimulation, and lastly M- medical co-morbidities.

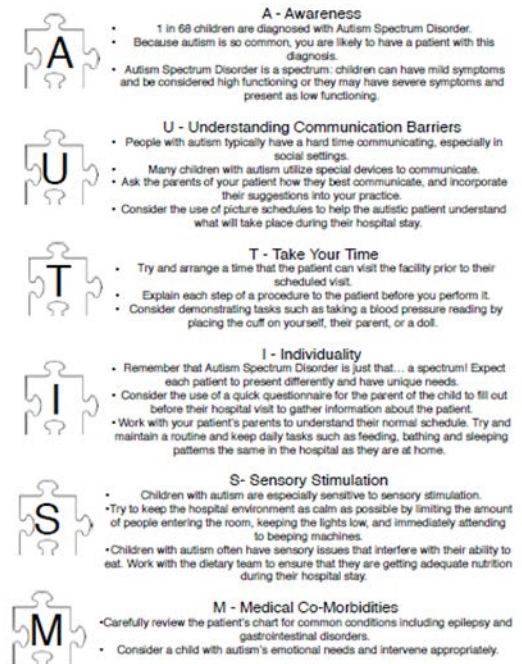


Figure 1: Handout that was provided to students

### Project Outline

As previously mentioned, the prevalence of autism is high, therefore it is likely that nurses will be caring for many patients with this diagnosis. The high prevalence of autism falls under the category A- awareness. In order to create a healthcare environment that is effective and efficient for both the nurse and patients with autism, it is important that the healthcare team

receives education on communication techniques to work with this special population. Autism is a spectrum, therefore not all patients will present the same. Some patients may be able to verbally communicate and others may require non-verbal techniques. This topic of communication falls under the category U- Understanding Communication Barriers.

In Dr. Jennifer Elder's article, "Communication in Autism Spectrum Disorder: A Guide for Pediatric Nurses", she discusses the importance of effective communication among pediatric nurses and their patients with autism. Dr. Elder explains how breakdowns in communication can result in both the nurse and patient feeling frustrated and confused. She also discusses the importance of recognizing behavioral outbursts as a sign of communication frustration. (Brown & Elder, 2014). Through this project we aimed to teach nursing students effective techniques to overcome communication barriers with patients who have autism to avoid frustration and facilitate effective patient care. We discuss the use of special devices to communicate, consulting with the parents about how their child communicates, and the use of Picture Exchange Communication Systems (PECS).

In order to enhance learning among the nursing students we incorporated some of the PCORI families' case studies to demonstrate examples of positive and negative health care experiences to share with the nursing students. An example of a positive experience was a case study of a young child with autism who was terrified to get a finger prick at the doctor's office. The nurse was aware of the child's fear and comforted the child by performing a finger prick on herself and explaining each step to the child. This nurse acted with understanding and patience, which significantly alleviated the child's fears related to health care and improved the overall experience for the child, their family, and the health care team. In our presentation, this particular case study would fall under the "T"- take your time. By taking your time with the child, it allows

both yourself and the child to become more comfortable and to have a positive experience.

The “I” in our A-U-T-I-S-M acronym represents individuality. As nurse it is important to understand that each patient with autism is unique. Children with autism function on various levels of the spectrum and require individual needs. The “S” signifies sensory stimulation. Children with autism have increased sensory stimulation. It is important to create a low stimuli environment in the hospital by turning lights down and limiting external noises including pump machines and televisions. It is also important to accommodate their heightened senses by offering a special diet and offering comfort measures such as special bedding, socks, hospital gown, etc.

Lastly, the “M” represents medical co- morbidities. As a nurse caring for a child with autism, it is important to recognize the common co-morbidities. In the *Journal for Specialists in Pediatric Nursing*, the article, “Caring for the Child with an Autism Spectrum Disorder in the Acute Care Setting”, provides information on the co-morbidities that occur with autism. The researchers address the most common co-morbidities: seizures, sleep disturbances, gastrointestinal (GI) disorders, and psychiatric disorders (Scarpinato et al., 2010).

With this literature and case study in mind we hope to increase the students’ awareness of autism, as well as provide the fundamentals to properly care for their patients with autism. My research partner and I incorporated this knowledge to formulate our survey questions. These survey questions allow us to gauge the effectiveness of our educational seminar.

**Results**

Question Number	Change in % correct
1	+8.84%
2	+62.32%
3	+72.77%
4	+31.34%
5	-1.32%
6	-15.83%
7	+2.14%
8	+5.16%
9	-2.09%
10	+4.36%

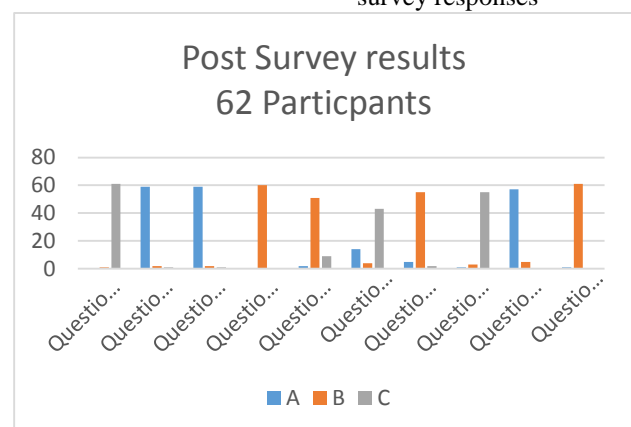
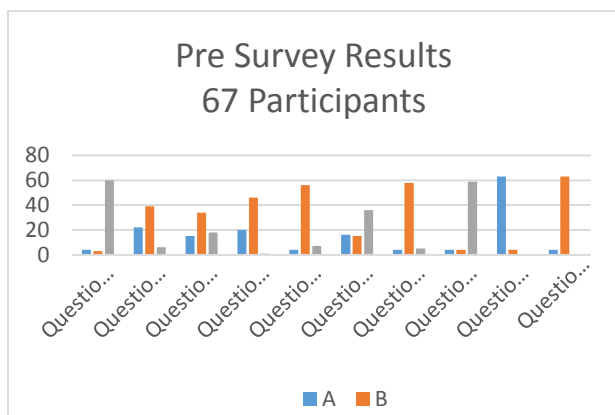
Table 1: Standard deviations between pre- and post-survey

We found that 67 out of 125 students submitted a pre-survey and 62 of those students submitted the post-survey. We were satisfied with the high number of participants, which contributed to the validity of our survey results.

One of the most significant survey questions was about the prevalence of autism. Question number two from the pre-survey asked, “What is the prevalence rate for autism?” More than half of the students, 58.2%, chose 1 out of 168 as the prevalence rate for autism. Only 32.84% of the students chose the correct answer, a prevalence rate of 1 out of 68. These results indicated that most nursing students, like other health professionals, are

unaware of the increasing prevalence of autism. After our presentation, 95% of students recognized the correct prevalence rate.

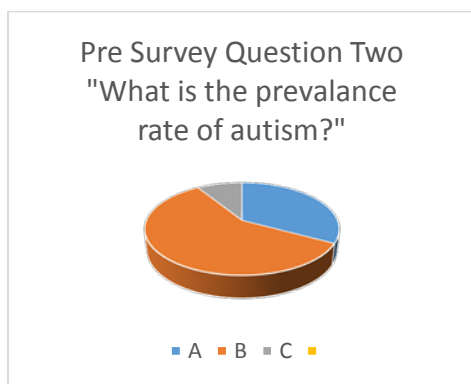
Graphs 1 and 2: Pre- and post-survey responses



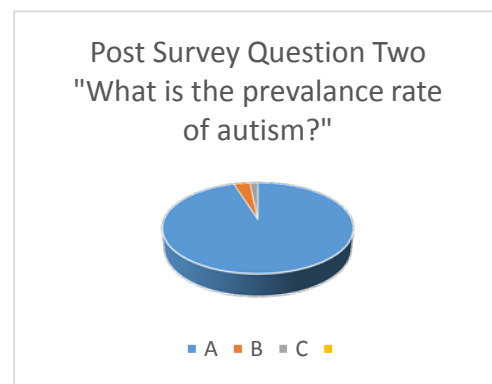


As shown in the graphs above, survey questions two, three, and four provided the strongest support that our educational seminar was beneficial to the nursing students. Questions one, seven, eight, and ten have less than a 10% increase in the correct answer choice compared between the pre- and post-survey. This is likely because these questions were not as difficult as questions two, three, and four, which required attentive focus during the presentation.

Early in the project development, we predicted that the students would be unable to identify the common co-morbidities people with autism develop. Question number three asked students about the co-morbidities related to autism. The pre-survey results show that 50.75% of students thought mitral valve prolapse was a common co-morbidity of patients with autism. Only 22.39% of the students chose the correct answer, which was Gastroesophageal Reflux Disease (GERD). After our educational seminar, 95.16% of the students chose the correct answer, GERD. We felt it was necessary for students to understand and recognize these co-morbidities because they are often the reason for hospital admission of patients, specifically children, with autism.



Graph 3: Survey results from question two  
(A= blue is the correct answer)



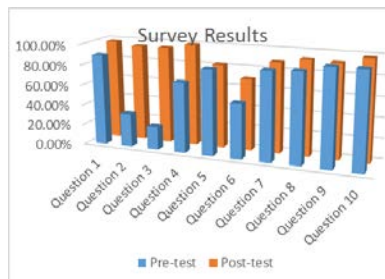
Graph 4: Shows increase in correct response of post-survey

When constructing questions five and six in the post-survey we accidentally changed one of the answer selections that corresponds with each of the questions. Therefore, the post-survey has

an answer selection that was not a previous answer selection in the pre-survey. Question five had a -1.32% change in answer response and question six had a -15.83% change. Overall, the correct answer choice was selected by the majority in both the pre- and post-survey responses. However, the negative percent of change could be a result of our mistake with the faulty answer choice selection.

Survey question seven asks about effective communication, “Which nurse demonstrates a need for further teaching when communicating with a child with autism?” In both the pre- and post-survey the majority of students answered correctly with option B “Speaks only to the patient’s parent/guardian when providing care.” There was only a slight increase of +2.14% between the pre- and post-survey. This is most likely because we are taught in our nursing curriculum how to communicate with pediatric patients. Nonetheless, we were impressed that the students recognized the importance of speaking to a child with autism as well as to their parent.

In addition, question nine had a -2.09% decrease in correct answer response. This is most likely because we did not explain this topic on Asperger’s Syndrome as clearly as we should have. We briefly mentioned Asperger’s Syndrome in the presentation, but we did not thoroughly explain its relationship to autism and how it falls “under the spectrum”. In future research, I would explain Asperger Syndrome.



Graph 5: Survey results

## Discussion

The survey results support our original hypothesis regarding the lack of autism awareness

and education among nursing students. After attending our seminar on the “Nursing Care of Children with Autism”, our classmates confirmed that they felt more confident about their nursing skills related to caring for their future patients with autism. We believe this project was a success because of the positive feedback from our nursing class, professors, and our strong survey results.

From the survey results, we suggest further research be conducted at nursing programs across the country addressing autism awareness. Conducting formal studies with larger number of participants instead of a preliminary project would lead to stronger outcomes and increased validity. We recommend autism awareness education programs be implemented in nursing curriculum.

### **Barriers**

The barriers of this study were the distance of the PCORI meetings, allocated class time to present our seminar, low class attendance for the day of our educational seminar, limited student survey participation, and limited access to technology to complete the surveys. Due to the distance of the meetings we had to make certain accommodations with our nursing schedule to attend these meeting. We believed it was necessary to attend these meetings, as they were a significant source of the primary information that our project was founded on.

Another barrier to this project was that the student survey was volunteer based. We encouraged participation through an active presentation with engaging discussion questions as well as passing around Autism Awareness lollipops and stickers upon completion of the post-survey. We confirmed that students would have devices to access the survey, including laptops, cell phones, and tablets.

Furthermore, we were prepared for technological barriers with the survey site. We had the students access the pre- and post-survey by posting the survey links on our Facebook group. In preparation for survey complications, my research partner and I created a sample survey prior to the seminar. By perfecting the survey format and access to the survey, we were able to overcome the technological barriers.

However, even with our survey preparation, we encountered a problem during the seminar. We came across difficulties when posting the pre-survey on our Facebook page. Two links to the survey were posted; we had to quickly delete the first link and explain the technical difficulties to the students. Some students had already begun to work on the additional link posted. We had to redirect those students to the new link in order to have all of our data cohesively collected.

Throughout the development of this project, we spent a significant amount of time editing the survey questions and answer selections. After editing our surveys, we consulted with Dr. Elder and Susan Brasher to receive their feedback and expertise. Overall, we agreed to create a survey with ten questions in total. The first eight of the survey questions had three answer choices, whereas the final two questions were true or false. We altered the order of the post-survey questions to avoid falsified responses. Finally, we kept the questions and answer choices concise to facilitate participation and ease of understanding.

### **Conclusions**

Through this project we were able to confirm the lack of autism awareness among nursing students and demonstrate the need for autism awareness and nursing education can be met through a simple seminar. From the educational seminar we provided, the senior nursing students at the University of Florida have developed the capability to make positive impacts on healthcare. Now these educated students have the knowledge to inform other nurses and health

care workers about autism and teach appropriate interventions to care for these patients by following the essential A-U-T-I-S-M tips provided in our presentation and handout (figure 1).

This project has positively impacted the senior nursing students at the University of Florida, as well as myself. I am more confident in my nursing skills to provide excellent care to my future patients with autism. Through my extensive research to create this project I have learned unique methods to overcome communication barriers, recognize common co-morbidities, and essential techniques; all that I have learned will allow me to effectively work with my patients who have autism. Most importantly, I have learned about the uniqueness of autism and have had the opportunity to work alongside incredibly strong individuals and families who cope with this disorder. Furthermore, I have had the honor to share my knowledge of autism to my fellow nursing peers.

It is my hope that this seminar, “Nursing Care on Children with Autism”, can be reintroduced to a new set of students and faculty in years to come. Families of children with autism should continue to be part of this progressive education as they provide a link between the community and health care. This educational platform will continue to increase autism awareness among nursing students and facilitate care of patients with autism.

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