

Autism Spectrum Disorder Care Provider Education Program

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Autism Spectrum Disorder Care Provider Education Program

Introduction

With the rising prevalence of autism, access to health care services by the patient with autism spectrum disorder (ASD) is inevitable. Although a great deal of literature exists regarding autism, limited research has been conducted regarding nurse knowledge, competence and awareness when caring for the ASD population. Evidence suggests that minimal education is provided to front-line nurses on how to work with ASD patients. When nurses are put in a position to care for a patient without adequate knowledge and training, outcomes and safety are jeopardized. The Autism Spectrum Disorder Care Provider Education Program (ASDCPEP) was designed to address these issues.

Background and Significance of the Problem

This author reviewed the literature, and it became evident that autism is a significantly under-represented population health issue that demands the attention of health care today. Autism not only creates burdens for the individual and families living with ASD, but health care providers as well. These burdens contribute to increased access to healthcare, significant economic burden to both the families and the health care systems in which they present, and long-term sequela overall. There is great opportunity for action to be taken at a community level to impact this population health issue. As the prevalence of autism continues to rise, it is essential for health care providers to be able to respond to patients and families in a manner that will improve outcomes and offer effective and efficient health care.

Target Population and Stakeholders

As the author of this study specifically considers a capstone project intended to increase nurse competence and awareness as it pertains to the ASD population in the health care setting,

there are several key stakeholders that must be considered. These stakeholders include but are not limited to nurses, respiratory therapists, advanced practice nurses, physicians, occupational therapists, speech therapists, physical therapists, nurse educators, and community partners.

Chiri and Warfield (2011) conducted the first study that evaluated the prevalence of unmet core health care needs among children with ASD. This study produced several essential findings that provide support for this capstone project. Chiri and Warfield (2011) found that children with ASD in comparison to those without ASD were more likely to encounter unmet needs and challenges with access to health care. In addition, the researchers found that the prevalence of unmet needs were greater when the child's functional ability was compromised (Chiri & Warfield, 2011).

This study will consider the health care professional that is not equipped to understand or manage the ASD patient with behavioral challenges or sensory issues. How might this influence the patient's outcomes? It is essential for stakeholders to understand the essence and degree of health disparities among the ASD population as a first step to create change that will bridge the gap (Chiri & Warfield, 2011). Bringing the multidisciplinary team to the table to engage in this project will serve as a great benefit to positive outcomes.

In an acute care setting, the ASD patient may encounter more than one health care professional along with their assigned nurse. Each health care professional becomes a stakeholder and each may have different needs to ensure successful patient outcomes, treatment compliance and service completion. Each stakeholder plays a unique role from education and service delivery to community and public awareness.

Problem Statement

With the rising prevalence of autism, access to hospital-based medical services has risen (Bultas, 2012). Evidence suggests that little education is provided to front-line personnel on strategies to work with the ASD patients (McGonigle et al., 2013). Nurses report lack of knowledge, awareness, and competence when working with this population (Bultas, 2012).

Purpose of the Project

The purpose of the ASDCPEP capstone project was to develop and implement an evidenced-based education program designed to increase nurse knowledge, awareness and competence when caring for the ASD patient in nurses working on a pre-surgical unit at a Midwest regional pediatric hospital.

Clinical Question

The ASDCPEP explored the following clinical question: In pediatric pre-surgical nurses at a Midwest regional pediatric hospital, what is the effect of a continuing education learning opportunity on nurse competence and awareness specific to the pediatric patient with ASD compared with no continuing education learning opportunity on nurse competence and awareness of the pediatric ASD patient?

Outcomes

Two measurable and attainable learning outcomes were identified for the ASDCPEP:

RNs who complete the ASDCPEP will demonstrate increased ASD competence and awareness as evidenced by improved pre-education and post-education test scores.

RNs will report ASDCPEP usefulness to practice leading to more effective patient care during a one-month follow up evaluation, as evidenced by a written clinical example of knowledge application provided by the nurse.

Assessment of Organization

The ASDCPEP was intended to promote a comprehensive, holistic integrated approach to nursing care provision for the ASD patient within a Midwest regional pediatric hospital. This advanced education was developed using the most current evidence-based practice and literature recommendations available. The purpose of the ASDCPEP was to address nurse competence and awareness when caring for the ASD patient, in an effort to promote quality outcomes. The mission of the Midwest regional pediatric hospital at the time of program implementation was “To improve the life of every child”. The purpose and intended outcomes of the ASDCPEP were congruent with the mission of the organization.

Prior to the ASDCPEP, RNs within the identified hospital had not receive any formalized education to care for this specialized population. This hospital maintains a very aggressive vision to become a national leader in children’s health care. To meet this demand, health care providers must be educated and equipped to serve children with many diverse needs. Improved service to specialized populations such as the autism community are in alignment with the organizational vision.

To safeguard the success of the ASDCPEP, it was necessary to ensure integration within the clinical education department of the organization, leadership support at unit and administrative levels, collaborative efforts among experts that already exist within the hospital, adequate time allotment for staff time complete education, and adequate allocation of resources. Additional factors for success included ease of access to education, accountability for completion, an organized course offering, and a formal evaluation process.

One potential barrier to success for the ASDCPEP was staff buy-in. The leadership team at this hospital played an integral role in establishing the organization's culture as it pertained to ASD competence and awareness. Fostering an environment of support for the ASDCPEP was necessary to ensure acceptance and engagement among front-line nurses. The leadership team helped to ensure program success by providing time for nurse participation, offering input during the planning and implementation phase, and providing resources such as computer use and funds for educational development. Participation in the ASDCPEP required one hour to complete, and nurses needed dedicated time to complete the education. To adequately serve the needs of the front-line nurse to better manage the patient with ASD, it was necessary for the ASDCPEP to be recognized as an essential continuing education requirement within the organization and supported by the leadership team at the Midwest regional pediatric hospital.

This author did not identify any risks or unintended consequences associated with the ASDCPEP project. The educational program was designed to increase nurse knowledge, competence, and awareness of patients diagnosed with autism spectrum disorder. Successful implementation of this project reduces risk and unintended consequences caused by the uneducated nurse caring for the child with ASD.

Review of the Literature

A literature search was completed using CINAHL Plus with Full-Text Database and ProQuest Database. Prior to the beginning of the search, the following limiters were set: English, Human, Peer Reviewed, Full Text and Research Article. Articles were selected based on identification of highest levels of evidence available with the key focus elements included the clinical question for this capstone project. Although it was most desirable to utilize research

conducted within the last five years, years were not restricted in the searches in the event that current research was not available and/or if a historical reference was needed. Full Text articles were also allowed, as they may have offered additional insight. Articles were excluded if they did not address the clinical question.

The Autism and Developmental Disabilities Monitoring Network [ADDM] is the surveillance system in the United States that provides epidemiological data for ASD (Baio, 2014). The most recent report released in 2014 provides estimates gathered from 11 ADDM sites in the United States. In 2010, the estimated prevalence among sites was 14.7 per 1000 or one in 68 children aged 8 years. Approximately one in 42 boys and one in 189 girls were identified as living with ASD (Baio, 2014; CDC, 2015). Non-Hispanic white children were 30% more likely to be identified with ASD compared to non-Hispanic black children, and almost 50% more likely to be identified compared to Hispanic children (Baio, 2014). The numbers are staggering, and continue to rise.

The economic impact associated with autism in the United States is significant. The CDC (2015) reports an estimated \$11.5 billion- \$60.9 billion dollars per year in total costs for children with ASD. The medical expenditures of children and adolescents with ASD exceeded non-ASD individuals by \$4110- \$6200 per year. In addition to extraordinary medical expenses, intensive behavioral interventions necessary for children on the spectrum ranged from \$40,000 - \$60,000 per child per year (CDC, 2015). The higher medical expenditures among children with autism in turn suggest increased use of inpatient care and office visits (Lokhandwala, Khanna, & West-Strum, 2012).

Hospitalization creates unique challenges for the ASD patient and the health care provider. According to Johnson and Rodriguez (2013), hospitalization may elicit challenging behaviors in the ASD child leading to increased stress among both families and health care providers. An enhanced comprehension of the behavioral aspects of ASD may contribute to a more effective plan of care and interventions for the hospitalized child. Health care providers who do not have experience with this population may not understand the antecedents to the behaviors and lack the ability to employ effective strategies to care for the child (Johnson & Rodriguez, 2013).

In a recent study designed to better understand autism health care experiences, Bultas (2012), found that health care providers have apprehensions when caring for the ASD population, including lack of confidence and awareness. Nurses who are equipped with a greater understanding of the distinctive needs of the ASD child are better able to adapt the plan of care to improve outcomes and reduce the stress of the visit on both the provider and child (Scarpinato et al., 2010).

According to Bultas (2012), health care providers are only going to see an increase in service provision to children with ASD. Many aspects associated with ASD can complicate effective service delivery, thus the provider needs to possess competence and awareness to achieve desirable outcomes. The benefit of empowering a nurse with increased knowledge of the ASD population through a continuing education initiative is two-fold; it will increase his/her competence and awareness while enabling him/her to identify and deliver a more effective plan of care.

Autism not only presents unique challenges for individuals and families living with ASD who attempt to access health care services, but health care providers as well. As individuals with autism access the health system at different points of entry, front line personnel must be equipped to effectively care for this specialized population (Bultas, 2012). There is great opportunity for the advanced practice nurse to impact this population health issue. It is imperative that nursing professionals have a solid understanding of the autism population and the impact of the disorder as they attempt to provide competent care.

Just as non-ASD adults require preventive care, so do individuals with ASD. Common health care interventions such as routine annual physicals, cardiovascular monitoring, cancer screening, management of co-occurring diseases such as asthma or diabetes, mammography, colonoscopy, as well as many other procedures can be very difficult for the individual on the spectrum (Giarelli & Gardner, 2012). As these individuals seek medical attention, whether emergent or non-emergent, health care providers are not always prepared to handle the significant sensory and/or behavioral challenges associated with simple routine tasks.

As the author of this study might anticipate with the rising prevalence of autism, access to hospital-based medical services has risen. McGonigle et al. (2013) conducted a needs assessment and developed educational materials for health care providers in pre-hospital and emergency department settings. Evidence suggested that little education is provided to front-line emergency personnel on how to work with the ASD patients, as well as the challenges faced by the individual with ASD when accessing services. The report submitted by McGonigle et al. (2013) is the first to document efforts made to educate emergency health care personnel regarding the ASD population.

Conceptual and/or Theoretical Framework

The Ottawa Charter for Health Promotion Model (World Health Organization, 2016) served as a guide for this project (see Figure 1). This model exemplifies four primary events that merge and allow individuals to improve health by assuming control. As the author of this study considers the desired outcomes of the ASDCPEP, the health care provider becomes the individual assuming control. Modification of this tool allowed the four events, similar to the original events intended for the patient, to contribute the health care provider's increased competence and awareness.

Figure 1

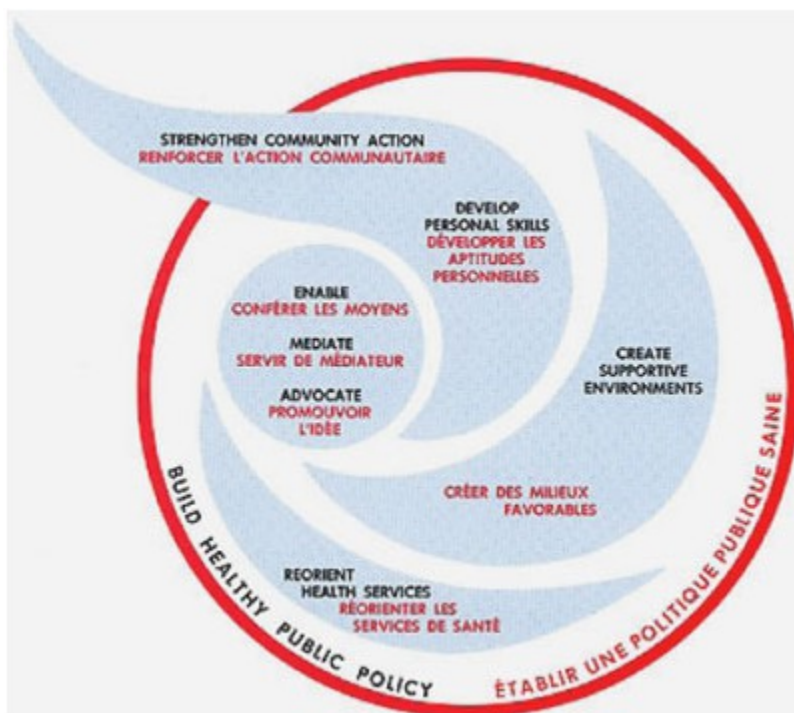


Figure 1. The Ottawa Charter for Health Promotion Model (World Health Organization, 2016)

Building health care competence and awareness when caring for the ASD population served as the overarching goal, and encompassed four primary events that lead to competence and awareness. The first event needed was to reorient health care providers to the basics of health

care as they pertain to the individual on the spectrum. The ASDCPEP included continuing education intended to increase the nurse's competence and awareness provided orientation to ASD patient care.

The second event was the establishment of a supportive environment. It was important to create a supportive environment for nurses caring for the ASD patient; this was initially done with education designed to increase competence and awareness. However, even with tools and education, there may be times when the nurse's efforts do not result in desirable outcomes with the ASD patient. Support from a peer who can offer alternative suggestions or simple reassurance continues to be essential.

The third event involved strengthening the action of the health care provider community and development of skills. Offering the front-line nurse effective tools that equipped him/her with increased competence and awareness allows him/her to better support her ASD patient (McGonigle et al., 2013).

The fourth event reflected the outcomes of the ASDCPEP leading to improved competence and awareness. Increased competence and awareness will enable the health care provider to better serve the patient with ASD, mediate solutions to barriers that arise in the health care setting, and better advocate for the patient (Bultas, 2012).

Methodology

Sample

Data provided by the Performance Improvement Department at the Midwest regional pediatric hospital indicated that a total of 285 children with ASD were cared for between 6/1/15 and 5/31/16. Of these children, 58 accessed cares through the Emergency Department, 98 patients received care on an inpatient unit, and 129 patients accessed care through the outpatient surgical unit.

In order to obtain achievable goals across a reasonable sample size by the end of the first quarter 2017, a goal was set to provide education to a minimum of 20 nurses in the outpatient surgical unit at the Midwest regional pediatric hospital. This unit was selected to launch the ASDCPEP program, as it served the greatest number of patients with ASD in 2015. A total of 11 nurses participated in the ASDCPEP, nine fewer than originally intended. Decreased participation was attributed to mandatory staff reduction on the unit on the day of the scheduled program.

Inclusion criteria of project participants included all part-time, full-time or casual Registered Nurses providing direct patient care on the outpatient surgical unit at the Midwest regional pediatric hospital. Exclusion criteria included any non-RN personnel, non-direct patient care RNs working on the outpatient surgical unit, and RNs with previous autism spectrum disorder training. Representative sampling was used. The representative sampling method allowed for the collected results to be generalized to a larger RN population.

Setting

The ASDCPEP was a structured educational program that provided high quality continuing education to the outpatient surgical nurse through a live continuing education course offered at the Midwest regional pediatric hospital. The course took place in a hospital-based auditorium.

Formal written support for the ASDCPEP capstone project was obtained from the Midwest regional pediatric hospital (See Appendix A).

Design

The ASDCPEP was a live continuing education session comprised of five learning objectives designed to increase ASD competence and awareness that highlight ASD foundational

knowledge, assessment strategies to guide care, environmental awareness in the health care setting, effective communication strategies, and recognizing and addressing caregiver burden among both the health care provider and ASD family members/care givers. The learning objectives for the ASDCPEP were identified based on deficits identified in the literature pertaining to nursing knowledge, competence and awareness of the ASD patient.

The ASDCPEP was developed with intended project outcomes as the framework for the program. It was predicted that completion of the continuing education session would increase ASD competence and awareness leading to more effective care of the ASD patient. The program included elements to test knowledge, in order to demonstrate increased ASD competence and awareness as evidenced by improved pre-education and post-education test scores. It was projected that the outpatient surgical unit RN would report ASDCPEP usefulness to practice leading to more effective care during a one-month follow up evaluation, as evidenced by identification of a clinical example of application of knowledge.

Program oversight for the ASDCPEP was provided by the Nursing Professional Department at the Midwest regional pediatric hospital. The Nursing Professional Department at this Midwest regional pediatric hospital included the Clinical Education Director, the Continuing Nurse Education Coordinator and the Performance Improvement Coordinator. This team of educators assisted with dissemination of ASDCPEP marketing materials and offered support during the development and implementation phase of the program. The Clinical Education Director and Continuing Nurse Education Coordinator were responsible for overseeing DNP student implementation of the program and overall development of course material related to ASDCPEP.

Data Collection Tools

A pre-test (see Appendix B) and post-test (see Appendix C) comprised of five questions that addressed the program objectives was administered to the participant at the live education program. The pre-test was administered and collected at the beginning of the educational program. The post-test was administered and collected at the conclusion of the educational program. The pre and post- tests provided to the participant were coded with a matching number so progression of knowledge could analyzed while maintaining the learner anonymity.

Learners who participated in continuing education at this Midwest regional pediatric hospital received a standardized electronic evaluation one month following the program. In addition to the standardized questions required by the organization, participants were also asked to answer two questions directly related to the ASDCPEP that allow the DNP student to ascertain usefulness to practice (see Appendix D). The data gathered from the electronic evaluation was de-identified by the Clinical Education Director prior to distribution to the DNP student to secure anonymity.

Reliability and validity of these instruments had not been established, as they were used for the first time with this project.

Data Collection

The DNP student collected data before and after administration of the continuing education session, and one month following completion of the education. Data was collected to measure progression of knowledge and useful application to practice. A multiple choice pre-test and post-test was administered to evaluate progression of knowledge. A Likert scale evaluation was administered one month later to assess useful application to practice. The learner was also asked to identify a clinical example that exemplified usefulness to practice.

Because of the uniqueness of this project, it was necessary to develop a pre-test and post-test tool specific to the ASDCPEP that would ascertain the data necessary to measure program outcomes. The one-month follow up questionnaire used a five-point scale that measured some form of agreement including strongly agree, agree, undecided, disagree, and strongly disagree. The participant was also asked to provide an example of “usefulness to practice” in the one-month follow up questionnaire.

Ethical

Integrity of the Data

The data collected for this project was housed in an electronic database maintained by the health system. Because this project was done in collaboration with the organization’s nursing professional development department, data was collected and housed along with all nurse continuing education. Data is kept confidential in this system. Nurses have access to their transcripts with a confidential login and password that is not shared with this investigator. Reports provided to the investigator were de-identified to maintain anonymity of the participants.

Conflict of Interest

As the developer of this continuing nurse education capstone project, conflict of interest had to be clearly articulated both for the IRB as well as the CME organization that credentialed the organization’s continuing education. There were no conflicts of interest related to this project identified by these entities.

It was noted that this DNP student maintained a role as a Clinical Education Specialist within the organization, and thereby had access to the organization as both an employee and a student. As an employee of this Midwest regional pediatric hospital, this writer worked with the organization’s Nursing Professional Development Team to ensure effective coordination of

ASDCPEP. All data used by this writer to develop the program and analyze outcomes was de-identified by members of the Nursing Professional Development department prior to use. This capstone project, was launched exclusively among nurses working in a pre-surgical unit at the Midwest regional pediatric hospital, within the role of DNP student investigator, and within a mutually agreed upon timeframe.

It was disclosed to program participants that this DNP student investigator was also an employee of the organization, however this did not create a conflict of interest, as this investigator had no evaluative power over the participants. This project was not directly related to any pay compensation or promotion for this student investigator in the work setting.

Informed Consent

Nurses who participated in the live learning session at the Midwest regional pediatric hospital were provided an informed consent packet when signing in to the educational event. The packet included an informed consent form (see Appendix E), pre-test and post-test. The nurse was asked to check a box indicating “I wish to participate” or “I do not wish to participate”. The informed consent form and pre-test were gathered by the Nursing Professional Development Coordinator prior to the start of the education session. The post-test was turned in to the Nursing Professional Development Coordinator at the conclusion of the educational session. If the nurse chose to participate, the pre-test and post-test questionnaires were returned completed. The DNP student investigator offered verbal instruction to ensure consent and anonymity at the beginning of the educational session, and again at the conclusion of the program.

Data Analysis

The ASDCPEP data analyzed for this capstone project was gathered from pre and post-test responses completed by 11 out of 11 program participants. Pre and post-test data was

analyzed as an aggregate, allowing for analysis of a mean pre-test score of all individuals as one “sum” score to a mean post-test score of all individuals as one “sum” score. A dependent samples t-test was conducted to investigate whether the ASDCPEP had a significant effect on the overall sum scores. This method of analysis allowed for measurement of overall improvement following the educational intervention.

The participants answered five pre-test questions prior to participating in the ASDCPEP. Immediately following program completion, the participant answered five post-test questions. The pre and post test questions remained the same in order to measure improvement following the educational intervention. The participants’ answers were analyzed and scored. Correct responses were coded with a 1 and incorrect responses coded with a 0. The data was transferred to an Excel spreadsheet. The results were calculated and analyzed for statistical significance. The mean pre and post test scores, standard deviations and degrees of freedom were reported.

Participants received an electronic one-month follow up evaluation that included two questions. If the participant had not cared for a child with ASD since participating in the ASDCPEP, the participant was prompted in the instructions to leave the questions blank. The information obtained from the one-month follow up evaluation was analyzed and reported.

Results

A total of 11 RNs participated in the ASDCPEP. All participants completed their pre and post-tests. The participants’ sum pre-test scores were compared to the sum post-test scores. A dependent samples t-test was conducted and the results indicated that there was a significant effect ($t= 4.0996003$, $p= 0.002146$). The mean for the pre-test was 2.3636364 while the mean for the post test was 4.1818182 (See Table 1).

Table 1. ASDCPEP Pre and Post Test Results

| | Pre-Test Mean (SD) | Post-Test Mean (SD) | <i>p</i> -value | <i>t</i> -value | <i>df</i> |
|-------|-------------------------|--------------------------|-----------------|-----------------|-----------|
| TOTAL | 2.3636364 (1.361817) | 4.1818182 (0.6030227) | 0.002146 | 4.0996003 | 10 |

The findings of this data suggest that in pediatric pre-surgical nurses at a Midwest regional pediatric hospital, a continuing education learning opportunity specific to the pediatric patient with ASD had a significant effect on nurse competence and awareness. RNs who completed the ASDCPEP demonstrated increased ASD competence and awareness as evidenced by improved pre-education and post-education test scores.

A total of 11 participants completed a one-month evaluation. Unfortunately no data was able to be extracted, as 11 out of 11 RNs reported that they had not yet cared for an ASD patient within the 30 day time frame from completing the ASDCPEP. Due to the nature of the evaluative question, RNs were unable to report ASDCPEP usefulness to practice leading to more effective patient care during the one-month follow up evaluation.

Discussion

Summary of Results

The ASDCPEP provided the participant with essential ASD information intended to increase ASD competence and awareness as it related to ASD foundational knowledge, assessment strategies to guide care, environmental awareness in the health care setting, effective communication strategies, and recognizing and addressing caregiver burden among both the health care provider and ASD family members/care givers. Improved pre and post test scores suggest that the education had a significant effect on the learner. The one-month evaluation had no reportable impact as it was not complete.

Clinical Implications

For a nurse on the front-line who lacks competence and awareness of the ASD patient, routine patient care can become an overwhelming experience. Nurses must be prepared to care for this unique population. Offering nurses ASD education will better equip the provider with an understanding of the distinctive needs of this specialized population.

Limitations

This project had a few limitations. The first limitation, sample size, was much smaller than anticipated and limited generalizability to a larger population of nurses. The second limitation, time constraints, also limited the ability to capture adequate follow up information from the participants to determine usefulness to practice. It may be beneficial to replicate this project to a broader population of nurses over a longer period of time.

Suggestions for Future Clinical Projects

With the increasing prevalence of ASD, nurses in both primary and acute care settings will need to be prepared to care for this specialized population (Bultas, 2012). Expanding this educational project to include a variety of setting-specific case studies/examples could be explored. Another idea includes development of pre-admission assessment tools appropriate for inpatient and outpatient settings that would alert the front-line nurse of critical patient-specific needs to help effectively guide the plan of care. It is essential that nurses not only possess knowledge competence and awareness, but also have dedicated resources to ensure safe and consistent care.

Conclusion

The health care environment can present significant challenges for the ASD child. This in turn, can present significant challenges for the health care provider who lacks competence and awareness to adequately care for this highly under-represented population. As the prevalence of autism continues to rise, nurses will need to be prepared for the challenges of the population in order to provide competent, safe, and developmentally appropriate care (Scarpinato et al., 2010).

The data collected from this study offers insight to the benefit of ASD continuing education to impact nurse competence and awareness. The findings of this capstone project offer a better understanding of the organizational needs and strengths at this Midwest regional pediatric hospital and better position the organization to set priorities and establish an action plan to properly educate nurses beyond the initial sample, increasing their competence and awareness of the ASD population. Empowering a nurse with this knowledge will enable him/her to identify an appropriate plan of care that more effectively serves the ASD patient.

The literature suggests that with the rising prevalence of autism, health care professionals will be interacting and caring for patients with ASD with increased frequency and regularity. Organizations need to properly educate nurses in order to ensure quality patient outcomes and efficient care. As a regional provider of pediatric care, this Midwest hospital must be prepared to care for the ASD patient. The ASDCPEP is only the first step necessary to prompt action. The ASDCPEP capstone project developed and implemented by this writer will enable the organization to evaluate current strengths and areas of growth as they pertain to nursing competence and awareness of the ASD patient. The data collected can be used to sustain the ASDCPEP and deliver useful education intended to prepare nurses to care effectively and efficiently for this unique population in the future. Increasing the nurse's competence and awareness not only benefits the nurse, but the autism population as well. There is significant

opportunity to positively influence both the nursing and autism community through further continuing education efforts. The ASDCPEP serves as a wonderful foundational education source for nurses providing direct patient care to the ASD patient.

References

- Baio, J. (2014). Prevalence of autism spectrum disorder among children aged 8 years- Autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *MMWR*, 63(2), 1-21.
- Bultas, M.W. (2012). The health care experiences of the preschool child with autism. *Journal of Pediatric Nursing*, 27(1), 460-470.
- Centers for Disease Control and Prevention (2015). *Autism spectrum disorder: Data and statistics*. Retrieved from: <http://www.cdc.gov/ncbddd/autism/data.html>
- Chiri, G. & Warfield, M.E. (2011). Unmet need and problems accessing core health care services for children with autism spectrum disorder. *Maternal Child Health Journal*, 16(1), 1081-1091.
- Giarelli, E. & Gardner, M.R. (2012). *Nursing of autism spectrum disorder: Evidence based integrated care across the lifespan*. Springer Publishing Company, LLC: New York, NY.
- Johnson, N.L. & Rodriguez, D. (2013). Children with autism spectrum disorder at a pediatric hospital: A systematic review of the literature. *Pediatric Nursing*, 39(3), 131-141.
- Lokhandwala, T., Khanna, R., & West-Strum, D. (2012). Hospitalization burden among individuals with autism. *Journal of Autism and Developmental Disorders*, 42(2), 95-104.
- McGonigle, J.J., Migyanka, J.M., Glor-Scheib, S.J., Cramer, R., Fratangeli, J.J., Hedge, G.G., Shang, J., & Venkat, A. (2013). Development and evaluation of educational materials for pre-hospitalization and emergency department personnel on the care of patients with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 44(2), 1252-1259.
- Scarpinato, N., Bradley, J., Kurbjun, K., Bateman, X., Holtzer, B. & Ely, B. (2010). Caring for

the child with an autism spectrum disorder in the acute care setting. *Journal for Specialists in Pediatric Nursing*, 15(3), 244-254.

World Health Organization (2016). *The ottawa charter for health promotion*. Retrieved from:

<http://www.who.int/healthpromotion/conferences/previous/ottawa/en/>

Appendix A: Formal Written Support

Letter of Support from Leadership

November 6, 2016

Dear Valerie Anderson,

Based on my review of your capstone project, I give permission for you to conduct the project entitled "Autism Spectrum Disorder Care Provider Education Project" at Children's Hospital and Medical Center. This permission is dependent upon approval of the study by the Methodist Hospital and Children's Hospital and Medical Center IRBs.

As part of this proposal, I authorize you to invite members of the outpatient surgical unit to participate in the project as program participants. Their participation will be voluntary and at their own discretion. Subjects reserve the right to withdraw from the project at any time. I also reserve the right at any time to suspend this project at Children's Hospital and Medical Center if I deem it necessary.

I understand your education project will take place in February 2017 and data collection with this group will conclude with your one month follow up following the education session. I also understand that the data collected will remain entirely confidential and may not be provided to anyone outside of the project team without permission from the Children's Hospital and Medical Center IRB and Methodist Hospital IRB.

Good luck on your project.

Sincerely,



Barb Schwarz, MSN, BS, RN, CNOR, CMNL
Director of Surgical Services, Children's Hospital and Medical Center



Appendix B: Pre-Test

ASDCPEP Pre-Test**Please answer the following multiple choice questions:**

1. Children with Autism Spectrum Disorder exhibit impaired functioning in the following critical domain(s). Select all that apply:
 - a. Social Skills
 - b. Language Development/ Communication Patterns,
 - c. Restricted Interests/Stereotypical Behavior
 - d. Developmental Age

2. Which of the following assessments are necessary when planning care for the Autism Spectrum Disorder patient. Select all that apply:
 - a. Developmental level
 - b. Hypersensitivity concerns
 - c. Emotional disturbances
 - d. Communication techniques
 - e. Previous interventions

3. Which of the following environmental considerations may trigger a negative response in the patient with Autism Spectrum Disorder? Select all that apply:
 - a. Fluorescent lights
 - b. Blood pressure cuff
 - c. Equipment noise
 - d. Health care providers

4. Which of the following communication strategies should be considered with the non-verbal Autism Spectrum Disorder patient? Select all that apply:
 - a. Picture cards
 - b. Text messaging
 - c. Visual scales
 - d. Communication board

5. You are caring for a patient with autism spectrum disorder and you notice the parent seems to be agitated and uncooperative with your recommended plan of care. You recognize this could be a sign of:
 - a. Depression
 - b. Caregiver burden
 - c. Non-compliance
 - d. Chemical Influence

Appendix C: Post-Test

ASDCPEP Post-Test**Please answer the following multiple choice questions:**

1. Children with Autism Spectrum Disorder exhibit impaired functioning in the following critical domain(s). Select all that apply:
 - a. Social Skills
 - b. Language Development/ Communication Patterns,
 - c. Restricted Interests/Stereotypical Behavior
 - d. Developmental Age

2. Which of the following assessments are necessary when planning care for the Autism Spectrum Disorder patient. Select all that apply:
 - a. Developmental level
 - b. Hypersensitivity concerns
 - c. Emotional disturbances
 - d. Communication techniques
 - e. Previous interventions

3. Which of the following environmental considerations may trigger a negative response in the patient with Autism Spectrum Disorder? Select all that apply:
 - a. Fluorescent lights
 - b. Blood pressure cuff
 - c. Equipment noise
 - d. Health care providers

4. Which of the following communication strategies should be considered with the non-verbal Autism Spectrum Disorder patient? Select all that apply:
 - a. Picture cards
 - b. Text messaging
 - c. Visual scales
 - d. Communication board

5. You are caring for a patient with autism spectrum disorder and you notice the parent seems to be agitated and uncooperative with your recommended plan of care. You recognize this could be a sign of:
 - a. Depression
 - b. Caregiver burden
 - c. Non-compliance
 - d. Chemical Influence

Appendix D: Program Evaluation

If you have cared for a patient with autism spectrum disorder since completion of the Autism Spectrum Disorder Care Provider Education Program, please complete the following questions:

1. I found the information I learned in the Autism Spectrum Disorder Care Provider Education Program to be useful to my practice.

| | | | | |
|----------------|-------|-----------|----------|-------------------|
| Strongly Agree | Agree | Undecided | Disagree | Strongly Disagree |
| 5 | 4 | 3 | 2 | 1 |

2. Please provide a clinical example in the comment box below:

Appendix E: Informed Consent

**Nebraska Methodist College
DNP Student Capstone Project**

Date:

Dear Program Participant:

You are invited to participate in a Doctoral of Nursing Practice (DNP) Capstone Project. The purpose of this project is to provide evidence-based nursing education designed to increase nurse competence and awareness when caring for the Autism Spectrum Disorder (ASD) patient.

We are inviting you to participate in this DNP Capstone project because you have been identified through Children's Hospital and Medical Center (CHMC) as a nurse who works in a unit where the greatest number of patients with ASD are accessing care.

If you agree to participate, we would like you to complete a short pre and post-test with questions that test your knowledge about caring for the patient with autism spectrum disorder. You will have the opportunity to complete the pre-test electronically when you sign up for the education and the post-test when you request your CNE transcript. It will take you approximately 5 minutes to answer the questions for each pre/post-test survey. You will also receive a survey monkey questionnaire via email approximately 1 month following completion of the education to determine if this program has been useful to your practice.

If you do not wish to participate, please check the box stating "I do not wish to participate".

We will keep the information you provide confidential, however federal regulatory agencies and the Nebraska Methodist Collage Institutional Review Board (a committee that reviews and approves research studies) may inspect and copy records pertaining to this project.

This project is confidential. Your personal information will be removed from the project data prior to being released to the student investigator for analysis. Findings will be reported without any identifying participant information.

There are no known risks from-participating in this project, and you will not benefit personally.

All survey responses that we receive will be treated confidentially and stored on a secure server. However, given that the surveys can be completed from any computer (e.g., personal, work, school), we are unable to guarantee the security of the computer on which you choose to enter your responses. As a participant in this project, we want you to be aware that certain login software programs exist that can be used to track or capture data that you enter and/or websites that you visit.

Your participation in this project is completely voluntary. If you decide not to be in this project, or if you stop participating at any time, you will not be penalized or lose any benefits for which you are otherwise entitled.

If you have any questions, concerns or complaints now or later, you may contact us at the number below. If you have any questions about your rights as a human subject, complaints, concerns or wish to talk to someone who is independent of the research, contact the Office for Human Research Protections at 866-447-4777. Thank you for your time and consideration.

Valerie Anderson, MSN, RN
Primary Investigator
Doctor of Nursing Practice (DNP) Student
Nebraska Methodist College
[REDACTED]

Connie Wallace, PhD
Secondary Investigator
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[REDACTED]