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Understanding the Autism Spectrum Disorder Population: An Opportunity to Improve Patient Care

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Understanding the Autism Spectrum Disorder Population:
An Opportunity to Improve Patient Care

by

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Abstract

There is a documented need for caring education regarding patients with autism spectrum

disorder (ASD) for nursing students and nursing staff. The autism spectrum population is

increasing, one in 59 children in the United States as reported by the CDC's Autism and

Developmental Disabilities Monitoring (ADDM) Network (as cited in Baio et al., 2018).

Nurses are expected to provide appropriate care, showing respect and understanding at all

times to both the client and family. Through lack of knowledge and misunderstanding

the ASD population has not been given this care. Based on Watson's Theory of Caring,

an educational ASD caring program was created for a summer session Family Nurse

Practitioner assessment class. This educational program provided basic knowledge of

ASD and appropriate communication skills for caregivers, guided by caring science

concepts.

Using the Caring Factor Survey-Care Provider Version, Short Version (CFS-CPV) by

Nelson, Thiel, Hozak, and Thomas (2016), and the Autism Knowledge Survey-Revised

(AKS-R) by Swiezy, Stuart, and Ashby (2005), *student perceived ability to care* and

student knowledge of ASD were measured. There was a 4.8% and 16% improvement,

respectively, from pre- to posttest, but the results are inconclusive due to the small

response rate. Nursing curriculums and continuing education offerings should include

knowledge related to working with special populations, such as those with

communication disorders. Nursing practice guided by caring science principles help

nurses to build authentic relationships with patients and families resulting in better health

outcomes.

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CHAPTER I

Introduction

Providing nursing care for children with autism in the inpatient acute care setting has become a common occurrence (Scarpinato et al., 2010). For nurses to responsibly create an appropriate nursing care plan for a person with autism spectrum disorder (ASD), the nurse needs to be educated about ASD and understand how each individual client with ASD communicates. ASD is defined as "a complex developmental condition that involves persistent challenges in social interaction, speech, and nonverbal communication, and restricted/repetitive behaviors" (American Psychiatric Association website, 2019, "What Is Autism Spectrum Disorder?" para. 1).

While working as a nurse at a well-known children's medical center, there have been occasional announcements heard over the alert system, stating a need for security back-up involving a patient with ASD. Being a psychiatric RN, and a mother of a child with ASD, the researcher is keenly aware when this happens. The hospital perioperative group at the author's facility, has created a perioperative care plan for children with ASD, and there are other committees that have been discussing the issues of caring for this population. There is no formal staff education program, however, to improve knowledge and care strategies for children with autism hospitalized at the facility.

In the author's experience, there is little information on ASD in the mental health and pediatric nursing curriculum for nursing students. McCarthy and Wyatt (2014) reviewed the pediatric curriculum at 315 United States undergraduate nursing schools and found only one to two hours of total time spent on child behavioral/mental health content in 41% of the programs (p. 133). When this researcher asked a nursing professor,

who teaches psychiatric education courses locally, if ASD is taught in her course, she

replied it may be mentioned briefly in the curriculum book and perhaps brought up

briefly in one lesson (I. Aguilar-Coker, personal communication, February 4, 2019).

In the psychiatric unit of the hospital where the researcher works, nursing staff

has been trained to work with clients with ASD. When the patient with ASD is admitted,

the psychiatric nurses assess for individual stressors or triggers, as well as

communication or sensory issues, and inform the staff. By doing so, the staff usually is

able to work well with the client, reducing aggressive outbursts and giving support,

understanding, and respect. If all medical center staff were trained on caring for and

understanding the children with ASD as the psychiatric staff have been, violent incident

codes would not be called as often, and the patients and families would experience better

care outcomes. "Effective interventions and management strategies can facilitate a

positive health care experience for all" (Souders, Freeman, DePaul, & Levy, 2002, p.

555). Nursing education is the starting point for learning these effective interventions

and management strategies.

Significance

According to the study conducted by the Centers for Disease Control's Autism

and Developmental Disabilities Monitoring (ADDM) Network, the prevalence of ASD in

children in the United States in 2000 was one in 150, increasing to one in 59 children by

2014 (Baio et al., 2018). ASD presents four times more often in boys than girls (Baio et

al., 2018). Chiri and Warfield (2012) found, "Families of children with autism spectrum

disorder were in fact significantly more at risk for having unmet specialty and therapy

care needs" (p. 1081). Xu et al. (2019) reported that nearly 30% of children diagnosed with ASD across the country did not receive behavioral or medication treatment.

The American Psychiatric Association updated the Diagnostic and Statistical Manual of Mental Disorders (DSM) in 2013 to improve the understanding and identification of mental health conditions (Autism Speaks website, 2019). Changes in the autism spectrum disorder diagnosis, listed under DSM-V, include a more accurate diagnosis, identification of symptoms that may warrant treatment or support services, and assessment of severity (Autism Speaks website, 2019). The four previous categories – autistic disorder, Asperger syndrome, childhood disintegrative disorder, and pervasive developmental disorder - not otherwise specified (PDD-NOS) – are currently listed under "autism spectrum disorder" (Autism Speaks website, 2019). According to Lobar (2016), "This change oversimplifies the core symptom identification, making it more difficult to determine just what behaviors may constitute an ASD and confusing providers" (p. 360). The DSM-V also consolidated three previous categories of autism symptoms: social impairment, language/communication impairment, and repetitive/restrictive behaviors; into two categories of symptoms – persistent deficits in social communication/interaction and restricted/repetitive patterns of behavior (Autism Speaks website, 2019). Sensory issues, added under the restrictive/repetitive behavior category, include hyper- or hypo-reactivity to stimuli (i.e. lights, sounds, tastes, touch), or unusual interests in stimuli, such as staring at lights or spinning objects (Autism Speaks website, 2019).

The Autism Speaks website (2019) identified additional assessments related to a diagnosis of ASD, including genetic testing (i.e. fragile X syndrome or Rett syndrome), language level, intellectual disability, and/or autism related medical conditions, such as

seizures, anxiety, GI issues, and sleep issues. According to Scarpinato et al. (2010), "With a high prevalence rate of comorbidities among this population, such as gastrointestinal complaints and seizures, nurses are likely to care for hospitalized patients with ASD" (p. 244). This DSM-V diagnosis exemplifies the term 'spectrum,' since there are multiple symptoms that occur in a variety of combinations as well as degrees of severity.

Centers for Disease Control and Prevention (2019) ASD signs and symptoms list (see Appendix A) gives examples of many observable attributes of people with ASD. "Despite vast differences within this population, awareness of similarities (including difficulty communicating, forming relationships with others, and understanding abstract concepts) that are common among individuals with ASD can augment and guide nursing practice" (Dunlap, 2018, p.16). This list is not definitive and should only be utilized as a guide for understanding what many with ASD live with daily.

The prevalence of patients with ASD at this researcher's medical center has increased to a point that there are committees discussing ideas and the facility has recently opened a new ASD two-room wing created specifically for patients with ASD admitted to the inpatient psychiatric unit. While this is a move toward helping this population, more needs to be done for patients with ASD who need medical attention for comorbidities. Nurses need ASD education prior to on-the-job training. It needs to begin in the classroom.

Problem Statement

The problem being addressed was how the ASD population is perceived when hospitalized for comorbidities, and how nurses have not been well educated to improve

nurse performance when caring for the ASD patient. There is literature supporting the need for better care for patients with ASD while hospitalized for co-morbidities (Baio et al., 2018; Chiri & Warfield, 2012; Dunlap, 2018; Scarpinato et al., 2010; Xu et al., 2019). There is literature supporting the continuing education of nurses based on the science of caring (Boev, 2012; Caruso, Cisar, & Pipe, 2008; Chan, Chu, Yen, & Chou, 2015). There is limited literature to support the need for more extensive mental health nursing education and no identified literature to support ASD curriculum in nursing programs at all in the United States (McCarthy & Wyatt, 2014; Pachkowski, 2018).

Purpose

The purpose of this MSN thesis was to educate nursing students to improve care outcomes and create a positive, more personal, care environment for clients with ASD. The goal was for nurses to perceive themselves as fully prepared to care for this population. "Understanding the physical and emotional needs related to the care of children with ASD can make the child more comfortable; this makes the caregiver's job easier and results in better care for this population" (Benich, Thakur, Schubart, & Carr, 2018, p. 35). Education is needed on how to give care to this population in order to promote a positive experience for the client with ASD. A greater understanding of how the ASD population experiences the world may be relevant to optimizing quality nursing interventions.

Theoretical Framework

This study was guided by Watson's Human Caring Science Theory (Watson, 2015). Watson's Theory of Human Caring was developed between 1975 and 1979 and emerged from her own views of nursing in combination with her background in

education, clinical, and social psychology, to create a theory "that transcended settings, populations, specialty, and subspecialty areas" (Watson, 2015, p. 322). Watson's original work entailed 10 carative factors, which have evolved into a more fluid movement known as caritas processes. This framework has a spiritual dimension of openness, authentic presence, and unconditional loving by the nurse as a conduit to healing, and creating an authentic transpersonal caring relationship (Watson, 2008).

Watson's Theory of Caring fundamentally supports the caring needs required by the ASD population from the nurse. By being present in the moment, the nurse is able to genuinely engage with the ASD client by staying within the client's frame of reference. Authentic presence and caritas consciousness are used to connect spirit-to-spirit between nurse and patient (Watson, 2008). "The one caring and the one being cared for are interconnected; the caring-healing process is connected with the other human(s) and the higher energy of the universe" (Watson, 2015, p. 328). This co-created caring relationship, promotes knowledge, growth, empowerment, and healing (Watson, 2019). "One of her [Watson's] greatest recognitions was when nurses treat patients as individuals and provide assistance with gratification of needs, and the patient feels recognized, appreciated, and loved, the patient will have more energy to move up the hierarchy toward self-actualization" (Clark, 2016, p. 3). (See Figure 1)

Using the science of human caring, more mindful nursing interventions which may support the care needs of the ASD client and family are:

1. For the nurse and staff to accept the client for who they are and where their frame of reference is pertaining to forms of communication comprehension, verbal skill level, and eagerness to learn and share with the staff.

2. For the nurse and staff to be open to understanding and learning from the individual and family, joining in the journey to help in the healing, sharing of information, coaching, and sharing options to meet the client in the client's present moment.

3. For the nurse and staff to fully immerse in the moment, committing to authenticity, being present, and speaking in a calm, quiet, respectful manner.

4. For the nurse and staff to create a warm, caring environment for the client and family, creating a stronger connection through active engagement and reflection (Watson, 2008).
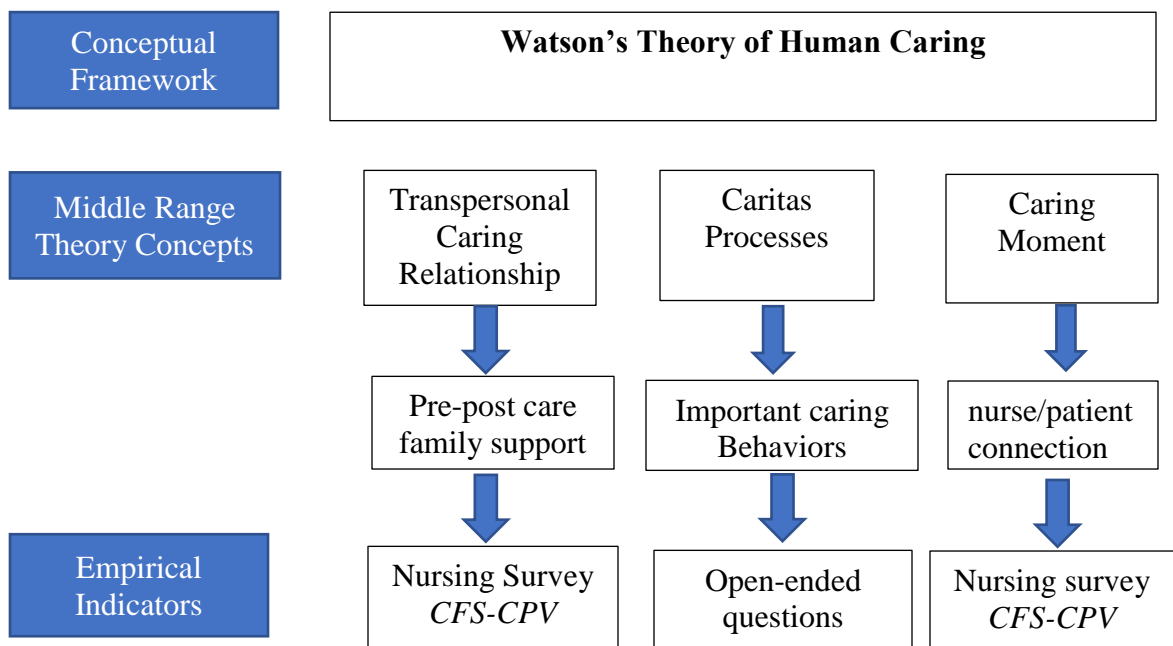
Figure 1. Conceptual-Theoretical-Empirical Structure (CTE) for the Study of Nurses' Perceptions of Nursing Care Abilities of Patients with ASD Post Education

Definition of Terms

- Autism Knowledge Survey-Revised (AKS-R): A tool developed by Stone (1987) and revised by Swiezy et al. (2005), to measure knowledge of autism spectrum disorder, using a Likert scale with 20 questions (Swiezy et al., 2005).

- *ASD:* Autism Spectrum Disorder

- Carative factors/Caritas processes**:** A group of ten "aspects of nursing that potentiate therapeutic healing processes and relationships – they affect the one caring and the one being cared for" (Watson, 2015, p.324).

- Caritas: is a "Latin word meaning to cherish or appreciate, giving special attention to or loving" (Watson, 2015, p.323).

- Caring Factor Survey-Care Provider Version (CFS-CPV): A tool developed to examine the human attribute of caring with this version asking the care provider their own interpretation of care knowledge, using a Likert scale with 20 questions or a revised version with 10 questions (Nelson et al., 2016).

- Coaching in Context (CinC): CinC includes three components: connecting to a previous action plan, brainstorming strategies to support progress towards goals, and strategies to try (Potvin, Prelock, & Savard, 2018).

- Concept of caring: To find some basis for respectful human connection with the person or persons (Clark, 2016).

- Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS): A patient satisfaction survey required by the Centers for Medicare and Medicaid Services for all hospitals in the United States.

- SQUIRE-EDU: A systematic inter-professional advisory team created to increase the "completeness, transparency, and replicability of reports that describe systematic efforts to improve the quality and value of health professions education" (Armstrong, 2019, p. 255).

- Transpersonal: "Transpersonal refers to values of deep connectedness, of relationship, subjective meaning and shared humanity … Transpersonal conveys a connection beyond the ego, capturing spiritual dimensions all humans share with a deeper self, others, nature, and the universe" (Watson, 2002, p. 13).

- Watson's Theory of Human Caring: A nursing theory guided by 10 caritas processes; transpersonal caring relationship between the nurse and patient, where there is a connection to another's spirit or soul; the caring occasion; and caring – healing modalities (Watson, 2015).

Summary

Nurses at all practice levels need an understanding of ASD, how to assess ASD symptoms, and how a person or parent obtains a formal diagnosis of ASD. Nurses should be knowledgeable about advocating for the ASD client and family, guided by Watson's Theory of Human Caring. The purpose of this MSN thesis was to educate nursing students to improve care outcomes and create a positive, more personal, care environment for clients with ASD. The goal was for nurses to perceive themselves as fully prepared to care for this population. "Education and community efforts need to be combined with advocacy at institutional, organizational, and national levels to improve access to appropriate, high quality inpatient care" (Rudnick, Henry, & Trost, 2019, p.3).

CHAPTER II

Literature Review

The purpose of this thesis was to improve the care of the autism spectrum disorder (ASD) population and to create and administer a caring nursing program, using Watson's Theory of Caring as the foundation, to educate nurses on the science of ASD and caring theory. Scholarly literature was reviewed to support the need for further education in caring for the ASD population, as well as nurses' perception of care of the ASD population. The examination of scholarly literature focused on the concept of caring and Watson's Human Caring Theory, nurse caring behaviors as perceived by patients, the rising prevalence of autism, and the needs and experiences of patients with ASD. This required an exhaustive, detailed search of scholarly literature.

Literature Search Strategies

The initial search for literature was conducted electronically using the following data bases: Cumulative Index for Nursing and Allied Health Literature (CINAHL), Medline, PubMed, and EBSCO host, scholar, and Google search. The first run of article searches were less than five years old. A later search included articles that were from 1987, with the majority reviewed from the past five to 10 years. There also was a search for Watson's Theory of Human Caring to help create the foundation for the caring nurse program for patients with ASD. Terms used in searches included autism disorders, ASD, autism, Asperger syndrome, nursing care plan, patient-centered care, [and] surveys, questionnaires, nursing school curriculum, and hospitalization. The other search for Watson's caring theory used the following terms in the search: Watson's Theory of Caring, caring nursing theories, carative factors, caritas processes, caring attributes, nurse

perceptions, caring factor survey, and evidenced based design. Article PMID#s were taken from CINAHL and placed into PubMed or Medline EBSCO host to pull up related articles. All articles were peer-reviewed journal articles published between 2001 and 2019.

Review of Literature

Literature Related to Care of the ASD Population

Unmet needs of ASD population. Salassi-Scotter, Scott, and Hunt (2014) discussed a pilot program conducted at Arkansas Children's Hospital, designed to improve communication with the child with ASD, family, and other providers, and to create an environment that better addressed the needs of the child with ASD. The goal of the study was to develop strategies to prevent and manage behavioral escalations without the use of restraints and sedation (Salassi-Scotter et al., 2014). The pilot workgroup focused on staff education, assessment tools identifying sensory and communication needs, and parental interviews to create appropriate interventions for the child with ASD (Salassi-Scotter et al., 2014). Interventions based on screening score, included a portable cart with tactile, hearing and visual items, iPad with games and apps, environmental modifications, traffic control, and visual story book, as well as consults with child life, social work, and nutrition. The study did not share specific results of improvement, but noted over the three-month pilot, "restraints and sedation for behavioral escalations greatly decreased, … parents anecdotally reported improved satisfaction, and the workgroup discovered that much is gained with a few simple interventions like the sensory cart" (Salassi-Scotter et al., 2014, "The results," para.1).

Diagnosis, management, and care coordination of the ASD patient are important facets of the overall care of this population. Lobar (2016) highlighted the differences between DSM IV-TR and the newer DSM-V, discussing how these changes may have actually limited the eligibility of some children for services. Prior to the DSM-V, primary care providers complained about lack of knowledge and difficulty in diagnosing ASD, recognizing early symptoms of developmental concerns, and managing care. The DSM-V may have diminished the ability of practitioners to screen for ASDs, making appropriate referrals even more difficult (Lobar, 2016).

Dunlap (2018) explained the signs and symptoms of ASD and offered nurses advice for caring for this population. Dunlap (2018) stated, "The burden is on us to understand them just as they must try to make sense of a "normal" world" (p.17). When a patient with ASD presents with new aggressive or other atypical behaviors, the medical staff need to think of untreated or undertreated medical conditions as possible causes. When working with this population, Dunlap (2018) states nurses are a vital part of the process since "The goal of ASD management is to maximize functionality, improve life quality, and promote independence" (p. 19).

Assessing the needs of hospitalized patients with ASD into various categories is the first step to facilitate improved quality of care and inpatient experience (Kopecky, Broder-Fingert, Iannuzzi, & Connors, 2013). The in-hospital needs of 80 patients with ASD were assessed via a 21-question survey completed by the primary caregiver (86% respondents were parents of the patients) while hospitalized at Massachusetts General Hospital. The average age of the ASD patient was 14.5 years, with an age range of two to 49 years. The survey was broken into three categories: communication,

social/pragmatic, and sensory, noting there was a diverse range of needs/challenges in all three areas. Under the communication category 38% of primary caregivers stated the child preferred to use sign language or gestures, 31% of primary caregivers stated the children with ASD used tools such as picture exchange communication systems (PECS) or an electronic device, and 23% of primary caregivers stated the child expressed needs verbally (Kopecky et al., 2013). In response to pain, 32% of primary caregivers indicated the patient would cry or scream, 27% reported aggression or self-harm, and 19% reported use of spoken language (Kopecky et al., 2013). Under the social/pragmatic heading, 50% of primary caregivers felt it was important to explain each step prior to examining the patient, 37% felt that trust was built when the patient was allowed to examine unfamiliar healthcare tools first or observe a trusted adult with the tools, and 65% of primary caregivers expressed concerns about elopement or wandering (Kopecky et al., 2013). Primary caregivers indicated, under the sensory category, that 35% of the patients use music, puzzles, and videos, and 18% of primary caregivers reported that low lighting was helpful (Kopecky et al., 2013). The intent of the survey was to help inform health care professionals in the areas of assessment and management of individuals with an ASD diagnosis, concluding that "an individualized approach must be used to assess and accommodate these needs" (Kopecky et al., 2013, p.658). The results of this survey inform other hospital centers about the unique needs of the patients with ASD, helping to promote improved accessibility and quality of health care for this population.

Using data from the 2016 National Survey of Children's Health, a nation-wide cross-sectional survey, Xu et al. (2019) analyzed over 43,000 questionnaires completed by parents or guardians. The prevalence of ASD across the country was relatively high at

2.5% with substantial variance from one state to another. Across the U.S., only 20.3% of current ASD diagnosed children, age three to 17, received both behavioral and medication treatment, and nearly 30% of children diagnosed with ASD received no behavioral or medication treatment. This information calls for further investigation into state health policies and the barriers to appropriate diagnosis and treatment.

Johnson and Robinson (2014) designed a qualitative study to describe the meaning attributed to challenging behaviors of ASD hospitalized patients and the prevention strategies used by the parents and health care professionals. Five mothers of ASD children and five health care professionals (HCPs) were studied. All participants were asked open-ended questions with follow up questions for clarification, while being taped for accuracy in a focus group setting. Mothers stated the behaviors were due to the child's communication of frustration, hyperactivity, and self-calming. The HCPs related the challenging behaviors to self-stimulation and aggression. Findings included the need for collaboration between the HCPs and caregivers of children with ASD to support the children and their parents by decreasing frustration leading to challenging behaviors.

To better understand the significant challenges caregivers encountered when caring for a child diagnosed with ASD, Russell and McCloskey (2016) administered a survey utilizing Interpretive Phenomenological Analysis (IPA) and the Measure of Process of Care (MPOC-20) to 11 parent volunteers. The survey, while small, noted parent perceptions of care and management deficits and needs for ASD children. The subscale "respective and supportive care" received the highest mean score of 5.3 with a standard deviation of .2; the subscale "providing general information" about the child with ASD had the lowest mean score of 3.2 with a standard deviation of .54, indicating

this occurs only "to a small extent" (Russell & McCloskey, 2016, p. 24). The researchers concluded that more research is needed on how providers, specifically APRNs, could provide managed care to this population, implementing the medical home model of care, and creating a more consistent positive caring experience.

Through the use of nationally-representative emergency department data, Kalb et al. (2016) was able to decipher the proportion of ED visits by ASD youth that were injury related, as well as compare the different methods and intent of the injuries between youth with ASD or were Intellectually Disabled (ID), and those who were not. The probability of being hospitalized post injury-related emergency department visit was compared. "In the multivariate analyses, the odds of an injury-related visit was 54% greater among those with ASD compared to youth with intellectual disability (ID), but 48% less compared to youth without ID or ASD" (Kalb et al., 2016, p. 2756). ED visits by children with ASD were more likely to be due to self-inflicted injury and poisoning, resulting in hospitalization more often than all other pediatric injury-visits in the US in 2008 (Kalb et al., 2016). This data has limitations, including use of only one year of data; inability to link ED visits to the same client, so one client may contribute to multiple visits; and data has limited explanations for hospitalization along with non-specific coding. The findings signify a need for prevention and monitoring programs to keep youth with ASD and ID safe in the community.

While investigating health care experiences of children diagnosed with ASD, Chiri and Warfield (2012) identified unmet needs of patients with ASD, as well as a variety of types and problems associated with accessing needed care. Using data from the 2005-2006 National Survey of Children with Special Health Care Needs (NS-

CSGCN), the researchers examined four core health care services, being routine preventative care, specialty care, therapy services, and mental health care (Chiri & Warfield, 2012). The researchers reported on provider and system characteristics, comparing children with ASD to other children with special health care needs (Chiri & Warfield, 2012). The analysis generated the following key findings: ASD children are more likely than the other groups to experience unmet needs and access problems, unmet service needs were found to vary by service type (specialty care 64.5% unmet for ASD vs. 51% others, and therapy services 75.1% unmet for ASD vs. 22.5% others), the prevalence of specific access problems varied by service type, and the prevalence of unmet needs was greater for children whose functional ability is always or often affected (Chiri & Warfield, 2012). While this study clearly described a discrepancy between unmet health care needs of ASD children and other groups of children with special needs, the survey also depended on the parents' accuracy when measuring their child's unmet needs as well as the child's diagnosis of ASD.

Using the 2007 Health Care Utilization Project Nationwide Inpatient Sample (HCUP-NIS), Lokhandwala, Khanna, and West-Strum (2012) assessed inpatient care burden among individuals with autism. The authors reported 26,000 hospitalizations with an overall rate of 65.5/100,000 admissions of those with a diagnosis of ASD. The NIS is discharge-level data, so each line represents a single episode, resulting in the possibility of individuals being represented more than once in the data. Furthermore, the data does not specify the severity level among those labeled as autistic in this survey. According to the authors, "the total length of stay [LOS] for hospitalizations among individuals with autism was 168,473 days, and the total charges incurred were $638

million," the LOS was 1.5 times longer, the number of diagnoses were higher (5.9 vs.

4.37), and charges were higher in comparison to the control group (Lokhandwala et al.,

2012, p. 97). The authors also identified epilepsy and psychiatric disorders as common

comorbidity conditions associated with hospitalized patients with ASD.

Rudnick et al. (2019) investigated why children are hospitalized longer than

expected if diagnosed with ASD and mental health co-diagnoses. A review of three

components of the medical system relevant to improvement of knowledge and quality of

care for this population was discussed. The first was training and education. The authors

stated these are needed to understand patients with ASD who are admitted for

comorbidities, noting difficulties with communication, procedures, and new

environmental stimuli are all issues of hospitalization. The second was multidisciplinary

inpatient care models. The introduction of autism focused care plans (ACPs), such as

Massachusetts General Hospital's parent/client questionnaire, completed prior to

admission and uploaded into the electronic medical record show a positive increase in

perceived parental hospital experience for their ASD child. The third was the status of

inpatient psychiatric facilities. The authors argued that inpatient psychiatric unit care

with ASD trained staff reduces LOS and improves long-term follow-up for the patient

with ASD and a psychiatric comorbidity, but there is an inadequate number of pediatric

psychiatric ASD units and trained ASD clinicians to meet current needs (Rudnick et al.,

2019).

Staff utilization of treatment plans. In another study designed to help staff deal

with the challenges that children with ASD face in coping with an acute hospitalization,

Scarpinato et al. (2010) described various issues patients with ASD face when

hospitalized for comorbidities. The level of social interaction, communication, and stereotypical ASD behavior impairments may further escalate anxiety or stress for the clients with ASD and families. An 18-month retrospective study was designed to examine the prevalence of a DSM-IV ASD diagnosis in children who were admitted for various comorbidities. Sixty-eight percent of the children identified during the time period were admitted to a medical unit, with epilepsy being the most frequently occurring reason for admission. This supports the assumption that nurses are likely to care for hospitalized patients diagnosed with ASD (Scarpinato et al., 2010). Assessment strategies to guide care were suggested along with the nurses' awareness of core features of autism and learning to work with ASD families to create a tailored-specific plan of care. The authors concluded that the treatment plan reduced patient and family anxiety, optimized treatment goals, and reduced the stress associated with hospitalization (Scarpinato et al., 2010).

There are several studies on individualized perioperative care for the ASD population. Swartz, Amos, Brindas, Girling, and Graham, (2017) studied 246 patients diagnosed with ASD, who were undergoing various diagnostic or surgical procedures between the years 2012 and 2014. The researchers implemented an individual ASD perioperative management program with caregiver input, giving specific attention to the ASD severity level as a predictive measure for preoperative sedation and perioperative cooperation from the patient. The researchers found cooperation and induction of anesthesia was 90.2% overall (222 of 246 patients), with no significant differences in cooperation between those who received sedation and those who did not (Swartz et al., 2017). Caregivers were contacted postoperatively (51% response rate), indicating a 98%

satisfaction level with the perioperative care experience, and expressing gratitude for recognizing their child's needs and for the opportunity to participate in the planning of the hospital visit (Swartz et al., 2017). Swartz et al. (2017) evaluated the usefulness of individualized plans based on the client's autism severity. "A significant proportion of children with autism spectrum disorder can be managed effectively without the need for preoperative sedation and awareness of severity level may be predictive of special requirements" (Swartz et al., 2017, p. 861-862).

In another study exploring optimal care during the perioperative process, Benich et al. (2018), interviewed parents of 12 children with ASD who had recently undergone otorhinolaryngology surgery. Recorded interviews were analyzed using qualitative software. The data produced the following categories, finding behavioral triggers such as responses to sound, pain, or anxiety, communication issues, comfort objects, identifying important people, and advice as common areas of concern (Benich et al., 2018). Data collected from the study was used to create a preoperative questionnaire for patients with ASD to improve surgical outcomes in the future.

To optimize best practices for the perioperative staff when working with the ASD population, Wittling, Palumbo Dufur, McClain, and Gettis (2018) implemented a coping plan with standardized questions that allowed staff to tailor interventions specific to each child's needs. As a result, health care stressors were reduced and the anxiety of patients and parents was decreased (Wittling et al., 2018). The authors reported that customer satisfaction scores from the National Research Corporation Picker Survey rose from 88% to 90.5% during a one-year period (Wittling et al., 2018). A staff satisfaction survey was given to all surgical services staff, measuring "comfort level, time management, and

knowledge of the interventions of the patient with ASD" (Wittling et al., 2018, p. 137). The author reported "overwhelmingly positive feedback" of 89% improvement from 2016 to 2017, stating, "…they were much more prepared caring for these patients, and having a coping plan to guide the care produced confidence in their abilities" (p. 137).

Nursing curriculum issues. Armstrong (2019) discussed new standardized reporting, where SQUIRE-EDU was created to help improve the quality and value of health professions education. The author stated the new focus needs to be on how the educational improvements impact not only the learner, faculty, and educational program, but also the patients, families, health care systems, communities, and delivery of care. "Nurse educators continually update curricula based on emerging practice guidelines, … SQUIRE-EDU will facilitate long-needed standardization in the planning and reporting of educational improvement" (Armstrong, 2019, p. 256). This is a necessity for the improvement in curriculum and nursing education in regards of understanding the ASD population.

Pachkowski (2018) discussed the issue of newly graduated nurses being ill-prepared to identify and address ethical dilemmas and lacking confidence. Nursing education programs need "to develop educational curricula that help mental health nursing students understand both ethical theories, explore their personal values and social dynamics that will inform and complicate ethical issues, and apply their knowledge in complex practice environments" (Pachkowski, 2018, p. 64). The author recognized a need for improved mental health curriculum to increase nursing competence, confidence, moral decision making, advocacy for the most vulnerable patients, and personal well-being (Pachkowski, 2018).

A review of undergraduate pediatric nursing education was completed by McCarthy and Wyatt (2014). Analyzing responses from 315 schools surveyed, the researchers reported 33% of faculty were considered undergraduate faculty and an average of 3.1% of faculty teaching pediatrics actually had a graduate specialization and/or recent clinical experience in pediatrics. When looking at the number of theory hours spent in the classroom, "more than 59% of programs reported two hours or less in pediatric genetics, environmental health, and child nutrition … more than 41% of programs reported two hours or less and 29.2% 3-4 hours in child/adolescent behavioral/mental health" (McCarthy & Wyatt, 2014, p.133). The nursing curriculum appears to focus on acute, specialty, and pediatric care, when environmental, behavioral, family, and chronic illness challenges have become daily issues in children's lives at this time (McCarthy & Wyatt, 2014). "This mismatch may compromise the ability of nursing programs to produce graduates who understand and can assist in the management of the broader health issues experienced by children and adolescents today" (McCarthy & Wyatt, 2014, p.136).

Nursing staff knowledge deficits. Dodd Inglese and Harrison Elder (2009) discussed the need for nurses to be knowledgeable about ASD and understand how children on the autism spectrum experience the world, as well as give guidance and direction in regard to treatment options and resources. The experts discussed nursing care for autistic children, the prevalence, etiology, core features, screening, diagnosis, and management of this population. "Realizing the variety of issues relevant to children and families with ASD will ensure that this population is positively taken care of" (Dodd Inglese & Harrison Elder, 2009, p. 47).

Souders et al. (2002) stated that the nurse should implement a plan of care that is individualized, using various appropriate interventions for each child diagnosed with ASD. The first step suggested is to have a 15 to 20-minute conversation with the care-giver prior to the clinical or in-patient visit, assessing for social, communication, and behavioral strengths and limitations, then prepare for behaviors, the environment, training staff, and allow adequate time during the visit for appropriate care needs (Souders et al., 2002). "Nurses need to embrace this special population and be committed to their care" (Souders et al., 2002, p. 561).

Children diagnosed with ASD represent a growing pediatric population and care for this population has been described as daunting and challenging according to Brown and Elder (2014). The authors discussed the diagnosis of ASD in children, the importance of early intervention and state simple adaptations made by nurses will help children with ASD communicate in a more effective manner. "To provide high quality nursing care to children with ASD, nurses need to understand how communication typically develops and how this differs in children with ASD, theoretical perspectives of ASD and their implications for communication, and practical applications that can improve the communication process" (Brown & Elder, 2014, para. 3). Challenging behaviors such as aggressive physical behaviors, self-harming behaviors, and loud vocalizations happen with some children with ASD when there is a breakdown in the communication process (Brown & Elder, 2014). Staff should allow time, be patient, and optimize communication with patients with ASD (Brown & Elder, 2014).

The emergency department is the typical starting point for hospital admission for the general public, yet McGonigle et al. (2013) reported that despite the rising prevalence

of diagnosed patients with ASD, there are unmet educational needs of ED staff regarding the characteristics and challenges faced by patients with ASD. The researchers recruited 110 emergency medical personnel to participate in a three-part training on ASD. The group completed a pre- and posttest survey, measuring knowledge and comfort levels when responding to acute care needs of ASD diagnosed patients. The researchers concluded that training and materials will improve the interaction between patients with ASD and staff during times of crisis (McGonigle et al., 2013).

Considering the increasing number of children with ASD, it is also time to consider the growing number of adult patients with ASD. Providers and institutions need to develop a deeper understanding of the needs of these patients when admitted to inpatient settings in order to provide the high-quality care expected. Carter et al. (2017) discussed the needs of medically hospitalized adult patients with autism, reviewing what they call a toolkit for both the providers and the patient. A team of multidisciplinary experts consisting of providers and staff from Massachusetts General Hospital (MGH) for Children, MGH, and parent advocates, created a multidisciplinary collaborative called the MGH Autism Care Collaborative. The collaborative's three goals are to educate providers and staff of the individualized needs of the patient with ASD when hospitalized, to create ASD specific resources for inpatient providers, and "to optimize patient care from admission to discharge among adults with ASD admitted to internal medicine services" (Carter et al., 2017, p.1512). The toolkit resources were piloted in various areas of the hospital and changes were decided based on feedback from all involved, where goals are continuously being re-evaluated. MGH has created this toolkit specifically for MGH, but the collaborative "hope that the concept of the toolkit generates

additional discussion and study focused on optimal case delivery for inpatient adults with ASD" (p. 1520).

The multidisciplinary team approach was also reported by Potvin et al. (2018). Key points are described in an interprofessional process program called Coaching in Context (CinC). CinC includes three components: connecting to a previous action plan, brainstorming strategies to support progress towards goals, and strategies to try. This program is family-driven, involving a variety of providers, including health professionals. The team members work together to increase everyday life activities of clients with ASD, not by remediating, but by changing the task demands and utilizing goal attainment scaling to monitor progress toward family-driven goals. The interprofessional team's collective knowledge is used to help implement a plan of care that will support the health care professional (coach), ensuring success for the family and individual with ASD (Potvin et al., 2018). Many of the coaching skills used in this process are congruent with Watson's caring theory, such as listening, empathizing, engaging, encouraging, reframing, guiding, being agreeable, compassionate, and warm and friendly.

Literature Related to Measurement Tools

Stone (1987) created a psychometrically appropriate knowledge assessment tool for ASD. Many ASD knowledge measurement tools have been created since, the majority being created solely for a particular study, and most have not been replicable for use in other studies. The Autism Knowledge Survey (AKS) was created to identify ASD knowledge deficits, focusing on lack of knowledge of symptoms, diagnosis, etiology, and treatment (Campbell, Reichle, & Von Bourgondien, 1996; Stone, 1987). Campbell et al. (1996) stated, "To assess individuals' beliefs and knowledge regarding the etiology,

diagnosis, and specific features of autism, Stone developed the Autism Survey (1987)"
(p. 622). Campbell et al. (1996) evaluated Stone's Autism Survey for reliability and
validity, finding the overall internal consistency total score using Cronbach's alpha
correlation analyses to be .66, but when re-evaluated with the exclusion of rogue items,
the survey internal consistency coefficient alpha reached .74. Swiezy et al. (2005) used
Stone's survey to measure autism knowledge, renaming it the Autism Knowledge
Survey-Revised (AKS-R). The survey now consists of 20 questions, with the removal of
the rogue questions from the original Stone version of the survey. This survey has been
utilized in several studies, such as Mogavero's (2018) study exploring the knowledge
base of criminal justice students prior to and post-graduation from the program,
identifying a need for further education. This tool might accurately measure ASD
knowledge deficits in nurse caregivers to properly educate staff about the ASD
population.

The original Caring Factor Survey was a 20-item scale designed to measure the
concept of caring as perceived by the patient, based on Watson's ten caritas processes
(Watson, 2010). DiNapoli, Nelson, Turkel, and Watson (2010) completed a quantitative
study to explore the 20-item survey structure and transformed the survey into a 10-item
concept of caring measurement tool. DiNapoli et al. (2010) found that the practice of
loving kindness was the most important factor for families and patients. The reliability of
the final 10-item CFS was .89, using Cronbach's alpha for a study of 450 nurses from
three facilities in the United States and Philippines (DiNapoli et al., 2010). DiNapoli et
al. (2010) challenged nurses to demonstrate behaviors of loving kindness to themselves
and others.

Watson's Caring Factor Survey - Care Provider Version (CFS-CPV) is used to assess employees' perception of caring in the care setting. This tool was created based on Watson's 10 caritas processes (Watson, 2010). Nelson et al. (2016) reduced the CFS-CPV from 20 to 10 items using factor analysis techniques on 670 respondents from the U.S. The Kaiser-Meyer-Olkin statistic (96), the Bartlett's test of sphericity ($p \leq 0.001$), and Cronbach's α (0.96) proved it to be psychometrically sound. This creates a more time-friendly instrument, minimizing reluctance to participate in a lengthy survey.

Literature Related to Theoretical Framework of Watson's Caring Theory

In the student nursing world of skills training and high-stress testing, the nurse educator needs to find ways to become supportive of nursing students' growth as transpersonal beings (Clark, 2016). Watson's Human Caring Theory and how it relates to transpersonal psychology and other humanities concepts was discussed by Clark (2016). The author makes suggestions on supporting nursing students in learning Watson's caring theory, understanding transpersonal states, and creating caring-healing spaces, thus giving meaning to the art and science of nursing care. By integrating Watson's Theory of Caring into nursing programs, both during and post nursing school, such as the ASD educational caring program, the quality of nurses will be higher when the science of caring is effectively utilized, creating caring-healing spaces (Clark, 2016).

The quality of nursing care can be improved by constantly and consistently reviewing caring behaviors of nurses per patient satisfaction surveys, such as Watson's CFS. Pajnkihar, Stiglic, and Vrbnjak (2017) explored relationships between the level of nursing education, the perception of Watson's carative factors by nurses and nursing assistants, and patient satisfaction (Pajnkihar et al., 2017). A descriptive cross-sectional

survey design was used to collect data. The Caring Nurse - Patient Interactions Scale -
Nurse Version (CNPI - nurse version) was used to measure caring and corresponded to
the 10 carative factors proposed by Watson's Theory of Human Caring (Pajnkihar et al.,
2017). The use of a modified Hospital Consumer Assessment of Health Plans Survey
(HCAHPS) was used to measure patient satisfaction. "Analysis of Variance (ANOVA)
was used to examine the difference in mean values for patient satisfaction with nurses'
and nursing assistants' care, carative factors, and overall caring scores between the four
health care institutes" (Pajnkihar et al., 2017, p. 6). Overall, higher mean caring scores
and overall satisfaction of care scores were reported by nurses and nursing assistants
compared to patient participants. The nurses' perception of caring was not congruent
with what the patients' perception of caring. Some study limitations included use of a
convenience sample, questionable validity of the patient survey not tested due to the
small number of questions used, and motivation to complete the CNPI due to high
numbers of questions which may have reduced participation (Pajnkihar et al., 2017). The
authors concluded that stronger emphasis was needed during nursing education and
continuing education, to support the relevance of caring theory in clinical practice.

Caring is the central focus of nursing (Chan et al., 2015). To determine the
effects of a care workshop for nurses, a pre- and posttest study was designed to measure
patient satisfaction as a critical indicator of nursing care quality. The care workshop
program consisted of formal educational sessions twice a week for six weeks, an angel-
master mentorship activity, and posts of exemplary caring behaviors and stories. A
demographic questionnaire, the Modified Nurse Caring Behaviors Inventory, and the
Hartford Hospital Satisfaction Survey were used to measure outcomes. The results

showed caring behaviors and patient satisfaction were positively correlated on the pretest ($p<0.05$) and 6-week posttest ($p<0.01$) (Chan et al., 2015). The results revealed improved patient satisfaction, when staff was educated on patient-centered care in clinical practice.

Finding ways to integrate Watson's Human Caring Theory into practice, Wei and Watson (2019) conducted a qualitative directed content analysis study. The purpose was "to describe interprofessional team members' perspectives on human caring based on the Ten Caritas Processes [and the] Caritas-Varitas Literacy of Watson's Human Caring Theory within the Unitary Caring Science" (Wei & Watson, 2019, p. 17). Twenty-seven health professionals from a children's hospital participated in a face-to-face in-depth individualized interview. The results were a compilation of statements giving examples of the healthcare professionals' perceptions of each of the Ten Caritas Processes. In conclusion, Watson's Human Caring Theory can be utilized by healthcare professionals to create a human-to-human, caring-healing environment where a caring consciousness promotes care of self, co-workers, and ultimately, patients (Wei & Watson, 2019).

Understanding the relationship of the physical structure/architecture of a hospital environment and nurses perceived care-of-self, other staff members, and the patients is a related perspective to Watson's caring theory. Utilizing Watson's 10 caritas processes and conducting a survey of hospital staff using the Caring Factor Survey - Care Provider Version (CFS-CPV), Hozak, Nelson, and Gregory (2016) evaluated the perceived relationship the design of the units appeared to have with facilitating or hindering nurses' ability to care for self, others, and satisfaction with the ability to facilitate care for patients. The results for the most favorable design for self-care supported a hallway

design of a straight shape (I), and the proximity to staff bathrooms had the strongest

relationship, more so than functional breakrooms and attractive places for staff to re-

energize (Hozak et al., 2016). The authors believed that since the impact of technology

as part of the caregiving process was not included, it might have been a study limitation.

The results support that direct care providers should be involved in architectural design

factors for the best outcomes of patient care and satisfaction.

Summary of Strengths and Limitations (Gaps) of Literature

The aim of this literature review was to explore the problems experienced by

children hospitalized with ASD and to provide better nursing education, resulting in

better patient outcomes. The autism spectrum population is increasing, one in 59

children in the United States as reported by the CDC's Autism and Developmental

Disabilities Monitoring (ADDM) Network (as cited in Baio et al., 2018).   Due to the

rising prevalence of autism (Baio et al., 2018), it is more important than ever to be

knowledgeable about comorbidities (Rudnick et al., 2019; Xu et al., 2019), understanding

challenging autistic behaviors (Benich et al., 2018), discrepancies in care of the ASD

population (Chiri & Warfield, 2012; Lokhandwala et al., 2012; Xu et al., 2019), and ways

to work with the autism population. Rudnick et al. (2019) stated training and education

are needed to understand patients with ASD who are admitted for comorbidities, noting

difficulties with communication, procedures, and new environmental stimuli. These are

all issues of hospitalization. Although caring is an integral part of being a nurse, many

nurses lack the understanding of the science of caring. By incorporating Watson's

Theory of Caring into the care of patients with ASD admitted for comorbidity diagnoses,

the nurse strives to create a positive, caring environment, and to develop a healing-

trusting relationship. Empathy is one concept the caring nurse needs to create a healing-trusting relationship. "Empathy is defined as the ability to sense the inner world of another and this also requires that the nurse be aware of his or her own inner world, creating a common emotional meeting ground" (Clark, 2016, p.4). Nurses need to be empathetic, aware of, and sensitive to the emotional state of the patients with ASD.

Nurses have the responsibility to ensure a positive pro-active approach when creating a plan of care, optimizing quality interventions to facilitate the most productive health care experience possible for each individual patient. "Nurses equipped with an understanding of the unique needs of a child with ASD can tailor the plan of care to reduce patient and family anxiety, optimize treatment goals, and reduce the stress of hospitalization" (Scarpinato et al., 2010, p. 244). When looking at the mental health and pediatric nursing curriculum in nursing schools, there is even less educational information on ASD given to nursing students. McCarthy and Wyatt (2014) looked at 315 United States undergraduate nursing schools' pediatric curriculum and found 41% reported only one to two total hours spent on child behavioral/mental health content.

The need for further education by nurses in caring for the ASD population is supported in the literature (Carter et al., 2017; Dodd Inglese & Harrison Elder, 2009; McGonigle et al., 2014; Souders et al., 2002). The literature also identifies the large number of patients with ASD that receive ED care each year (Kalb et al., 2016), experiences of families of patients with ASD in the inpatient setting, and strategies to help prevent challenging behaviors of hospitalized patients with autism. Nurses' perception of care challenges of the ASD population has been identified (Brown & Elder, 2014; Dodd Inglese & Harrison Elder, 2009; McGonigle et al., 2014; Souders et al.,

2002), as well as misunderstanding from care professionals of ASD characteristics and communication deficits (Johnson & Robinson, 2014). There are published reports of parent or caregiver dissatisfaction with care (Russell & McCloskey, 2016; Salassi-Scotter et al., 2014). Patient perceptions of nurse caring behaviors have been measured by the Centers for Medicare and Medicaid Services report, Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey.

The examination of scholarly literature included the concept of caring and Watson's caring theory (Clark, 2016; Hozak et al., 2016; Wei & Watson, 2019), as well as caring behaviors as measured by patients using patient satisfaction surveys (Pajnkihar et al., 2017). A review of several studies, implementing the science behind Jean Watson's Theory of Caring, demonstrated the importance of creating educational programs on caring for nursing staff training, with the purpose of improved patient survey outcomes (Chan et al., 2015). There were no studies in the literature utilizing Watson's Theory of Caring to guide improvements in nursing care of hospitalized children with ASD.

Through peer-reviewed literature, it has been duly noted professional care staff have not been educated on the ASD diagnosis and how to best care for this population. McGonigle et al. (2014) stated with the rising prevalence of diagnosed patients with ASD, there are unmet educational needs of ED staff on understanding the characteristics and challenges faced by patients with ASD. Parents of patients with ASD have stated dissatisfaction of care on various surveys conducted (Benich et al., 2018; Chiri & Warfield, 2012; Kopecky et al., 2013; Rudnick et al., 2019; Russell & McCloskey, 2016; Salassi-Scotter et al., 2014). In several studies, Watson's caring theory has been found to

be a positive influence in supporting the training programs of nursing staff on the science

of caring, showing improved patient satisfaction of caring by nurses, post education

(Pajnkihar et al., 2017). An ASD educational caring program, based on Watson's Theory

of Caring, may provide nurses the opportunity to understand nursing as a caring science,

significantly improving the caring outcome for patients with ASD in the inpatient setting.

      Therefore, the research question for this study was, what is the effect of education

on caring for persons with ASD using Watson's caring theory on nursing students'

knowledge and perceived ability to care for clients with ASD?

CHAPTER III

Methodology

Introduction

Few studies have researched nurses' knowledge of ASD and how to improve care for this population. The purpose of this MSN thesis was to educate nursing students to improve care outcomes and create a positive, more personal, care environment for clients with ASD. The goal was for future nurses to perceive themselves as fully prepared to care for this population.

The research question was:

What is the effect of education on caring for persons with ASD using Watson's caring theory on nursing students' knowledge and perceived ability to care for clients with ASD?

Study Design

This was a descriptive pretest/posttest quantitative study. Student volunteers were asked to fill out surveys, using an online link, before and after an online educational program that was part of a nursing assessment course.

Setting and Sample

The study was conducted using a convenience sample of 28 Family Nurse Practitioner (FNP) students, enrolled in a summer semester nursing course. The setting was a liberal arts university in Southeastern United States.

Intervention

The independent variable was a researcher created ASD educational program guided by Watson's Human Caring Theory. The program has validity from experts and

current literature support (DiNapoli et al., 2010). This program consisted of a Blackboard

module with a 40-minute video lesson that included:

- a short video on how a child with ASD typically experiences the world

- a list of ASD signs and symptoms

- a sensory considerations check-off sheet

- an autism preliminary identifier check list

- the M-CHAT-R/F (Robins, Fein, & Barton, 2009)

- a power point presentation guided by Human Caring Theory (Watson, 2019),

  relating the Ten Caritas Processes to caring for a person with ASD in a clinical

  setting (see Appendix B).

The ASD caring education program was validated and agreed upon by the nursing

faculty. The instructor gave the researcher permission to teach the ASD education program

to nursing students via a Blackboard module, as well as administer the pre- and posttest

surveys to student volunteers, using a separate online link.

Measurement

The outcome *student knowledge* was measured using the Autism Knowledge

Survey-Revised (AKS-R) by Swiezy et al. (2005). The AKS-R is a 20-item measure,

using a six-point Likert-scale format that assesses a participant's degree of agreement or

disagreement for each statement pertaining to ASD knowledge. The AKS-R measures

knowledge of ASD etiology, interventions, diagnosis, and outcomes, a representation of

all ASD-relevant constructs. The results of multiple comparison tests support the validity

of the AKS-R survey: Tukey's honest significance test ($p < .05$) (Campbell et al., 1996;

Stone, 1987; Swiezy et al., 2005). It has been found to be a stable measure, exhibiting

good test-retest reliability, and has been used as an indicator of training success over time (Campbell et al., 1996; Stone, 1987; Swiezy et al., 2005). The reliability of this tool shows reasonable internal consistency (Cronbach's a =.74), and stability (Campbell et al., 1996; Stone, 1987; Swiezy et al., 2005).

The outcome *student perceived ability to care* was measured using the Caring Factor Survey-Care Provider Version, Short Version (CFS-CPV) by Nelson et al. (2016). The CFS-CPV tool consists of 10 questions covering 10 dimensions of caring as proposed by Watson's theory. The CFS-CPV tool is a 10-item measure, using a seven-point Likert-scale format, that assesses a participant's degree of agreement or disagreement for each statement pertaining to her/his perception of care she/he provides to the patients in her/his care. The validity for this tool reveals high internal consistency and stable reliability: Bartlett's test of sphericity ($p \leq .001$), and Cronbach's a (.96) (Nelson et al., 2016). The researcher obtained written permission from the authors to use both the instruments.

Methodology

After IRB approval, the researcher scheduled a date for the course instruction to be downloaded onto Blackboard, in collaboration with the course faculty. The researcher explained the ASD study to the students in an introductory consent letter at the beginning of the module. The education was required, but completion of the surveys was voluntary. Using the link provided, students volunteered to participate by completing the survey, or elected not to participate.

The ASD caring education program was taught by the researcher using a video with PowerPoint. It took approximately 40 minutes. After the formal education, students

were encouraged to ask questions to the professor and complete a writing assignment relating the information learned to their clinical experience, followed by the link to the post-survey.

Students were given two weeks to complete the module and the pre and post surveys. All data collected was completely anonymous and handled confidentially. All data was analyzed in a password protected computer in a locked office. The researcher compiled the results using descriptive statistics. A t-test, using aggregate mean scores, analyzed pre- and post-differences.

Protection of Human Subjects

Participation in this study was voluntary. There were minimal anticipated risks in this study. Participants had the right to withdraw from the research study at any time without penalty. Participants also had the right to refuse to answer any question(s) for any reason without penalty. Original data was stored by the University's IRB for three years and then destroyed.

CHAPTER IV

Results

The purpose of this study was to educate nursing students to improve care outcomes and create a positive, more personal, care environment for clients with ASD. The goal was for future nurses and nurse practitioners to perceive themselves as fully prepared to care for this population.

The research question was:

What is the effect of education on caring for persons with ASD using Watson's caring theory on nursing students' knowledge and perceived ability to care for clients with ASD?

Study Process

The study was conducted using a convenience sample of 28 Family Nurse Practitioner (FNP) students enrolled in a summer semester nursing assessment course. The introductory letter, the ASD Learning Module, and the voluntary pre- and posttest surveys were uploaded into the course by the faculty-of-record. Students received a reminder email after seven days. After two weeks only 7% of the students completed the surveys (N=2).

Major Findings

The outcome *student perceived ability to care* was measured using the Caring Factor Survey-Care Provider Version, Short Version (CFS-CPV) by Nelson et al. (2016). The mean of the pretest was 6.3 out of 7 possible points. The mean of the posttest was 6.6 out of 7 possible points, resulting in an improvement of 0.3 test points, with a standard deviation of 0.55 test points. This is a 4.8% improvement. T-tests were not

done to determine differences between pre- and post-surveys due to the limited response rate. The results are not generalizable due to the response rate.

The outcome *student knowledge* was measured using the Autism Knowledge Survey-Revised (AKS-R) by Swiezy et al. (2005). The mean of the pretest was 4.5 out of 6 possible points. The mean of the posttest was 5.23 out of 6 possible points, resulting in an improvement of 0.73 test points, with a standard deviation of 0.52 test points. This is a 16% improvement. T-tests were not done to determine differences between pre- and post-surveys due to the limited response rate. The results are not generalizable due to the response rate.

CHAPTER V

Discussion

To responsibly create an appropriate nursing care plan for a person with autism spectrum disorder (ASD), the nurse needs to be educated about ASD and understand how each individual client with ASD communicates. The problem being addressed is how the ASD population is perceived when hospitalized for comorbidities, and how nurses have not been well educated to improve clinical performance when caring for the ASD patient.

Implication of Findings

The purpose of this MSN thesis was to educate nursing students to improve care outcomes and create a positive, more personal, care environment for clients with ASD. The goal was for nurses to perceive themselves as fully prepared to care for this population.

The results of this study, while inconclusive due to response rate, demonstrate that FNP students' knowledge and perceived ability to care for patients with ASD might be improved with best practice education. There needs to be more studies on the effects of education on the quality of ASD care. This study was unique in that it was guided by Watson's Theory of Human Caring (Watson, 2008). There is need for education of both nursing students and nursing staff to acquire greater understanding and knowledge about the needs of this population.

Application to Theoretical/Conceptual Framework

When integrating Watson's theory into the nurse's daily practice, the nurse will be better prepared to accept the client with ASD for who they are in the moment and consider their subjective frame of reference when assessing individual forms of

communication comprehension, verbal skill level, and eagerness to learn and share with the staff (Watson, 2008). Caring science guides the in understanding and learning from the individual and family, co-creating the journey of healing, sharing of information, coaching, and committing to authenticity, being present, and speaking in a calm, quiet, respectful manner (Watson, 2008).

Limitations

The research on access to pediatric mental health curriculum and/or continuing education and nurse knowledge of the needs of a patient with ASD is lacking. While this study had a small response rate, it showed a slight improvement of ASD knowledge and perceived ability to care for clients with ASD. This group of subjects may not be representative of all nursing students. This researcher did not ask if these students had prior knowledge of ASD and/or Watson's caring theory or whether the subjects may have any degree of experience in either, whether personally or professionally.

Future Recommendations

This study was a starting point for future studies where the education is much more in-depth, with a larger population of nurses and for a much longer period. There needs to be more in-depth studies completed pertaining to education on ASD, combined with education on Watson's 10 caritas processes, and investigation of documented improvements when caring for patients with an ASD diagnosis. There may be more data collected on whether education is positively impacting the nurses' performance, using the same two combined surveys, the CFS-CPV and AKS-R, using the technique described in this study. There also could be an added element to a larger in-depth study where the ASD population and/or their families complete a survey, such as the Hospital Consumer

Assessment of Healthcare Providers and Systems (HCAHPS) at discharge showing whether the education has helped the nurse to better care for the client with ASD or not.

Implications for Nursing

Part of truly understanding a patient diagnosed with ASD, is for the nurse to understand that each individual with ASD is unique. The nurse must be present in the moment and realize what worked for one client may not be appropriate for another. Nurses who commit to authenticity and are present in the moment with the patients, offering a warm caring environment, will be open to understanding the patient's needs, alleviating undo negative responses from the patient with ASD.

Nurse educators at all levels need to create appropriate mental health curriculum which guides nursing students to a better understanding of patient and family needs, giving opportunities to grow as caring partners in relation to the patients being cared for and to implement education models that support those diagnosed with autism spectrum disorder. Continuing education conferences, webinars, and competency programs are also needed for continued support and continuity throughout the community. Clinical practice guidelines should be developed collaboratively between nursing faculty and mental health nurses, in an effort to use caring science principles to improve ASD care.

Conclusion

Due to the rising prevalence of autism (Baio et al., 2018), it is more important than ever to be knowledgeable about comorbidities (Rudnick et al., 2019; Xu et al., 2019), understanding challenging autistic behaviors (Benich et al., 2018), discrepancies in care of the ASD population (Chiri & Warfield, 2012; Lokhandwala et al., 2012; Xu et al., 2019), and ways nurses are able to positively work with the autism population. This

study has focused on the need for education of both nursing students and nursing staff to acquire greater understanding and knowledge when caring for the needs of the ASD population. Through education and understanding, the nurse becomes open and able to empathize with the autism spectrum population, becoming present in the moment, creating a caritas caring environment.

Utilizing Jean Watson's caring theory was both appropriate and needed with the ASD population. Guided by the 10 caritas processes, nurses are better able to be present with the patients, give empathy as appropriate, and use appropriate verbal and nonverbal communication techniques to create a safe environment for the. It is recommended that modules related to working with special populations, such as those with communication disorders, be incorporated into nursing curriculum and continuing education courses in order to better serve these populations. Nursing practice guided by caring science principles help nurses to build authentic relationships with patients and families resulting in better health outcomes.

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Appendix A

Educational Materials for the ASD Educational Program

Sensory Considerations

Individuals with autism often process sensory information differently than others in their environment. These sensory processing difficulties can lead to distractibility, anxiety, pain, and frustration. Lending predictability and a sense of control to these sensory issues can also be of benefit. This form will provide information useful to adapting the environment to better accommodate your child's sensory difficulties.

Sample sensory issues are noted below. Please check which items you have observed to be of concern to your child. If a certain item is missing, please include it at the end of that particular section.

Auditory (Sounds)
- Loud, unpredictable sounds:
- Fire alarms
- School bell
- Fireworks

Ordinary/daily sounds:
- Toilet
- Vacuum
- Blow dryer
- Baby crying
- Singing or talking

Subtle sounds:
- Fluorescent light bulbs
- Fans
- Vent noises
- Distant plane/train
- White noise

Doesn't respond to:
- Sound of own name
- Most sounds
- Other _____

Responds to dislikes with:
- Hands over ears
- Yelling, screaming or crying
- Running away
- Other _____

Gustatory (Taste)
- Tastes/eats non-food items

Preference for:
- Carbohydrates
- Salty
- Sour

- Sweet
- Crunchy
- Pureed
- Certain temperature ____
- Other _____

Responds to dislikes with:
- Gagging
- Vomiting
- Yelling
- Other _____

Olfactory (Smells)
- Responds to subtle smells
- Investigates items by smelling
- Bothered by foul smells
- Bothered by everyday scents:
- Food cooking
- Perfume
- Soaps
- Hands/fingers
- Other _____

Proprioceptive (Pressure in Joints)
- Seeks activities involving:
- Pushing/pulling
- Lifting
- Tight spaces
- Jumping
- Other _____
- Grinds teeth
- Difficulty sitting up in a chair
- Other _____

Responds with:
- Falling hard
- Hugging
- Breaking toys
- Slamming doors
- Stomping
- Hitting
- Playing rough
- Other _____

Tactile (Touch)
- Preference for textures _____
- Irritated by textures _____
- Dislikes bare feet
- Insists on having bare feet
- Dislikes light touch
- Avoids "messy" play
- Seeks "messy" play
- Irritated by having hair touched
- Dislikes having face washed
- Dislikes being tickled
- Strong tolerance to pain
- Insensitive to touch
- Other _____

Vestibular (Movement)
- Negative reaction to movement
- Enjoys movement:
- Swinging
- Rocking
- Spinning
- Exhibits poor balance
- Enjoys being upside down
- Fearful of not being upright
- Enjoys climbing
- Other _____

Visual (Sight)
- Focus on parts of objects
- Bothered by visual distracters:
- Fans
- Lights
- Mirrors
- Other _____
- Looks at items up close
- Looks at items at angles
- Difficulty focusing/tracking items
- Other _____

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1. Modified Checklist for Autism in Toddlers, Revised, with Follow-Up (M-CHAT-R/F) TM

   By: Diana L. Robins, Ph.D. Deborah Fein, Ph.D. Marianne Barton, Ph.D.

https://mchatscreen.com/wp-content/uploads/2015/09/M-CHAT-R_F_Rev_Aug2018.pdf

2. Autism Spectrum Disorder Screening Tool. www.handsinautism.org

Autism Spectrum Disorder
Screening
Endorsement of any of these areas should warrant referral for evaluation
Children under 2 years of age

- Inactive
- Limp or floppy
- Very little crying
- Limited social response
- Limited social smile or eye contact
- Limited engagement/awareness of others
- Irritable
- Difficult to comfort
- Comforted only by motion
- Limp/stiff when held
- Unusual sensitivity to environmental input (example: touch, smell, vision, or sound)
- Difficulty communicating
- Limited understanding and/or use of specific gestures

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Autism Spectrum Disorder
Screening
Endorsement of any of these areas should warrant referral for evaluation
Children over two years of age

- Inconsistency in use of functional communication
- Difficulty expressing wants or needs
- High levels of distress over minor changes
- Limited conversation skills
- Significant time spent seeking sensory input
- Slamming into objects/people
- Wedging self in tight places
- Spinning in circles
- Decreased sensitivity to pain
- Any regression or loss of language skills
- Interacting with others only to meet a particular need (example: ask mom to fix a toy rather than to play)
- Focused and repetitive interests dominate play
- Little creative and imaginative play
- Intense difficulty in understanding social interaction and safety rules
- Greater understanding of visual information
- Self-injurious behavior
- Repetitive whole body movements
- Repetitive movement of objects/toys

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3. ASD Signs and Symptoms from cdc.gov/ncbddd/autism/signs.html

ASD signs and symptoms

Signs and symptoms of autism spectrum disorder (ASD) include:

- displays a lack of interest in others and has difficulty relating to them (absence of joint attention—the shared focus of two people on one object)
- avoids eye contact
- fails to point at objects to convey interest or fails to look at objects when others point at them
- prefers solitude
- does not empathize
- has difficulty conveying personal needs and desires
- exhibits unusual responses to sights, smells, tastes, textures, or sounds
- does not engage in pretend play
- prefers not to be touched or to be touched only on his or her own terms
- appears unaware when others address him or her and/or is hyperattentive to other sounds
- fails to initiate play/interactions
- repeats/echoes words or phrases said, or repeats words or phrases in place of normal language (scripting)
- displays restricted, repetitive actions
- has difficulty navigating routine changes
- exhibits loss of skills previously attained (regression).

Source: Centers for Disease Control and Prevention. Autism spectrum disorder (ASD): Signs and symptoms. 2015. cdc.gov/ncbddd/autism/signs.html

4. Core Concepts of Jean Watson's Theory of Human Caring/Caring Science

   Handout from

https://www.watsoncaringscience.org/files/PDF/watsons-theory-of-human-caring-core-concepts-and-evolution-to-caritas-processes-handout.pdf

Appendix B

Understanding Autism Spectrum Disorder PowerPoint Presentation

UNDERSTANDING AUTISM SPECTRUM DISORDER: ASSESSMENT AND CARE OF THIS POPULATION
By: Jean Timmons, RN

THE GOAL OF THIS PROGRAM:
- To create a program educating future nurse practitioners on the autism spectrum population and how to care for this population in the hospital setting, utilizing the basics of Jean Watson's caring theory as a foundation.
- To create an outcome of improved nursing perception of administering quality care to ASD individuals.

AUTISM SPECTRUM DISORDER OR ASD IS DEFINED AS…
"A complex developmental condition that involves persistent challenges in social interaction, speech and nonverbal communication, and restricted/repetitive behaviors" (American Psychiatric Association website, 2019, "What Is Autism Spectrum Disorder?" para. 1).

What is ASD?
- Primarily a social communication disorder characterized by differences in information processing.
- Encompasses Asperger's disorder, childhood disintegrative disorder, and pervasive disorder otherwise not specified
- Main features include:
- Persistent deficits in social communication and social interaction across multiple contexts
- Restricted, repetitive patterns of behavior

American Psychiatric Association. Diagnostic and statistical manual of mental disorders, fifth edition (DSM–5). Washington, DC: American Psychiatric Association, 2013.

Prevalence of ASD
- In 2014 the CDC determined that approximately 1 in 59 children are diagnosed with an autism spectrum disorder (ASD), but in 2000, it was 1 in 150 children.
- Boys are four times more likely to be diagnosed with autism than girls.
- Most children are still being diagnosed after age 4, though autism can be reliably diagnosed as early as age 2.
- 31% of children with ASD have an intellectual disability (intelligence quotient [IQ] <70), 25% are in the borderline range (IQ 71–85), and 44% have IQ scores in the average to above average range (i.e., IQ >85).
- Autism affects all ethnic and socioeconomic groups.
- Minority groups tend to be diagnosed later and less often.
- Early intervention affords the best opportunity to support healthy development and deliver benefits across the lifespan.
- There is no medical detection for autism.
https://www.autismspeaks.org/autism-facts-and-figures

Diagnosing autism spectrum disorder (ASD)
Diagnosing ASD can be difficult, since there is no medical test, such as a blood test, to diagnose the disorder. Clinicians look at the child's behavior and development to make a diagnosis.
Diagnosing an ASD takes two steps:

1. Developmental Screening - a short test to tell if children are learning basic skills when they should, or if they might have delays.
2. Comprehensive Diagnostic Evaluation – a thorough review that may include looking at the child's behavior and development and interviewing the parents. It may also include a hearing and vision screening, genetic testing, neurological testing, and other medical testing.

Specialists who can do this type of evaluation include:
Developmental Pediatricians
Child Neurologists
Child Psychologists or Psychiatrists
https://www.cdc.gov/ncbddd/autism/screening.html

Developmental Screening:
Developmental screening is a short test to tell if children are learning basic skills when they should, or if they might have delays. During developmental screening the doctor, or NP, might ask the parent some questions or talk and play with the child during an exam to see how she learns, speaks, behaves, and moves. A delay in any of these areas could be a sign of a problem.
All children should be screened for developmental delays and disabilities during regular well-child doctor visits at:
9 months, 18 months, 24 or 30 months

Additional screening might be needed if a child is at high risk for developmental problems due to preterm birth, low birth weight or other reasons.
In addition, all children should be **screened specifically for ASD** during regular well-child doctor visits at:
18 months and 24 months

Additional screening might be needed if a child is at high risk for ASD or if behaviors sometimes associated with ASD are present. It is important for doctors to screen all children for developmental delays, but especially to monitor those who are at a higher risk for developmental problems due to preterm birth, low birth weight, or having a brother or sister with an ASD. If the doctor sees any signs of a problem, a comprehensive diagnostic evaluation is needed.

https://www.cdc.gov/ncbddd/autism/screening.html

Causes

- Research indicates that genetics are involved in the vast majority of cases.
- Children born to older parents are at a higher risk for having autism.
- Parents who have a child with ASD have a 2-18% chance of having a second child who is also affected.
- Studies have shown that among identical twins, if one child has autism, the other will be affected about 36-95% of the time. In non-identical twins, if one child has autism, then the other is affected about 31% of the time.
- Over the last two decades, extensive research has explored whether there is any link between childhood vaccinations and autism. The results of this research are clear: vaccines do not cause autism.

https://www.autismspeaks.org/autism-facts-and-figures

Intervention and Supports

- Early intervention can improve learning, communication, social skills, and brain development.
- Applied behavior analysis (ABA) and therapies based on its principles are the most researched and commonly used behavioral interventions for autism.
- Many children affected by autism also benefit from other interventions such as speech and occupational therapy.
- Developmental regression, or loss of skills, typically occurs between ages 1 and 3, affecting approximately 1 in 5 children who will go on to be diagnosed with autism.

https://www.autismspeaks.org/autism-facts-and-figures

"Medical Definition of *applied behavior analysis*
: psychological therapy that uses techniques (such as operant conditioning) developed from the objective analysis of observable behavior to make changes to socially significant behaviors that are abnormal or harmful" (https://www.merriam-webster.com/medical/applied%20behavior%20analysis).

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Associated Challenges

- An estimated 1:3 people with autism are nonverbal.
- Almost 50% of children with autism wander or bolt from safety.
- Nearly 2/3 of children with autism between the ages of 6 and 15 have been bullied.
- Approximately 28% of 8-year-olds with ASD have self-injurious behaviors. Head banging, arm biting and skin scratching are among the most common.
- Drowning remains a leading cause of death for children with autism and accounts for approximately 90% of deaths associated with wandering or bolting by those age 14 and younger.

https://www.autismspeaks.org/autism-facts-and-figures

Associated Medical & Mental Health Conditions

- Autism can affect the whole body.
- Attention Deficit Hyperactivity Disorder (ADHD) affects an estimated 30 to 61% of children with autism.
- Greater than 50% of children with autism have one or more chronic sleep problems.
- Anxiety disorders affect an estimated 11 to 40% of children and teens on the autism spectrum.
- Depression affects an estimated 7% of children and 26% of adults with autism.
- Children with autism are nearly eight times more likely to suffer from one or more chronic gastrointestinal disorders than are other children, such as constipation, food intolerances, GERD, dysphagia, and esophagitis.

https://www.autismspeaks.org/autism-facts-and-figures

Associated Medical & Mental Health Conditions Continued

- As many as 1/3 of people with autism have epilepsy (seizure disorder).
- Studies suggest that schizophrenia affects between 4 and 35% of adults with autism. By contrast, schizophrenia affects an estimated 1.1% of the general population.
- Autism-associated health problems extend across the life span – from young children to senior citizens.
- 32% of 2 to 5 year-olds with autism are overweight and 16% are obese.
- By contrast, 23% of 2 to 5 year-olds in the general population are overweight
  and only 10% are medically obese.
- Risperidone and aripiprazole (Abilify), mood stabilizers, are the only FDA-approved medications for autism-associated agitation and irritability.

https://www.autismspeaks.org/autism-facts-and-figures

FACTS ABOUT AUTISM SPECTRUM DISORDER

- Xu et al. (2019) reported that nearly 30% of children diagnosed with ASD across the country, did not receive behavioral or medication treatment.
- Chiri and Warfield (2012) found, "Families of children with autism spectrum disorder were in fact significantly more at risk for having unmet specialty and therapy care needs" (p. 1081).
- According to Scarpinato et al. (2010), "With a high prevalence rate of comorbidities among this population, such as gastrointestinal complaints and seizures, nurses are likely to care for hospitalized patients with ASD" (p. 244).

Education is needed on how to give care to this

population in order to promote a positive

experience for the client with ASD. A greater

understanding of how the ASD population

experiences the world may be relevant to

optimizing quality nursing interventions.

ASD signs and symptoms

Signs and symptoms of autism spectrum disorder (ASD) include:

- displays a lack of interest in others and has difficulty relating to them (absence of joint attention—the shared focus of two people on one object)
- avoids eye contact
- fails to point at objects to convey interest or fails to look at objects when others point at them
- prefers solitude
- does not empathize
- has difficulty conveying personal needs and desires
- exhibits unusual responses to sights, smells, tastes, textures, or sounds
- does not engage in pretend play
- prefers not to be touched or to be touched only on his or her own terms
- appears unaware when others address him or her and/or is hyperattentive to other sounds
- fails to initiate play/interactions
- repeats/echoes words or phrases said, or repeats words or phrases in place of normal language (scripting)
- displays restricted, repetitive actions
- has difficulty navigating routine changes
- exhibits loss of skills previously attained (regression).

Source: Centers for Disease Control and Prevention. Autism spectrum disorder (ASD): Signs and symptoms. 2015. cdc.gov/ncbddd/autism/signs.html

These children usually show attachment to parents, but in a different manner than most children. Not all children with ASD display poor eye contact.

When looking at screening Tools Barton, Dumont-Mathieu, & Fein (2012) discuss the importance of sensitivity and specificity. Sensitivity is the ability of the screening test to identify a high proportion of the children suspected of having the disease. Sensitivity should be relatively high to insure that children with the disorder will not be missed. A second important criterion is specificity, or the extent to which the measure correctly classifies those individuals who do not have the disorder. Specificity should also be high, and it is equally difficult to assess, since it too requires follow-up of a population sample.

1168   J Autism Dev Disord (2012) 42:1165–1174

Table 1 Level 1 screens for autism spectrum disorders in young children

Measure	Age (months)	Format	Time required	Sample	Sensitivity	Specificity
CHAT	18–24+	Parent questionnaire; Professional observation	5 min; Unclear	Population	0.18–0.38	0.98–1
M-CHAT	16–30	Parent questionnaire	5–10 min	Mixed population and clinical	0.87*	0.99*
CHAT 23	18–24***	Parent questionnaire; Professional observation	5–10 min; 5 min	Clinical	.84	.85
					.74	.91
ESAT	14–15	Parent questionnaire; Clinician observation	5–10 min; Unclear	Population	nr	nr
PDDST-II	12–24	Parent questionnaire	10–15 min	Clinical	.92	.91
FYI	12	Parent questionnaire	15+ min	Clinical	nr	nr
DBC-ES	20–51	Parent questionnaire	5–10 min	Clinical	.83	.48
ITC	9–24	Parent questionnaire	5–10 min	Mixed population and clinical	.93	nr

* Estimated
** With follow-up interview
*** Mental age

Barton, M. L., Dumont-Mathieu, T., & Fein, D. (2012). Screening young children for autism spectrum disorders in primary practice. Journal of Autism and Developmental Disorders, 42(6), 1165–1174. https://doi.org/10.1007/s10803-011-1343-5

https://mchatscreen.com/wp-content/uploads/2015/09/M-CHAT-R_F_Rev_Aug2018.pdf

Hand out ASD screening forms.

10 EARLY SIGNS OF AUTISM:
UPDATED, MAY 14, 2014; 6:37 MIN.

Please click on the link to watch the video, then please return to
the power point when the video is completed.

Using screening forms, identify ASD signs and symptoms.

Sensory Considerations

Individuals with autism often process sensory information differently than others in their environment. These sensory processing difficulties can lead to distractibility, anxiety, pain, and frustration. Lending predictability and a sense of control to these sensory issues can also be of benefit. This form will provide information useful to adapting the environment to better accommodate the patient's sensory difficulties. Sample sensory issues are noted below. Please ask the parent or caretaker to check which items have been observed to be of concern regarding the child. If a certain item is missing, please ask the caretaker to include it at the end of that particular section.

https://handsinautism.iupui.edu/pdf/SensoryConsiderations.pdf

Communication Tips:
- Speak in short sentences with clear, precise language
- Use concrete, literal words.
- Supplement with visual strategies – Individuals with ASD are generally stronger in visual processing.
- Avoid abstract questions.
- Set up a plan, using terms "First, then…"
- Ask patients and caregivers for specific information.
- Give exact instructions.
- Do not ask "Can you … , instead state Please do…"
- Only offer choices when it is TIME to make a choice.
- Be specific when you praise.
- Listen actively.

SUPPORTING INDIVIDUALS WITH ASD

- Avoid figures of speech, analogies, sarcasm, and exaggerations.
- Be aware that body language and facial expressions may not be understood.
- Give time to prepare for transitions and use visual supports.
- Consider using visual schedules, timers, and other cues both to let the individual know a transition is coming as well as to let him/her know what to expect after the transition.
- Always assess for patient understanding, such as repeating back what will happen next.
- Realize behavior is a form of communication, and is often an attempt to communicate needs and desires rather than a personal attack on others.
- Even verbal individuals can struggle to use their words in times of stress or anxiety.

www.handsinautism.org

Ways the healthcare provider can create a more positive office/procedural visit experience:

- Conduct a Pre-visit interview, obtaining sensory issues, communication preferences, behavioral concerns – triggers, warning signs of escalation or distress, cognitive functioning, successful approaches to soothing.
- Schedule for first procedure or appointment time of the day to limit disruptions in routine and meal times.
- Have appropriate household/toy/communication device items brought that support the patient's comfort and lessen anxiety.
- Have a step by step visual narrative to describe the sequence of a planned event or visit.
- If in a hospital setting – all team members should introduce themselves clearly and explain their role to the patient, explain the steps of procedures or tasks, and anticipate that the encounter may take longer than usual.

Examples of visual schedules to help children with ASD understand what to expect when seeing a doctor or nurse practitioner.

HANDSinAutism.iupui.edu
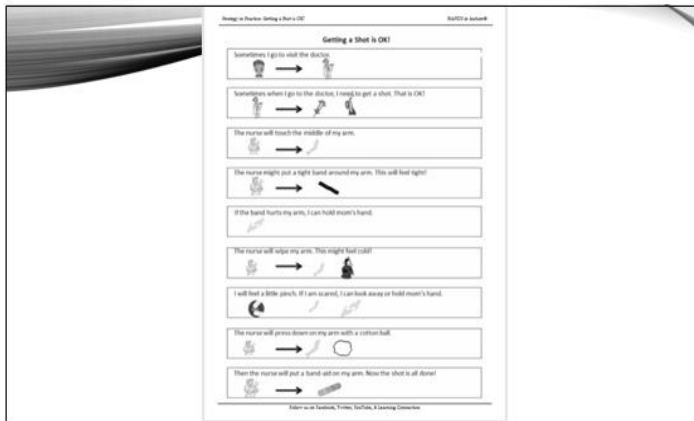
HOW DO NURSE PRACTITIONERS CARE FOR THE PATIENTS WITH ASD?

Through Jean Watson's Theory of Human Caring, the nurse practitioner is able to foster an open, honest dialogue with the ASD client and the family, in a supportive and caring relationship.

Watson's Theory of Human Caring fundamentally supports the caring needs required by the ASD population from the nurse practitioner.

By being present in the moment, the nurse practitioner is able to genuinely engage with the ASD client by staying within the client's frame of reference.

Authentic presence and caritas consciousness are used to connect spirit-to-spirit between nurse practitioner and patient (Watson, 2008).

"The one caring and the one being cared for are interconnected; the caring-healing process is connected with the other human(s) and the higher energy of the universe" (Watson, 2019).

This co-created caring relationship, promotes knowledge, growth, empowerment, and healing (Watson, 2019).

"One of her [Watson's] greatest recognitions was that when nurses treat patients as individuals and provide assistance with gratification of needs, and the patient feels recognized, appreciated, and loved, the patient will have more energy to move up the hierarchy toward self-actualization" (Clark, 2016, p. 3).

10 CARITAS PROCESSES®

1. Sustaining humanistic-altruistic values by practice of loving-kindness, compassion and equanimity with self/others.
2. Being authentically present, enabling faith/hope/belief system; honoring subjective inner, life-world of self/others.
3. Being sensitive to self and others by cultivating own spiritual practices; beyond ego-self to transpersonal presence.
4. Developing and sustaining loving, trusting-caring relationships.
5. Allowing for expression of positive and negative feelings – authentically listening to another person's story.

https://www.watsoncaringscience.org/jean-bio/caring-science-theory/10-caritas-processes/

10 CARITAS PROCESSES® CONTINUED

6. Creatively problem-solving-'solution-seeking' through caring process; full use of self and artistry of caring-healing practices via use of all ways of knowing/being/doing/becoming.
7. Engaging in transpersonal teaching and learning within context of caring relationship; staying within other's frame of reference-shift toward coaching model for expanded health/wellness.
8. Creating a healing environment at all levels; subtle environment for energetic authentic caring presence.
9. Reverentially assisting with basic needs as sacred acts, touching mind-body-spirit of spirit of other; sustaining human dignity.
10. Opening to spiritual, mystery, unknowns-allowing for miracles.

https://www.watsoncaringscience.org/jean-bio/caring-science-theory/10-caritas-processes/

USING THE SCIENCE OF HUMAN CARING, MORE MINDFUL NURSING INTERVENTIONS TO SUPPORT THE CARE NEEDS OF THE ASD CLIENT AND FAMILY ARE:

Nursing Intervention #1

For the nurse and staff to accept the client for who they are and where their frame of reference is pertaining to forms of communication comprehension, verbal skill level, and eagerness to learn and share with the staff (Watson, 2019).

- Caritas Processes #1: Models self-care and caring for others.
- **Validates uniqueness of self and others.**
- Acknowledges acts of kindness.
- Recognizes vulnerabilities in self and others.
- **Treats self and others with loving kindness.**
- Listens respectively with genuine concern to others.
- **Accepts self and others as they are.**
- Demonstrates respect for self and others.
- **Listens to others.**
- **Honors human dignity of self and others.**

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Nursing Intervention #2

For the nurse and staff to be open to understanding and learning from the individual and family, joining in the journey to help in the healing, sharing of information, coaching, and sharing options to meet the client in the client's present moment (Watson, 2019).

- Caritas Processes #7 - **Actively listens with one's whole being to others telling their life experiences.**
- **Speaks calmly, quietly, and respectively to others, giving them full attention at the moment.**
- **Seeks first to learn from others, understand their worldview; then shares, coaches, and provides information, tools, and options to meet others' needs (works from others' frame of reference).**
- **Accepts others as they are and where they are with their understanding, knowledge, readiness to learn.!!!**
- Helps others understand how they are thinking about their illness/health.
- **Helps others formulate and give voice to questions and concerns to ask health care professionals.**

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Nursing Intervention #3

For the nurse and staff to fully immerse in the moment, committing to authenticity, being present, and speaking in a calm, quiet, respectful manner (Watson, 2019).

- Caritas Processes #2: Promotes intentional human connection with others.
- Incorporates other's values, beliefs, and what is meaningful and important to them into care plan.
- Utilizes appropriate eye contact and touch. (Very important to understand with patient with ASD.)
- Helps others to believe in themselves.
- Views person as human being and not object. !!!

Nursing Intervention #4

For the nurse and staff to create a warm, caring environment for the client and family, creating a stronger connection through active engagement and reflection (Watson, 2019).

- Caritas #8 - Creates space for human connections to naturally occur.
- Participates in caring-healing consciousness.
- Creates a healing environment attending to:
  Nurse as environment; other as unique person; light; art; water; noise; cleanliness; privacy;
  nutrition; beauty; safety; hand washing; comfort measures; others' times frames.
- Pays attention to others when they are talking.
- Anticipates others' needs

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Discussion

Using the "Core Concepts of Jean Watson's Theory of Human Caring/Caring Science" Packet, please write a short 200 to 400 word paragraph stating how, as the nurse practitioner, you will fully immerse yourself in the moment, committing to authenticity, being present, and speaking in a calm, quiet, respectful manner with the patient with ASD and the family members.

Using the Sensory Considerations sheet, find ways to adapt the physical environment to help alleviate any sensory processing difficulties, sharing options to meet the client in the client's present moment.

https://handsinou.rfgmiupui.edu/pdf/SensoryConsiderations.pdf

https://www.watsoncaringscience.org/files/PDF/watsons-theory-of-human-caring-core-concepts-and-evolution-to-caritas-processes-handout.pdf

- If time permits.
- Creates space for human connections to naturally occur.
- Participates in caring-healing consciousness.
- Creates a healing environment attending to:
  Nurse as environment; other as unique person; light; art; water; noise; cleanliness; privacy;
  nutrition; beauty; safety; hand washing; comfort measures; others' times frames.
- Pays attention to others when they are talking.
- Anticipates others' needs

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SUMMARY

Nurses at all practice levels need an understanding of ASD, how to identify possible ASD symptoms, and how a person or parent obtains a formal diagnosis of ASD. Nurse practitioners are required to be knowledgeable in all phases of the diagnosis, as well as how to advocate for the ASD client and family, utilizing Jean Watson's Theory of Human Caring.

Thank you for participating in this educational program on autism spectrum disorder, and I hope, as nurse practitioners, you have an opportunity to care for your patients with a loving authentic presence, where you create a stronger connection through active engagement and reflection.

Thank you,
Jean Timmons, RN

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