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DOI: <https://doi.org/10.31979/etd.9ck7-c9dr>

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ABSTRACT

BARRIERS TO PROVIDING QUALITY CARE FOR PEDIATRIC PATIENTS WITH AUTISM SPECTRUM DISORDER AS IDENTIFIED BY BACCALUAREATE PREPARED REGISTERED NURSES: A BASIS TO ENHANCE PROFESSIONAL PRACTICE

The increased prevalence of autism spectrum disorder (ASD) foretells that this sector of the population will be accessing health care services in greater numbers; thus, it behooves healthcare providers to prepare for their impending needs. This qualitative study describes the experiences of baccalaureate prepared registered nurses caring for children and adolescents with ASD in order to identify challenges that hinder providing comprehensive and individualized care. A purposive sample of 10 baccalaureate degreed registered nurses (RNs) who have worked or work in the pediatric unit was used to gather rich descriptive experiences. The qualitative data analyses were based on an interpretive phenomenological approach. The participants identified two significant barriers to the quality care of the individuals with ASD in the pediatric setting. The first barrier, “Knowledge Deficit About ASD,” embodies lack of general knowledge about the ASD population. The second barrier, “Not Knowing the ASD Patient,” entails the importance of having the knowledge needed to individualize the care of individuals with ASD. The unresolved barriers that nurses face when caring for patients with ASD, along with the absence of guidelines, limited educational content, and insufficient in-service training underscores the need to establish evidence-based practice guidelines for individuals with ASD. Additionally, the resounding findings of this study, “Knowledge Deficit About ASD,” and “Not Knowing the ASD Patient,” indicate a need to change nursing education to

efficiently train undergraduates, graduates, and faculty to adequately care for patients with ASD.

Ugo Ndubaku
May 2018

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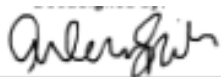
A project
submitted in partial
fulfillment of the requirements for the degree of
Doctor of Nursing Practice
California State University, Northern Consortium
Doctor of Nursing Practice
May 2018

APPROVED

For the California State University, Northern Consortium
Doctor of Nursing Practice:

We, the undersigned, certify that the project of the following student meets the required standards of scholarship, format, and style of the university and the student's graduate degree program for the awarding of the Doctor of Nursing Practice Degree.

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ACKNOWLEDGMENTS

With the most profound gratitude and appreciation, the author would like to thank the gracious pediatric nurses of UCLA, Santa Monica, for taking the time to share their experiences, and the unit director and the nursing staff for their welcoming presence. The author would like to acknowledge the study chair, Dr. Arlene Spilker, for her invaluable insight and encouragement, and Dr. Bonnie Rainbauger for her generous input on the study design and interpretation. The author would also like to extend her thanks to the academic advisor, Dr. Nisha Nair; study committee members, Judith Foyabo, MSN, NP-C and Amy Nguyen, BCBA, Autism specialist; and Dr. Susan McNeish for their enthusiasm and support of this project.

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CHAPTER 1: INTRODUCTION

Autism spectrum disorder (ASD) is a neuro-developmental disorder of the brain that is associated with, but not limited, to significant impairments in social interaction, learning, language and speech utilization, and repetitive patterns of behaviors (American Psychiatric Association, 2013). Currenti (2010) suggested that the etiology of autism is comprised of multifactorial events relating to environment and genetics. The number of children diagnosed with ASD has increased tremendously over the last decade and currently represents a significant and growing group of the United States' pediatric population (Brown & Elder, 2014). According to the most recent data from the Centers for Disease Control and Prevention (CDC, 2014), autism currently affects 1 in 68 children, with the highest prevalence occurring in boys in the ratio of 1:42.

Although science has gained ground in identifying the causes of autism, several studies have shown that the care and management of people with ASD remains challenging for doctors, nurse practitioners (NPs), registered nurses (RNs), and other healthcare providers (Cheak-Zamora & Teti, 2015; Chiri & Warfield, 2012; Johnson, Burkett, Reinhold, & Bultas, 2015; Magana, Parish, Timberlake, & Swaine, 2012).

Problem Statement

What are the facilitators and barriers (as described by baccalaureate degreed registered nurses) to providing adequate care for the children and adolescents with ASD in the pediatric medical surgical unit?

Purpose

The aim of this study was to describe the experiences of a sample of baccalaureate degreed RNs caring for children and adolescents with ASD in the pediatric unit in order to guide the delivery of more comprehensive and individualized care. Perhaps this information will help to establish evidence-based-practice guidelines related to the care of patients with ASD.

Background and Significance

The prevalence of ASD has increased significantly since it was first identified in the 1940s (Bultas, 2012). Currently, ASD is a health crisis in the public health system because it affects 1 in every 68 children in the United States—a 78% increase in the prevalence within the last 6 years (Brown & Elder, 2014). The imposed threat from ASD cannot be overestimated, as its prevalence rate surpasses juvenile diabetes, cancer, and HIV/AIDS, combined (Johnson et al., 2015).

Some have argued that the upward trend in ASD is due to an increase in public awareness and services (Chiri & Warfield, 2012; Johnson et al., 2015; Magana et al., 2012). In addition, several studies have demonstrated that the marked increase in the prevalence of autism is reflected in a concomitant increase in demand for health care and health care related services (Bultas, 2012; Chiri & Warfield, 2012; Liptak, Stuart, & Auinger, 2006). Irrespective of the current debate about the rise in prevalence of ASD, the significance of this problem is that the increasing rate of ASD (or perhaps, more accurate diagnosing of ASD) foretells that this rising population will potentially contribute significantly to the general population accessing the health care system. Thus, it is imperative for the healthcare provider to be adequately prepared to care for this vulnerable population. Furthermore, the economic burden of ASD necessitates the need to act

now. Leigh and Du (2015) estimated that the cost of medical and nonmedical care of the ASD population will hover around \$460.8 billion by the year 2025. Furthermore, several studies have asserted that ASD is associated with extensive comorbidities not limited to intellectual disabilities, sleep disorders, inflammatory bowel disease, developmental disabilities, epilepsy, anxiety, depression, schizophrenia, and other psychiatric disorders (Russell & McCloskey, 2015; Simonoff et al., 2013; Vohra, Madhavan, Sambamoorthi, & St Peter, 2014) Given the numerous comorbidities associated with ASD, and the enormous burden on the U.S. economy, the significance of this problem must not be ignored.

Theoretical Framework

The present investigation was guided by the Neuman Systems Model (NSM) to meet the requirements of the Doctorate of Nursing Practice curriculum, recognizing that interpretive phenomenology, the selected approach, does not utilize theoretical or conceptual frameworks. The NSM was selected specifically because (a) it is predominantly wellness-oriented and holistic, (b) it views the ASD person as a layered multidimensional whole, (c) it defines the ASD person as an open system who is interactive with the environment, (d) it calls for health care providers to explore the impact of stressors on the system when rendering care, and (e) finally, the model possesses the potential to unify other health professions in order to provide coordinated care for this vulnerable population. The healthcare provider should expand his or her perspective, taking into account all variables that will affect a patient's response to stressors. As a proponent of novelty, the NSM calls for nursing practice, including the nursing research, education, and administration, to encourage a more inclusive and comprehensive care for all

individuals. As a result, this model will efficiently guide the delivering of coordinated and individualized care to the population of interest.

In Betty Neuman's own words, "development of the holistic systemic perspective of the Neuman Systems Model was facilitated by my own basic philosophy of *helping each other live*" (Neuman & Fawcett, 2011, p. 333). The ultimate goal is to help patients with ASD live quality lives.

CHAPTER 2: LITERATURE REVIEW

The investigator examined the accumulated knowledge on current health care management and practices for children and adolescents with ASD as a basis to identify barriers to care, perceptions of providers, and caregivers' needs. The investigator conducted the search using three databases: (a) Cumulative Index of Nursing & Allied Health Literature, (b) Cochrane Library, and (c) Elton B. Stephens Company. Keywords used in the search, singly or in combination, included *autism spectrum disorders, perceptions of pediatric registered nurses and healthcare providers, autism, barriers to accessing care, children, and adolescent.*

Studies were selected using pre-specified inclusion and exclusion criteria. Studies were included if they met three of the following criteria in a practical screen: (a) written in English within the last 12 years, (b) published in a peer-reviewed journal, (c) provided data on autism or ASD on ages 3 to 19 years, and (d) addressed or identified the needs of individuals with ASD. Studies were excluded if they (a) were letters or editorials, (b) lacked full access for review, (c) were printed in a language other than English, or (d) were published before 2005. A total of 138 articles were reviewed, but only seven were selected for the in-depth review and synthesis of the literature after application of the inclusion and exclusion criteria.

Will, Barnfather, and Lesley (2013) conducted a survey inquiring how NPs in the primary care setting perceived the care they rendered to patients 18 years and younger with ASD. A convenience sample of 126 NPs (n = 106 primary care, n = 15 pediatrics, n = 2 adults, n = other, n = 117 females) was recruited from a national NP Conference. It is significant to note that the number of total

participants the study reported ($n = 126$) was two subjects fewer than what was conveyed in the study demographics ($n = 124$). However, the participants were mostly female ($n = 117$), with an average age of 48 years ($SD 7.2$), 9 years in practice ($SD 7.2$), and master's degrees in science as their highest level of education. The researchers received permission to use a survey previously created by physicians, but modified the demographic questions to include NP education and practice. The study questions aimed to obtain data regarding three main components: self-perceived competency, perceived barriers to care, and ASD education.

The study by Will et al. (2013) used descriptive statistics to analyze the demographic data, a paired *t*-test to compare the NPs autism competency scores against other neurodevelopmental disorders and chronic illnesses, and McNemar's test to determine the barriers to providing care. The findings revealed that 79% of the NPs perceived fragmented care as a major obstacle to effectively caring for patients with ASD. The Likert scale (1 = never, 7 = always) score of 6.42 ($SD 1.02$) demonstrated that the NPs were highly interested in obtaining more education about how to adequately care for the patient with ASD; however, their reported self-perceived competence score of 4.75 ($SD 1.18$) and the Cronbach's alpha score of 0.79 indicated that the NPs rated their competency levels significantly lower when providing care to these patients.

The strengths of the study included a power analysis to determine the appropriate sample size before the sample selection, and that this was the first known study to focus primarily on the NP's competency. The findings of this study were limited to NPs in family practice; therefore, they may not be generalizable to NPs in specialty practice. Additionally, the study examined only the perceptions of the NPs and not the perspectives of the family members.

Nevertheless, the results of this study underscore the critical need for further ASD training for healthcare providers (Will et al., 2013).

Similarly, Warfield, Crossman, Delahaye, Weerd, and Kuhlthau (2015) conducted a case study to explore the perspectives of physicians on providing primary health care to adults with ASD, including their recommendations on increasing the number of providers and the quality of clinical training. The study used a purposive sampling method to recruit doctors (n = 9) and an RN (n = 1) from Autism Treatment Network (ATN), an online registry of physicians who actively provide primary medical care to adults with ASD.

Data were collected through structured 45-minute phone interviews focusing on the providers' perspectives on providing care to ASD patients. The study used a structured interview guide to ask the same specific questions regarding the provider's experience, care coordination, clinical environment, and recommendation about how to attract potential physicians to care for individuals with ASD (Warfield et al., 2015).

The data were analyzed using a framework analysis approach with three stages. In the first stage (data management), one member read the transcripts several times to identify themes using the participant's word choices. The second stage is known as the descriptive accounts. Here, the second researcher independently reviewed the transcripts several times and refined the previous categories (Warfield et al., 2015). To guarantee rigor, the two investigators independently coded the data. Finally, in the explanatory account, the researchers further examined the data for associations or patterns. The researchers separated the data into three coded subcategories: (a) training and education levels, (b) systems level, and (c) practice or provision level (Warfield et al., 2015).

The findings of Warfield et al. (2015) demonstrated that all the providers faced challenges and obstacles at all levels when aiming to provide adequate care to the persons with ASD. Challenges identified at the system levels included a shortage of medical and nonmedical services to support youths with ASD, a lack of providers willing to work with this population, and financial disincentives for providers to include ASD patients in their patient population. In the provision level, the study reported that the office environments were not appropriately designed to address the sensory needs of the ASD patient, the family dynamics and involvement, and communication barriers. Challenges in the training/education levels included a lack of formal training regarding ASD in medical school and a lack of clinical knowledge and experience working with individuals with ASD. The findings of this study are mirrored by the findings of several other studies (Chiri & Warfield, 2012; Magana et al., 2012; Muskat et al., 2015; Nicholas et al., 2016). However, there is a limitation attributed to the fact that this study did not provide demographic information on the participants, such as ethnicity, age, and gender.

Nicholas et al. (2016) conducted a focus group to the perspectives of emergency department (ED) healthcare providers from previous studies; their goal was to identify clinical priorities and endorsements to guide efficient emergency healthcare services for individuals with ASD. A random sampling method was used to convene a focus group made up of ED care providers (n = 37), caregivers of children with ASD (n = 16), and ED administrators (n = 7), totaling 60 participants. Participants were recruited from the Hospital for Sick Children in Toronto and the Stollery Children's Hospital in Edmonton. The researchers aimed to answer the following two research questions:

1. “*What are the identified needs in the care of children with ASD in the ED department?*” (Nicholas et al., 2016, p. S206).
2. “*What is required to optimize care for children with ASD in the ED?*” (Nicholas et al., 2016, p. S206).

Data were collected through recorded sessions with the participants and exhaustive field notes taken by research assistants. Emails and verbal invitations to participate in the study were distributed to two Autism Treatment Network (ATN) sites. The willing participants were provided with informed consent and furnished with results from an earlier phase of the study. The previous findings reported challenges that healthcare providers face when facilitating care for children with ASD in the ED department. The focus group identified new ways to prioritize and improve the care of the ASD patients in the ED. The data analysis utilized an interpretive descriptive method and qualitative analytic software (N-Vivo 10). The transcripts were transcribed line by line, coded, and subjected to theme analysis. They reported achieving data saturation with six focus group sessions (Nicholas et al., 2016).

Nicholas et al.’s (2016) findings demonstrated that the ED healthcare delivery services to children with ASD were inadequate to address their needs. The study identified clinical priorities to modify and standardize in order to meet the unique needs of children with ASD. The focus group recommended (a) education and practice development, (b) partnering with parents and internal champions who are aware of the challenging needs of the ASD patients, (c) staff training on the care of the acutely agitated patient, and (d) reducing communicating barriers with the ASD patient. The study was strengthened by the survey that clearly identified and answered its research questions. However, the

study did not convey the training of the research assistants who collected the data for analysis.

Muskat et al. (2015) conducted a qualitative study to understand the hospital experiences of children and families with ASD. A purposeful sampling strategy was used to recruit 42 participants (n = 19 mothers, n = 3 fathers, n = 14 health care providers, n = 6 youth with ASD). Recruitment strategies included word of mouth, advertisements at day care centers, and care provider's websites. Eligible families included those with an ASD child(ren) aged 6-18 years, who had been hospitalized within the last 3 months in one of the two major Canadian pediatric hospitals. The study did not reveal the setting of the interviews.

Data were collected through semi-structured audio-recorded interviews with open-ended questions to generate rich descriptions of participants' hospitalization experiences. The interviews were transcribed verbatim. The study utilized a methodological interpretive descriptive framework to generate themes to give meaning to the participants' perspectives. To maintain rigor and trustworthiness, the investigators gave the participants opportunities to ensure that their analyses were reflective of the experiences they shared. The Social Responsive Scale (SRS), a sensitive and reliable tool for ASD, was used to measure the extent of autistic social impairment (Muskat et al., 2015).

Findings from the qualitative analyses indicated that ASD patients and their families faced various challenges in the hospital setting, including, but not limited to, communication challenges, intensified sensory feelings, environmental factors, and difficulties navigating the hospital organizations. The results revealed that prompting the ASD patient before procedures would be helpful. Perhaps the most striking or resounding finding was the significance of listening to the parents so that optimal care could be provided to children with ASD (Muskat et al., 2015).

The strength of this qualitative study included a good sample size to enable maximum variability in the hospital experiences. On the other hand, the patient population in this study may not have been a good representation of patient experiences in other settings, given that this study used two specialized Canadian hospitals.

In 2012, Johnson, Lashley, Stonek, and Bonjour conducted a pilot study to evaluate the effectiveness of staff education on managing children with challenging behaviors in a hospital setting. This pilot study was designed to answer the question, “Do nursing staff and students who receive the training have increased knowledge and decreased fear of working with children with developmental disabilities, as measured on a 10-point Likert scale?” (Johnson et al., 2012, p. 744). The education program was created by a group of staff members with both personal and professional experience handling children with ASD. The team members included advanced practice nurses (APNs), physicians, RNs, child life specialists, security personnel, and other healthcare extenders. This staff education pilot program was designed for new nursing staff education and new employee orientation at Midwestern Pediatric Hospital.

The researchers collected data over an 18-month period as the hospital hired new employees and nurses. The education was administered in two parts: a 1-hour online training and a 1-hour instructor-led class. The online lessons delivered background knowledge about ASD, including communication and play strategies used for persons with ASD. The curriculum for the instructor-led course was based on Bandura’s self-efficacy theoretical framework. It aimed to increase the staff’s knowledge on autism, while decreasing the fear of caring for children with ASD. The investigators used pre and post questionnaires to measure the reduction in fear and knowledge gained (Johnson et al., 2012).

A total of 604 (n = 346 [RNs], n = 253 [student nurses and nursing assistants], n = 5 [other]) Midwestern Pediatric Hospital employees participated in the online portion of the program, whereas, the instructor-led course was limited to only 42 participants. Johnson et al. (2012) analyzed the online portion utilizing a 5-point Likert scale, while the class-led training was evaluated with a 10-point Likert scale.

The findings revealed that the average rating of the staff knowledge increased from 5.5 to 8.7, while average fear scores decreased from 3.2 to 2.7. This pilot program demonstrated improved nursing staff knowledge, and decreased fear associated with caring for children with developmental disabilities, after the administration of a training program. Johnson et al. (2012) claimed that this was the first study to measure the effectiveness of training nurses in handling the challenging behaviors of children with ASD. The results of this pilot study are valuable and encouraging, but have the following limitations: the lack of participant demographic information and a lack of explanation for the discrepancy in the number of participants. The study reported that 346 RNs participated in the online version, whereas only 42 RNs participated in the instructor-led course.

In 2012, Chiri and Warfield investigated the unmet health care needs of children with ASD and the barriers they faced when accessing necessary care. This survey study used the data from the 2005-2006 National Survey of Children with Special Health Care Needs (NS-CSHCN) to compare the unmet healthcare needs of children with ASD to two other groups: (a) children limited to special health care needs not caused by ASD, emotional, developmental, and behavioral diagnoses (CSHCN); and (b) children who had emotional, developmental, and or behavioral needs (EDB). Chiri and Warfield (2012) claimed that the survey was “sponsored by the Maternal and Child Health Bureau (MCHB)” (p. 1083).

Participation requests were sent to the caregivers and guardians of the 363,183 children identified by screening through the NS-CSHCN database for children with ASD, CSHCN, and EDB.

Initially, Chiri and Warfield (2012) derived a sample size of 40,723 participants. However, after restricting the participants' ages to between 3 and 17 years, Chiri and Warfield (2012) settled for a final sample size of 38,373 (ASD = 2,088: 21% male and 79% female; EDB = 9,534: 62.4% male and 37.6% female; and CSHCN = 26,751: 56.8% male and 43.2% female). The study did not offer a justification for reporting that the females dominated the males in the ASD category (79%). Races of the ASD participants reported were 12% Hispanic, 67.8% White, 14% Black, 2.9% Multiracial, and 3.1% Other. Reported CSHCN races were 11.2% Hispanic, 66.5% White, 15.8% Black, 3.5% Multiracial, and 3.0% Other. Races of CSHCN with other EDB were 12.4% Hispanic, 62.8% White, 18.1% Black, 4.1% Multiracial, and 2.5% Other.

The study contained 10 survey questions to evaluate four core health care services, namely (a) routine preventive care, (b) specialist care, (c) physical therapy, and (d) occupational and/or speech therapy services sought by parents of children with ASD, EDB, and SHCN. Weighted logistic regression was used to analyze the differences in the parent reports of unmet needs amongst the three groups (Chiri & Warfield, 2012).

Chiri and Warfield (2012) reported that in comparison to the parents of children with EDB and CSHCN, parents and caregivers of children with ASD perceived that most healthcare facilities were ill-equipped to manage the sensory and environmental challenges experienced by their children during hospital and clinic visits. As a result, the children with ASD succumbed to fragmented care. Furthermore, the results revealed that parents of children with ASD struggled

more than the other groups, to find providers who were capable of adequately caring for their children; thus, they were “significantly more at risk for having unmet specialty and therapy care needs” (Chiri & Warfield, 2012, p. 1088).

The results of this study were similar to the findings of several other studies (Cheak-Zamora & Teti, 2015; Nicholas et al., 2016; Will et al., 2013). This study was limited by the fact that reports that came from only the parents, without the inclusion of the providers’ perspectives. Additionally, the authors failed to clearly state the setting of the survey and include parents’ levels of education, which threatened the reliability of the data they provided. However, the data from this study came from a large sample size (Chiri & Warfield, 2012).

Likewise, the population-based survey study by Magana et al. (2012) used the data from 2005-2006 NS-CSHCN to examine the racial and ethnic disparities in the quality of care of children with ASD and other developmental disabilities. Magana et al. (2012) proposed three research questions: “Are there racial and ethnic disparities in quality of care?”, “Do children with ASD have worse quality of care outcomes when compared to children with other developmental disabilities?”, and “Do children with autism experience an increase in racial disparity when compared to children without developmental disabilities?” (p. 287-289). Magana et al. (2012) used a 5-question screening instrument to identify children with special needs. The study randomly sampled the identified children with ASD for a total study sample of 5,109 (White, n = 3,762; Black, n = 682; Latino n = 665). An in-depth telephone survey was conducted with a well-informed parent or guardian to gain insight into the child’s healthcare needs, quality of care, and condition.

The researchers conducted bivariate and multivariate analyses of cross-sectional data from NS-CSHCN, comparing the health care services received by

Black, Latino, and White children with ASD to determine any racial or cultural disparities. The six binary measures of health care services were (a) child does not have personal doctor or nurse, (b) doctor does not spend enough time with child, (c) doctor does not listen carefully, (d) provider is not sensitive to family values, (e) doctor does not make child's parents feel like partners, and (f) doctor does not provide enough information. The bivariate result demonstrated that Black and Latino families reported more often than did White families that the providers did not include them in decision making and did not spend enough time with them. Also, these parents often felt that their opinions were not only devalued, but unheeded (Magana et al., 2012).

The multivariate result indicated significant racial disparities in the quality of services. Latino and Black families reported that doctors were not culturally competent and often discharged them with insufficient information. This study demonstrated that race exacerbated the barriers faced by children with ASD and clearly stated and answered its research questions. However, it failed to include the ages of the participants and account for unmeasured variables that could have affected access to care, such as immigration status (Magana et al., 2012).

Summary of Gaps in the Literature

This review of the available literature showed unsettling disparities in the unmet healthcare needs of children with autism; albeit significant gains have been made in the research of ASD (Chiri & Warfield, 2012; Magana et al., 2012; Muskat et al., 2015; Nicholas et al., 2016; Warfield et al., 2015; Will et al., 2013). Financial restraints, health literacy, sensory challenges, limited support system for caregivers, and lack of competent providers are just a few barriers that individuals with ASD face (Chiri & Warfield, 2012; Johnson et al., 2012; Leigh & Du, 2015;

Magana et al., 2012; Muskat et al., 2015; Weitlauf, Vehorn, Taylor, & Warren, 2014; Will et al., 2013).

In reviewing the literature, several gaps were noted in the perspectives of healthcare providers caring for persons with ASD, suggesting the need for future investigations. Although several studies have explored the perspectives of MDs, NPs, and RNs from different settings about the care of patients with ASD, there is a scarcity of evidence describing the perspectives of baccalaureate degreed pediatric RNs on the obstacles to quality care of ASD children and adolescents. Additionally, literature has a dearth of information regarding evidence-based practice guidelines for the care of children and young people with ASD in the pediatric setting. Thus, this DNP research is a novel addition to the current literature as it seeks to describe the challenges experienced by pediatric nurses and enhance the care for the individuals with ASD.

To achieve the purpose of the study and bridge the gap in literature, the study will address the following questions:

1. What are the barriers/limitations faced by baccalaureate degreed registered nurses caring for children and adolescent patients with ASD?
2. What are the perspectives of baccalaureate degreed registered nurses regarding the adequacy of the educational content on ASD in their baccalaureate program?

CHAPTER 3: METHODOLOGY

Upon obtaining IRB permission from the University of California Los Angeles (UCLA), and Fresno State University, the investigator posted flyers in the lunchrooms of the Santa Monica pediatric units requesting participation by RNs. Additionally, the unit director emailed the study flyer to the nurses, and announced the opportunity to participate in the study during morning huddles. The flyer included the title of the study, the purpose, the method of data collection (including that the interview would be video recorded on Zoom, a web based conference system), the length of the interview, the option to decline participation at any time, an incentive of a \$20 Starbucks card for participation, and contact information for the researchers. The flyer also stated that the nurses would be asked demographic questions (age range, ethnicity/race, years of experience, and level of education) (see Table 1).

Research Design

A qualitative design based on Interpretative Phenomenological Analysis (IPA) was used for this research. Research based on IPAs examines the meaning behind individual experiences with detailed analysis of the perspectives, followed by the presentation of heuristic themes, combined with the investigator's personal interpretation—a process described as “an expression of double hermeneutics in practice” (Smith & Pietkiewicz, 2012, p. 1). Hence, IPA reinforced the purpose of this study by using phenomenology and hermeneutics to paint a meaningful picture of the participants' perspectives.

Table 1

Study Demographics Questions

-
- What is your ethnicity/race? (White, African American, Hispanic/Latino, Asian, and Other).
1. Asian, and Other).
 2. What is your gender? (Male or Female).
- What is your highest level of education? (Diploma, AA, BSN, MSN, DNP/PhD).
3. DNP/PhD).
- How many years have you worked as an RN in the pediatric unit? (<1, 1-3, 5-10, >10).
-

Setting

A comfortable location with Internet access at a time designated by the participant.

Population and Sample

A purposive sampling strategy was used, which included 10 baccalaureate prepared RNs who have worked or work in the pediatric medical surgical unit at the University of California, Los Angeles (UCLA) Santa Monica Medical Center. All participants met the following criteria: (a) be an active RN, (b) have been an RN for at least 1 year, (c) have cared for a child or adolescent with ASD in the pediatric medical surgical setting, and (d) have a BSN as the highest level of education.

The study recruitment started on September 5, 2017 and ended on October 2, 2017. A purposive sampling method was used to recruit pediatric RNs who worked at UCLA Santa Monica. The first 10 participants who expressed interest in the study were given study information, including the study questions and consent

form. At their convenient time and location, the participants arranged for interviews individually. Further detail regarding the demographic characteristics of the participants is illustrated in Table 2.

Investigative Techniques

Before the first interview, the researcher read a variety of IPA studies, including books regarding how to conduct studies using a phenomenological approach, and practiced mock interviews with colleagues and other pediatric nurses who were not part of the study sample. Such preparation bolstered this researcher's active listening and interview skills and deepened her appreciation of what the IPA entails. During the interview, the investigator did not need to "warm up" or "build rapport" to gain the trust of the participants, as the participants were once co-workers of the investigator. However, the investigator used prior experience from working with individuals with ASD and insights gained from preparatory materials to make occasional input to ensure that the key points were addressed adequately.

Instrumentation

No standardized instrument was used in this study other than the seven structured and open-ended research questions used to guide the interviews.

Table 2

Demographic characteristics of the participants (N = 7)

Characteristics	Results
Sex (%)	
Male	14.3
Female	85.7
Age (%)	
18-25	14.3
26-32	42.9
33-40	14.3
>41	28.5
Ethnicity	
Asian/Filipino	14.3
Black/African American	28.5
Caucasian/White	42.9
Hispanic	14.3
Profession (%)	
Pediatric registered nurse	100.0
Highest level of education (%)	
BSN	100.0
Number of years worked as a pediatric nurse (%)	
1-2	28.6
3-5	14.3
5-7	0.0
8-10	28.5
>11	2.85

Data Collection

Data were collected during an in-depth, semi-structured, 45-minute, video-recorded Zoom interviews, in a quiet and comfortable setting designated by each participant. The semi-structured nature of the research did not only allow the investigator and the participants to engage in an active dialogue in real time, but allowed the researcher to investigate the phenomenon in more detail with further questions. The investigator utilized open-ended questions to facilitate discussion and provoke insightful contributions (see Table 3). Participants were provided with samples of the open-ended questions, including the notification that the questions might be phrased in more than one way to enhance the clarification of the answers given. All participants consented to the study before the interview. The consent form explained that the recordings would be destroyed after the accuracy of the transcription had been verified and that voluntary withdrawal could happen at any time without any consequences. Although no special procedures were involved in this research, all participants were offered breaks during the interview process. The participants were interviewed from September 28, 2017 to October 22, 2017 and follow-up interviews were conducted between two to three months after the initial interviews to confirm the interpretation of the participants' experiences. It is important to note that two participants changed their appointment times three times and subsequently dropped out due to the inability to commit despite the investigator's effort to accommodate them. Another participant later withdrew her willingness to participate and did not have to state why. Total participation was $N = 7$. The investigator collected the data independently, but contracted a professional qualitative research specialist to help transcribe the data. All the interviews were recorded on Zoom and transcribed verbatim.

Table 3

Study Open Ended Questions

1. Tell me about a child or adolescent with ASD you cared for. From your perspective, what were the most important aspects of that care? What do you think were the most important elements of care from the parent's perspectives?
 2. Please share what resources you needed to provide adequate care for a child or adolescent with ASD?
 3. What do nurses need to know to adequately care for children or adolescents with ASD? Share with me examples of something you needed to know.
 4. Please tell me your discharge experiences of children or adolescents with ASD. From your perspective, what resources did you have or not have to discharge adequately?
 5. Please share the educational content you received in school or via continuing education about the care of a child or adolescent with ASD. What educational contents did you lack to adequately care for an autistic child or adolescent?
 6. Tell me the ways a template that guides you to obtain the needed/pertinent information you once lacked would help during the care of an autistic child or adolescent.
 7. Is there anything else you would like to add to the discussion?
-

Data Analysis

Interpretive phenomenology was used to examine the rich experiences of the participants. The investigator reviewed transcripts, watched the video recordings, and listened to the audio recordings several times to support data immersion and gain an intimate understanding of the participants' perspectives. Notes were made from the reflections of the transcripts and interview experiences. These themes were analyzed for meaning and clustered according to conceptual similarities. The clustered themes were substantiated with quotes from the nurses. This process was applied to each interview to guarantee the compilation of salient and important themes. Afterwards, statements from the transcripts to support the themes were collated in a table. Consensual validation of the findings was made by sharing the compiled themes and statements with two independent experts in qualitative research to track the development of the themes and subthemes, including commenting on their validity. Initially, there were partial agreements on the themes. However, the team resolved this via active dialogue, and reviewing of transcripts and quotes, to come to a full agreement and confirmation of the results. Descriptive statistics were used to analyze the demographic characteristics of the participants (see Table 4).

Ethical Considerations

An IRB protocol was submitted to UCLA and California State University, Fresno to grant ethical approval. After the relevant committees gave the approval to proceed, study information and consent forms were provided to the prospective participants. Furthermore, the participants were assured that the shared experiences would be turned into themes and the study data would be locked away in a safe place, where only the investigator had access. In honor of that promise, the nurses were identified as Nurses A – G. Additionally, the data were destroyed

after the accuracy of the transcription had been verified. The only foreseeable risk to the study participants was emotional stress from the Zoom video recording. To handle this, participants were offered breaks during the video recording and also reminded of the option to withdraw at any time without consequence.

Furthermore, they were given the UCLA Office of the Human Research Protective Program telephone number (1-310-206-2040) in order to discuss any concerns pertaining to the study, including the Zoom video recording. There was no special procedure noted in this research. It is noteworthy to mention that participation was voluntary and did not impact participants' employment positively or negatively.

Table 4

Steps of IPA Data Analysis

1. Immersing oneself in the original data – reading and re-reading each participant's verbatim transcript.
 2. Initial detail and comprehensive notes on data.
 3. Developing and identifying emerging themes.
 4. Searching for connections across emergent themes.
 5. Moving to the next case and repeating steps 1-4.
 6. Looking for patterns across transcripts to formulate structure of the phenomenon.
 7. Taking the findings back to the participants to ensure credibility of the data.
-

(Smith et al., 2012)

Trustworthiness

The data collection and a majority of the data analysis were done by the first author; however, the credibility of the study was ensured through an ongoing discussion of the emerging themes and quotes amongst the other authors, two qualitative experts. This constant comparative analysis enabled the investigators to identify themes and supportive quotes to convey a meaningful understanding of the participants' experiences. Additionally, the researcher followed up with the participants after the interviews to share preliminary interpretations, and afford them opportunities to confirm that the investigators' analyses aligned with their experiences, thus allowing for the triangulation of data to further strengthen the rigor of the study. The participants confirmed that interpretations accurately reflected their shared experiences.

CHAPTER 4: RESULTS

After an exhaustive data analysis, the themes “Knowledge Deficit About ASD” and “Not Knowing the ASD Patient” emerged as significant barriers to the nursing care of ASD patients. Theme I had five important subthemes and Theme II had two (see Figure 1). A detailed report of significant statements to support the interpreted themes can be viewed in Appendix A, which includes all of the relevant quotes for each theme and subtheme.

Knowledge Deficit about ASD – Theme 1

The issue of knowledge deficit resonated amongst all the participants. It echoed at different points, silently, sincerely, and sometimes painfully: *“It’s like we briefly breeze through cancer. We breeze through anorexics. We breeze through, um, kids that—like have psych disorders, like suicide. But we never—we never had anything on autism in the unit. Ever.”* It was a heartfelt acknowledgment of the lack of education. Unanimously, the nurses acknowledged that “knowledge deficits” exist in the nursing care and management of the ASD patient; however, further interpretation of the transcripts revealed many contributing factors to the lack of knowledge about ASD. Those factors emerged as subthemes I – V: Lack of understanding of ASD classifications and presentations, limited educational content about ASD in the baccalaureate program, lack of in-service or continuing education on ASD, lack of knowledge of language development and communication in patients with ASD, and lack of guidelines for the nursing care and management of a pediatric patient with ASD.

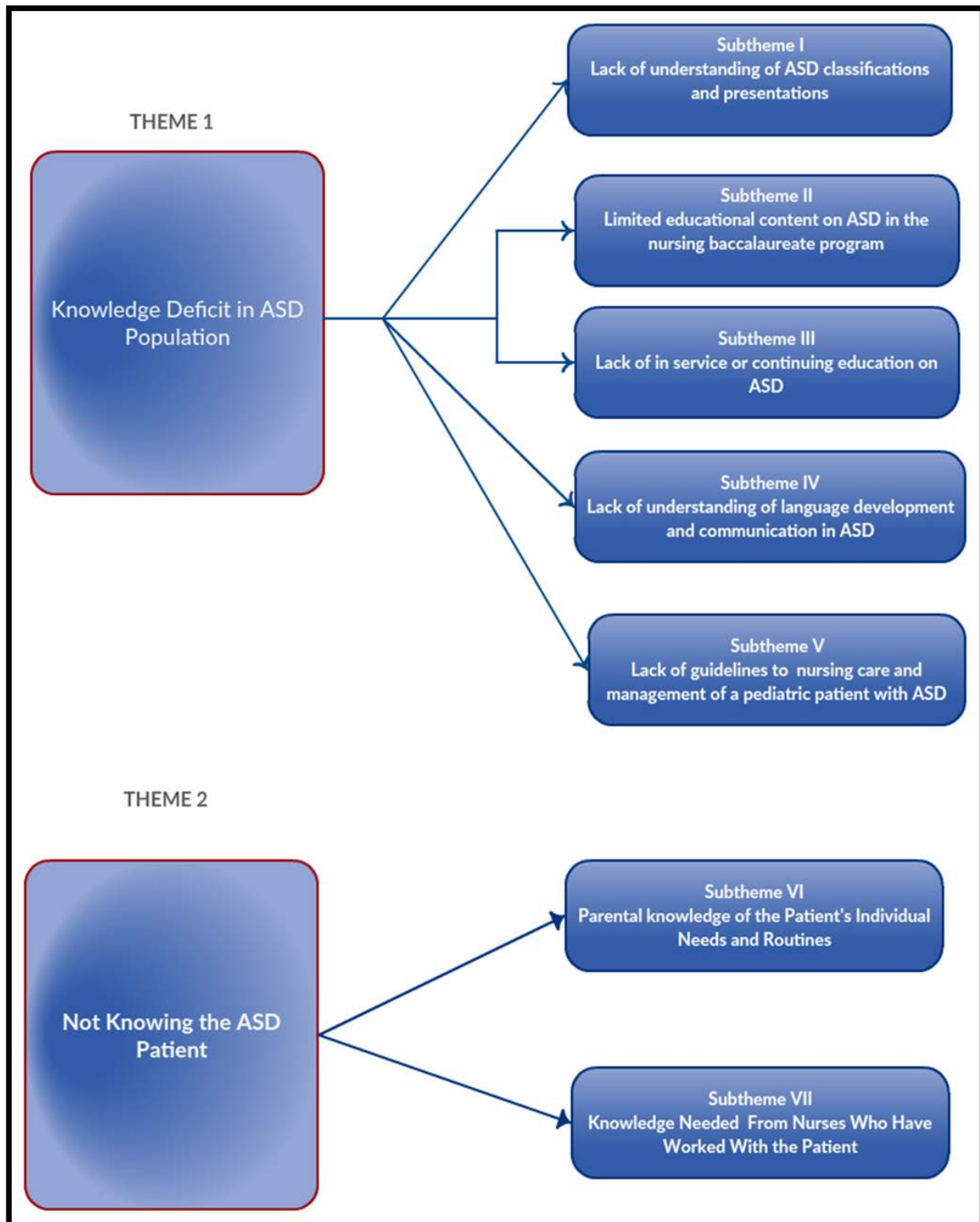


Figure 1. Outline of themes and subthemes.

**Lack of Understanding of ASD
Classifications and Presentations
– Subtheme 1**

While the nurses' levels of understanding of ASD classifications and presentations varied, the interpretations of their shared experiences demonstrated a consistent and profound deficiency of understanding of the severity and impact of autism as it relates to nursing care and management. As Nurse C evidently affirmed: *"I don't know if there's an autism section, like autism spectrum part one, part two, part three. I don't know if they're typed, if there are letters, you know. I'm not sure, of any of that."* Similarly, Nurse E stated: *I think there are couple of things I would like to know, but one of the main things is the different classifications of, um, ASD, and having that said, like, what types of help do they need in terms of socializing or in terms of how to communicate with them.*

All the participants shared this reaction. The unanswered questions were written in their faces: What are the differences between mild, moderate, and severe autism? How could those differences impact the nursing care? After deep reflection, Nurse D exhaled: *"I don't know a lot about autism types, but I know that, um, people sit there and say, 'Oh, they're kind of spectrumy,' and I'm like, 'What does that mean?'"* Irrefutably, the nurses are aware that autistic individuals present differently, but the meaning of those differences and how they impact nursing care remain elusive. The sense of frustration due to many unanswered questions related to the nursing care of the patients' with ASD was also evident in their voices.

**Limited Educational Content on
ASD in the Nursing
Baccalaureate Program –
Subtheme II**

All participants, except Nurse C, affirmed receiving some information regarding autism in nursing school, but in a limited or trivial amount when asked to *please share the educational content you received in school or via continuing education about the care of a child or adolescent with ASD*. In fact, after roughly a one-minute pause, Nurse C asserted, *“I honestly can’t remember anything from my nursing school.”* It is also important to note that most of them paused when trying to recall the content given, raising more questions about the sustainability of the materials provided to them on ASD in school. The sense of uncertainty of what was learned reverberated among the rest of the participants’ narratives. Nurse A said,

When we were in school, we received a small portion of autism and what autism is. Maybe a page or two of autism, but nothing in-depth to where they fall on the spectrum and how you communicate with them and just caring for them in and out of the hospital.

Additionally, some participants described having to self-educate about autism and related nursing management after graduation. Nurse B affirmed: *“The stuff I know is what I learned from like watching TED Talks on the Internet. It’s not stuff that I learned in nursing school.”* It was apparent that the participants knew that they might have missed the opportunity to learn fundamental information on the nursing care and management of patients with ASD in the baccalaureate program.

Lack of In-Service or Continuing Education on ASD – Subtheme III

The issue of lack of in-service or continuing training is analogous to that of limited educational content—although perhaps, more frustrating. While most of the participants reported having received minimal information on autism while in school, they all acknowledged nonexistent in-services or continuing education provisions about ASD. It seemed as though they did not even know it was deserved, as some found the question almost shocking.

Interviewer: Please share with me the in-service or continuing education you received on ASD.

Nurse D: That's so interesting that you asked that. None of my, like, continuing education or, you know, yearly/annual competency, skills lab, none of them has ever covered ASD. None of them. That's not even something that's even considered. It's not even considered or even deemed worthy or important—to even cover. But now that you mentioned it, I mean, yeah, that's so shocking. Uh, yeah, it's never been covered.

Interestingly, it appeared as though the participants realized that they had been denied something when the question was asked. In the same tone of frustration, Nurse F stated:

I do think that we lack the in-services and continuing education available to us regarding this population. We have in-services on the eating disorder that occurs at a smaller rate than autism, so why don't we have in-services on autism?

This appalling reaction was fairly typical among Nurses A, B, and C. They also wondered why there is a dearth of in-services on autism given its prevalence. Nurse A declared, *“If you just add something to the competency, I think that would*

even be beneficial. So, we could have a little hint of anything autism in the annual training.” Evidently, the participants yearned for some in-service on autism; however, Nurse B’s narrative on this question underscores the imperative of an in-service education on autism:

You don’t just go to school and get to know everything about cancer. There are new procedures. There are new medications. There is new technology coming out about it. And that’s the same thing with autism. There is just—there is new stuff. So, I think continuous education, getting the education and continuing being educated on how to care for them would be helpful.

Indeed, this argument is logical and sensible in any pedagogical measure. Procedures and techniques are always changing; hence, the need to stay updated has become the essence of evidence-based nursing practice. Although sometimes, their voices cracked, they sighed, and their eyes narrowed, the realization that they now had an opportunity to tell their stories, and possibly make a difference, provided a relief.

Lack of Understanding of Language Development and Communication in ASD – Subtheme IV

The perspectives shared by the participants disclosed that the normal nurse-patient therapeutic relationship suffers within the ASD population, not because the nurses or the patient do not desire it, but because of the general misunderstandings among the parties involved and the near absence of meaningful therapeutic communication. Nurse E noted,

So I think, in terms of, like, you know, trying to communicate and trying to have that nurse-patient therapeutic relationship with the child is a lot harder, because you don’t know how to approach it, you know.”

Likewise, Nurse F affirmed that “communication, obviously, was like a big, big problem for him, because he did not know how to communicate. He did not do well with new people and new surroundings. That posed a great challenge for us.” The narratives of these nurses highlight one of the hallmark symptoms of ASD—speech and language impairments. As a result of this impairment, the ASD individual experiences difficulty in understanding the intricacies of language; thus, approaches language differently from the societal norm. An approach that is unfamiliar to the participants’ consequently creates a significant barrier to providing quality care. Similarly, Nurses B and G’s narratives reverberated the same concern about knowledge deficit in understanding and communicating with the ASD patient. In Nurse B’s words, “Not knowing how to communicate with him was hard; the communication thing stood out the most.” This barrier was not only their experiences’ but was witnessed in the struggles of their colleagues when caring for the ASD population.

I believe 90 percent of us on the unit probably kind of just, like, guess on how to deal with these patients, but there should be a better way in terms of dealing, you know, and, like, figuring out how to actually deal and communicate with these patients,” declared Nurse G.

Evidently, the inability to communicate with ASD individuals creates a substantial barrier, since effective communication is vital to providing quality care. Irrefutably, an estimated “90 percent” of nurses guessing about how to handle these patients’ necessitate the need to provide RNs with a better way to understand language development and communication in the ASD population.

**Lack of Guidelines for the Nursing
Care and Management of a
Pediatric Patient with ASD –
Subtheme V**

One of the standard practices in the baccalaureate-nursing program is to learn how to write a care plan. As such, student nurses get introduced to the custom of patient care, organizing and prioritizing their patient needs, and patient advocacy. In these customary practices, the student nurses are familiarized with templates to aid in the care and management of diseases. Eventually, this habit will graduate them into enhancing the care they provide with evidence-based practices and guidelines—all to benefit the patient, provide efficiency, and expedite the healing process. However, the lived experiences of the participants demonstrated that not only did they lack such resources in school when it came to ASD, but the lack of ASD care and nursing management guidelines continued into their professional practices—a fact stated by all the participants:

Nurse A: I wish there were just tools for me or even someone to tell me—“Hey, by the way, you’re going to get a patient who is, you know, autistic, and these are what you should know. Here’s a handout or template to follow.”

Nurse G: I just can’t emphasize enough as to how important I feel it would be to have some guidance when caring for patients with autism. Like a tool or a template, you know, things to remember to ask.

Participants also reflected on the time it took to figure out things and allocate the resources needed to provide care. They also compared ASD to other chronic diseases, such as diabetes, and noted that there were templates in the nursing resources at work to care for those patients, but nothing existed for the ASD patient. It is almost as if autism has not garnered enough attention in the

pediatric setting to be discussed, as though the prevalence of 1 in 68 children in the U.S. is insufficient to necessitate an active dialogue on the nursing care and management of this vulnerable population.

Without guidelines or evidence-based practices for the care of ASD patients, nurses reflected on the anxiety and stress associated with caring for them. The fact is, there are nursing guidelines for patients with diabetes, cystic fibrosis, respiratory illness, eating disorders, depression, and countless other chronic and acute diseases, but none for the ASD individual. The need to address this troubling oversight was well illustrated by Nurse E, who stated, *“Educating me and giving me guidelines to take care of any child, whether that child’s autistic or anything else, helps.”* Nurses are inherently creative, but the efficiency of nursing practice has always depended on having evidence and guidelines to follow.

It must be noted that the participants acknowledged Child Life Services as the closest thing to having some ASD resource in the unit. Nurse G: *“When he started tantrums, I had no idea what to do. There were no guidelines to follow... luckily, Child Life was around to assist in finding things he liked. I wonder what I would have done without the help of the Child Life.”* However, only the day shift nurses praised Child Life for their unwavering support in assisting in calming the ASD patients and helping with procedures—since Child Life is mostly present during the day shift. Meanwhile, the night shift nurses only wished they had Child Life services. Regardless of the work hours, all the participants agreed that a nursing guideline for ASD care and management was highly needed. Nurse C called it a *“prepackaged kit or template designed towards autistic children.”* While Nurse B referred to it as *“a cute little pamphlet”* for the ASD patient. Irrespective of what the guideline is to be called, the present findings suggest that it is imperative that resources and guidelines for the nursing care and management

of the ASD patient be developed in order to establish an evidence-based practice for the disorder. It is highly important to recognize that the idiosyncrasy of ASD requires an individualized care. Therefore, having a guideline should not contradict this concept rather the guideline-based care should emphasize the need to individualize care to accommodate the uniqueness of people with ASD. Thus, utilizing a guideline-based care and individualizing care based on the needs of the particular child must be done contemporaneously.

Not Knowing the ASD Patient – Theme II

The previous themes have alluded to the lack of general knowledge about ASD. However, the further interpretation made it apparent that besides the general knowledge about ASD, one needs to know the specific attributes of the individual ASD patient, and how he or she presents the marked traits. Undoubtedly, the idiosyncrasies and various presentations of ASD make the disorder unique. As with the natural beauty of the zebra pattern, from a distance, the herd looks alike; however, a closer look reveals that each zebra is covered with a distinctive coat, a coat that is inheritably different from the others. Similarly, while most ASD individuals have comparable features and present with visible symptoms, each one of them has personal routines and likes. Needless to say, each ASD individual is uniquely different. Thus, it takes general knowledge of ASD and knowing the “uniqueness” of the patient to provide adequate and effective care.

Interviewer: From what you shared, it sounds like you've cared for more than two patients with ASD. So tell me collectively or maybe specifically, what stands out the most once you get to know them?

Nurse B: *Um, what stands out the most is, I guess, is that there is no one ASD patient that's the same. [Chuckles] they're all different. Um, so, you know, some are verbal. Some are nonverbal. Some, you know, smile a lot and some don't... they react differently to things. Is fun because you never can guess who they are until you get to know their routines, what they like, um and what triggers them [Chuckles].*

The narratives of the nurses supported the notion that to adequately provide care to an ASD patient, one not only needs to have a general knowledge of ASD, but also needs to know the patient's routines, likes and dislikes, and triggers to behaviors. Additionally, since ASD individuals react differently to new environments, knowledge from nurses who have previously cared for them would also be helpful. As a result, the participants shared perspectives on what it takes to know the ASD patient were interpreted to include two sub-themes: (a) knowledge needed from the parents and (b) knowledge required from nurses who have cared for the ASD patient.

Parental Knowledge of the Patient's Individual Needs and Routines – Subtheme VI

The nurses emphasized how parental knowledge of the child's needs and routine made the care they rendered efficient and less stressful. As Nurse E rightfully said, *"I think that I would not know what to do if the parents were not there to tell me how she likes to take her medication and that allowing her to brush her hands calms her down."* Similarly, another participant noted that not having the parents near presented a huge problem because they alone knew the *"child's likes and dislikes."* All the participants admitted that not knowing the patient's individual needs and routines presented a significant barrier to nursing

care, and they also identified the parents as liaisons to adequate care or as an intermediary pathway, if you will, to gaining access to the individualized needs and wants of the patient.

Nurse C: I think that one of the most challenging things I've had to deal with is usually performing, like, tasks, you know, like, skill-skill-oriented things, like starting IVs or putting an NG tube, like, all those things. And without having a parent, it becomes complicated knowing how to approach the child.

The Nurses also acknowledged that having a helpful parent is highly dependent on how much the parents are in tune to the routines and care of their children since the presence of the parents alone does not make things more comfortable; preferably, the invaluable knowledge of the child's routines and behaviors is what is indispensable.

Nurse F: It makes it harder for us to take care of the patient if the parents can't communicate with us what their child has or how their child is. This participant admitted that while the collaboration with caregivers is assumed to be significant, she had experienced an adverse effect where the presence of the caregiver exacerbated the child's behavior and prolonged the time it took to do things. In her own experience, the mom of a 3-year-old was not able to understand the child's needs, and that seemed to frustrate the child further. However, she did note that this was a child who had just been diagnosed with autism and that the mother was still discovering the diagnosis herself. Consequently, the situation made her feel helpless as a nurse because she did not understand the needs of her patient and also wished that she could help educate the mom on the new diagnosis, if only she knew what to say or do. Nevertheless, the nurse stated that the presence of the mother was soothing to the child regardless of whether mom understood the

child or not. All the participants wanted the parents by the bedside not only for the comfort their presence brings to the child, but for the knowledge of what their children were like, and ultimately to get things done efficiently. As nurse G commented:

His mother knew a lot about him, and she knew the cues that he would give and what the cues meant. However, his mom was not able to be at the bedside at all times. Therefore, not having her there presented a huge problem.

It is quite understandable that basic nursing tasks and routines would be challenging in the presence of the identified communication barriers, notwithstanding invasive procedures such as IV and NG tube insertions. Some participants noted the IV insertion as a daunting task that demanded not only parental knowledge, but entertainment of the Child Life Services and a stretch of golden patience. That “golden patience” could be hard to come by when the nurse had two or three other patients to care for.

Thus, a few nurses suggested that it would be helpful for the charge nurse or nurse manager to be mindful that the ASD patient requires patience and time to acclimate to the hospital environment and medical/nursing procedures. This consideration would then necessitate a decrease in the number of other patients assigned to the nurse who has an ASD patient, to afford the nurse the opportunity to exercise the patience needed to provide adequate care. Such an approach is consistent with decreasing nurse-patient ratios when patients are suicidal, manic or aggressive.

**Knowledge Needed from Nurses
Who Have Worked With the
Pediatric Patient – Subtheme
VII**

As stated earlier, the narratives by the participants demonstrated that it takes more than the general knowledge of ASD to effectively provide nursing care to the ASD population. In addition to the parental experience, the knowledge from nurses who have cared for the patient was deemed significant to knowing the ASD patient. Apparently, the characteristics of ASD patients make them unique. However, those characteristics and attributes present substantial challenges to nursing care if not recognized, identified, and addressed. Consequently, the participants emphasized that it is imperative to acquire as much information as possible from the nurse handing over the patient.

Nevertheless, such effort would be beneficial only if the nurse handing over the patient has gathered the necessary information to report. Nurse E perceptively painted a clear picture of this interpretation:

I think the lack of knowledge in taking care of these patients makes it a little bit longer to care for them because it's either, you're not arguing, but you don't know how to approach certain things. So, I think it would've been beneficial to have more information in the report. You need information before you are at the bedside and you're dealing with it then and trying to figure out how to take care and manage the child.

Notably, the participants confessed that as much as they would want to obtain the right information, the lack of nursing care's knowledge that does exist in this population derails such effort. As a result, this knowledge deficit creates cycles of "trials and errors," inefficient processes, and wastes the nurses' and patients' valuable time. This interpretation was noted in the participants' descriptions, including this affirmation by Nurse C: "... so, when I get a report,

it's usually trials and errors from what the previous nurse has gone through." The consequences of not having the necessary knowledge from the previous nurses who had cared for the ASD patient, were described as negative experiences by the participants, and contributed to either a "rough day" or a "difficult shift" for the receiving nurse. It was also described as a feeling of being "blindsided" going into the patient's room.

The emotional impacts of these experiences were substantial and the frustration resonated amongst the participants. Throughout the interviews, they were transparent about their need for resources and information in order to adequately care for the patients, and how empty it felt not having them. They also reminisced about the information they wished they could have had and illustrated how it could have improved care.

Nurse G: If I get a report, and they do believe that there is some, like, autism with the patient, then that's literally all I get, is "that patient has slight autism." That's all I can tell you.

Nurse F: I would have appreciated knowing, like, how he usually sleeps, if he had favorite treats, if there are things that he liked to eat that makes him happy, so that I could try to give him rewards of like food or snack rewards. If there was music that I can play for him or anything that would make him happier.

These findings suggest that the nursing barriers of caring for a pediatric patient with ASD exceed the general knowledge of what ASD entails; it involves knowing the pediatric patient through the lenses of the parents/caregivers and the previous nurses who have cared for the patient. At this developmental stage and in consideration of the assault ASD renders to the language and communication

abilities of this vulnerable population, it is imperative to empower children with ASD to speak through their parents and caregivers. Such empowerment can be liberated only when their needs and routines are sought from the parents, caregivers, and nurses who have cared for them.

CHAPTER 5: DISCUSSION

This study answered its research two research questions: *What are the barriers/limitations faced by baccalaureate degreed registered nurses caring for children and adolescent patients with ASD?*, and *What are the perspectives of baccalaureate degreed registered nurses regarding the adequacy of the educational content on ASD in their baccalaureate program?* The study identified two significant barriers to effective and adequate care of the pediatric patient with ASD: (a) lack of general knowledge about ASD and (b) not knowing the ASD patient on an individual level. These were described by the baccalaureate degreed pediatric nurses as unequivocally significant to adequately caring for the pediatric patient with ASD. The answer to the second research question was a convincing “inadequate educational content on ASD” in the baccalaureate nursing program and in-services or continuing education programs. The findings of this research highlight the vital need to revise the pediatric nursing curriculum to sufficiently address the current health problems facing the pediatric population with ASD. Training and equipping competent undergraduates to handle intellectual and developmental disabilities, such as ASD, will not only relieve the current health problem, but also ameliorate the economic burden ASD presents.

It must be noted that the findings of this study mirror several studies that, over the decades, have emphasized the need for nursing practice to reform its curriculum to reasonably accommodate the needs of individuals with developmental, intellectual, and mental disabilities, and chronic medical challenges (Gardner, 2012; Gardner, Suplee, & Jerome-D’Emilia, 2015; Giarelli, Ruttenberg, & Segal, 2012; McCarthy & Wyatt, 2014). Correspondingly, Betz (2017) called for a change in the nursing curriculum to adequately address the

current health concerns identified in the Healthy People 2020, such as ASD, that is affecting children, adolescents, and families.

In this study, the “knowledge deficit in ASD” regarding providing adequate care, as described by the nurses, encompasses different deficits that are both related to policy and education. Undoubtedly, this problem necessitates the collaboration of nurse leaders, nurse educators, clinical educators, nurse managers, and nurse administrators. The study by Gardner et al. (2015), which explored nurse educators’ abilities and readiness to teach nursing students how to care for patients with ASD, demonstrated that only 18% of the 295 faculty members sampled felt ready and competent to do so. That is an alarming result that validates the finding of the present study: lack of educational content on ASD in the baccalaureate-nursing program as a barrier to the adequate nursing care of the ASD patient. How do we ask a nurse to garner the necessary information from an ASD parent or caregiver when no one has taught him or her what to seek? How can we expect faculty and in-service educators to teach on a subject upon which they feel inadequately knowledgeable and skilled? It is a cycle of inefficiency that has yielded failed results and must be corrected. The argument that there are too few clinical opportunities to afford the student nurse or graduate nurse time to practice caring for a patient with ASD is no longer tenable. McIntosh, Thomas, Allen, and Edwards (2015) provided evidence that students felt more prepared to care for the ASD patient after autism simulation scenarios. Research is also needed to determine if autism simulation training could be used to enhance the skill and knowledge of faculty members and of nurses who offer in-service education in hospital-based settings.

Besides filling the gaps in the lack of general knowledge of ASD, partnering with the parents, caregivers, and previous providers, including nurses

who have worked with the patient, is crucial to appropriate care. These people, the stakeholders, possess the knowledge needed to understand the unique attributes and characteristics of the patient to individualize care. Thus, they must be included in the plan of care. The participants demonstrated how significant parental knowledge was to the care of their patients with ASD. Indeed, they noted that parental knowledge is significant to any child or adolescent and even more crucial in the ASD population given the impairments associated with the disorder. These findings have been supported by several other studies (Chiri & Warfield, 2012; Johnson et al., 2015; Magana et al., 2012). Additionally, studies have shown that persons with ASD need time to acclimatize to the hospital environment and may have heightened anxiety and sensory needs due to the change (Magana et al., 2012; Muskat et al., 2015; & Nicholas et al., 2016). As a result, previous nurses must be viewed as stakeholders because their knowledge of the patients' hospital routines and needs is essential to providing adequate care. Perhaps inviting family members of children with ASD to lecture in college classrooms or to assist with offering in-service education would help convey how important it is to have an individualized understanding of how to best provide care based on the child's routines and preferences.

Correspondingly, the participants in this study noted how vital it was to obtain a concise report from colleagues, instead of scrambling with "trials and errors." They all confirmed that a limited report not only prolongs care and time spent getting to know the patient, but also sets the stage for inefficiency. However, most of the participants admitted that obtaining an adequate report is contingent on knowing the right questions to ask, and their lack of general knowledge regarding ASD only exacerbates the matter. Collectively, the thread of the dialogue underscored the need for guidelines for the nursing care and management of the

pediatric ASD patient. Nurses need the information and resources required to care for the ASD patient efficiently. There should be handouts, templates, in-service training, and continuing education to update the profession on the treatments, management, and plan of care. Parents and caregivers may not always be present, but if the nurses know the right questions to ask and the knowledge needed, an enhancement would be seen in the professional practice of nursing for the ASD population. The results of this research demonstrated that the nurses are “thirsty” for the knowledge and resources needed to care efficiently for the person with ASD. Scrambling for ways to care for the ASD patient due to an insufficient educational preparation left a feeling of incompetence and inadequacy in front of the patient—a deep frustration that echoed throughout the participants’ voices. Knowing that there is something inadequate in the care they provided, and the inability to pursue the right course of action, created a moral problem—a moral distress that was evident in their comments, voice tones, and facial expressions. This must change.

The theoretical framework selected for this study eloquently propels changes within the healthcare system to include the vulnerable population of people with ASD; hence, it reinforces the findings of this study even though a theoretical framework is not typically used in interpretive phenomenology. The NSM has always called for the comprehensive guide for nursing practice, research, education, and administration to be open to an innovative implementation and seek the delivery of comprehensive and individualized care to vulnerable populations of society. Betty Neuman’s theory is rooted in helping others live quality lives.

The most recent data from the CDC (2014) states that ASD affects children in the U.S. at a staggering rate of 1 in 68—a rate that has been declared a health

crisis. Despite the economic burden of ASD and the present health crisis it poses, there is no cure for it. Several studies have demonstrated that the prevalence could be even more devastating in the future (Chiri & Warfield, 2012; Warfield et al., 2015). Irrefutably, this high prevalence foretells that the demand for healthcare and related services from individuals with ASD will equally increase. Sadly, the literature shows that healthcare providers, including those in the nursing profession, have been inadequately prepared to manage this crisis (Bultas, 2012; Chiri & Warfield 2011). While this may sound extreme, ignoring the issue at hand is not just a disservice to those patients affected, it is a failure to the profession itself, and to the professionals. Thus, the need for the nursing curriculum and continuing education to adequately prepare nursing graduates to care for those with intellectual, developmental, and mental disabilities can no longer be delayed—the time is now. Nurses can, and want to, help individuals with ASD live better lives. However, such desire can be fulfilled only when nurse leaders, nurse educators, nurse administrators, clinical educators, and nurse practitioners are willing to promote and facilitate the needed changes in the pediatric curriculum to improve and enhance the care of individuals with ASD.

Limitations

The findings of this study exist with limitations. While the homogenous pediatric sample provided penetrating insight into the intimate experiences of people contending with ASD; it may apply to but not generalizable to other settings. Furthermore, there were challenges to some of the recruited participants faithfully committing to their scheduled interviews despite the substantial accommodation provided by the investigator. However, the final sample of seven was still a significant size for the qualitative study. Additionally, the measures the

investigators took to ensure rigor suggest that the reported themes and subthemes captured the perspectives of the participants represented in this study.

Notwithstanding these limitations, the results of this study have noteworthy implications.

Nursing Implications

This research is the first to examine the perspectives of baccalaureate degreed pediatric nurses regarding their care of children and adolescents with ASD, as well as their perception of the adequacy of ASD educational content and in-service teachings. Thus, the findings of this study not only highlight the inadequacy of the current undergraduate nursing curriculum in addressing the needs of the ASD patient, but they underscore the demand to establish evidence-based practice guidelines for this vulnerable population. The overall prevalence of ASD is 1:42; yet it receives minimal, if any, attention in the undergraduate curriculum. Interestingly, common topics like congenital heart defects, which are discussed in detail, affect 1% of births per year in the U.S. (CDC, n.d.).

This is disproportionately wrong and indeed worthy of change. However, it is necessary to reiterate that the required change is needed in both academic and practice settings; thus, it will demand the collaboration of nurse administrators, nurse educators, clinical nurse specialists, nurse managers, and advanced practice nurses. Additionally, it is significant to note that this study demonstrated that nurses are willing to help children and adolescents with ASD; truly, they are hungry for the knowledge to do so. Therefore, it is time to give undergraduates and graduate nurses the educational content, tools, and resources they need to care for ASD patients adequately. Consequently, the next logical research would take the responses from the participants and develop a toolkit or set of guidelines to

enable the effective and efficient care of this vulnerable population. Indeed, this could serve as a platform for establishing evidence-based practice guidelines to the nursing care and management of individuals with ASD.

Recommendations

Until the necessary education about caring for patients with ASD is available via an academic curriculum or in practice settings, it will benefit nurses, and advanced practice nurses to ask parents and/or previous caregivers some questions regarding the needs and routines of the pediatric patient with ASD. Thus, to optimize care and enhance professional practice, an ASD Cheat Sheet (see Appendix B) has been developed based on the findings of this study to assist nurses and advanced nurses in providing adequate care for the patient with ASD.

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APPENDICES

**APPENDIX A: SIGNIFICANT STATEMENTS FROM ORIGINAL
TRANSCRIPTS**

Appendix A

Examples of themes and significant statements from original transcripts

Themes	Supporting quotes from transcripts
Lack of understanding of ASD classifications and presentations	<p><i>I don't know if there's autism section, like autism spectrum part one, part two, part three. I don't know if they're typed, if there's letters, you know. I'm not sure, of any of that.</i></p> <p><i>I think there are couple of things I would like to know, but one of the main things is the different classifications of, um, ASD, and having that said, like, what types of help do they need in terms of socializing or in terms of how to communicate with them.</i></p> <p><i>I don't know a lot about autism types, but I know that, um, people sit there and say, "Oh, they're kind of spectrumy," and I'm like, "What the does that mean?"</i></p> <p><i>I just think that there is a lack of knowledge. There really is a lack of knowledge [related to ASD].</i></p> <p><i>I need someone to go over the different types, like, spectrums and, you know, like, a high-functioning, maybe, like, an Asperger's versus, you know, like, a mild to low-functioning, nonverbal kid, like, how they're different and how just to like overall manage them.</i></p>

Limited educational content on ASD on the educational baccalaureate program

When we were in school, we received a small portion of autism and what autism is. Maybe a page or two of autism, but nothing in-depth to where they fall on the spectrum and how you communicate with them.

I don't remember, like, having a full-on course on autism in school.

The stuff I know is what I learned from like watching TED Talks on the Internet. It's not stuff that I learned in nursing school. So, I would think it would be great if they had a section about autistic kids, where they talked about, "This is what autism is. This is what it looks like. This is what your nursing care can be."

I honestly can't really remember anything about autism from my nursing school.

Lack of in service or continuing education on ASD

You, don't just go to school and get to know everything about cancer... So, I think continuous education, getting the education and on how to care for them would be helpful.

I haven't been presented with any updates on autism since I became a registered nurse.

I do think that we lack the in-services and continuing education available to us in terms of this population. We have in services on eating disorders that occur at a smaller rate

than autism, so why don't we have in services on autism?

If you just add something to the competency, I think that would even be beneficial. So, we could have a little hint of anything autism in the annual training.

It's like we briefly breeze through cancer. We breeze through anorexics. We breeze through um kids that—like have psych disorders, like being suicidal. But we never—we never had anything on autism. Ever.

Lack of knowledge of language development and communication on ASD

I feel like learning more about how to communicate with them would be very beneficial, not just to me, but, like, everyone that works on our floor.

Communication obviously was like a big, big, big problem for him, because he did not know how to communicate. He did not do well with new people and new surroundings. That posed a great challenge for him. It was a big challenge for nurses too.

Not knowing how to communicate with him was hard, the communication thing stood out the most for me.

So I think, in terms of, like, you know, trying to communicate and trying to have that, you know, like, the nurse-patient therapeutic relationship with the child is a lot harder, because you don't really know how to approach it, you know?

I believe 90 percent of us on the unit probably kind of just, like,

guess on how to deal with these patients but there should be a better way in terms of dealing, you know, and, like, figuring out how to actually deal and communicate with these patients.

It was him screaming and him yelling, and like hitting his face. So, it was like, come on. Like there was like nothing I could really get out of him in terms of communication.

Knowing the triggers is a big thing, and then not knowing the factors that can help relax him or make him feel better. That was huge. Um, language barrier with this patient.

I would've wanted the nurse to tell me, you know his verbal capacity because there're so many different—depending on where on the spectrum ... how to communicate best with him.

Lack of guidelines for nursing care and management of a pediatric patient with ASD

Maybe there could be a prepackaged kit or template designed towards autistic children. Um, again, having that, uh, communication or that informative piece of information that's given to us at least annually on caring for an autistic child.

Educating me and giving me guidelines to take care of any child, whether that child's autistic or anything else, helps.

So, it's like, you know, we rarely get autism cases, but there should be like, "Hey, just in case, here's a cute little pamphlet," or, "Hey, just in case, here's like a resource guide.

I wish there were just tools for me or even someone to kind of

tell me—”Hey, by the way, you’re going to get a patient who is, you know, autistic, and these are what you should know. Here’s a handout or template to follow.

I just can’t emphasize enough as to how important I feel it would be to have some guidance when caring for patients with autism. Like a tool or a template, you know, things to know to ask.

Lack of access to the knowledge needed from nurses who have worked the ASD patient.

I think the lack of knowledge in taking care of these patients makes it a little bit longer to care for them because it’s either you’re not arguing, but you don’t know how to approach certain things.

So, I think it would’ve been beneficial to have more information in report other than once the child gets at the bedside and you’re dealing with it then and trying to figure out how to take care and manage the child.

If I get a report, and they do believe that there is some sort of, like, autism with the patient, then that’s literally all I get is “that patient has slight autism.” That’s all I can tell you.

So, when I get a report, it’s usually trial and error from what the previous nurse has gone through.

I would have appreciated knowing like how he normally sleeps, If, he had favorite treats, if there are things that he liked to eat that makes him happy, so that I could try to give him rewards of like food or snack rewards. If there was a

music that I can play for him, or anything that would make him happier.

Lack of access to the parental knowledge of the individual needs and routines of the ASD patient.

His mother knew a lot about him and she knew the cues that he would give and what the cues meant. However, his mom was not able to be at the bedside at all times. Therefore, not having her there presented a huge problem.

I did not have information on what the parents/caregivers perceive as the best way to take care of them daily.

Well, I think the barrier I faced was that if the parents weren't there to tell me what I can do... then I would not know what to do.

I had this kid that would hit me when I would give her medications. There was no parent involved in his care. So, it was a little bit harder.

I think that one of the most difficult things I've had to deal with is usually performing, like, tasks, you know, like, skill-skill-oriented things, like starting IVs or putting an NG tube, like, all those things. And without having a parent, it becomes very difficult.

It makes it harder for us to take care of the patient, if the parents can't communicate with us what their child has or how their child is.

APPENDIX B: ASD TOOL


Appendix B

ASD Tool

Nurses want to and can care for a pediatric patient with autism spectrum disorder (ASD) effectively


ASD Cheat Sheet

These questions will help.
Ask my caregivers




1. Would you consider your child's autism to be mild, moderate, or severe?
2. How does your child communicate? Is there anything I can use to facilitate communication and or help your child comprehend what I am saying?
3. What upsets your child? How can I calm him/her down?
4. Which hospital interventions or activities cause them the most distress?
5. Do they have comfort items or activities that ease their anxiety?
6. How does your child show or describe pain? What pain medication works best and how do they like to take it?
7. Is there a particular way they like to eat and sleep?
8. Please share with me any other special routines your child has.

Yippee. Now, I just have to ask the previous nurse



★ My goal is to individualize care based on the needs and routines of this patient



It takes a special nurse to care for a special and unique patient. On behalf of all the children with ASD, thank you for caring.