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Nurses Caring for Adults with Autism in an Emergency Department: A Survey of Knowledge

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ABSTRACT

NURSES CARING FOR ADULTS WITH AUTISM IN

AN EMERGENCY DEPARTMENT: A

SURVEY OF KNOWLEDGE

Autism is a complex neurodevelopmental disorder characterized by social impairments, communication difficulties, and restricted, repetitive, and stereotyped patterns of behavior. The nurse (RN) in the emergency department (ED) plays an important role in the receiving, treatment, and management of the patient with autism.

RNs must understand the unique challenges of caring for individuals with autism. Fortunately, autism is an active area of research, with copious resources available to assist those affected by this disorder; however, no studies were found evaluating nurses' knowledge of autism and the number of resources for nurses caring for this population was limited. Nursing is an information-intensive profession and the information obtained from this survey of knowledge and beliefs was valuable in identifying the ED nurse's educational needs and providing support for the provision of accurate information to health care professionals.

This survey found a slight majority of ED nurses having accurate knowledge, correctly identifying causes and comorbidities, and choosing appropriate interventions. This survey confirmed the limited knowledge and resources available for ED RNs. Further research on nursing care of adults with ASD is clearly warranted.

Shauna Marie Miller
April 2015

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Doctor of Nursing Practice

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APPROVED

For the Department of Department of Nursing

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Background

Autism spectrum disorder (ASD) is a complex neurodevelopment disorder, characterized by significant social, communication, and behavioral challenges. There is often nothing different about how people with ASD look that sets them apart from other people, but people with ASD may communicate, interact, behave, and learn in ways that may be unfamiliar to others. The severity of the impairment can vary greatly, as well as the ways the characteristics are displayed. The ability to learn, think, and problem solve can range from mild difficulties to profound difficulties involving all aspects of daily life.

ASD affects over 2 million individuals in the United States and tens of millions worldwide (CDC, 2014). ASD, also called autism, occurs in all ethnic and socioeconomic groups and age groups, affecting males four times more frequently than females. There is no known cause or cure for ASD, and the core characteristics and associated behaviors may impede or even prevent the delivery of appropriate health care.

The prevalence of ASD is clearly rising. In 1984, just 30 years ago, only 3 in 10,000 children were diagnosed with this "rare" disorder. In 1999, the autism rate was thought to be around 4-5 in 10,000. By the year 2000, estimates had climbed to a rate of 4-5 per 1000 children (Bertrand et al., 2001). From 2002, the prevalence of ASD increased 57% across the country (CDC, 2009). Using the most current and widely adopted prevalence statistics, the CDC (2014), reported that 1 in 68 American children were on the autism spectrum. This dramatic increase is only partly explained by increased awareness and improved diagnosis (Autism Speaks, 2014).

However, a true increase in the number of people with an ASD cannot be ruled out, the increase

in ASD diagnoses is likely due to a combination of factors (CDC, 2014) (see Figure 1).

Autism is one of the most challenging developmental disabilities nurses may encounter in

the emergency department (ED) setting. The Registered Nurse (RN) in the ED plays a significant

role in the receiving, treatment, and management of the patient with autism who presents for

emergency care. While generally considered a disorder of childhood, autism's dramatically

increasing prevalence means it is rapidly becoming a disorder of adulthood as well. As the

number of children diagnosed with autism increases, and the population ages, adult EDs are

likely to encounter an increased number of patients with autism (Patrizzi & Giarelli, 2012). It is,

therefore, imperative for ED nurses to understand the unique challenges of providing care for
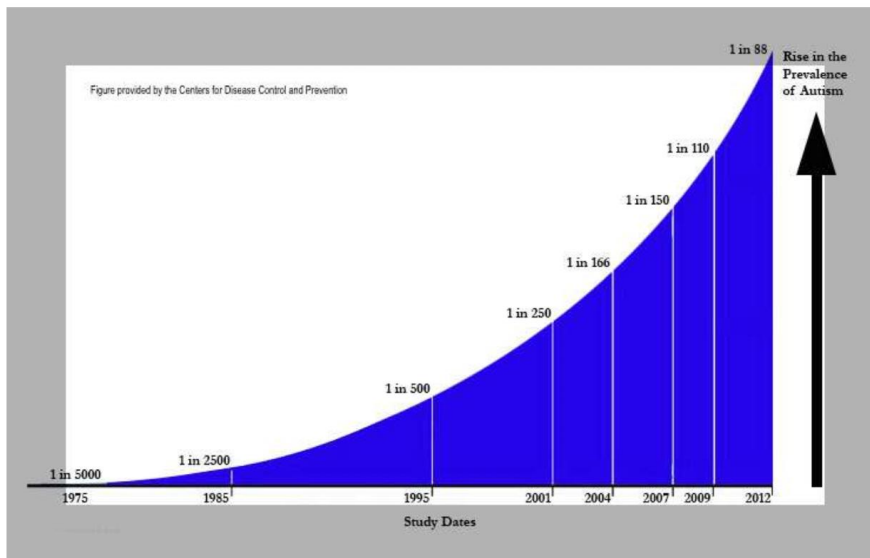
individuals with autism.

Figure 1. Rate of autism diagnoses from 1975 to 2012.

As a public health concern, ASD is an active area of research. Over the last several decades, many organizations, public and private, have been working towards understanding ASD through research. Organizations such as the CDC, The Autism and Developmental Disabilities Monitoring (ADDM) network, and Autism Speaks are committed to searching for causes, risk factors, prevention, and the development of resources that help identify and assist those with ASD. Fortunately, research has resulted in the development of a better understanding of ASD, the development of early intervention services, and treatment approach options. However, resources for the provision of nursing care of adults with ASD were found to be quite limited, and no studies evaluating registered nurses' knowledge and understanding of autism were found.

In 2005, a study demonstrated primary-care physicians had different understandings of the diagnosis, treatment, and prognosis of autism than those professionals considered experts in autism (Heidgerken, Geffken, Modi, & Frakey, 2005). This renders a high potential for inconsistent and possibly negative provisions of health care across services, settings, and professional practice. This finding should guide nurses to adopt a thoughtful process of caring for people with ASD, beginning with understanding autism and its unique characteristics.

The prevalence of ASD has clearly risen and surpassed any predications of this public health phenomenon, and a continued increase in prevalence is expected. The cause of ASD is unknown, there is no cure, and treatment options are limited. ED nurses must consider the impact of ASD on their practice and reach out to understand this disorder so individuals with ASD receive safe, appropriate, and effective care.

The purpose of this Doctor of Nursing Practice (DNP) project is to assess ED RN knowledge deficits and educational needs by conducting a survey of general knowledge of autism and nursing care of adults with autism. The survey sought information on RNs' general

knowledge, prevalence, causes, and comorbidities, in addition to diagnostic criteria, treatment, and nursing care of autism. In addition to increasing knowledge and awareness of adult ED patients with ASD, the information gathered serves as a needs assessment for the development of educational resources for those who may have interactions in the ED with adults with autism.

Theoretical Framework

The framework for this project encompasses two theories: The Recovery Model as an approach to improving patient outcomes for individuals with ASD and Bloom's Taxonomy to develop a future learning module based on hierarchical learning objectives to promote knowledge and educational needs resulting in improved nurse satisfaction in their delivery of care. The Recovery Model is a concept wherein the patients have primary control over decisions about their own care, in contrast to traditional models in which the patient is minimally, if at all, consulted on their plan of care. Bloom's Taxonomy uses a holistic form of education to promote higher forms of thinking in education allowing the nurse to move towards applying their knowledge of ASD to providing safe and effective care.

The Recovery Model

Approaches to understanding ASD generally draw on a deficit model, seeking to identify impairments and deficiencies in people with autism. An alternative approach argues for valuing diversity and viewing ASD as a difference rather than a deficit (Brownlow & O'Dell, 2009). The National Association of Social Workers (2006) describes the recovery model as "based on the concepts of strengths and empowerment," with "respect for the value and worth of each individual as an equally important member of society" (p. 1). An understanding of ASD, and an understanding of the recovery model, can assist the nurse in embracing and implementing the

recovery model in tandem with the nursing process in providing best-practice care for the individual with ASD.

The recovery model is based in mental health where there is a shift toward a recovery-oriented service framework. This shift has been evolving slowly in the literature and research in three dimensions: (a) consumers who discuss their own recovery and give personal accounts and experience of treatment as well as recovery efforts (Swarbrick, 2006); (b) practitioners who support rehabilitation and recovery and specify the provision of an array of rehabilitative and educational experiences in partnership with consumers (Anthony, 1993; Schiff, 2004); and (c) researchers who have documented clients in recovery using support services in living successfully in the community (Harding, Brooks, Ashikaga, Strauss, & Breier, 1987).

Though there is still no universally accepted definition of recovery, the meaning of the word "recovery" has expanded from the absence of symptoms that characterize a medical condition to a broader perspective of social and occupational functioning (Craig, 2008). The Substance Abuse and Mental Health Services Administration describes recovery as an individual's journey of healing and transformation to live a meaningful life in a community while striving to achieve maximum human potential (2006). Individual life circumstances, such as the absence or presence of friends or significant others, independent accommodation, or employment opportunities are important for both alleviating symptoms, sometimes referred to as the first order change, and social integration and inclusion, referred to as the second order change (Onken, Craig, Ridgeway, Ralph, & Cook, 2007). Both the individual (internal) and environmental (external) factors and circumstances are dynamically linked and can either promote or hinder personal recovery (Onken et al., 2007).

Integrating the recovery model into nursing care of individuals with ASD in the ED will enable those on the autism spectrum and their support team to identify those strategies that are helpful to meeting their objectives and targeting concerns. Collaboration with the individual, parents, caregivers, and others involved in this individuals' life is vital to achieving the goals set forth (Caldwell, Sciafani, Swarbrick, & Piren, 2010). The ED nurse provides care based on the concept of respect for the value and worth of each individual as an equal and important member of society—a concept inherent in the nursing profession (see Figure 2).

Figure 2. The ten components of recovery.

Objectives for learning, based on Bloom's Taxonomy, were the first step in the development of a learning module for ED nurses (see Figure 3). According to Bloom, there are three domains in which people learn: the cognitive domain, the psychomotor domain, and the affective domain. Using Bloom's Taxonomy, in which patient-centered objectives are the focus, will guide the nurse towards increasing her understanding of ASD, resulting in

safe and effective care. The three domains overlap in the learning module as the foundational

aspects of ASD are introduced and progress to higher-levels of learning affecting the nursing
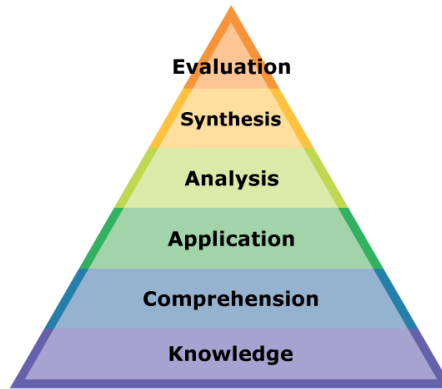
plan of care (see Figure 4).

Figure 3. Bloom's Taxonomy (Original).
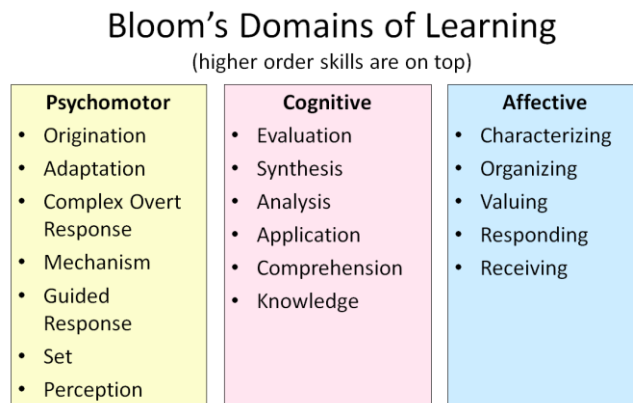
Figure 4. Bloom's Domains of Learning.

Literature Review: The Importance and Evidence for Educating ED

Nurses Caring for Adults with Autism

The purpose of this DNP project is to assess ED RNs' knowledge deficits and educational needs by conducting a survey of general knowledge of autism and nursing care of adults with autism. The information gathered serves as a needs assessment for the development of educational resources for RNs who may interact in the ED with adults with autism.

According to the U.S. Census, there are 50 million Americans who have some type of disability, including developmental disabilities. The provision of quality health care for this population is becoming recognized as a public health issue as adults with disabilities are living longer and encountering the health issues of the typical aging population (Drum, Krahn, Peterson, Horner-Johnson, & Newton, 2009; Henry, Long-Bellil, Zhang, & Himmelstein, 2011; Smith, 2008). Adults with ASD are a specific component of this population, and little is known about the parameters of health care needs for them, in particular their access to medical care and quality outcomes (Bruder, Kerins, Mazzarella, Sims, & Stein, 2012). The rising prevalence underscores the need for nurses to expect that more people who pass through their clinical practice will have a diagnosis or be a member of a family with an affected relative (Giarelli & Gardner, 2013).

Research

Research on healthcare experiences of individuals with autism has been almost uniformly limited to studies of children and their families, who consistently report more difficulty obtaining health care for their children and less satisfaction with that care, once received (Mandell, 2013). The rates of ASD are increasing and since the disorder is life long, there are many more adults than children who evince the condition. Despite this, more research is conducted on children than

is on adults with ASD. A Scopus search conducted in April 2010 yielded almost 3-fold as many studies on ASD with children versus adults (16518 versus 5691, respectively) (Matson, Sipes, Fodstad, & Fitzgerald, 2011). People with autism spend the majority of their lives as adults, and yet, seem to be less understood.

In recognition of the critical dearth of research regarding adults with autism, the Interagency Autism Coordinating Committee (IACC, 2012), the body charged with advising the Secretary of Health and Human Services on autism research, policy and practice, devoted an entire chapter of its seven-chapter strategic plan to the needs of adults (Mandell, 2013). The needs of adults with ASD continue to be understudied. Over the last 2 years, relatively few peer-reviewed published studies have examined the needs of adults with ASD or service interventions to improve their functioning and quality of life (IACC, 2012).

Comorbidity/Co-occurring Conditions

Most of the literature documenting co-occurring conditions is based upon clinical samples and can have widely varying figures regarding prevalence, presumably due in part to the type of practice and the source of the sample. Levey et al. (2010) used the following population-based data to describe four groupings of co-occurring disorders: (a) developmental diagnoses, (b) psychiatric, (c) neurological diagnoses, and (d) possibly causative medical diagnoses (Giarelli & Gardner, 2012).

Studies about the health care status of adults with ASD have focused on the existence of co-morbid conditions (Koritsas & Iacono, 2009), heart rate changes as a result of stress (Groden et al., 2005), and quality of life for those with Asperger syndrome (Barnhill, 2007; Bruder, 2012). A study in 2012 of comorbidities in schoolchildren with ASD showed a strikingly high prevalence of comorbidities; 72.5% having at least one comorbidity and

obesity and psychiatric and neurologic disorders as the most prevalent items. Results showed

that attention-deficit/hyperactivity disorder and epileptic disorders were the leading

comorbidity in respective categories (Memari, Ziaee, Mirfazeli, & Kordi, 2012). Presumably,

these comorbidities are not limited to children with ASD, and the ED RN can expect to

manage co-occurring, comorbidity, and normal aging process conditions in the adult patient

with ASD as well.

Access to Healthcare

Access to healthcare for adults with autism can be especially difficult, as many primary

care providers may not be knowledgeable or comfortable caring for the additional complexities

that accompany ASD. Adults with autism are just as likely as other adults to have primary care

providers, but are more likely to have unmet physical and mental health needs, less likely to

receive preventive care, and more likely to end up in the ED (Mandell, 2013). Outdated and

inaccurate beliefs regarding the prognosis and treatment of autism differentially impact the

services that the health care providers are likely to advocate for their patients (Heidgerken et al.,

2005).

Core Characteristics of ASD

ASDs are on a range of complex developmental disorders that can cause problems with

thinking, feeling, language, and the ability to relate to others. They are neurological disorders,

which means they affect the functioning of the brain. How autism disorders affect a person and

the severity of symptoms are different in each person (American Psychiatric Association [APA],

2015). The nurse's level of understanding of autism can greatly impact the patient's outcome

(Salamonsen, 2007). Knowledge and an awareness of the core characteristics of ASD greatly

improve the nurse's ability to provide care with confidence. The emergency nurse can adapt and

modify his or her plan of care for a patient based on this knowledge (Patrizzi & Giarelli, 2012) (see Figure 5).

Social	Communication	Restricted & Repetitive Behaviors
• Difficulty interacting with others • Must adhere to routine	• Difficulty with language • Limited speech • Repeating phrases	• Spinning • Fixated on objects • Hand flapping

Figure 5. Core characteristics of ASD

Challenging Behaviors

In addition to the many reasons any person may arrive at the ED for treatment, some reasons are specific to the patient with ASD. Challenging behaviors (CBs) are commonly seen in individuals with ASD. CBs can be defined as those behaviors that place the safety of the individual displaying them or others in jeopardy, or behavior that results in an individual displaying the behavior being denied address to community facilities (Matson et al., 2011). Some of the most common CBs in individuals with ASD include aggression, destructive behavior, and self-injurious behavior. In many cases, challenging behaviors have clear environmental antecedents (Matson et al., 2011). For example, people with ASD frequently have difficulty transitioning from one activity to another, resulting in an escalation of CBs. Knowing this, the ED RN can prepare the patient for the multiple transitions necessary in providing emergency care and modify the plan of care whenever possible.

Autism itself does not cause CBs. It is likely, however, that some of the underlying processes that result in autism might also result in behaviors that are outside of a person's control, similar to how the tremors associated with Parkinson's Disease are brought on by impulses that the person cannot direct (Autism Speaks, 2012). Behavior is a form of communication; signs of increasing stress and agitation or self-injury can reflect sensory issues, including pain (Oliver & Richards, 2010), illness, or other problems. Managing escalation is one of the most important skills ED nurses can learn as they work with patients with ASD (Patrizzi & Giarelli, 2012).

<div align="center">**Nurse's Role**</div>

The ED nurse must integrate routine ED care with special considerations for ASD (Patrizzi & Giarelli, 2012). The initial encounter with a patient with ASD may be in the triage area or in a treatment room. The ASD diagnosis may not be disclosed due to the circumstances leading to the ED visit, such as a motor vehicle accident, or the ASD diagnosis may be immediately or indirectly disclosed or observed. If the patient's behavior indicates the possibility of an ASD diagnosis, the nurse should approach the patient using evidence-based practices, consisting of methods that have been scientifically researched, studied, and proven to improve outcomes. Collaboration is an important approach for the ED nurse caring for adults with autism. The importance of involving the patient's caregiver throughout the patient's visit to the ED is one of the most important factors for success for the patient and the health care team (Patrizzi & Gialari, 2012). Collaboration among various service systems and agencies confers a number of benefits (Glassheim, 2008).

Project Survey Methods

The purpose of this DNP project is to assess ED RN knowledge deficits and educational needs by conducting a survey of general knowledge of autism and nursing care of adults with autism. The information gathered serves as a needs assessment for the development of educational resources for RNs who may have interactions in the ED with adults with autism.

To gain information on current ED RNs' knowledge and understanding of autism, a convenience survey was distributed to ED nurses in a tertiary-care hospital in the central valley of California. The survey was offered by the author at change of shift huddle over a 2-week period in the nurse's break room. The director of ED nursing had informed the charge nurses to expect the survey and allow sufficient time for the nurses to complete the survey. The survey was collected after completion, or if completed at a later time, given to the charge nurse. At the end of 2 weeks, the author received all the completed surveys.

The purpose of the survey is two-fold: assess general knowledge of autism in RNs currently working in an ED and identify knowledge deficits and educational needs of the ED nurses. The information from this survey could serve as a needs assessment for the development of educational resources for ED RNs caring for adults with autism.

Survey Design

The survey was organized into simple, descriptive tables by four themes, as seen in Figure 6. Analysis of the measurements of central tendencies of the four themes was reviewed as to which of the areas has the greatest knowledge gaps, indicating which areas educational resources should be focused.

1. General Knowledge and Prevalence	2. Causes and Comorbidities
3. Diagnostic Criteria and Treatment	4. Nursing Care

Figure 6. The four themes of survey for survey analysis

Setting

The surveyed hospital ED provides emergency care services to patients of all ages and health conditions on a 24-hour/7-day/week basis. The survey was introduced by the author at change of shift and was made available for the nurse to complete immediately and collected by the author.

Population and Sample

There were approximately 80 ED RNs at the surveyed hospital, including full-time, part-time, and per diem. The survey was available to all nursing shifts and 28 surveys were completed.

To show any demographic differences, the following demographic information was gathered: age, years of nursing experience, educational background, and gender (see Figure 7).
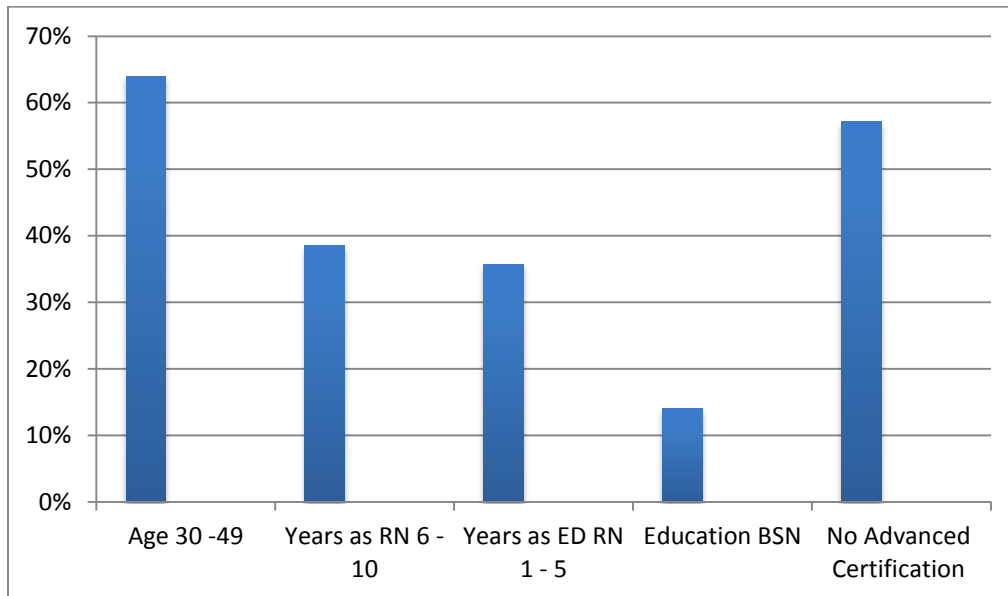
Figure 7. Demographic information collected.

Instrumentation

The survey tool was developed by the author and based on literature obtained from professional sources, such as the CDC, the Diagnostic and Statistical Manual 5th edition (DSM-5), Autism Speaks, medical textbooks, and current peer-reviewed journals. There are quantitative and qualitative portions of the survey. It consisted of 20 Likert-scaled questions with five possible responses: I Strongly Disagree, I Disagree, No opinion/Uncertain, I Agree, and I Strongly Agree (see Figure 8). The end of the survey provided free text space for sharing personal and/or professional experiences with autism and questions, concerns, and/or thoughts. The survey was evaluated for content validity by Dr. Deborah Steele, an author and expert in human behavior.

1. Autism is defined as a complex, neurological developmental disorder

2. Autism occurs more commonly among higher socioeconomic populations

3. With proper treatment, most children outgrow autism

4. The cause of autism is unknown

5. Autism is caused by the MMR vaccine

6. The cause of autism is currently a very active area of research

7. The onset of symptoms occur usually before three years of age

8. Criteria required for the diagnosis of autism includes difficulty with communication and difficulty with social interactions.

9. There is no known cure for autism.

10. Treatment of autism is often a combination of behavior therapy and medication.

11. According to the Centers for Disease Control, 1 child in 68 will be diagnosed

12. with autism.

13. Poor eye contact and lack of facial expression appropriate to the situation

14. are characteristics of severe autism.

15. Repeating words or phrases over and over are characteristics of autism

16. Repetitive motor movements such as hand flapping are used as a method of self-calming in stressful situations.

17. Co-occurring conditions include rigid eating patterns and difficulty with sleep.

18. ED Nurses should approach a patient with autism by giving personal space, and limiting touching if possible.

19. Avoiding physical contact with patients with autism is a good approach.

20. Caregiver involvement is essential when caring for patients with autism

21. Seizure disorders affect many adults with autism

22. Agitated behavior can be decreased by minimizing sensory overload, such as decreasing the number of personnel in the patient's room.

Figure 8. Survey questions.

Data Collection

Data calculations were completed by the author. Simple descriptive tables were created showing the responses of participants by question. Free text responses were transcribed and analyzed for content theme by examining recurring patterns and statements.

Data Analysis Methods

Data were calculated by hand. Simple descriptive tables were created showing the responses of participants by question. Free text responses were transcribed and analyzed for content theme by examining for recurring patterns and statements.

Ethical Consideration

(Human Subject Protections)

Approval from both the hospital's Institutional Review Board (IRB) and the author's school of nursing was obtained prior to administration of the survey. There was no compensation or financial responsibility for the survey participants, confidentiality was assured as no personal identifying information is required or used in this survey.

Demographic information such as age, sex, nursing education, length of time as an ED nurse, specialty certifications was collected for correlational data to enhance potential educational needs. Data will be stored in a password-protected laptop to which only the author has access.

Bias

The survey is a convenience sampling offered to all ED RNs and answered by those who chose to do so. As such, there is inherently a degree of selection bias in the survey; only those interested or experienced in the topic, or those who have the time the answer the questions are likely to respond. The survey may not capture nurses uncomfortable with the topic or those

nurses with limited knowledge or experience with autism. Further, the survey construction could

be inadvertently affected by the authors own interest and experience with autism. The survey has

not previously been validated and should not be considered a pre-test instrument. In addition,

using a Likert-type scale may prompt artificially enthusiastic responses (i.e., "strongly agree" or

"strongly disagree"), which can polarize results.

Assessment of Results

The purpose of this DNP project is to assess ED RN knowledge deficits and educational

needs by conducting a survey of general knowledge of autism and nursing care of adults with

autism. The information gathered serves as a needs assessment for the development of

educational resources for RNs who may have interactions in the ED with adults with autism.

Data are collapsed due to low number of respondents.

Theme 1: General Knowledge and Prevalence

Questions 1, 2, 3, 4, 11, 12, 13, & 14 in the survey measured ED RNs' general

knowledge of ASD. Although it seems there are more questions than answers with ASD,

researchers do agree that autism is a complex, neurologic development disorder, knows no

socioeconomic boundaries, and is a life-long disorder. Eighty percent of the respondents agreed

with the researchers overall and correctly identified ASD as a developmental disorder. Question

2 asked about the influence of individual socioeconomic status on ASD, and the majority (37%)

responded "uncertain." Question 3 was correctly identified by the majority (85%), that one does

not "grow out" of autism. For Question 4 (66%), the majority agreed that the cause of autism

was unknown, 30% were uncertain. For Question 11, 69%, were aware of the latest prevalence

rate published by the CDC; Questions 12, 13, and 14 asked about common characteristics of

ASD, and were correctly identified by 93%.

Question 1

Autism is defined as a complex, neurological developmental disorder

	Strongly agree	I agree	No opinion/ uncertain	I disagree	I strongly disagree
Number of respondents/ percentage	13 (42.3)	10 (38.5)	4 (15.4)	1 (3.8)	0

Question 2

Autism occurs more commonly among higher socioeconomic populations.

	Strongly agree	I agree	No opinion/ uncertain	I disagree	I strongly disagree
Number of respondents/ percentage	0	3 (11)	12 (37)	8 (30)	6 (22)

Question 3

With proper treatment, most children outgrow autism.

	Strongly agree	I agree	No opinion/ uncertain	I disagree	I strongly disagree
Number of respondents/ percentage	1 (3.7)	3 (11)	5 (18.5)	9 (33.3)	10 (33.3)

Question 4

The cause of autism is unknown.

	Strongly agree	I agree	No opinion/ uncertain	I disagree	I strongly disagree
Number of respondents/ percentage	9 (33)	9 (33)	8 (29.7)	1 (3.7)	0

Question 11

According to the CDC, 1 child in 68 will be diagnosed with autism

	Strongly agree	I agree	No opinion/ uncertain	I disagree	I strongly disagree
Number of respondents/ percentage	5 (18.5)	14 (50)	8 (29.7)	1 (3.7)	0

Question 12

Poor eye contact and lack of facial expression appropriate to the situation are characteristics of severe autism.

	Strongly agree	I agree	No opinion/ uncertain	I disagree	I strongly disagree
Number of respondents/ percentage	8(29.7)	14(50)	5(18.5)	1(3.7)	0

Question 13

Repeating words or phrases over and over are characteristics of autism.

	Strongly agree	I agree	No opinion/ uncertain	I disagree	I strongly disagree
Number of respondents/ percentage	5(3.7)	8(29.7)	11(39)	3(11)	1(3.7)

Question 14

Repetitive motor movements such as hand-flapping are used as a method of self-calming in stressful situations.

	Strongly agree	I agree	No opinion/ uncertain	I disagree	I strongly disagree
Number of respondents/ percentage	6(21)	18(64)	5(18.5)	0	0

Theme 1

Correct response	158	66%
Incorrect response	22	9%
No opinion/uncertain	59	25%
Total responses	239	100%

Theme 2: Causes and Comorbidities

Although there is no known cause of ASD at this time, researchers are actively working on solving this puzzle. Over the last 5 years, scientists have identified a number of rare gene changes, or mutations, associated with autism. Most cases of autism, however, appear to be caused by a combination of autism risk genes and environmental factors influencing early brain development (Autism Speaks, 2015). Over the years, there were concerns that vaccines may be a cause of autism. A new study evaluating parents' concerns of "too many vaccines too soon" and autism has been published online in the Journal of Pediatrics, March 29, 2013. It adds to the conclusion of a 2004 comprehensive review by the Institute of Medicine (IOM) that there is no causal relationship between certain vaccine types and autism (CDC, 2015). Of the surveyed RNs, 21% answered No Opinion/Uncertain to Question 5, "Autism is caused by the MMR vaccine" and 32% stated I Disagree. Even with many public health announcements since 2004 from the CDC and other stakeholders, and extensive media coverage, only 46% of the respondents answered correctly. Nurses caring for adults with autism must have current and correct information to practice care that is evidence based and scientifically proven and to provide factual information to others.

Questions 15 and 19 asked about co-occurring conditions and comorbidities. Often, individuals with ASD have neurological, medical, and psychiatric conditions and their reported association and prevalence is varying in the literature. The literature discusses seizures, gastrointestinal problems, as sleep issues as common maladies, in addition to psychiatric diagnoses, such as depression, anxiety disorder, and mood disorder. In 2006, a review of the literature was published on the co-occurrence of autism and mental retardation (Edelson, 2006). It was generally assumed prior to this research that 70% to 80% of children with ASD have mental retardation. Edelson found that 55% of the empirical studies were conducted prior to 1980 and 75% prior to 1990. Edelson pointed out that the claims that a majority of children with autism have mental retardation may be erroneously referenced in journal articles, child psychopathology textbooks, in abnormal psychology textbooks, and most troublesome, in the *DSM-IV-TR* criteria (Edelson, 2006). Edelson's review of the literature was significant in that it demonstrated a concern for the reliability and validity of information influencing perceptions and treatments of children with ASD. As these children progress towards adulthood, where the majority of one's life is lived, one cannot emphasize strongly enough the importance of scientific research for this population so they can receive the comprehensive and appropriate course of health care they deserve. Despite the issues within the literature, the majority of the respondents answered correctly, or No Opinion/Uncertain, with just 3% incorrect answers.

Question 5

Autism is caused by the MMR vaccine.

	Strongly agree	I agree	No opinion/ uncertain	I disagree	I strongly disagree
Number of respondents/ percentage	1(3.7)	0	6(21)	9(32)	13(46)

Question 15

Co-occurring conditions include rigid eating patterns and difficulty with sleep.

	Strongly agree	I agree	No opinion/ uncertain	I disagree	I strongly disagree
Number of respondents/ percentage	6(21)	11(39)	11(39)	1(3.7)	0

Question 19

Seizure disorders affect many adults with autism.

	Strongly agree	I agree	No opinion/ uncertain	I disagree	I strongly disagree
Number of respondents/ percentage	0	10(36)	17(60.7)	1(3.7)	0

Theme 2

Correct response	46	58%
Incorrect response	3	3%
No opinion/uncertain	31	39%
Total responses	80	100%

Theme 3: Diagnostic Criteria and Treatment

Theme 3 covered questions 7, 8, 9, & 10 and looked at diagnostic criteria, with 82% of the ED RNs responding correctly and the highest score of correct answers within the four themes by a significant margin (82% versus 66%, theme 1, 64%, theme 4 and 58%, Theme 2). ASD is a growing public health problem that continues to be widely discussed in healthcare, education, and media venues. Autism is a complex neurodevelopmental disorder with a range in expression

from mild difficulties in social communication to profound difficulties with all aspects of daily

living (Giarelli & Gardner, 2012). The heterogeneity in the behavioral expression of ASDs is

likely a reflection of the complex genetic profile associated with this spectrum of disorders

(Caglayan, 2010).

One of the most important changes in the 5th edition of the DSM is to autism-related

disorders. The diagnosis of autism spectrum disorders represents a more accurate and medically

and scientifically useful way of diagnosing individuals with autism-related disorders. The DSM-

5 does not outline recommended treatment and services for mental disorders, instead determining

an accurate diagnosis is a first step for a clinician in defining a treatment plan for a patient. The

recommendation for the DSM-5 criteria by the Neurodevelopmental Work Group is thought to

be a better reflection of the state of knowledge about autism, believing a single umbrella disorder

will improve the diagnosis of ASD without limiting the sensitivity of the criteria, or substantially

changing the number of children being diagnosed (APA, 2013). Although this DNP project

focused on adults with ASD, the onset of autism is usually before the third birthday and ED RNs

can expect to provide guidance and education to many people with concerns about autism.

Question 7

The onset of symptoms occurs usually before three years of age.

	Strongly agree	I agree	No opinion/ uncertain	I disagree	I strongly disagree
Number of respondents/ percentage	8(29.7)	17(60.7)	3(11)	1(3.7)	0

Question 8

Criteria required for the diagnosis of autism includes difficulty with communication and difficulty with social skills.

	Strongly agree	I agree	No opinion/ uncertain	I disagree	I strongly disagree
Number of respondents/ percentage	11(39)	14(50)	3(11)	1(3.7)	0

Question 9

There is no known cure for autism.

	Strongly agree	I agree	No opinion/ uncertain	I disagree	I strongly disagree
Number of respondents/ percentage	9(32)	13(46)	5(18.5)	2(6)	0

Question 10

Treatment of autism is often a combination of behavior therapy and medication.

	Strongly agree	I agree	No opinion/ uncertain	I disagree	I strongly disagree
Number of respondents/ percentage	3(11)	21(75)	5(18.5)	2(7)	0

Theme 3

Correct response	88	82%
Incorrect response	4	4%
No opinion/uncertain	15	14%
Total responses	107	100%

Theme 4: Nursing Care

Questions specific to nurses providing care in a manner unique for patients with ASD were included in Theme 4. The ED RN approach can be pivotal in the outcome of the adult ED patient with ASD. Understanding the core characteristics of ASD is vital before proceeding with assessments and care; the ED nurse must recognize manifestations that the core characteristics will be different for each individual. The process of emergency care is complicated and can be overwhelming for any patient (Patrizzi & Giarelli, 2012). The patient with ASD may exhibit behaviors unfamiliar to the ED staff and others in the area. Obtaining information from the patient, family, or caregiver is essential; how does the patient respond to touch, noise, light, activity, is the patient able to communicate verbally, how does the patient express pain/discomfort/anxiety are questions to ask ahead of establishing a trusting, patient-centered relationship. The ED RNs answered the questions in Theme 4 correctly, at 64%, with 20% uncertain of the correct response and 16% incorrectly answering. Knowledge of patient behaviors, preferences, and tendencies, as well as successful methods that have worked in prior visits, will contribute to best-practices nursing care in the ED. If the ED admission is managed thoughtfully, the patient's experience will begin as a therapeutic encounter and set the example for subsequent contacts with health services providers (Patrizzi & Giarelli, 2012).

Question 16

ED Nurses should approach a patient with autism by giving personal space, and, limiting touching if possible.

	Strongly agree	I agree	No opinion/ uncertain	I disagree	I strongly disagree
Number of respondents/ percentage	6(21)	18(64)	3(11)	1(3.7)	0

Question 17

Avoiding physical contact with patients with autism is a good approach.

	Strongly agree	I agree	No opinion/ uncertain	I disagree	I strongly disagree
Number of respondents/ percentage	3(11)	8(29.7)	11(39)	5(18.5)	1(3.7)

Question 18

Caregiver involvement is essential when caring for patients with autism.

	Strongly agree	I agree	No opinion/ uncertain	I disagree	I strongly disagree
Number of respondents/ percentage	17(60.7)	10(35.7)	0	1(3.7)	0

Question 20

Agitated behavior can be decreased by minimizing sensory overload such as decreasing the number of personnel in the patient's room can be beneficial to decreasing behavior escalations

	Strongly agree	I agree	No opinion/ uncertain	I disagree	I strongly disagree
Number of respondents/ percentage	9(32)	18(64)	0	0	0

Theme 4

Correct response	83	64%
Incorrect response	20	16%
No opinion/uncertain	27	20%
Total responses	130	100%

The survey offered two areas for free-text: (a) Please share any experiences with autism you have had either personally or professionally. and (b) Please write any questions, concerns, and/or thoughts you would like to share with Shauna Miller (author).

There were five responses for the first free-text and one response for the second. In the first free-text area, four nurses shared personal relationships with individuals with autism and one nurse shared her professional experience. In the second free-text area, the nurse asked if there was a correlation between autism and induction of labor.

Discussion and Conclusion

The results of the survey, when seen in the context of the RN's general knowledge and nursing care of adults with autism, present a picture of awareness of autism, but an uncertainty of the known facts of ASD, indicating a tendency towards lacking confidence in caring for this population. Validating the author's premise that knowledge of autism is vital to providing appropriate nursing care, the RNs surveyed showed similar results in their levels of knowledge of autism in general (66% correct) and their ability to provide safe and effective nursing care (64% correct). Just over half (58%) of the responses were correctly identified in the causes and comorbidity theme, an area that is actively researched with few definitive answers, yet of great importance in planning care and patient/family education. The diagnostic inclusion criteria and treatment options are topics actively researched and publicly discussed, with 82% of the RNs answering those questions correctly, validating the importance of integrating scientific and evidence-based knowledge with the clinical nursing care.

Correlations were not noted between the demographic data; answers were not more correct for those in particular age or gender groups, or level of education and nursing experience. Data obtained from the demographic information were not statistically significant. Those RNs

who identified themselves by their age and were between the ages of 26 and 39 were analyzed

for an increased awareness due to possibly having young children with autism. This was

nonsignificantly relevant, leading to the inclusion of general knowledge and prevalence

information in the development of general knowledge resources.

Limitations

In this project, the author sought to better understand the general knowledge of RNs with

regard to the characteristics of autism and the implication for nursing care to identify knowledge

gaps and areas of concerns. It is the first step to qualifying the issue of the impact the growing

number of adults with autism will have on providing emergency care.

The limitations for this project were numerous: the sample size was small and limited to

one ED. Asking RNs to complete a survey during change of shift could have caused some to rush

through the answers without careful consideration. Some of the respondents were former

students of the author, others were colleagues known to the author which could have caused bias.

Finally, the author herself was well aware of the many biases her own frame of reference brought

to the project, causing her to choose one question over another and emphasize a certain wording.

Implications for Nursing Practice

A nurse must apprehend the reality of the patient with ASD by trying to see the ED

through his or her eyes (Garielli & Gardner, 2012). The role of the ED RN is essential in the

management of the care of adults with autism. Working together with the patient, family, and

health care team, the nurse ensures patient care is effective and appropriate. Knowledge of ASD

and its common characteristics is invaluable in caring for these patients; however, ED nurses

must recognize that each of these patients is unique and he or she will need to modify the

approach depending on the patient (Giarelli & Gardner, 2012). Effective and appropriate nursing

care is the result of evidence-based care and best-practices. By increasing their knowledge of ASD, nurses can deliver effective and appropriate care, resulting in personal and patient-centered care.

A study of autism knowledge (Heidgerken et al., 2005) mostly among primary care providers (physicians) and specialists (psychiatrists that are expert in autism) reported different understandings of autism, treatment options, and prognoses. This translates to a high potential for inconsistent health care across services, settings, and professional practice (Giarelli & Gardner, 2012). Individuals with ASD may have had negative health care experiences that resulted in poor outcomes. Each and every interaction between the adult patient with ASD and the RN should be thoughtful and purposeful, resulting in a positive experience and improved outcomes.

Evidence-Based Practice (EBP) – "Integrate best current evidence with clinical expertise and patient/family preferences and values for delivery of optimal health care" (Cronenwett et al., 2007, p. 600) is imperative for providing a quality and safe environment for the adult patient with autism in the ED and for the health care team. Recognizing the limited research available is the first step to addressing this knowledge gap and nurses working in EDs should insist that their care and resources be guided by EBP not only for optimal health care, but for nurse satisfaction. This survey points to how sufficient knowledge of adults with ASD, its potential causes and comorbidities, and strategies for providing nursing care would lead to more positive experiences, effective care, and integrated care plans.

Because of the prevalence of autism and its possibly overwhelming impact on the ED, it is critical that adults with autism are treated within a system that is coordinated and integrated. Without integration, all aspects of health care fall short of the ideal. Patients' needs may be incorrectly identified, services are not delivered or delayed, and quality of care and patient

satisfaction break down (Charns & Tewksbury, 1993; Shortell, Gillies, Anderson, Mitchell, & Morgan, 1993). Integrated, comprehensive nursing care is the profession's response to the fragmented delivery of health and social services that characterize the care of people with ASD (Giarelli, 2012). The ED is often the most frequent point of medical service for many patients, and may be the only point of health care, and as such is an ideal environment for nurses to apply their knowledge and provide coordinated and integrated care and resources to this special population.

In the DNP project survey, RNs showed an awareness of the diagnostic criteria and lack of available treatment for ASD. More education on adults with ASD may be needed at all levels of health care. Caring for individuals with developmental disabilities beginning at the undergraduate level may be indicated, but a more formal educational format for ED RNs specific to ASD should be included in orientation and ongoing education and training. With increased knowledge of ASD, nurses can lead other members of the health care team as more patients with ASD reach adulthood and present for emergency care (Patrizzi & Giarelli, 2012). By teaching nurses the core characteristics, providing appropriate resources and interventions, utilizing a patent-centered approach, the ED RN can plan care and provide a thoughtful and therapeutic encounter for the adult with autism.

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Appendix: Demographic Tables

Table 1

Ages of Survey Respondents (in Years)

Age	Frequency	Percent
26 – 29	3	10.7
30 – 39	9	32.1
40 – 49	9	32.1
50 - 59	4	14.3
60 - 66	1	3.6
Total	26	92.7
Missing	2	7.3
Total	28	100

Table 2

Years as RN

Years as RN	Frequency	Percent
< 1yr	2	7.3
1 – 5 yrs	6	21.4
6 - 10	8	28.5
11 - 20	6	21.4
> 20	5	17.8
Total	27	96.4
Missing	1	3.6
< 1yr	2	7.3
Total	28	100

Table 3

Years as RN in ED

Years as RN	Frequency	Percent
< 1yr	2	7.3
1 – 5 yrs	10	35.7
6 - 10	6	21.2
11 - 20	2	7.3
> 20	2	7.3
Total	22	79.0
Missing	6	21.2
Total	28	100

Table 4

Nursing Education

Degree	Frequency	Percent
AA	7	25.0
BSN	14	50.0
MSN	4	14.3
	2	7.3
Total	27	96.4
Missing	1	3.6
Total	28	100

Table 5

Advanced Emergency Nursing Certification

	Frequency	Percent
Yes	12	42.8
No/blank	16	57.2
Total	28	100