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**NURSING STRATEGIES TO MEET THE COMMUNICATION NEEDS OF
CHILDREN WITH AUTISM SPECTRUM DISORDER**

**A MASTER'S CAPSTONE PROJECT
SUBMITTED TO THE GRADUATE FACULTY
OF THE GRADUATE SCHOOL
BETHEL UNIVERSITY**

BY

ELIZABETH A. VOSS

**IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF
MASTER OF SCIENCE IN NURSING**

DECEMBER 2019

BETHEL UNIVERSITY

**NURSING STRATEGIES TO MEET THE COMMUNICATION NEEDS OF
CHILDREN WITH AUTISM SPECTRUM DISORDER**

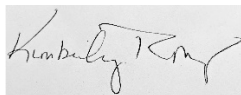
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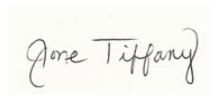
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Acknowledgements

The nursing professors at Bethel University, and writing specialists at the Bethel Graduate School Resource Center academic resource center were the compass for my journey to seek answers about the communication impairments of children with ASD and strategies nurses can implement to meet their needs. During the exploration and examination of the practice questions, your expertise, insights, confidence in my ability, and caring support kept me searching, learning, writing, and finally understanding that the best practices to meet the communication needs of children with ASD were centered on “caring moments”. I am blessed and grateful for the opportunity to share this journey of exploration, and experience the mystery of miracles with professors who are Caritas Nurses.

Abstract

Background: Parents reported their children with autism spectrum disorder (ASD) needs are unmet or delayed in health care settings. Health care providers stated they were not comfortable caring for children with ASD. Since communication impairment is the hallmark of ASD, nurses have a duty to know how children with ASD communicate and provide strategies to meet their communication needs.

Purpose: The purpose of this critical review was to examine the literature for answers to the practice questions: How do children with ASD communicate? And, what strategies could a nurse implement to meet the communication needs of children with ASD?

Results: Applying *Johns Hopkins Research Evidence-Based Model* (2018), the critical review yielded 18 articles with strong evidence from research and nonresearch. Throughout the literature, the findings included: children with ASD communicate differently, parents are a primary resource, behavior challenges are related to unmet communication needs, and integrating Watson's (1979) ten carative factors into strategies is best practice. A gap in literature identified a need for more evidence-based communication strategies.

Conclusion: This critical review identified three strategies to meet the communication needs of children with ASD in health care settings: (a) provide calm environment with sensory sensitive distractions and assistive communication tools; (b) integrate into the child's plan of care, the parents' insights about their child's unique communication presentation, coping skills, and home routines; and (c) with caring moments, nurses provide time for children with ASD to process information, to cope with change, to relax, to feel heard, to feel safe, and to have their needs met.

Implications for Research and Practice: Since, variation in communication impairments is the hallmark symptom of ASD in children, further level I research is needed to provide evidence-based strategies to meet their needs in health care settings, and Watson's (2009) carative factors: four to develop trusting-caring relationships, and six creative problem solving to meet their heightened need for quality relationships and communication.

Keywords: autism spectrum disorder, children, parents, communication impairment, nurses, communication strategies, Watson Caring Science Theory.

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Chapter One: Introduction

Nurses are increasingly caring for children diagnosed with autism spectrum disorder (ASD). According to the Center for Disease Control and Prevention (CDC, 2018), one in every 59 children is currently diagnosed with ASD in the United States. The *Diagnostic and Statistical Manual of Mental Disorders* (DSM-V, 2013) defined autism as a single diagnosis (ASD) with social, behavioral and communication impairment from mild to severe (Johnson, Burkett, Reinhold, & Bultas, 2016). A life-long neurodevelopmental disorder, ASD has no known cause or cure. The communication, social skills and developmental delays correlated with ASD typically manifest prior to 36 months and are categorized based on support needed. Under the DSM-5 diagnostic criteria the symptoms must present in early childhood, even if they aren't recognized until later in life. According to the American Psychological Association (APA; 2013), DSM-5 diagnosis criteria for ASD include: (a) none or minimal eye contact, nonverbal, echolalia, limited or no social communication, emotionally disconnected from others, or have difficulty developing friendships; (b) repetitive behaviors such as, hand flapping, spinning, singular interests, or depend on routines; (c) symptoms present in early development, (d) clinical impairment affects social, occupational , or other basic life skills related to ASD symptoms; and (e) intellectual disability or global delay are not primary causation (Johnson et al., 2016; Jolly, 2015). Children with ASD require more medications and experience frequent clinic visits, and longer hospital stays (Johnson & Rodriguez, 2013; Vaz, 2013; Zwaigenbaum, et al., 2016). Since ASD is such a challenging disorder, nurses have a duty to be familiar with communication strategies to provide quality care to children with ASD and their families.

Evidence for Critical Review

Communication skills are necessary for a nurse to provide quality care. Since children with ASD have a communication impairment, their frustrations, which are partially created from not being understood, may sometimes manifest in behavioral outbursts. Research studies report that communication barriers between healthcare providers and children with ASD contribute to delayed care (Jennings, 2018; Russell & McCloskey, 2015). In fact, there are emergency room case studies of children with ASD who required sedation and restraint (Koski, Gabriels, & Beresford, 2016). According to APA (2013), the severity of communication impairment for individuals with ASD is categorized on three levels. A child with level one severity will use language as a tool to get needs met, resist redirection, and require support to initiate a conversation because of their limited social awareness. The child with level two severity will require substantial support with scripted language and picture prompts because of their nonverbal and verbal communication deficits. The child with level three severity require the most support because of their limited or complete absence of functional language, which often leads to frustration and meltdowns (Vaz, 2013; Brown & Elder, 2014; Jolly, 2015). To address the needs of children with ASD, nurses must understand how the child communicates and what communications strategies are most effective.

Significance to Nursing

According to the American Nurses Association (2002), the nursing profession is responsible to the public for incorporating caring, evidence-based practices and measuring their efficacy. The American with Disability Act of 1990 (ADA) requires health professionals to have a communication plan to address all disabilities. Verbal and non-verbal communication is how

individuals learn about each other. Even though the process is complex, it happens quickly. Through communication, the nurse establishes a therapeutic relationship.

Researchers suggest assessing and documenting the child's communication preferences each time they enter the health care system (Johnson et al., 2016; Jolly 2015). From birth through the stages of adulthood, the individual with ASD develops language in a unique manner. Language characteristics of autism include: echolalia, delayed comprehension, contact gestures, pronoun reversal and neologisms. The communication complexity of the child with ASD, often requires the parents or primary caregiver to serve as the child's interpreter (Brown & Elder, 2013; Jolly, 2015; Russel & McCloskey, 2015). Less than fifty percent of children with ASD will develop functional language, and they will require supportive communication strategies (Inglese, 2009). Through understanding how they communicate, the nurse can integrate supportive communication strategies in the child's care plan.

Statement of Purpose

The purpose of this critical review is to examine the literature to answer two practice questions: How do children with ASD communicate? What strategies could a nurse implement to meet the communication needs of children with ASD? Over the past decade, research has continued to identify the organic cause for autism and develop new interventions to support the developmental delays. Many children with ASD do not develop enough functional language required to meet their daily communication needs (Johnson et al., 2016; Llaneza, et al., 2010; Russell & McCloskey, 2016, Zwaigenbaum, et al., 2016). Both research and nonresearch articles suggest incorporating evidence-based communication tools used in schools and at home as communication care strategies in health care settings. The impact of this literature review will

provide nurses with an understanding of ASD communication impairment and effective communication strategies to provide pediatric patients with ASD quality care.

Theoretical Framework

Dr. Jean Watson's (1979) *Theory of Human Science and Human Caring* provides a relationship-centered caring framework for professional nursing practice. The major elements of her theory are the ten carative factors, the transpersonal caring relationship, and the caring occasion/caring moments (Watson, 2009). The act of caring requires the individual to engage in all ways of knowing and being. Dr. Watson identified congruent, empathetic, and warm communication as the foundation of patient-centered care. Her theory provides the tools to guide and evaluate the efficacy of caring communication strategies as measured by an individual's progress on the health wellness continuum.

Watson's (1979) Science of Caring Theory is built upon ten carative factors that guide nurses to establish healing relationships through intention. The first carative factor addresses the humanistic-altruistic values through practicing loving-kindness such as accepting the uniqueness of a child with ASD and recognizing the child's communication preferences. The second carative factor instills faith and hope, such as honoring a child with ASD's need for rituals and listening to their parents/caregivers explain the child's home routine. The third carative factor cultivates sensitivity for oneself and others through self-reflection for prejudice to reduce the risk of bias which could contribute to a child's frustration and meltdown. The fourth carative factor is developing a helping-trusting human caring relationship such as the nurse taking time to hear the child's story as told by the parent or caregiver and addressing their concerns in the plan of care. The fifth carative factor is promoting and accepting expression of positive and negative feelings by anticipating and addressing a child's communication needs with a quiet, low-light room to

reduce anxiety and improve their ability to follow verbal or nonverbal directions. The sixth carative factor is systematic use of a scientific (creative) problem solving caring process; for example, this could mean the implementation of adaptive communication tools like an android with pictures to explain procedures or asking questions about pain. The seventh carative factor is promoting transpersonal teaching-learning. For example, nurses would familiarize themselves with the communication impairment of children with ASD; and how the parents' role as his or her child's interpreter is a caring communication strategy. The eighth carative factor is providing a supportive, protective and/or corrective mental, social, spiritual environment; for example, to reduce the anxiety of children with ASD, the nurse would provide picture schedules to explain the hospital routine. The ninth carative factor is assisting with gratification of human needs; for instance, providing a child with ASD their preferred communication strategy or daily routine as explained by their parents or caregivers. The tenth carative factor is allowing for existential-phenomenological dimensions through observing the best possible outcome and celebrating the miracles found in the unexpected positive patient outcome. Through application of the ten carative factors, caring communication strategies would reduce discomfort, address anticipated needs, convey concern for the child's well-being, and reveal professional competence to their families (Giarelli & Gardner, 2012; Greenspan, 2006; Watson, 2009).

Summary

Nurses have an ethical responsibility to provide children with ASD and their families the right care, at the right time, for the right reason. To provide quality care for children with ASD, nurses must understand effective communication strategies. Research reports that when a child with ASD does not have his or her needs addressed, they experience frustration, confusion, meltdowns, pain, and delayed care. Dr. Watson's (1979) caring theory guides nurses to acquire

knowledge about children with ASD, and then apply or create effective communication strategies. With the application of the ten curative factors, the literature review will provide nurses an overview of ASD communication developmental milestones, behavioral challenges, and effective communication strategies.

Chapter Two: Methods

Today, nurses are expected to use an evidence-based approach to integrate research into practice. This critical review was a structured literature review of published journal articles found in academic libraries or on-line databases. Each search included a predetermined inclusion and exclusion criteria. Then articles were further appraised using an evidence-based practice model for strength and quality of evidence. Once an article was selected, the evidence was organized on a matrix to answer the research question, and provide nurses information they could apply to their practice, which is located in the Appendix.

Search Strategies

The aim of this review is to discuss the background questions: How do children with autism spectrum disorder communicate and what effective strategies could a nurse implement to meet the communication needs of children with ASD? The critical review followed Johns Hopkins Nursing Evidence-Based Practice Process (2018): (a) practice question, (b) evidence, and (c) translation. The search engines included a variety of data bases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline (PubMed), Education Resources Information Center (ERIC) and a psychological database, APA Psych NET, Center for Disease Control and National Institutes of Health. The initial simple search terms included: autism spectrum disorder, children or pediatrics, parents, communication, picture schedules, social script, anxiety, Watson's Caring Theory, health care provider, and nurse. These terms yielded 133 articles published from 2005 to present. Limits were placed on PubMed and CINAHL: randomized controlled

clinical trials, practice guidelines, systematic reviews, literature reviews and continuing nurse education. The advanced search with limits yielded 55 articles.

Inclusion and Exclusion Criteria

Multiple searches were conducted specifically to address ASD communication challenges with pediatric populations, specifically in clinical practice. The inclusion criteria included; (a) children defined as ages 18 months to 18 years with a diagnosis of ASD and parent or caregiver, (b) ASD communication impairment in children, (c) communication strategies for children with ASD, (d) health care settings, (e) peer reviewed, performed in the United States, Canada or Europe; and (f) published in English no earlier than 2009. Exclusion criteria included; (a) editorials, books, dissertations, (b) ASD articles that did not address communication strategies and autism communication impairment, and (c) ASD articles on subjects age greater than 18. All abstracts were reviewed based on their relevance to the review. Of the 55 articles yielded, 18 were found relevant for the critical review.

Selected Articles for Critical Review

Every article explained pediatric ASD complex care challenges, discussed the importance of understanding the spectrum disorder communication impairment, and the impact of effective communication strategies on the healing process. The 18 articles were selected on criteria and soundness of evidence to answer the critical review practice questions. Of the 18 articles, eight were research studies and ten were nonresearch articles.

The research articles discussed pediatric ASD communication impairment, communication tools, outcomes including limitations and recommendations for further

research. The research articles included quantitative studies and qualitative studies. The two quantitative studies were experimental designs (Johnson, et al., 2014; Johnson & Bree, 2014). The six qualitative studies included: two nonexperimental descriptive comparative design studies (Bultas & McMillin, 2016; Drake et al., 2012), one quasi-experimental descriptive feasibility study (Chebuhar et al., 2013), one quasi-experimental predictive design study (Vaz, 2013), and two basic qualitative descriptive designs studies (Russell & McCloskey, 2015; Zwaigenbaum et al., 2016). The findings for all research studies were consistent with current literature.

The nonresearch evidence included research literature reviews, American Nurse Credentialing Center (ANCC) certified continuing education articles (CNE), and expert opinions. The articles discussed clinical diagnoses of ASD, prevalence, communication impairment, behavior challenges related to communication impairment, parents' experience and recommended care strategies (Brown & Elder, 2014; Bultas et al., 2016; Inglese, 2009; Inglese & Elder, 2009; Johnson et al., 2016; Johnson & Rodriguez, 2013; Jolly, 2015; Koski, et al., 2016; Llaneza et al., 2010; Scarpinato et al., 2010)). The authors of the articles were experts in the field of autism, discussed current practice, limitations and need for further research. All of the nonresearch articles were supported with extensive references from diverse disciplines.

Appraisal Criteria

According to Melnyk and Newhouse (2014), the level of evidence is determined by the strength and quality of evidence (as cited in Dearholt & Dang, 2018). Effective communication strategies based on valid research and non-research articles are the foundation of best practice. In this critical review, the strength and quality of evidence

was validated using the Dearholt and Dang's (2018) John Hopkins Nursing Evidence-based Practice (JHNEBP) model. The model divides the evidence into two categories: research (scientific) or nonresearch (summaries of research).

Scientific evidence is the strongest predictor of a clinical intervention resulting in a positive patient experience (Dang & Dearholt, 2018). Scientific research has three levels: Level I, Level II, and Level III. The critical review included two level I quantitative studies and six qualitative that included: four Level II studies and two-Level III studies. The Level I studies' research designs were experimental, which included: an intervention, control, random assignment and manipulation of one variable (Johnson & Bree, 2014; Johnson, et al., 2014). The quality of the evidence was further appraised for external validity, reliability, and measure of precision. In this critical review, one study had a quality rating of High (A) with generalizable results (Johnson, et al. 2014), and the other study was Good (B) with reasonably consistent results (Johnson & Bree, 2014). Two level II studies were quasi-experimental and neither withheld the intervention because it would be unethical. One study evaluated the intervention with descriptive surveys (Chebuhar et al., 2013); one study evaluated the intervention through a predictive design (Vaz, 2013). The other level II studies were nonexperimental with descriptive comparative designs, and both used cross-sectional survey designs to collect data, and descriptive statistics for analysis (Bultas & McMillin, 2016; Drake et al., 2012). The level III studies were basic qualitative with descriptive designs that captured themes for greater understanding of parents' and children with ASD' health care setting experience (Russell & McCloskey, 2015; Zwaigenbaum et al., 2016). The level II and level III studies were evaluated for validity by their: transparency, credibility, dependability, and reflexivity.

Consistently, the data found in the studies supported the findings found in current literature about children with autism. The quality of all six level III studies were appraised as High/Good (A/B) (Bultas & McMillin, 2016; Chebuhar et al., 2013; Drake et al., 2012; Russell & McCloskey, 2015; Vaz, 2013; Zwaigenbaum et al., 2016).

Nonresearch evidence captures the intersection of art and science. Since communication is both art and science, most of the articles found in this critical review were nonresearch. According to Dang and Dearholt (2018), the types of nonresearch evidence include: Level IV clinical guidelines and consensus/position statements; Level V literature reviews, integrative reviews, quality improvement reports, financial evaluations, expert opinions, case reports, community standards, clinician experience, and patient/consumer experience. The critical review yielded 10 level V articles that included: a literature review, expert opinion and clinician experience. Consistently, the articles had several references from multiple sources, expert authors in the field of autism and children, and provided recommendations for current practice and future studies. The appraised quality of evidence for all 10 level V studies was High (A). (Brown & Elder, 2014; Bultas et al., 2016; Inglese, 2009; Inglese & Elder, 2009; Johnson et al., 2016; Johnson & Rodriguez, 2013; Jolly, 2015; Koski et al., 2016; Llaneza et al., 2010; Scarpinato et al., 2010).

Evaluating the level and quality of evidence was vital to the process of determining the usefulness of the information to provide nurses an understanding of communication impairment in children with ASD and effective communication strategies to ensure quality care. Every article was published in a peer reviewed journal. First, each study was appraised for both strength and quality of evidence, applying the

appropriate JHNEBP appraisal form (Dang & Dearholt, 2018). Next, clinical information about pediatric ASD communication impairment and effective communication strategies were collected on a matrix. Finally, the communication strategy recommendations were evaluated as evidence of a caring practice, applying Watson's ten carative factors.

Summary

If you were to query "autism" in the Google search box, there would be over 20 million hits in 0.21 seconds (D'Auria, 2010). To find an answer to the practice question, the critical review of literature search required the rigors of an evidence-based search. "A systematic use of problem-solving method for decision making..." (Watson, 2009, p. 30). The initial search yielded 55 articles that were further evaluated by inclusion/exclusion criteria, practice problem and strength of evidence, which created a matrix of 18 articles. The evidence included: answers to the practice questions, gaps in current knowledge and strategies nurses can use to address the needs of children with ASD. The method of inquiry supported the Institute of Medicine's (IOM) 2020 goal that 90% of health care decisions in the United States would be evidence-based (Melnyk, Fineout-Overholt, Stillwell, & Williamson, 2009).

Chapter Three: Literature Review and Analysis

This literature review explored the varied communication impairments of children with autism spectrum disorder including challenges, and identified potential strategies to meet their communication needs across all health care settings. Multiple articles examined the correlation between maladaptive behaviors, anxiety, delayed care and communication challenges experienced by children with ASD (Inglese, 2009; Inglese & Elder, 2009; Scarpinato et al., 2010; Zwaigenbaum et al., 2016). Research studies identified parents as the primary resource and interpreter for their child with ASD (Johnson & Rodriguez, 2013; Llaneza et al., 2010). Experts suggested a lack of knowledge about the disorder and limited effective communication systems integrated into health care settings as two of the greatest challenges for health care providers caring for children with ASD (Russell & McCloskey, 2015; Scarpinato et al., 2010; Zwaigenbaum et al., 2016). Two pilot studies suggested effective communication strategies used in other community settings, such as home or school, are transferable to health care settings (Chebuhar et al., 2013; Johnson et al., 2014). Through application of a matrix the information was organized, five themes identified, and research evaluated for potential answers to the practice questions.

Matrix

The matrix was organized to answer the critical review practice questions, which were: How do children with autism spectrum disorder communicate and what strategies could a nurse implement to meet the communication needs of children with ASD? Data was collected from each article and arranged on the matrix by: purpose, sample and setting, strength and quality of evidence, design and method, results and conclusion,

strength and limitations of study, author recommendations and implications for nursing. The purpose was a statement to explain how the article explored, described, discussed; and/or evaluated information about children with ASD and care strategies. The sample and setting identified the geographic population of children with ASD. The strength and quality of evidence was based on Johns Hopkins Evidence-Based Practice Model (2018). The design and method explained the process used to discover, and evaluate or create the information discussed in the article. The results included: empirical evidence, themes and subjective observations, which were evaluated with a conclusion. The strength of the article provided confidence to integrate the information into practice for future studies. In contrast, limitations provided evidence to use caution before generalizing recommendations into nursing practice or future studies. The author recommendations were scientifically logical ideas that evolved from their inquiry. Implications discussed and reflected the potential for the information on the matrix to answer the practice questions. The matrix can be found in the Appendix.

Major Findings

The literature review presented five themes:

1. Communication features of children with ASD are the hallmark of their clinical presentation.
2. Social communication impairment was the primary reason for anxiety, behavior challenges and unmet needs of children with ASD and their parent's anxiety.
3. Parents were the primary interpreter for the child with ASD.

4. Health care providers were not comfortable communicating and managing challenging behaviors of children with ASD.

5. Communication media which included both visual and auditory information were preferred by children with ASD.

The five themes explained the unique varied challenges of children with ASD and the potential strategies to meet their communication needs.

Core communication features, which are the hallmark for children with ASD.

Children with ASD display impaired functioning in two domains: (a) social communication and interaction and (b) restricted interests or repetitive behaviors (APA, 2013). Developmental language delays between ages 18 – 36 months are a criterion used to assess and diagnosis ASD (Inglese, 2009). Brown and Elder (2014) state “impairments in communication are a hallmark of ASD” (p.219). The clinical presentation of their communication impairment includes: delayed processing time, sensitivity to sensory overload, cognitive comprehension doesn’t correlate with chronological age, over 50% of the children do not have a functional language, and they experience a feeling of “aloneness”. The severity of impairment ranges from no verbal language to an ability to use some language, but with inappropriate responses (Inglese, 2009; Johnson et al., 2016; Llaneza et al., 2010; Scarpinato et al., 2010). Experts explain the severity of communication impairment of children with ASD is unique with each child (Brown & Elder, 2014; Inglese, 2009; Jolly, 2015; Llaneza et al., 2010). Researchers have shown up to 60 percent of the children will not develop functional language or an ability to advocate for their personal needs (Bultas & McMillin, 2016; Drake et al., 2012; Johnson

et al., 2014; Zwaigenbaum et al., 2016). Further, increasing their vulnerability, nonverbal children with ASD will either use behavior to communicate with individuals in their environment, or withdraw and fail to thrive (Scarpinato et al., 2010). At times, all children with ASD experience a feeling of “aloneness” (Brown & Elder, 2014; Inglese & Elder, 2009; Scarpinato et al., 2010).

Children with ASD are sensory sensitive and become anxious when change occurs in their environment. They do not have the neuro-processing ability to filter unfamiliar sounds, odors, routines and people of health care settings. Unable to filter, children with ASD become anxious from their sensory overload; and have difficulty following directions, which presents as noncompliance during their health care visits (Chebuhar et al., 2013; Johnson & Rodriguez, 2013; Russell & McCloskey, 2015). When overwhelmed, children with ASD express their feelings by yelling, screaming, injuring self or others, breaking property, or eloping during their health care visit (Johnson & Rodriguez, 2013; Scarpinato et al., 2010).

The three main theories experts applied to explain the varied communication impairment of children with ASD include: theory of mind, weak central coherence theory, and weak executive function (Brown & Elder, 2014; Llaneza et al., 2010; Scarpinato et al., 2010). All three theories point to an altered neuro-processing system as the primary cause for the varied communication differences of children with ASD. Baron-Cohen’s (1995) theory of mind found children with ASD are unable to imagine what the other person is thinking and appear uninterested in a reciprocal relationship. They are ego-centered and only use language as a means to get their needs met. Next, Firth’s (1989) weak coherence theory explains children with ASD process information in

pieces like a puzzle, but lack an ability to put it all together. Unable to grasp the meaning, they will echo what is said by the other person, but their echo is not evidence of understanding. Finally, Baron-Cohen's (1995) weak executive function theory explains children with ASD's thought processes are rigid and fixed, which makes it difficult for them to problem solve, adapt to change and cope with their anxiety. Most children with ASD will appear emotionally immature compared to their chronological age, because they lack the cognitive maturity to understand what is expected from them in a health care setting (Baron-Cohen, 1995; Brown & Elder, 2014; Greenspan, 2006; Jolly, 2015; Llaneza et al., 2010). These theories will be discussed in more detail in Chapter four as they help to answer the first practice question.

Impact of social communication impairment on children with ASD anxiety, behavior challenges, unmet needs, and parent anxiety.

Communication frustration is the primary reason children with ASD developed anxiety and behavior challenges. Anxiety and behavior challenges occur because children with ASD are unable to communicate their fears of the unknown, frustrations about unanswered questions and feeling unprepared for an upcoming procedure or exam (Johnson, et al, 2014). Factors that contribute to communication breakdown include: bright lights, loud noises, strong odors, time constraints, child's communication preference unknown, and parents unavailable to interpret and pain (Brown & Elder, 2014; Jolly, 2015; Johnston et al., 2016). Parents reported communication breakdown was the primary reason for their children with ASD's behavior challenges (Bultas & McMillin, 2016). The behaviors challenges included: lack of cooperation, internalizing feelings with

self-injury such as head banging, and externalized feeling with yelling, biting, hitting and property destruction (Drake et al., 2012; Johnson et al., 2014; Zwaigenbaum et al., 2016).

Parents as primary interpreters for children with ASD.

Parents are the primary interpreters for their children with ASD. They were the first to identify their child's language delay (Inglese, 2009). The parents' perspective of their child's care and communication strategies must be part of the admission process across all health care settings (Zwaigenbaum et al., 2016). Collaboration between the parent and health care provider (HCP), must address the sensory and communication needs of the child with ASD to ensure a positive health care exam (HCE) experience (Bultas & McMillin, 2016; Russell & McCloskey, 2015). Parents have critical information about their child's previous experiences, communication preferences and coping strategies (Brown & Elder, 2014; Inglese, 2009; Scarpinato et al., 2010; Russell & Rodriguez, 2013). Parents know their children, and they are familiar with what strategies work to help their children acclimate to stressful events. The literature suggests that the family centered approach provides the best patient outcome (Bultas et al., 2016; Johnson & Rodriguez, 2013).

Barriers that contribute to health care providers' discomfort when caring for children with ASD.

Health care environments and providers are not prepared to manage the anxiety and challenging behaviors of children with ASD (Bultas & McMillin, 2016). Most children with autism present with a variety of comorbid conditions, which often require frequent clinic and hospital visits (Chebuhar, McCarthy, Bosch, & Baker, 2013). Many parents reported unmet needs of their hospitalized children with ASD resulted in behavior

challenges and anxiety. Often, nurses and physicians lack basic knowledge about caring for children with ASD (Chebuhar et al., 2013; Zwaigenbaum et al., 2016). It is important for nurses to recognize children with ASD may not verbally express their feelings, questions or pain. Instead, the ill child with ASD may present with increased anxiety and behavior challenges, such as head banging or yelling.

Health care settings were not designed for the sensory needs of children with ASD. Health care exams are stressful for children with ASD; they are unprepared for procedures and exposed to unusual sounds, tastes, odors and unfamiliar people (Bultas & McMillin, 2016; Stokes, 2016). The hospital and exam rooms are unfamiliar to the child with ASD. Overwhelmed by the sensory overload, the child with ASD becomes anxious. The increased anxiety affects the child's behavior and ability to follow direction. Recent data reported 25% of children with ASD were sedated or restrained during acute or emergent care (Venkat, Migyanka, Cramer, & McGonigle, 2016).

Communication preferences of children with ASD.

The literature review identified communication media, which included iPad, picture schedules, picture exchange cards (PECs), and social stories are preferred by children with ASD across all community settings (Drake et al., 2012; Johnson & Bree, 2014; Johnson et al., 2014; Jolly, 2015; Vaz, 2013). Children with ASD use pictures schedules, social stories and picture exchange communication systems (PECs) to guide them through transitions and learn new skills or routines. Created by Carol Grey (2003) picture schedules and social stories were developed to assist children with ASD communicate (Johnson et al., 2014). Picture schedules are a set of four to six sequential images on card stock that explains the steps of a new task or a routine (Chebuhar et al.,

2013; Vaz, 2013). Social stories are a narrative of ten sentences long with developmental age appropriate content that explains what to expect from an unfamiliar event (Johnson et al., 2010). Picture exchange systems (PECs) are pictures of items on card stock that children with ASD use to communicate their needs (Llaneza et al., 2010; Scarpinato et al., 2010). For example, if a child wanted a drink of water, he or she would present the nurse with a picture (PEC) of a glass of water. The National Autism Center (2009) identified picture schedules as established evidence-based practice to promote self-regulation of children with ASD ages 3 through 14 (Chebuhar et al., 2013). The pictures schedules in the health care setting were designed to prepare a child with ASD for a medical exam or procedure and reduce anxious behaviors (Scarpinato et al., 2010; Chebuhar et al., 2013; Jolly, 2015). The findings of the study are representative of the literature review (Vaz, 2013). As a result, nurses could implement picture schedules and PECs to guide children with ASD through procedures or exams and reduce anxiety behaviors.

Two research studies identified evidence-based iPads with social stories and picture schedules used by children in school and homes, were not integrated into health care settings (Johnson & Bree, 2014; Johnson et al., 2014) An electronic tablet, iPads are a device that delivers social stories to describe or explain an unfamiliar event to children with ASD, or picture schedules to sequentially explain steps to a new task or activity to children with ASD. Two pilot studies were designed to evaluate the efficacy of the tools to reduce anxiety and challenging behaviors in children with ASD going through an imaging procedure in a health care setting. The positive outcome in both studies were consistent with the literature review, and suggests communication strategies used in the

community (home and school) were transferable into health care settings (Chebuhar et al., 2013; Johnson et al., 2014).

Experts further support the potential of iPad, picture schedules, and distractions to meet the communication needs for a child with ASD during stressful medical procedures (Brown & Elder, 2014; Jolly, 2015; Koski, Gabriels, & Beresford, 2016; Llaneza et al., 2010; Scarpinato et al., 2010). One study findings supported the use of coping kits, which included the use of visual and auditory distractions to meet the communication needs of nonverbal children with ASD during a hospital stay (Drake et al., 2012). Distractions are sensory sensitive specific items like a squish ball, a hand help spinner or video game that promotes relaxation in children with ASD (Drake et al., 2012; Inglese & Elder, 2009; Jolly, 2015). Experts explained that distractions reduce anxiety and reduced anxiety improves a child with ASD's ability to communicate and follow direction (Inglese & Elder, 2009; Llaneza et al., 2010).

Medical visits are stressful because children with ASD are unfamiliar with the event. Visual and auditory communication media is effective with helping the child with ASD follow direction and transitions during a health care visit. It is critical for nurses to learn these communication strategies and understand how to integrate auditory and visual tools into their practice (Elder & Brown, 2014; Jolly, 2015; Bultas, Johnson, Burkett, & Reinhold, 2016).

Strength and Weaknesses of the Salient Research Studies

Two studies in the literature review found communication strategies used successfully in schools and home were not tested in health care settings (Chebuhar et al., 2013; Johnson et al., 2014). To address the gap in research, Chebuhar, McCarthy, Bosch

and Baker's (2013) pilot study, evaluated the feasibility of picture schedules in health care settings; and Johnson et al. (2014) pilot study evaluated the efficacy of the use of an iPad with social script in a health care setting (Chebuhar et al., 2013; Johnson et al., 2014). The positive outcomes of both studies were representative of similar findings in school and home settings. They recommended communication tools used in schools and home are potential strategies nurses could implement to meet the communication needs of children with ASD in health care settings.

Chebuhar et al.'s (2013) pilot study, *Using Picture Schedules in Medical Settings for Patients with an Autism Spectrum Disorder*, evaluated the feasibility of picture schedules in health care settings as an effective communication strategy. The strength of this article was supported by the Johns Hopkins Evidence-Based Practice Model (2018). This descriptive feasibility study included: qualitative research with clarity of purpose, evidenced-based intervention (picture schedules), comprehensive literature review, valid survey, institutional review board (IRB) approved study, and strong logical conclusions and recommendations. The National Autism Center (2009) identified picture schedules as established evidence-based practice to promote self-regulation of children with autism ages 3 to 14. The study's review of the literature identified a gap in research; there was no research to evaluate the efficacy of picture schedules in a health care setting. The purpose of this pilot study was to evaluate the efficacy of picture schedules to reduce anxiety and maladaptive behaviors of children with autism in a health care setting. The pictures that explained several medical procedures were developed by a team of medical technicians, physicians and nurses.

The survey was created by the primary author, and then validated by a committee of four autism experts' consultants from the University of Iowa. The parent survey and health care provider survey contents included three questions:

1. Did the picture schedules reduced challenging behaviors and reduce anxiety in the health care setting (parent and health care provider)?
2. Did the parents/ caregivers feel less anxiety (parent and health care provider)?
3. Is the tool feasible in a health care setting (health care provider) or does the child use picture schedules in other settings (parents).

To measure perception of parent and health care provider, both parent and health care provider survey questions 1 and 2 were identically written. Finally, the descriptive feasibility study received IRB approval from the University of Iowa.

The method and design of this study followed the Johns Hopkins Evidence-Based practice guidelines (2018). Each participating staff member received education about autism, pictures schedules and the study survey process. For six months at the time of the appointment, staff explained the purpose of picture schedules, and offered parents the option to participate in the study. After the appointment, staff and parents were expected to complete a survey. Consistent with literature findings, both parents and health care providers felt picture schedules reduced maladaptive behaviors and reduced anxiety for both child and parents. Parents reported their children used picture schedules at school and home. Staff agreed to use picture schedules in future clinic appointments. The authors discussed the limitations and weaknesses of the study, which were low survey returns and staff forgetting to use picture schedules during exams. Finally, the researchers logically recommended "Taking into account that picture schedules are used routinely in

schools and other community settings, it would be prudent for nurses taking care of children with autism to educate themselves on picture schedules and how to use them” (Chebuhar, et al., 2013, p. 133).

The weaknesses of this study identified the challenges of implementing a qualitative study to evaluate an intervention with a complex population. The limitations of this study include a small sample size of 16, because only a small number of surveys were returned. Upon review of the study, health care providers stated they used the picture schedule but the surveys were not returned. No exclusion or inclusion criteria was established. Staff were asked to track the number of parents who participated and their responses, but the tracking did not occur. The study did not apply statistical analysis to the results, which is preferred to generalize an outcome to a larger population.

Johnson et al.’s (2014) pilot study, *Effect of a Social Script iPad Application for Children with Autism Going to Imaging*, evaluated the efficacy and feasibility of the use of iPads with social scripts to meet the communication needs of children with ASD going to imaging. The strengths of this study included: clarity of purpose, two study hypotheses, theoretical rationale (Family self-management: FMS), an experimental randomized intervention (iPad social script app) with a control (treatment as usual: TAU) and manipulation of one variable (anxiety). The two-study hypotheses were: (a) children with ASD exposed to app will experience decreased anxiety, reduced behavior challenges and shorter procedural time compared to control (TAU); (b) parents of children with ASD who are exposed to app. will experience less anxiety compared to control. The feasibility study tested the efficacy of the iPad social script intervention for children with ASD going to imaging compared to the control group (TAU). According to Johnson et

al., (2014), teachers used social stories and technology to meet the communication needs of a child with ASD. A review of literature stated the intervention (iPad social script app) was evidence-based. Guided by Family Management Theory (FMS), the study addressed parents' vigilance about protecting their child with ASD. The iPad social script was created to support parents and reduce their anxiety in the health care setting.

The strength of the sample included oversight of an academic board. The inclusion/exclusion criteria and parent/child dyad recruitment process was approved via an institutional review board (IRB). The strength of the measures included use of instruments with reliability > 0.7 . Stress response (anxiety), challenging behavior, and procedural durations were primary variables that were measured by valid scientific instruments. To measure behavior challenges that occurred during the study, research assistants and principal investigators in the study developed a BOT (behavioral observation tool) with a 90% inter-rater reliability. The anxiety of the child was measured pre and post procedural with battery operated wrist cuffs. The anxiety of parents was measured with STAI-S (internal reliability 0.86-0.95) scored pre – post = stress parent response (Spielberger & Gorsuch, 1983).

The strength of the procedures included: ethical practices, random selection, consistent measures, and the fact that the researcher collecting data measuring effect was blinded. The IRB was obtained from both universities prior to the study. The treatment group and control group (TAU) were randomly selected. Parents signed consent for self and child. Every dyad variable was measured at similar predetermined times. The researcher who measured procedural BOT and post stress responses was blinded to the intervention and pre-imaging measures.

The strength of analysis included application of evidence-based Statistical Package for Social Sciences (2010). Descriptive statistics examined the demographic data. Frequencies captured by other measures. Next, all collected data was analyzed; then Cohen's *d* effect was calculated to determine standardized differences between app and TAU groups (Johnson et al., 2014).

The strength of the study findings included: iPad social script intervention outcome measures were consistent with the literature; the sample size was small but the study design provided an opportunity to report findings, and both hypotheses were supported, which gives confidence to the study recommendations and observations.

The weaknesses of Johnson et al.'s (2014) study included a small heterogeneous sample size, a large span of ages, and no validation if the child completed the iPad app. The study took place at a Midwestern USA tertiary care pediatric health system. The location limited access to parent/child participation in the trial. Criteria included ages 3-18 that contributed to the large span of ages. Weak data validation included: parents self-reported their child's ASD diagnosis, and physician documentation was not required. Finally, treatment as usual protocol (TAU) included medication and restraint as needed, and the protocol conflicted with IRB approved criteria that children with planned sedation or anesthesia were excluded.

Summary

The review of literature was an evidence-based nursing process. The review surveyed the literature to explain how children with autism communicate and identify the best strategies a nurse can implement to meet the communication needs of children with ASD. The information was extracted from each article and organized on a matrix to seek

answers to the practice questions. The research studies identified communication strategies including: iPad social script, picture schedules, PECs, coping kits and quick tip cards for HCP. Each research study identified the child with ASD communication impairment, anxiety behaviors and a specific strategy to ensure the needs of the child were met. Nonresearch studies identified a need to improve health care provider confidence when working with children who have ASD, and provided a comprehensive historic overview of autism diagnoses and communication strategies with recommended resources.

Chapter 4: Discussion, Implications, and Conditions

This critical review of literature explained how children with ASD communicate and identified effective strategies for nurses to meet the communication needs of children in health care setting. Expert opinions that answered practice questions included: explanations about autism etiology, social communication impairment and interaction, parent as primary resource, and strategies to meet the communication needs of children with ASD (Brown & Elder, 2014; Inglese, 2009; Scarpinato et al., 2010). A few well-designed research studies discovered communication strategies used in homes and schools were transferable to health care settings, and their findings were consistent with the nonresearch evidence (Chebuhar et al., 2013; Johnson & Bree, 2014; Johnson et al., 2014). As a result, equal weight was given to nonresearch and research evidence when answering the practice questions: How do children with autism spectrum disorder communicate, and what effective strategies would a nurse implement to meet the communication needs of children with ASD? Finally, Watson's (2009) Caring Science Theory critique of the critical review found that children with ASD are unable to communicate their needs and require others to advocate for them, and best practices for nurses to meet their communication needs are caring moments. The gaps in literature identified a need for Level 1 scientific research that supports evidence-based autism specific nursing guidelines.

Varied Communication Presentations: Hallmark for Children with ASD

Current researchers identified three theories for cognitive functioning of children with ASD, they including: theory of mind (mind-blindness), weak central coherence theory and weak executive function (Brown & Elder, 2014; Johnson et al., 2016; Llana

et al., 2010). According to Baron-Cohen's (1995) theory of mind, children with ASD are unable to imagine the other person's thought or motivation (Brown & Elder, 2014; Johnson et al., 2016; Llaneza et al., 2010). As a result, children lack an ability to be empathetic, participate in a reciprocal relationship, or feel motivated to maintain relationship (Brown & Elder, 2014; Llaneza et al., 2010). Often, children with ASD were described as robotic, and their speech patterns were monotone and loud. For example, if a crying or upset parent entered their child's room, the child would not ask how the parent was feeling; instead, he or she might ask in a loud voice if the parent brought the child's favorite toy from home. The child does not recognize the parents' distress; instead, he or she sees the parent only as a means to an end. Many children with ASD use communication only as a tool to get their needs met (Baron-Cohen, 1995; Brown & Elder, 2014; Giarelli & Gardner, 2012; Greenspan, 2006; Llaneza et al, 2010).

Happe and Frith (2006) suggested children with ASD present with a weak central coherence (Brown & Elder, 2014). Frith's (1989) weak central coherence theory (WCC) explained a child with an ASD mind prefers to process, store and retrieve information in pieces, and not a whole concept. For example, if a nurse asked a child, what he or she was using to color the picture, the child would reply "red" (Llaneza et al., 2010). Further, Frith explained that the child with ASD lacks an ability to recognize the meaning or intention of a message, generalize information, or use expressive or receptive language (Brown & Elder, 2014). Instead, the child with ASD focuses only on part of the verbal message and echoes the last phrase or word spoken (Bultas et al, 2016). For example, if a nurse asked a child "do you have pain?" the child would simply reply "do you have pain?" In most cases, echolalia is the child's attempt to communicate or practice

language, but it is not evidence of understanding. For children who did not acquire functional language, nurses must provide alternative communication strategies to meet their needs in health care settings (Brown & Elder, 2014; Giarelli & Gardner, 2012; Jolly, 2015; Llana et al., 2010).

According to Baron-Cohen's (1995) theory of executive function (EF), children with ASD have a diminished ability to plan, organize, predict, make decisions, develop judgement, and control impulsive behaviors (Brown & Elder, 2014; Inglese & Elder, 2009; Llana et al., 2010). For example, if a nurse asked a child with ASD "when do you want to take a bath?", the child would only reply "yes" and not state a preferred time. Further, Baron-Cohen (1995) explained after a concept was learned, it was difficult for children with ASD to change their thinking pattern (Johnson, Burkett, Reinhold, & Bultas, 2016). To prevent frustration, children with ASD require extra time to process information and adapt to changes in routine. Researchers have shown there is a correlation between children with ASD limited flexibility and behavior challenges (Brown & Elder, 2014; Johnson, et al., 2016; Llana et al., 2010).

According to the APA (2013), the symptomatology of an under-developed neurobiological processing system in children with ASD typically present between ages 18 to 36 months (Jolly, 2015). These symptoms include: loss or no eye contact, closing of the hands, unmet language milestones, regression of previous milestones, self-stimulation such as hand flapping or spinning, fixed attention to objects, and a lack of spatial awareness (Brown & Elder, 2014; Jolly, 2015). During wellness visits, parents may describe it as their child seems to have gone within him or herself, which creates a feeling of "aloneness" (Inglese, 2009; Russell & McCloskey, 2015). As a result, children with

ASD are slow to mirror behavior and don't engage in social or pretend play. Further, up to 50% of the children will never develop functional language, and children who did develop functional language struggle with meaning and syntax (Brown & Elder, 2014; Jolly, 2015; Llana et al., 2010). An example of language delay in children with ASD is the misuse of pronouns. Baron-Cohen (1995) explained that children with ASD also lack the ability to answer yes and no questions accurately; a developmental milestone that is typically developed at 24 months (Inglese, 2009; Llana et al., 2010; Scarpinato et al., 2010) For example, if a nurse asked a thirsty toddler if he or she wanted a drink of water, the toddler with ASD would reply "no." The answer did not match the observation, because the child doesn't understand the meaning of yes or no.

Research has shown that children with ASD present with a delay going through the three phases of communication development: intentional communication with gestures, symbolic communication with joint attention, and the final phase of linguistics (Brown & Elder, 2014; Johnson, et al., 2016; Llana et al., 2010). As a result, they have difficulties with intonation, body language, and personal space (Johnson & Rodriguez, 2013; Llana et al., 2010). For example, a child with ASD might be unaware of his or her inside voice and be too loud for the patient visitor's lounge; not make eye contact during a conversation, or walk between a nurse and parent who are talking. Often, children with ASD present with a large verbal vocabulary, but with low skills in comprehension; the average adolescent with ASD literacy age is less than 9 years of age (Inglese, 2009; Inglese & Elder, 2009; Jolly, 2015; Scarpinato et al., 2010). For example, the child talks like a little professor, but when asked a question, he or she is unable to provide an appropriate answer.

The diagnosis of ASD includes a clinician rating the severity of social communication: Level 1 requires support, Level 2 requires substantial support, and Level 3 requires very substantial support (Johnson, et al., 2016). Children with ASD level 1 communication have functional language, and are able to follow simple verbal and or nonverbal directions. Sometime, they may need to be prompted to initiate a conversation or meet their basic needs (Johnson, et al., 2016; Jolly, 2015). For example, a hungry child with ASD might not request food. Children with ASD level 2 communication have limited or no functional language, but are able to follow simple directions using picture prompts, distractions, iPad social stories or scripted language (Johnson & Rodriguez, 2013). Further, three research studies reported positive outcomes using visual and auditory strategies that explained medical procedures to children with ASD level 2 communication (Drake, et al., 2012; Johnson, et al, 2014; Vaz, 2013). Children with ASD level 3 communication have no functional language and are unable to follow directions (Johnson, et al., 2016). Often, these children required their parent's presence, sedation, medication and/or restraints for medical procedures or exam; however, recent studies have suggested an iPad as a potential communication strategy (Johnson & Bree, 2014; Johnson, et al., 2016; Jolly, 2015).

Strategies to Meet the Communication Needs of Children with ASD

Health care is a high anxiety environment, and children with ASD struggle to understand the experience because of their social communication and social interaction impairment. Across most health care settings, nurses are the first contact for a child with ASD. Experts suggest nurses should use a template, and involve parents when they assess the communication skills, home routine, and coping strategies of a child with ASD

(Stokes, 2016). The goal of the template is to capture the child's current communication presentation from the following questions: What is the best way to approach your child's personal space? What triggers your child's anxiety? How does your child cope with frustrations? What strategies help your child calm down? How does the child report pain? and What are your child's strengths? (Jolly, 2015). Researchers recommend nurses collect and document an accurate measure of literacy skills, because children with ASD verbal vocabulary might not match their comprehension. Also, a nurse should not assume that a child's limited communication skills are an accurate measure of his or her intelligence (Brown & Elder, 2014; Scarpinato et al., 2010). Then, nurses must integrate the child's unique communication preferences, home routines, and coping strategies into his or her care plan.

Research findings found communication strategies used in the community (home and school) are transferable into health care settings (Chebuhar et al., 2013). The recommended strategies included picture schedules with or without an iPad, picture exchange communication systems (PECs), distractions, reward systems, consistent staff and routines. A pilot study suggested iPad social script had the potential to improve communication for a child with ASD during stressful medical procedures (Johnson, et al., 2014; Koski, Gabriels, & Beresford, 2016). Prior to the procedure, a male child with ASD prepared for the CT scan watching the iPad social story about his procedure. Even though the child was anxious, his anxiety lessened during the procedure, no medications were required, and no behavioral challenges occurred. In contrast, prior to the procedure, a male child with ASD prepared for the CT with a verbal explanation of the scan. The child's anxiety increased during the procedure; medications were required and two

behavior challenges presented. The study supported the transferable use of iPad social script into a health care setting. As a result of the study, a free app called *Going to Imaging* was developed by Marquette University and released by Apple in 2014 (Johnson & Bree, 2014).

Children with ASD use pictures schedules and PECs to guide them through transitions. The National Autism Center (2009) identified picture schedules as an evidence-based practice to promote self-regulation of children with ASD ages 3-14 in community settings (Chebuhar et al., 2013). Often, children with ASD become anxious with change (Inglese, 2009). Picture schedules were designed to help children with ASD understand what to expect from an unfamiliar routine or activity (Bultas & McMillin, 2018; Chebuhar et al, 2013; Vaz, 2013). Often, medical visits are stressful for children with ASD because they are unfamiliar with the event. To address the communication need, two pilot studies evaluated the efficacy of picture schedules as a communication guide for children with ASD during a clinic or hospital visit (Chebuhar et al., 2013; Vaz, 2013). Picture schedules are a set of pictures telling a sequential story or explaining the steps to an activity. The picture schedules in the health care setting were designed to prepare a child with ASD for a medical exam or procedure and reduce anxiety behaviors (Chebuhar et al., 2013; Vaz, 2012). The findings of these studies were representative of the literature review (Jolly, 2015; Scarpinato et al., 2010; Vaz, 2013). As a result, researchers recommended further research for nurses to implement picture schedules and PECs to guide children with ASD through procedures or exam and reduce anxiety behaviors.

The remaining strategies found in the literature review included distractions, social stories, reward systems, consistent staff and routines. Research has shown and experts agree, distractions reduce anxiety, and reduced anxiety improves a child with ASD's ability to communicate and follow direction (Brown & Elder, 2014; Drake et al., 2012; Inglese, 2009; Jolly, 2015; Scarpinato et al., 2010). In the critical review, one qualitative study measured the nurse's perception of the effectiveness of a coping kit (Drake et al., 2012). The kit included communication cards, pencil and paper, social script book and toys as a distraction. The study found toys as a distraction was the most effective strategy to reduce anxiety and improve the cooperation of children with ASD (Drake et al., 2012). Other factors that reduced anxiety included: parents present while the kit was in use and having the nurse spend more time with parents when introducing the kit. Overall, the kits reduced anxiety, and stress for nurses and children with ASD. According to the study, nurses observed most children with ASD who did not have functional speech, seldom used the social script book or communication cards, and recommended a need for other strategies to prepare children for procedures other than distraction (Drake, et al., 2012). Finally, with all strategies, experts recommended consistent staff and routine, age appropriate content, and positive reinforcements to improve the compliance and reduce the anxiety of children with ASD in health care settings (Brown & Elder, 2014; Inglese & Elder, 2009; Johnson et al., 2016; Jolly, 2015).

Effective communication occurs when the children with ASD are able to follow direction, experience reduced anxiety, and exhibit few or no behavioral challenges. Experts recommend health care providers integrate communication tools, techniques and care strategies to meet the communication needs of children with ASD. To provide the

right communication care, the nurse must take the “time” to know the child’s communication preference, coping strategies, sensory challenges, developmental age, and anxiety behaviors (Brown & Elder, 2014; Bultas et al., 2016; Jolly, 2015). Understanding the child’s way of being, will provide nurses the information required to create a therapeutic plan. For example, a nurse could provide the child with ASD an iPad with a social story to explain what will happen when he or she goes to surgery, which experts suggest would reduce the child’s anxiety and challenging behavior (Johnson et al., 2014). To reduce anxiety and prevent behavior challenges, it is critical for nurses to use a calm low voice, provide time for the children to process the information, and anticipate the supports they may require to have their communication needs met (Brown & Elder, 2014; Jolly, 2015; Scarpinato et al., 2010).

Gaps in the Literature

Applying the *Johns Hopkins Nursing Evidence-Based Practice: Model and Guidelines* (2018), the articles from the critical review of the literature yielded only one evidence-based nursing behavioral observation tool (Johnson et al., 2014), and no level IV clinical guidelines. The broad range of features with ASD diagnosis create challenges with level I research and a possible reason for the lack of clinical guidelines in the literature and few Level I scientific research studies. The limited research hampers the development of practice guidelines that requires practical information from both research and nonresearch to support clinical decisions (Hanson, Hoss, & Wesorick, 2008). The gap of evidence suggests a need for nursing to create language that explains how children with ASD communicate in health care settings; and evidence-based tools for evaluating the efficacy of nursing strategies to meet the communication needs of children with ASD.

(Brown & Elder, 2014; Bultas & McMillin, 2018; Johnson, et al., 2016; Johnson & Rodriguez, 2013). In the literature review, most of the language used to explain how children with ASD communicate borrowed from other disciplines (Brown & Elder, 2014; Chebuhar et al., 2013; Johnson et al., 2014). Only two articles provided a narrative perspective describing how the communication impairment of children with ASD affected their ability to function in health care settings (Russell & McCloskey, 2015; Zwaigenbaum et al., 2016).

In addition, all of the research studies in the review referenced other professional disciplines when discussing strategies that could meet the communication needs of children with ASD (Brown & Elder, 2014; Bultas & McMillin, 2018; Chebuhar et al., 2013; Drake et al., 2012; Johnson & Bree, 2014; Johnson, et al., 2016; Vaz, 2013). Of the 18 articles, only one study created an original tool. Johnson et al. (2014) created the behavioral observation tool (BOT) with an inter-rater reliability of 0.9. The outcomes of two research studies were consistent with the literature findings that community evidence-based tools are transferable to health care settings. The findings supported further research, but did not discuss the transferability of evidence-based tools into practice guidelines (Chebuhar et al., 2013; Johnson, et al.; 2014). The two continuing nursing education articles provided a general knowledge of ASD; strategies to meet the needs of children with ASD, but no clinical trials (Brown & Elder, 2014; Jolly, 2015). Further, only one study considered the fiscal cost of implementing an intervention (Drake et al., 2012). Finally, the evidence suggested there is a need for autism specific nursing care model and hospital care policies to support the unique communication needs for

children with ASD (Bultas & McMillin, 2018; Chebuhar et al., 2013; Drake et al., 2012; Zwaigenbaum et al., 2016)

Implications for Nursing Practice

Experts discussed the importance for nurses understanding the etiology of ASD and how it affects the child with ASD's ability to communicate; and for nurses to learn and implement communication strategies to ensure the needs of the child are met. Most often, nurses are the first point of contact for the children with ASD and their parents. During the admission process, parents are the primary resource for the nurse to acquire current information about their child's communication presentation which includes: cognitive function, communication preferences, home routines, environmental triggers and coping strategies. Experts suggest nurses develop and apply a standardized template to capture the parents' information about their child's communication presentation. After collecting the parent's input, it is critical that nurses integrate the information into the child's care plan and share communication strategies with other staff. A consistent approach will reduce the child's anxiety and increase his or her ability to follow directions in a health care setting.

For children who do not have a system in place, research suggested evidence-based tools used in other community-based settings (school and home) are transferable to a health care setting. Since change creates anxiety, which further delays processing and decreases their ability to understand or follow direction; nursing strategies that support the communication needs of children with ASD must include: a quiet environment, speaking in low tones, providing simple directions both visual and auditory and whenever feasible home routines. Finally, experts recommend nurses request an occupational

therapy consult, on behalf of the child, for an adaptive device such as iPad with scripts or picture schedules to help explain hospital routines or procedures (Llaneza et al., 2010).

Nurses are responsible for meeting the communication needs of children with ASD across all health care settings. While caring for the child with ASD, nurses must consider maladaptive behaviors as a symptom of frustration and anxiety related to unmet communication needs. Symptoms of frustration in ASD include: melt downs, not following direction, increased restrictive behaviors; hand flapping, spinning, or echolalia. To reduce anxiety and improve a child with ASD's understanding of the unknown, it is critical that nurses provide the right communication, right environment, and right routine.

Prior to children with ASD requiring health care, nurses should identify resources available to support their communication needs. For example, nurses could use a template to capture information from parents or caregivers, provide a quiet room with positive distractions to help the children cope with change and create a cart with communication tools adapted for health care settings. It is important the communication tools use simple language or pictures to explain a medical activity or schedule, avoid yes or no questions and frame questions with providing the child two choices. Finally, nurses must remember children with ASD become lost in the meaning of words and depend on others to be their guides.

Recommendations for Nursing Research

The review of the literature identified a need for further research to develop evidence-based guidelines, which meet the communication needs of children with ASD in health care settings (Bultas & McMillin, 2018; Chebuhar et al., 2013; Inglese, 2009; Inglese & Elder, 2009; Johnson et al., 2014; Llaneza et al., 2010; Zwaigenbaum et al.,

2016;). To address the gaps in literature, future research must continue to evaluate how communication strategies used in other community settings are transferable to health care settings. This type of research involves creating simple visual and auditory content for children with ASD. The content must be designed to explain the steps for medical procedures or routines for children with ASD; as evidenced by their compliance, reduced anxiety, and absence of challenging behaviors. Further, nurses could either consider the current evidence-based tool BOT, or create another tool to evaluate the effectiveness of a strategy to meet the communication needs of children with ASD. Next, the research should consider available resources and financial feasibility for an organization to implement the strategy. Finally, through professional collaboration and critiquing of evidence for quality and strength with consensual validation, the Level I scientific research would contribute information required for evidence-based clinical guidelines.

Integration and Application of Watson's Caring Science Theory

According to Watson (2009), nurses are ethically responsible to seek information about communication needs of children with ASD, and creating strategies to meet their needs in health care settings. Watson (2009) stated "caritas processes seek information, knowledge, understanding and wisdom" (p. 110). Founded on the ten carative factors, the ten caritas processes translate conventional nursing tasks toward purposeful healing acts (Watson, 2009). Applied to the critical review, the Caritas model explains the varied communication presentation of children with ASD and evaluates the healing effectiveness of strategies to meet the communication needs of their needs in health care settings.

Communication is both an art and science. It is the foundation for establishing and sustaining a caring (*caritas*) relationship (Watson, 2009). As a science, communication requires neuro processing, which supports the cognitive ability for an individual to create a reciprocal relationship, whereas each party discloses information with the other. As an art, communication requires being fully present with the other person's mind, body and spirit, with the intention of creating a caring relationship. For children with ASD, their communication impairment is scientifically identified as developmental delay, which decreases their ability to establish a reciprocal relationship. As an art, their communication impairment creates a barrier for understanding another person's mind, body and spirit, making it a challenge for them to establish caring relationships. As a result, parents become their child's interpreter; guiding them through their activities in the community and speaking for their child's behalf. Therefore, experts recommend nurses to include parents when developing their child's plan of care.

Researchers have shown children with ASD have comorbid disorders and will require frequent clinic or hospital visits. Upon admission, nurses are responsible for establishing a therapeutic relationship, gathering the child's personal story and following through with his or her medical treatment plan. Often, the child with ASD will be scared, anxious and unable to communicate their needs or follow directions. Integrating the Watson's first *caritas* process of loving kindness to self and others, experts recommend nurses calmly approach an anxious child with ASD, speak in low tones, and follow the parent's relaxation prompts (Brown & Elder, 2014; Inglese, 2009; Inglese & Elder, 2009; Jolly, 2015). During this caring moment, the child and parents will begin to trust the nurse, which promotes healing (Watson, 2009). Next, applying Watson's second *caritas*

process of hope and faith, the nurse could integrate a coping kit for distractions and reduce the child's anxiety, which will improve his or her ability to follow procedural directions (Drake et al., 2013). By creating a healing environment, both the nurse and child experience less anxiety and stress (Brown & Elder, 2014; Drake et al., 2013; Jolly, 2015; Watson, 2009).

In the critical review, experts explained health care organizations must provide staff education, create environmental modifications and staffing resources to ensure the communications needs of children with ASD are met (Scarpinato et al., 2010; Zwaigenbaum et al., 2016). Applying Watson's third *caritas* process of self-reflection, studies found a lack of basic autism care management knowledge among nurses; therefore, experts provided nurses an educational opportunity to further their understanding about caring for children with ASD (Brown & Elder, 2014; Jolly, 2015; Scarpinato et al., 2010; Zwaigenbaum et al., 2016). With case studies, experts pointed out the importance of nurses examining their feelings prior to caring for a child with ASD with behavior challenges (Jolly, 2015; Scarpinato et al., 2010). Through self-reflection, nurses become aware of their biases, patient centered and spiritually prepared to meet the communication needs of children with ASD (Watson, 2009).

Applying Watson's fourth *caritas* process of developing and sustaining a helping trusting relationship, research has shown health care organizations must consider staffing resources to provide nurses the time needed to address the communication needs of children with ASD (Bultas & McMillin, 2018; Johnson et al., 2014; Zwaigenbaum et al., 2016). Children with ASD require more time to process information, follow direction and acclimate to changes in their routine (Brown & Elder, 2014). Without enough time, the

child will become frustrated, anxious and present with a melt-down (Inglese, 2009; Johnson & Rodriguez, 2013; Jolly, 2015; Llana et al., 2010) Time to create effective communication between the nurse and child is critical to establish a helping trusting relationship (Watson, 2009).

Integrating Watson's fifth caritas process of promoting acceptance including both negative and positive feelings, researchers and experts recommend nurses provide parents and their children with ASD time and space to share their feelings and concerns (Chebuhar et al., 2013; Jolly, 2015; Russell & McCloskey, 2015). Studies report children with ASD struggle with change and, whenever possible, the nursing care plan should mirror their home routine (Brown & Elder, 2014; Inglese & Elder, 2009; Jolly, 2015). Further, nurses should ask parents about their child's communication presentation to provide the appropriate strategies to explain a procedure or inquire how a child is feeling and develop a trusting relationship (Inglese & Elder, 2014; Llana et al., 2010; Russell & McCloskey, 2015; Watson, 2009).

Children with ASD rely on their parents, caregivers, teachers and health care providers to provide cognitive systems and sensory friendly environments to support their communication needs (Inglese, 2009; Johnson et al., 2016; Llana et al., 2010). Applying Watson's sixth caritas process of creative use of self and knowing to provide quality care, four research studies in the critical review have shown strategies used to meet the communication needs of children with ASD in the community are transferable to health care settings (Chebuhar et al., 2013; Johnson & Bree, 2014; Johnson et al., 2014; Vaz, 2013; Watson, 2009). Further, the evidence from the studies were consistent

with the literature findings, which is necessary to understand the human complexities of meeting the communication needs of children with ASD (Watson, 2009).

The emerging research evidence and expert opinions reveal communication impairment is the primary barrier that decreases children with ASDs' ability to engage in their world, which increases their anxiety and behavior challenges (Brown & Elder, 2014; Jolly, 2015; Johnson et al., 2016). Applying Watson's seventh *caritas* process to engage in genuine teaching and learning experiences, for the purpose of understanding another's frame of reference, experts published articles that translates research into practice (Watson, 2009). The purpose of the articles is to increase health care providers' knowledge and understanding of evidence-based care for children with ASD (Bultas et al., 2016; Johnson et al., 2016). From the articles, nurses could increase their understanding of children with ASD cognitive, physical, social and spiritual challenges related to their communication impairment (Watson, 2009).

Integrating Watson's eighth *caritas* process of creating healing environments, experts recommended health care organizations provide sensory sensitive spaces for children with ASD to reduce anxiety related behavior challenges and improve their compliance (Inglese, 2009; Johnson & Rodriguez, 2013; Jolly, 2015). Researchers have proven a child with ASD anxiety decreased when their sensory needs were met (Brown & Elder, 2014; Inglese, 2009; Llaneza et al., 2010; Zwaigenbaum et al., 2016). Further, expert opinion suggests nurses, as the primary architects, create private rooms with music and adaptive devices such as iPads, to support the communication needs of children with ASD (Brown & Elder, 2014; Jolly, 2015; Scarpinato et al., 2010; Watson, 2009).

Cohen (1995) described the neuro-processing of children with ASD as mind-blindness (Brown & Elder, 2014). Unable to find meaning in words, over 50% of children with ASD rely on their parents, caregivers and health care providers for their basic needs (Brown & Elder, 2014; Inglese & Elder, 2009; Llaneza et al., 2010; Scarpinato et al., 2010). Since many children with ASD lack the ability to communicate, nurses must anticipate their basic need and utilize strategies to support their communication deficits. Applying Watson's ninth caritas process to administer Sacred Acts of healing, research studies and experts recommend integrating visual and auditory communication devices such as picture schedules or iPad devices to assist children with ASD express their needs in health care settings (Bultas & McMillin, 2018; Chebuhar et al., 2013; Johnson et al., 2014; Koski, Gabriels & Beresford, 2016). Through technology, the nurse honors the child's dignity by supporting his or her physical and emotional needs, reducing anxiety, and increasing compliance (Watson, 2009).

As the number of children with ASD is rising, research continues to search for answers to the autism puzzle. Watson (2009) explains, when society is experiencing a human condition that the rational mind and modern science struggles to find a cause or solution; we should consider Caring Science framework and embrace life's mysteries. By applying Watson's tenth caritas process to be open and attending to the spiritual/mysterious and existential unknown of life, with a pilot study, researchers evaluated iPad with social scripts and discovered nonverbal children with ASD were less anxious, and with no behavioral challenges compared to the control group (Johnson & Bree, 2014; Johnson et al., 2014). Another researcher, open to discovery, observed and found that picture schedules, which are successful in home or schools, are transferable to

health care settings (Chebuhar et al., 2013). With positive intention, researchers and experts are beginning to find some answers to support the communication needs of children with ASD.

Summary

Watson (2009), states “the ultimate goals of nursing care, Caring Science and research are to deliver humane quality care” (p. 110). The Caring framework identified the quality of evidence as measured by its congruence with other findings, systematic use of cognitive, rational logic and formal use of creative problem solving. Research and nonresearch were given equal consideration because the scientific-technical, empirical knowledge, along with the discussion and opinions of nurse experts are necessary to yield best practices (Watson, 2009). Consequently, caring moments that increase the child’s ability to communicate his or her needs, feel safe, and establish a trust relationship; as evidenced by a child’s level of comfort and compliance, are the best nursing practices for meeting the unique communication needs and challenges of children with ASD in health care settings.

References

- American Psychiatric Association (APA). (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, Virginia: American Psychiatric Association Publishing.
- Baron-Cohen, S. (1995). *Mindblindness: An essay on autism and theory of mind*. Denver Colorado: Bradford Publishing.
- Brown, A. B., & Elder, J. H. (2014). Communication in Autism Spectrum Disorder: A Guide for Pediatric Nurses. *Pediatric Nursing*, 40(5), 219-225.
- Bultas, M., Johnson, N., Burkett, K., Reinhold, J. (2016). Translating research to practice for children with autism spectrum disorder: part 2. *Journal Pediatric Health Care*, 30(1), 27-37.
- Bultas, M.W., & McMillin, S.E. (2016). Reducing barriers to care in the office-based health care setting for children with autism. *Journal of Pediatric Health Care*, 30(1), 1-14.
Retrieved from <http://dx.doi.org/10.1016/j.pedhc.2015.08.007>
- Chebuhar, A., McCarthy, A. M., Bosch, J., & Baker, S. (2012). Using picture schedules in medical settings for patients with an autism spectrum disorder. *Journal of Pediatric Nursing*, 28(2), 125-134. Retrieved from <http://dx.doi.org/10.1016/j.pedn.2012.05.004>
- Dang, D., & Dearholt, S. (2018). *Johns Hopkins nursing evidence-based practice: Model and guidelines* (3rd ed.). Indianapolis, Indiana: Sigma Theta Tau International.
- D'Auria, J.P. (2010). Autism on the web: "oh, the places you'll go!". *Journal of Pediatric Health Care*, 24, e11-e15. doi: 10.1016/j.pedhc.2010.07.007

- Drake, J., Johnson, N., Stoneck, A. V., Martinez, D. M., & Massey, M. (2012). Evaluation of a coping kit for children with challenging behaviors in a pediatric hospital. *Pediatric Nursing, 38*(4), 215-221.
- Giarelli, E., Garnder, M.R. (2012) *Nursing of autism spectrum disorder: Evidence-based integrated care across the lifespan*. New York, New York: Springer Publishing.
- Greenspan, S. (2006). *Engaging autism*. Cambridge, MA: Da Capo Press.
- Hanson, D., Hoss, B. L., & Wesorick, B. (2008). Evaluating the evidence: Guidelines. *AORN Journal, 88*(2), 184-195.
- Inglese, M. D. (2009). Caring for children with autism spectrum disorder, part II: Screening, diagnosis, and management. *Journal of Pediatric Nursing, 24*(1), 49-59.
doi:10.1016/j.pedn.2008.06.005
- Inglese, M.D., & Elder, J.H. (2009). Caring for children with autism spectrum disorder, part I: Prevalence, etiology, and core features. *Journal of Pediatric Nursing, 24*(1), 41-48.
doi:10.1016/j.pedn.2007.12.006
- Jennings Dunlap, J. (2018) Interacting with individuals on the autism spectrum. *American Nurse Today, 13*(4), 16-19.
- Johnson, N., & Bree, O. (2014). Social script iPad application versus usual care before undergoing medical imaging: Two case studies of children with autism. *Journal of Radiology Nursing, 33*(3), 121-126. Retrieved from
<http://dx.doi.org/10.1016/j.jradnu.2014.04.001>
- Johnson, N., Bree, O., Lalley, E., Rettler, K., Grande, P., Gani, M., & Ahamed, S. (2014). Effect of a Social Script iPad Application for Children with Autism Going to Imaging. *Journal of Pediatric Nursing, 29*(6), 651-659.

- Johnson, N., Burkett, K., Reinhold, J., & Bultas, M. (2016). Translating research to practice for children with autism spectrum disorder: part I. *Journal Pediatric Health Care*, 30(1), 15-26.
- Johnson, N. L., & Rodriguez, D. (2013). Children with autism spectrum disorder at a pediatric hospital: A systematic review of the literature. *Pediatric Nursing*, 39(3), 131-141.
- Jolly, A. A. (2015). Handle with care: top ten tips a nurse should know before caring for a hospitalized child with autism spectrum disorder. *Pediatric Nursing*, 41(1), 11-22.
Retrieved from
http://link.galegroup.com.ezproxy.bethel.edu/apps/doc/A403916296/EAIM?u=clic_bethel&sid=EAIM&xid=97db05eb
- Koski, S., Gabriels, R. L., & Beresford, C. (2016). Interventions for pediatric surgery patients with comorbid autism spectrum disorder: A systematic literature review. *Archives of Disease in Childhood*, 101(12), 1090. doi: 10.1136/archschild-2016-310814
- Llaneza, D. C., Deluke, S. V., Batista, M., Crawley, J. N. Christodulu, K.V., & Frye, C. A. (2010). Communication, interventions, and scientific advances in autism: A commentary. *Physiology & Behavior*, 100(3), 268-276. doi: 10.1016/j.physbeh.2010.003
- Mazurek, B., Fineout-Overhold, E., Stillwell, S.B., & Williamson, K. (2009). Igniting a spirit of inquiry: An essential foundation for evidence-based practice. *American Journal of Nursing*, 109(11), 49-52.
- Russell, S., & McCloskey, C. R. (2015). Parent perceptions of care received by children with an autism spectrum disorder. *Journal of Pediatric Nursing*, 31(1), 21-31. Retrieved from <http://dx.doi.org/10.1016/j.pedn.2015.11.002>

- Scarpinato, N., Bradley, J., Kurbjun, K., Bateman, X., Holtzer, B., & Ely, B. (2010). Caring for the child with an autism spectrum disorder in the acute care setting. *Journal for Specialists in Pediatric Nursing, 15*(3), 244-54. doi:10.0000/j.1744-6155.2010.00244.x
- Spielberger, C. D., & Gorsuch, R. L. (1983) *Manual for the state-trait anxiety inventory (form Y) ("self-evaluation questionnaire")*. Palo Alto, California: Consulting Psychologist Press.
- Stokes, D. (2016). Empowering children with autism spectrum disorder and their families within the healthcare environment. *Pediatric Nursing, 42*(5), 254-255.
- Vaz, I. (2013). Visual symbols in healthcare settings for children with learning disabilities and autism spectrum disorder. *British Journal of Nursing, 22*(3), 156-159.
- Venkat, A., Migyanka, J.M., Cramer, R., & McGonigle, J. J. (2016) An instrument to prepare for acute care of the individual with autism spectrum disorder in the emergency department. *Journal of Autism & Developmental Disorder, 46*, 2565-2569. doi: 10.1007/s10803-016-2778-5
- Watson, J.W. (1979). *Nursing human science and human care: A theory of nursing*. Sudbury, Maryland: Jones and Bartlett.
- Watson, J.W. (2009). *Nursing: The philosophy and science of caring* (Rev.ed.). Boulder, Colorado: University Press of Colorado.

Zwaigenbaum, L., Nicholas, D. B., Muskat, B., Kilmer, C., Newton, A. S., Craig, W. R., & ...

Sharon, R. (2016). Perspectives of Health Care Providers Regarding Emergency

Department Care of Children and Youth with Autism Spectrum Disorder. *Journal of*

Autism & Developmental Disorders, 46(5), 1725-1736. doi:10.1007/s10803-016-

2703-y

Appendix: Evidence of Synthesis

Source: Brown, A. B., & Elder, J. H. (2014). Communication in Autism Spectrum Disorder: A Guide for Pediatric Nurses. <i>Pediatric Nursing</i> , 40(5), 219-225.			
Purpose/Sample	Design (Method/Instruments)	Results	Strengths/Limitations
<p>Purpose: To familiarize nurses about the pediatric population with ASD complex communication challenges with interventions</p> <p>Sample/Setting: none</p> <p>Johns Hopkins Evidence Appraisal</p> <p>Level of Evidence: V</p> <p>Quality: A</p>	<p>Expert nurses develop continuing nurse education (CNE) to provide pediatric nurses an overview of strategies to provide quality care for children with ASD.</p> <p>Objectives:</p> <ol style="list-style-type: none"> 1. Define autism disorder 2. Explain why effective communication is a priority of care for children with ASD 3. List three theories to explain how children with ASD communicate 4. Describe environmental strategies nurses can adapt to enhance communication for children with ASD. 	<p>Communication development: from infancy through adolescence: Typically developed (TD) children versus children with ASD.</p> <p>Three skills phases: Intentional, symbolic and linguistic.</p> <p>Theory: Theory of Mind Central Coherence Theory Executive Function Theory</p> <p>Conclusion: Deficits for children with ASD: vocalic, kinesthetic and proxemic.</p> <p>Sensory Impairments: Limit ability to filter light and sounds Sending and Receiving Messages: ASD population prefer visual cues and require a longer time to process. Communication requires both parties being fully engaged. Recommend: Alternative or Augmentative Communication (AAC) Meltdowns/Outbursts: Communication Breakdown</p>	<p>Strengths: Expert Opinion 52 references ANCC Provider accredited article for pediatric CNE.</p> <p>Limitations: No literature appraisal No clinical trials with communication strategies.</p>
<p>Author Recommendations: Effective communication between a nurse and patient is an essential part of providing quality care. Small adaptations in communication style can help facilitate a successful nurse-patient relationship. When caring for children with ASD, allowing extra time in the process is critical to ensure their needs are met and to reduce the risk of meltdowns.</p>			
<p>Implications: Communication strategies for nurses caring for children with ASD require extra time. By providing quiet spaces, using low tones with simple words and time; a fully engaged a nurse could address the needs of the child and address the concerns of the parents.</p>			

Source: Bultas, M., Johnson, N., Burkett, K., Reinhold, J. (2016). Translating research to practice for children with autism spectrum disorder: Part 2. <i>Journal Pediatric Health Care</i> , 30(1), 27-37.			
Purpose/Sample	Design (Method/Instruments)	Results	Strengths/Limitations
<p>Purpose: To review current science and strategies to guide parents, health care providers toward improving cognitive function and reducing challenging behaviors in children with ASD.</p> <p>Sample/Setting: 83 articles 1985-2015 Criteria Children with autism behavior challenges and care strategies Health care providers (HCP) Families and home Acute health care settings</p> <p>Johns Hopkins Evidence Appraisal</p> <p>Level of Evidence: V</p> <p>Quality: A</p>	<p>A multi-disciplinary literature review of evidence-based care strategies to manage a child with ASD challenging behavior across community systems including primary and acute care setting.</p> <p>Objectives: 1. Shaping desired behavior Three parenting programs ABC's of behavior</p> <p>2. Communication Resources: picture cards, communication board, augmentative communication devices (AAC); verbal instruction slow low speech allowing time for processing.</p> <p>3. Teach/practice child's self-care skills</p> <p>4. Staff training</p>	<p>Evidence suggests learn, do and teach approach to improve cognitive function, shape behavior and increase child with ASD self-care skills.</p> <p>Family centered care reinforce positive behavior w/praise. Ignore undesirable behavior.</p> <p>Communication frustration contributes to behavior challenges. Communication strategy: plan time for child to process information and reciprocate a reply. A child's home communication strategies transfer to health care setting</p> <p>Conclusion: Each child with ASD require HCP to know and use care strategies that improve cognitive function and manage behavior challenges.</p>	<p>Strengths: Multiple expert authors. 83 up to date references include scientific evidence, case studies, clinical guidelines, evidence-based tools used in other community settings. Family centered care Resources can be implemented across all community care settings. Information could be used to create organizational policies and guidelines.</p> <p>Limitations: No appraisal of literature.</p>
Author Recommendations: Through advanced planning, HCP's can provide a healing environment that promotes positive cognitive and self-care development while decreasing behavior challenges. To increase better health outcomes, HCP's integrate family self-management of daily living skills and behaviors.			
Implications: The research provides information nurses could apply to their practice. The evidence suggests the family centered approach provides the best outcome. Communication is the key to establishing and sustaining a healthy family relationship. Implementing effective communication strategies, the nurse could guide the child toward less "aloneness", frustration and more hope.			

Source: Bultas, M.W., McMillin, S.E. (January/February, 2016). Reducing barriers to care in the office-based health care setting for children with autism. <i>Journal of Pediatric Health Care</i> , 30(1), 1-14. Retrieved from http://dx.doi.org/10.1016/j.pedhc.2015.08.007			
Purpose/Sample	Design (Method/Instruments)	Results	Strengths/Limitations
<p>Purpose: To evaluate the feasibility of a researcher developed tool designed to facilitate communication and improve health care outcomes from office-based health care service, identify barriers, and available resources for children with ASD.</p> <p>Sample/Setting Convenient samples 54 Health Care Providers (HCP) providing health care exams (HCE) for children w/ASD 59 English speaking parents of children w/ physician diagnosed ASD ages 3 - 15 Internet access Midwestern pediatric hospital Johns Hopkins</p> <p>Evidence Appraisal Level of Evidence: III Quality: A/B</p>	<p>IRB approved Cross-sectional survey design to collect data from both parents and HCP perception of barriers/resources during child HCE</p> <p>Feasibility of Quick Tip Cards (QTP) for HCE</p> <p>14 questions applying Likert style survey with multiple choice and one free response question.</p> <p>152 pediatricians and 150 nurse practitioners were sent surveys via email</p> <p>59 parents surveyed via autism LISTSERV local email list</p> <p>Analysis with descriptive statistics with aim to summarize data with frequently recurring themes</p>	<p>27 physicians 25 PNP complete survey. 60% HCE 1-2x/month. 35% HCE 1-2x/week. 55% uncomfortable w/communication 78 % uncomfortable w/behavior 59 parents complete survey. 72% HCE 1-2x/yr 24% HCE 1-2x/month 3% HCE < 1x/yr 42% report HCP don't understand ASD challenges/care strategies</p> <p>QTP card: 94% HCP and 77 % parents report confidence of tool to facilitate communication and improve outcomes.</p> <p>Conclusion: HCP's identify parents as a key resource. Partnership between HCP and parent is a priority to provide quality care. Parents and HCP agreed QTP card was usable, helpful and agreed to use it during HCE visits.</p>	<p>Strengths: Expert authors Extensive literature review of 28 articles identified population risks, challenges related to etiology, communication impairment, and recommendation for communication tool</p> <p>Limitations: Voluntary convenience sample may not have a representative sample. Local sample not representative sample and may cause for limited disclosure of demographic information. Parent self-report child with ASD. Completion of surveys by HCP was less than usual completion reported in literature review.</p>
Author Recommendations: Quality care for children with ASD require collaboration between parents and HCP. Identifying barriers help HCP understand how the child with ASD communicate and cope with anxious events such as HCE. Future research should include a randomized pilot study to measure efficacy of QTP to facilitate communication as measured by reduced anxiety, clinic visit times, and behavior challenges.			
Implications: Research reports children with ASD frustration and behavior challenges are related to communication and sensory impairments. Through collaboration between parent and HCP, adapted resources should address the sensory and communication needs of the child with ASD. to create a positive HCE experience. Nurses should collect, document and integrate into plans of care the child with ASD parents' communication strategies and behavior management insights.			

Source: Chebuhar, A., McCarthy, A. M., Bosch, J., & Baker, S. (2012). Using picture schedules in medical settings for patients with an autism spectrum disorder. <i>Journal of Pediatric Nursing</i> , 28(2), 125-134. Retrieved from http://dx.doi.org/10.1016/j.pedn.2012.05.004			
Purpose/Sample	Design (Method/Instruments)	Results	Strengths/Limitations
<p>Purpose: To measure efficacy of pictures in a medical setting to communicate with children who have autism as measured by maladaptive behavior, and stress level of parent/caregiver.</p> <p>Sample/Setting: Convenience sample of 17 participants obtained over 6 months' time, Six nurses, one child-life specialist, one medical assistance nine parent/caregiver University of Iowa, Pediatric Clinic and Center of Disabilities and Development, Johns Hopkins Evidence Appraisal Level of Evidence: II Quality: A/B</p>	<p>A pilot project – descriptive feasibility study – Velcro laminated picture schedules of specific medical procedures. vital signs, lab procedures, dressing changes etc. Nurse would create picture story board after completing a procedure task, the child would remove picture. When completed, child received award.</p> <p>Nurse and Parents complete interview survey of 4-5; 7 point rated questions: to assess child distress level. Caregiver survey included child's age, gender, date. Staff survey included their role.</p>	<p>87.5% of the staff and 77.8% of parent/caregivers picture schedules decreased child anxious behaviors.</p> <p>87.5% staff and 88.9% parents/caregiver child exhibited less distress.</p> <p>77.8 % parent/caregivers overall experience more tolerable for their child and less stressful for themselves.</p> <p>50% less anxious about the next visit knowing picture schedules would be available.</p> <p>75% staff pictures helpful and 100% training received on autism very helpful.</p> <p>Conclusion: During medical procedures, pictures schedules reduced anxiety for children with autism.</p>	<p>Strengths: Comprehensive literature review to design and implement picture tools.</p> <p>Limitations: Small number of surveys were returned. Staff and or caregiver would forget to complete survey. Staff would forget to use the available picture schedules.</p>
<p>Author Recommendations: Similar to other community settings, the use of picture schedules could be successful in the healthcare setting. The pilot study uncovered lack of communication standardization in the clinical approach to providing health care to children with autism. The primary clinical barrier is staff limited knowledge about the autism diagnosis and best practice for communication.</p>			
<p>Implications: Nurses are responsible to address the communication and developmental needs of children with autism across all health care settings. Picture schedules are successful in other community settings and research suggests they could be a best practice in clinical settings.</p>			

Source: Drake, J., Johnson, N., Stoneck, A. V., Martinez, D. M., & Massey, M. (2012). Evaluation of a coping kit for children with challenging behaviors in a pediatric hospital. <i>Pediatric Nursing</i> , 38(4), 215-221.			
Purpose/Samp0le	Design (Method/Instruments)	Results	Strengths/Limitations
<p>Purpose: To evaluate the nurse’s perception of coping kits efficacy as a communication and care strategy to calm children with ASD.</p> <p>Sample/Setting: A convenience sample of 24 nurses over five months. Nurses experience with ASD or other cognitive delays. Midwestern freestanding children’s hospital; three inpatient units and emergency room.</p> <p>Johns Hopkins Evidence Appraisal</p> <p>Level of Evidence: II</p> <p>Quality: A/B</p>	<p>A cross-sectional post-test survey study design. IRB approved Framed on Bandura’s self-efficacy theory. “Nurses need to perceive coping kit efficacy to justify its use”</p> <p>Coping kits include: communication cards, a social script, distraction items, pap of paper and a pencil.</p> <p>Nurse/parent instructed on use of kit included child supervision while using kit.</p> <p>Nurses identified child who would benefit</p> <p>Inclusion criteria: child ages 2 through 18 developmental disabilities such as ASD</p> <p>excluded: child without cognitive disability.</p> <p>Post intervention Data collected: survey monkey on line questions consisted of 9 demographic and 16 effective intervention.</p>	<p>Demographic: majority bachelor prepared nurses, female ages 21-20.</p> <p>79% report use of kit improved child’s ability to cope through distraction.</p> <p>91% report child used kit appropriately</p> <p>90% of the parents were present when child used kit.</p> <p>70% noticeable decreased agitation after kit given</p> <p>70% report kit improved transition</p> <p>16% children could use cards to communicate needs.</p> <p>62% of nurses felt stress during interaction which involved kit.</p> <p>Conclusion: The study suggests that a coping kit could be part of a strategy to alleviate anxiety and provide quality care for children with developmental delays such as ASD.</p>	<p>Strengths: Expert multi-skilled and disciplined 28 articles referenced Population clearly defined. Hudson (2006) intervention effectiveness survey. Analysis included descriptive statistics (range and frequencies) for demographics and survey results evaluated through Survey Monkey and Excel.</p> <p>Limitations: Child’s diagnosis was not confirmed for the study. Small sample size of nurses in one facility. No scientific measures for child anxiety or behavior. Limited generalizability. Questionnaire modified for free-form text and no validation was possible.</p>
Author Recommendations: The nurses found using the kits as a distraction improved the child’s ability to cope before and during the procedure. The study suggests the kit reduced a nurse’s stress because the child was less anxious and more directable. At the time of admission, the kit provided a proactive communication opportunity between parent and nurse. Finally, a behavioral observation tool is needed as an objective measure of a child’s behavior.			
Implications: The study suggests a coping kit is a potential strategy for providing quality care to children with ASD. Upon admission, the kit provides an opportunity for the nurse to communicate with the parents about their child’s language, social and sensory preferences. Even though the kit took time, the child’s decreased anxiety improved their ability to cooperate which reduced nurse stress.			

<p>Source: Inglese, M. D. (2009). Caring for children with autism spectrum disorder, part II: Screening, diagnosis, and management. <i>Journal of Pediatric Nursing</i>, 24(1), 49-59. doi:10.1016/j.pedn.2008.06.005</p>			
Purpose/Sample	Design (Method/Instruments)	Results	Strengths/Limitations
<p>Purpose: To provide pediatric nurses and practitioners the information required to assist in identifying infants and toddlers at risk of ASD and advocate for further interventions.</p> <p>Sample/Setting: Families with children at risk of ASD or recently diagnosed with ASD. Pediatric nurses at all practice levels.</p> <p>Johns Hopkins Evidence Appraisal</p> <p>Level of Evidence: V</p> <p>Quality: A</p>	<p>Overview expert guide to support pediatric nurses identifying and managing children with ASD.</p> <p>Screening and Diagnosis Early Identification Infant development and ASD Toddler development and ASD Evaluation/ Screening In primary care infant/toddler well checks. Level 1 M-CHAT 16-48 months Formal Diagnosis Level II screening Autism Diagnostic Interview (ADI-R) and the Autism Diagnostic Observation Schedule (ADOS).</p> <p>Treatment management Multidisciplinary Medical comorbidity Hospitalization</p> <p>Management of care for children with ASD through young adulthood</p>	<p>90% of parents of children with ASD report retrospective poor eye contact, language delay and diminished social responsiveness before 12- 24 months. 18-month evaluation: 82% parents identify child absent of “directing attention” and “attention to voice” 36 months: formal diagnosis by expert. Rx approach: family centered with multidisciplinary team 33% have comorbidities Lifelong disorder</p> <p>Conclusion: Nurses are responsible to know ASD core features, identify at risk infants/toddlers; create comfortable healing environments; involve parents; advocate for the child’s IEP, provide resources and plan for transitions.</p>	<p>Strengths: Expert Author Article supported by over 50 articles with scientific findings, evidence-based tools, and parent preferences. Excellent resources for health care providers.</p> <p>Limitations: No appraisal of literature.</p>
<p>Author Recommendations: There is no cure for autism. Throughout the life of their child with ASD; parents will require guidance and direction from health care providers. As an advocate, nurses are in a position to provide resources and support regarding treatment options.</p>			
<p>Implications: Autism continues to be underdiagnosed. Over 50% of children are identified after age five. For best possible outcomes, early intervention is critical. During well-check visits, nurses are often the first to assess the infant, teach parents about developmental milestones and provide resources. The article provides nurses with tools, and online resources for further education about children with ASD.</p>			

Source: Inglese, M.D., & Elder, J.H. (2009). Caring for children with autism spectrum disorder, part I: Prevalence, etiology, and core features. <i>Journal of Pediatric Nursing</i> , 24(1), 41-48. doi:10.1016/j.pedn.2007.12.006			
Purpose/Sample	Design (Method/Instruments)	Results	Strengths/Limitations
<p>Purpose: Given the prevalence, most pediatric nurses will care for a child with ASD. The extensive overview will provide nurses the expert information required to meet the health needs of children with ASD</p> <p>Sample/Setting: 55 referenced sources Dated: 1964-2007. Keywords: Autism Spectrum Disorder, Pervasive developmental disorders; Asperger's disorder; Childhood disintegrative disorder; Rhetts disorder; Pervasive developmental disorders-not otherwise specified.</p> <p>Johns Hopkins Evidence Appraisal Level of Evidence: V Quality: A</p>	<p>Historical comprehensive discussion about Autism Spectrum Disorder.</p> <p>Prevalence: evidence and rationale for growing population</p> <p>Etiology: genetics, environmental influences, vaccines, psychological perspectives</p> <p>Core Features: DSM IV criteria Autism (ASD) Asperger's Disorder (AD) Pervasive developmental disorder-not otherwise specified (PDD-NOS) "atypical autism"</p>	<p>Autism is defined as spectrum disorder Childhood Autism Risks from Genetics and the Environment (CHARGE, 2002-present) 1600 families CDC (2007) ASD Monitoring Network</p> <p>ASD population increase r/t broadening pheno-type. 60%-92% monozygotic 0% dizygotic twins Environment/inconclusive Vaccines: no link to ASD</p> <p>Three Core Features: 1. socialization impairment 2. verbal/nonverbal communication impairment 3. restricted and repetitive behaviors and or interests.</p> <p>Conclusion: Nurses need to understand: Autism is a spectrum disorder because the core features occur in a variety of combinations and severity. Each child has a unique presentation.</p>	<p>Strengths: Expert authors Over 55 articles referenced Referenced articles provide a historic and current understanding of ASD. Excellent resources for health providers</p> <p>Limitations: No literature appraisal</p>
<p>Author Recommendations: Autism is a complex disorder with social impairment, communication impairment and restricted or repetitive behavior that often results in a child experiencing social aloneness. Often, parents are the first to report a language concern. During well baby visits, it is important for nurses to teach parents infant/toddler growth and development milestones and when to report delays or concerns to HCP.</p>			
<p>Implications: Autism is growing exponentially with no cure. A complex developmental disorder with three key domains: social impairment, communication impairment and repetitive or restricted behaviors. It is critical that nurses know how to identify the domains because early detection and interventions are a child with ASD best hope for optimal outcomes.</p>			

Source: Johnson, N., & Bree, O. (2014). Social script iPad application versus usual care before undergoing medical imaging: Two case studies of children with autism. <i>Journal of Radiology Nursing</i> , 33(3), 121-126. Retrieved from http://dx.doi.org/10.1016/j.jradnu.2014.04.001			
Purpose/Sample	Design (Method/Instruments)	Results	Strengths/Limitations
<p>Purpose: To describe social script intervention using iPad and its experiential effect on the child with ASD and parent throughout imaging procedure</p> <p>Sample/Setting: (2) child with severe ASD/parent dyads. Male gender ASD severe Same imaging procedure: CT of Head Midwestern United States tertiary care children's hospital</p> <p>Johns Hopkins Evidence Appraisal</p> <p>Level of Evidence: I</p> <p>Quality: B</p>	<p>University and Hospital IRB approved. RCT Variable: iPad pre-CT Control: treatment as usual (TAU). Two researchers assigned per dyad. Parents provided informed consent prior to data collection.</p> <p>Data Collection Procedural Time T1, T2, T3, T4 Anxiety: Pre-Post Child HR/BP Parents STAI-S BOT: Pre, CT, post.</p> <p>First Researcher preprocedural/post procedural point</p> <p>(New) second researcher blinded to intervention pre-CT</p>	<p>Both children completed procedure.</p> <p>Procedural Time Intervention < control Pre-post anxiety change Parent and Child Intervention > control BOT Intervention < control</p> <p>Neither child required sedation. Both wore seat belts and head straps.</p> <p>Conclusion: A child and parent benefit from the iPad communication strategy as measured by decreased procedural time, less BOT, and less anxiety.</p>	<p>Strengths: Expert author IRB approved study Double Blind BOT HCS internal reliability 0.71 interrater reliability (0.9) STAI-S internal reliability .86-.95 Social Story intervention results consistent with previous research in other settings. Similar population Comprehensive literature review: 28 references</p> <p>Limitations: Small sample size No statistical analysis</p>
Author Recommendations: The case-study demonstrated feasibility and potential efficacy of social story communication strategy via iPad tool to prepare children with ASD for imaging for a larger study (n=32). Future studies could explore other communication strategies to reduce child and parent anxiety.			
Implications: The iPad communication strategy is used in other community settings and the study supports the efficacy of the tool in the health care setting. The study further supports the importance of communication for creating a positive healing experience.			

Source: Johnson, N., Bree, O., Lalley, E., Rettler, K., Grande, P., Gani, M., & Ahamed, S. (2014). Effect of a social Script iPad application for children with autism Going to imaging. <i>Journal of Pediatric Nursing</i> , 29(6), 651-659.			
Purpose/Sample	Design (Method/Instruments)	Results	Strengths/Limitations
<p>Purpose: To examine the efficacy of an iPad social script app to reduce anxiety, challenging behaviors and procedure time among children with ASD and their parent's anxiety</p> <p>Sample/Setting: Recruited: IRB approved flyers, autism newsletter, Clinicaltrials.gov 32 parents/child dyad Male child 82% Female child 17.2% Midwestern USA tertiary care children's health system.</p> <p>Johns Hopkins Evidence Appraisal</p> <p>Level of Evidence: I</p> <p>Quality: A</p>	<p>A pilot feasibility study, experimental, RCT, Variable: iPad app. Control group: TAU (treatment as usual). FSM theory</p> <p>Inclusion: parents/child with ASD DSM IV diagnosis including PPD-NOS Asperger Syndrome medical imaging order</p> <p>Exclusion: individuals requiring procedural sedation.</p> <p>Data Collection: Anxiety: Pre-Post Child HR/BP Parents STAI-S BOT: Pre, Pro, post. Procedural Time D1pre +D2imaging +D3 post = Time</p> <p>Analysis Descriptive statistics Anxiety: Pre-post scores BOT: Chi-square Time: Mann-Whitney <i>U</i> test. Cohen's d effect size between app and TAU</p>	<p>Five children of 16 with iPad intervention required restraint and or medication. All 16 TAU children were restraint and or give medication per procedural protocol. iPad social script effect: Pre-Post Anxiety change Intervention >TAU effect size small 0.33 BOT scores Intervention< TAU effect size medium 0.56 Procedural time No statistical difference effect size 0.15</p> <p>Conclusion: Preliminary results demonstrate the iPad social script does reduce behavior challenges and anxiety among children with ASD and their parent's anxiety during an imaging procedure.</p>	<p>Strengths: RCT, double blind, random intervention. Use of FSM framework to measure parent effect on child anxiety Extensive literature review iPad evidence-based tool for communication in other community setting BOT 90% inter-rater reliability STAI-S internal reliability .86-.95 Social Story intervention results consistent with previous research in other settings.</p> <p>Limitations: Small heterogeneous sample size, large span of ages, and no validation if the child completed the iPad app. TAU protocol is restraints and or medication as needed.</p>
<p>Author Recommendations: Based on the principles of FMS framework, the findings of this study demonstrated the feasibility of our iPad social script app approach to reduce procedural anxiety, behavior challenges among children with ASD. Since the app has potential to change procedural practices, there is a need to collect additional data demonstrating the iPad app. efficacy during health care procedures.</p>			
<p>Implications: The findings of this pilot study addressed the gap in literature, feasibility of the iPad social script as a health care communication strategy and the need for future studies to establish practice standards. In the community, the iPad is an evidence-based communication tool used at school and home. This study suggested iPad social script has the potential to improve communication for a child with ASD during stressful medical procedures. A creative tool, the iPad app promotes a healing experience and is an example of sixth caritas factor.</p>			

Source: Johnson, N., Burkett, K., Reinhold, J., & Bultas, M. (2016). Translating research to practice for children with autism spectrum disorder: Part I. <i>Journal Pediatric Health Care</i> , 30(1), 15-26.			
Purpose/Sample	Design (Method/Instruments)	Results	Strengths/Limitations
<p>Purpose: To provide nurses the current science related to diagnosis and best practice strategies for children with autism spectrum disorder (ASD).</p> <p>Sample/Setting: 109 articles Evidence-based Inclusion criteria: children with autism, families of children with ASD, Health care providers (HCP)</p> <p>Johns Hopkins Evidence Appraisal</p> <p>Level of Evidence: V</p> <p>Quality: A</p>	<p>Literature overview of the emerging science related to ASD diagnosis and interventions for children with ASD.</p> <p>Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-V) criteria for ASD.</p> <p>HCP screening Diagnostic process Interventions for children with ASD</p> <p>Family-centered ASD treatment</p>	<p>Early diagnosis 18-24 months with evidence-based interventions have best outcomes.</p> <p>DSM-V has two domains: 1. persistent social communication and social interaction deficits; 2. restricted, repetitive patterns of behavior, interest, or activities; and three severity ratings:</p> <p>Primary screening: MCHAT if failed refer to level 2 expert diagnostics.</p> <p>ABA is best practice Individuals Education Improvement Act (IDEIA) support parent partnership with HCP.</p> <p>Conclusion: No known cause or cure or consensus to most effective care strategy for child with autism. Family-centered ASD with ABA studies report improved receptive communication.</p>	<p>Strengths: Multiple authors are experts in the field of nursing. Multidisciplinary approach with consideration of 109 sources. Research is applicable for nursing care across all health care settings. Article provides just in time autism care resources.</p> <p>Limitations: No literature appraisal.</p>
<p>Author Recommendations: The research of 109 articles provides valuable information for health care providers to establish best practice policies/ procedures to ensure individual with autism and their families obtains the greatest benefit for the health care services available. Further research needs to test the efficacy of interventions that improve cognitive function, and reduce behavior challenges of children with ASD, as related to communication impairment or social impairments.</p>			
<p>Implications: The article provides nursing a multidisciplinary inclusive care model for individuals with autism and their families. It supports the importance of the relationship between the child and parent. The primary theme continues to address the value of health care partnerships for optimal outcomes. The greatest determination for the success of an individual's rehabilitation and family support is an engaged relationship with each other and with the health care provider.</p>			

Source: Johnson, N. L., & Rodriguez, D. (2013). Children with autism spectrum disorder at a pediatric hospital: A systematic review of the literature. <i>Pediatric Nursing</i> , 39(3), 131-141.			
Purpose/Sample	Design (Method/Instruments)	Results	Strengths/Limitations
<p>Purpose: The aim of this review is to describe health care provider behavior concerns and strategies to provide for children with ASD quality care.</p> <p>Sample/Setting: 34 journal articles 1997-present Inclusion criteria: Parent or HCP and a child with ASD in acute health care or outpatient settings, such as dental visits. All abstracts reviewed on their relevance to the review.</p> <p>Johns Hopkins Evidence Appraisal</p> <p>Level of Evidence: V</p> <p>Quality: A</p>	<p>Systematic review of literature. Cooper, Patel and Lindsay (2009) approach.</p> <p>Database: CINAHL, ProQuest, PsycINFO, and Medline.</p> <p>Keywords: autism, autism spectrum disorder, ASD, Asperger's, child life specialist, nursing, staff, behaviors, procedure, hospital, acute care hospitalization, staff, and parents.</p> <p>Appraised with Melnyk and Fineout-Overholt's (2005) system of seven levels of evidence (Level I- VII). Level I is superior to Level VII</p>	<p>11 theory-based studies: Level II – 1 article Level III – 3 articles Level VI – 7 articles</p> <p>23 clinical practice articles: Level VII</p> <p>Identified four behavior categories 1. Non-compliance from high level anxiety 2. Hyperactivity 3. Self-stimulatory 4. Self-injury</p> <p>Strategies: Calm, quiet environment Involve parents Picture communication with Social stories with time to process information Distraction, restraint, medication sedation.</p> <p>Conclusion: The literature review identified four behavior categories with evidence-based strategies and one common thread “parent involvement”.</p>	<p>Strengths: Extensive up to date literature review. Appraisal of evidence strength and quality. Expert authors Logical conclusions with strategies supported by several expert references.</p> <p>Limitations: Study only considered the HCP view of behavior challenges. Majority of articles are low level appraisal.</p>
Author Recommendations: Consistently, research suggests parent involvement. Parents are the child's interpreters and can provide HCP information upon admission to reduce or prevent behavior challenges. Research is needed to find the best approach to capture parent information and a standardized behavioral observation tool to accurately measure children's behavior.			
Implications: The low-level appraisal of the literature identifies the lack of standardized care for children with ASD. In the meantime, parents' involvement as the child's advocate remains consistent throughout literature. Nurses should include the parents throughout the child's clinical or hospital experience: pre, procedural and post procedural care. Parents know their children and are familiar with what strategies work to help their child acclimate for changing routines.			

<p>Source: Koski, S., Gabriels, R. L., & Beresford, C. (2016). Interventions for pediatric surgery patients with comorbid autism spectrum disorder: A systematic literature review. <i>Archives of Disease in Childhood</i>, 101(12), 1090. doi:http://dx.doi.org.ezproxy.bethel.edu/10.1136/archdischild-2016-310814</p>			
Purpose/Sample	Design (Method/Instruments)	Results	Strengths/Limitations
<p>Purpose: Survey perioperative management practices for pediatric population with ASD.</p> <p>Sample/Setting: Case reports and empirical studies</p> <p>Johns Hopkins Evidence Appraisal</p> <p>Level of Evidence: V</p> <p>Quality: A</p>	<p>Systematic review of peer reviewed journals of best practices and strategies for pediatric patients with ASD who had surgery</p> <p>Search strategy: Electronic databases: OVID, PubMed, Medline, PsycINFO, AMED and Google Scholar.</p> <p>Search Terms and inclusion criteria: ASD, Pediatrics, perioperative interventions, and behavioral strategies. original, empirical and/or case report.</p> <p>Exclusion: comorbid epilepsy, sedation protocols in perioperative setting.</p>	<p>11 articles published between 1997 – 2016 met inclusion criteria.</p> <p>Three common themes</p> <ol style="list-style-type: none"> 1. Collaborate with child and parents regarding communication, sensory and daily routine preferences. 2. Communication process to share patient preferences with other staff 3. Modify environment to meet a child's sensory needs. <p>Conclusion: Children with ASD having surgery will benefit from staff who take the time to listen and implement in the plan of care, the parent/caregiver knowledge about the child's unique ASD symptoms and coping strategies.</p>	<p>Strengths: Expert authors 66 journals identified 11 studies meet criteria included qualitative synthesis, no meta-analysis occurred due to heterogeneity of study designs, interventions and outcome measures.</p> <p>Limitations: Small number of case reports/studies. The review should not be interpreted as evidence for a particular perioperative intervention for ASD.</p>
<p>Author Recommendations: Improved communication is critical to provide quality care for children with ASD. Findings suggest parents are a wealth of knowledge about the child's unique care strategies. Further investigation is needed to establish a process of acquiring information from the parents/caregivers about the child with ASD's daily routines, communication and behavior coping strategies.</p>			
<p>Implications: Hospitals and surgical centers are very stressful and create a feeling of chaos for a child with ASD. Time is critical to gather information about the child's previous experiences, communication preferences and coping strategies. Through effective communication, the nurse will establish trust, reduce anxiety, improve comfort and create a healing environment.</p>			

Source: Jolly, A. A. (2015). Handle with care: tTop ten tips a nurse should know before caring for a hospitalized child with autism spectrum disorder. <i>Pediatric Nursing</i> , 41(1), 11-22. Retrieved from http://link.galegroup.com.ezproxy.bethel.edu/apps/doc/A403916296/EAIM?u=clic_bethel&sid=EAIM&xid=97db05eb			
Purpose/Sample	Design (Method/Instruments)	Results	Strengths/Limitations
<p>Purpose: Nursing Education to provide nursing care strategies for hospitalized children with ASD</p> <p>Sample/Setting:</p> <p>Johns Hopkins Evidence Appraisal</p> <p>Level of Evidence: V</p> <p>Quality: A</p>	<p>Pediatric Nursing Journal: Continuing Education Case Scenario and Resolution ASD diagnosis overview Care strategies and outcomes</p>	<p>Priority of Care: Familiarize with ASD Family involvement communication “Best Method” Challenges of change Consistent caregivers Safe environment Reward system Multidisciplinary team Family support Care documentation</p> <p>Conclusion: To address the needs of children with ASD nurses must be familiar with the disorder, understand how the child communicates, the importance of family to provide communication history and support, and consistent approach by all caregivers.</p>	<p>Strength: Article was reviewed and formatted for contact hour by ANCC. Author is a nurse expert and supported article with 26 resources.</p> <p>Limitations The care strategy is not applied in a clinical trial</p>
Author Recommendations: Nurses caring for children with ASD must be familiar with the disorder, ASD pediatric care challenges, understand the importance of family, utilize communication strategies, minimize change and provide a safe environment.			
Implications: The article provides ANCC approved continuing education 1.3 hours with the purpose of providing nurses care strategies to better meet the needs of hospitalized pediatric patients with ASD.			

<p>Source: Llaneza, D. C., Deluke, S. V., Batista, M., Crawley, J. N. Christodulu, K.V., & Frye, C. A. (2010). Communication, interventions, and scientific advances in autism: A commentary. <i>Physiology & Behavior</i>, 100(3), 268-276. Retrieved from http://doi:10.1016/j.physbeh.2010.01.003</p>			
Purpose/Sample	Design (Method/Instruments)	Results	Strengths/Limitations
<p>Purpose: To review the reciprocal relationship between observations made during evidence-based behavioral interventions of high versus low-functioning children with ASD.</p> <p>Sample/Setting: University of Albany New York 2010 review of the accumulating body of ASD research</p> <p>Johns Hopkins Evidence Appraisal</p> <p>Level of Evidence: V</p> <p>Quality: A</p>	<p>Review the accumulated 154 articles related to ASD research for children inclusive of both high and low functioning; Animal studies Basic Research models</p> <p>Identify best practice behavioral techniques, Current understanding of ASD through animal models and recommendation for further research to understand human communication and develop evidence-based strategies.</p> <p>Keywords: ASD, social, communication, language, gender differences, behavior modeling, (PECS), mice, genetics, BTBR, Center for Autism and related disabilities, education programs, translational research.</p>	<p>Diagnostic Criteria Speech/language deficits Functioning language and social development. Communication strategies Epidemiology Genetic heterogeneity and identification markers Mouse models: to review communication, socialization strategies, and model validity Autism awareness</p> <p>Conclusion: Both human and animal models can facilitate evidence-based strategies for children with ASD.</p> <p>As of 2010, clinicians have developed behavioral techniques to challenge both high and low functioning individuals with ASD.</p>	<p>Strengths: Manuscript published by the National Institute of Health. Historic review of ASD research from 1943 to 2010. Diverse accumulation of research by experts.</p> <p>Limitations: Research presented without evidence levels or quality rating.</p>
<p>Author Recommendations: Given the accumulation of evidence, there is potential for advancement in creating evidence based behavioral interventions, discovering the etiology for ASD and possible cure. Future funding for ASD research and public education is necessary to reach this community health goal.</p>			
<p>Implications: Autism is a complex neurobiological developmental disorder affecting a child's ability to communicate. The research review provided an understanding of autism language/social deficits and the evidence-based communication strategies created to guide caregivers. Adaptation of evidence-based communication strategies is an opportunity to facilitate a caring moment between nurse and child with ASD.</p>			

Source: Russell, S., & McCloskey, C. R. (2015). Parent perceptions of care received by children with an autism spectrum disorder. <i>Journal of Pediatric Nursing, 31</i> (1), 21-31. Retrieved from http://dx.doi.org/10.1016/j.pedn.2015.11.002			
Purpose/Sample	Design (Method/Instruments)	Results	Strengths/Limitations
<p>Purpose: To explore why Children with ASD continue to experience higher risks of unmet health needs and parents are less satisfied.</p> <p>Sample/Setting: 11 parents of children with ASD volunteer 75% boys 25% girl Snowball and purposeful sampling Female/white Upstate New York IRB at St. John Fisher College</p> <p>Johns Hopkins Evidence Appraisal</p> <p>Level of Evidence: III</p> <p>Quality: A/B</p>	<p>Exploratory Sequential Design</p> <p>Investigate the lived experience utilized Interpretive phenomenological analysis (IPA)</p> <p>Quantitative data collection focused on responses from MPOC-20.</p> <p>Recruitment flyers placed in waiting room ASD diagnosis occurred at age 8 and verified by parent only</p> <p>Tape interview MPOC-20 completed by 10/11 parents</p> <p>Final themes compared for accuracy</p> <p>Final analysis IPA</p> <p>Descriptive statistics for MPOC-20</p> <p>ATLAS for coding and theme development</p> <p>Demographic and MPOC-20 with Excel 2011.</p>	<p>MPOC-20 parents Respectful, supportive care, and general information is 5</p> <p>Enabling and partnership and specific information about child is 3</p> <p>Themes:</p> <p>Overwhelming emotion</p> <p>Medical home is only medical</p> <p>On our own</p> <p>School stress</p> <p>Future goals</p> <p>Conclusion:</p> <p>The parent view of the primary provider is compassionate, supportive, medical focus but no direction for management of ASD. Parents are unfamiliar with family-centered or medical home terms</p> <p>Parents feel alone and lost with no real direction for their child's current or future disability needs.</p>	<p>Strengths:</p> <p>Extensive literature review. Expert authors</p> <p>Supervised by academic center.</p> <p>Analysis instruments</p> <p>Researchers discussed their influence on interview process.</p> <p>Sample represents population</p> <p>Limitations: Small sample size</p> <p>Child ASD diagnosis not confirmed by medical record.</p> <p>Child diagnosed later than national average</p> <p>Rural Health Service limits care access.</p>
<p>Author Recommendations: The study addressed a greater understanding of the parent perception of care and role as the child's interpreter. Advanced practice registered nurses are well-suited to address the needs of the children with ASD and their families. Further research is needed to explore how advanced practice registered nurses could provide holistic care management for children with ASD.</p>			
<p>Implications: The art of nursing recognizes the value of parents in making choices for their children's health care. The parent's experience will directly affect the child's outcome. Since each child is unique, the parent's perspective of the child's care and communication strategies are important sources of information to guide the nurse's plan of care.</p>			

Source: Scarpinato, N., Bradley, J., Kurbjun, K., Bateman, X., Holtzer, B., & Ely, B. (2010). Caring for the child with an autism spectrum disorder in the acute care setting. <i>Journal for Specialists in Pediatric Nursing</i> , 15(3), 244-54. Retrieved from https://search-proquest-com.ezproxy.bethel.edu/docview/609335339?accountid=8593			
Purpose/Sample	Design (Method/Instruments)	Results	Strengths/Limitations
<p>Purpose: Explore the challenges of children with ASD experience when hospitalized and familiarize nurses' assessment strategies and plan of care.</p> <p>Sample/Setting: Hospital setting</p> <p>Johns Hopkins Evidence Appraisal</p> <p>Level of Evidence: V</p> <p>Quality: A</p>	<p>Nine Case Examples</p> <p>Initial Assessment Questions</p> <p>-impaired social skills</p> <p>-impaired communication</p> <p>- Restricted interest/stereotyped behaviors</p> <p>Routine/flexibility tolerance</p>	<p>Assessment guide includes: language comprehension level</p> <p>Sensory sensitivities</p> <p>Coping behaviors for emotional disturbances</p> <p>Interventions worked previously</p> <p>Effective communication strategies</p> <p>Plan of care:</p> <p>Impaired social skills: consistent nursing staff limit staff changes</p> <p>Communication: partner with parents/school for community strategies</p> <p>Restricted/Stereotyped behaviors: Behaviors triggered by frustration from miscommunication, anxiety, and fear of the unknown.</p> <p>Routine: Adhere to home/school routines with picture board.</p> <p>Conclusion:</p> <p>The most effective plan of care will address the unique symptoms and needs of the child with ASD.</p>	<p>Strengths:</p> <p>Expert Authors</p> <p>Peer Reviewed Journal</p> <p>Extensive literature review: 41 references</p> <p>Case studies</p> <p>Limitations:</p> <p>Practice guidelines applied to clinical case studies; no clinical trials.</p>
<p>Author Recommendations: Nurses need to work closely with parents or caregivers to better understand what home strategies help the child cope with stress. During the admission process, link the parent's strategies to identified challenges, and adapt the environment to provide safety and sensory sensitivity.</p>			
<p>Implications: Hospitalization for children with ASD is overwhelming. Nurses who are familiar with the disorder and care strategies could integrate the child's communication styles, adopt home routine and promote healing to reduce patient anxiety and stress.</p>			

Source: Vaz, I. (2013). Visual symbols in healthcare settings for children with learning disabilities and autism spectrum disorder. <i>British Journal of Nursing</i> , 22(3), 156-159.			
Purpose/Sample	Design (Method/Instruments)	Results	Strengths/Limitations
<p>Purpose: Develop clinical picture exchange communication systems (PECs). Evaluate their appropriateness for children with ASD and feasibility in health care settings.</p> <p>Sample/Setting: 50 health care professionals working with children diagnosed with ASD and LD at South Warwickshire district hospital. 20 consecutive children with ASD and LD familiar with PECs attending special school clinic.</p> <p>Johns Hopkins Evidence Appraisal</p> <p>Level of Evidence: II</p> <p>Quality: A/B</p>	<p>Predictive Design. A service development project didn't require IRB. 150 Visual symbols developed with Widget Software by author to represent medical examinations, clinical procedures, and treatments common to children. Placed on strip or fobs in a sequential order of PECs to explain expected event.</p> <p>Parents given symbols to practice with their children to prepare for clinic/hospital appointments.</p> <ol style="list-style-type: none"> 1. Show picture 2. Give verbal explanation <p>Professionals experienced with children who have ASD and LD were provided PECs.</p> <p>Informal qualitative survey of professionals with brief questionnaire</p>	<p>Professionals survey responses: "excellent idea" "visual prompt helpful" "symbols are useful for children" 50/50 professionals reported: 1. PECs are relevant and would help increase the child's understanding of verbal explanations in clinical setting. 2. PECs helpful communication strategy before and during clinic visits. 3. PECs on strips most helpful in clinic 40/50 professionals report using key fob when away from their usual clinical area.</p> <p>Conclusion: Survey of professional's report PECs of common medical procedures and treatments make it easier for children to understand the clinic visit.</p>	<p>Strengths: Expert author PECs developed in partnership with expert software. PECs evidence-based communication tool for children with ASD 50 professionals from 12 clinical sites.</p> <p>Limitations: Single geographic area Small sample of children involved in survey. No scientific measure to validate collected data.</p>
Author Recommendations: The survey suggests PECs used successfully by children with ASD and LD in other community settings are effective in health care settings as well. The study will be expanded to a larger random sample of children attending hospitals and community clinics.			
Implications: In most health care settings, nurses are the first point of contact for children with ASD and their parents. Communication is the primary tool nurses use to establish nurse/patient relationship. PECs are an effective communication strategy for children with ASD. They are used as visual communication tools in schools and at home. The survey suggests nurses could use PECs as a communication strategy when providing care for children with ASD.			

Source: Zwaigenbaum, L., Nicholas, D. B, Muskat, B., Kilmer, C., Newton, A. S., Craig, W. R., & ... Sharon, R. (2016). Perspectives of health care providers regarding emergency department care of children and youth with Autism Spectrum Disorder. <i>Journal of Autism & Developmental Disorders</i> , 46(5), 1725-1736. doi:10.1007/s10803-016-2703-y			
Purpose/Sample	Design (Method/Instruments)	Results	Strengths/Limitations
<p>Purpose: To identify ED health care providers' clinical knowledge of children with ASD and optimal ASD care strategies.</p> <p>Sample/Setting: Convenience 10 physicians 12 nurses 22 parents of children under 18 with ASD Two ED high-acuity pediatric center with mental health services</p> <p>Johns Hopkins Evidence Appraisal</p> <p>Level of Evidence: III</p> <p>Quality: A/B</p>	<p>Grounded Theory Replicated from previous study 2015</p> <p>Parents recruited at time of care and interviewed within 4 months.</p> <p>Clinical descriptive data - severity of ASD -social/language -anxiety</p> <p>HCP Individual Interview Semi-structured with open ended questions -relationships -experiences -processes -decision/making -outcomes</p> <p>Interview digitally recorded qualitative analysis -open coding -Axial coding -Selective coding</p>	<p>Factors contributing to ED <i>challenges</i>: Characteristics of child Age, size, ASD severity Language deficit ED chaos not therapeutic Limited time in ED to address child care</p> <p>Factors that facilitated effective ED care: Communication strategies – take time, use visual cues, assess anxiety while engaging child Involve parents for both communication and facilitating best approach for physical care Calm environment Training and teamwork</p> <p>Conclusion: Best approach to care -parent-health care provider partnership -sensory environment -flexibility for individual ASD presentation -staff ongoing clinical knowledge/skills of ASD</p>	<p>Strengths: Sufficient sample size Consistent with previous study 2015 Comprehensive literature review Facility network with academic resources</p> <p>Limitations: Voluntary participant could create bias – parents or HCP with negative experience might refuse. Children with ASD were seen for physical concerns/ not mental health.</p>
<p>Author Recommendations: Adopting flexible, child centered approach in the ED environment for children with ASD will help reduce anxiety but the approach requires a culture change in the ED. For example, an administrative policy allowing for more time to care for the child, creating low sensory spaces for children and modifying clinical approach to meet the child's need.</p>			
<p>Implications: The study provides possible communication strategies for nursing practice. Starting with the environment, a nurse could reduce sensory overload. Next, the nurse could partner with parents about what is the best communication approach. Finally, the nurse continues to assess the patient's level of anxiety to measure efficacy of the strategy and adjust the clinical approach to meet the child's coping abilities.</p>			