

ABSTRACT

THE ROUTINE SCREENING PRACTICES OF NURSE PRACTITIONERS FOR AUTISM IN CHILDREN

By Sarah A. Vande Hey

Autism, a severe disorder of development, is becoming increasingly common among children. The prevalence of autism is estimated to be 1 in 150 children (Johnson & Myers, 2007) and the incidence is on the rise. Autism can cause disabilities in all areas of psychological development, from cognitive, language, and behavioral deficits to impairments in social interaction (Crane & Winsler, 2008). Early detection of autism increases the chance of early intervention, which has proven to lead to better outcomes. However, previous studies have shown that less than 30% of providers are screening children for autism (Blackwell & Niederhauser, 2003).

Nurse practitioners in a primary care or pediatric setting are in a significant position to improve outcomes for children through routine screening for autism. The purpose of this study was to explore the routine screening practices of nurse practitioners for autism in children. The following three research questions were explored: 1) Are nurse practitioners routinely screening for autism in children? 2) At what age do nurse practitioners begin screening for autism in children? 3) What are the barriers to routine screening for autism in children? Orlando's Nursing Process Theory was used as the theoretical framework for this study.

A quantitative study approach was used to explore the routine screening practices of nurse practitioners for autism in children. The convenience sample included 102 nurse practitioners working with pediatric patients in a primary care or pediatric setting in Northeastern Wisconsin. Data was collected through the use of a 16-item questionnaire with closed-ended questions. A list of local nurse practitioners, along with their home addresses, was obtained from the Wisconsin Department of Regulation and Licensing. Questionnaires were mailed to the nurse practitioners' homes and responses were kept anonymous.

Descriptive statistics were used to analyze the data. Findings indicated that only 23% of the nurse practitioners routinely screen pediatric patients for autism. The age at which this sample began screening children for autism was not consistent with current recommended guidelines. The main barriers to routine screening for this sample were 1) unfamiliarity with the screening tools, 2) absence of formal training to screen for autism, and 3) limited time. These barriers are consistent with findings of studies reviewed in the literature. The majority of the participants in this sample would benefit from learning more about autism. Overall, it appears that the recommended guidelines for autism screening are not being followed.

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by

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This project is dedicated to my husband, Jake, for inspiring me to pursue my dreams and always believing in me. I love you with all my heart and am deeply thankful for your endless love and support.

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CHAPTER I

INTRODUCTION

Autism is a lifelong condition that is characterized by developmental disability. With wider recognition in the recent years, autism has become one of the most common developmental disabilities in children (Blackwell & Niederhauser, 2003). Autism is characterized by a variety of disabilities, from cognitive, language, and behavior deficits to impairments in social interaction. With the wide spectrum of disabilities seen among these children, the creation of a category to encompass several diagnoses was created, which is called autism spectrum disorders (ASD) (Crane & Winsler, 2008). The prevalence of ASD has risen to an alarming 1 in 150 children (Johnson & Myers, 2007).

Despite the prevalence of ASD in children, the surveillance and screening of ASD in children has been met with barriers in the primary care setting. Studies show that children may be showing signs of autism in infancy, yet most children are not diagnosed until the age of four to seven years of age (Gray & Tonge, 2004). Early detection of developmental delay will lead to early intervention, resulting in better outcomes for the child. With heightened public awareness and reports of increased prevalence, early detection and intervention of ASD has become a priority for parents. But has it become a priority for providers? According to Blackwell and Niederhauser (2003), fewer than 30% of primary care providers perform standardized screening for developmental delays

during well-child visits. A study by Dosreis, Weiner, Johnson, and Newschaffer (2006) reported that only 8% of primary care pediatricians routinely screen children for ASD.

Numerous studies on screening and diagnosis of ASD by primary care physicians and pediatricians have been completed, while exploring the efficacy of various screening tools available (Boggs, Gross & Gohm, 2006; Dietz, Swinkels, van Daalen, van Engeland & Buitelaar, 2006; Gray & Tonge, 2004; Gray, Tonge, Sweeney & Einfeld, 2008; Robins, Fein, Barton & Green, 2001; Sand, Silverstein, Glascoe, Gupta, Tonniges, & O'Connor, 2005; Sices, Feudtner, McLaughlin, Drotar & Williams, 2004). However, few articles were found that examined the primary care nurse practitioner's role in surveillance and screening of ASD in children. Blackwell and Niederhauser (2003) explain that as nurse practitioners continue to enter the world of primary care and pediatrics, it is inevitable that they will encounter children with developmental delays in their practice. Their article is aimed at raising awareness of current ASD screening methods for nurse practitioners. Schnur (2005) specifically discusses the role of the nurse practitioner in continual developmental surveillance and screening for ASD at serial well-child visits. Much of the literature examines the role of the nurse practitioner; however, there seems to be a large gap in the literature regarding the current practices of nurse practitioners in the screening of ASD in children.

Significance to Nursing

Autism is among the most challenging of child developmental disorders. It severely affects development in social interaction, communication, and behavioral patterns (Holzer, Mihailescu, Rodriguez-Degaeff, Junier, Muller-Nix, Halfon, et al., 2006). According to Sand et al. (2005), 95% of children from birth through 3 years of age see healthcare providers regularly. With increasing publicity and rising prevalence of autism, parents will likely look to their provider for answers regarding their child's behavior. The advanced practice nurse (APN) is in a significant position to identify early signs of ASD and provide appropriate management. The role of the APN includes routine surveillance and screening of developmental delays, providing anticipatory guidance, continuity of care, and parental counseling (Schnur, 2005). Routine surveillance and screening for autism should be increasingly emphasized to parents and health care providers for referral and diagnosis in order to intervene at the earliest point possible (Twedell, 2008). Early intervention for autistic children has shown to greatly improve a child's development (AAP, 2006; Blackwell, 2001; Blackwell & Niederhauser, 2003; Crane & Winsler, 2008; Filipek, Accardo, Ashwal, Baranek, Cook, Dawson, et al., 2000; Goin & Myers, 2004; Holzer et al., 2006; Johnson & Myers, 2007; Schnur, 2005).

Due to the widespread research conclusions that early intervention leads to better outcomes in autistic children, recommendations and practice parameters are continuously being implemented for the early surveillance and screening for ASD in children. Practice

parameters for the screening and diagnosis of ASD were introduced by the American Academy of Neurology and the Child Neurology Society to give specific recommendations for the identification of children with autism (Filipek et al., 2000). These parameters are one of several sets of guidelines that have been proposed by various pediatric organizations for routine developmental screening. The Council on Children with Disabilities (2006) recommends that developmental surveillance be incorporated into every well-child preventive care visit. Several algorithms have also been presented in the literature to assist providers in the process of assessment and screening for autism in children (Council on Children with Disabilities, 2006; Dietz, et al., 2006; Filipek et al. 2000; Hix-Small, Marks, Squires, & Nickel, 2007; Johnson & Myers, 2007). It is important for the nurse practitioner to follow these parameters and utilize the available algorithms and screening tools to provide routine screening for ASD in children.

Problem Statement

With the increasing prevalence of autism in children, it is important for healthcare providers to routinely screen children for developmental delays associated with this disorder. Routine screening will lead to early detection of autism and early intervention, which is fundamental in achieving positive outcomes for autistic children and their families. However, research indicates that a high percentage of health care providers are not routinely screening children for autism. The lack of routine screening in many cases

has led to late diagnosis, delayed intervention, and decreased long-range potential for these children.

Purpose of the Study

The purpose of this study was to evaluate the routine screening practices of nurse practitioners for autism in children. In addition, the age of the child at which nurse practitioners start screening for autism, as well as barriers to screening for autism in children was explored.

Research Questions

The study examined the following questions:

1. Are nurse practitioners routinely screening for autism in children?
2. At what age do nurse practitioners begin screening for autism in children?
3. What are the barriers to routine screening for autism in children?

Definition of Terms

Conceptual Definitions

Nurse Practitioner: registered nurses who have advanced skills in the assessment of the physical and psychosocial health-illness status of individuals, families, or groups in a variety of settings through history taking and physical examination. If special skills are developed in family health, the nurse may be called a family nurse practitioner (FNP); if in pediatrics, a pediatric nurse practitioner (PNP) (O'Toole, 1992).

Children: a group of individuals in the period between birth and adolescence; roughly from birth to 11 years of age (Mosby, 1998).

Age: a stage of development at which the body has arrived, as measured by physical and laboratory standards to what is normal for a male or female of the same chronologic span of life (Mosby, 1998).

Autism: a pervasive developmental disorder with onset in infancy or childhood, characterized by impaired social interaction, impaired communication, and a remarkably restricted repertoire of activities and interests (Mosby, 1998). The American Psychiatric Association's (2000) Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition-Text Revision (DSM-IV-TR) defines autism by the following criteria:

DSM-IV-TR (2000) criteria for Autistic Disorder:

- A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

1. qualitative impairment in social interaction, as manifested by at least two of the following:
 - a. marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - b. failure to develop peer relationships appropriate to developmental level
 - c. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
 - d. lack of social or emotional reciprocity
 2. qualitative impairments in communication as manifested by at least one of the following:
 - a. delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
 - b. in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
 - c. stereotyped and repetitive use of language or idiosyncratic language
 - d. lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
 3. restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
 - a. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - b. apparently inflexible adherence to specific, nonfunctional routines or rituals
 - c. stereotyped and repetitive motor manners (e.g., hand or finger flapping or twisting, or complex whole-body movements)
 - d. persistent preoccupation with parts of objects
- B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.
- C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder (p. 69).

Barrier: something nonphysical that obstructs, hinders, or restricts (Mosby, 1998; Webster, 1995).

Routine: a prescribed and detailed course of action to be followed regularly; standard procedure (Webster, 1995).

Screening practices: a preliminary procedure, such as a test or examination, to detect the most characteristic sign or signs of a disorder that may require further investigation (Mosby, 1998).

Operational Definitions

Nurse Practitioners: any male or female licensed pediatric nurse practitioner and family nurse practitioner practicing in a primary care or pediatric setting in the state of Wisconsin, with at least one year of experience.

Children: individuals between 6 months to 11 years of age who obtain health care in a primary care setting and have received care from a primary care nurse practitioner.

Age: the point in the child's life in which the nurse practitioner assesses for developmental delays, as reported by the participants.

Autism: includes autism spectrum disorders (ASD) as defined by the DSM-IV-TR for children (see conceptual definition).

Barrier: factors related to the nurse practitioner's lack of routine screening for autism in children.

Routine: a prescribed and detailed course of action to be followed regularly at the 6, 9, 12, 18, and 24-month well-child preventive visit, as reported by the participants.

Screening practices: the use of clinical assessment or specific screening tools to appropriately identify children with or at risk for autism, as reported by the participants.

Assumptions

1. Participants in this study will be honest and forthright in their answers.
2. Participants are involved in the primary care of children.
3. Participants will understand and speak the English language.
4. Closed-ended questions are a valid and efficient method to elicit the process by which nurse practitioners screen for autism in children.

Summary

Autism is a health concern in children that cannot be ignored. Outcomes for children with developmental delays are likely to be improved with early intervention. Considering that the primary care setting is an opportune place to identify developmental delays, nurse practitioners are in a significant position to aid in the routine screening for autism in children. The literature does not reveal the routine screening practices of nurse

practitioners. This researcher hopes that the current study will shed light on this issue so that nurse practitioners can become aware of the significance of routine screening and early intervention, as well as improving their knowledge base regarding ASD in children. In this chapter, an introduction to the topic, its significance to nursing, and details on the problem, purpose, research questions, and conceptual and operational definitions of the study were outlined.

CHAPTER II

THEORETICAL FRAMEWORK AND REVIEW OF LITERATURE

The purpose of this study was to investigate the routine screening practices of nurse practitioners for autism in children. In this chapter, a discussion of the theoretical framework and a review of the current literature are provided. In the first section, Ida Jean Orlando's Nursing Process Theory is discussed, as well as its application to this study. The literature review follows and includes studies on early detection of autism in children, screening tools for autism, screening guidelines, and barriers to routine screening.

Theoretical Framework

The theoretical framework guiding this research was based on Ida Jean Orlando's Nursing Process Theory (1961). The Nursing Process Theory was derived from the overall goal to develop a theory of effective nursing practice. Orlando has made major contributions to nursing theory and practice with her conceptualizations of the nursing process through the following: interrelated concepts that represent a systematic view of nursing phenomena; specific relationships among the concepts; explanation of what happens during the nursing process, and explanation of how the control leads to the

prediction of outcomes (Schmieding, 2006). The Nursing Process Theory revolves around five major interrelated concepts:

1. The function of professional nursing
2. The presenting behavior of the patient
3. The immediate or internal response of the nurse
4. The nursing process discipline
5. Improvement

Orlando's major assumption about nursing is that it should be a distinct profession that functions autonomously. The function of professional nursing is conceptualized as finding out and meeting the patient's needs. It is the responsibility of the nurse to meet the needs of the patient, either directly or indirectly by calling in the help of others. The nurse must provide direct assistance to the individual for the purpose of avoiding, relieving, diminishing, or curing the person's sense of helplessness (Orlando, 1961).

The presenting behavior of the patient is conceptually defined as any observable verbal or nonverbal behavior. Orlando emphasizes the importance of observing changes in a person's behavior. Each person is unique and individual in their presentation of behaviors; therefore, the professional nurse must be able to recognize that the same behavior in different patients can signal different needs (Orlando, 1961).

The immediate or internal response of nurses includes their perceptions, thoughts, and feelings. Because the patient's needs may not be what they appear to be, nurses must

use their perceptions, thoughts about the perception, or feelings engendered from their thoughts to explore with patients the meaning of their behavior. This process enables the nurse to find out the nature of the distress and determine the patient's needs (Orlando, 1961).

The nursing process discipline involves the nurse communicating to the patient his or her own immediate reaction, clearly identifying that the item expressed belongs to the nurse, and then asking for validation or correction from the patient. The immediate reaction of the nurse includes automatic nursing action and deliberate nursing action. Automatic nursing actions are those having to do with finding out and meeting the patient's need for help. Deliberative nursing actions are those designed to identify and meet the patient's immediate needs and to fulfill the professional nursing function (Orlando, 1961).

The Nursing Process Theory focuses on how the actions of the nurse can improve patients' behaviors and fulfill their needs. Evidence of relieving a patient's distress is determined by positive changes in the patient's observable behavior. The nurse evaluates his or her actions at the end of the patient encounter by comparing the patient's verbal and nonverbal behavior with that which was present when the process started (Orlando, 1961).

The Nursing Process Theory was used as the model for this study due to the focus on the nurse-patient interaction and the nurse's actions. Each of the five concepts of the Nursing Process Theory fit with the variables of this study. The function of professional

nursing is to find and meet the needs of the patient, which equates to the nurse practitioner recognizing the child's abnormal behavior and proceeding to the next step of screening for autism. The presenting behavior of the patient is associated with the abnormal behavior of autism presented by the child. The immediate or internal response of the nurse practitioner is to screen for autism. Routine screening practice is a deliberative nursing action of the nursing process discipline which may lead to improvement because screening is likely to lead to diagnosis and early intervention for the child. The correlation of concepts is presented in Figure 1.

Case Study Exemplifying Theory Relevance to Current Study

J.V., a 35-year-old female nurse practitioner working in an urban, family practice clinic, examines a 12-month-old boy for his well-child preventive visit. The boy is accompanied by his mother. During the initial history of present illness, the mother notes that the boy has been exhibiting some abnormal behaviors at home. He does not like to cuddle, does not return a happy smile back at her, does not seem to notice when his name is called out, and acts as if he is in his own world. J.V. makes every effort to explore the behaviors that the boy is exhibiting at home by asking questions and observing the presenting behavior of the patient (the function of professional nursing). The boy is sitting in his mother's lap, holding a ballpoint pen, and is looking around the room. J.V.'s immediate response is to follow the Denver II Developmental Model as she does her examination on the boy. This is the standard model that is used for every well-child

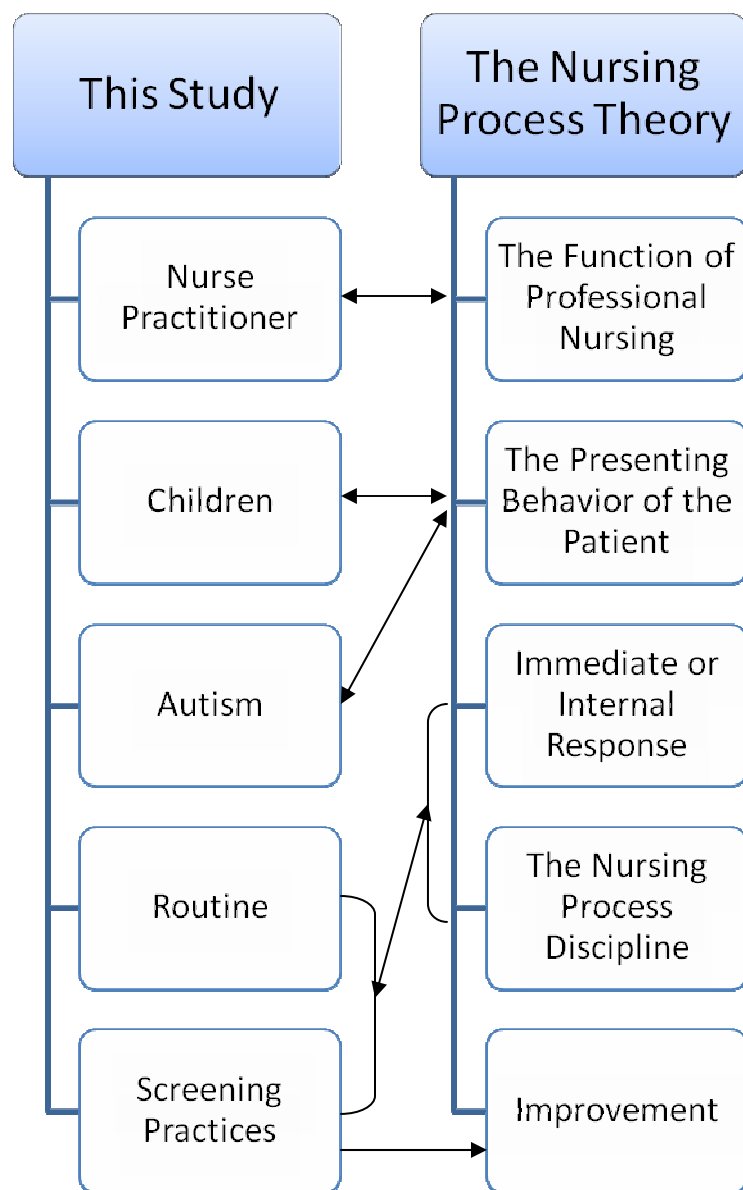


Figure 1. Integration of Orlando's theory with the current study concepts.

visit in this particular clinic. When J.V. is finished with the examination, she discovers that the boy is exhibiting developmental delays that are consistent with a diagnosis of autism. The mother is very concerned about her son's behavior and asks if there is something wrong with him.

J.V. is uncertain what to do at this point. She has been a nurse practitioner in the primary care setting for two years and has minimal experience with autism in children. She cannot remember receiving any training or literature in this sensitive area in her formal education, and has no personal experiences with autism. She does not recall ever seeing a screening tool for autism at the clinic. J.V. steps out to consult with one of the family practice physicians in his office. The physician supports her assumption of autism, but states that he has no experience with screening tools and suggests that J.V. refer the child to a pediatrician for further evaluation. J.V. is able to obtain an appointment for the child with a pediatrician at a different clinic in 2 weeks.

J.V. returns to the exam room for further discussion with the mother on her assessment (nursing process discipline) of the boy's developmental delays and subsequent referral to a pediatrician (deliberative action). She feels frustrated that she is not able to better assess the child for autism and realizes that she has minimal knowledge on the topic of autism. She also recognizes that this 30-minute scheduled appointment has required much more time in order to provide her patient with the best care possible and answer the mother's questions. J.V. vows to take personal responsibility in increasing her knowledge base, researching the various screening tools that are available,

and improving the overall process by which she routinely screens children for autism (improvement).

In summary, Ida Jean Orlando's Nursing Process Theory focuses on the function of the nurse; the presenting behavior of the patient; immediate or internal response of the nurse; the nursing process discipline; and improvement. This case study illustrates the importance of the nurse practitioner recognizing the patient's need for help and deliberately acting in a way as to improve the outcome for the patient. This case study also paints a realistic picture of the lack of routine screening by providers in the clinic. In this case, the barriers to screening were lack of time, knowledge, and experience related to available screening tools.

Literature Review

The literature surrounding autism in children is quite extensive. The benefit of early detection of autism in children is abundant in the literature and several studies have revealed the positive outcomes associated with early intervention. There are numerous studies on the efficacy of various screening tools for autism and the barriers to screening, along with well-documented literature explaining the current screening guidelines recommended by various organizations. Several studies were found that focus on providers' screening practices for autism; however, none of these studies were specifically aimed at the practice of nurse practitioners. Despite the lack of studies found

related to nurse practitioners, the review below provides an analysis of the literature on autism.

Early Detection of Autism

Statistics indicate that autism is reportedly on the rise, with the prevalence estimated to be 1 in 150 children (Johnson & Myers, 2007). According to the American Academy of Pediatrics (AAP) (2006), the reason for the increase may be due to a number of factors, including an increased awareness of autism, the availability of more screening tools and services, and changes in how autism is defined and diagnosed. Autism is defined as a brain-based disorder that affects a child's behavior, social, and communication skills. This disorder is a lifelong condition with no known cure. However, children with autism are able to progress developmentally and learn new skills as long as they receive the proper interventions (AAP). Early detection of autism can lead to immediate access to intervention services for the child, and the potential for less stress on the family (Goin & Myers, 2004).

The National Institute of Neurological Disorders and Stroke indicate that the onset of developmental impairments associated with autism is before the age of 3 (as cited in Johnson & Myers, 2007). Several studies indicate that children show signs of autism throughout infancy, especially in social and language skills. Because diagnosis of autism is often not made until 3 years of age or later, infants and toddlers with autism are missing out on immediate therapeutic opportunities (Goin & Myers, 2004). Dietz, et al. (2006) focused their study on a population of very young children. The screening of

31,724 children aged 14 to 15 months with the Early Screening of Autistic Traits Questionnaire (ESAT) resulted in 18 children being identified with autism. Limitations of this study included high attrition due to uncooperative parents. The results of the study indicated that early identification of autism is possible. Chawarska, Klin, Paul, and Volkmar (2007) examined the syndrome expression of autism in children at the age of two years. They reported data on 31 infants between 14 and 25 months of age referred to a specialized clinic for a comprehensive multidisciplinary assessment with the use of two tools, the Autism Diagnostic Observation Schedule-Generic (ADOS-G) and the Autism Diagnostic Interview-Revised (ADI-R). Out of the 31 infants under the age of 2 years, 19 were diagnosed with autism. The authors researched the symptoms of autism in the second year and the changes in the syndrome expression by the age of three. The ADOS-G captured the symptoms of the infants as (a) limited response to name, (b) poor eye contact, (c) limited response to joint attention bids, (d) lack of pointing, and (e) delays in functional and symbolic play. The results of the study showed that symptoms of autism in the second year were pronounced and stability of the clinical diagnosis was high. Changes in the symptoms from second to third year were limited and the pattern was similar in both diagnostic groups. The results provided support for strength of clinical diagnosis and highlighted the advantages of diagnosing and documenting symptoms of autism in infants.

In the past decade, a number of studies using retrospective video analysis have begun to identify differences in early behavior in infants associated with later diagnosis

of ASD in children. Using home videos has given researchers a way to observe children early on in their naturalistic social environments. Osterling, Dawson, and Muson (2002) used a retrospective approach to analyze home video of a child's first birthday party. The results of the study indicated that the child failed to orient to name, and did not look at the faces of other people. A similar study by Maestro et al. (2002) showed that children 6 months or younger observed in home videos had poor social attention, failed to seek contact, and exhibited excessive exploratory activity with objects. These studies support the fact that developmental differences, specifically failure to respond to names, failure to orient toward people, and showing less verbal and nonverbal communicative behaviors, are detectable in infants.

Parents are typically the first to notice that their child is not developing normally. This usually occurs during infancy (Goin & Myers, 2004). According to Volkmar, Stier, and Cohen (as cited in Chawarska et al., 2007), a majority of parents voice their concerns before their child's second birthday, and about 50% notice some abnormalities in the first year. Bertrand et al. (2001) reported that parents often suspect autism in their children at the age of 12 to 15 months. A study by Chawarska et al. (2007) revealed that the mean age of onset of parental concerns was 14.7 months. These concerns were related to language development and social relatedness. Parents typically notice that their infant may be unresponsive to them, focus intently on one item exclusively, and not like being cuddled. Failing to respond to their name and avoiding eye contact are also signs that may appear as they age (Twedell, 2008).

With early recognition of developmental abnormalities by parents, families may experience frustration in trying to get a diagnosis and services for their child. Twoy, Connolly, and Novak (2007) examined the time lag between parents' suspicion of autism and the actual professional diagnosis. Questionnaires were distributed to 94 families who were recruited from a nonprofit parental support group. Results of the study indicated that the time from parents' suspicion of developmental delays to a professional diagnosis of autism in their children was at least 6 months or greater. Parents may look to their provider for answers and experience feelings of fear, confusion, and uncertainty. Another benefit of early diagnosis is to alleviate the stress that families often experience when their child is displaying developmental delays. Parents need accurate information about their child's difficulties so that they can learn how to best care for and manage them at home. With an early diagnosis of autism, parents can become educated about the disorder, make informed decisions on therapeutic practices, and move in an appropriately beneficial direction for their family (Goin & Myers, 2004).

Much of the literature suggests that early intervention in children with autism leads to positive outcomes (AAP, 2006; Blackman, 2002; Crane & Winsler, 2008; Committee on Children with Disabilities, 2001; Council, 2006; Dietz, et al., 2006; Filipek et al., 2000; Freeman & Cronin, 2002; Goin & Myers, 2004; Gray, et al., 2008; Gupta et al., 2007; Johnson & Myers, 2007; Kasari, 2002; Leekam, Libby, Wing, Gould, & Taylor, 2002; McConnell, 2002; Myers & Johnson, 2007; Persson, Nordstrom, Petersson, Mansson, & Sivberg, 2006; Pinto-Martin, Souders, Giarelli, & Levy, 2005; Rhoades,

Scarpa & Salley, 2007; Robins, Fein, Barton, & Green, 2001; Sand et al. 2005; Schnur, 2005; Sigman, Dijamco, Gratier, & Rozga, 2004; Tebruegge, Nandini, & Ritchie, 2004; Twedell, 2008; Watson et al., 2007). Kasari examined 10 different early autism intervention studies and found that all of the interventions reported significant child improvements in behavior, cognition, or social interactions, and one reported complete recovery in 47% of participants through early adulthood. Other study results indicate that autistic children who receive early treatment exhibit significant improvements in functioning as opposed to older autistic children undergoing the same interventions (Blackman, 2002; McConnell, 2002). These discoveries reveal that early detection that leads to early intervention is fundamental for autistic children.

The Committee on Children with Disabilities (2001) reported that early intervention services for children with autism are widely available in the United States. However, a 1999 legislative study on early intervention services indicated that even though between 8% and 13% of the total population between birth and 3 years of age could qualify and benefit from early intervention services, only 2.6% were served. This is likely due to late diagnosis of autism in children. The results of a study by Rhoades, et al. (2007) revealed a delay in diagnosis of autism through an online survey that consisted of questions about demographics, the diagnostic process, sources of information, and the need and availability of local services for autism. The surveys were given to 146 ASD caregivers. The data showed that the average age of autism diagnosis was 4 years, 10 months, which is later than optimal in order for children to receive the benefit from early

intervention. These findings support the need for early detection and the important role that providers can play in this regard. A similar study by Mandell, Novak, & Zubritsky (2005) examined factors associated with the age of diagnosis of autism in children. Surveys were collected in Pennsylvania from 969 autism caregivers and a linear regression was used to identify clinical and demographic characteristics associated with age of diagnosis. The average age of diagnosis was 3.1 years for children with autism. These studies provide evidence that children are not being diagnosed early enough to reap the benefits of early intervention.

Screening Instruments for Autism

There are currently several screening tools available for the detection of autism. Some tools are completed by parents, others are completed by lay personnel or trained professionals, and some are completed by both. The benefit of screening is that there may be earlier diagnosis which may then result in early intervention (Schnur, 2005). The advantages of developmental screening instruments are that they state their norms explicitly, serve as a reminder to the provider to observe for development, are an efficient way to record the observations, and help the provider identify more children with delays (Committee on Children with Disabilities, 2001). The ideal screening tool is both sensitive and specific. A test that has high sensitivity means that a high percentage of individuals who truly have the condition are detected. Specificity refers to lowering the number of falsely identified individuals. A screening tool high in sensitivity and

specificity would identify all children who have autism and rule out every child who does not (Goin & Myers, 2004).

Parent observations and reports are one important method of screening for autism. As previously discussed, parents are often the first to recognize developmental delays in their children at an early age. They are in the best position to provide historical information concerning skill regression, patterns of behavior, and developmental difficulties (Goin & Myers, 2004). However, parental observations may suffer from poor reliability and validity compared to biologic methods.

Since autism has shown to be difficult to diagnose in young children, many researchers have made attempts to develop more sensitive screening tools. The Checklist for Autism in Toddlers (CHAT) was developed by Baron-Cohen, Allen, and Gillberg (1992) to be used as a screening tool for 18-month-old children. One part is completed by parents and the other by the health professional. A six-year follow-up study of CHAT by Baird, Charman, Baron-Cohen, Cox, Swettenham, Wheelwright, et al. (2000) reported high specificity, but very low sensitivity. This led Robins, et al. (2001) to develop the Modified—Checklist for Autism in Toddlers (M-CHAT), which consists of 23 yes/no items to be completed only by the parents. This instrument was used to screen 1076 children, of which 30 to 44 children were diagnosed with ASD. The results indicated that the M-CHAT is a promising instrument for early detection of autism. Dietz, et al. (2006) developed the Early Screening of Autistic Traits Questionnaire (ESAT). A random sample of 31,724 children, aged 14 to 15 months, was screened with resultant 18 children

identified to have autism. They concluded that the ESAT is far from a diagnostic instrument, but could easily be used as a screening tool. Persson, et al. (2006) conducted a study to develop an instrument for the early detection of developmental deficits and/or autistic spectrum disorders among children by the age of 8 months. The study was a cross-sectional prospective pilot study at eight child health care centers in southern Sweden. The researchers screened 312 infants with their instrument (SEEK). The instrument proved to be very satisfactory, efficient, and easy to use.

Many studies have tested the efficacy of various autism screening tools. Gray, et al. (2008) compared the Developmental Checklist-Early Screen (DBC-ES) with the M-CHAT and the Autism Screening Questionnaire/Social Communication Questionnaire (SCQ). The parents of 207 children aged 20 to 51 months completed the DBC-ES prior to their child undergoing assessment. According to their study, the DBC-ES appeared to perform slightly better in very young children compared to the M-CHAT and SCQ. A study by Saemundsen, et al. (2003) investigated the diagnostic assessment efficacy of the Autism Diagnostic Interview—Revised (ADI-R) and the Childhood Autism Rating Scale (CARS). The sample consisted of 54 children aged 22 to 114 months that were referred for possible autism. The study resulted in the CARS instrument identifying more cases of autism than the ADI-R.

With a great variety of screening tools available, it is important to recognize the most commonly used autism screening tools. The Denver-II (DDST-II, formerly the Denver Developmental Screening Test-Revised) has been a traditional tool used for

developmental screening, but research has found that it is insensitive and lacks specificity (Johnson & Myers, 2007). Autism screening tools may rely entirely on parent report, or they may require direct observation and engagement by the clinician. Although several tools are in development for screening children younger than 18 months, none are available yet for routine clinical use (Johnson & Myers). Table 1 displays a sample of commonly used autism screening tools.

Guidelines for Screening for Autism

In 1998, a Consensus Panel comprised of thirteen organizations including the Child Neurology Society, American Academy of Neurology, and liaisons from the National Institutes of Health was formed. The panel analyzed 2500 related research articles and formulated a practice parameter for the screening and diagnosis of ASD (Filipek et al., 2000). These parameters are one of several sets of guidelines that have been proposed by various pediatric organizations for routine developmental screening. The Council on Children with Disabilities (2006) recommends that developmental surveillance be incorporated into every well-child preventive care visit. Any concerns that are raised during the surveillance should be promptly addressed with standardized screening tests. In addition, screening tests should be routinely administered at the 9, 18, and 30-month visits. Even though there are recommendations in place, there is a considerable body of evidence that suggests that current guidelines are not being followed by providers.

Table 1

Sample of Common Autism Screening Tools

CHAT	<ul style="list-style-type: none"> • For 18 month old infants
Checklist for Autism in Toddlers	<ul style="list-style-type: none"> • Parent interview and interactive • 5 minutes to complete • Demonstrated to be less sensitive to milder forms of autism • Available at: www.autismresearchcentre.com/test/chat_test.asp
M-CHAT	<ul style="list-style-type: none"> • For 2-year-old children
Modified Checklist for Autism in Toddlers	<ul style="list-style-type: none"> • Parent questionnaire • 5-10 minutes to complete • Still being validated • Available at: www.dbpediatrics.org/media/mchat/pdf
ASQ	<ul style="list-style-type: none"> • For 4-year-olds and older
Autism Screening Questionnaire	<ul style="list-style-type: none"> • Parent questionnaire • 5-10 minutes to complete • Available at: www.wpspublish.com
PDDST-II	<ul style="list-style-type: none"> • For birth to 3-year-olds
Pervasive Developmental Disorders Screening Test-II	<ul style="list-style-type: none"> • Parent questionnaire • 10-15 minutes to complete • Still being validated • Available at: www.harcourtassessment.com
Adapted from Blackwell & Niederhauser, 2003; Johnson & Myers, 2007.	

In their 2000 Practice Parameter, the American Academy of Neurology reported that 25% of children seen in a primary care practice showed developmental problems such as speech delays, motor delays, or cognitive deficiencies; however, only 30% of general practitioners followed the recommended guidelines and actually screened for developmental delays (Filipek et al., 2000). A group of researchers surveyed 646 members of the AAP to gain information about their developmental surveillance practices (Sand et al., 2005). Their results were consistent with previous research in that fewer than 30% of these physicians used a standardized assessment instrument for developmental surveillance.

Several studies have explored the impact of implementing routine developmental screening into practice. A study by Hix-Small, et al. (2007) investigated the effectiveness and costs of incorporating a parent-completed developmental screening tool into the 12 and 24-month well-child visits. A convenience sample of 1428 caregivers and children presenting for their 12 and 24-month well-child visit participated and the Ages and Stages Questionnaire was used. By incorporating the screening tool into routine preventive care visits, the referral rates increased dramatically, with the greatest increase at 12 months. The results of the study provided evidence that reliance on clinical impressions or developmental milestone review led to significantly fewer children receiving developmental services. A similar study by Rydz et al. (2006) explored the effectiveness of implementing parent-completed questionnaires into a busy ambulatory pediatric clinic to accurately screen for developmental delays in children. The sample

consisted of 317 parents who were bringing their children for the routine 18-month well-child visit. Most parents completed the Ages and Stages Questionnaire (81%) and the Child Development Inventory (75%). The results of the study concluded that parent-completed questionnaires can be feasibly used in the setting of a pediatric clinic.

According to Earls and Hay (2006), integration of developmental and behavioral screening and surveillance into the office process and flow is necessary for making screening a routine activity. The North Carolina Assuring Better Child Health and Development Project, which has implemented training for routine screening into the office process, has resulted in a significant increase in screening rates to greater than 70% of the designated well-child visits. This data has prompted changes in Medicaid policy, and screening is now statewide in primary practices. The success of this project has fueled interest from other states. Although there are features that are unique to North Carolina, most elements of the project are transferable to any practice or state interested in integrating child development services into the medical home.

Several algorithms have been presented in the literature to assist providers in the process of assessment and screening for autism in children (Council, 2006; Dietz, et al., 2006; Filipek et al. 2000; Hix-Small et al. 2007; Johnson & Myers, 2007). The recommendations have been based on research that shows that fewer than 30% of delays are detected by clinical judgment alone and that the use of a validated developmental screening tool can greatly increase the number of children who are referred for further evaluation (Glascoe, 2005). It is evident that without full participation and cooperation

from providers in following the recommended guidelines, the process of early detection, diagnosis, intervention, and treatment cannot take place.

Barriers to Screening

Recent literature suggests that current detection rates for developmental delays are lower than would be expected based on the actual prevalence of delays (Council, 2006). Thus, there are challenges and barriers to detecting developmental delays in family practice that need to be addressed. According to Goin and Myers (2004), it may be difficult to distinguish between autism and other childhood disorders, such as developmental delays and mental retardation. In addition, no two children with ASD have the exact same symptoms. The number of symptoms and their severity can vary greatly. About 25% of children will seem to have normal development until about 18 months, after which they will slowly or suddenly regress in developmental milestones (AAP, 2005).

Although there are a number of reliable and valid screening instruments available for autism, there are practical barriers to the routine use of these tools. The main barriers to routine screening are time and effort necessary to administer tools and interpret the results, and the lack of reimbursement (Committee on Children with Disabilities, 2001; Pinto-Martin et al., 2005). The costs of screening are estimated to be from \$11 to \$82 per screening implementation (Dobrez et al., 2001). Other barriers include limited staff, large patient volume, diminished reimbursement, failure of at-risk patients to attend well-child appointments, and the length of screening tools. The variety of screening

instruments, lack of uniformity, and absence of formal training in the administration of the tool may confuse providers and result in misuse or nonuse (Pinto-Martin, 2005).

Barriers to early diagnosis of autism in children younger than 2 to 3 years of age involve limited information about normal infant social development versus the development of infants with ASD (Crane & Winsler, 2008). Clinicians rely on diagnostic systems that are based on behavior of much older children (e.g. DSM-IV). Holzer et al. (2006) investigated the implementation of practice parameters for routine screening into primary practice, while surveying the providers on perceived barriers. The barriers to use of the practice parameter included: (a) unfamiliarity with the procedure, (b) the high volume of information, (c) the time required in order to understand and implement the program, (d) disagreements over specific guidelines, (e) the extra work involved, (f) low expectations concerning results, (g) a lack of motivation, and (h) the inertia of routine and habit.

According to Rhoades, et al. (2007), other possible reasons for delay in diagnosis of autism in children are that providers may be concerned about the strong emotional reaction of parents when they are told that their child has autism, fear of negative consequences from labeling the child, and hope that the symptoms will reverse. A study by Mandell, et al. (2005) revealed several factors related to delayed diagnosis of autism in children. The findings suggested a lack of resources in rural areas and for near-poor families. Healthcare providers continually struggle to meet the current demands for

routine screening. An elimination of the barriers is not feasible; however, if developmental screening is to be routine and universal, the issues must be addressed.

Summary

Orlando's Nursing Process Theory (1961) was used as the framework for the study of the routine screening practices of nurse practitioners for autism in children. The concepts of Orlando's theory were matched with the variables of the current study and the symbolic representation clearly depicted the relationships. The theory appears to be an appropriate model to study this topic.

A review of the literature demonstrated numerous quantitative studies with wide variation in early detection, screening tools, and barriers related to routine screening for autism in children. In addition, recommended guidelines from various organizations were explored. The literature review captured an overwhelming agreement that early detection of autism in children leads to early intervention which results in positive outcomes for the child. Much of the literature provided guidelines, screening tool information, and algorithms to assist providers in the early detection and diagnosis of autism. Regardless of the available recommendations, screening tools and algorithms, studies revealed that providers are not following the current guidelines. The barriers to routine screening were explored in the literature, which attempted to explain the lack of adherence by providers. The lack of studies reporting the routine screening practices of

nurse practitioners was discussed. The current study explored the routine screening practices of nurse practitioners of autism in children. Studies such as this can set the stage for future quantitative and qualitative research.

CHAPTER III

METHODOLOGY

The purpose of this study was to explore the routine screening practices of nurse practitioners for autism in children. In this chapter, the study design, sample, setting, data collection procedures, and data analysis are discussed. Reliability, validity, protection of human participants, and limitations of the study are also addressed.

Research Design

A descriptive quantitative research design was most suitable for exploring the routine screening practices of nurse practitioners for autism in children. According to LoBiondo-Wood and Haber (2006), descriptive survey studies are often used to explore facts and describe what exists within a particular field of study. A descriptive design may be used to determine what other practitioners in similar situations are doing, and to identify problems with current practice (Burns & Grove, 2006). The research design is appropriate for this study because the goal of the researcher was to assess current conditions of screening practices and the frequency of occurrence.

Population, Sample, and Setting

The target population for this study was nurse practitioners in primary care and pediatric settings. The accessible population was family nurse practitioners and pediatric nurse practitioners in a primary care or pediatric setting in the state of Wisconsin. The study was designed to utilize a convenience sample of 250 primary care nurse practitioners according to the following inclusion criteria: (a) current licensure as a family nurse practitioner or pediatric nurse practitioner in the state of Wisconsin, (b) presently working in a primary care or pediatric setting with at least one year of experience, (c) able to converse and speak in English, and (d) agreeable to participate in the study and complete a questionnaire. A list of local nurse practitioners, along with their home addresses, was obtained from the Wisconsin Department of Regulation and Licensing. Of the abundant list of family and pediatric nurse practitioners, 250 names were randomly selected and questionnaires were mailed to their homes on November 17, 2008. Participants were asked to complete the questionnaire and return it to the researcher by December 19, 2008.

Data Collection Instruments

The questionnaire that was used for this study consisted of demographic questions and researcher-developed, closed-ended questions related to autism screening (Appendix B). The demographic questions included items on gender, age, location, health care

setting, years of experience, specialty, and frequency of contacts with pediatric patients. The demographic questions were included in the beginning portion of the questionnaire. The closed-ended questions consisted of fill-in-the-blank and multiple-choice questions about routine screening, screening tools, age of child when screening begins, barriers to screening, previous autism education, personal confidence in screening, and benefitting from additional screening education. These types of questions were used in order to ensure comparability of responses and to facilitate analysis.

According to Polit and Beck (2006), the use of questionnaires for self-report is advantageous, as they are less costly and are less time-consuming to administer. Questionnaires also offer the possibility of complete anonymity and eliminate any biases, which is crucial in obtaining honest information about the routine screening practices of nurse practitioners. The use of structured self-report with a questionnaire was appropriate for this study as it enabled the researcher to obtain anonymous responses from a large sample of nurse practitioners regarding their routine screening practices for autism in children.

Procedures for Data Collection

Protection of Human Participants

Approval was obtained from the University of Wisconsin Oshkosh Institutional Review Board (IRB) for Protection of Human Participants prior to data collection

(Appendix A). There was no direct participation of minors or protected/sensitive populations in this study. A consent form, along with a complete description of the study was sent to all study participants (Appendix C). Completion of the questionnaire was considered informed consent to participate in the study. All responses were anonymous, with the questionnaires distributed through the mail in unmarked return-address envelopes.

Procedures for Collecting Data

Questionnaires were mailed to the homes of 250 nurse practitioners in Northeastern Wisconsin. Twelve of the 250 questionnaires were not deliverable as addressed and were returned to sender. Of the 238 questionnaires that were delivered as addressed, 129 (54%) were returned and 102 participants (43%) fit the inclusion criteria of (a) having current licensure as a family nurse practitioner or pediatric nurse practitioner in the state of Wisconsin, (b) presently working in a primary care or pediatric setting with at least one year of experience, (c) being able to converse and speak in English, and (d) agreeing to participate in the study and complete a questionnaire. The 102 participants in this convenience sample mailed the questionnaires to the researcher in self-addressed, prepaid postage envelopes with unmarked return-addresses. The purpose of the study and written consent were provided with the questionnaire. Participants were informed of their rights, and methods were established to safeguard their confidentiality. Anonymity was maintained with unmarked return envelopes.

Data Analysis Procedures

The study used a descriptive quantitative design. The data obtained from the questionnaires was analyzed using statistics of percent and frequencies. Descriptive statistical techniques reduced the data to manageable proportions by summarizing it, and allowed the strength and quality of the findings to be displayed.

The first part of the questionnaire consisted of seven questions covering demographic data. The second portion of the questionnaire contained nine questions related to the routine autism screening. Responses to all questions were tabulated by frequencies and percentages for each item.

The data analysis of the questionnaire responses were linked to the concepts of Orlando's Nursing Process Theory, as this theory was used to guide the study. The Nursing Process Theory addresses the function of the professional nurse in recognizing the patient's need for help and deliberately acting in a way to improve outcomes for the patient. The Nursing Process Theory revolves around five major interrelated concepts: (a) the function of professional nursing, (b) the presenting behavior of the patient, (c) the immediate or internal response of the nurse, (d) the nursing process discipline, and (e) improvement. When applied to this study, it was assumed that the nurse practitioner was routinely screening pediatric patients for autism in order to implement the necessary early referral, diagnosis, and intervention. The findings did not support the tenets of the theory in that the actions of the majority of participants were not consistent with the nursing process discipline.

Anticipated Limitations

1. Since the study relies on self-reported measures, it lends itself to the potential of response bias.
2. The use of a non-probability convenience sampling method lends itself to the possibility that the available participants might not be representative of all nurse practitioners functioning in a primary health care setting and having contact with pediatric patients.
3. The inexperience of the researcher may have introduced researcher bias.
4. The size of the sample was limited to one geographic area thereby limiting generalizability of the findings.
5. The questionnaire, which was used in the study, was developed by the researcher and did not undergo reliability and internal consistency testing. This may have affected study outcomes and interpretations.

Summary

In this chapter, a description of the design of the study, the sample, the setting, and methods for data collection were discussed. Protection of human participants, methods for data analysis, and limitations of the study were also described. A quantitative descriptive analysis was used to study the routine screening practice of nurse

practitioners for autism in children. The researcher used a convenience sample of 102 nurse practitioners in Northeastern Wisconsin. Data was collected through the use of mailed questionnaires consisting of both demographic and closed-ended screening questions.

Permission to conduct the study was obtained from the University of Wisconsin Oshkosh Committee for the Protection of Human Participants. Questionnaires were sent to 250 nurse practitioner's homes on November 17, 2008. A consent form, along with a complete description of the study was sent to all study participants and completion of the questionnaire was considered informed consent to participate in the study. Of the 238 questionnaires that were delivered as addressed, 129 were returned to the researcher by mail and 102 fit the inclusion criteria. Responses that were returned were kept anonymous. The data collected from the questionnaires was analyzed using the descriptive statistics of frequencies and percentages.

By eliciting a better understanding of the routine screening practice of nurse practitioners for autism in children, the researcher hopes to raise awareness of the importance of routine screening, the age at which screening should begin, the potential barriers to screening, and the favorable outcomes that occur with early intervention.

CHAPTER IV

FINDINGS AND DISCUSSION

The purpose of this study was to identify and describe the routine screening practices of nurse practitioners of children for autism. The study was undertaken to answer three research questions:

1. Are nurse practitioners routinely screening for autism in children?
2. At what age do nurse practitioners begin screening for autism in children?
3. What are the barriers to routine screening for autism in children?

The results of this study, as related to these research questions, were analyzed and described. Demographic data and statistical tabulation of the questionnaire results are presented in this chapter.

Description of Sample

A total of 250 questionnaires were mailed to a convenience sample of nurse practitioners. Twelve questionnaires were not deliverable as addressed and were returned to sender. Of the 238 questionnaires that were delivered to the addressed participants, 129 were returned via mail to the researcher's home. The response rate was 54%. One

hundred and two of the participants' questionnaire responses fit the inclusion criteria and therefore were considered useable for the study. Inclusion criteria included (a) current licensure as a family nurse practitioner or pediatric nurse practitioner in the state of Wisconsin, (b) presently working in a family practice or pediatric setting with at least one year of experience, (c) able to converse and speak in English, and (d) agreeable to participate in the study and complete a questionnaire.

Demographic Characteristics

The demographics of the sample of participants (n=102) consisted of 99 (97%) females and 3 (3%) male participants. The age ranged from 25 to 60 years of age with a mean age of 44.5 years. Eighty-one (79%) participants currently work in a primary care setting and 21 (21%) participants work in a pediatric setting. Forty-six (45%) of the participants work in a rural setting and 56 (55%) participants work in an urban setting. The number of years of experience ranged from 1 year to 32 years with a mean of 8 years of experience. Specialties included family practice (51; 50%), pediatrics (37; 36%), urgent care (5; 5%), internal medicine (3; 3%), occupational health (2; 2%), emergency room (2; 2%), gastrointestinal (1; 1%), and asthma and allergy (1; 1%). The frequency of pediatric patient contact on a weekly basis included every day (59; 58%); four to five times per week (9; 9%); one to three times per week (14; 14%); none per week (14; 14%); and other (6; 5%). Table 2 represents frequencies and percentages of demographic variables of the sample.

Table 2

Demographic Variables of the Sample

Demographic Variables	Frequency (n = 102)	Percent (%)
Gender		
Female	99	97
Male	3	3
Age (years)		
25-35	20	20
36-45	27	26
46-55	47	46
>56	8	8
Health Care Setting		
Primary Care	81	79
Pediatrics	21	21
Location		
Rural	46	45
Urban	56	55

(table continues)

Demographic Variables	Frequency (n = 102)	Percent (%)
Years of Experience		
1-10	54	53
11-20	23	23
21-30	3	3
>31	1	1
Unknown*	21	20
Specialty		
Family Practice	51	50
Pediatrics	37	36
Urgent Care	5	5
Internal Medicine	3	3
Occupational Health	2	2
Emergency Room	2	2
Gastrointestinal	1	1
Asthma & Allergy	1	1
Pediatric Patient Contact (times/week)		
Every day	59	58
4-5	9	9
1-3	14	14
None	14	14
Other	6	5

*Unknown represents an unmarked response on the questionnaire.

Discussion of Findings

Research Question One

Are nurse practitioners routinely screening for autism in children? Question number 8 on the questionnaire asked the Nurse Practitioner if they routinely screen for autism in their pediatric patients (see Appendix B). If they responded yes, three additional questions about screening tools were asked. A summary of the findings are found in Table 3.

According to the data, a significant number of participants do not routinely screen their pediatric patients for autism (74; 73%). Only twenty-three (23%) participants admitted to routinely screening children for autism, which is slightly lower than findings from several studies. According to Blackwell and Niederhauser (2003), fewer than 30% of primary care providers perform standardized screening for developmental delays during well-child visits. Filipek et al. (2000) reported that 30% of general practitioners screened for developmental delays in children. However, other studies indicated a much lower percentage of providers who were routinely screening for autism in their pediatric patients. Studies by Dosreis, Weiner, Johnson, and Newschaffer (2006) and Armstrong (2007) reported that only 8% of primary care pediatricians routinely screen children for ASD. Similarly, a recent survey of licensed pediatricians in Maryland and Delaware showed that only 8% routinely screened for ASD (Carr & LeBlanc, 2007). Studies regarding the screening practices of nurse practitioners were not found in this extensive literature search, therefore indicating a need for the current study.

Table 3

Routine Screening Practices

Screening Practices	Frequency (n = 102)	Percent (%)
Do you routinely screen for autism?		
No	74	73
Yes	23	23
Unknown*	5	4
Have you ever used a screening tool?		
No	16	15
Yes	10	10
Unknown*	76	75
Screening Tools Used		
M-CHAT	9	90
DDST-II	1	10
Do you routinely use screening tools?		
No	29	28
Yes	9	9
Unknown*	64	63

*Unknown represents an unmarked response on the questionnaire.

According to Ida Jean Orlando's Nursing Process Theory, the function of professional nursing is to find and meet the needs of the patient (Orlando, 1961).

Because the prevalence of autism has risen to an astounding 1 in 150 children, a vital part

of the function of professional nursing is for the nurse practitioner to address the needs of his or her pediatric patients. This study shows that many children's needs are not being met in relation to autism screening with only 23% of the participating nurse practitioners routinely screening their patients.

Of the 23 participants who do routinely screen, only 10 (10%) participants admitted to ever having used a screening tool and only 9 (9%) participants used screening tools on a routine basis. These statistical findings are significantly less than previous research, which indicate that 23% of surveyed physicians used a standardized assessment instrument for developmental surveillance (Sand et al., 2005). A survey of Connecticut physicians found that 20% reported using formal developmental screening instruments (Dobos, Dworkin, & Berstein, 1994). In the Nursing Process Theory, Orlando (1961) emphasized the importance of observing the patient's behavior and responding to those behaviors. In this case, the participants may have been observing the child's developmental behaviors, but only 9% were responding to those behaviors with the use of screening tools.

When participants were asked which screening tools they used, the most commonly used tool was the Modified—Checklist for Autism in Toddlers (M-CHAT) (8; 80%). Two participants responded that they used the Denver Developmental Screening Tool-II (DDST-II). A general requirement of a screening tool before implementation into practice is that it should deliver both theoretical and clinical prevalence, be easy and clear to use, and be cost-effective (Persson et al., 2006). The

M-CHAT consists of 23 yes/no items to be completed by the parents, and research findings indicate that it not only fits the general requirements of a screening tool, but is a promising instrument for early detection of autism (Robins, et al., 2001). Researchers have found that the traditional screening tool, the DDST-II, is lacking in sensitivity and specificity, and therefore should not be used as a screening tool for autism (Blackwell, 2001).

There is not one specific screening tool that is recommended, but rather several instruments that are age-exclusive and have proven to be appropriately sensitive and specific in the screening for autism. These instruments include The Checklist for Autism in Toddlers (CHAT) for 18-month-old infants, the Autism Screening Questionnaire (ASQ) for children 4 years and older, The Pervasive Developmental Disorders Screening Test-II (PDDST-II) for infants 18 to 24 months, and the Modified Checklist for Autism in Toddlers (M-CHAT) for infants 16 to 86 months (Filipek et al., 2000).

The participants were then asked if they routinely use screening tools for autism. Nine (9%) participants responded yes, 29 (28%) responded no, and 64 (63%) left an unmarked response. This data seems to be consistent with previous study findings, even though statistical percentages were not available for comparison. Several studies have found that when given a choice, most providers rely on clinical judgment to detect potential developmental problems instead of using a screening instrument. This practice has been shown to identify fewer than half of children with developmental delay (Pinto-Martin et al., 2005; Sand et al., 2005). Just as Orlando emphasized the importance of

observing and recognizing the presenting behavior of the patient, it is necessary for the nurse practitioner to routinely use screening tools in addition to clinical observation of developmental behaviors in children. Current screening parameters from the American Academy of Pediatrics recommend that providers use standardized screening for all children at 9, 18, and 24 or 30 months and an ASD-specific tool at 18 and 24 months.

Research Question Two

At what age do nurse practitioners begin screening for autism in children?

The participants were asked at what age they typically start screening children for autism. Table 4 presents the statistical data related to this question.

The ages at which most participants typically started screening were at 12 months (11; 11%) and 6 months (8; 8%). These statistical findings are inconsistent with current practice recommendations, which state that screening should begin at 9 months. According to the American Academy of Pediatrics, all children should receive periodic developmental screening using a standardized test at the 9, 18, and 30-month well-child visits. At 9 months of age, many issues involving motor skills development, along with visual and hearing abilities, can be reliably identified.

Early communication skills may be emerging, and evidence suggests symptoms of autism, such as lack of eye contact, orienting to name being called, or pointing, may be recognizable in the first year of life (Council, 2006). Although these early symptoms are

often insufficient for reliable diagnosis, they highlight the importance of early screening, early intervention, and comprehensive follow-up (Carr & LeBlanc, 2007).

Table 4

Age of Child When Screening Begins

Age of Child	Frequency (n = 102)	Percent (%)
6 months	8	8
9 months	1	1
12 months	11	11
18 months	2	2
24 months	4	4
3 years	1	1
Other	4	4
Unknown*	71	69

*Unknown represents an unmarked response on the questionnaire.

According to the Nursing Process Theory, the actions of the professional nurse can improve the patient's behavior and fulfill their needs (Orlando, 1961). Early intervention has been demonstrated to be very successful with children diagnosed with autism and can improve the developmental behaviors of the child. In fact, Rogers (1996) found that gains for young children with ASD were actually more rapid than for young children with other severe neuro-developmental disorders. This is likely due to the brain of the child with ASD showing unique plasticity, which may indicate a critical time

frame for intervention. Effective early intervention may actually help reshape the brain and help to prevent the development of the typical, autistic brain.

Research Question Three

What are the barriers to routine screening for autism in children? A list of barriers was given and participants were asked to choose all options that applied. Table 5 presents the data related to this question.

There are several barriers which hinder the practice of routine screening for autism in children. Participants were asked to choose all barriers that applied to them and the majority of the participants selected more than one barrier. The data shows that 39 (38%) participants felt that unfamiliarity with the screening tools and absence of formal training to screen for autism were barriers to screening. Thirty-two (31%) participants felt that limited time was a barrier. According to a survey of pediatricians by the American Academy of Pediatrics, the major barriers included (a) inadequate training in developmental assessment (65%); and (b) insufficient time to conduct developmental assessment (64%) (Miller, 2007).

A study by Sand et al. (2005) mailed surveys to a random sample of American Academy of Pediatric members, asking them a variety of questions regarding their developmental screening practices, including barriers to screening. The barriers included (a) time limitations in current practice (83%), (b) lack of staff to perform screening

(49%), (c) inadequate reimbursement (46%), (d) language barriers (19%), and (e) lack of confidence in ability to screen (10%).

Table 5

Perceived Barriers to Screening

Barriers to Screening	Frequency (n = 102)	Percent (%)
Limited Time	32	31
Limited Staff	9	9
Lack of Resources	23	22
Reimbursement Issues	5	5
Variety of Tools	6	6
Unfamiliarity With Tools	39	38
Length of Screening Tools	6	6
Absence of Formal Training	39	38
Large Patient Volume	13	13
Limited Information about Autism	21	20
Concern about Parents' Reaction	7	7
Fear of Consequences of Labeling Child	7	7
Hope that Symptoms will Reverse	0	0
Other	15	15
Unknown*	23	22

*Unknown represents an unmarked response on the questionnaire.

Although the percentages from previous studies are different than the percentages found in this study, they do show consistency with the types of barriers that

providers feel are deterring them from practicing routine screening for autism. The main barriers are inadequate training to screen for autism and time limitations, which is consistent with the current findings.

According to the Nursing Process Theory, the nursing process discipline involves deliberative nursing actions designed to identify and meet the patient's immediate needs and to fulfill the professional nursing function. Routine screening practice is a deliberative nursing action of the nursing process discipline. Findings show that 74% of the nurse practitioners in this study are not fulfilling the professional nursing function of the nursing process discipline in relation to routine screening for autism in their pediatric patients. However, there seems to be some valid reasons for the lack routine screening.

The participants were asked if they had any formal autism training, and if they had attended any autism-related seminars or in-services. The participants were also asked if they felt confident screening a child for autism and if they felt they would benefit from receiving more autism training. Table 6 presents the data related to these questions.

Of the 102 participants surveyed, 93 (91%) responded that they had no formal autism training and 71 (70%) had never been to an autism-related seminar or in-service. These findings are higher than in previous studies. For instance, a survey of pediatricians by the American Academy of Pediatrics showed that 65% reported inadequate training in developmental assessment (Miller, 2007). This data supports the evidence that certain barriers, such as unfamiliarity of screening tools and absence of formal training in autism, are causing significant interference with routine screening practices.

Table 6

Autism Training and Perceived Benefit From Additional Training

Training and Perceived Benefit	Frequency (n = 102)	Percent (%)
Formal Autism Training?		
No	93	91
Yes	9	9
Seminars or In-service Training?		
No	71	70
Yes	31	30
Feel Confident Screening a Child?		
No	56	55
Yes	46	45
Benefit from Learning More about Autism?		
No	10	10
Yes	92	90

When asked if they felt confident screening a child for autism, 56 (55%) of the participants in this study replied that they did not feel confident. A majority (92; 90%) of the participants felt they would benefit from learning more about autism. Orlando's Nursing Process focuses not only on the improvement of the outcome for the patient, but also the improvement of the process by which this is achieved. The nurse practitioner must take personal responsibility in increasing his or her knowledge base about autism,

researching the various screening tools that are available, and improving the overall process of routine screening for autism in children.

Summary

In this chapter, the researcher presented the study findings in relationship to the three research questions. The routine screening practices of nurse practitioners for autism in children was slightly lower than previous studies reviewed during the literature search, with only 23% of the participants indicating that they routinely screen their pediatric patients for autism. The age of the child at which these participants typically began screening for autism (12 months) was not comparable to current practice guidelines, which recommend standardized screening to begin at 9 months of age. In contrast, the barriers to screening were comparable to previous study findings, with the main barriers being (a) unfamiliarity with screening tools (38%), (b) absence of formal autism training (38%), and (c) limited time (31%).

Overall, the majority of the sample had not received any formal autism training or had attended an autism-related seminar or in-service. Because of the obvious lack of knowledge regarding autism, it is not surprising that 55% of participants did not feel confident screening children for autism. Almost all of the participants felt that they would benefit from learning more about autism.

CHAPTER V

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

This chapter contains a summary of the research study describing the routine screening practices of nurse practitioners for autism in children. Conclusions made based on study findings and implications of the findings for nursing practice, education, and research will be discussed.

Study Summary

As one of the most common pediatric developmental disabilities, autism is now said to affect 1 in 150 children. Evidence shows that early intervention leads to positive outcomes in autistic children. Therefore, health care providers should be following current screening guidelines, which recommend routine screening for autism in all pediatric patients. Studies, however, indicate that despite the current screening guidelines and availability of several screening tools, the majority of healthcare providers are not routinely screening children for autism.

The purpose of this study was to describe the routine screening practices of nurse practitioners for autism in children, to identify the age at which children are being screened, and to identify the perceived barriers to routine screening. While numerous

studies have been done with family practice physicians and pediatricians, there is a paucity of information regarding the screening practices of nurse practitioners. This information is important because nurse practitioners are often the primary source of well-child care and developmental assessment for many children. Three research questions were addressed in this study:

1. Are nurse practitioners routinely screening for autism in children?
2. At what age do nurse practitioners begin screening for autism in children?
3. What are the barriers to routine screening for autism in children?

Orlando's Nursing Process Theory provided the theoretical framework in which this research study was based upon. The focus of this framework is on the function of the professional nurse in recognizing the patient's need for help and deliberately acting in a way to improve outcomes for the patient. The five key concepts used to guide this study were (a) the function of professional nursing, (b) the presenting behavior of the patient, (c) the immediate or internal response of the nurse, (d) the nursing process discipline, and (e) improvement.

The target population for this study was nurse practitioners in a primary care or pediatric setting. The researcher used a non-probability convenience sample of 250 nurse practitioners in northeastern Wisconsin. Of the 238 questionnaires that were delivered as addressed, 129 were returned to the researcher by mail. The response rate was 54%.

Participation was voluntary and all the participants received a written explanation regarding the study.

A researcher-developed questionnaire was used as the questionnaire tool for this study. Data were analyzed using descriptive statistics. Statistics were based on the responses of 102 questionnaires that fit the inclusion criteria. The demographics of the sample of participants (n=102) consisted of 99 (97%) females and 3 (3%) males. The age range was shown to be 25 to 60 years of age with a mean age of 44.5 years. Eighty-one (79%) participants currently work in a primary care setting and 21 (21%) participants work in a pediatric setting. Responses to the screening questions were tabulated by frequencies and percentages, and distribution tables were utilized to display the data.

Conclusions

Based on the findings of the study, the following conclusions were reached:

1. The frequency of routine screening for autism in this sample was slightly lower in comparison to findings of studies reviewed in the literature.
2. The age at which this sample began screening children was not consistent with the recommended screening guidelines.
3. The main barriers to routine screening for this sample were a) unfamiliarity with the screening tools; b) absence of formal training to screen for autism;

and c) limited time. These barriers are consistent with findings of studies reviewed in the literature.

4. The majority of the participants in this sample would benefit from learning more about autism.
5. Overall for this sample, it appears that the recommended guidelines for autism screening are not being followed.

Implications for Nursing

Health promotion and preventative health services are a large part of nursing practice. Nurse Practitioners who provide care for pediatric patients have a unique opportunity to address issues related to developmental delays, early surveillance, and detection of autism. Given the variety of settings that nurses practice in, the ability to increase awareness and knowledge of autism, screening tools, and the recommended screening guidelines is limitless. The need clearly exists for healthcare provider education through individual and group programs advocating autism screening. This in turn will increase the likelihood of routine screening, early diagnosis, and intervention. Studies have shown that earlier interventions result in better outcomes for the child and their family.

If routine screening for autism is to be universal, the barriers must be addressed. To eliminate the barrier of inadequate training, an education program could be designed for a group of providers with mixed skill levels, including PNPs, RNs, pediatricians, medical assistants, and LPNs. Education by an expertly trained provider should include the importance of developmental screening and the correct use of screening tools such as M-CHAT. Instruction and role modeling of a developmental screening protocol should also be provided to the health-care providers during a routine 9, 12, and 30-month well child visit (Pinto-Martin et al., 2005).

Given the hectic pace of most family practice and pediatric offices, other options must be considered to eliminate the time limitation barrier. Nurses and medical assistants can be instructed to administer the tools and can complete the assessment in conjunction with performing other tasks such as weighing and measuring the child. Secondly, the use of parent-completed report tools can be used in conjunction with clinical observation and can facilitate communication between parents and providers on developmental issues of concern. By asking parents to complete a standardized evaluation of their child's development, this will aid in the timely and appropriate referral process for diagnosis and early intervention (Pinto-Martin et al., 2005).

Limitations

This researcher has noted the following limitations:

1. The use of a non-probability convenience sample in the northwestern region of Wisconsin may have limited the representativeness of the sample therefore affecting the generalizability to the target population.
2. A large sample of females versus three males limits generalizing the results of the study to a male target population.
3. The questionnaire was developed by the researcher and was not tested for validity or reliability.
4. There were many unmarked response on the questionnaires, which were displayed in the distribution tables as “unknown.” This should be kept in mind when interpreting data and using study results.

Recommendations for Future Research

This researcher makes the following recommendations:

1. There appears to be a need for further development and testing of quality tools for exploring screening practices for autism in children.

2. Replicate this study with a larger sample and with a diverse population in other geographical areas, including more male participants.
3. Perform a qualitative study to identify the perceived role of the nurse practitioner in autism detection that a questionnaire is unable to obtain.

APPENDIX A

University of Oshkosh IRB Approval Letter



November 6, 2008

Ms. Sarah Vande Hey
3556 N. Casaloma Dr.
Appleton, WI 54913

Dear Ms. Vande Hey:

On behalf of the UW Oshkosh Institutional Review Board for Protection of Human Participants (IRB), I am pleased to inform you that your application has been approved for the following research: The Routine Screening Practices of Nurse Practitioners for Autism in Children.

Your research protocol has been classified as EXEMPT. This means you will not be required to obtain signed consent. However, unless your research involves **only** the collection or study of existing data, documents, or records, you must provide each participant with a summary of your research that contains all of the elements of an Informed Consent document, as described in the IRB application material. Permitting the participant, or parent/legal representative, to make a fully informed decision to participate in a research activity avoids potentially inequitable or coercive conditions of human participation and assures the voluntary nature of participant involvement.

Please note that it is the principal investigator's responsibility to promptly report to the IRB Committee any changes in the research project, whether these changes occur prior to undertaking, or during the research. In addition, if harm or discomfort to anyone becomes apparent during the research, the principal investigator must contact the IRB Committee Chairperson. Harm or discomfort includes, but is not limited to, adverse reactions to psychology experiments, biologics, radioisotopes, labeled drugs, or to medical or other devices used. Please contact me if you have any questions (PH# 920/424-7172 or e-mail: rauscher@uwosh.edu).

Sincerely,

Dr. Frances Rauscher
IRB Chair

cc: Vicky Moss
1464

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APPENDIX B

Questionnaire

QUESTIONNAIRE

Please answer each question by circling the answer or filling in the blank.

1. Gender: Male Female

2. Age _____

3. Do you practice in a primary care setting? Yes No

4. If yes, how long have you been practicing as a primary care nurse practitioner? _____

5. Do you practice in an urban or rural setting? _____

6. What is your specialty? _____

7. How many times a week do you see pediatric patients?

None
1-3
4-5
Every day
other _____

8. Do you routinely screen for autism in your pediatric patients? Yes No

If you answered yes, go to # 9; if no, skip to question #12.

9. If you answered yes to #10, have you ever used a screening tool for autism? Yes No
 If yes, what tool or tools have you used for autism screening? _____

10. Do you routinely use screening tools for autism? Yes No

11. At what age do you typically start screening children for autism?

6 months 9 months 12 months 18 months 24 months 3 years

other_____

12. If you do not routinely screen, what do you feel are the barriers involved with screening for autism? (circle all that apply)

Limited time	Limited staff	Lack of resources
Reimbursement issues	Variety of tools	Unfamiliarity with tools
Length of screening tools	Absence of formal training	Large patient volume
Limited information about autism	Concern about parents' reaction	Fear of negative consequences of labeling a child
Hope that symptoms will reverse	Other_____	

13. Did you have any formal training/classes in your education program regarding the use of screening tools to screen for autism in children? Yes No

14. Have you attended seminars or in-service training related to this topic? Yes No

15. Would you feel confident screening a child for autism at a well-child visit? Yes No

16. Could you benefit from learning more about autism and screening tools? Yes No

APPENDIX C

Informed Consent

UNIVERSITY OF WISCONSIN OSHKOSH

INFORMED CONSENT

The Routine Screening Practices of Nurse Practitioners for Autism in Children

Thank you for taking the time to read this material. My name is Sarah Vande Hey, RN, BSN, and I am a graduate student and the University of Wisconsin Oshkosh completing requirements for the Family Nurse Practitioner Master's degree. As a part of my program of study, I am conducting a research study on the routine screening practices of nurse practitioners for autism in children. I would appreciate your participation in this study, as it will assist me in understanding the process by which children are screened for autism. If you are willing to participate, please complete the attached questionnaire and this will be considered your consent to participate in the study.

For this study, I would like to ask you questions on a questionnaire. The first part of the questionnaire consists of demographic questions. The second part of the questionnaire contains questions related to screening practices for autism in children. The questionnaire should take approximately 10 minutes to complete.

Although there are other methods of data collection, I believe that the use of a questionnaire is the best way to quickly and easily obtain information on this topic.

I do not anticipate that the study will have any medical or social risks to you, other than the time required to complete the questionnaire. Participation in this study may not benefit you directly, but can assist me and other health care professionals in understanding the screening practices for autism in children.

Please do not sign the questionnaire, as your responses will remain anonymous. I will not release information in any way that will identify you as a participant in the study.

Your participation in this study is completely voluntary and you may withdraw at any time without penalty. If you decide to complete the questionnaire, please return it by mail in the self-addressed, stamped envelope provided. The completed questionnaire will then be placed in a confidential file in my home.

This research project will be approved by the University of Wisconsin Oshkosh Institutional Review Board for Protection of Human Participants. If you have any complaints about your treatment as a participant in this study, please call or write:

Chair, Institutional Review Board
For Protection of Human Participants
c/o Grants Office
UW Oshkosh
Oshkosh, WI 54901
920-424-1415

Although the chairperson may ask for your name, all complaints are kept in confidence.

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