

Healthcare Experiences of Parents of children with Autism Spectrum Disorder: A  
Phenomenological Study

by

Victoria I Yutko RN, BSN

A Thesis presented to the  
FACULTY OF THE SCHOOL OF NURSING  
POINT LOMA NAZARENE UNIVERSITY

in partial fulfillment of the  
requirements for the degree  
MASTER OF SCIENCE IN NURSING

February 2015

Committee

Jeanne Maiden RN, PhD, CNS-BC, Chair

POINT LOMA NAZARENE UNIVERSITY

School of Nursing

Master of Science in Nursing

NAME OF STUDENT: Victoria I Yutko RN, BSN

TITLE OF THESIS: Healthcare Experiences of Parents of children with Autism  
Spectrum Disorder: A Phenomenological Study

COMMITTEE:

---

Jeanne Maiden RN, PhD, CNS-BC, Chair

Date

## **Abstract**

Today, more children in the United States are diagnosed with Autism Spectrum Disorder than childhood cancer, juvenile diabetes, and pediatric AIDS combined. Research is currently being conducted regarding the causes, prevalence and treatment for Autism, however little is known regarding care for this population in healthcare settings. The purpose of this Interpretative Phenomenological study is to explore the lived healthcare experiences of mothers of children with Autism Spectrum Disorders. The sample for this study was composed of two mothers of children diagnosed with Autism Spectrum Disorder. After rigorous review of the interview material, two major themes were identified regarding the participants' healthcare experiences. First, the mothers reported that they had to be their child's main advocate when it came to coordination of care. They did not feel as if their pediatricians' office was well prepared with information on special services or treatments available. Second, neither mother has noticed any special treatment by the provider or nurses in regards to their child's diagnosis. The mothers expressed the feeling that their child was treated like they did not have an Autism Spectrum Disorder diagnosis. Both themes provide an opportunity for improvement in providing healthcare to Autistic. Due to the increasing prevalence of autism, additional research is recommended in all areas but specifically in nursing care. This study identifies a gap in educating nurses on the best way to care for this patient population. Caregivers need to feel comfortable with the nursing care their children are receiving, and nurses need to feel comfortable providing safe and effective care to their patients. Increased education and awareness in the nursing community could lead to increased patient advocacy and assistance to parents as they coordinate care for their children.

*Keywords:* Autism Spectrum Disorder, Nursing Care, Pediatrics, Caregiver

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## **Chapter One**

### **Introduction**

Today, more children in the United States are diagnosed with Autism Spectrum Disorder (ASD) than childhood cancer, juvenile diabetes, and pediatric AIDS combined (Autism Speaks, 2011). According to a 2008 study by the Autism and Developmental Disabilities Monitoring Network (ADDM), one in every 88 children in the United States is classified as having ASD (NIH.gov, 2012). Research is currently being conducted regarding the causes, prevalence and treatment for Autism, however little is known regarding care for this population in healthcare settings. In 2006, 44% of primary care providers reported that they had at least 10 ASD patients in their practice (Inglese & Elder, 2009). Due to the increasing number of children being diagnosed with ASD it is very likely nurses in an outpatient setting will be asked to care for an Autistic patient in the near future. Research shows that children with ASD spend more hours at medical appointments than developmentally normal children; it is estimated that health care costs are between 3 and 10 times greater for these patients (Butlas, 2011). In addition to developmental delays, children with ASD are frequently diagnosed with coexisting medical conditions such as seizures, gastrointestinal disturbances, allergies, and visual and hearing impairments to name a few (Johnson & Rodriguez, 2013). These comorbidities have children with ASD attending numerous doctors' appointments each month.

An interpretive phenomenological study by Butlas (2011) found that many mothers of children with ASD felt like their primary care physicians and nurses did not completely understand the complexity of ASD, and the effect it has on their lives. Currently, there is no standard of care, and very little information published regarding best practices for caring of ASD

patients in healthcare settings (Scarpinato et al., 2010). There is a significant need for a better understanding of this diagnosis by health care workers in order to successfully care for the ASD population.

### **Significance of Problem**

Children with ASD find any change in their routine stressful; this along with sensory dysfunctions makes healthcare visits challenging (Inglese & Elder, 2009). Because Autism is a spectrum disorder, each patient will present with different symptoms and behaviors, and it is imperative that nurses are equipped with the appropriate skills and tools to make a positive healthcare experience for these patients and their families (Gaspar de Alba & Bodfish, 2010). Whether nurses are working for an inpatient or outpatient setting, a basic understanding of Autism is necessary in order to adequately provide care to this patient population (Inglese & Elder, 2009).

Stress in children on the spectrum typically manifests in challenging behaviors, which produce a stressful situation for both the healthcare provider and the parents. Healthcare providers frequently rely on the child's parent to calm the behavior so they can proceed with the visit. Johnson and Rodriguez (2013) report that pressure and stress on the parents create feelings of embarrassment, which may put them at risk for a poor mental state. The authors concluded that one of the most important aspects of a successful healthcare visit for ASD children is involving a parent in the plan of care (Johnson & Rodriguez, 2013). In order for this strategy to be effective, the parents need to be in a healthy mental state where they are able to participate fully as a member of the healthcare team.

Children diagnosed with ASD require considerably more time, education, and resources, which primary care physicians struggle with providing during a short appointment time (Butlas,

2011). The stress levels in parents can be significantly decreased when provided with adequate time, and resources. Parents report that physicians and nurses do not always listen to their requests in regards to special health care needs of their child. For example, if mom knows that her child has anxiety related to the physician wearing a white coat, she may relay these concerns prior to appointment. Some physicians do not take the request seriously, which leads to a difficult visit for the patient, and increased stress levels for the parents (Butlas, 2011). Being a primary caregiver for a child with ASD takes an emotional toll on not only the parents, but also the whole family. Mothers report that most physicians overlook this aspect of their child's care, and are only focused on medical issues (Butlas, 2011). Parents feel providers frequently dismiss their concerns because they do not know how to handle them (Butlas, 2011).

### **Problem Statement**

For an autistic child, a negative experience during a medical visit can have an impact on every visit to the physician in the future (Beard-Pfeuffer, 2008). Increasing awareness of the difficulties these patients experience during physician visits is imperative in improving nursing care. Health care providers reported to having little confidence in treating this special population (Butlas, 2011). The concern is related to lack of confidence in dealing with the complex issues, which are individualized to each child. Also, providers feel that there is not enough time to address all issues while accommodating the child's special needs (Butlas, 2011).

It is easy for the nurse to get anxious and frustrated in caring for an autistic patient if he or she is not familiar with the diagnosis. In the best interest of the ASD patient, it is important for nurses not to show any signs of being upset because this may increase patient or parent anxiety levels (Autism Speaks, 2011). Caring for ASD patients takes considerably more time, especially when collaborating with parents to successfully plan out each individual visit.

Preparation of the environment, including decreasing unnecessary noise, minimizing time in the waiting room, and planning for additional staff are all examples of extra steps competing for the health care provider's time (Souders et al., 2002). For the busy nurse with many other patients to care for, this important step of planning can easily be skipped (Scarpinato et al., 2010). Failure to properly prepare for a visit may negatively affect the children, as well as increase stress levels for their parents.

In addition to a basic understanding of the diagnosis, nurses should be able to communicate with ASD patients using picture boards, and be aware of simple calming techniques that can be utilized if needed (Autism speaks, 2011 & Butlas, 2011). With proper planning and education the health care team can decrease stress and anxiety for the patient.

### **Purpose Statement**

The purpose of this study is to explore the lived healthcare experiences of mothers of children with Autism Spectrum Disorders. The number of children diagnosed with ASD continues to grow every year, as does the research pertaining to diagnosis, treatment, and causes. A review of the literature shows that all research related to ASD and healthcare was conducted from a healthcare provider's point of view (Johnson & Rodriguez, 2013.) Since parents may have a different perception of the quality of their child's healthcare visits, it is imperative to collect their experience. In addition, as primary caregivers, parents know the strategies and interventions that work best for their children. Collecting this information is an essential step in creating specialized health care for this patient population, and improving quality of care.

## **Chapter Two**

### **Literature Review**

Literature pertaining to this topic was located using an advanced search of CINAHL, Cochrane Database of Systemic Reviews, Health Source: Nursing/Academic Edition, Science Direct, Google Scholar, and Proquest was done. Key words used were autism, ASD, nursing, caregivers, outpatient, parent, mother, and primary care. The results included many expert opinions of how to improve the healthcare experience of patients with ASD. Main themes found in the review of literature to focus on are: defining ASD, understanding sensory dysfunction, using effective communication techniques, safety, parents of autistic children, and teaming up with families.

#### **Autism Spectrum Disorder**

Autism Spectrum Disorder encompasses a range of developmental disabilities including Autism, Asperger disorder and Persuasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) (“Facts about Autism” 2010). Autism is considered to be a spectrum disorder because children with ASD range in their severity of symptoms (Rice 2006). There are three main components involved in ASD; impaired social skills, decreased or impaired verbal and non-verbal communication, and repetitive behaviors (Autism speaks, 2010). Developmental delays and characteristics of ASD usually present themselves in children before the age of three, and the prevalence of ASD is three to four times greater in males over females (Souders, Freeman et al. 2002). The American Academy of Pediatrics (AAP) recommends that every child be screened for autism at the eighteen and twenty-four month well-child visits (Inglese & Elder, 2009).

The most common characteristic reported to pediatricians is speech delays. Parents come with concerns that their child is either not talking yet, or was talking and then stopped (Inglese &

Elder, 2009). Nurses can help recognize signs of ASD while they are checking a patient in for the appointment. Since the social aspect is usually the most obvious manifestation the nurse should observe how the child interacts with his or her parents. Signs of autism would include: no pretend play, the child does not pick up toys and show them to his/her parents, and the child does not make eye contact with his/her parents (Inglese & Elder, 2009, Scarpinato et al., 2001). The nurse should share these observations with the pediatrician so the child can be more thoroughly screened for autism. Current research shows there is not a single cause for autism, though this is a popular topic on which studies continue (Inglese & Elder, 2009, Butlas, 2011). A few explanations related to increasing prevalence are greater awareness among providers, improving diagnostic criteria, variation of assessing methods, and actual increase of incidence of ASD (Butlas, 2011).

### **Understanding Sensory Dysfunction**

Children with ASD often have difficulty interpreting sensory information which makes caring for these patients in a healthcare setting a challenge (Beard-Pfeuffer 2008). Being aware of sensory dysfunction in this population and using techniques to minimize anxiety is beneficial for ASD patients. For patients with a heightened tactile sense, nurses should be aware of the textures of materials that may touch them, and caregivers should always announce themselves before touching to let them know what is going to happen (Beard-Pfeuffer 2008).

Because children with ASD can be increasingly sensitive to any noises, nurses should try to keep the environment as quiet as possible (Beard-Pfeuffer 2008). Having a *quiet room* away from the noises of a busy hospital is helpful in keeping anxiety levels down (Van der Walt & Moran, 2001). Certain smells such as perfumes or cleaning products may cause patients with ASD to vomit or gag (Beard-Pfeuffer, 2008). This is another example of an increased sense,

which nurses need to be aware of. Children with ASD should be given a longer appointment to allocate enough time for the nurse and physician to deal with these challenges (Inglese & Elder, 2009).

### **Communication Techniques**

Children with ASD have varying degrees of communication, which range from non-verbal to sounding like an *adult* (Inglese & Elder, 2009). Based on the child's level, nursing practices should be modified by determining effective communication techniques such as pictures or sign language (Scarpinato et al., 2010). For example, some children with ASD may benefit from using step-by-step instructions, or pictures of what will happen during a procedure or visit (Scarpinato et al., 2010). A visual schedule is a sequence of events shown in pictures. In order to decrease the patient's anxiety, this schedule can be used throughout the visit, and followed until all activities are completed. It is always a good idea to end the sequence with a positive activity such as a reward so the child sees motivation to finish (Autism Speaks, 2011). A *first then* board is another option where a picture of the activity to be accomplished is paired with a reward, "First you will feel a pinch, then I will give you a sticker" (Appendix A). A child with ASD may need to see an object or a picture of an object before using it (Beard-Pfeuffer 2008). Another way to decrease anxiety is to allow the patient with Autism to touch and feel any devices used during a procedure beforehand (Scarpinato et al., 2010).

Children with ASD take what is communicated to them very literally and harmless jokes used with other pediatric patients may cause this population more anxiety (Baas 2006). It is important to communicate with autistic patients in a clear manner and they should be given direct commands that cannot easily be confused ("Tools you can use," 2011). A command such as "sit in that chair" is more helpful than "why don't you go ahead and sit down." With autistic

children it is important to be honest in what will hurt them because being surprised may bring on increased anxiety (Van der Walt & Moran, 2001). Autistic children also have trouble interpreting social cues such as tone of voice or facial expressions; this is an important aspect for nurses to keep in mind when caring for this patient population. In order to show autistic patients they are doing a good job during the visit, positive reinforcement and rewards should be used (Inglese & Elder, 2009). Parents can be consulted beforehand for ideas on rewards, they will know what will motivate the child best (“Tools you can use,” 2011).

### **Safety**

Children with ASD tend to get “bored” faster than non-developmentally delayed children and this may become a safety concern in a medical facility (Scarpinato, Bradley et al. 2010). Having age-appropriate toys in the waiting and exam rooms and minimizing wait times as much as possible can keep them safe throughout the visit (Scarpinato et al., 2010). Another safety concern has to do with a condition called Pica. Thirty percent of children with Autism have Pica, which means they eat non-food items such as sand or dirt (Beard-Pfeuffer 2008). Nurses should keep this in mind when preparing the exam rooms for a visit with an ASD patient.

### **Nurses’ experiences**

Nurses in practice report feeling that their educational preparation to deal with the ASD population was inadequate (Gardner, 2012). Most nurses reported that they had minimal content regarding patients with developmental delays, including autism, and no clinical involvement (Gardner, 2012). In a survey of 234 nursing programs, 79% reported that a small part of the curricula included material on developmental disabilities in general (Gardner, 2012). Though nurses working with certain populations may be considered “specialists” in caring for children

with ASD, nurses practicing in all health care settings should be equipped with the knowledge needed to be successful.

### **Parents of Autistic Children:**

Interviews with parents of children with ASD have shown that the parents are so used to being the “experts” on autism whenever they bring their child into a health care setting that they do not have time to focus on what the physician is saying (Butler 2011; Van der Walt & Moran, 2001). Parents have strategies and routines that they use to calm their child’s behavior at home, and this information may be helpful during a healthcare visit (Johnson & Rodriguez, 2013). Many of the articles summarized in the review of literature by Johnson & Rodriguez (2013) suggest involving parents whenever possible, consulting them regarding triggers before the appointment, and consult them for calming techniques.

### **Teaming up with Parents**

Several studies suggest that caregivers should form a partnership with parents and families, using them as a resource to learn about the child prior to interacting with him or her. (Butlas, 2011; Scarpinato et al., 2010). Scarpinato et al. (2010) suggest that nurses should ask the parents what has worked for the child at healthcare visits in the past, and use screening questions to identify potential stressors for the child. One study sent a pre-developed survey to parents of ASD patients prior to the patient being admitted for surgery. In addition to the survey the reviewers found it was also beneficial to call the parents and interview them before surgery (Van der Walt & Moran, 2001). The survey included questions regarding the severity of the patient disorder, their likes or dislikes, developmental level, and any special needs. This completed questionnaire was then distributed to everyone involved in the patient’s care during

the admission which overall improved the experiences of the patient and parents (Van der Walt & Moran 2001).

Developing a patient specific care plan where the nurse collaborates with the patient's parent prior to the appointment, to determine what usually causes the patient's anxiety contributes to a more successful visit (Butlas, 2011). The nurse who contacts the parents prior to the appointment can also take that time to explain what will go on at the visit, and discuss any paperwork that may have to be completed, which the parents in this study found to be very helpful (Butlas, 2011). Another aspect to discuss with parents is positive or negative experiences the patient has had during a past visit ("Tools you can use," 2011). If the healthcare team knows before the visit that the patient is afraid of white coats, they can modify their actions in order to decrease anxiety for the patient.

### **Summary**

Caring for a child diagnosed with ASD is complex and requires a comprehensive and well-planned approach. Without the proper training, skills, and knowledge, a healthcare visit has the potential to be an extremely stressful experience for the patient and family. With many aspects to consider, caring for this patient population is a complicated task for all members of the healthcare team. With an increasing number of patients being diagnosed with ASD, nurses and providers need to focus on understanding the healthcare experiences of this patient population in order to provide safe and effective care.

### **Conceptual Framework**

The conceptual framework of this research study was based on the Parse's Human becoming school of thought. The humanbecoming school of thought states that nursing should be based on a person' or groups' quality of life as described through lived experience (Cody,

2010). The three themes of the theory are meaning, rhythmicity, and transcendence. The assumption of meaning states that a person's reality is given meaning through lived experience (Nursing Theories, 2011). Rhythmicity refers to man and the environment co-creating in rhythmical patterns. Transcendence is reaching beyond the limits that a person sets (Nursing Theories, 2011). Research guided by humanbecoming is useful in exploring human lived experiences such as hope, taking life day-by-day, grieving, suffering, and courage (Cody, 2010). Parse's theory is best utilized in nursing research to understand lived experience, quality of life, quality of health, and quality of nursing practice (Nursing Theories, 2011).

## **Chapter Three**

### **Methods**

The purpose of this study was to explore the lived experience of parents whose children are diagnosed with Autism Spectrum Disorder, and understand how they perceive their child's healthcare experiences. Using purposeful interviewing, the goal was to identify areas for improvement, and also successes, in caring for this important and growing population.

#### **Design**

The design chosen for this study was interpretative phenomenology. Phenomenology allows researchers to explore different phenomena, where the goal is to collect the lived experience of the subjects. Researchers using this design aim to arrive at a deeper understanding of human existence by examining the information provided (Streubert & Carpenter, 2011). Phenomenology is frequently chosen for a research design when there is an area with little research. Interpretative phenomenology has a holistic focus.

Specific goals of interpretive phenomenology are to describe lived experience, hear the voice of the participant, explore and describe the phenomena, and search for relationships and meanings that the context have for each other (Streubert & Carpenter, 2011). Every patient and parent has a different perception of how ASD affects his or her everyday life. The spectrum of the Autism diagnoses creates a population who has a variety of different experiences. Listening to their stories, and examining their lived experience would be helpful for gaining a better understanding of these experiences.

#### **Sample**

Purposive sampling was used to collect subjects for this study. The inclusion criteria for potential subjects were parents of children with Autism Spectrum Disorder ages 2 to 10 years of

age. Recruitment posters were placed in public establishments such as Starbucks and local food stores. The interested participants contacted the principal investigator by email and or phone. The interview was conducted in a location with an environment conducive to the participants sharing sensitive information and respecting privacy.

### **Instrument**

The question of trustworthiness is a topic that has been a frequent concern in qualitative research (Streubert & Carpenter, 2011). Streubert and Carpenter report that asking negative descriptions of the phenomenon being investigated helps to establish trustworthiness of the data (2011). The semi-structured interview questions were developed by the principal investigator, and included inquiries regarding both positive and negative experience (Appendix B). The participants in this study were asked to describe times when their child had a negative experience with a health care visit, or to describe when things did not go as they would have liked them to.

Each participant was also asked to complete a demographic data form, developed by the principal investigator (Appendix C). Aside from commonly requested data regarding age, and educational level, it also requested information about their child's diagnosis, gender and age.

### **Procedure**

This study was reviewed and approved by the Institutional Review Board (IRB) at Point Loma Nazarene University (*Appendix D*). The subjects contacted the principal investigator by phone, and were first screened to determine eligibility to participate. Once inclusion was determined, the participants were asked to meet the principal investigator at a scheduled date and time in a safe location as chosen by the participant. Both participants signed a written consent form (*Appendix E*) prior to participation in the study. All completed forms were placed in an envelope only accessible by the researcher, to maintain confidentiality of the subjects.

The principal investigator was responsible for conducting all interviews to ensure consistency in the style of questioning. The interviews were recorded using a tape recorder and names of the subjects were not used during the recording of the interview to preserve anonymity of the participants. When completed, all interviews were transcribed by the principal investigator and stored on a password-protected computer. The transcriptions were labeled and categorized by number, and did not include the names of the participants. The tapes used for recording were used only until fully transcribed, and were destroyed so the voices of participants will no longer be able to be used to identify the individual.

### **Data analysis**

Data analysis in qualitative research requires the principal investigator become immersed in the data by listening to the interview, then repeatedly reviewing the transcriptions. After the interview was recorded, the researcher manually transcribed the encounter. Self-transcription was chosen over using an outside party in order to provide the researcher another opportunity for reviewing the data. Once transcribed, the principal investigator reviewed the interview material for common themes. Significant statements regarding healthcare experiences were identified and noted for future reference. To increase trustworthiness and authenticity of the data the interviews were transcribed verbatim so that the participants' views and experiences were accurately expressed.

## **Chapter Four**

### **Results**

After rigorous review of the interview material, two major themes were identified regarding the participants' healthcare experiences. First, the mothers reported that they had to be their child's main advocate when it came to coordination of care. They did not feel as if their pediatricians' office was well prepared with information on special services or treatments available. Second, neither mother has noticed any special treatment by the provider or nurses in regards to their child's diagnosis. The mothers expressed the feeling that their child was treated like they did not have an ASD diagnosis. Both themes provide an opportunity for improvement in providing healthcare to ASD patients.

#### **Sample**

The sample for this study was composed of two mothers of children diagnosed with ASD. The demographic results revealed that the mothers were ages 29 and 39. Both have 4-year-old boys diagnosed with Autistic Disorder. One child was diagnosed at 2 years old, the other at 3 years old. Both mothers have a college level education.

#### **Parent as patient advocate**

Both subjects shared that they were their child's own advocate when it came to getting them set up with services that the child required. One Mom stated: "If a pediatrician says your child has autism no one comes to your door, you have to look up things for yourself. There are so many resources out there, you just have to go get them." For both mothers, their pediatrician's office did not coordinate any of their child's care, or follow up on it. Regarding follow up, one subject shared: "His pediatrician will sometimes quickly ask "oh what services is he going to now" but he doesn't follow up to make sure he is going". Both mothers felt that if

they had not done the research themselves, that their child would not have been enrolled in the variety of programs they were.

### **No special treatment at the pediatrician's office**

Both mothers reported that no special practice was followed by the pediatrician's office while caring for their children. One mother reported that her son saw a different pediatrician every time she went in the office, so she didn't see how they could remember what was best in catering to behavioral issues with her son. The appointment times were not any longer than for a typical child, which did not give extra time to discuss mental health, or availability of proper resources. Long wait times and open waiting rooms were also a reported issue. One mom reported "the problem is the waiting area, he just takes off and runs all the time, and he just runs, especially if there is no play area, he will take off and just run." For some appointments the wait was up to forty-five minutes in the waiting room, and there were no toys or activities to keep the child occupied.

### **Nursing care**

In regards to nursing care, one mother recounts both a positive and negative experience. Her son reacts the best the nurse or provider lets him touch the equipment first, the otoscope or ophthalmoscope, which makes her son feel more comfortable and in turn is more cooperative during the exam. One mother described a specific visit when her son was not cooperating during a hearing test. The nurse did not try and calm him down, or work with mom to get the test done. Mom described the nurse, "they were just like "its fine we just won't do it." And they gave up." This situation made the mother upset because she does not want her child missing out on important exams, just because her child takes additional time and patience. That same mother described what stands out as her son's most successful health care visit, which took place in a

local emergency room. Even though it was late at night, and her son was very sick, the nurses made it a positive experience for them. They offered her son choices, gave special toys as rewards, and worked with her to make the exams and treatment as small of an impact on the child as possible.

## **Chapter 5**

### **Discussion**

#### **Interpretation of the Findings**

The feedback from both participants in this study confirms that there is a deficit in providing effective care to the ASD population. In both cases, these children have been cared for in the same manner as any other patient. With a growing number of children being diagnosed with ASD, it is imperative that awareness is brought to the healthcare community. In addition to the emotional stress and anxiety for the primary caregivers related to the diagnosis, the quality of the healthcare their children are receiving should not be their focus.

#### **Compare and Contrast to Existing Evidence**

The interviews conducted in this study yielded very similar results when compared to several other interpretative phenomenological studies on this topic. Margaret Bultas interviewed eleven mothers of preschool children with an ASD diagnosis in 2011. One main conclusion was the mothers felt that healthcare providers didn't fully understand the diagnosis, and the associated behaviors. In addition, the mothers expressed that they know their children best in regards to anxiety triggers and challenging behavior, however healthcare providers did not include them in the care of the patient (Bultas, 2011).

#### **Implications for Nursing**

With the increasing number of pediatric patients being diagnosed with ASD, it is certain that all nurses working with this patient population will have frequent contact with these children. Understanding the diagnosis is imperative to effective treatment. Children with an ASD diagnosis are not only treated in specialty areas, but in common healthcare settings such as the pediatrician's office, or the emergency room. Nurses in working in all areas of healthcare

need to have the proper training in the aspects of this diagnosis in order to provide safe and effective care. With the adequate knowledge, caregivers can create an environment safe for their patients and their sensory needs. Reviewing effective techniques such as providing choices to patients can reduce anxiety and assist in the delivery of necessary care in a safe manner. In September 2011, “Autism Speaks” released a kit for healthcare providers, with tools that can be used to help patients with ASD tolerate blood draws or simple office procedures (“Tools you can use,” 2011). The kit provides strategies for healthcare providers in decreasing stress for patients and parents during medical procedures. The kit includes an overall explanation of autism, what to expect when treating an ASD patient, and tools which can be used to make the healthcare visit a more positive experience for these patients. This is an example of an easily accessible resource for nursing staff to implement in their department.

### **Limitations**

This study has two major limitations, which are small sample size, and a lack of diversity in the participants. Traditionally, sample sizes are small for an interpretative phenomenological study (Streubert & Carpenter, 2011). Though the initial thought was that many mothers would be interested in participating, recruitment was difficult and resulted in a small sample size of only two participants. Among those participants, both children were boys, and 4 years old. Also, both mothers have a college degree. There is a possibility that the similarities in the mothers’ experiences were related to their shared characteristics. In addition, both mothers reported that their sons were “high functioning,” which refers to the lack of severe symptoms related to their ASD diagnosis. Since few studies have been completed researching this specific topic, there is not much to compare these results to. It is difficult to determine the validity of the results without many studies with a similar focus.

### **Areas for Future Research**

An abundant amount of research exists regarding diagnosis, treatment, and components of Autism Spectrum Disorder; however, studies regarding nursing care of this population are not as common. Currently, there are no evidenced based standards of nursing care for children with ASD. Additional studies examining specific nursing practice, and the effect on safety and efficacy in caring for this patient population are recommended.

### **Conclusions**

Due to the increasing prevalence of autism, additional research is recommended in all areas but specifically in nursing care. As the number of children being diagnosed increases, the number of children with ASD being cared for in a healthcare setting increases as well. This study identifies a gap in educating nurses on the best way to care for this patient population. Caregivers need to feel comfortable with the nursing care their children are receiving, and nurses need to feel comfortable providing safe and effective care to their patients. Increased education and awareness in the nursing community could lead to increased patient advocacy and assistance to parents as they coordinate care for their children.

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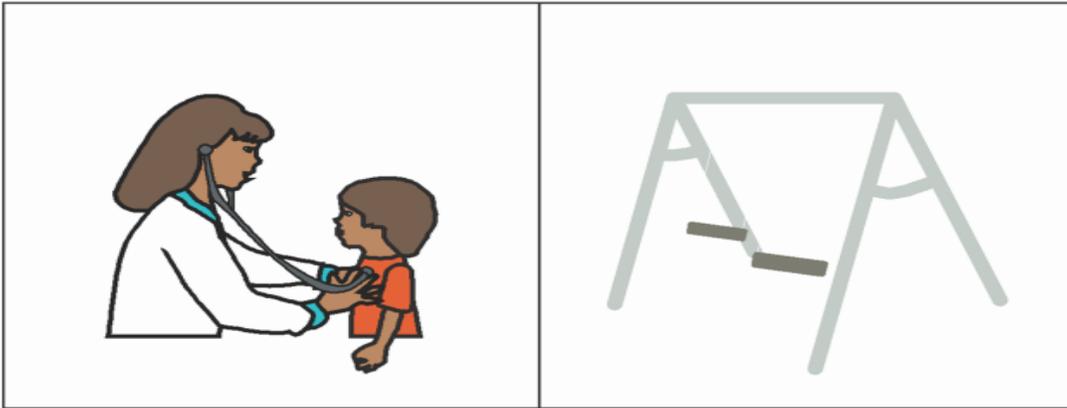
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**Appendix A**

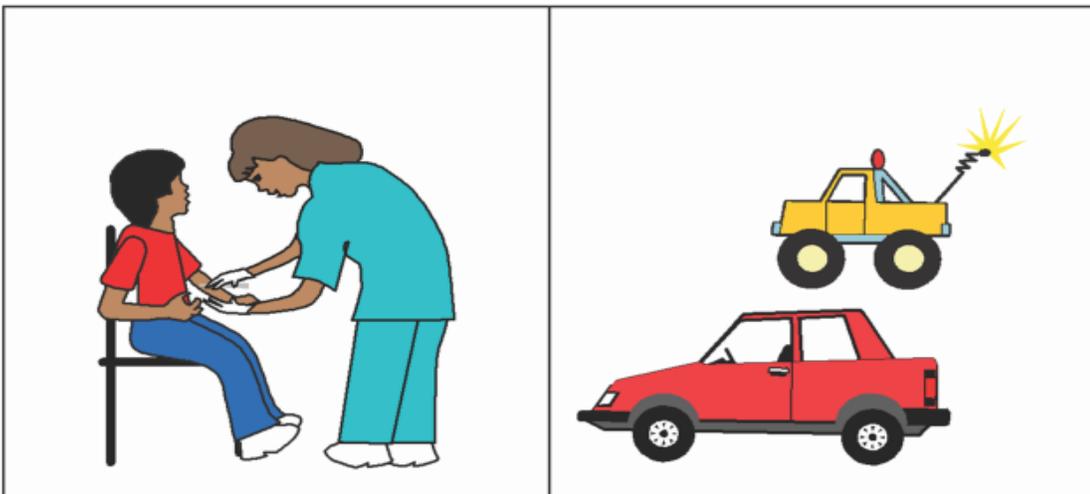
**First doctor's visit**

**Then go to the playground**



**First feel pinch**

**Then play with cars**



("Tools you can use," 2011)

**Appendix B**

### Interview questions

1. Tell me a little about your child, in general
2. Can you share with me the story of when your child was diagnosed?
3. Does your child have any specific triggers that cause him/her to be anxious or agitated?
4. How many set doctors appointments or therapies does your child have monthly or weekly.
5. What is the routine like when he/she goes for his/her annual check up?
6. Would you say that the doctors or nurses do anything special to help your child through that?
7. How do the nurses react with your child if he/she starts getting freaked out during a visit?
8. When you see a new provider, do they ever ask, or call you prior to the visit and to see if there is anything special they can do to help your child through the visit?
9. What would you say was the best healthcare experience for your child?
10. Do any healthcare experiences stick out in your mind as being really bad?
11. For all the resources that your child has, who coordinates that?
12. Is there anyone following up on if your child is getting these services?
13. Do you have anything in general, if you had a magic wand that you would want to see more out of in healthcare?

### Demographic Data Form

Directions: As with all of the content shared during this interview, your answers will be kept confidential. Please read the questions below and respond appropriately. Your completion of this demographic data form will serve as your consent to participate in this study.

1. What is your age?  
\_\_\_\_\_ years old
2. What is your child's age?  
\_\_\_\_\_ years old
3. What is your child's gender?
  - a. Male
  - b. Female
4. What best describes your ethnic group?
  - a. Hispanic
  - b. Black (Non-Hispanic)
  - c. White (Non-Hispanic)
  - d. Asian/Pacific Islander
  - e. Multi-Ethnic
  - f. Other
5. At what age did was your child diagnosed with Autism Spectrum Disorder?  
\_\_\_\_\_ years old
6. Which category below best describes your child's ASD diagnosis?
  - a. Autistic disorder
  - b. Asperger Syndrome
  - c. Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS).

**Appendix D****PLNU IRB  
Expedited Review  
# 1094****8/27/2012****PI: Piderit, Victoria****Additional Investigators: NA****Faculty Advisor: Son Kim, PhD****Title: Perceptions of Healthcare Experiences: Lived Experiences as told by the mothers of autistic children**

The research proposal was reviewed and verified as an expedited review under category 7 and has been approved in accordance with PLNU's IRB and federal requirements pertaining to human subjects protections within the **Federal Law 45 CFR 46**, subpart 101 (b) as expedited in part 110. Your project will be subject to approval for one year from the 8/27/2012 date of approval.

After completion of your study or no later than the same month and day in 2013, you must submit a summary of your project or a request for continuation to the IRB. If any changes to your study are planned or you require additional time to complete your project, please notify the IRB chair.

For questions related to this correspondence, please contact the IRB Chair, Patricia Leslie, M.A., S.S.A. at the contact information below. To access the IRB to request a review for a modification or renewal of your protocol, or to access relevant policies and guidelines related to the involvement of human subjects in research, please visit the PLNU IRB web site.

Best wishes on your study,

Patricia Leslie, M.A. – S.S.A.  
Associate Professor  
Department of Sociology and Social Work  
Director, Social Work Program  
IRB Chair

Point Loma Nazarene University  
3900 Lomaland Dr.  
San Diego, CA 92106  
619.849.2676  
PatriciaLeslie@pointloma.edu

## Appendix E

### Consent Form

Victoria Piderit RN, BSN is conducting a study to assess your perceptions about the healthcare experiences of your Autistic child. You have been asked to participate in this study because you have a child aged 2-10 years old who is diagnosed with Autism Spectrum Disorder.

Completing this interview will take approximately one hour.

Your participation in this study is voluntary, and if you do not wish to participate, you do not need to do anything further. If you choose to take part, your completion of the demographic data form and interview questions will indicate that you have read this consent form, had the chance to ask any questions you have about the study and that you consent to participate. You can change your mind and stop your participation at any time. If you choose not to participate there will not be any negative consequences.

Your individual response to the interview questions will be held in strict confidence. Your individual responses will not be shared with anyone and will only be accessible by the researchers. There will be no individual respondent identifiers attached to the survey. Your individual responses will be aggregated with all other participants in the study and reported only in the aggregate form.

There are minimal risks associated with your participation in this study. There may be emotional discomfort caused by answering questions about your child's healthcare experiences. You may choose to refuse to answer the questions or withdraw from the study at anytime. To maintain confidentiality of your response, your interview responses will be kept in a secure and locked office. By sharing your story, you might help others facing similar experiences. It is hoped that the information collected during this study may be used to improve nursing care for Autistic patients.

If you have any questions at any time, please feel free to contact Victoria Piderit at 631-513-5304. In addition, if you have any questions about your rights as a participant in research you may contact the Point Loma Nazarene Institutional Review Board at 619-849-2710.

**Name** \_\_\_\_\_ **Date** \_\_\_\_\_

**Signature** \_\_\_\_\_

