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Caring for Children and Adolescents With Autism Who Require Challenging Procedures

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Abstract and Introduction

Abstract

Providing nursing care for children with autism or autistic spectrum disorders (ASD) can be challenging. As part of a larger study of 62 children with autism ages 3-8 years (Coplan et al., 2001; Levy et al., 2001) that required difficult procedures, strategies were developed for providing care that incorporated theories and knowledge from the disciplines of nursing, child development, psychology, applied behavior analysis, and pain management. Applications of these strategies are illustrated through the process of a physical exam, phlebotomy, and intravenous (IV) insertion during a health care visit. The nurse can develop a plan of care to achieve the goals of the visit and optimize the quality of the care for the child and family. Interventions presented can be individualized to each child.

Introduction

The prevalence of children with autism or autistic spectrum disorders (ASD) has increased over the past two decades. According to recent studies, the rate of ASD [including autism, childhood disintegrative disorder, Asperger's syndrome, Rett's syndrome, or pervasive developmental disorder - not otherwise specified (PDD-NOS)] may approach 1% of school age children (Bertrand et al., 2001; Gillberg & Wing, 1999; Wing, 1996, 1997). This is a dramatic difference compared to previously published occurrence rates of 4-5 per 10,000 (Lotter, 1966). ASD is three to four times more prevalent in boys than girls and knows no racial, ethnic, and social boundaries (Autism Society of America [ASA], 2000). Reasons for the increased rates are multiple and may include increased awareness, commitment to early diagnosis and intervention, and other unknown etiologies. Research has shown that siblings of individuals with ASD have a 3% to 8 % chance of being diagnosed within the spectrum (Rodier, 2000). Health care professionals have increased exposure to this special population. Pediatric nurses will most likely encounter at least one child with ASD in their practice setting.

ASD recently has received greater media attention because of the increased prevalence and controversy about potential causes and effective treatment. Increased awareness is needed among health care administrators, service providers, and leaders in research. Families, support groups, and professionals are actively lobbying the federal government for research monies to investigate this brain-based developmental disability.

Children's Hospital of Philadelphia (CHOP) recently created a Regional Autism Center, and nursing plays a vital role in caring for these children and participating in research. During May of 1999 through February of 2000, a study of a 2 X 2 randomized, crossover double blind placebo controlled trial of a single dose of human synthetic secretin for 62 children ages 3-8 years of age with ASD was undertaken at CHOP. Findings of this study are reported in Levy et al. (2001) and Coplan et al. (2001). The study required procedures (e.g., venipunctures, IV insertions) that are difficult for this group of children due to their deficits in social affective skills; communication; language; and restrictive, repetitive behaviors. Few studies on medical compliance among children with ASD exist; therefore, nursing care interventions and management strategies were developed for the children and families who participated in the study, which included 310 physical examinations, 310 venipunctures, and 124 IV insertions. Theories and knowledge of nursing, child development, autism, pain management, psychology, and applied behavioral analysis were incorporated.

Children with ASD can have difficulties with new environments and changes in their normal routine. Components of a health care visit can be very stressful to the child, parent, and health care professional and painful procedures can leave lasting negative memories. These memories can have a significant impact on future visits resulting in behaviors such as tantrums and aggressions toward health care personnel. Information gained while conducting this study can be used with this population during a health care visit. Effective interventions and management strategies can facilitate a positive health care experience for all.

ASD is a brain-based developmental disability, which differs from mental retardation. A characteristic feature of ASD is a dramatic deviation from normal development and not a delay in development that one would observe with mental retardation (Reber, 1992). Deviations become apparent by 3 years of age (Filipek et al., 1999; Reber, 1992). The core clinical characteristics of ASD include impairment in social interaction, communication, language, and a restrictive repertoire of behaviors, interests, and activities (see). Examples of the core deficit categories are listed in .

Table 1. Table 1. DSM-IV Criteria for 299.00 Autistic Disorder

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A. A total of six (or more) items from 1, 2, and 3 with two from 1, and at least 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 posture, and gestures to regulate social interaction.
   b) Failure to develop peer relationships.
   c) Lack of spontaneous seeking to share enjoyment, interests, or achievements with others.
   d) Lack of social or emotional reciprocity.

2. Qualitative impairments in communication as manifested by at least one of the following:
   a) Delay or lack 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 ability to initiate or sustain conversation.
   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 mannerisms.
   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.

Note: From American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: Author. Reprinted with permission.

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Table 2. Table 2. Examples of the Core Deficits of Autistic Disorder Using the DSM-IV-TR Criteria

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Area of Deficit	Examples
Social interaction	Poor or limited eye contact; limited use of proximal and distal gestures such as pointing, waving, nodding, shrugging; no social smile; does not respond to name. Difficulty in initiating and sustaining conversation. Prefers to spend time alone. Limited ability or motivation to show and give toys or point out objects of interest. Difficulty with empathy and identifying feelings.
Communication	Difficulties with semantics (multiple word meanings) and pragmatics (hidden meanings) of language. Often one word responses, problems with intonation, difficulty comprehending more than one concept in a sentence. Repetitive use of favorite phrases from a video, echolalia, rote phrases out of context, talk in third person. Often are concrete thinkers, have difficulty with symbolism, and require both verbal and visual cues to understand abstract concepts.
Repetitive patterns of behavior	Preoccupation with a certain toy, hobby, topic, or activity where the intensity or focus is so great it is difficult to transition to another activity, topic, or toy. Strong desire to line up toys or objects, collect them, or hold them. Need to have objects and situations ordered in a way with which they are familiar. Has odd movement patterns such as finger flicking, hand flapping, spinning, or sniffing. Preoccupation with playing with parts of toys or objects: wheels, switches, or keyboards.

Each child with ASD manifests a range of characteristics of the disorder including mild to severe symptoms of autism. Children's cognitive levels can range from normal to above average intelligence to profound mental retardation, with up to 80% having mental retardation (Fombonne, 1999). Children with ASD also may have somatosensory disturbances that may include hypersensitivity to sounds, smells, touch, textures (oral or tactile), and visual perception distortion. They have difficulties with commotion and crowds. Many children have abnormal sensory inspection and exploration exhibited by mouthing and smelling of toys and pressing objects against their face (Siegel, 1996). Some children have hypotonia, fine motor deficits, and difficulties with motor planning. Children with developmental disabilities, including those with ASD, have an increased rate of behavioral or emotional difficulties (Levy, 1996). Children with ASD may have emotional difficulties such as low frustration tolerance, mood swings, over-reactivity, or they are easily overstimulated, which could result in agitation and inattention.

The sensory integration issues, emotional difficulties, and the core deficits of autism can lead to feeding disorders and other maladaptive behaviors such as severe tantrums, aggression, disruptions, and self-injury. Speech and language pathologists, occupational therapists, and behavioral psychologists are key team members who need to work together in formulating protocols that promote functional behaviors in children with ASD. This allows the children to develop and learn at home, at school, and in the community.

The Health Care Visit

Health care professionals need to prepare, be creative, and have a sense of humor when caring for children with ASD and other developmental disabilities. Parents of children with ASD are often extremely knowledgeable and are an excellent resource for the nurse providing care for their child. Parents take solace in health care providers' empathy and understanding of the disability and challenges that parents of children with ASD face. Often parents fear the stigma associated with ASD that still exists today. Society as a whole knows very little about ASD, and parents fear that this lack of knowledge may lead to preconceived judgements about their child or that the child is just like the autistic man in the movie *Rain Man.*

To provide comprehensive nursing care for children and adolescents with ASD, it is optimal that a preliminary assessment of each child and family be accomplished prior to the health care visit or interaction. A 15-30 minute conversation in person or by telephone with a parent prior to the clinical visit can make a significant difference in the efficiency and quality of the visit.

Assessment

A nursing assessment incorporates the child's communication, social, sensory, and behavioral skills and successful strategies for compliance. Discussing a child's social, communication, and behavioral strengths and limitations with the parents is the first step. Identify the child's strengths; these can help the child participate in the health care visit. Children with ASD often have good vocabularies and rote memories. This could be incorporated as part of a behavioral strategy. For example, having children count or say their letters during a procedure may distract them from the procedural activity.

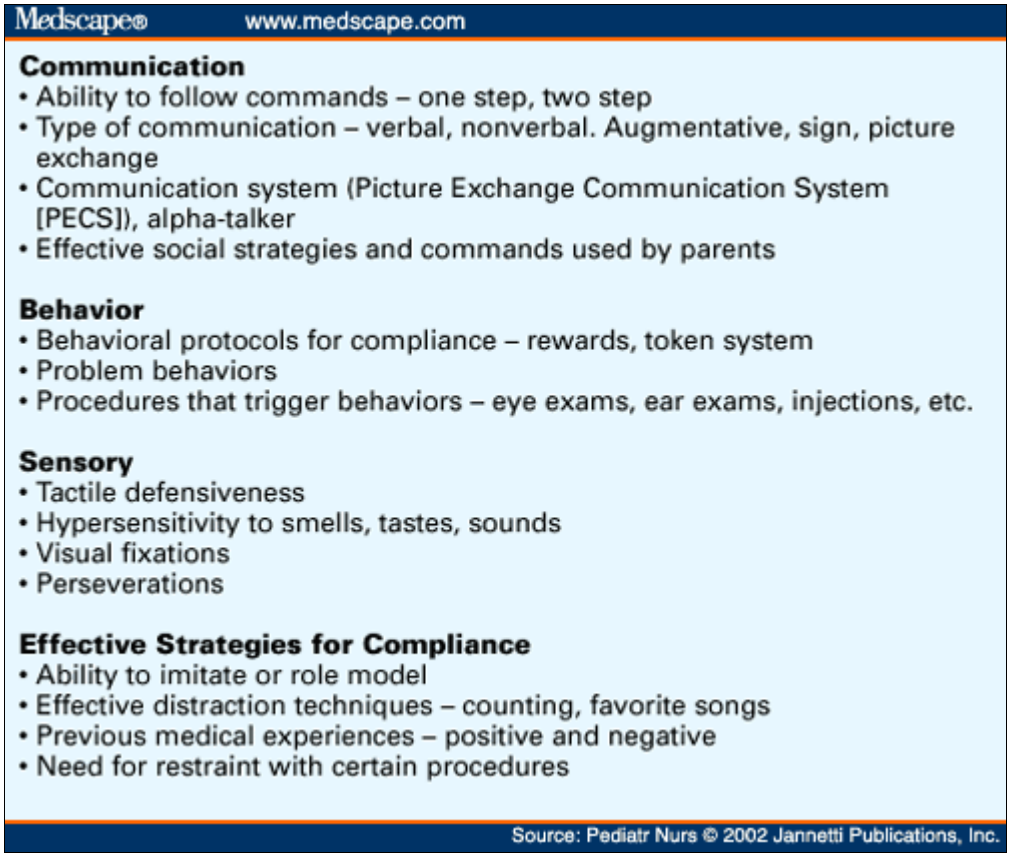
Assess the child's ability to follow commands and how the child communicates - verbally or non-verbally. If the child is non-verbal, augmentative systems may be used by the child and may increase communication during a health care visit. The Picture Exchange Communication System (PECS), sign language, and/or an electronic communication board (e.g., alpha talker) are examples of augmentative systems.

Identify strategies that can facilitate the visit such as the use of role modeling, imitation, or effective distraction techniques. Familiarity with behavioral protocols that are used at home or in school to gain compliance with tasks is helpful (e.g., tokens and rewards). Assessment of problem behaviors and what precipitates them may include aggressions, tantrums, self-injury, behavioral vomiting, and preservative and repetitive routines. Typical aggressions exhibited by children with ASD include biting, spitting, head butting, scratching, pinching, punching, slapping, and kicking. Aggression, screaming, flopping to the floor, stripping, and property destruction are common components of tantrums. Self-injury may include head banging, skin picking, scratching, punching, eye poking, and biting. Discuss protocols to be employed in response to these behaviors that have been developed between the child's behavior therapist and parents. If no protocols exist, the nurse can ask the parents how they handle the problem behaviors.

Children with ASD often exhibit somatosensory disturbances, an over-reactivity or under-reactivity of the senses. These include tactile sensitivity issues. Many children can not tolerate bandages, dressings, arm-boards, and blood pressure (BP) cuffs. Certain noises and smells can trigger inappropriate behaviors. Many children have visual attractions and fixations. Abhorrence to certain textures can contribute to feeding difficulties or conversely, attraction to certain textures, can lead to tasting of nonfood items and pica.

Parents can provide important information about their child's previous health care experiences. Discussing the tasks that need to be accomplished during the health care visit will contribute to proper planning and identification of potentially problematic procedures such as obtaining vital signs, phlebotomy, physical exam, intramuscular (IM) injections. summarizes the areas of the nursing assessment.

Table 3. Table 3. Areas of Assessment



Planning

Upon completion of the nursing assessment, the nurse prepares and plans for the interaction with the child, parents, and/or caretakers bringing the child for the health care visit. If the assessment is done prior to the visit, the nurse can instruct the family to bring materials from home to facilitate the visit. The environment must be safe and conducive to the purpose of the health visit. Children may become anxious upon arrival for a medical visit due to the unfamiliar surroundings or memories of past experiences. To address these issues, Rainey and Van Der Walt (1998), from the Department of Pediatrics, Women and Children's Hospital, Adelaide, South Australia, have created a special quiet room for children with ASD who require anesthesia management. In their practice, they found that a quiet place to give pre-op anesthesia medications and pre-admission planning with the family prior to the day of the procedure were crucial strategies in providing adequate care to this special population. The environment should be uncluttered, with supplies and equipment set up ahead of time and screened from view prior to the patient entering the exam or procedure room. Mobiles and other child friendly decorations should be kept high and out of reach. Furniture should be durable and easy to clean, and waiting rooms, bathrooms, and play areas should be childproofed. For this study, a quiet treatment room was available with an adjoining waiting room. The treatment room was 15 ft. by 7 ft. and contained an exam table, phlebotomy chair, cart, and scale. Only necessary equipment was in the room. All supplies were hidden from view.

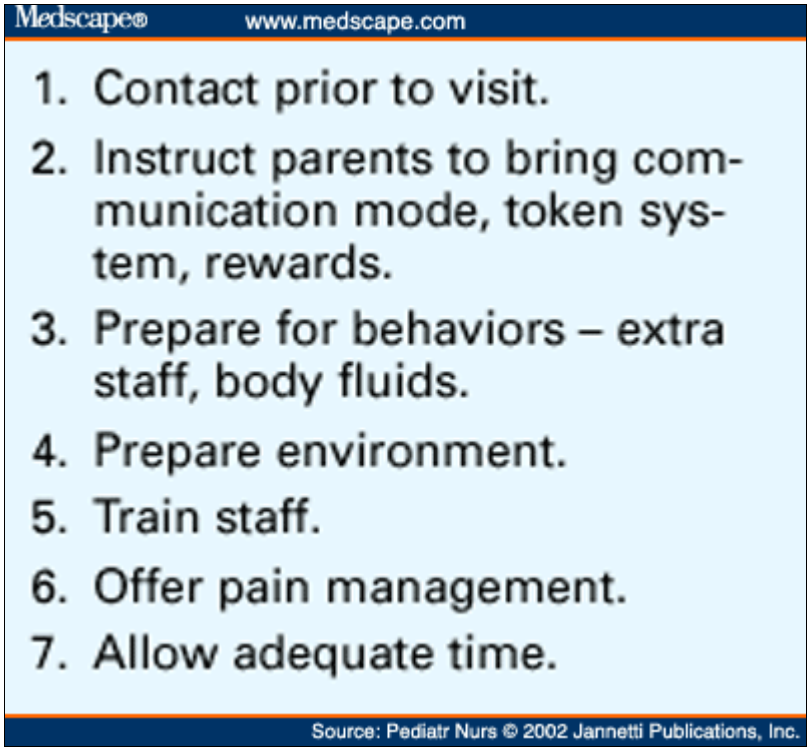
Planning also should include consideration of additional equipment and staffing requirements. For example, if the child spits, gown, gloves, and goggles should be used. If the child is large, aggressive, or requires restraint for a procedures such as a phlebotomy, IV insertion, or immunization, an appropriate number of helpers needs to be identified and available. The use of trained staff is ideal.

Offer the option of pain relief for immunizations, phlebotomy, or IV insertion with an analgesia cream, such as EMLA® (Fradet, 1990; May, Britt, & Newman, 1999; Walco, Cassidy, & Schechter, 1994). EMLA can be ordered by the family physician and obtained by the parent at a local pharmacy. EMLA cream is an emulsion mixture of 2.5% lidocaine and 2.5% prilocaine. The absorption of this eutectic cream into the epidermal and dermal layers of the skin provides local analgesia. Supplied in the form of discs similar to EKG lead patches, or a cream, with an occlusive dressing, the parent can apply the EMLA to the antecubital area in anticipation of a venipuncture during a health care visit (Koh, Fanurik, Stoner, Schmitz, & VonLanthen, 1999). In our study, 90% of the parents opted for the EMLA cream to prevent pain and expressed appreciation

for the intervention. The remaining 10% of the parents felt their child would not tolerate the cream due to tactile defensiveness. It was recommended to the parents that their child wear a long sleeve shirt to conceal the EMLA patch once applied. EMLA cream was applied to both antecubital spaces on each child. Most children were able to keep the cream on for 45-60 minutes with distraction techniques. EMLA was effective in providing pain relief. No facial wincing or attempts to retract the arm at time of puncture were noted by nursing staff.

Scheduling adequate time for all assessments and procedures is important. Several strategies may be employed to identify the one that is successful, requiring time and patience. Components of the nursing care plan can be found in .

Table 4. Table 4. Key Components in Nursing Care Plan



Implementation

A successful health care visit for a child with ASD can be accomplished by employing specific behavioral interventions that can be used with all children, but are especially important with the ASD population. The goal is to help the child comply with the assessment or treatment using behavioral strategies and, if necessary, to ensure that successful or safe, holding techniques are used. The following behavioral interventions were successfully implemented during our study by the nursing staff to obtain physical exams, vital signs, phlebotomy, and IV insertion. An example of each strategy can be found in .

Table 5. Table 5. Examples of Behavioral Strategies

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Strategy	Example
Imitation/role-modeling paired with reinforcement	To obtain an axillary temperature, initially use a non- threatening object, such as a pen. Model the procedure on a doll, and then have the parent and then the child do the same. Next, have the child use the thermometer probe on the doll, then on himself or herself. Follow each step with praise or reward. The process is as follows: at first, it is the nurse's turn, "my turn," and then it is the child's turn, "your turn."
Rewards	After a child complies with a request, such as "open your mouth" during a physical examination, offer a reward (high five or "good job").
Shaping	Shaping can be used in the task of open mouth. Say "open," and if a small attempt is made, praise the child. Ask again for the desired behavior (imitation can be incorporated here). Initially, reward any attempt. Slowly delay praise or reward until a close imitation of the behavior is achieved.
High-probability request/ low-probability request	To obtain a blood pressure (BP) reading. In a fashion similar to the Simon-Says game, quickly give requests: "Touch your ear, touch your nose, and hold your arm out straight." Praise. Repeat, and then put on the cuff. Repeat, pump up cuff, and then deflate. Praise. Repeat and auscultate BP. Praise.
Differential reinforcement	Praise the child when he or she is compliant to a request or behaving appropriately. Give no reaction, praise, or reinforcer when a request is refused or when an inappropriate behavior is demonstrated. Catch the autistic child being good, responding to a request, or making a good effort, and immediately praise and/or reward the child.
Token systems	At the start of the physical exam, give the child a token upon compliance with a simple request. Intervals for tokens should be short initially, and as exam proceeds, the frequency of token reward can be reduced. The predetermined reward can be a new toy, trip to McDonald's, watching a video, or parent- engaged activity. The key is that the anticipation of the reward will motivate the child to comply.
Choices	Whenever possible, offer choices to the child. Do it in such a way that the choice is a detail within the task, not the task itself. For example, ask, "Which arm would you like me to use to check your blood pressure?" or "Which color cuff would you like?"
Visuals	To decrease anxiety before the visit, use pictures at home in preparation for the procedure. During the visit, show equipment prior to use. Encourage parents to read a book about going to the doctor to their child, such as *Berenstain Bears, Barney and Baby Bop Go to the Doctor,* and *A Visit to the Sesame Street Hospital.*
Distraction techniques	*Conversation:* Ask questions about family, school, pets, hobbies, and favorite toys. Ask closed-ended questions since children with autism are often unable to sustain conversation. Prompt continually to retain distraction. *Singing:* Sing a familiar song, asking the child to finish the ending. *Counting and reciting the alphabet:* Ask the child to count to a certain number or to recite the alphabet. *Toys:* Encourage the child to bring in a favorite toy or have a supply of toys available.
Body-hold techniques	For venipucture, instruct the parent to sit in the phlebotomy chair and pull the child in close to the chest. Have the parent position one arm across the chest of the child, holding on to the hand of the arm not being used. Place the other arm across the abdominal/hip area and pull in securely but comfortably to decrease the child's ability to move. Tuck the child's legs between the holder's legs with the knees bent so that the child has no leverage to stand or arch. Place the child's arm on a pillow for greater comfort. Have a staff member secure the arm on the pillow. The person performing the venipuncture concentrates only on getting the stick completed, another staff member helps stabilize the child in the phlebotomy chair, and another staff member hands supplies to the person performing the procedure. Keep yourself and the child safe; do not verbally attend to inappropriate behaviors. Continue whatever activity was being conducted, and praise the child when he or she exhibits acceptable behaviors.

Imitation/role-modeling paired with reinforcement. Modeling is a procedure that presents a sample of a given behavior to an individual to induce that individual to engage in a behavior (Martin & Pear, 1996). When paired with reinforcement, modeling can be an effective nursing strategy. If the child is cooperative, the modeling is paired with a "reinforcer," such as praise or a reward, which can be anything that follows the behavior and increases the probability of that behavior (Miller, 1997). Consistent increases or decreases of the behavior allow for the identification of potential reinforcers of behavior (Berg et al., 2000). Gewirtz and Baer (1958) demonstrated the phenomenon of using social reinforcers such as verbal praise. The

nurse or parent demonstrates the desired action to the child. When the child imitates the action, the parent and/or nurse gives a "reinforcer" such as verbal praise.

Rewards. A reward is synonymous with a positive reinforcer, which is an event that, when presented immediately following a behavior, causes the behavior to increase in frequency or be more likely to occur again (Martin & Pear, 1996). A reward is something that a child is motivated to obtain, which could be parental attention, praise, food, a break, a favorite activity, or a toy. The key is choosing a reward that is motivating. The parent usually knows these items and is typically the most appropriate person to deliver the rewards to the child.

Shaping. Shaping is the development of a new behavior by successive reinforcement of closer approximations and the extinguishing of preceding approximations (Martin & Pear, 1996). In other words, shaping involves rewarding a small stride and slowly increasing the expectation before reward is given. Hagopian and Thompson (1999) addressed the noncompliance of respiratory treatment for an 8-year-old boy with cystic fibrosis, mental retardation, and autism by shaping cooperation through reinforcement or reward. The amount of time of inhalation treatment required to be compliant and receive a reward was gradually increased over numerous sessions. Rewards proved to be effective in achieving compliance and reducing aggression. The strategy of shaping is used for tasks that the child has not mastered on command and that are not in the child's repertoire (Nicolosi, Harryman, & Kresheck, 1989).

High-probability requests/lowprobability requests. High probability requests (high-p) are requests that have a high likelihood of compliance; low probability requests (low-p) are those with less expectation of compliance. McComas, Wacker, and Cooper (1998) reported mean levels of compliance of 78% when low-p requests were preceded by high-p requests, compared to 44% when low-p requests were not preceded by high-p requests. "Touch your head," "Say Mom," or "Blow Mom a kiss," are examples of high-p requests. Once the momentum of compliance is established, a low-probability request is made, such as "Hold still." When completed, praise and delivery of the next request in the sequence immediately follows. After the child holds still (low-p request), allowing the procedure step to be completed, the child's mother holds or plays with the child for 5 seconds. This gives the child the best reward for the toughest task (to hold still). With this strategy, the best performance deems the best reinforcement. If the child is not compliant with a low-p request, no praise or reward should be given. Another high-p request would follow and the sequence would start again. The child's undesirable behaviors (e.g., kicking, hitting, screaming, crying) should be ignored or put on extinction. Extinction is a technical term of showing no observable or subjective response to the behavior. Extinction is used for behaviors which are attention seeking or used by the child to escape a demand (Powers, 2000). Gentle restraint with assistants is required if compliance strategies are not successful in having the child hold still. If the nurse stops when the child becomes aggressive, then the child has learned that aggression gets him or her out of performing what is requested. This can lead to increasing levels of aggression for future demands. Otherwise, the child quickly learns how to get the nurse to stop and relieves the child of the demand to stay. A hierarchy of reinforcement exists for each child and can be identified based on the parent's report. The nurse should give reinforcement at the peak of the hierarchy (often candy or food) for the best performance by the child. A mediocre performance may receive verbal praise. The reinforcement is differentiated based on the performance.

Differential reinforcement. This technique involves reinforcing desirable behaviors while ignoring unacceptable ones, and can reinforce any appropriate behavior for longer and longer periods of time, when the child is not engaged in the identified "target" inappropriate one. The differentiation is based on the behavior. Reinforcement is given, for example, for the lack of an inappropriate behavior, the decreased frequency of the inappropriate behavior, the increased frequency of an appropriate behavior, and the use of an alternate appropriate behavior (Holmes, 1998). In their study, Vollmer, Roane, Ringdahl, and Marcus (1999), demonstrated that differential reinforcement of alternative behaviors eventually increased appropriate behavior.

Token systems. A token is a stimulus that is not reinforcing in itself, but is paired or associated with another reinforcer and is sometimes called a back-up reinforcer. Reinforcers that can be accumulated and exchanged for a back-up reinforcer is called a token system (Carton & Schweitzer, 1996; Epstein & Masek, 1978; Martin & Pear, 1996). Koegel, Koegel, Hurley and Frea (1992) explored a token system to increase appropriate verbal responses by children with ASD to social initiations by adults. Four children with ASD were trained to use a wrist counter to tally their appropriate responses. Their points (tokens) would be traded for rewards. The reinforcement schedule was thinned within the first few training sessions. The children demonstrated rapid improvement and were able to maintain high levels of appropriate responses throughout the study. The use of token systems must be in place prior to the health care visit, and the child usually chooses the reward that

will be earned. Tokens are used to obtain compliance with medical procedures by giving the child a token when any request is met.

Choices. It is important for children with ASD to express preferences and make choices to increase personal autonomy and quality of life (Bannerman, Sheldon, Sherman, & Harchik, 1990; Guess, Benon, & Sigel-Causey, 1985). Research has found that choice making can help decrease avoidance behavior (Koegel, Dyer, & Bell, 1987) and improve task performance (Mithaug & Mar, 1980; Parsons, Reid, Retnolds, & Bumgarner, 1990). Research has indicated that individuals with severe developmental disabilities have not been offered many opportunities of choice by their educators or caregivers (Reid & Parsons, 1991).

Visuals. Children who have ASD are usually visual learners (Freeman & Dake, 1997). When information is presented with a visual as opposed to verbal cues, children with ASD are more successful at accomplishing the presented task (Bryan & Gast, 2000; Quill, 1997). In the Bryan and Gast (2000) study, four first grade students with ASD quickly learned the mechanics of the visual cues and gestures, and they maintained high levels of independent on-task and on-schedule behaviors as the cues and gestures were faded.

Distraction techniques. Seid, Sherman, and Seid (1997) describe successful pre-and postoperative techniques of role-playing and distraction techniques to manage the operative course for tonsillectomies and adenoidectomies with children with autism. Distraction techniques can be used to decrease the amount of anxiety related to the procedure. Examples of distraction techniques include the following:

- Conversation - Engaging children in a conversation may distract them from the procedure. Children with high functioning ASD or Asperger's syndrome can participate in a conversation but need prompting often to initiate one. Krantz and McClannahan (1998) showed increased socialization in preschoolers with ASD using one-word stimulus to prompt the child to initiate interaction, which was followed by a reward.
- Singing - Songs may allay some of the child's fears. In our study, having the child finish the ending to a familiar song provided distraction from the task at hand and worked surprisingly well for some children.
- Counting and reciting the alphabet - Autistic children are often good at labeling objects and have good rote memories. Having the child participate in counting and reciting the alphabet helps redirect their attention and incorporates the high probability requests theory. In some instances, the children cried during the recitation but were able to hold still.
- Toys - The nurse can encourage the child or family to bring in a favorite toy. A supply of toys can also be available. The toys that were a novelty to the children in this study often provided the greatest distraction.

Body hold techniques. Minimizing the use of restraint is optimal. Gentle holding by parents and health care providers is preferred over devices. It is important to work as quickly as possible to decrease the frustration level of all involved. Preparing the parents for their role in the procedures, particularly phlebotomy or IV insertion, is an important step. This can be done via demonstration by the staff. If the preparation is not thorough, parents may become upset by their feelings of inadequacy to help their child through the process or embarrassed by their child's reaction to the procedure.

In our study, sometimes it was necessary to physically help the child look away from the procedure, as some children's anxiety increased by seeing the needles and blood. The number of assistants required for holding depends on the age of the child and their range of characteristics of ASD.

Many challenging procedures and assessments were part of this research protocol and were successfully obtained during our study using behavioral interventions. provides suggestions of behavioral interventions for each procedure.

Table 6. Table 6. Procedures and Behavioral Strategies

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Procedure	Behavioral Strategies
Measurements: height, weight, and head circumference	Imitation Modeling Reward
Auscultation using stethoscope: heart, lung, abdomen	Modeling Distraction with favorite toy Choices Reward
Blood pressure	High probability/low probability Distraction Reward
Otoscope: ears, nose, mouth	Shaping (oral exam) Choices Gentle restraint (ears) Reward
Ophthalmascope: eye exam	Demonstration Imitation High probability/low probability Reward
Palpation: abdominal, lymphatic, pulses, head, face	Distraction (singing, finishing songs, counting) Reward
Test reflexes/hammer	Imitation Demonstration Reward
Thermometer/temperature	Choices Reward
Pulse oximetry/finger probe	Distraction Modeling Reward
Venipuncture/IV insertion	Gentle restraint Distraction Reward

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The outlined behavioral strategies, holding techniques, and pain management can be creatively executed when caring for children and adolescents with ASD. The most important part is the preparation and plan devised in collaboration with the family prior to the visit. Every child with ASD is unique, and implementation needs to be individualized with different combinations of techniques for each child and family. The concept of "forewarned is forearmed" is key to effective strategies (Rainey & Van Der Walt, 1998).

During the study it was observed that children with high functioning ASD with normal to above average IQ tended to be more adherent with procedures using modeling, choices, distraction with conversation, and token systems. Children with mild-moderate ASD seemed responded to imitation, shaping, choices and distraction. Children with severe ASD and mental retardation often required high-p/lowp strategies, distraction with singing and counting and holding techniques. Holding techniques for simple assessments, such as obtaining a head circumference, may be necessary for some children. If one approach is unsuccessful in achieving compliance, another strategy can be adapted and evaluated. These nursing observations have generated some hypotheses that will be investigating in future qualitative nursing research.

A negative experience for the child can have long-lasting effects, making every subsequent visit a difficult one for the parent, the health care provider, and the child. Collaborating with the parents in devising a plan of care that gives them the support and emotional reassurance they need as primary caretakers influences their effort to continue to pursue quality health care for their child with this chronic, life long disorder. Nurses must be strong advocates for children and adolescents with ASD, and this requires knowledge, patience, and time. Time is a valuable commodity, and spending 15-30 minutes with a family on the telephone or in person prior to a visit will make a world of difference when formulating a nursing care plan. Nurses need to embrace this special population and be committed to their care.

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