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Recommendations for Providing Competent Nursing Care to Individuals with Pervasive Developmental Disorders and Their Families

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RECOMMENDATIONS FOR PROVIDING COMPETENT NURSING CARE TO INDIVIDUALS WITH PERSASIVE DEVELOPMENTAL DISORDERS AND THEIR FAMILIES

An Undergraduate Honors Project Presented

By

Christopher Harrigan

To

The School of Nursing

Rhode Island College

2008

Approved:

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Project Advisor                                    Date

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Chair, Department Honors Committee                     Date

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Department Chair                                          Date
RECOMMENDATIONS FOR PROVIDING COMPETENT NURSING CARE TO
INDIVIDUALS WITH PERVERSIVE DEVELOPMENTAL DISORDERS AND THEIR
FAMILIES

By

Christopher Harrigan

An Honors Project Submitted in Partial Fulfillment
of the Requirements for Honors

To

The School of Nursing

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Abstract

Individuals with Pervasive Developmental Disorders (PDDs) have the same nursing care needs as the general population. With the increasing incidence of these spectrum disorders, nurses are bound to care for this population and their families. The extremely diverse range of functional, communication, and self-regulatory abilities present challenges when providing nursing care. The primary source of strength, support, and understanding for these individuals is their families. This qualitative research is designed to identify some of the major nursing implications described by parents of children diagnosed with a PDD. The data are compiled from questionnaires distributed to parents, and are presented as recommendations for providing competent nursing care to affected children and their families. The questionnaire included three demographic questions: age, sex, and diagnosis, as well as one question seeking qualitative self-report regarding the parent’s assessment of the knowledge needs of a nurse to skillfully care for their child. The open-ended question: “What information is essential for nurses to know and understand about your child and/or diagnosis to provide him/her with satisfactory nursing care?” was used to allow for rich, complete, and reflective responses.
Background

For the past four years, this writer has worked as a home-based therapeutic treatment worker in a program for children and adolescents diagnosed with PDDs. The conditions included under the PDD spectrum disorders are Autism, Rett’s syndrome, Asperger’s syndrome, Childhood Disintegrative Disorder, and PDD- not otherwise specified (NOS) (Diagnostic and Statistical Manual of Mental Disorders-IV-TR [DSM], 2000).

Koenig & Scahill (2001, p. 159) defined PDDs as “a group of disorders characterized by deviance in social functioning, and communication skills, as well as restricted and repetitive behaviors.” In the time working in this field, this writer has observed extreme variances in communication and overall functioning among individuals with PDDs.

Throughout his nursing education, this writer has been asked by other students, faculty, and nurses about the work he does. Following explanation, he is often presented with a myriad of questions regarding the capabilities, characteristics, and needs of this population. These questions indicate an interest in the population, and a knowledge deficit.

Unless personally touched by an individual with one of these disorders, society tends to stereotype them. On countless occasions, the writer has had experiences of saying “Autism”, and someone tells him a story of a little boy, who didn’t talk, banged his head, and played with a toy in a repetitive way for hours on end. Although some children with these disorders do fit this profile, most do not.

One of the most challenging activities for families, with whom the writer has worked, is taking the child to the doctor or dentist, and this hardship has peaked his interest. When doing his pediatric rotation at Hasbro Children’s Hospital (Providence, RI), he considered what it would be like to be assigned to a child with an acute illness, who was hospitalized for treatment,
and had Autism. This would be a significant challenge for the writer even with his experience and knowledge; so, for an individual practicing with only the information obtained his/her nursing education, it would be an extreme stressor for the child, his or her family, and the nurse.

Although there is disagreement about the prevalence of Autism in the general population, the Centers for Disease Control and Prevention (2007) estimated the prevalence of Autism to be 1 in 150 births. In 2001, Koenig and Scahill (2001, p. 159) described PDDs as “relatively rare” in the general population. Today however, many reliable sources are reporting the incidence of PDDs to be “epidemic” (Barrett, 2004, p. 7). According to Autism Speaks, a non-profit organization dedicated to research in finding causes, prevention, and treatment of Autism, the rate of Autism in the state of Rhode Island has increased 1800% since the early 1990s.

With the increasing rate of diagnosis and the growing numbers of those affected by PDDs, nurses are bound to care for this population, who are widely misunderstood and potentially difficult to care for. Nursing care of these individuals is not limited to those working in mental health, or pediatrics, as the PDDs are chronic, and these patients have the same nursing care needs as the population at large (Browne, 2006).

As with any group of spectrum disorders, there are some key defining characteristics that the disorders have in common, and more subtle differences set them apart from each other. A nurse who is educated about these differences has a huge advantage when providing efficient, effective, client-centered care to these clients.

The three most commonly occurring PDDs are Autism, Asperger’s Syndrome, and PDD-NOS (Koenig, & Scahill, 2001), and these disorders are the focus of my interest. The purpose of this honors research project is to develop recommendations for providing competent nursing care to individuals with a PDD.
Literature Review

There is scant nursing literature that provides guidelines and recommendations for providing proficient care to these individuals by a nurse generalist in the acute or primary care setting. Literature that does exist provides a basic overview of how to manage a “typical” PDD client. For example, Thorne (2007) provided an overview of Autism and how to prepare for an Autistic child visiting a healthcare facility, what to expect, and how to interact with the individual. On first glance, this article appeared to be helpful, however Thorne primarily described negative behaviors that could be expected from these clients, and this perspective could actually hinder a therapeutic nurse-client relationship by illustrating a potentially disastrous visit.

Browne (2006) provided suggestions for effective communication with individuals on the Autism spectrum. The article discussed the many barriers that individuals on the spectrum have with communication, as well as augmentative communication devices used by non-verbal members of the population. The information contained in both of these works may be useful, but is limited; most of the information was based on what an “expert” found to be important and was not based on actual research.

When this writer first started working with children on the Autism spectrum, he had absolutely no prior experience with them. Before starting the position, he read what seemed to be every book available on the topic. On the first day, he thought he knew everything he could possibly know; unfortunately, that was not the case.

The most valuable tool available to this writer when working with children on the Autism spectrum is their parent. No one knows a child better than the family that they live with, and without the guidance provided by these families much of the functional gains the child makes
would not be possible. Each child on the spectrum has very different capabilities, personalities, and interests. Baas (2006) discussed how the diagnosis of Autism affects the entire family unit, and that parents are the best resources to help others understand their child. For this reason, this writer believes it only makes sense for nurses to consult parents when providing care.

Purpose

The research topic was identified through the consideration of clinical exposure, existing nursing literature, and the researcher’s interactions with faculty and peers in the School of Nursing community. The purpose of this study was to provide a description of the special nursing needs of individuals and families affected by PDDs, and from the identification of those needs provide recommendations to guide clinical practice provided by a nurse generalist to this population.

Method

The research design chosen for this study was qualitative and descriptive in nature. The qualitative design was found to be most suitable as it is flexible, holistic, and participant directed (Polit & Beck, 2006). Additionally, the research topic demanded this approach as it allowed for the anticipated variety of responses from parents.

Parents were asked to complete a questionnaire that included three demographic questions about their child’s age, sex, and DSM IV-TR medical diagnosis, as well as one question seeking qualitative self-report regarding the parent’s assessment of the knowledge needs of a nurse to skillfully care for their child. The open-ended question: “What information is essential for nurses to know and understand about your child and/or diagnosis to provide him/her with satisfactory nursing care?” was used to allow for rich, complete, and reflective responses.
Participants in this study were considered a vulnerable population, as they are parents of disabled children with a chronic developmental disorder. For this reason, strict ethical considerations were in place and the research plan was reviewed and revised to meet the approval of the Rhode Island College Committee on Human Participants in Research.

The study utilized a convenience sampling method. The single criterion to be included in this study was for participants to be the parent of a child (under 18 years of age) diagnosed with a PDD. The researcher collaborated with two community-based agencies to recruit participants for the study. The cooperating agencies included a community advocacy agency whose mission is to empower parents and professionals to support and educate individuals and families affected by PDDs.

The community advocacy agency sent out a large volume electronic mailing to all parents affiliated with the agency with a summary of the research goals and information about how to participate. In addition, a display was posted in the agency’s waiting area that included a summary of the study, a copy of the questionnaire to be completed by the participants, and the informed consent letter. Participant packets were available at this display for interested individuals who chose to participate.

The second agency is a provider of state funded home-based therapeutic services for families with children affected by a variety of behavioral disorders. Case managers were provided with a binder that contained a summary of the research study, a copy of the questionnaire to be completed by the participants, and the informed consent letter, which they presented to individuals who met the criteria for the research sample. If after reviewing this material, an individual were interested in participating, case managers provided him/her with a participant packet.
All participants received an informed consent, and were given the opportunity for debriefing. Other than the potential for emotional distress related to consideration of their child requiring a hospital stay; no other risks were identified. If a participant had felt any distress, they were advised to discontinue. Additionally, if the participant wanted to discuss this discomfort, a psychiatric clinical nurse specialist was available to meet those needs. No distress was reported.

The participant packet included a letter of informed consent, a questionnaire, and a self-addressed stamped envelope for return. Data were collected through the distributed questionnaire, and returned confidentially with no identifying information from the participant. To ensure security of participant data, the completed questionnaires are maintained in a locked filing cabinet at the college.

Sample

The sample included ten participants, all of whom were parents of children with one, or more of the PDDs. Each of the ten respondents submitted questionnaires for one child (nine males and one female) between 4.5-18 years of age, with a mean age of 8.65. Diagnoses of the children included seven with Autism, one with Asperger’s syndrome, and two with Autism and Sensory Integration Disorder. The specific demographic characteristics of each participant’s child are included in Table 1 below.

*Table 1. Demographic characteristics of participants’ children*

<table>
<thead>
<tr>
<th>Participant Id</th>
<th>Child’s Age</th>
<th>Child’s Sex</th>
<th>Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>4.5</td>
<td>Male</td>
<td>Autism</td>
</tr>
<tr>
<td>2</td>
<td>4.5</td>
<td>Male</td>
<td>Autism</td>
</tr>
<tr>
<td>3</td>
<td>6</td>
<td>Male</td>
<td>Autism</td>
</tr>
</tbody>
</table>
Table 1. (continued)

<table>
<thead>
<tr>
<th>Participant Id</th>
<th>Child’s Age</th>
<th>Child’s Sex</th>
<th>Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>9</td>
<td>Male</td>
<td>Autism, Sensory Integration Disorder</td>
</tr>
<tr>
<td>7</td>
<td>9</td>
<td>Male</td>
<td>Autism</td>
</tr>
<tr>
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<td>Autism</td>
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<tr>
<td>10</td>
<td>18</td>
<td>Male</td>
<td>Autism</td>
</tr>
</tbody>
</table>

Data Analysis

Data analysis was completed utilizing a template analysis style (Polit & Beck, 2006). This method was chosen due to the inherent flexibility of identifying common themes in responses, and its ability to attribute quantitative values with the identified themes. Qualitative analysis employing this method follows a process by which: preliminary themes and codes are identified by the researcher, followed by transcription of data, assignment into themes, template development, and finally interpretation. All of the steps are done in an ongoing fashion, rather than in distinct stages. As the researcher transcribes each data submission, new themes are identified and developed, and are added to the theme set (King, 2008). After all of the submissions for this study were transcribed, the final set of themes served as the template, and the numerical frequency of each theme was included.
Results

Considering that the first DSM-IV-TR criterion for a childhood Autism diagnosis is “Qualitative impairment in social interaction with 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…” (DSM-IV-TR, p. 69), it is not surprising that the highest frequency themes found in this study were related to communication. More specifically, the most commonly reported need for nurses to properly care for these individuals was how to deal with the non-verbal individual. Five of the ten respondents included this on their questionnaire. The variability in communication ability within the PDDs is vast with individuals ranging from no verbal communication, to those with near typical language and communication. Consider this story provided by participant 4:

“Our daughter had an IV become dislodged and nearly had a compartment syndrome as a result. The nurses on the regular floor did not check her IVs it was only when dad lifted up the sheet that he found her hand blown up with no circulation in her fingers that a potential disaster was averted. Please take special care of individuals who cannot communicate.”

Although there was certainly negligence in nursing assessment in this particular case, a child who could communicate that he is in pain, may have alerted the nurse to this problem much earlier. Obviously, individuals on the low functioning end of this spectrum would present the most amount of difficulty to nursing. Since there is much variability in individual level of functioning, people with a PDD are generally described as low or high functioning. Low functioning individuals are those with the largest deficit in daily living and communication.

Nursing students are taught to utilize non-verbal communication techniques when interacting with clients, however verbal communication is used most often to facilitate the
nursing process. Thorough assessment of communication skills and needs are critical to provide nursing care for these clients. Many of these clients will be able to offer “yes” and “no” responses, as, throughout their lifespan this has been adaptive to having their needs met. Others will be able to express needs with one word requests, unfortunately, these individuals also tend to have small vocabularies, so at times it can become frustrating for both parties to identify the actual need.

For some individuals diagnosed with autism, augmentative communication devices may be used, or need to be implemented. There are many different types of these devices, some examples of these are: the Picture Exchange Communication System (PECS), computer assisted speech, and write boards. PECS is the most widely used system both to help individuals develop verbal communication, and to augment the speech of those without sufficient language. Small cards with pictures, and words describing items, activities, tasks, needs, and virtually any topic that requires communication on the part of an individual are available. To utilize this system, the sender of information hands a communicative card to a receiver, or points to the picture on a PECS board, which has a collection of cards attached with Velcro. These boards are used for teaching transition in activities, as well as steps in processes, and time. To develop and teach verbal communication, the receiver of the information models the word or phrase.

Computer assisted speech is achieved by programmable, and individualized computer software that enables communication, either by exchanging pictures between the sender and the receiver, or by the sender choosing a picture or word that is sounded verbally by the device. The increased availability of powerful handheld computers has allowed for the development of this software to be run on devices easily carried in a pocket.
Many individuals with PDDs have difficulty with expressive language, but many also struggle with receptive language, or both. Therefore, some individuals may utilize augmentative communication devices for expressive communication, and may also need help facilitating receptive communication. Write Boards are small chalk, dry-erase, or magnetic pen boards used to exchange communication between the non-verbal individual and the receiver facilitating both expressive and receptive language between sender and receiver allowing them to communicate reciprocally.

Speech processing is also common problem for individuals with PDDs, and three parents considered this to be essential for a nurse to understand. Smith and Bennetto (2007) described how individuals with autism have “audiovisual speech perception impairment” (p. 815). This deficit makes it difficult for individuals with Autism to integrate information such as voice, non-verbal communication, lips, face, expressions, etc. Smith and Bennetto’s study (2007) compared neurotypical adolescents, and adolescents diagnosed with high functioning autism on their ability to comprehend audiovisual-speech. Both groups were rated on their ability to comprehend auditory-only speech, and then audiovisual-speech in which they were able to see the sender of the information. The researchers found that the groups were very similar in comprehension of auditory-only information, however there was a marked difference when presented with audiovisual information. Individuals with autism comprehended much less than the typical adolescents when presented with audiovisual sensory information, and lip-reading was also found to be severely impaired.

Browne (2006) developed a practical guide for communicating with children who have a PDD and the guide’s recommendations take this communication deficit into account. By keeping sentences brief, speaking slowly, but clearly, as well as utilizing simple and literal language, the
need for lip-reading, and advanced comprehension skills are kept to a minimum. Browne also recommended refraining from using the word “no,” and “stop,” and suggested telling the child what they can do in place of the undesired item or activity.

Although the guidance and information provided regarding communication with an individual diagnosed with a PDD has been developed from the input of the parent participants, and other published sources, one parent participant of a 9 year-old male diagnosed with Autism described much of this succinctly. The parent wrote:

“…treat him like you would treat a “normal” child, don’t talk down to them. Use a lot of eye contact so he can feel comfortable with you. Smile, but don’t be a push over. Use pictures and small words.”

The second most frequently mentioned topic by the parent participants was the need for nurses to be flexible, and honest. These qualities, which should truly be required of any nurse, are especially needed to provide optimum care to this population. Flexibility was identified directly by parents; however many parents also reported other specific needs that would require flexibility when nurses provided care to this population. Some of these included: safety, special diets, sleeping patterns, self-regulation, constant supervision, incontinence, and common behaviors.

Individuals with PDDs exhibit “restricted repetitive and stereotyped patterns of behavior, interests and activities,” (DSM-IV-TR, 2000, p. 69). Interruptions of these repetitive behaviors can lead to escalation in level of arousal, as well as excessive anxiety. Consequently, nurses need to be aware of the individual’s routines, interests, and preferred activities.

This population generally exhibits extremely regimented, and concrete thinking patterns, which tend to lead them to have extremely structured schedules and routines to help them deal
with the anxiety that the looseness of everyday life brings. Simply asking high-functioning individuals about these topics may elicit this information, for others who are lower functioning, it might be necessary to confer with his or her caregivers.

It would be impossible for nurses to understand everything about these disorders, and no one knows as much about individuals as the people who take care of them on a daily basis. Caregivers will be comforted by the fact that the nurse is interested in these topics, and recognizes their importance in appropriately caring for their loved one. Parent participant 2 described, “patience and understanding,” as key to providing the best possible care. Understanding can only be achieved through individualized assessment of needs, and accommodating (as much as possible) to meet them.

It is unfortunate, but nursing on a general medical floor tends to become task-oriented, rather than a systematic, ongoing implementation of the nursing process (Tonuma & Winbolt, 2000). If a task-oriented approach is taken when providing nursing care to this population, outcomes for both the nurse, and the client will suffer; assessment of these clients’ at-home schedules and routines are critical. Therefore, flexibility is needed when providing care, as that will determine the effectiveness of the care. Although client-centered care is a standard of nursing practice, it is not seen as often as it should be in the workforce (Tonuma & Winbolt, 2000). Nurses will need to integrate this into their work in order to properly care for the growing population of individuals with PDDs.

From personal experience, this writer has noted that the parents of children with PDDs tend to mistrust the healthcare system. Many are distraught about the many unanswered questions regarding causes and effective treatments for PDDs; and medicine has provided few answers. Trust in the healthcare system is further threatened by the highly debated possibility
that the diagnoses may be attributable to vaccines preserved with thimerosal, and the use of Pitocin (oxytocin) for induction or augmentation of labor.

Although no research data has indicated a relationship between development of a PDD and either of the medical practices, the approach that medicine takes toward parents who hold these beliefs is often condescending leaving parents feeling demeaned and discontented. Although the writer does not suggest nurses and medicine ‘agree’ with clients’ opinions, and beliefs; families deserve to be listened to, and not belittled.

It is important for nurses to maintain a neutral position, and to openly listen and understand the perspective of these families. The more complex nursing needs of this population further necessitates the need for a therapeutic nursing relationship. When trust is not earned, the nurse-client relationship doesn’t exceed social interaction and superficial care (Potter & Perry, 2005). It is not possible for the nurse to meet the needs of this population when only superficial care is given.

The third most commonly reported need for nurses to understand to provide competent nursing care was related to the problems with sensory integration and perception commonly exhibited by individuals diagnosed with PDDs. It is widely accepted that individuals with PDDs process sensory information differently from normal individuals (Iarocci & McDonald, 2006). These abnormalities can affect all of the senses, but tend to be most present in hearing, touch, and pain (Iarocci & McDonald, 2006). Problems integrating sensory information can cause vast impairments in functioning for these individuals, because they affect many aspects of everyday life.

Grandin (1996), a high-functioning individual with Autism, who is also a doctorally prepared author, educator, and scientist, asserted that it was necessary for a larger allocation of
funds dedicated to research in sensory therapies in an open letter to the National Institutes of Health. Her book (Grandin, 1996), “Thinking in Pictures,” presented a first hand discussion of the intense sensory issues she has dealt with as a result of her disorder.

The most frequently seen sensory disturbance observed by this writer has been auditory hypersensitivity. Research studies (Dawson & Watling, 2000) have also found this to be the most common sensory issue in those diagnosed with Autism (prevalence of 30-100%). Individuals with PDDs can be very disturbed by loud, or high-pitched noises. Sometimes, such noises are barely even recognized by others in the same vicinity. It is easy to realize how debilitating this could be for someone affected. Hospitals tend to be very noisy places, with medical equipment constantly beeping to alert staff, people screaming in pain, etc… This can be overwhelming for any individual, especially for those with such a heightened sensitivity to sound. It is essential that nurses recognize the potential hypersensitivity to sound that individuals with PDD can have, and reduce excessive auditory stimulation to comfort these individuals.

Tactile sensory perception is another issue that is very often disturbed in these individuals who tend to feel things differently from others; certain textures, temperatures, and clothes can inflict pain, disgust, or discomfort. This perceptual alteration greatly impacts food preferences; certain food textures nauseate individuals, and intensely limit dietary intake. In hospitals, food selections tend to include a lot of soft, mushy foods, which also seem to be the most bothersome to this population. Considering that, accommodations in dietary selections, as well as hospital gowns, clothing, and bedding may be necessary to meet the needs of clients with PDDs.

As stated previously (Iarocci & McDonald, 2006), clients’ with a PDD may have an altered perception of pain. Although it is questionable whether pain management is a perceptual issue, or if it has its origins in the communicative problems of the PDDs, it is surely a topic of
concern for nurses. This client population certainly senses pain, however, individual clients may have difficulty identifying intensity, and origin of pain, or may be unable to express that they are even experiencing it. Additionally, these individuals’ hyperactive responses to sensory stimulation could elicit a hyperactive response to pain as well.

At present, there is no definitive way for nurses to assess this potential hyperactive pain response in clients with a PDD, however it is reasonable to expect a certain level of pain with certain illnesses, and injuries, so nurses should thoroughly assess for any presence of pain. In the non-verbal individual, pain may be expressed in different ways, such as hyperactive, and repetitive motor activity, or heightened levels of arousal. These behaviors are even adaptive, as the increased levels of endorphins released by the activity can reduce the sensation of pain in the body (Potter & Perry, 2005).

Many families and individuals dealing with the sensory issues that accompany these disorders find that “sensory breaks,” and sensory integration therapy help with maintaining an appropriate level of arousal. In this therapy, individuals are engaged in play activities that utilize all of the senses, and by so doing, they get used to these more intense sensory experiences, and function better in their daily living.

These methods have been found to be effective by many researchers. Bhatera et al. (1981) found that spinning a child in a chair twice per week reduced hyperactivity. Grandin (1992) found that application of pressure on sizable body areas reduced anxiety, and sensory over-stimulation. If families utilize these methods, nurses need to include them in their plan of care. This will help both with routine maintenance, and behavioral regulation.

Depending on the level of functioning the individual has attained, safety can be a significant concern for both families and nurses. This writer has dealt with children who needed
constant supervision, as well as those who were safe being alone for extended periods of time. Three out of ten of the parent participants mentioned safety as a priority concern for nurses to be aware of when caring for their children. One parent stated that her 9 year-old diagnosed with autism “needs to be supervised as a 24 month-old child.”

Additionally, many in this population don’t understand normally accepted dangers such as a hot stove, moving vehicles, etc. Another parent reported that his 9 year-old with autism had “no sense of immediate danger or risks, like in a parking lot running in and toward the road.”

A considerable number of clients with PDDs appear ‘normal’ in many areas, including their appearance, which makes these dangers easily overlooked. Nurses need to assess the safety risks for each individual without assuming that the client understands what most ‘normal’ clients would.

Some parents of children with PDDs believe in, and utilize therapeutic diets to help deal with the problematic behaviors and overall functioning of the affected individual. Regardless of whether they are, or are not effective, nurses need to have some understanding about these diets.

Two of the parent participants included concerns about diet in their submissions. One parent reported that their child was on a strict elimination diet, and that “any deviation could result in several days of little sleep, and increased stimming.”

The most commonly utilized diet is the gluten-free/casein-free diet, which eliminates all foods containing wheat or dairy. These products are found in a significant number of food items, and maintenance of this diet is very costly, and time consuming. Additional diets sometimes used are: additive-free, sugar elimination, and fatty acid supplementation diets (Cormier & Elder, 2007). Nurses need to be aware of the necessity of collaboration with dietary services within the
hospital setting to meet the clients’ special dietary needs, since replacing food items will be difficult with standard kitchen stock.

The final topic for discussion is the sleep habits of individuals with PDDs. The parents who mentioned this in their submissions reported issues with their children not sleeping, or sleeping very little. Sleep problems are very common among the Autism spectrum disorders. Liu et al. (2006) reported a prevalence rate of 86% among individuals with PDDs. Sleep problems are very common among individuals with PDDs, and nurses need to understand, comfort, and ask families about strategies they use to help the individual sleep.

Discussion

Much of the ‘need-to-know’ information reported by parents as important for nurses to care for their children are, in fact, common characteristics of the disorders. However, individuals with these disorders are very unique, and have unique nursing needs that require extensive assessment. It should be noted that three parents explicitly indicated that nurses needed to be educated about the Autism spectrum disorders, which, in essence, was the goal of this research study. With the increasing numbers of individuals diagnosed with PDDs, nurses will encounter more clients in the general medical census therefore nurses need to have a basic understanding of these disorders.

Some limitations of this study include a small sample size, which likely isn’t representative of all parents of children with PDDs. Additionally, the unique treatment needs of each member of the population make it difficult to generalize findings. Further nursing research in this area could investigate the nursing needs of a larger sample of the population using quantitative analysis for better control.
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