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Opening Our Eyes to Mind Blindness Within the Home

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Opening Our Eyes to Mind Blindness Within the Home

By

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of Western Kentucky University

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Approved by

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Dedication

This project is dedicated to my nephew, Joshua, who has been my inspiration through the whole process.

Abstract

Being a parent of a child with autism and/or a developmental disorder may cause profound effects on the parents' relationships with others (Trepagnier, 1999). This qualitative study describes how a diagnosis of autism and/or a developmental disorder for a child affects the parent's relationships with others. The goal is to help nurses determine appropriate interventions for these clients. Following Human Subjects Review Board approval, a researcher-developed questionnaire was completed by a convenience sample of six parents known to the researcher and known to have a child with autism and/or a developmental disorder.

The findings of the study indicate that all of the parents first seemed to notice a speech development problem with their child. Following an initial visit with the child's pediatrician, each set of parents was encouraged to take their child for a hearing consultation. Other evaluations by a speech therapist, an occupational therapist, and a physical therapist were conducted. Along with the doctor's advice, the Internet seemed to be the most valuable source for information regarding the condition and treatments. All of the mothers tended to be more open about the effects that the pervasive developmental disorder diagnosis has on the relationships around them. Four out of six parents admitted that the diagnosis has affected other relationships. An overall sense of powerlessness was reported among each of the participants. Knowledge of parents' perceptions is essential as nurses meet the needs of families whose child has been diagnosed with autism and/or a developmental disorder.

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Chapter I

Introduction

Many years ago the mere mention of the word *autism* brought about negative connotations: a bleak future spent within a mental institution, isolation in a blind world. Today, however, the connotation is no longer negative. In fact, people with autism are now living relatively normal lives and have tremendous outlooks for success (National Institute of Mental Health, 2000).

Although autism is not a new disorder, research has increased over the last few years, now making the disease familiar to society. Autism has no boundaries; it is found in every country and region of the world. Regardless of a family's racial, ethnic, religious, or economic background, there is no stopping the disease. Because of a lack of knowledge about the subject, the cost of health and educational services for the autistic person exceeds three billion dollars each year. So, at some point, autism affects us all (National Institute of Mental Health, 2000).

Parents of autistic children are also tremendously affected by autism. Being a parent of a child with autism and/or a developmental disorder causes profound effects on the adult's relationships with others. This study is designed to help find out how parents deal with their child's diagnosis and how it affects their relationships with others, thus helping nurses determine appropriate interventions for these potential clients.

Definition

Like many medical disorders, *autism* is a familiar term; however, the true definition of the disorder is not always known. Autism is classified as a pervasive developmental disorder. These developmental disorders are characterized by impaired and deviant social and communication skills. Due to the manifestations of the disorder, ranging from mild to severe, autism is considered a spectrum disorder (Nissenbaum, Tollesfson, & Reese, 2002). According to the Autism Society of America (ASA), autism is a complex developmental disability that typically appears during the first three years of life. The disease is a result of a neurological disorder that affects the functioning of the brain. Social interactions and communication skills are impacted. Boys are four times more likely to develop autism than girls (Autism Society of America, 2000). Autism occurs in approximately one out of five hundred individuals. Over one-half million people in the United States today have autism (Dorman & Lefever, 2000).

Etiology

Scientists once regarded autism as a psychological disorder caused by traumatic experiences that forced a child to retreat into a world of fantasy. Some theorized that parents caused autism by unconsciously rejecting a child or by failing to bond emotionally. These theories caused extreme guilt in parents but lacked any scientific validity. Although scientists today still do not know what causes autism, they have discredited and rejected theories about a parental cause (National Institute of Mental Health, 2000). Today, it is generally accepted that autism is caused by abnormalities in brain structures or functions. So what causes normal brain development to go awry? Researchers at the National Institute of Mental Health have been investigating the role that heredity and genes play in passing the disorder from one generation to the next. Other researchers say that there are other factors (National Institute of Mental Health, 2000). Some of the documented biological conditions associated with autism are tuberous sclerosis, congenital rubella syndrome, phenylketonuria, and fragile x syndrome (Dalidorf, 2000).

Diagnosing Criteria

Autism often remains unrecognized and undiagnosed until or after late preschool age, because appropriate tools for routine developmental screening and screening specifically for autism have not been available (Practice Parameter, 2000). In 1,300 families recently surveyed, the average age for diagnosis of autism was when the child was about six years of age, although most parents felt something was wrong by eighteen months of age and usually sought medical attention by two years of age. Fewer than 10% of the children were diagnosed at initial presentation; another 10% of the parents were either told to return if their worries persisted, or that their child "would grow out of it." The remaining children were referred to another professional (at a mean of forty months), of which only 40% were given a formal diagnosis, 25% were told "not to worry," and 25% were referred to a third or fourth professional (Practice Parameter, 2000). Given the lack of responsiveness in physicians, many autistic children do not receive the early intervention treatments that they need.

Because several conditions can cause symptoms that resemble those of autism, parents and pediatricians need to rule out other disorders, including hearing loss, speech problems, mental retardation, and other neurological problems. Once these possibilities have been eliminated, a visit to a professional who specializes in autism is necessary.

Autism specialists use a variety of methods to identify the disorder, including a standardized rating scale, observation of the child's language and social behaviors, a structured interview, and a review of the child's developmental milestones through family films and pictures. The specialist then usually makes a diagnosis only if there is clear evidence of poor or limited social relationships, underdeveloped communication skills, and repetitive behaviors, interests, and activities (National Institute of Mental Health, 2000).

Characteristics

At first glance, some persons with autism may appear to have mental retardation, a behavior disorder, a problem with hearing, or even odd and eccentric behavior. To complicate matters further, these conditions can co-exist with autism (Dorman & Lefever, 2000). Most infants with autism start out developing normally; however, around 18-24 months, the development stops. Infants begin to avoid eye contact, seem deaf, and stop talking altogether. They appear unaware of the coming and going of others. They frequently physically attack and injure others without provocation. Many times these children seem inaccessible, as if in a shell. Instead of exploring their environments, autistic children often become fixated on a single item or activity. They practice strange actions like hand flapping or rocking. They often sniff or lick toys. One of the most harmful characteristics is that these children often show no sensitivity to burns or injury, and often engage in self-mutilation such as eye gouging. Autistic children also have extreme difficulty learning the give and take of human relationships. Part of this problem is due to the fact that they only see situations from their perspective and it takes longer to learn to interpret what others are thinking and feeling. A smile, wink, or grimace all have the same meaning to an autistic child, thus making the world a very bewildering place (National Institute of Mental Health, 2000).

Because of their eccentric behavior, autistic children are often labeled as being bad. In many ways, this could not be farther from the truth. Most children with autism cannot be deceptive because they do not comprehend the feelings and thoughts of others. Autistic children are most often not manipulative because this, too, requires a higher level of socialization which most of these children do not possess (Trepagnier, 1999).

Treatment

When parents learn that their child is autistic, most wish that they could magically make the problem go away. Even though this is not possible children with autism can be helped. A combination of early intervention, special education, support, and in some cases medication is helping increasing numbers of children with autism to learn to live normal lives (National Institute of Mental Health, 2000).

Many educational options help autistic children with their social, communication, and cognitive skills. According to the Disabilities Education Act of 1990, children with learning disabilities are assured free and appropriate public education programs. The 1991 version of the law extends service to preschoolers who are developmentally delayed. By law, public schools are also required to prepare and carry out a set of specific instructional goals for every child. These skills are known as the child's individual educational program (IEP). The IEP serves as an agreement between the school and the family on the educational goals. Parents play an important role in creating this plan, because they know their child best (National Institute of Mental Health, 2000).

Parents and caregivers need to remember that although there is not yet a clear cure for autism, there is a tremendous amount of help available. Today, with the correct help, a child has every hope of using his or her unique capacity. Even severely mentally retarded children can master self-help skills. Many autistic children can complete high school and even earn college degrees. Soon researchers may even be able to discover the cause of autism so that a cure can be found (National Institute of Mental Health, 2000).

Parental Concerns

This research paper has already mentioned that at some point autism affects us all; however, one cannot even begin to imagine how profoundly it affects the parents. Every aspect of the parent's life is touched by autism. Family and friends tend to shy away -- some from fear of the unknown and some from embarrassment. The community as a whole is not accepting of odd behaviors in anyone. Employers often do not understand the difficulty with childcare and the unexplained number of daily interruptions at work related to the child. Often these parents feel utterly alone.

As mentioned, most parents would love to wave a magic wand and watch the symptoms of the disorder disappear; however, this is not reality. Most parents blame themselves for the disorder. With the etiology focused on genetics, many parents feel as if there was something that they could have or should have done to prevent the disorder from occurring (Trepagnier, 1999). This unnecessary worry causes a strain on the parents of these children. Most of these parents are "treatment seekers," a title that can have positive as well as negative meanings. On the positive side, most parents are willing to explore all options in order to help their child. On the negative side, many parents are also willing to try any treatment -- experimental or not-- to help their child. They often try these unproved treatments, hoping that their child will be that positive statistic (Trepagnier, 1999).

Financial burden is another major parental concern. Since there are still many unknown facts concerning autism, insurance companies still shy away from taking responsibility for the expenses. Although parents want what is best for their child, they often cannot afford the treatments that are necessary (Trepagnier, 1999).

There are emotional expenses as well. Each parent usually follows the same pattern: hope, expectation, and disappointment. This pattern is expressed with each new treatment. This emotional roller coaster certainly takes its toll on the parents. To a certain extent, it also takes its toll on the family and the autistic child personally. Parents often begin to lose hope and feel resentful towards others and towards the autistic child (Trepagnier, 1999).

Chapter II

Literature Review

Autism research has increased in recent years, although the body of knowledge is still minimal. The findings from the literature review are summarized according to assessments focused on the families and assessments of parental needs.

Assessments Focused on the Families

Koenig and Scahill (2001) researched assessments of both the child and family. The Autism Diagnostic Interview-Revised (ADI-R) was an interview tool that was clinician administered. This tool incorporated both the child's developmental history and the parent's report regarding the child's behavior. ADI-R was found to be effective only if the clinician had been properly trained before using the tool. Clinical observations appeared to be one of the most effective assessment tools. The findings suggested that nurses must focus on the coping skills of the parents to guide them through effective interventions. Many parents have inaccurate information about their child's diagnosis, so it is the nurses' responsibility to educate the parents. Nurses should also teach the parents how to become advocates for their children.

Merzer (2001) focused on the comments of parents with autistic children. The purpose of the retrospective study was to find out something about their relationships with other family members and the school system. A pilot questionnaire was sent to parents of individuals who were diagnosed with an autism spectrum disorder. Findings revealed that no two parents were alike in their reactions to the autism diagnosis. Some parents reacted with despair, while other parents were glad to finally get a diagnosis for their child.

In a qualitative study by Nissenbaum, Tollefson, and Reese (2002), 28 individuals were interviewed. The individuals consisted of 11 professionals who had previously diagnosed autism and 17 parents of children with autism. Using Lincoln and Guba's method of naturalistic inquiry, data were collected in three phases. Data analysis was completed after each round of interviews. A total of 65 interviews were completed. Approximately 2,260 units of information were categorized into seven areas and subcategories. The end results involved the perceptions of the definition of *autism*, ways for professionals to present the diagnosis to family members, the benefits of receiving a diagnosis, and reactions of giving and receiving the diagnosis.

Assessments of Parental Needs

Sharpley & Bitsika (1997) assessed 219 parents of children with autism to gain information about the nature of the child's disorder, parental well being, parents' daily level of stress arising from parenting, and their confidence in handling their child's major difficulty. A demographic questionnaire was sent out to each of these parents in order to assess these areas. Standardized instruments were used to test for anxiety and depression. The three most stressful factors of being a parent of a child with autism included the permanency of the condition, the lack of acceptance of autistic behavior by society and family members, and the low level of social support. Although mothers reported more feelings of anxiety and depression than fathers, they felt more confident in handling problems related to the child. Nearly two-thirds of the parents sampled who utilized family members for childcare reported a lower stress level. Over half of the participants felt that they were unable to cope at times. About 13% felt anxious or stressed, nine percent felt depressed, and three percent felt lonely.

Trigonaki (2002) conducted a qualitative study on the five basic needs of parents of children with autism. The study was based William Glasser's Choice Theory, which identifies the five basic needs of children (love/belonging, fun/enjoyment, self-worth/empowerment, freedom, and survival/health). There were twenty eight (28) mothers, eight (8) fathers, and two (2) grandmothers that comprised the participants in the study. The results of the study suggested that parents of children with autism rarely meet their own basic needs, and the diagnosis of autism causes the parents' "quality worlds" to collapse. The parents tended to rely on other immediate family members during the first year of the diagnosis. Eventually, they learned to accept the diagnosis and attempted to return to a normal life.

As a result of the literature review, little information was found addressing the impact of autism on parents. Although more emphasis has been placed on assessment tools and the needs of parents, a gap in the literature exists regarding implications/suggestions for health care providers who care for autistic children and their parents.

Chapter III

Methodology

Design

This study was a qualitative descriptive investigation was conducted involving three sets of parents (N=6) of an autistic child and/or a child with a related developmental disorder. The questionnaire focused on how a diagnosis of autism and/or a related developmental disorder for a child affects the parents' relationships with others. Consent to carry out the study was obtained from the Human Subjects Review Board and the Honor's Department (both located at Western Kentucky University).

Population and Sampling Process

The subjects were chosen using convenience sampling of individuals known to the researcher and known to have a child with autism and/or a developmental disorder. After the subjects' agreed to participate, the researcher mailed each subject a consent form to read and sign along with the questionnaire. The researcher explained the consent form to the subjects verbally over the phone. The consent form included the nature and purpose of the project, explanation of the procedures, discomforts and/or risks associated with the participation of the study, benefits, confidentiality, and right to refusal/withdrawal from the study. The consent form also included the names, addresses, and phone numbers of contact persons. All contacts with the subjects were made at their convenience and only to clarify information on the questionnaires by telephone. The sample included three females ranging in age from 29 to 47 (mean age of 40), and three males ranging in age from 30 to 45 (mean age of 38.3).

Human Subjects Protection

Each subject was informed that the participation in the study was voluntary and that he or she could withdraw from the study at any time with no repercussions. The subjects were informed that refusal to participate in the study would have no effect on any future services that they may be entitled to from the University.

Confidentiality was maintained as follows: no identifying information was released about the subjects except to those involved with the study (e.g. the researcher, the thesis director, the second thesis reader, and the honor thesis coordinator). The notes, data, and results will be kept in locked files in the Department of Nursing at Western Kentucky University for three years. Each envelope and questionnaire was labeled only with the subject's initials. The names of the subjects and their children were changed to protect the person's identity.

It was explained to each subject that there were no known risks or anticipated risks to him or her by participating. They were informed that the purpose of participating in the study was to provide more information to the body of nursing literature pertaining to parents with an autistic or developmentally delayed child.

Instruments

A researcher-developed questionnaire was based on the literature review. Questions focused on diagnosis, information seeking, and the impact of the diagnosis on relationships for parents of a child with autism and/or a developmental disorder.

Specific questions included:

1. What made you suspect that your child had a problem?
2. What steps did you take first? Why?

3. How did you find information concerning treatments for your child?
4. What was the diagnosis?
5. What were all of the steps taken to reach the final diagnosis?
6. How has this diagnosis affected your family life?
7. How has this diagnosis affected your relationship with your spouse?
8. How has this diagnosis affected your relationship with other children?
9. How has this diagnosis affected your relationship with your extended family?
10. How has this diagnosis affected your relationship with your friends, neighbors, and co-workers?
11. How has this diagnosis affected you financially?
12. Has your insurance (if applicable) been responsive to suggested strategies?

Data Collection Procedure

Data were gathered using a written questionnaire that was mailed to the subject's address. Each subject was asked to elaborate as much as possible on the open-ended questions. The researcher reserved the right to contact the subject(s) via phone and/or in writing in case of questions or a need for elaboration. Each questionnaire was accompanied by a brief overview of the project as well as an expression of gratitude for their participation. Each subject was asked to complete the form and return it to the researcher within two weeks. The questionnaire was estimated to take twenty to thirty minutes to complete. Follow up interviews were conducted for clarification with two of the three families.

Chapter IV

Results

Sample

Six parents responded to the questionnaires (N=6). The parents ranged in ages from 29 to 47 years of age (mean age of 39.2). The mothers' ages varied from 29-47 (mean age of 40). The fathers' ages varied from 30-45 (mean age of 38.3). The children ranged in ages from 3 to 12 years of age (mean age of 6.7). Family A consisted of a mother, father, and five children. Family B consisted of a mother, father, and child. Family C consisted of a mother, father, and child.

Family A.

Mother's view

The first concern arose when the child did not say his name, a language milestone that the mother believed to be one of the first for most children. In fact, all aspects of the child's language appeared to be delayed. The couple presented the problem to a pediatrician during a regular visit. The pediatrician suggested a hearing test to determine if a hearing loss was contributing to the language delay. The problem did not appear to be overwhelming to the couple at first. The pediatrician who referred the family to Vanderbilt University for the hearing consultation provided all of the initial information about autism. After the hearing test proved to be normal, the family was referred to Vanderbilt again for developmental testing. The testers interviewed both parents as well. The diagnosis was pervasive developmental disorder in the autistic spectrum.

The mother stated that the family had made adjustments to allow for the child's occasional behavior problems (e.g. temper tantrums). The child's siblings learned how to interact with him to produce desired behaviors from him. Since he was mildly affected, his "symptoms" included some forms of pattern behaviors and a dislike of change. The family opted not to go to specific restaurants if the child chose to stay home. If they made him go (which she stated that they sometimes had to do), he would constantly ask when the family would be going home. "He is a real 'homebody'," the mother proclaimed.

The marital relationship was most affected due to disagreements over the child's abilities. The mother claimed that she tended to be more protective (e.g. not asking the child to do things that might make him uncomfortable or unhappy), whereas the father tended to push the child's boundaries.

According to the mother each sibling has reacted individually to having an autistic brother. All of them experience some frustration with his behavior, some more than others. Some of the siblings perceived him as being "spoiled" and allowed to "get away" with bad behavior. That often puts the burden on the mother who tries to help the other children to comprehend the extent of his problem. She often pointed out to the other children that they would not likely wish to trade lives with him, because he might never live on his own, marry, hold a job, etc. She agreed that her relationship with her other children had changed due to this situation.

The extended family was relied on more often than if the child were "normal." On some occasions when the child chose not to go out, a family member (often a great aunt or great uncle who lived next door) was asked to "baby-sit" him. According to the mother, some members of the extended family did not want to accept that he had a problem. Outside social groups (ex. friends, neighbors, church members, and co-workers) were understanding since they had known the child since he was born.

The child's parents did not pursue any treatments for him outside of his education, which was provided through the public school system. His autistic behaviors were mild and the parents did not feel the need for special treatments, so the financial impact was minimal. Even his testing was conducted through the school system.

Father's view

The father suspected that there might be a problem with their child when he and his wife noticed that the child's speech development was slow, his potty training was difficult, and his attention tended to be fixated on certain topics. He recalled that the first step taken was a visit with the child's doctor. They were finally referred to the development center at Vanderbilt University, where a team of doctors and nurses performed several tests of cognitive and physical skills. The diagnosis was pervasive developmental disorder.

The father grew up with a mentally retarded brother, so he "didn't have as many adjustments to make as (the) other family members." He stated that his son, Bill, required more patience than most children. The child was "kind-hearted but could be an annoyance." He did not believe that the child's diagnosis/condition had affected his marital relationship. He loved his wife before the child was born and insisted that he still does. He stated, "I love and accept each of my five children for their uniqueness. I have tried to teach them all to be themselves."

He mentioned that the child was very close to one specific aunt due to the fact that she used to live in the same household when he was young. He believed that Bill loved everyone. He thought that most of his wife's family accepted the child's condition. The father's family was "used to having handicapped individuals around." He was unaware of any effects of the diagnosis on relationships with friends, neighbors, and co-workers. He did state that his wife tended to shelter the child more than he did.

The financial impact was minimal, due to the fact that the family had "good" insurance. The father said that he did not hesitate to demand the required and necessary services from the school system. He commented that developmental disorders were more about loving and caring family relationships rather than a given diagnosis. Since he had always been around handicapped individuals, he admitted that he might not be able to appreciate the changes required by others to adapt to developmental disorder diagnoses.

Family B.

Mother's View

She noticed that there was a problem when their son was around eighteen months old and his speech started to decrease. He seemed happier when he could be by himself and watch cartoons. By the time that he was three, he was barely talking at all. "We were lucky if he said *Mama* and *Daddy,*" she said. He also hummed a lot. She and her husband decided to take him to his pediatrician in May of 2000, the day after his third birthday.

After the parents expressed their concerns, the doctor's first response was that they should not worry unless he was not talking by the age of four. When he started to hum; that was the first time autism was mentioned. The parents were then referred to the

Regional Child Development Clinics, Inc. Their child was diagnosed with delayed expressive language development, possible attention deficit hyperactivity disorder (ADHD), and possible pervasive developmental disorder. The parents were then referred to a speech language pathologist at the Kentucky Commission for Children with Special Health Care Needs. She recommended speech therapy and enrolling him into preschool.

In July of 2000, they started to see a psychologist who gave them the diagnosis of autism. They went to this psychologist for over a year for behavioral therapy. In the spring of 2002, they were referred to Bingham Child Guidance Center by a relative. They agreed to be part of an ongoing research study that examined social communication in children with autism spectrum disorders. The mother stated, "It was the best decision that we had made." In the beginning, the only source of information was the Internet or from the doctors who cared for their child. The mother said that since autism was on the rise, information was more readily available.

Their child's final diagnosis was attention deficit hyperactivity disorder (ADHD) and autism. A nationally renowned expert on autism, said that their son, Jim, was a unique case because he had some autistic tendencies but was not autistic. However, in order to get him the help that he needed, he would have to be classified as autistic. It took the family two years to finally get that diagnosis and the help that they needed.

The mother stated that recently their family life had been calmer. Jim was now on medication, which had calmed him down considerably. That, in turn, had made it easier to handle him. His speech was easier to understand, which had made communication easier for other family members. As a couple, she admitted that she and her husband had their good and bad days, but the good days far outnumbered the bad. "We had hope that wasn't there before," she acknowledges. The couple did not argue as much. Discipline was always a problem before because their child was "so wild." Recently, it had become easier for the parents to agree on disciplinary actions. Her husband was less strict and she was more strict, so she believed that they have now evened out. Since Jim was calmer, they would visit others, and engage in activities that before were almost impossible because of his behavior. She also noticed that at family functions she and her husband were more relaxed. They now enjoyed being together as a family instead of being embarrassed of each other.

The mother admitted that she was jealous of other children to a certain point. When she heard them talking, especially small children, she started wondering if her child would ever be able to talk like them. She believed that she had pays closer attention to other children's development. The mother admitted, "...in a selfish way, I'm looking for their shortfalls."

The mother believed that their extended family wanted them to be around them more since Jim was calmer, although they still did not want him on a one-to-one basis. She felt hurt knowing that because her child required more attention than the other children in the family, he was not as welcomed in others' homes. She felt that the family members would disagree with her; however, she stated that she had observed them with other children, and Jim was the only one treated like he was not welcomed. She did admit though that things were getting better.

She commented that people used to think that her child was just spoiled and used to getting his own way. People would stare, whisper, and make rude comments. She admitted that she did not like to be around a lot of people. Even when others thought that they were helping, they were often construed as being rude or hurtful. She observed that most people who knew of his diagnoses were very understanding. They were curious, so they asked a lot of questions. She stated that asking a lot of questions was fine, because she would rather people understand than to smile and nod their heads. A co-worker had asked her about special schools, because she said that when she went to school, "kids like that" were not seen in "normal school." The mother admitted that although the co-worker's comments might have been innocent, it hurt the mother's feelings just the same.

The financial impact was rough, but "the outcome was worth every penny" that they had to pay. She stated that she argued almost continuously with the insurance company. "I loved it when their so-called specialist tried to diagnosis him over the phone. The insurance company believed that it was a waste of time to take him to Bingham; I, on the other hand, knew better."

Father's view

He suspected that their child had a problem around eighteen months of age due to his lack of development (talking). He stated that he and his wife first consulted a pediatrician to make sure that the cause was not physical (hearing, etc.). He gained information concerning treatments from doctors, relatives, and media news. He stated that their child's diagnoses were autism and ADHD, which were determined after observations by several doctors and experts.

The impact of their child's diagnoses made him more aware of what caused outbursts within the family and how to cope with them. He stated, "It is more stressful and frustrating to know that there's not a whole lot you (as a parent) can do." There was more stress in the marital relationship than before, but also more understanding of what each partner was going through.

When the father interacted with other children, he admitted that he did not take healthy children for granted anymore. He noticed children's milestones more often and was often resentful of them. He and his wife wanted more children; however, they were now more hesitant. "It aggravated me that people took healthy children for granted," he insisted. He stated that there were still a lot of "what ifs."

He felt that everyone in the extended family seemed to be really understanding and closer to their child. There had been no effects of the diagnoses on relationships with friends, neighbors, and co-workers. He stated that people were more aware of autism and problems within their own families. He did admit, though, that since it was hard to control their child sometimes, it was often easier not to go places.

The expenses of medication and specialists were considerable. However, the father stated that the family seemed to be managing rather well. He admitted that the insurance company had not been responsive to suggested strategies. The insurance company did not want them to deviate from their coverage plan; however, through persistent phone calls from the couple and the doctors, necessary treatments were provided.

Family C.

Mother's view

She began to realize that their child might have a problem when she noticed him around other children his age and realized that he was not talking as they were. She took him to the pediatrician, who referred him to speech therapy and hearing evaluations. The pediatrician wanted to rule out hearing and speaking problems first. She gained information about her child's condition via the Internet. She admitted that speech therapy told her about the First Steps Program and services at Western Kentucky University.

The final diagnosis was suspected pervasive developmental disorder, which was determined after a series of steps. First, the child had a hearing test, then an assessment of the tongue and mouth structures. Next, he had a psychological evaluation, developmental testing, occupational therapy evaluation, physical therapy evaluation, speech therapy evaluation, and a developmental interventions evaluation.

The diagnosis had affected her family life in that the members were more aware of how much one-on-one time they needed to spend with their child. They tried to give him at least three hours of applied behavioral analysis (ABA) per day. Marital life was affected because the spouses were busier now spending time interacting with their child.

She stated that her child's diagnosis had not affected her relationship with other children, because they did not have any other children. Extended family relationships had been affected; for example she stated that her mother-in-law has made some crude remarks about their child. "She (the mother-in-law) seemed to be ashamed of him." The mother admitted that she did not have time to interact with friends, neighbors, or co-workers. She stated that she just had time to get her work completed and spend time working with her child.

There were no real financial effects on the family as a result of the diagnosis. The family's insurance company was responsive to the suggested treatments for their child.

Father's view

He realized that there could be a possible problem with his child when his mother and wife said that there was a potential problem. They took their child to the pediatrician and an ear, nose, and throat doctor (ENT) for evaluation to rule out hearing problems and/or tongue problems. He gave credit to his wife for finding information about treatments. The final diagnosis, suspected pervasive developmental disorder, was given after developmental testing was done, along with a speech therapy, physical therapy, occupational therapy, and developmental interventions evaluations.

He maintained that there were no real effects on the family life due to the diagnosis; nor was there any change in the relationship with his wife, other children, extended family, friends, neighbors, or co-workers. Financially, the diagnosis had required no change because their insurance had been responsive to suggested strategies.

Follow-up Interviews

Follow up interviews were conducted for clarification with two of the three families. The parents were contacted by telephone. From the follow up interviews, information about the parents' personal feelings were gathered. The parents verbalized feelings of hopelessness, powerlessness, embarrassment, guilt, inadequacy, and misunderstanding.

CHAPTER V.

Findings, Nursing Implications, and Conclusion

Findings

All of the parents seemed to notice a problem with their child related to speech development, and each proceeded to take the child to the pediatrician who referred them for a hearing consultation. Along with doctors' advice, the Internet seemed to be the most valuable source for information regarding the condition and treatments.

Two out of three of the diagnoses were pervasive developmental disorder. The steps to obtain the diagnosis included:

- A pediatrician consultation
- A hearing test referral
- A speech therapy evaluation
- An occupational therapy evaluation
- A physical therapy evaluation
- A developmental interventions evaluation.

All of the mothers tended to be more open about the effects that the diagnosis of autism and/or a developmental delay for the child had on the relationships around them. An overall sense of powerlessness was reported among each of the participants. These findings were consistent with the findings from Sharpley and Bitsika (1997). Four out of six parents admitted that the diagnosis had affected other relationships, such as jealousy of other children's accomplishments, lack of time to interact with friends, neighbors, or co-workers, and the inabilities of others to relate to the child's problem with understanding. The martial relationships had both negative and positive outcomes from the diagnosis. All of the parents reported that their martial relationships had been strengthened due to the fact that each spouse could understand what the other spouse was going through. One mother reported that the marital relationship was most affected due to disagreements over the child's abilities. Another mother stated that marital life was affected because the spouses were busier now spending time interacting with their child. As Trepagnier (1999) states, "The experience (diagnosis) is different for everyone, but it is not an easy period for any family" (p. 39).

The financial impact related to treatments for autism and developmental delays appeared to be minimum. Only one set of parents out of three had a problem with their insurance company; however, it is important to note that all of the parents interviewed did have insurance plans, many parents of children with autism and/or a developmental disorder may not have health insurance.

Merzer (2001) found in her study that no two parents react the same to the diagnosis of autism and/or a developmental disorder; this holds true in this study. All of the parents had differing views on the impact that the diagnosis has had on their relationships with others.

Nursing Implications

Parents of children with autism and/or developmental disorders often suffer from feelings of powerlessness, hopelessness, embarrassment, guilt, inadequacy, low self-esteem, and being misunderstood. If there are disagreements regarding discipline, then there may be parental distance and family breakdowns (Foster, Hunsberger, & Anderson, 1989). Mothers often suffer from psychological trauma due to spending more time with the child. Relationships with an understanding and sympathetic person(s) (e.g.. doctor, nurse, therapist, etc.) appear to be helpful for parents of autistic or developmental delayed children. Respite care should also be offered occasionally for the parents to avoid caregiver burnout (Foster, et al, 1989).

Based on the findings of this study, an in-home initial assessment performed by a nurse with the family may be a very beneficial way to learn more about the child's condition, the home atmosphere, interactions among family members, and potential needs of the family which may or may not be explicitly expressed. Parents and caregivers should be referred to The National Society for Autistic Children so that they can express their feelings with others who have similar experiences. It often helps a parent to know that he or she is not alone.

Possible nursing diagnoses include (but are not limited to):

- Ineffective Coping
- Hopelessness
- Anxiety
- Caregiver Role Strain
- Denial
- Ineffective Family Coping
- Altered Family Processes
- Knowledge Deficit
- Parenting, Altered
- Role Performance, Altered

- Social Interactions, Impaired
- Social Isolation

Recommendations for Further Study

There is a need for replication of studies in the area of intervening with parents of children with diagnoses of autism and/or developmental disorders. The research in this area is still in its infancy and the relationships of parents are often understated. Semi-structured interviews would be recommended to allow for more elaboration of how the diagnosis had affected (if any) different aspects of the parents' lives. A larger sample size would be more representative of the general population. A longitudinal study would be beneficial in exploring the impacts from the initial diagnosis until the child reaches adulthood. A longitudinal study would help nurses observe parental reactions over time to help them prepare for different phases of the child's life. An experimental study using relaxation techniques may offer parents ways to deal with the impact of the stressors of dealing with a special needs child.

Conclusions

The purpose of this study was to find out how parents deal with their child's diagnosis and how it affects their relationships with others, thus helping nurses determine appropriate interventions for these potential clients. In order to understand how autism affects parents, health care professionals must first understand the concept of autism and the characteristics relating to this disorder. As Trepagnier stated in *Families with Autism* (1999), "It is important for the people who will be teaching our children, who will see them in day-care programs, and who will meet them as neighbors, co-workers, and we, hope, friends, to understand that these are individuals first, who are struggling to manage in a world for which they are profoundly poorly equipped" (p. 42).

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Appendices

WESTERN KENTUCKY UNIVERSITY
Human Subjects Review Board
Office of Sponsored Programs
104 Foundation Building
270-745-4652; Fax 270-745-4211
E-mail: Phillip.Myers@Wku.Edu

In future correspondence please refer to HS03-034, November 4, 2002

Melissa Johnson
2200 Mohawk Road
Brownsville, KY 42210

Dear Melissa:

Your research project, "Opening Our Eyes to Mind Blindness Within a Home," was reviewed by the HSRB and it has been determined that risks to subjects are: (1) minimized and reasonable; and that (2) research procedures are consistent with a sound research design and do not expose the subjects to unnecessary risk. Reviewers determined that: (1) benefits to subjects are considered along with the importance of the topic and that outcomes are reasonable; (2) selection of subjects is equitable; and (3) the purposes of the research and the research setting is amenable to subjects' welfare and producing desired outcomes; that indications of coercion or prejudice are absent, and that participation is clearly voluntary.

1. In addition, the IRB found that: (1) **signed informed consent will be obtained from all subjects.** (2) Provision is made for collecting, using and storing data in a manner that protects the safety and privacy of the subjects and the confidentiality of the data. (3) Appropriate safeguards are included to protect the rights and welfare of the subjects.

    a. Your research therefore meets the criteria of **Expedited Review** and is **Approved.**

2. Please note that the institution is not responsible for any actions regarding this protocol before approval. If you expand the project at a later date to use other instruments please re-apply. Copies of your request for human subjects review, your application, and this approval, are maintained in the Office of Sponsored Programs at the above address. Please report any changes to this approved protocol to this office. **A Continuing Review protocol will be sent to you in the future to determine the status of the project.**

Sincerely,

Phillip E. Myers

Phillip E. Myers, Ph.D.
Director, OSP and
Human Protections Administrator

c: Human Subjects File Johnson 03-034
Mrs. Rhonda Helm

B. INFORMED CONSENT DOCUMENT

Project Title: *Opening Our Eyes to Mind Blindness Within the Home* (HS03-034)

Investigator: Melissa C. Johnson, Department of Nursing, (270) 597-8434

You are being asked to participate in a project conducted through Western Kentucky University . The University requires that you give your signed agreement to participate in this project.

The investigator will explain to you in detail the purpose of the project, the procedures to be used, and the potential benefits and possible risks of participation. You may ask him/her any questions you have to help you understand the project. A basic explanation of the project is written below. Please read this explanation and discuss with the researcher any questions you may have.

If you then decide to participate in the project, please sign on the last page of this form in the presence of the person who explained the project to you. You should be given a copy of this form to keep.

1. Nature and Purpose of the Project:

Being a parent of a child with autism and/or a developmental disorder causes profound effects on their relationships with others. This study is designed to help find out how parents deal with their child's diagnosis and how it affects their relationships with others, thus helping nurses determine effective coping mechanisms for these potential clients. This research study will be a qualitative study focusing on the causal effects of being a parent of an autistic child and/or a child with a related developmental disorder with developmental delays in one or more of the following areas: cognitive, language, social skills, self-help skills, and/or behavioral learning; and the parents' relationships with others.

2. **Explanation of Procedures:**

Three families will be chosen to participate in the study. Individual and/or parent interviews will be performed via a written questionnaire mailed to the subject's address. Each questionnaire should be completed and returned to the researcher within two weeks. A self-addressed stamped envelope will be included for your convenience. The questionnaire is researcher developed after conducting a literature review. Each questionnaire should take approximately 20-30 minutes to complete. You will be asked to elaborate as much as possible on the questionnaire. The researcher reserves the right to contact you via phone and/or in writing in case of questions or a need for elaboration. Each question pertains to how being a parent of a child with autism and/or a developmental disorder affects your relationship(s) with others in their lives.

3. **Discomfort and Risks:**

There are no known risks or anticipated risks to you, the subject.

4. **Benefits:**

You will receive no direct benefit as a result of your participation in the study. The benefit of the study will be to provide more information to the body of nursing literature pertaining to nursing care related to parents with a child who has autism and/or a developmental disorder. Being a parent of a child with autism and/or a developmental disorder causes profound effects on their relationships with others. This study is designed to help find out these effects, thus helping nurses determine effective coping mechanisms for these potential clients.

5. **Confidentiality:**

Your participation is voluntary, all information is confidential, and your identity (and your child's identity) will not be revealed. Confidentiality will be maintained by aggregate data reporting. No video or audiotapes will be used during the interviews. No information will be released about the subjects except to those involved with the study (e.g. the researcher, the thesis director, the second thesis reader, and the honor thesis coordinator). The notes, data, and results will be kept in locked files in the Department of Nursing at Western Kentucky University for three years. Each envelope and questionnaire will be labeled only with the subject's initials.

6. **Refusal/Withdrawal:**

You are free to withdraw form the study and discontinue participation at any time. The researcher named above or the Human Protections Administrator for WKU, Phillip E. Myers, telephone (270) 745-4652, will answer any questions you have about the project.

Refusal to participate in this study will have no effect on any future services you may be entitled to from the University. Anyone who agrees to participate in this study is free to withdraw from the study at any time with no penalty.

You understand also that it is not possible to identify all potential risks in an experimental procedure, and you believe that reasonable safeguards have been taken to minimize both the known and potential but unknown risks.

Signature of Participant Date

Witness Date

THE DATED APPROVAL (November 4, 2002) ON THIS CONSENT FORM INDICATES THAT THIS PROJECT HAS BEEN REVIEWED AND APPROVED BY THE WESTERN KENTUCKY UNIVERSITY HUMAN SUBJECTS REVIEW BOARD

Dr. Phillip E. Myers, Human Protections Administrator

TELEPHONE: (270) 745-4652

C. Instrument

Project Title: *Opening Our Eyes to Mind Blindness Within the Home*

Investigator: Melissa C. Johnson

Thank you for your participation in this study. Below is a questionnaire that was developed by the researcher/investigator after performing a literature review of relevant articles pertaining how being a parent of a child with autism and/or a developmental disorder causes profound effects on their relationships with others.

The questionnaire should take approximately 20-30 minutes to complete. Please send the completed form back to the researcher in the self-addressed stamped envelope that is enclosed within two weeks. Please elaborate as much as possible on each question. Additional sheets can be attached.

The researcher reserves the right to contact you via phone and/or in writing in case of questions or a need for elaboration.

1. What made you suspect that your child had a problem?

2. What steps did you take first? Why?

3. How did you find information concerning treatments for your child?

4. What was the diagnosis?

5. What were all of the steps taken to reach the final diagnosis?

6. How has this diagnosis affected your family life?

7. How has this diagnosis affected your relationship with your spouse?

8. How has this diagnosis affected your relationship with other children?

9. How has this diagnosis affected your relationship with your extended family?

10. How has this diagnosis affected your relationship with your friends, neighbors, and coworkers?

11. How has this diagnosis affected you financially?

12. Has your insurance (if applicable) been responsive to suggested strategies?

Please feel free to add additional pages for your answers. Again, thank you for your participation in this study.