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Spring 5-2004

## **An Exploration of the Family's Lived Experience of Autism**

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Appendix E - UNIVERSITY HONORS PROGRAM  
SENIOR PROJECT - APPROVAL

Name: Christina Becraft

College: Nursing Department: \_\_\_\_\_

Faculty Mentor: Susan Speraw

PROJECT TITLE: An Exploration of The  
Family's Lived Experience of Autism

I have reviewed this completed senior honors thesis with this student and certify that it is a project commensurate with honors level undergraduate research in this field.

Signed: Susan Speraw Faculty Mentor

Date: 5-3-04

General Assessment - please provide a short paragraph that highlights the most significant features of the project.

Comments (Optional):

Excellent work on a pilot project developing & refining a questionnaire to explore the lived experience of families who have an autistic child. Work has extreme relevance for nursing.

Running head: THE FAMILY'S LIVED EXPERIENCE OF AUTISM

An Exploration of The Family's Lived Experience of Autism

Christina Anne Becraft

University of Tennessee, Knoxville

In partial satisfaction of requirements for the University

Honors Program

May 2004

## Abstract

This pilot study's purpose is to develop a questionnaire that will be used to study the lived experience of families with children who have an autism spectrum disorder. A pilot questionnaire was given to a mother of a 9-year-old boy who has an autism spectrum disorder. The questionnaire was adapted from a model used in a previous study involving families who had a child with cystic fibrosis and uses open-ended statements to be completed by the participant. After analyzing the participant's responses to the questionnaire the themes of truthfulness, social isolation, experience with professionals, guilt, and dichotomy of emotions were identified. From these themes, implications for nursing practice are discussed. Ideas for refining the questionnaire for a larger study are also discussed.

### Introduction

Autism is defined as the presence of a marked impairment in development of social interaction and communication with restrictions in activity and interest (Boyd, 2002). Autism is one of several Autism Spectrum Disorders (ASD), with symptoms ranging from mild to severely incapacitating. The disorders in the spectrum include Asperger's Disorder, Pervasive Developmental Disorder, Autistic Disorder, Rett's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified or Atypical Autism (Diagnostic and Statistical Manual of Mental Disorders-IV, 1994). Children who have autism are distant and indifferent to those around them, have delayed and abnormal language development, and tend to display repetitive behaviors. They may also manifest unusual non-verbal communication techniques, such as eye contact, body postures, gestures, and facial expressions. Their verbal communication can be impaired by their repetitive use of words and abnormal intonation. Their repetitive behaviors may include hand flapping, finger twisting, or complex whole-body movements (Diagnostic and Statistical Manual of Mental Disorders-IV, 1994). Diagnosis is based on criteria in the American Psychiatric Association's fourth edition of the Diagnostic and Statistical Manual of Mental Disorders.

Leo Kanner first described autism in the 1940s when he noticed a subset of children who demonstrated profound isolation and an extreme desire for sameness. In the 1950s and 1960s, theories arose linking autism to the indifference shown by professional parents (Boyd, 2002). This is no longer considered a legitimate theory for the cause of autism; however, some parents still believe that they have somehow caused their child's disorder. There are now several hypotheses about the cause of autism; however, no one theory is universally accepted, and the specific cause of autism remains unknown. It is agreed that it probably arises from multiple factors (Boyd, 2002). For reasons that are not completely known, autism has apparently been on the rise since the late 1980s. The prevalence rates have risen from 2-4 per 10,000 children in the late 1980s to as high as 34 per 10,000 children in a study done in 2003 (Coury & Nash, 2003).

#### Purpose of Study

Because of the pervasiveness and chronicity of this disorder and the severity of its symptoms, families with children who have autism must deal with so much more in raising their children than families with normally developing children. It is not a disorder that can simply be treated with medication. Ongoing treatments and education must be part of autistic children's lives everyday. As health care professionals, nurses

need to understand what a family with a child who has autism's life is like. A nurse cannot care for the child with autism without also caring for the family. Knowing what this family deals with on a day to day basis, what its worries and needs are, and what is important to them can aid a nurse in providing excellent care.

This pilot study deals with the development of a questionnaire that will ultimately be used to explore the lived experience of families with children who have an autism-spectrum disorder. This paper includes a literature review on the topic of families dealing with chronic disorders, a discussion of the method of the pilot study, a summary of the themes found in the answers to the questionnaire, and a discussion of the ways that these findings could be used by nurses.

#### Literature Review

While researching the topic of the lived experience of families with autism, it was difficult to find literature that directly dealt with this topic. There were many articles dealing generally with experiences of families of children with chronic illnesses and disabilities (Cowen & Reed, 2002; Heiman, 2002; Mu, Ma, Huang, & Chao, 2002), which could potentially have implications related to autism as well. Mu et al. (2002) studied the anxiety experienced by fathers of children with cancer and found that fathers with a higher educational level were most

likely to have a higher anxiety level. Also, the study found that the higher the level of uncertainty about the child's cancer the higher the anxiety. In an article by Heiman (2002), the resilience of parents with children with disabilities was studied using the Parent's Perception Interview. Using the definition of resilience as "the ability to bounce back or return to a previous way of functioning," the study found 3 main factors that enabled parents to function resiliently. These were a) "an open discussion and consultation with family, friends, and professionals;" b) "a positive bond between the parents, that supports and strengthens them;" and c) "a continuous and intensive educational, therapeutic, and psychosocial support for family members" (Heiman, 2002). A third article by Cowen and Reed (2002) evaluated the effects of respite care on families of children with developmental disabilities. It was found that "the extensive care needs of the children or the families' inability to meet or cope with those needs are major factors contributing to the high stress in the parent-child relationship". While all of these articles give a view into the window of the lives of families with disabilities or chronic illness, none of them pose to explain the overall experience of living with a child with autism. However, these studies on fathers' anxiety, parents' resilience, and the



importance of respite care all aid in beginning to study and interview families of children with autism.

Another theme that emerged while researching this topic was that of the relationship of the siblings of children with disabilities (Fleitas, 2000; Nixon & Cummings, 1999). In her study, Fleitas (2000) interviewed siblings of children with complex illnesses and disabilities and divided their comments into themes of stress (responsibility, loneliness/resentment, fear, jealousy, guilt, sadness, embarrassment, and confusion) and resilience (lessons learned, independence, and altruism). After analyzing the comments and themes, Fleitas suggested using an intervention process for siblings called SIBS, which stands for psychosocial **S**upport, educational programming (**I**nformation), **B**alancing sibling emotions and parental energy, and **S**ensitivity to timing and resources. In another study, Nixon and Cummings (1999) explored the reactions of siblings of children with disabilities to family conflict. This study found that siblings assumed more responsibility for, became more involved in, and perceived more threat to conflict situations. Also, these siblings had a higher reaction to lower intensity conflicts than did siblings not living with a disabled brother or sister. These lessons about siblings may apply to the experience of siblings in a family with a child with autism. However, these articles

did not give a clear picture of the impact that autism has on the siblings.

One study that directly dealt with families of children with autism was one by Rivers and Stoneman (2003). Sibling relationships of a family with a child with autism were studied in regards to marital stress and support systems. They found that stress in the marriage led to problems in the sibling relationship. When social support was in place, it protected the sibling relationship from problems with the positive aspects of the relationship; however, the social support did not protect against greater negative aspects in the sibling relationship, such as unkindness and avoidance.

A final area of interest explored during the literature review was how to study families living with autism. Two articles were helpful in guiding this study. The first study, by Trute and Hiebert-Murphy (2002), evaluated their Family Impact of Childhood Disability (FICD) scale which measured the meaning for parents of their child's disability in regards to their family life. This assessment tool is composed of 15 statements in which the participants score on a four-point Likert scale. In this study, the FICD scale was found to be useful in assessing the parental evaluation of the effect of their child's disability on their family. Also, this parental evaluation was shown to be formed early in their child's life and is unchanged

through the preadolescent years. Through this study, Trute and Hiebert-Murphy came to believe that the FICD scale shows promise tool to better understand the parental cognitive appraisal (2002). Another article, by Åstedt-Kurki, Paavilainen, and Lehti (2001), discussed methodological problems in family research. These problems included defining the family, gaining access to the family, number of informants from the family, children as informants, creating the interview relationship, and ending the interview. The article used two studies conducted in Finland to define and discuss these problems and make recommendations on how to deal with these problems. These two articles are very helpful in developing a process for studying families of children with autism.

#### Method

This pilot study used an open-ended questionnaire (see Appendix A) adapted from a previous questionnaire used in a similar study of the lived experience of families with a child who has cystic fibrosis (Speraw & Dallenback, 1996). The questionnaire has 21 open-ended statements to be filled in by the respondent, for example, "What I remember most about the day that I was told about the diagnosis is..." This type of questionnaire was chosen because it allows for richer and fuller responses from the participant and does not limit the responses that the participant can give (Polit, Beck & Hungler, 2001).

Included in the questionnaire are statements about the time of the diagnosis, how it has affected the family, how things are currently, how it has affected siblings and the spousal relationship, and how the participant feels about the professionals that work with his or her child.

The original questionnaire used in the cystic fibrosis study was adapted for use with families of children with autism. In the process of adapting the original questionnaire, statement stems related to lung treatments were removed, and terms such as "cystic fibrosis" were replaced with "autism." Other than these minor changes, the questionnaire was used in a form that was essentially unchanged. Despite the minor nature of the changes, before it could be used in a large-scale sample of families with autistic children, it is necessary to pilot the instrument with someone from the desired, autistic family population.

The adapted pilot questionnaire was given to a mother of a boy diagnosed with an autism spectrum disorder when the child was 5-years-old. The participant's son is now 9-years-old. She is married, college-educated, and has one other typically developing son who is 12-years-old.

## Findings

### *General Observations*

Directions given to the participant were that she could answer items with responses that were as long or as brief as she

desired. She was also free to skip items that she preferred not to answer. Finally, she was asked to offer suggestions about items relating to their clarity, their completeness, and to make suggestions for other items that needed to be included. Once she was given the questionnaire, she responded within 48 hours. She stated that she thought the process was "fun!" The answers she gave were very lengthy. Though the initial questionnaire was one page long, her responses filled a little more than 4 pages, single-spaced. She responded to every item, and offered a number of suggestions for additional items.

#### *Truthfulness of Responses*

In the participant's responses to the questionnaire, there is evidence that her responses are genuine and truthful. In several areas, the respondent revealed things about her life and her thoughts that were not necessarily good or noble. In response to the statement "Because of the ways that ASD has affected us [the spouses], our relationship...", she says, "We are also too exhausted for intimacy." A person's intimate relationships are just that, intimate, and the fact that she is willing to even bring up the subject, and then admit that she and her husband are too tired to maintain that part of the relationship shows that she is being candid and honest. She also admits to another personal and negative truth about her life in response to "I remember thinking...". She responded, "I am going

to have to eat my words...after having been giving grief to my school system's parent advisory council on spending money 'only' in programs for Autism, now it turns out my kid is in the spectrum!!!!" She had previously argued against something she now must use, and admitting that must not be easy; however, she is willing to be open and truthful even about the negative things in her life. If the participant is willing to be candid about the less socially acceptable aspects of her life, then she is more likely to be truthful about the rest.

#### *Social Isolation*

A theme that was identified in many of the participant's responses was social isolation due to having a child with autism. In response to "The biggest change in our family because of ASD has been...", she says that the family now has a new lifestyle. "There are a lot of things we do not do anymore (like dinner parties) and we have really turned a lot into ourselves. A kid with a behavioral disability is the farthest thing to being 'the most popular'." It is apparent from this response that prior to having a child with autism this family was social and valued being social. In a round about way she is explaining that her family used to be "popular" and do lots of social things; however, now that they have a child with a behavioral disability, they are not as social as they once were, whether

that be a choice they made voluntarily or felt they were forced to make.

She also talks about the social isolation of her child's sibling in response to the statement "My other child/children have been impacted by ASD...". She says, "...he thinks it is not fair to have a brother who is aggressive and because he can't have friends over." She realizes that her other son is affected by autism by not being able to do things that normal children do, such as have their friends over to play. It is apparent that she finds this lack of social contact a potential problem because in her response to "The best advice that I could give to another parent whose child has just been diagnosed with ASD is...", she says, "Seek out other families...". She says to be proactive in seeking out socialization and support. In all the other worries that come with having a child who has autism she is saying that seeking out social contact, especially with other families dealing with autism, is so important that it is something that she thinks anyone going through what she is going through should know.

#### *Experience with Professionals*

A whole section of the survey is devoted to discovering the participant's opinion of the professionals who work with her son. Statements about doctors, psychologists, nurses, therapists, and schools are elicited. The participant has

differing opinions of each. In response to "Based on my experience as a parent, I can say that the doctors (MD)...", the participant was quite negative. She feels that "Most doctors do not know how to communicate, interact with a person with ASD..." and "They should learn to recognize the social deficits that are detectable at 2 months, 4 months of age, so that appropriate early interventions can be put in place!" Her opinion of MDs basically is that they do not know enough about the medical side of autism and how to treat a child with autism. She says, "A lot of doctors believe that ASD is more of psychiatric disorder..."

When responding to the statement, "The psychologists who have evaluated my child have been...", the participant says, "I do not think they have even begun to 'understand him', and how he best learns!!!!" She has not had positive experiences with psychologists. She feels that they need to take the time to understand him and not be "solely focused on behavior (what he said, what he did, and yes, aggression)." She is saying that in order to do anything about the behaviors, the psychologist must take the time to understand her son as a person.

The participant was a little more positive about nurses and therapists. She says, "Nurses who have come in contact with my child have been...for the most part very nice and cooperating, even when presented with unusual requests!!!!" She does not say that nurses are any more knowledgeable about autism than the



doctors or psychologists, but she does imply that they are easier to work with and more helpful, since she does not say anything negative about them. However, she also does not say that nurses have really ever done anything to help in treating her child. Nurses have the potential to educate, provide support, or give referrals for community resources.

Unfortunately, the participant does not mention anything of this nature about nurses, so she has not had this type of experience with nurses. She is also relatively positive about therapists, saying, "...most of them have been very good, have a good understanding of his needs. Some of them have not been able to help him progress." While not all of the therapists have necessarily been successful in helping her son progress with skills, she does say that they understand his needs, something that she says is missing in her dealing with doctors and psychologists.

The participant's opinion about her son's schooling varies. In the beginning of the survey in response to "Over time my thoughts and feelings...", she says "I have felt very disappointed of teachers and therapists who would not think he has potential - I have wasted so much energy and time in relationships with the school system!" In this statement, it seems that she has not been happy with her experience with the schools at all; however, later her response to "Our child's experience of school has

been..." paints a little bit better picture of the schools. She says the following:

[It has been] sweet and sour. I learned a lot of what I know today from my son's first preschool teacher. He had a terrible year when he was 5, his needs were not met appropriately. His behavior problems were solved when he was in K, just to regress at the beginning of 1<sup>st</sup> grade (new teacher) and 2<sup>nd</sup> grade was a complete disaster...except for he learned some social skills in inclusion.

While there have been some problems in her child's school career, she learned a lot from one of his first teachers and some of his problems have been solved at school.

### *Guilt*

As mentioned earlier, an outdated theory on the cause of autism is that emotionally cold or indifferent parents were the cause of their child's autism. Although this theory is no longer considered in educated circles, it is still thought of by those in the older lay public. Also, researchers are not certain how much of autism is genetic and how much of it is environmental. These two factors cause a great deal of guilt to be put on the parents of autism. In the participant's response to "Over time, my thoughts and feelings...", she says, "I feel guilty sometimes (not for having caused my son's disability, anymore, but for not being able to provide what he needs)..." In this statement, she

reveals that she did feel guilty at one time for causing her son's autism. She does not say in what way she felt she had caused it (whether through indifference, genetics, or something the child was exposed to), but she does admit to feeling guilty for that at one time. Now, she feels guilty for not being able to provide for his needs.

The participant returns to the theme of guilt in her response to "If I could ask somebody who had all the answers, just one question about ASD, I would want to know...". She replies, "Where is it that is more productive for the future to invest today my time, effort and money: dietary interventions, biomedical interventions, educational interventions, speech, OT, physical therapies or social skills training." She is struggling with not knowing what is best for her son. Earlier she had said she felt guilty for not being able to provide for her son, and here she says she wished she knew what the best interventions are for her son. In essence, she feels guilty for not being knowledgeable enough to know exactly which interventions would be the most beneficial to her son. She has limited resources (possibly in personal energy, finances, time), and she does not know the "right" way to spend what resources she has. What if she makes the "wrong" choice? Then will she be guilty of harming him more?

*Dichotomy of Emotions*

In the participant's responses, there are a wide range of emotions. In one sentence she'll be talking about something positive and in the next something negative. This is first apparent in her response to "What I remember most about the day that I was told about the diagnosis is..." She first says, "My disbelief! Although I had been reading a lot about Autism, Mental Retardation, etc...I could not believe that my son actually had such social deficits." Then in the next sentence she goes on to say, "I also remember relief, as the psychologist described to us that other children out in the world were obsessed with trains, just like my son was, and had similar sensory issues. We had finally 'fit' somewhere." In a matter of 4 sentences, the participant describes two different feelings that she experienced when receiving the diagnosis of autism. She felt disbelief and relief at the same time.

Another example of the participant's dichotomy of emotions is in response to "Because of the ways that ASD has affected us [the spouses], our relationship...". She replies to this statement with, "[Our relationship] has grown closer, but also farther apart." On one hand she feels that her and her husband have grown closer because of dealing with their son's autism, but on the other hand, she also says that they are farther apart emotionally, as she describes their intimate relationship.

*Suggestions for Questionnaire*

At the end of the questionnaire the participant was given the chance to give any final thoughts that she wanted with the statement, "Finally...If there is anything else that you would like to add, or that you think is important for me or other parents to know, please write it on the other side of this page, or add it below." The participant suggested several things to add to the questionnaire. Her first suggestion was as follows:

The ASD label includes people with such a wide range of challenges!!! Children who are non verbal, and other who can't be quiet (like mine); children who are passive and others that are hyperactive; children who are exceptionally intelligent and others who do not measure to tests; children who are very talented in one area, and others who seem so very limited. Children who are healthy, and others who are sickly. These all make for such a different experience for parents. Don't know if a little bit more background information would be needed.

Another suggestion the participant made was to add a few more statements to the questionnaire. These were interesting because it shows things she is thinking about and wants to know what others in her same shoes are thinking about regarding these statements. The statements she suggested were:

The funniest (or most ridiculous thing) I was ever told regarding my child with ASD is... The most embarrassing moment I had was when... If I could trade places for a day, I would like to be... Something that makes me mad is... I think a lot about \_\_\_\_\_, but don't worry about... What I learned from mother is that... My doctor never told me that... If I had a million dollars I would...

A lot of the participant's previous themes come out again in her suggestions for new statements. She touches on the social isolation she deals with when she asks about trading places for a day. She goes back to her worries about what she should be spending time and money on in her statements about what people think about and if they had a million dollars. She also again talks about her relationship with doctors in her statement of what the doctor never said.

#### Implications for Nursing

While studying these findings, it is easy to identify areas in which nursing could care for this family and help meet some of their needs. The nursing process includes assessment, diagnosis, planning, implementing, and evaluation. This study is part of the assessment process. With this study, a nurse can assess which areas of life the family is struggling with and develop nursing diagnoses based on those problems. From the nursing diagnoses, nursing care plans can be developed and those

plans implemented. At the end of this process, the nurse evaluates how the family is doing in meeting the goals of the care plan. From this study, several areas have been identified to use nursing to care for the participant's family.

#### *Social Isolation*

One of the most important themes identified for this family is social isolation. The participant said, "There are a lot of things we do not do any more (like dinner parties) and we have really turned a lot into ourselves." She also stated, "We [her husband and she] both have different stress relief methods, and have to 'take turns' to go out." This is evidence that not being able to be social as a family is something that is a problem for their family. As mentioned earlier, she and her husband do not have time for an intimate relationship, so not only is her social life lacking, she is also unable to have a normal relationship with her husband. A nursing diagnosis for this problem would be social isolation related to full time parenting of a child with a developmental delay. Their son with autism needs round the clock supervision from someone who is able to handle an autistic child. As she said, she and her husband cannot go out together because one must stay with the child. They also cannot do social things like they used to because of their son's behavior.

A nursing plan for this diagnosis could include several interventions to help improve this family's ability to socialize. First, respite care that specializes in children with ASD could be found as an option for this family when they need some time to be social. Secondly, a nurse could encourage the family to use other family members as sitters. The nurse could take time to educate the other family member about how to interact with a child with autism so that they feel comfortable taking care of him. A third way to help increase the family's socialization would be to give the family information on local support groups for families with children with ASD or other behavior problems. This would give the family a place to go and talk to other families that are facing the same problems they are as well as give them a place to socialize. Another way the support group can help is that the families in the support group trade off taking care of each other's children. The nurse should also realize that the family might not have the same social support as other families and be sensitive to that fact. It may help the family to use some type of home health care because of their lack of social support.

#### *Nurses as Professionals Working with the Family*

Another important area for nurses to understand from this study is how the family perceives the professionals that work with their son. Even though this mother did not have anything



negative to say about nurses, something can still be learned from the comments she had about other professionals and from the fact that she has not experienced the true potential of what nurses have to offer. She said that doctors did not know enough about autism; therefore, nurses that could come in contact with children with autism should strive to know as much about the disorder and how to take care of these children as they possibly can. Nurses should be aware of when a child has not met their appropriate developmental milestones and should refer those children to a specialist. She also complained that psychologists do not understand her son or know how to interact with him. Nurses should take time to get to know a child with autism to learn that child's specific needs and behaviors. A nurse should not assume that every child with autism can be treated the same way or has the same needs.

Also, because she does not see nurses as professionals that can really help, the nurse needs to be proactive in offering education, support, and referrals. If she does not know from experience that nurses can provide this, she will not ask, and if she does not ask, the nurse might not offer. Nurses can educate her about the things that they can help with, like procuring home health care, finding support groups, or providing information about medications and their side effects or other treatments and interventions. It is important that she

understand that nurses have just as much to offer as other health care professionals.

*Powerlessness with School System*

Another theme that can be developed into a nursing diagnosis for the participant would be her frustration with the school system. As discussed previously, the participant has had ups and downs with her school system. In one response she states, "I have wasted so much energy and time in relationships with the school system!" A nursing diagnosis for this problem would be risk of powerlessness related to unpredictable outcomes of child's schooling. Because of her experience of highs and lows of her son's overall education, she feels as if her time with the school has been wasted. From this statement, it can be assumed that she has probably spent time trying to make her son's education as beneficial as possible, but ultimately, she felt that time was wasted. After this process, a person could start to feel powerless to change a situation that he or she feels needs to be changed. In working with a client with this nursing diagnosis, it would be important for the nurse to understand the client's frustrations and work with the school to make sure they are doing everything possible for the child. A school may need more up to date information on how to work with a child with autism. The nurse should also discuss with the

client which areas are most frustrating to focus on those areas with the school.

### *Guilt*

Another area of concern for nurses is the participant's admission of feelings of guilt. As discussed earlier, she feels guilty for not knowing what is best for her son and had previously felt guilty for causing her son's autism. A nursing diagnosis of risk for parenting alteration related to guilt could be formulated for the participant. This mother's ability to parent could be altered by her feelings of guilt. She may feel that she has to overcompensate for places that she has let her child down. A plan for this diagnosis includes being aware of and sensitive to her feelings of guilt. An important intervention for a family newly diagnosed with autism would be to help them understand what possibly causes autism and that bad parenting is absolutely not a cause of this disorder. However, one must be careful to not give false reassurance, as genetics could be a possible cause of autism. The family does need to blame themselves because of false information about what causes autism. Also, an intervention specific for the participant would be to keep her informed of the most up to date information on the treatment of autism so she knows what the best treatment is for her son. Also, the nurse should observe for signs of depression related to guilt or social isolation. If signs of

depression or other mental illness are noted, a referral to a mental health professional would be needed.

#### *Effect on Other Family Members*

This questionnaire includes questions related to the immediate family members. The nurse must also be sensitive to the needs of the spouse and siblings. In regards to her husband, the participant's main concern was that they did not have enough time to spend together and she felt as if they had grown apart. A nursing diagnosis for this problem would be risk for family process alteration related stresses on the marriage. The nurse must be sure to make sure that the couple has ways to deal with the day to day stressors of marriage. If problems seem to be arising, the nurse could refer the couple to counseling so that they have a place to work through their problems.

The nurse must also be aware of how having a sibling with autism affects the other children. The participant says that her other son is somewhat jealous of his brother with autism. When planning care for this family, the nurse should be sure to include education on how having a child with autism can affect the siblings. The family should be careful to not leave out the "normal" children because they are focusing all their attention on the child with the disorder. A suggestion of the parents trading off one-on-one time with the siblings could be made. One parent could take time to take a sibling out with friends so

that the sibling is able to have normal peer relationships. The nurse should also make a special attempt to include the siblings when taking care of this family.

#### Conclusion

This pilot study for developing a questionnaire to explore the lived experience of families with children who have autism resulted in establishing basic themes from the questionnaire and turning them into implications for nursing, as well as formulating ideas for refining the questionnaire for future use. The themes established in this study can be used when looking at future studies. While many more themes will emerge in a larger scale study, these original themes will probably be repeated. The same is true for the implications for nursing. Although, the other participants situations will be different, if the same themes are seen in future studies, the nursing care will also apply. One important aspect for nursing care that was identified in this study is changing the family's perception of what nurses can provide them. Nurses have a wide range of skills and resources at their disposal, and they should not be wasted. In regards to refining the questionnaire, the participant's suggestions for new statements for the questionnaire will be taken into consideration. Also, more background information will be obtained from the participant's on the specifics of their child's ASD, their specific diagnosis, and typical behaviors of

the child. Exploring families' experiences when dealing with children with autistic spectrum disorders is an important area that must be continued in order to maximize the care given to these clients.

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Appendix

Appendix A

Study Questionnaire

Appendix B

Honors Project Power Point Presentation

**FOR PARENTS/ STEP-PARENTS OF THE PERSON WITH AN AUTISM-SPECTRUM DISORDER**

I am the \_\_\_\_\_ of a child who has been diagnosed with an autism-spectrum disorder (ASD).  
(mother/ father/ stepmother/ stepfather)

My \_\_\_\_\_ was formally diagnosed \_\_\_\_\_ ago, when he/she was \_\_\_\_\_ old.  
(son/daughter/ step-child) (years / months)

What I remember most about the day that I was told about the diagnosis is \_\_\_\_\_

My initial reaction was \_\_\_\_\_

I was told that \_\_\_\_\_

I wish that I had also been told \_\_\_\_\_

I remember thinking \_\_\_\_\_

I felt \_\_\_\_\_

Over time, my thoughts and feelings \_\_\_\_\_

**Now** when I think about my child/ step-child having ASD, \_\_\_\_\_

The biggest change **in our family** because of ASD has been \_\_\_\_\_

Speaking personally, as the result of having a child with an ASD the biggest change **in me** has been \_\_\_\_\_

My **other child/children** have been impacted by ASD \_\_\_\_\_

My \_\_\_\_\_ has taken the whole ASD experience \_\_\_\_\_  
(husband / wife / partner)

Because of the ways that ASD has affected us, our relationship \_\_\_\_\_

What has helped me get through difficult times has been \_\_\_\_\_

If I could ask somebody who had all the answers, just one question about ASD, I would want to know \_\_\_\_\_

Based on my experience as a parent, I can say that the doctors (MD) \_\_\_\_\_

The psychologists who have evaluated my child have been \_\_\_\_\_

Nurses who have come in contact with my child have been \_\_\_\_\_

Therapists (for example, OT/PT/Speech) have been \_\_\_\_\_  
\_\_\_\_\_

Our child's experience at school has been \_\_\_\_\_  
\_\_\_\_\_

I would say that the best thing(s) that professionals can do to help a family who is living with ASD is \_\_\_\_\_  
\_\_\_\_\_

The best advice that I could give to another parent whose child has just been diagnosed with ASD is \_\_\_\_\_  
\_\_\_\_\_

**FINALLY....If there is something else that you would like to add, or that you think is important FOR ME OR OTHER PARENTS TO KNOW, please write it ON THE OTHER SIDE OF THIS PAGE, or add it below.**

## Nursing and the Lived Experience of Autism

Christina Becraft  
March 31, 2004

## Lived Experience of Autism

- • • •
- **Purpose of Study:**
  - To explore and describe the lived experience of families who have a member diagnosed with an autism-spectrum disorder
- **Method:**
  - Open-ended questionnaire

- • • •
- **Why would we want to study families?**

## Importance of Families

- • • •
- **Partners in care**
- **Family must be functioning in order to care for child**
- **Must understand ways to help families as well as child**

## Nursing Process

- • • •
- **Blueprint for care**
- **Used to diagnose and treat HUMAN RESPONSES to health and illness**



## Steps of Nursing Process

- • • •
- **Assessment:** collecting data
- **Nursing Diagnosis:** describing health patterns
- **Planning:** outlining a care plan with specific goals
- **Implementation:** carrying out plan
- **Evaluation:** using outcome measures to assess progress in meeting goal

### How the Study Fits

- • • •
- Turn responses into themes
- Use themes as a basis for assessment data
- What problems should we be looking for with autistic families?

### Pilot Study Results

- • • •
- Many themes identified
  - Obviously, it is only one study
  - It will help when looking at other questionnaires...same themes or different ones?
- Refining the questionnaire

### Themes Identified

- • • •
- Dichotomy of Emotions
- Guilt
- Stress in Spousal Relationship
- Social Isolation

### Dichotomy of Emotions

- • • •
- What I remember most about the diagnosis day....
  - "my unbelief!...I also remember relief..."
- Overtime my thoughts and feelings...
  - "Sometimes I am frustrated...some other times I am just marveled and delighted."

### Dichotomy Con't

- • • •
- Our relationship...
  - "has grown closer, but also apart."
- How can this theme be used?
  - Remember when working with a family that their emotions might vary greatly.
  - Also, might get a response that is not expected.

### Guilt

- • • •
- Over time my thoughts and feelings...
  - "I feel guilty sometimes (not about having caused my son's disability, anymore), but for not being able to provide what he needs."
- Inform families that it is not their fault; however, understand that guilt will still probably be a factor

## Spousal Relationship

- • • •
- Our relationship...
  - "We both have different stress relief methods, and have to 'take turns' to go out."
  - "We are too exhausted for intimacy."
- Respite is very important.
  - Assess if family is not getting time to themselves without taking care of child.
  - Explore options respite options for family

## Social Isolation

- • • •
- The biggest change in our family...
  - "There are a lot of things we do not do any more (like dinner parties) and we have really turned a lot into ourselves."
  - "A kid with a behavioral disability is the farthest thing to being 'the most popular'."
- My other child has been impacted by ASD...
  - "...he can't have friends over..."

## Social Isolation

- • • •
- Assessment
  - Reports of decreasing social activity, spending less time with friends, not going to church, etc.
- Diagnosis
  - Social isolation
- Planning
  - Family will report increased socialization within 6 weeks

## Social Isolation

- • • •
- Implementation
  - Provide information on support groups for families with ASD
  - Provide information on caregivers specifically trained in handling children with ASD
- Evaluation
  - Has socialization increased?
  - Which interventions worked?
  - Which interventions need to be continued?

## Refining the Questionnaire

- • • •
- Add a question about what the family would want us to know about their child with ASD.
- The most embarrassing moment I had was when...
- If I had a million dollars I would...
- Paper vs. Electronic

## Summary of My Project

- • • •
- What is nursing research?
- Human Subjects?
- Developing the Questionnaire
- Literature Review
- Identifying Themes
- Refining for a larger study

The End!!

- • • •
- Questions?
- Comments?