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Katelyn Retaskie
St. Catherine University

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Parents Perceptions of Autism Spectrum Disorder

by

Katelyn Retaskie, B.S.

MSW Clinical Research Paper

Presented to the Faculty of the
School of Social Work
St. Catherine University and the University of St. Thomas
St. Paul, Minnesota
in Partial fulfillment of the Requirements for the Degree of
Master of Social Work

Committee Members

Michael Chovanec, Ph.D, LICSW, LMFT (Chair)

Whitney Wessels, MSW, LGSW

Julie Kraft, MA

This Clinical Research Project is a graduation requirement for the MSW students at St. Catherine University/ University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social work research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis or a dissertation.

Abstract

This study examines the parents of children with autism spectrum disorder perspectives on the initial diagnosis. This research is of qualitative design in which four mothers of children with autism were asked a series of interview questions. The results indicate an emotional impact on not only the mothers, but the family as a whole. In addition the results indicate a need for more education around the topic of autism itself. Implications for social work indicate a need for change at the micro, mezzo, and macro levels.

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I would like to thank my parents, Anne and Tony, for always pushing me to succeed and for their unfailing support. Without them I would not be here today. In addition to my parents I'd like to thank my grandparents for their support as well. The support of my family has enabled me to complete my goals, whatever they might be.

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Table 1. Interview Themes

Parents Perceptions of Autism Spectrum Disorder

Autism spectrum disorder (ASD) affects individuals' worldwide. ASD affects the neurodevelopment of children and has a complex and wide range of ways it impacts the neurodevelopment. Individuals with ASD have social impairments, communication difficulties and restrictive, repetitive challenging behaviors. ASD has a wide spectrum from severe autism, in which the individual can have disabilities with cognition, speech, and aggressive behaviors, to a milder form of ASD such as Asperger syndrome, which is no longer in the DSM-5, however was in the prior DSM-IV (National Institute of Neurological Disorders and Stroke, 2014).

According to the Centers for Disease Control and Prevention (CDC) in 2010 about 1 in 68 children have been diagnosed as being on the spectrum. AutismSpeaks.org (2014) reports that the prevalence of children with autism has drastically increased since 2000 going from one in 166 children to what is now one in 68. Autism can occur in any and all racial and socioeconomic groups. ASD has also been proven to be almost five times more prevalent in males (1 in 42) than it is in females (1 in 189). If a family has one child with ASD they have any where from a 2% to an 18% greater chance of having a second child with ASD. It has also been reported that children born to older parents also have a greater risk of being born with ASD (Center for Disease Control and Prevention, 2014).

Autism is seen in other various cultures beyond the typical American culture. In the Twin Cities area, specifically in Minneapolis, it has been found that Caucasian children and Somali children were about equally identified as being diagnosed with autism and were more likely to have autism than African American children or Hispanic

children. It is estimated that 1 in 32 Somali children have autism as compared to 1 in 32 Caucasian children that have autism, and 1 in 80 Hispanic children that have autism (University of Minnesota, 2013).

ASD can be diagnosed as early as two years of age. Some say that it can be diagnosed as early as one year. Parents of children with ASD often say they started to notice the developmental issues before their child's first birthday, noticing delayed or nonexistent social skill development as early as six months of age. Most children with ASD do not receive the actual diagnosis until around age four (Center for Disease Control and Prevention, 2014).

Caring for a child with ASD can cost a family roughly \$17,000 more a year than it does to care for a child who is typically developing. This cost is so high due to the need for education, specialized therapy for the child, and health care. A child with more severe ASD can cost the family roughly \$21,000 more a year than typically developing children. It is estimated that in 2011 the total societal, in the United States, cost of caring for children with ASD was more than \$9 billion. Children with ASD tend to need more medical attention than those without it. It is estimated that medical expenses for children with ASD are four to six times greater than those without ASD. In 2005 annual medical costs for children with ASD on Medicaid were around \$10,709 per child. Not only are the medical costs for a child with ASD expensive, but so is the specialized therapy children with ASD often require. This specialized therapy can cost anywhere from \$40,000 to \$60,000 a child per year. The cost of this affects the public due to the fact that many children with ASD are on Medicaid, which is paid for by the state and taxes taken out by the government (Center for Disease Control and Prevention, 2014).

Social workers typically work with the vulnerable populations. Children or individuals with ASD are one of those within the vulnerable populations in which social workers serve. A social worker helps families coordinate care and therapies in which the individual with ASD require. Social workers are able to connect families with community resources that they might otherwise not have found. Not only do social workers provide resource information to families with children with ASD, but they can also provide parents and other family members with any type of counseling they may need due to having a family member who requires a lot of attention and time.

Social workers are found in a variety of different job settings, and with those different settings come different job descriptions. When in a school social workers work with the children in both the general education setting and the special education setting. Often times the social workers are apart of a team that evaluates children when there are behavioral or mental health concerns. This is where social workers would be working with the special needs populations that children with autism are in. Often times the school social workers are providing counseling needs to both groups of children or in an individual setting. The issues these children are typically seen for include behavioral issues, getting along with peers and adults, coping skills, and various other functional skills (helpstartshere.org, 2006).

When social workers are not working within a school setting they can be found in child welfare agencies where they help families, such as those families with a child with autism, gain access to community resources such as disability services for the child. Social workers can also be found in community mental health agencies and private practice where they often provide therapy services to both the child and the family

members. Social workers have a variety of different opportunities to help families of children with autism throughout their lives due to the variety of settings one can encounter social workers (helpstartshere.org, 2006).

The purpose of this study is to find out what the parents experiences are with having their child diagnosed with ASD and how their perceptions have changed. This study will also look at what was most and least helpful for the parents from the professionals they encountered. This researcher will conduct qualitative interviews with parents; care givers, and family members of individuals with autism to answer these questions.

Literature Review

It is estimated that there are 730,000 Americans under the age of 21 diagnosed with ASD (Nealy, O'Hare, Powers, & Swick, 2012). Current trends predict that there will be 36,500 new cases of diagnosed autism each year in the US (Nealy et al., 2012). With the continued increase in prevalence of autism the more services will be needed from social workers to support the individual with autism as well as the family members. As the rate of autism continues to rise, the more we need to know about how the parents and caregivers are feeling and their perceptions of autism. This literature review will discuss the different perspectives to consider once a child is diagnosed with autism. It will look at, the father's perspective, the mother's perspective, parental mood and the grief process, the diagnostic process, and treatment options.

Mothers Perspective

Throughout history mothers are the ones who are typically portrayed as a child's primary caretaker. Typically it is a mother who is pictured next to their child when it

comes to taking care of their every day needs. Mothers are the ones who caring a child while still in the womb and are the ones who most children bond with before anyone else. After a methodical review of the literature (Nealy et al., 2012) this was most commonly found individual to care for children with autism as well.

The emotional impact the diagnosis of autism has on the mother of the diagnosed child is evident throughout the literature. Nealy et al. (2012) found four key themes when conducting a qualitative study involving eight mothers of children with ASD. The themes found were *emotional impact*, *familial relationships impact*, *social impact*, and *financial impact*.

The first theme discussed is *emotional impact*. The mother's responses indicated several emotions not only to the initial diagnosis, but also the day-to-day struggles of caring for a child with autism. Initially the mothers described feeling depressed and having anxiety of being able to provide care for the child. On a day-to-day basis mothers described feeling exhausted and powerless (Nealy et al., 2012).

The theme of *familial relationships impact* discusses the effects of having a child with ASD on the family. Half of the mothers of this study indicated that there were changes in the family structure or the relationships within the family. The mothers also stated that they felt as though they were required to give more attention to the child with autism rather than any typically developing children within the family. Additionally the mothers described extended family members not understanding what the mothers were going through, which created tension and distance amongst them (Nealy et al., 2012).

The third theme discussed was that of *social impact*. The mothers described their lives being affected negatively by having a child with autism. The relationships that did

remain were decreased in quantity and quality. The mothers felt that they had a hard time relating to old friends after their child was diagnosed with autism. They stated that their positive social ties consisted of members of support groups (Nealy et al., 2012).

The theme of *financial impact* was the final theme discussed. This theme detailed what it was like to care for a child with special needs, specifically autism. The mothers described having poor insurance coverage as well as having to drive long distances to get to specialty providers. Another *financial impact* was needing to install more various safety devices around the house to insure safety of the child with autism (Nealy et al., 2012).

The feelings of guilt or low self-worth as a parent described were by Meirsschaut, Roeyers, and Warreyn (2010) in themes they found to be common while conducting their own qualitative data analysis involving seventeen mothers. Two of their themes hold similar meaning involving the emotional impact autism can have on a parent, specifically the mother. One of those themes found is that of the diagnosis of ASD affecting the family's whole lives. The mothers describe how the family's schedule no longer is what works for the whole family, rather what schedule works for the child with autism. Activities that are typically described as 'normal' such as going to parks are made increasingly difficult due to the frequent behavior outbursts children with autism exhibit.

Another one of the themes found in this study that goes along with the emotional impact autism has on a mother is that *lack of understanding* these mothers experience. The mothers describe feeling isolated from family members and friends. They state that this is due to family members and friends lack of understanding of autism and therefore the mothers tend to isolate themselves rather than attempt to help others to understand.

This isolation leads to feelings of depression and stress on the mother (Meirsschaut et al., 2010).

Individuals with autism often have behavioral outbursts as children and can often go on into adulthood. As stated above, this can be a reason for the emotional impact described by mothers of children with autism. Kring Greenberg, and Seltzer (2009) set out to see if these behavior problems displayed by children with autism were caused by other health problems. The information gathered by this study came in from both quantitative and qualitative data. Part of the data collected came from daily diaries the mothers kept. The diaries described how the physical health of the child greatly impacted the mothers wellbeing. The diaries indicated that health and behavioral problems independently affected the level of maternal burden (Kring et al., 2009).

Fathers Perspective

A majority of the existing research out there is about the mothers of children with ASD or both parents as one unit. Upon a review of the literature, along with the help of a research librarian it was determined that there is a lack of information in regards to the fathers of children with autism. There were various articles about fathers and children with intellectual disabilities or other various special needs, however this researcher was only able to come across one article specifically related to the fathers of children with autism.

Keller, Ramisch, and Carolan (2014) conducted a study involving seven married biological fathers of children with autism. Similar to study's done involving mothers of children with ASD, Keller et al. (2014) found that fathers also have a sense of isolation due to having a child with autism. The isolation the fathers felt was reportedly due to the

fact that there are not many, if any, support groups geared towards fathers of children with autism. Support groups typically involve both parents or just mothers.

Another theme found by the authors is that of *fatherhood expectations*. This theme highlighted feelings of protectiveness over their children in regards to individuals within society. Additionally this theme highlighted the idea that fathers tend to deny that their children have autism as well as hopes that it is something that they will 'grow out of'. These fathers described a sense of loss once their child was diagnosed (Keller et al., 2014).

Parental competency is an additional theme found. The fathers described feeling like they are responsible for being involved in their child's life and feeling as though they need to give equal attention to all of the children within the family (Keller et al., 2014). This idea of parental competency is similar to what was found regarding mothers by Meirsschaut et al. (2010) in terms of the mothers feeling low self-worth as a parent.

Parental Mood and Grief Process

The literature also looked at the grief process and how the diagnosis affected daily mood. Pottie and Ingram (2008), a study of 93 participants, consisting of 60 mothers and 33 fathers, aimed to find the relationship between daily stress of the parents, coping, and mood of the parents. According to Pottie and Ingram (2008) higher levels of daily positive mood are associated with social support, positive reframing, emotional regulation and compromise coping. The decrease in daily positive mood was found to be linked with escape, blaming, withdrawal, and helpless coping. Negative parental mood, or parental grief, is associated with blaming, worrying, and withdrawal coping (Pottie & Ingram, 2008).

The results found by Pottie and Ingram (2008) is similar to what the mothers of children with ASD said that on a day-to-day basis feeling exhausted and drained as found by Nealy et al. (2012). This feeling drained is a form of parental grief. These mothers are engaging in helpless coping. Coping has a great deal to do with positive or negative daily mood. Increased coping strategies often allows for parents to have a more positive daily mood. There appears to be a lack in literature about the actual grief process parents go through once the diagnosis of autism is made.

Diagnostic Process

Autism is a spectrum disorder and is diagnosed using the Diagnostic and Statistical Manual of Mental Health Disorders, or the DSM. Prior to the release of the DSM-5 there were five subtypes, Autistic disorder, Asperger's disorder, Rett's disorder, Childhood disintegrative disorder, and Pervasive developmental disorder- not otherwise specified (Lock, Bradley, Hendricks, & Brown, 2013). After the release of the DSM-5 Asperger's disorder was taken out and is no longer recognized as a standalone disorder.

As of today there is no one cause of autism. Today more research is being done that suggests various factors such as biomedical, environmental, and genetic (Ennis-Cole, Durodoye, & Harris, 2013). Recent studies show that there is in fact a genetic link to autism. Mutations in genes is thought to be this cause. These mutations are not found in the parents, however occur spontaneously in the sperm or egg prior to conception (Farley, 2014). Autism is often characterized by having impairments in social and communication developments. Autism is a life long disorder and often times have comorbid conditions such as anxiety, insomnia, obsessive-compulsive disorders, and many others (Ennis-Cole et al., 2013).

According to the CDC (2015) there are two steps to diagnosing autism. Step one is the developmental screening. This is a short screening done to ensure that children are hitting developmental milestones when they should and is done during regular well-child checks at the doctors. Well-child checks occur at 9months, 18months, and at 24 or 30 months. If a child is at higher risk for autism, say if a sibling already has autism, then it is likely that there will be additional developmental screenings done.

The second step to diagnosing autism is a comprehensive diagnostic evaluation. This is more thorough and looks at several different things such as the child's behavior, development, and parent interviews. Other testing may also be done such as hearing tests or neurological testing. A specialist such as a developmental pediatrician, child neurologist, or a child psychologist may be called in to do this more comprehensive setting (Centers for Disease Control and Prevention, 2015).

Treatment Options

Early intervention is pivotal when treating a child with autism. With the use of early childhood interventions and other health professions such as occupational therapy the child's life can be significantly improved. By getting treatment early the child may experience improved cognitive skills, adaptive skills, and/or social skills. Common treatment modalities used are speech-language therapy, occupational therapy, and applied behavior analysis, ABA (Irvin, McBee, Boyd, Hume, & Odom, 2012).

ABA is a treatment model that encourages the positive behaviors the children display rather than the negative behaviors. This helps the child improve various skills, which are tracked and measured over time. Various types of ABA such as discrete trial training, which uses a systematic set of trials to teach a child a skill, as well as pivotal

response training, which the goal is to increase the child's motivation to learn, encourage the child to initiate communication, and to monitor their behaviors (Centers for Disease Control and Prevention, 2015).

A study by Ennis-Cole, Durodoye, & Harris (2013) found that the top four rated treatment modalities used were ABA, discrete trial teaching, pivotal response training, and learning experiences: an alternative program for preschoolers and parents. In addition to those already widely used practices there are several other up and coming practices that show promise as well, such as picture exchange communication or PECs which uses a set of picture symbols for communication and sensory integration, which aids the individual in dealing with sensory input (Ennis-Cole et al., 2013).

In addition to specific therapy techniques more technology is being integrated in to treatment. The use of technology can aid a child with communication, social interactions, and can allow the child to observe more appropriate behaviors. Technology devices such as augmentative and alternative communication devices (AACs) allows for the development of language in individuals who have limited to no verbal communication abilities. Such AAC devices could be simply some sort of tablet (Ennis-Cole et al., 2013).

Summary

Looking at the literature it is clear that mothers of children with autism are more likely to discuss the emotional toll having a child diagnosed with autism as compared to fathers. Mothers described feeling depressed and stressed over feelings of isolation from others (Meirsschaut et al., 2010). This is similar to the emotional distress found by Nealy et al. (2012).

Conversely fathers of children with autism discussed distress over not being able to perform parental duties. Fathers often felt that they were incompetent due to the fact that parenting a child with autism is different from parenting a typically developing child. One fact that would found to be true for both parents was the feeling of isolation. This isolation was due to the parents feeling as though their friends and family did not understand what they were going through (Meirsschaut et al., 2010) (Nealy et al., 2012).

Conceptual Framework

The perspective in which this research is framed by is the ecological perspective (Barker, 2003). The ecological perspective focuses on the individual at the same time as the environment, rather than each at a separate time. This framework provides a wide lens by which to examine the psychosocial problem of autism.

Rational

The ecological perspective allows for one to examine multiple levels of an identified problem. This allows the researcher to examine the perspectives of those closest to the problem presented. This framework examines the context of a presenting problem, such as autism in young children. For the purpose of this research we will be focusing on the systems theory, which is a key feature of the ecological perspective. This theory focuses on the whole picture rather than just bits and pieces of it. By looking at the big picture, so to speak, one can really get an idea of what is going on with everyone involved rather just a microcosm. This allows for more flexibility in terms of intervention. As we know autism affects a large population, not only just those with diagnosis but the others around them. By using the systems theory we can get a better

idea of what needs to happen for intervention, involving the environment and the individual rather than just the individual.

Key Concepts

When the individual and the environment mutually influence and change with each other is called *adaption* (Friedman & Allen, 2011). An example of this is when a child with autism exhibits a challenging behavior; a parent or caregiver who has experienced this time and time again, will thus be capable to calm the child down eventually. The parent has adapted their parenting styles over the years to help achieve a calming environment in which allows for the child to then ease themselves out of a challenging behavior.

When using the ecological perspective one must also look at everything from the different levels in which is involved. From the *micro-system*, professional actions done to help solve difficulties faced by the clients we serve (Barker, 2003). An example of this is looking at the child with autism within the family, more specifically examining the parent-child interaction. When it comes to parent-child interaction one can look at the intervention in place or the environment in which the interaction is occurring.

From there one would look at the *mezzo-system*, which is practice with groups or families, rather than just the individual (Barker, 2003). In reference to working with individuals with autism one would look at working with the family as whole, rather than just the child or just the parent. This could be done in the form of family therapy rather than just individual treatment.

Lastly one looks at the *macro-system*, which is practice that looks at bringing change to the larger general society (Barker, 2003). In relation to autism an example of

this could be educating the public of what early signs of autism are so parents are better prepared if their child should be diagnosed with autism. Public education is not the only part of the *macro-system* that can pertain to autism, but creating or aiding in the creation of community organizations that are geared to aiding parents of children with autism would also be part of the *macro-system*.

Use of Framework

For the purpose of this study the ecological perspective will aid in the creation of interview questions. The interview questions will address more of the *mezzo-system* in terms of how the diagnosis of autism changed the family and the reactions family members had. From the micro stand point the questions will address the parents' internal reactions to the diagnosis and their knowledge base. Also from a macro standpoint the questions will look at what the parents thought would be useful for other individuals to know about the diagnosis of autism.

Methodology

Research Design

The purpose of the current research is to gain a better understanding of parents and caregivers perspectives on autism once a child has been diagnosed. For this research the most helpful information was that which gives the research more insight into the initial reactions once the diagnoses has been made. In particular, the research explored parents' and caregivers' knowledge to uncover areas of commonality and where support may be needed given the diagnosis of autism on a loved one. To address the current research questions, an exploratory qualitative study was conducted through the use of

interviews. Qualitative research methods seek to understand the personal and subjective experience of individuals, according to Monette, Sullivan, and Dejong (2011).

Sample

The type of sampling procedures used was snowball sampling. Research participants knowing and identifying other members of the same population that would be appropriate for this study characterizes snowball sampling. This researcher has been in the field of autism for many years, which has allowed for relationships to be built with other professionals who are also in the field. In order to be chosen as a participant the individuals must either be a parent or primary adult caregiver of an individual with autism. The diagnosis should have been given to the individual a minimum of five years prior to the interview. The sample did not need to have any specific level of education, nor do they need to be of any nationality. The sample size was intended to be anywhere from eight to ten people (Monette et al., 2011).

Protection of Human Subjects

To ensure the protection of human subjects, each participant was given an informed consent to sign, see appendix C. This informed consent detailed what the research was about, how long the information will be kept, and how the participants will remain confidential throughout the research process. Potential subjects were given a copy of research questions ahead of time to help them decide if the study was something they were interested in participating in. Participants were given the opportunity to withdraw from the study at anytime.

All data obtained will be kept in a secure locked location at the researcher's residence. Also no identifying information was used in the reporting of findings. All

interviews were voice recorded and kept on a password-protected iPad. Interviews were recorded to allow for the researcher to create a word for word transcription of the interview to be coded by the researcher.

The potential risk of being a part of this study is the possibility of bringing up feelings of discomfort by talking about a stressful time in the participants life. This feeling of discomfort comes from talking about when the participants' child was diagnosed with autism, which can be a stressful time for these parents or caregivers. This risk was reduced by ensuring participants that they do not have to answer any questions they did not want to. In addition researcher offered to do a debriefing with the participants if they wanted to. Lastly the researcher provided the participants with information about contacts if they felt the need to explore these feelings of discomfort further.

Instrument

The instrument included a series of eight to ten open ended questions related to the research questions as well as demographic information in terms of age of diagnosis, gender, date of birth, and if there are any siblings. The open ended questions inquired about feelings regarding the initial diagnosis, what parents had found to be helpful in regards to the diagnosis, and how others reacted to the child with autism. All of the interview questions were reviewed by the committee members to increase the face validity of the questions. See appendix A for a sample of the interview questions.

Data Collection

Data collection consisted of the following steps:

- 1) Participants were chosen based on having experienced a child with autism in the family. The participants were not from one central agency, rather were contacted through other professional connections within the autism community. As stated above the sample will be snowball sampling.
- 2) Potential subjects were introduced to the study by the committee members and were issued a flyer detailing the purpose of the study and what the study required of them, as well as the researchers contact information. Committee member were also be asked to provide a minimum of two to three potential subject each.
- 3) Potential subjects were contacted post internal review board approval by phone call or email. The research questions, flyer, and consent form was mailed or emailed to the participant a week prior to the interview-taking place.
- 4) The committee member contacted the subjects one week after they were sent out the flyer detailing the research project if the subjects do not call the researcher first.
- 5) If interested in taking place in the study, the potential subjects were contacted to set up a proper interview time and location based on what is best for the subject in a public meeting place such as a library.
- 6) All interviews were voice recorded and transcribed. The interviews did not last longer than 60minutes.

- 7) Each participant was asked to give an additional name or two for potential participants that the researcher may contact and the data collection process was repeated.

Data Analysis

Interviews were voice recorded to allow for the researcher to transcribe after the interview. Once the interview was transcribed the researcher then coded the interviews to identify common themes that immerge from the data. The transcripts were analyzed using the grounded theory approach. The ground theory approach is a method for developing a theory in an inductive manner (Padgett, 2008). By using open coding, a process by which the researcher went sentence by sentence in the transcript and summarize it in a few words to describe the main concept, the interviews were analyzed. Codes were organized into categories to find overarching themes relevant to the current research study (Padgett, 2008).

Researcher Bias

This researcher has been involved with the autism community for over six years, thus it can be assumed that the researcher had some bias as to the reactions to both the interview questions and research questions. This researcher expects that common responses include fear from the caregivers about having a child diagnosed with autism, as well as blaming oneself for having caused the child to have autism some how. Committee members to help the researcher avoid asking leading questions or questions with too narrow a focus reviewed interview questions.

Findings

Sample

The participants of this study were parents of children diagnosed with autism spectrum disorder. Seven potential respondents were offered the opportunity to participate in the study. Four participants were interviewed. Two people chose to decline the offer to participate and one person was unable to due to unforeseen issues within their family. All participants were mothers; the fathers either could not participate due to timing or chose to decline the interview. All interviews took place during a month and a half time frame, with most interviews happening on the weekend. Three of the participants are located within the grater twin cities area and one participant is from northern Minnesota.

Themes

For the purpose of this research themes will represent two or more participate response with the same core idea. Themes are overarching words or phrases that come about from participants’ responses to the interview questions that are asked. Nine core themes were found from eight of the ten questions asked. Themes will be described by quotes from the participants. Being in italics will indicate all quotes.

Table 1					
<i>Interview Themes</i>					
	Responses				
Question	Parent A	Parent B	Parent C	Parent D	Theme
Please describe your initial reaction when your child was first diagnosed.	Why? Sad	Relieved	Relieved	Sad	Relief 2/4 Sad 2/4
What were some of first signs that something was different about the individual’s development?	Late with milestones	Late with milestones	Late with milestones	Late with milestones	Late with milestones 4/4
Please describe your knowledge of autism did you know prior to diagnosis?	Nothing	Was a spectrum disorder	Stereotypical behaviors	Nothing	Nothing 2/4

Can you tell me what your earliest questions were when your child was first diagnosed?	How to help	Altruism	Altruism	Altruism	Altruism 3/4
How did Diagnosis affect your self-care?	No affect	Feeling drained	Isolation	Feeling drained	Drained 2/4
How did the diagnosis impact the child's siblings/other family members?	Level of understanding	Split family	Frustration	Level of understanding	Level of understanding 2/4
What have you learned about Autism that has been helpful to you in the years since diagnosis was made?	Adaption	Advocacy	Advocacy	Adaption	Adaption 2/4 Advocacy 2/4
What kind of reactions did you get from other family members about diagnosis?	Denial	Denial	Denial	Poor knowledge of diagnosis	Denial 3/4
What has the individual with autism taught you about autism that you didn't expect?	More family time	Live in the moment	Care less about what others think	Unconditional love	No theme
Is there anything else you would like to tell me that you think would be helpful to my study and me?	Need of more education about diagnosis	Eventual ability to not need services	Limited childcare for kids with autism	Kids with autism are very individual	No theme

Relief. When the parents were asked to described their initial reactions to when the first diagnosed with autism two out of the four parents indicated that they were relieved to finally have an answer. The parents described a long process of trying to understand what was going on with their child. One parent described their relief by stating

It was actually one of relief, as there was a definite diagnosis, and a specific plan for intervention. It was also a relief to know that the early interventions already in place were appropriate and effective for the eventual diagnosis we got of autism (Parent 1, line 4).

This parent indicated the sense of relief to finally know what was going on with their child and that there was help out their for them.

Sadness. Sadness, two out of four, was also one of the first themes to come up. While some parents described feeling relieved to finally get that initial diagnosis of

autism, others reacted the opposite and described feeling sad (See table 1). The parents who indicated feeling sad about the diagnosis wondered what they had done to cause their child to have autism. One parent stated: *We were very sad. We had never heard of autism before. It's one thing to hear about autism, it's another a whole different wave of emotions when it's your child that is the one being diagnosed with it (Parent 3, line 10).*

Late milestones. The parents described first realizing there was something different about their child's development by the being late reaching certain milestones. The milestones they notice the delay in were with speech and with walking. Most children begin talking around age one and are saying short phrases by age two, all of the parents noted their children did not hit these core language milestones. One parent also noted that while children begin walking around age one as well and her child was at least four months later than this. One parent stated *when she was around two years old, when children should be talking in phrases, she was only using one word to communicate, or on rare occasions two words (Parent 2, line 14).*

Lack of accurate knowledge. This theme, two out of four, was found with response to two of the questions asked during interviews (see table 1). When asked about what their previous knowledge of autism was two parents stated have very little to no knowledge. One parent said *We did not know anything about it. I ended up printing off a big packet from the internet of what autism is and read it (Parent 1, line 17).*

Altruism. The parents were asked about their earliest questions about when their child was first diagnosed. The majority, 3 of 4, of respondents stated that they wondered how they could help their child succeed or when they should start getting help for their child. One parent said she asked *When can I start getting him help? What tools can you*

give me to increase his speech (Parent 4, line 15)? While another said The main question on our minds was how we could help her (Parent 3, line 16).

Drained. The participants were asked about self-care and how or if it has changed since their child was diagnosed. Parents (2 of 4) described feeling drained by the diagnosis process and by learning how to care for their child. One participant said

To be honest, I was really drained by the time he got help and I knew what was going on. I felt that all of my energy and effort was put into my child, I was very exhausted. He couldn't go many places, unless I was willing to tackle a long behavior over multiple things (Parent 2, line 19).

Another respondent said *I don't think we slept well for a long time. She was a runner. We couldn't take our eyes off of her o she was gone. We were very tired parents when she was younger. We did the best we could (Parent 1, line 20).*

Denial. Denial was a common reaction of some of the participants', two out of four, family members. The described how in-laws or even the opposite parent would deny that there was anything different about the child. When responding to the question about the reactions from family members about the diagnosis one parent's response was *Denial and I'm still not sure if they believe it now (Parent 4, line 20).*

Another participant responded to the same question by saying *My son's dad wanted no part in getting him diagnosed or help, nothing. We divorced, and that is when I took it all on my own. He refused to know anything about the diagnosis, or do speech sessions or therapy for 3 years. He wont acknowledge the diagnosis still, either will his family (Parent 1, line 25).*

Level of understanding. This theme came up with two of four participants in regards to how the diagnosis had impacted the family (See table 1). Participants described how family members' level of understanding of the diagnosis impacted family relationships. One participant stated

My kids are not like normal kids their age. It makes it difficult because there is a standard of what children should act like at certain ages and my kids don't fall into that category of standard behavior. I feel like my family at times chalk it up to my parenting skills verses a symptom of autism (Parent 3, line 23).

Adaption. The participants, two out of four, described needing learn how to adapt and how having a child with autism has taught them how to do that. The ability to adapt to things that the child does allows for the parents' lives to run a little smoother rather than trying to fight the way the child is. One parent said *We have learned that she can learn and do things with a different teaching approach and that keeping a schedule helps her live in a way that makes sense to her (Parent 4, line 27).* This is one way a parent used adaption to better their life and the life of their child with autism.

Advocacy. This theme was very clear while conducting the interviews. Two of the four parents had strong feelings about being able to advocate for their child and the importance of doing so. When responding to the question about what they have learned about autism that has been helpful one participant said *First you need to advocate for your child. You know them better then anyone (Parent 2, line 29).*

Additional Findings

Two of the interview questions did not generate any themes. The questions were that of *What has the child with autism taught you about autism that you didn't expect and*

is there anything else you would like to tell me that you think would be helpful for my study. These things generated such different responses, thus no theme could be found.

Discussion

Sample

The participants for this research are all from the mid-west and currently live in Minnesota. The sample recruited for this study was less than expected. One had hoped to get a minimum of eight participants, however that did not happen, likely because of the limited time frame in which the study needed to be completed. Given the sample consisted of parents from an urban setting as opposed to a more rural setting, it is speculated that they have better access to resources as there is a variety of autism agencies in the Twin Cities versus those in a more rural setting.

In addition the sample is made up of all women, the fathers of the individuals with autism were not represented. All of the participants were married; however one had remarried since the divorce from her son's birth father.

Interview Themes

Participants described how the diagnosis of autism impacted their family relationships because of family member's level of understanding, which is very similar to themes found in the literature. The literature talked about mothers feeling that others have a lack of understanding (Meirsschaut et al., 2010) as well as the theme of emotional impact (Nealy et al., 2012). These themes are similar to those found during this research. One of the core themes found was in fact the level of understanding.

The theme of denial, feeling drained, sadness, and relief are all impacted by our emotions. These themes are similar to what was found in the literature of emotional

impact directly relates to several of the themes found in this research. The literature discussed a sort of wave of emotions that the mothers felt from the research conducted here we can see that these participants also go through a wave of emotions.

Themes that were not similar to the literature were those of adaption, advocacy, altruism, and lack of knowledge. It's possible that these themes were not found in the literature because of the difference in the regions the research was conducted or the time in which the research was done. As stated before, the Twin Cities area has an abundant amount of resources for individuals with autism, thus making living in this area with a child with autism a little easier than other places. In addition we do not know the exact towns the prior research was conducted which could also have impact on the literature.

Researcher Reaction

The researcher was surprised by the emotions that were brought up during the interviews for the researcher herself. Listening to the mothers speak about their children was harder than expected. At times the participants became emotional. The emotion shown by the mothers was powerful. Seeing the pain in their eyes and the love they have for their children at the same time gave the researcher a better idea of what it really is like to be a parent of a child with autism.

The researcher has a background providing one to one therapy to children with autism however had spent more than a few hours with one of the children. To speak with people who spend all of their free time raising a child with autism and working to better that child's life is truly inspirational. An unfortunate piece is that I am not surprised by the lack of understanding of autism by others or the fact that most participants did not know much about autism prior to diagnosis.

Limitations / Recommendations for Future Research

Limitations of this research include the fact that the participants were all mothers of children with autism. Being that only mothers chose to participate in this research we were unable to get a clear voice and understanding of the fathers' perspectives. This limits and skews our data to only represent one side of the parenting dynamic. For future research it would be recommended to interview more fathers to get a broader representation of caregivers. This could be done by broadening the sample base, by recruiting from support groups, or by contacting local agencies that work with children with autism. In addition it would be helpful to conduct research solely on the fathers perspectives. Gaining more information on the fathers' perspectives will help professionals working in the world of autism better understand the fathers needs in addition to the mothers needs.

Another limitation to the study is the specific location it was done. A majority of the participants were located in the Twin Cities area thus really limiting the ability to generalize to the United States as a whole. The information gathered can really only be generalized to mothers within the Twin Cities area. To generalize the study further research should be around the Midwest rather than just the Twin Cities. One would recommend broadening the sample to include urban and rural communities or possibly a national survey.

An additional limitation is that of the sample size. The sample consisted of only four participants. The limited sample size decreases the number of themes possible. With a larger sample size more concrete themes could have been found, thus altering the

findings. It would be recommended to increase the sample size to allow for more concrete findings.

Implications for Social Work

Micro-level

At the micro-level social workers can work to ensure that families are receiving case management. With case management stress can be decreased from the parents and would allow for continuity of care. This would ensure that all the providers working with the child know what the other providers are doing. The case manager would help the families set up case meetings in order to ensure that their needs and wants for their child are being met.

Mezzo-level

All parents reported their child hitting late milestones at the start of recognizing something was different about their child. This indicates the importance of early intervention and education on child development, which can be done by social workers. In addition to the importance of more general knowledge of child development, the key findings of this research also indicate a need for better general knowledge of autism. This general knowledge needs to be widely known by new parents, not to scare them, but to inform them of the possibilities. Autism is not a death sentence; it is just another way to live life. If social workers participated in educating new parents or even the general public then having a child with autism would not be such a scary thing. Better autism education to the public would decrease the level of denial some family members have when a child is diagnosed with autism.

In addition more programs need to be in place for the parents, as well as the programs for the children with autism. The parents of this study indicated feeling drained by the diagnosis process as well as having to always advocate for their child to be treated equally. Social workers should be putting more programs such as support groups or autism friendly daycare programs out there for these parents. The support groups would allow the parents to feel more connected to other parents of children with autism. This would increase their feelings of relief in addition to giving them a little sense of normalcy by being supported by a community that is like-minded.

Macro-level

Social workers advocating for more autism friendly daycare options would allow for the parents to know that their child is being better cared for by individuals that know how to handle the periodic behavioral issues some children with autism have. As a child with autism ages their behaviors change. Some can become aggressive, which limits daycare options because parents of typically developing children wouldn't want an aggressive child, as many with autism can be, around their child. The autism specific daycare options would allow for children to continue to gain social interaction skills and would allow for them to be cared for by trained professionals.

Conclusion

The purpose of this study was to gain a better idea of what the parents' perspectives of autism spectrum disorder were initially post diagnoses. This study aimed to focus on the diagnostic process and emotions the parents encountered. It was our aim to hear from the voices of those who daily deal with children with autism. The research also shows support for previous studies. It confirms the emotional feelings indicated by

prior research in the form of the current participants feeling drained in addition to sadness.

This study has shown the importance of better education for the public and for parents whose child might be newly diagnosed. Navigating the system to ensure that a child is receiving the proper care can be hard for parents; with better education parents have a better chance of finding those resource sooner. This is a strength because the research findings here clearly support the need for increased education on resources out there for the children with autism as indicated by the theme of lack of knowledge as well as level of understanding.

Children with autism are just that, children. One quote from a parent perfectly illustrates the love this participant has for her son and the amazing bond they have, which is what all parents want, a great bond and connection with their child.

The participant stated *This kid has the biggest heart of anyone. He has taught me to live in the moment, and to let a lot of things go. I have changed how I feel about myself in a lot of ways, for the better, because this kid believes in me like nobody else (Parent 1, line 35)* when describing her son.

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Appendix A

Parents Perceptions of Autism Spectrum Disorder

Participants are encouraged to fill-out demographic information and bring it to the interview

Childs Demographics

Gender: MALE FEMALE **DOB:** ___/___/_____

Age of Diagnosis: _____ **Age first symptoms emerged:** _____

Family Demographics

Parents/ Caregiver Highest Level of Education: _____

Siblings: Yes, How many? ___ Older/ Younger No

- 1) Please describe your initial reaction when your child was first diagnosed.

- 2) What were some of first signs that something was different about the individual's development?

- 3) Please describe your knowledge of autism did you know prior to diagnosis?

- 4) Can you tell me what your earliest questions were when your child was first diagnosed?

- 5) How did Diagnosis affect your self-care?

- 6) How did the diagnosis impact the child's siblings/other family members?

- 7) What have you learned about Autism that has been helpful to you in the years since diagnosis was made?

- 8) What kind of reactions did you get from other family members about diagnosis?

- 9) What has the individual with autism taught you about autism that you didn't expect?

- 10) Is there anything else you would like to tell me that you think would be helpful to my study and me?

THANK YOU FOR YOUR TIME

Appendix B



Parents Experiences with AUTISM STUDY

- I. **Graduate social work student looking for parents/caregiver of individuals with autism**
 - A. Graduate student seeking to interview parents, caregivers, and family members of individuals with autism about their experience with the diagnosis process. Interviews will take no more than 1 hour of time and will be conducted face to face. Interviews will be voice recorded. Information obtained will be compiled and presented in the form of a research presentation. ALL identifying characteristics will be kept 100% confidential.

Reta8322@stthomas.edu

Appendix C

CONSENT FORM
ST. CATHERINE UNIVERSITY

Parents Perceptions of Autism Spectrum Disorder

I am conducting a study about parents perceptions of autism spectrum disorder a minimum of 5 years post diagnosis. I invite you to participate in this research. You were selected as a possible participant because you currently or have previously cared for an individual diagnosed with autism spectrum disorder. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Katelyn Retaskie, a graduate student at the School of Social Work, St. Catherine University/University of St. Thomas and supervised by Dr. Michael Chovanec, Ph.D, LICSW, LMFT, a professor at the school of social work.

Background Information:

The purpose of this study is to gain a better understanding of parents of children diagnosed with autism spectrum disorders perceptions post diagnosis. There is a lack of research into parents or caregivers experiences with the diagnostic process. In addition this information will potential be used to better prepare professionals who work with parents who have a child with autism.

Procedures:

If you agree to be in this study, I will ask you to do the following things: participate in an in person interview taking no longer than one and a half hours, allow for the interview to be auto-recorded

Risks and Benefits of Being in the Study:

This study has minimal risks. One risk is that the discussion may trigger emotional memories from the past diagnostic process. To address this a debriefing will be done at the end of the interview and each participant will be provided a list of resources.

The study has no direct benefits.

Confidentiality:

The records of this study will be kept confidential. Transcripts will be identified with case numbers and the final paper will not have any identifiable information about the participants. Research records will be kept in a password-protected file on my computer. All transcriptions of this interview will be kept within a locked drawer in the researchers home. A research partner will see a transcription of the interview. The research partner will sign a confidentiality agreement as well. Findings from the transcript will be presented in a research paper. The audiotape and transcript will be destroyed by May 15, 2015.

Voluntary Nature of the Study:

Your participation in this study is entirely voluntary. You may skip any questions you do not wish to answer and may stop the interview at any time. Your decision whether or not to participate will not affect your current or future relations with St. Catherine University, the University of St. Thomas, or the School of Social Work. If you decide to participate, you are free to withdraw at any time without penalty. Should you decide to withdraw, data collected about you will not be used.

Contacts and Questions

My name is Katelyn Retaskie. You may ask any questions you have now. If you have questions later, you may contact me at (906) 458-1008 or at reta8322@stthomasedu. You may also contact Michael Chovanec, Ph.D., LICSW, LMFT at (651)-690-8722 or at mgchovanec@stkates.edu. In addition you may also contact the St. Catherine University Institutional Review Board at 651-690-6204 with any questions or concerns.

You will be given a copy of this form to keep for your records.

Statement of Consent:

I have read the above information. My questions have been answered to my satisfaction. I consent to participate in the study and to be audiotaped.

Signature of Study Participant

Date

Print Name of Study Participant

Signature of Researcher

Date