

5-2016

Somali Parents and their Perceptions of the Autism Spectrum Disorder Diagnosis

Aragan Samatar

St. Catherine University, aragan09@hotmail.com

Recommended Citation

Samatar, Aragan. (2016). Somali Parents and their Perceptions of the Autism Spectrum Disorder Diagnosis. Retrieved from Sophia, the St. Catherine University repository website: https://sophia.stkate.edu/msw_papers/668

This Clinical research paper is brought to you for free and open access by the School of Social Work at SOPHIA. It has been accepted for inclusion in Master of Social Work Clinical Research Papers by an authorized administrator of SOPHIA. For more information, please contact amshaw@stkate.edu.

Somali Parents and their Perceptions of the Autism Spectrum Disorder
Diagnosis

Aragan Samatar, BSW

MSW Clinical Research Paper

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

Master of Social Work

Committee Members
Lisa R. Kiesel, Ph.D., MSW, LICSW. (Chair),
Kristin Hamre, MPH, MSW
Hamdi Adan, BSW, MSW, LGSW

The Clinical Research Project is a graduation requirement for 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 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 nor a dissertation.

Abstract

The design of this research study is a qualitative methodology utilizing semi-structured interviews. The purpose of this study was to explore specifically how Somali parents experience, perceive, and understand their child's diagnosis, the diagnostic process, and treatment services. A total of four Somali parents were interviewed for this research study. Following the interviews, themes that were identified during the analysis process involve understanding of autism, support, and feelings during the diagnostic process, self-advocacy and education. The themes discovered in this study were similar to many of the key themes present in the Autism and Somali related literature. However, the data also showed some findings that were underrepresented in the current literature such as the barriers Somali parents face while raising a child on the autism spectrum. The implication from this study suggests more qualitative research is needed about mental health in the Somali community in general.

Keywords: Somali, autism, parent, diagnosis, stigma

Acknowledgment

First of all, I would like to praise Allah for providing me the strength, patience, and blessings from the beginning to the end of the study. This study would not have been possible without the contribution of many people whom I am greatly for.

Secondly, I would like to thank my committee chair, Dr. Lisa R. Kiesel without her guidance and monitoring I would not be where I am today. It has been an honor to have her as an advisor, teacher throughout my graduate education. I would also like to thank my advisory committee members Kristin Hamre, and Hamdi Adan for their contributions and advice and encouragement.

I also want to thank my mentors Beth Hamer and Shelly Bjick from St. Catherine's Access & Success program, who are the most accepting and intelligent persons who have helped and inspired me throughout this journey. Thank you for the encouragement, support, venting when I got discouraged, and celebration.

Most importantly, none of this would have been possible without the love and patience of my family. My mother, my father, my aunt, my grandmother, my in-laws and my two beautiful children Ayub and Layan to whom this study is dedicated to, has been a constant source of love, support, and strength all these years. I would like to express my heartfelt appreciation to my family. The patience you all had with me while learning, and preparing for this journey means more to me than you will ever know.

Lastly, to my dear husband, you push me when I need it and thank you for believing, and giving me the confidence to accomplish this goal. You support my ambitions and my dreams and keep me grounded. I could not ask for a better partner. I truly appreciate you.

Table of Contents

Introduction	1
Literature Review	2
Conceptual Framework	10
Methodology	11
Findings	15
Discussion	21
Reference	26
Appendix A	31
Appendix B	32

Introduction

Emerging study shows that Somali immigrants are one of the population groups significantly affected by autism. In the Twin Cities area, particularly in Minneapolis, it has been discovered that there is a high prevalence of autism within the Somali community. According to the Centers for Disease Control and Prevention (2013) “Somali children are more likely to have both autism spectrum disorder and intellectual disability than children with autism spectrum disorder in all other racial and ethnic groups in Minneapolis” (p.1). In a recent study conducted by the University of Minnesota (2013) Somali children were also more likely to have autism than African American children or Hispanic children. The report determined 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”(Hewitt, Gulaid, Hamre, Esler, Punyko, Reichle, & Reiff, 2013, p. 2).

The purpose of this research is to find out exactly how Somali parents experience, perceive, and understand their child’s diagnosis, the diagnostic process, and treatment services. The particular focus on the autistic population is critical due to the rise in its prevalence. This study is also important in addressing the increasing numbers of Somali children diagnosed with ASD. This researcher conducted qualitative interviews with Somali parents with autistic children.

Literature Review

Autism

An Autism Spectrum Disorder (ASD) is a developmental disorder that affects multiple aspects of a child's functioning. ASD includes an extensive group of developmental disorders, the diagnosis of which, according to the DSM-5 (Diagnostic and Statistical Manual of Mental Disorders-V, 2013) includes the occurrence of two core symptoms in early childhood: disorders of social communication and restricted, repetitive behaviors (Goldstein, 2009). Some characteristics include social interactions that may be displayed through the lack of social or emotional exchange and the lack of impulsive sharing of experiences with others. More common features of ASD can be characterized by lack of eye contact, facial responsiveness, or socially directed smiles, as well as by failure to respond to parent's voices (Hattier & Matson, 2012). Features in communication skills may be demonstrated through delays in or lack of language development, repetitive speech, or in unusual patterns of speech such as in excessively high pitch or a monotone (Hattier & Matson, 2012). Impairments may change in those diagnosed with ASD over time.

The Diagnostic Process

Similar, to other mental diagnosing medical test such as blood tests cannot determine if a child has an autism spectrum disorder although there are genetic tests for some disorders that may be associated with behaviors on the autism spectrum. An accurate diagnosis of ASD is based on observation of the child's communication, behavior, and developmental levels (Coplan, 2010). Clinicians rely on direct observations and use the DSM to determine if a child has ASD. The Diagnostic and Statistical Manual

of Mental Disorders (DSM) is established by the American Psychiatric Association to provide the measures by which clinicians define and diagnose various psychiatric and developmental conditions, including autism spectrum disorders. The DSM lists the signs and symptoms of ASD and specifies how many of these symptoms must be present to verify a diagnosis of ASD. Clinicians that are qualified to make a diagnosis of ASD include pediatricians, psychiatrists, and psychologists (Coplan, 2010). However, the assessment process of ASD also includes a multidisciplinary such as; occupational therapist, speech pathologists, physical therapist, teacher, and social workers (Coplan, 2010). Appropriate treatment of ASD should begin with a careful assessment to determine the child's particular strengths and needs (Coplan, 2010). James Coplan, M. D. additionally emphasizes the importance of the diagnostics process of ASD and professional relationship:

“Your child's future well-being depends on upon implementing the right therapies. This, in turn, requires the right developmental diagnosis, profiling your child's strengths as well as his or her areas of greatest need. It's also essential; to determine whether there are any underlying medical issues that have the potential to impact negatively on your child's development. Finally, only you and your child physician will have a long-term perspective on your child's development. Only someone who has a long-term relationship with your child will be able to view current problems within the context of your child's long-term development” (2010, p.54).

Racial and Ethnic Disparities

Race and ethnicity play a significant role in autism. Minority children are more likely to be diagnosed at a later stage of autism, rather than whites (Wiggins, Carpenter, Daniels & Thomas, 2009). According to Wiggins, (2009) “there is increasing evidence that autism spectrum disorders (ASDs) are often diagnosed several years after the onset of symptoms, or are misdiagnosed as other disorders even though an experienced

clinician can accurately diagnose ASD in children as young as of two years” (p.2). They examined differences between racial and ethnic disparities in the recognition of autism. The study was conducted on 8-year olds from a variety of cultural backgrounds, with ASD identified by population surveillance. Variables that were measured were the use of documented ASD classification as dependent and race and ethnicity as the independent variable. This study concluded that children who were black were less likely to have ASD compared with white children (Wiggins, et al., 2009).

Similar studies have also been conducted in Minnesota, by the Minnesota Department of Health (2009). The Somali community raised concerns due to the high rate of children with ASD in the preschool programs. The Minnesota Department of Health conducted a study of their own that focused on the occurrence of (ASD) among preschool aged Somali children in Minneapolis. Other sample groups were Asians, Native American, and African American. According to The Minnesota Department of Health the “study involved analyzing special education data, known as administrative prevalence, about the number of children who are eligible to receive ASD services and are participating in ECSE programs”(p.2). The study did not include the population prevalence in the Somali community but only provided information about children of various races participating in the Minneapolis School District's Early Childhood Education ASD program. According to the Minnesota Department of health “administrative prevalence of Somali children, ages 3 and 4, who participated in the MPS ECSE ASD programs, were significantly higher than for children of other races or ethnic backgrounds” (p.2). The Minnesota Department of Health concluded that more Somali

children participated in this program. However, the reason why Somali children outnumber other races, or ethnic groups is unknown.

A prevalence study done in 2013 by the University of Minnesota also investigated Somali children in Minneapolis and the prevalence of the autism spectrum disorder compared to other races. The study determined “the Somali estimate of 1 in 32 compares to 1 in 36 white children, 1 in 62 Black children and 1 in 80 Hispanics”(p.3) was identified as having ASD in Minneapolis, in 2010 (Hewitt et al., 2013). This data concludes that Somali children and white children are similarly likely to be diagnosed with ASD (Hewitt et al., 2013). The study could not determine why Somali and White children were predominantly identified as having ASD in Minneapolis than black and Hispanic children (Hewitt et al., 2013).

A similar study was done in Sweden involving Somali and non-Somali children, with a diagnosis of autistic disorder or pervasive development disorder and learning disability. This study found the prevalence of autism to be three to four times higher in the Somali community (Barnevik-Olsson, Gillberg, & Fernell, 2008). The researcher’s objective was to evaluate the prevalence of autism in children of parents who were from Somalia, living in Sweden, and compare them with a non-Somali group. The target groups were all children ages 7-17, residing in Stockholm, Sweden in 2005. The result of the study was that Somali children diagnosed with autism outnumber the non-Somali. The researcher states “prevalence was threefold to fourfold that in children of non-Somali origin living in the country (0.7% vs 0.19%). At the habilitation centers, children from Somalia constituted 3.4% (17 of 501) and the rate of Somali children in the county was 0.96 %”(Barnevik-Olsson,et al. , 2008, p.8). Researchers discovered that most of the

mothers who were living in Sweden had been there for the entire pregnancy (Barnevik-Olsson, et al. ,2008).

Parents' Experiences with Children who have Autism Spectrum Disorder

Autism spectrum disorder is a severe developmental disability that presents a particularly difficult challenge for a family unit (Dewey & Kaminsky, 2002). This disorder has a different impact on every person affected. There is existing research regarding parent's experiences with children who have autism spectrum disorder.

Parents experience a significant amount of stress when a child with autism spectrum disorder is added to their family (Dunlap, Plienis, & Robbins, 1988). When parents have a child with autism spectrum disorder, parental stress can be attributed to the child's behaviors, lack of support both professionally and personally, and the social stigmas along with the lack of understanding (Pisula, 2011).

Nevertheless of the severity of the diagnosis, parenting a child with ASD has a negative effect on not only the parents but also the family as a whole (Dewey & Kaminsky, 2002). Stress related to having a child with ASD typically begins before a formal diagnosis is received, usually starting when differences in social behaviors, play, communication, and motor skills are first noticed (Bolton, Golding, Emond, & Steer, 2012). Once a formal diagnosis is received, parents feel a sense of relief having been given a concrete answer to address their child's differences. However, 63% of parents surveyed, shared a great dissatisfaction with the way in which the diagnosis was delivered to them (Chamak, Bonniau, Oudaya, & Ehrenberg, 2011).

Somalis Perceptions of Mental Health

In general, mental illness is considered taboo within the Somali community.

According to WHO (2011) “One in three Somali’s has been affected by some kind of mental illness, a prevalence which is higher than in other low-income and war-torn countries”(p.1). Somali Mental Health (2004) explains that the Somali culture considers mental illness “as one is either crazy or not crazy” (p.2). Hewitt et al., (2013) explain in their report that there is no actual word or term in the Somali language describing mental health illness. Furthermore, Somali’s who are labeled or present mental health symptoms are isolated or even shunned from their families and community. A report completed by WHO evaluated Somalia’s Mental Health in Somali in 2013 and discovered that:

“Mental illnesses are widely addressed solely in a repressed and outmoded manner. The mentally ill are generally chained and/or confined. Next to extreme isolation, discrimination and stigmatism, expressed through violent actions, such as throwing of stones, represent the most common behavioral attitudes towards the mentally ill. Those actions constitute barriers to societal reintegration and acceptance of the practice of medical treatment itself”(p.22).

There is a major stigma regarding mental health issues, which prevents many Somalis from requesting care (Somali Mental Health, 2004). According to Schuchman (2004), Somalis view mental illness a punishment from God for something done wrong in the past, and instead of seeking help from others they believe that it is the family’s duty to absorb the problem, and to endure the consequences on their own. Wall, Mohamud & Abdirahman, (2008) state “therefore a large number of Somali clients will resist treatment because in their religion, whatever happened in God’s will should not be questioned or acted upon in anyway”(p.1). One Somali researcher said that in the Somali community “Someone who is mad is not a part of the society. They don’t want anyone to know so they will reject all your ideas. Nobody seems to be talking about it in the community. They don’t seem to be seeking help and will keep it indoors” (Wall, et al.,

2008). Furthermore, Somalis typically seek traditional treatments such as ceremonies, reading from the Quran, and rituals performed by healers known as “mina” or “wadda” (Somali Mental Health, 2004). Somali Mental Health also goes on to say, “People’s beliefs and understanding of mental illness are predominately spiritual and metaphysical: mental illness comes from evil spirits; it can be brought on by another person or oneself through curses or bad behavior” (p.1). Ingstad (1997) also found a similar reaction when he visited Somali and describes “the evil eye” is one of the possible primary causes of any unforeseen misfortune, which people will consider in their search for an explanation.

Autism and Somalis

Individuals with autism are one group who are perceived of as being outside of the realm of “typical”. In the Somali context, it is notable that the behaviors associated with autism do not fit neatly in the “sane”/”insane” contrast (Kediye et al., 2009). A report done by the Minnesota for Department of Health (2014) that focused on Somali families with children on the autism spectrum disorder and other immigrant groups determined that the Somali community in particular, believed that autism is caused by God and or linked it to vaccines. Furthermore, Somali parents in the study also used the term “insane” to describe autism (Minnesota for Department of Health, 2014).

Another study that was done in Canada by Kediye, Valeo, and Berman’s (2009) was about the experiences of Somali-Canadian mothers of children with autism and it offered an important foundation for this line of inquiry. This qualitative study is based on focus groups and individual interviews with ten Somali- Canadian mothers of children diagnosed with autism. The findings establish the fact that both mothers of children with disabilities and members of a “visible minority,” face a unique combination of stressors

(Kediye et al., 2009). This work approaches important questions about the challenges faced by immigrant mothers of children with autism.

Cultural and Language Barriers

Many health services are very limited to Somali immigrants because of the limited numbers of professionals who speak the Somali language and their level of cultural competency. According to Elmi (1999) the lack of knowledge about Somali cultural perspectives makes it difficult for service providers to recognize if certain aspects of the client behavior are cultural or mental health related. This could lead to misdiagnosis and lack of, or wrong treatment (Elmi, 1999).

Additionally, studies explain that it is important in many cultures to have the availability of ethno racial -specific mental health workers with full language ability (Schuchman, 2004) This appears to be particularly important for the Somali community. Many people feel uneasy or unwilling to seek help or talk of their problems in institutions where none of the staff belong to their culture or speak their language (Elmi, 1999). According to Elmi (1999), a large number of Somalis lack a sense of belonging and trust.

Many health services use interpreters when working with non-English speaking patients (Schuchman, 2004.) However, according to Schuchman (2004) the use of language interpreters has a inadequacy because “word-for- word” translating is seldom capable of expressing an idea across cultures. Using interpreters also limits the ability to build a trusting relationship between the social worker and client (Schuchman, 2004). Since, the Somali culture and language has no interpretation of mental health diagnoses (Elmi, 1999). Both authors state how difficulty it is to explain what mental health is to Somali immigrants and is also challenging for mental health practitioners.

Research Question

Researchers have indicated that rates of autism have risen significantly over the last decade. Outstanding trends in the research specifies that children of immigrants are at higher for autism, up to four times the risk as children of native- born parents (Barnevik-Olsson, Gillberg, & Fernell, 2008). Although little research exists exploring how immigrants experience autism, and no research exists to date particularly exploring how the Somali families understand and perceives autism. Thus, through the use of interviews with Somalis, the purpose of this study is to answer the question: How do Somali parent's experience, perceive, and understand their child's diagnosis, the diagnostic process and treatment services?

Conceptual Framework

The conceptual framework for this research is based upon the empowerment theory. In social work, empowerment is defined as a process that allows individuals, families and communities to increase and is about recognizing what is there already, and highlighting their personal, socio- economic and political strength, thereby enabling them to improve their quality of life (Parsons, 1991). Zimmermann (1995) states "empowerment is a construct that links individual's strengths and competencies natural helping system and proactive behaviors to social policy and social change" (p.1). This strengths perspective theory focuses not only on empowering the individuals but the community as whole by providing resources and tools.

According to Rappaport (1987) empowerment is viewed as a process: the mechanisms by which people, organizations, and communities gain mastery over their lives. The empowerment theory informs this study, recognizing the importance of

educating Somali families who are impacted by autism, and of providing them with the tools and resource they need to understand autism better.

Methodology

Research Design

This research utilizes qualitative methodology via semi-structured interviews. This research design approach was chosen because it allows for both an in-depth and flexible exploration of ideas and experiences, allowing the researcher “to capture the lived experience from the perspective of those who live it and create meaning from it” (Padgett, 2008, p.16). By examining real-life situations, the qualitative method provides an opportunity for Somali parents who have children on the autism spectrum to describe their understanding of autism, including the process involved in receiving the diagnosis, education regarding the diagnosis, treatment services, and recommendations to other Somali families who are impacted by autism. Also this research aims to add meaning and understanding to the existing body of research in this area.

Sample

The target sample size for this research was eight to ten individuals from the population of Somali parents of who have a child diagnosed as on the autism spectrum disorder. However, due to recruitment issues, only four respondents participated in the study. The purpose was to specifically to explore Somali parents and their understanding of their child's diagnosis, and the diagnostic process, and treatment services. Proposed sampling limited the study to Somali families living in Minneapolis and St. Paul area. The study was also limited to Somali participants who are 18 years or older.

Snowball-sampling techniques were used to identify participants. Snowball sampling is a non-probability sampling technique allowing prospective research participants to identify other potential subjects of the same population that would be appropriate for the study (Monette et al., 2011). Utilizing a snowball sample method-identifying parents who have already disclosed the autism diagnosis within the community. The participants were contacted through personal networks. The researcher's community acquaintance acquired contact information of participants who showed interest. The participants who did show interest were then contacted by phone from the researcher and were then explained in details what the study would imply and to also determine their interest in participating in the study. Once the participant agreed to participate in the study, a mutually agreed upon time and location for the interview was scheduled. Participants were also encouraged to forward researcher contact information to other potential subjects, who might have been interested in this study.

Protection of Human Subjects

This study was reviewed and approved by the St. Catherine University Institutional Review Board (IRB) prior to any recruitment or data collection activities. All the participants in this study were voluntary. During the initial recruitment of subjects, participants were explained in details the steps that would be taken to preserve confidentiality and was given a consent form. Once the participants agreed to partake in this study they were given a consent form, prior to the interview-taking place. Consent forms were reviewed and signed prior to the interview describing the purpose of the study, procedure, risks and benefits, and confidentiality. The participants were offered the choice to have the consent read aloud to him or her and/or translated into the language

(Somali/English) of his or her choosing. A written Somali consent form was also offered to participants. Participants were then asked questions about the study to determine their understanding prior to data collection. Participants were also encouraged to ask questions throughout the study. Researcher's contact information, as well as that of the researcher's supervisory chair, was provided.

The anticipated risk for participating participants in the study was minimal. However, due to the culturally sensitive nature of this topic and asking questions that might be considered private. Participants were informed that they could stop the interview and withdraw from participating at any time. Furthermore, participants were informed that the interview would be audio taped and transcribed by the researcher and that they would be identified by a respondent code, not by name and all identifiable information will be kept out of the transcription.

All the data obtained from this study will be kept confidential. No identifiable information was used in this report. These items would be kept in a locked file cabinet and in a password protected computer in the researcher's home. The researcher will be the only one to have access to these records. In addition, the respondents were informed that data from the interview would be kept in a password-protected file on the computer, which is to be destroyed May 30, 2016.

Data Collection

The design used in this research study was a qualitative methodology utilizing semi-structured interviews. Participants were interviewed in the participant's home, or in a private place of their choosing. Participants had the choice to have the interview in Somali or English as needed or as requested. These questions were formulated after

reviewing literature addressing Somali families and their understanding of autism. In addition, to the data being collected the eleven questions were established and approved by Dr. Lisa Kiesel, the research project committee chair. Throughout the interview, the participants responded to 11 open-ended questions, followed by probing questions (Appendix A). The interviews began with demographic questions regarding the respondent's child age, gender, place of birth and the participant's marital status, place of birth, the level of education, and how long they have resided in the United States. The participants were also asked questions regarding the respondent's experience with their child diagnosis, and education they received when the child was initially diagnosed and also about their experiences and perceptions of their child's services and service providers. Each interview lasted about 30 to 60 minutes each. The interviews were recorded using a recorder app on an iPad. After each interview was conducted, the data was transcribed verbatim for data analysis.

Data Analysis Plan

Following the interviews, the researcher analyzed the transcript to examine any codes or themes that are developed. The interviews were voice recorded in order to allow the researcher to transcribe after the interview. Once the interview was transcribed the researcher then coded the interviews to distinguish common themes that immerge from the data. The transcripts were examined using the ground theory approach. The ground theory approach is a method for developing a theory in an inductive mode (Padgett, 2008).

Findings

The purpose of this study was to explore specifically how Somali parents experience, perceive, and understand their child's diagnosis, the diagnostic process, and treatment services. A total of four Somali parents were interviewed for this research study. The demographics of this study include of three females and one male who were all born in Somalia. Two of the participants had a college level degree and the other two hold a high school degree. All four of the participants' children were born in the United States and range from ages three to fifteen.

Themes that were identified during the analysis process involve understanding of autism, support, and Somali's communities perceptive, feelings during the diagnostic process, self- advocacy and education.

Understanding of Autism

Participants were asked to describe their understanding of autism. All four of the participants used the notion of "delay" and "mental health condition" when describing autism.

One participant said: *Kids that are delayed in everything. Speech delay, social problem, they cannot communicate with other children.*

Another parent explained: *Autism is a mental health condition where child's brain develops less comparing to normal children.*

The parents were also asked about where had they learned autism and from what source. One woman said she was familiar with the term autism before her son's diagnosis:

Schools, and again working in a medical setting you are exposed to kids who have all this kind of delays, and you are part of that referral team that's sending them to different and appropriate places.

However, a participant described that she had never heard of autism up until her child was diagnosed. For example, when asked from what sources did you learn about autism, she said:

Before my son was diagnosed, I didn't know what autism was, there is no autism back home in Somali you know.

Support System

Support. The four parents were asked to describe their support system. Three of the participants reported that they had no support from family members or the Somali community. The following quote supports these findings:

My family does not support me. They don't know anything about autism. They used to tell me like oh he will be fine and his boy, he will talk one day, he will grow out of it, but they don't know what autism is...

However, one participant mentioned how her family has been very supportive and continued to be understanding of their child's diagnosis:

I do have support. I guess, my husband. I have my family; I have my husband's family and also my brother in-law's son. He was diagnosed with autism, I think at a very early age, and he was a big support actually in guiding us and giving me more information and more educational materials

Somali's Community's Perceptive

Hide. Many of the participants stated that other Somali parents tend to "hide" their child's diagnosis of Autism from the Somali community. Participants explained that Somali families deny or hide their child diagnosis from others in the community because

they are afraid that their child will be labeled as “crazy “or “not normal.” One woman shared:

Somali people are very judgmental and are afraid of what other Somalis might think of them. So you see they hide their child's diagnosis from others, and they won't tell people what their kid has because of the stigma you know. They don't want to be known in the community as the family with the crazy kid.

Several of the participants discussed how Somali families prefer not to disclose their child's diagnosis to other Somalis in the community in fear of being stigmatized.

The following quotes supports the theme presented by the participants:

Somali parents, they are hiding, if their kid has autism, they don't share with the other parents. If you ask what's going on with your kid, they don't explain to you exactly what they have, and they deny it. They don't want other Somali people to know about their kid.

Another participated stated:

Most of the Somali families especially those who are less educated or inexperienced would hide the health condition of their child and be hesitant to seek help or talk about their child's health issue.

Wrong. All four participants specifically used the word “wrong” when speaking about the Somali community and how it views autism. For example, one parent says:

It depends some already know or heard about autism and won't bother you, where some will ask you personal questions, by saying what is wrong with your child? Why is he acting this way?

Another parent voices how she believes her child is perceived when they are out in the Somali community:

“My community, they think my kid is crazy. They think he has a behavioral problem, or something is wrong with him. Some think he's acting weird or believe his spoiled. They think my child is different, but they don't know anything about autism”.

However, one participant uses the word “wrong”, but shares the reaction she gets when she questions other Somali parents in the Somali community:

I see some parents whose kids are like 5 and 4 years old, and I say to them have you ever thought your kid might be autistic? Or might be developmentally delayed and their responses are his just normal, nothing is wrong, have other kids, I am busy, I didn't put time into this kid.

The Diagnostic Process

Themes among participants regarding their child’s diagnostic processes included misdiagnosis and feelings of frustration. Some of the parents spoke about how their physicians did not give them clarifying responses to why their child was not communicating and was concerned that their doctors didn’t accurately diagnose their child.

Misdiagnosis. All four parents in this study reported that their physician did not initially diagnose their child with Autism spectrum disorder. Participants explained they were first given a diagnosis of “speech delay,” “developmental delay”, and “learning disability.” One parent spoke about how he recognized that his child was on the spectrum at age one, but felt that the doctor failed to acknowledge it:

When my child was one year’s old, we noticed that my child was not talking. I told the doctor that my child wasn't talking, and I needed to know why. My child's doctor kept saying that my child only had a speech delay, but I already knew that my child was autistic, based on the research I made by googling and what I learned from the Internet. And again even though the doctor said it wasn't autism but speech delay, it turned out that my child had autism.

Two other parents described similar concerns when they approached their doctor:

I approached the doctor and brought the issue, that you know I feel his not on target with his age group. I felt his language was kind of limited and he was more quiet. He had this aggressive behavior. My doctor did not want to diagnose him with autism, but he put specifically developmentally delay, and I'm like ok,

but why is he not talking you know? I know 3-year-olds are talking and are more active. His like you know every child is different. And you know doctors will tell you this, just wait.

We went to the doctor when he was in three years old. They took an assessment, and they said this child his speech delay, and they said his fine he will grow out of it.

Frustration. Another theme that was discussed throughout all of the participants was their particular feelings of “frustration” during their child’s evaluation. Furthermore, the parents described the diagnostic process as “confusing” and “sad”. The following report observations of participants:

At first, I was shocked and frustrated because I didn't know what was going on with my son. But then I started to learn about autism.

I was frustrated because we knew it was autism, after several visit and diagnosis

I was frustrated because I wanted him to at least refer me to a specialist. And maybe do more testing to find out why he was not talking, but then again you don't want to cross your doctor, he knows better, and I didn't want to go against his wish, but if feels this way, his the one with this knowledge, I trust him. But I took it outside, and took it upon myself.

Treatment Services

Self-Advocacy. Several of the participants reported that they were aware of services available for their child, but did not receive support accessing them. In fact, two of the participants explained that they obtained the services on their own:

He has an IEP, and if you have a case manager you can get more programs, but I don't have a case manager, I found the programs myself, speech therapy, occupational therapy, social groups, and psychologist doctor... ”

I didn't wait. I actually took further steps, and there is a co-worker of mine whose son is autistic so he referred me to this school called (autism school center) here he goes now which is an autism center. I just called, and I referred myself”.

Though, one participant talked about how he had not yet obtained treatment services other than what his child is already receiving at school:

I have not had help or sought help for my child except the help he gets from school. But I'm planning to seek help for my child as I heard there is help from state agencies for autistic children.

Lack of Education

Education. Several of the participants reported that lack of education might be the reason why Somali parents are not accepting of the diagnosis of Autism. One participant argued that the unfamiliarity of autism was due to the lack of knowledge, which may contribute to the feelings of shamefulness. She states: *I think if Somali parents were more educated they would be able to understand autism and not feel so shameful.*

Two other parents echoed similar responses:

“They don't take their kids to programs because they are scared, they don't know what to do, or they don't have an education.”

“Where on another hand an educated or experienced Somali family would seek help and sometimes could talk about the child's health.”

All four parents expressed the significance of education and how education is required to understand their child's diagnosis of autism. When the participants were asked what do they think is the most important thing that could be done to help other Somali families understand their child's diagnosis/Autism, all of them exactly said education. For instance, one parent says: *I think education and acceptance of its existence to seek help.* Another parent said she would: *Try to educate the parents. I know*

there is a lot of parents who don't have an educational background, and they don't understand the severity of the condition.

Discussion

This qualitative study provided an opportunity for Somali parents to share their personal experiences raising a child on the autism spectrum. Through this study the Somali parents were able to describe their understanding of autism, including the process receiving the diagnosis, education regarding the diagnosis, and treatment services. The themes discovered in this study were similar to many of the key themes present in the Autism and Somali related literature such as understanding of autism, support, and feelings of the diagnostic process, self- advocacy and education. However, the data also showed some findings that were underrepresented in the current literature such as the barriers Somali parents face while raising a child on the autism spectrum as well as Somali parents and of what helped them that was focused on therapeutic interventions. These findings have contributed to existing research and hold implications for both social work practice and policy. However as the study was primarily exploratory in nature, more research will need to be done on themes identified to support policy change. Parents in this study appeared to be very passionate and concerned about their child's diagnosis of autism and also the Somali community interpretations of autism. Many of the participants explained that because autism is not recognized in their society, thus there is a stigma around autism within the Somali community. These findings appear consistent with the results of Igstad (1995) who states that in Somali people who are mentally disabled are labeled and told to (iska caaddi) "be normal" and (ha is walan)

“don’t be crazy.” Parents in this study expressed similar responses on how they perceive autism in the Somali community. It’s important to note that all the of the participants in this study used the exact word “crazy” at one point during their interview. For instance, one woman stated:

My community, they think my child is crazy. They think he has a behavioral problem, or something is wrong with him. Some think he's acting weird or believe his spoiled. They think my child is different, but they don't know anything about autism.

The literature also indicated a similar report, that if individuals of the Somali community are labeled crazy, the community then shuns them. According to Somali Mental Health they explain, (2004) “in a conceptual framework, Somali culture considers mental health, as one is either crazy or not crazy” (p.2). The findings in this study indicate that there is a stigma around autism and that autism is a sensitive subject in this particular community. In fact, some the participants in this study appeared to be guarded when telling their stories. This finding may link back to the notion of autism being a sensitive topic, and also it being a somewhat a new concept in the Somali community. Though autism may be a complex issue, many parents in this study seemed empowered to help other Somali families who are impacted by autism by sharing their personal experiences and providing recommendations.

Participant’s responses implied that parents recognized and comprehended their child’s diagnosis of autism spectrum disorder. Parents provided numerous quotes such as *Kids that are delayed in everything. Speech delay, social problem, they cannot communicate with other kids* and *Autism is a mental health condition where child's brain develops less comparing to normal children*. These findings appear consistent with the results of Hattier & Matson, (2012) study in which they explain Autism communication

skills may be demonstrated through delays in or lack of language development, and repetitive speech.

Another theme that was discovered in this research was parents and their feelings during the diagnostic processes. The responses suggest that though some parents understood their child's diagnosis of autism spectrum disorder, there might have been a lack of communication between the parents and physicians. The findings from this study were consistent with Chamak, Bonniau, Oudaya, & Ehrenberg, (2011) who found that 63% of parents surveyed in a study, shared a great dissatisfaction with the way in which the diagnosis was delivered to them. The participants in this study felt that their physicians were not explaining the diagnosis correctly or simply misdiagnosing their child. The lack of communication with their providers during a critical time in their life left many parents feeling frustrated and upset.

Another interesting finding in this study was regarding treatment services and self-advocacy. Parents in this study reported that they had no help accessing services for their child and was required to do it on their own. One woman shared that she had referred herself to an autism center for her child, and another parent echoed a similar response as she also found the services for her child herself. There was no research supporting or disagreeing with this finding.

Strengths and Limitations

This research offered much strength. There is minimal research regarding autism in the Somali community, specifically exploring Somali parents and their understanding of their child's diagnosis, and the diagnostic process, and treatment services. In using a qualitative approach this study, the researcher was able to gain in-depth information from

participants on the topic to contribute detailed information to the field of literature. The use of a semi-structured interview model allowed the researcher to have greater flexibility and to explore new or unfamiliar ideas that participants reported. Another strength of the research is that all participants were Somali parents who have an autistic child.

Limitations to this research study were the sample size due to recruitment. The final sample size was four participants. Due the stigmatization of autism within the Somalia, community families may have been reluctant to participate. Also, the sample size was relatively small because the ability to generalize the findings to the entire Somali community is limited.

Implication for policy and practice

More qualitative research is needed about mental health in the Somali community in general. There is substantial research available around autism and mental health in other populations but limited research on the Somali community and their experiences.

The findings in this study hold many implications for social workers. Social workers will encounter or provide service for clients who have autism and should be aware of the signs and symptoms to better assist their clients. According to, Shtayermman (2005) “professionals working with individuals with AS not only need to keep the idiosyncratic expression of this disorder in mind but also need to adopt a long-term case management perspective to assessment and treatment. As the individual with Asperger’s ages, the social worker will be presented with a series of challenges depending on the client’s developmental stage, the level of family support, social isolation, and personal strengths”(p.4). Also, being culturally competent and understanding this significant rise of autism in this particular community, social workers

can give Somalis the resource they need to cope with issues and problems they face with this diagnosis. Social workers and providers should be mindful of the barriers that Somali parents face when accessing services. Parents in this study shared that they had a negative experience with providers during the diagnostic process and a barrier to seeking help was reported by some participants was not knowing who or what services was available to them. This approach by social workers could greatly diminish or eliminate that barrier.

Another implication for practice is that social workers should understand that this is culturally sensitive topic in the Somali community. This study suggests that further outreach in the Somali community is needed to help promote awareness and to reduce the stigma of mental health. Also providing education and information about childhood development is needed to help families in recognizing the signs of autism.

Reference

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: *American Psychiatric Publishing*.
- Autism Speaks. (2014). What is autism. Retrieved October 1, 2015, from <http://www.autismspeaks.org/what-autism/faq>
- Barnevik-Olsson, M., Gillberg, C., & Fernell, E. (2010). Prevalence of autism in children born of Somali origin living in Stockholm: brief report of an at-risk population. *Developmental Medicine & Child Neurology*, 52, 117-1168. Doi: 10.1111/j.1469-8749.2010.03812.x
- Callahan, K., Shukla-Mehta, S., Magee, S. & Wie, M. (2010). ABA versus TEACCH: The case for defining and validating comprehensive treatment models in autism. *Journal of Autism and Developmental Disorders*, 40, 74-88.
- Centers for Disease Control and Prevention (2013, March 29). Centers for disease control and prevention. Retrieved from <http://www.cdc.gov/ncbddd/autism/facts.html>
- Coplan, J. (2010). *Making sense of autistic spectrum disorders: Create the brightest future for your child with the best treatment options*. New York: Bantam Books.
- Chamak, B., Bonniau, B., Oudaya, L., & Ehrenberg, A. (2011). The autism diagnostic experiences of French parents. *Autism*, 15(1), 83-97.
- Dewey, D., & Kaminsky, L. (2002). Psychosocial adjustment in siblings of children with autism. *Journal of Child Psychology and Psychiatry*, 43, 225-232.

- Dunlap, G., Plienis, A. J., & Robbins, F. R. (1988). Parent adjustment and family stress as factors in behavioral parent training for young autistic children. *Journal of the Multihandicapped Person*, 1, 31-52.
- Elmi, A. (1999). A study on the mental health needs of the Somali community in Toronto. Toronto: York Community Services & Rexdale Community Health Centre.
- Fernell, E., Barnevik-Olsson, M., Bågenholm, Gillberg, C., Gustafsson, S., & Sääf, M. (2010). Serum levels of 25-hydroxyvitamin D in mothers of Swedish and of Somali origin who have children with and without autism. *Acta Paediatrica*, 99(5), 743-747.
- Gorman, E. (2008, July 24). A mysterious connection: Autism and Minneapolis' Somali children. *Minnpost*. Retrieved from: <http://www.minnpost.com/politics-policy/2008/07/mysterious-connection-autism-and-minneapolis-somali-children>
- Goldstein, S. (2009). *Assessment of autism spectrum disorders*. New York: Guilford Press.
- Hewitt, A., Gulaid, A., Hamre, K., Esler, A., Punyko, J., Reichle, J. & Reiff, M. (2013). Minneapolis Somali autism spectrum disorder prevalence project: Community report 2013. Minneapolis, MN: University of Minnesota, Institute on Community Integration, Research and Training Center on Community Living.
- Ingstad, B. (1995). *Disability and culture*. Univ of California Press.
- Karst, J. S., & Vaughan Van Hecke, A. (2012). Parent and family impact of autism spectrum disorder: A review and proposed model for intervention evaluation. *Clinical Child and Family Psychology Review*, 15(3), 247-277.

- Kediye, F., Valeo, A., & Berman, R. C., (2009). Somali-Canadian mothers' experiences in parenting a child with autism spectrum disorder. *Journal of the Association for Research on Mothering*, 11 (1), 211–223
- Konstantareas, M. M., & Homatidis, S. (1989). Assessing child symptom severity and stress in parents of autistic children. *Journal of Child Psychology and Psychiatry*, 30(3), 459-470.
- Lovaas, O. I. (1987). Behavioral Treatment and Normal Educational and Intellectual Functioning in Young Autistic Children. *Journal of Consulting and Clinical Psychology*, 55, 3-9.
- Mandell, D. S., Wiggins, L. D., Yeargin-Allsopp, M., Carpenter, L., Daniels, J., Thomas, K. C., & ... Kirby, R. S. (2009). Racial/Ethnic Disparities in the Identification of Children With Autism Spectrum Disorders. *American Journal Of Public Health*, 99(3), 493-498.
doi:10.2105/AJPH.2007.131243
- Matson, J. L., Hess, J., Neal, D., Mahan, S., & Fodstad, J. C. (2010) Trend of symptoms in children diagnosed with autistic disorder as measured by the Autism Spectrum Disorders-Diagnostic for Children (ASD-DC). *Journal of Developmental and Physical Disabilities*, 22(1), 47–56.
- Minnesota Department of Health. (2009) Autism and the Somali Community - Report of Study Fact Sheet <http://www.health.state.mn.us/ommh/projects/autism/>
- Minnesota Department of Health. (2009). *Autism Spectrum Disorders Among Preschool Children Participating in the Minneapolis Public Schools Early Childhood Special Education Programs*.
<http://www.health.state.mn.us/ommh/projects/autism/report090331.pdf>

- Olivos, E. M., Gallagher, R. J., & Aguilar, J. (2010). Fostering collaboration with culturally and linguistically diverse families of children with moderate to severe disabilities. *Journal of Educational and Psychological Consultation*, 20, 28-40.
- Parsons, R. J. (1991). Empowerment: Purpose and practice principle in social work. *Social Work with Groups*, 14(2), 7-21.
- Pisula, E. (2011). Parenting Stress in Mothers and Fathers of Children with Autism Spectrum Disorders. A Comprehensive Book on Autism Spectrum Disorders, Dr. Mohammad-Reza Mohammadi (Ed.), <http://www.intechopen.com/books/a-comprehensive-book-on-autism-spectrum-disorders/parenting-stress-in-mothers-and-fathers-of-children-with-autism-spectrum-disorders>
- Wall, L. Mohamud M., & .Abdirahman Ahmed (2008) Community Engagement Project NIMHE Mental Health Programme. *National Institute for Mental Health in England*
- WHO. (2011) *Mental Health in Somalia*. (n.d.). Retrieved April 13, 2016, from http://www.who.int/hac/crises/som/somalia_mental_health/en/
- Rappaport, J. (1987). Terms of empowerment/exemplars of prevention: Toward a theory for community psychology. *American journal of community psychology*, 15(2), 121-148.
- Schuchman, D. M. and McDonald, C. (2004) Somali Mental Health. *Bildhaan: An International Journal of Somali Studies*: Vol. 4, Article 8.
retrieved from <http://digitalcommons.mcalester.edu/bildhaan/vol4/iss1/8>

- Siklos, S., & Kerns, K. A. (2006). Assessing need for social support in parents of children with autism and Down syndrome. *Journal of Autism and Developmental Disorders*, 36, 921-933.
- The University of Minnesota. (2013). *Minneapolis Somali Autism Spectrum Disorder Prevalence Project*. Retrieved April 3, 2015, from Research and Training Center on Community Living: <http://rtc.umn.edu/au>
- VanBergeijk, E. O., & Shtayermman, O. (2005). Asperger's Syndrome: An Enigma for Social
- Volkmar, F., Siegel, M., Woodbury-Smith, M., King, B., McCracken, J., & State, M. (2014). Practice parameter for the assessment and treatment of children and adolescents with autism spectrum disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, 53(2), 237–257.
- Zimmerman, M. A. (1995). Empowerment theory, research, and application. *American journal of community psychology*, 23(5), 569-579.

Appendix A: Interview Questions

Demographic Questions:

- What is your child's age and gender?
 - What is your marital status?
 - In what country were you born?
 - In what country was your child born?
 - What is your level of education?
 - How long have you resided in the United States?
1. What is your understanding of autism? Do you think your understanding is different from the Somali community's view?
 2. From what sources did you learn about autism? If any?
 3. When did you first notice that child was growing or acting differently than other children?
 4. Do you have a support system? If so, can you describe it?
 5. When you saw the doctor for the first time, what did you tell the doctor at the beginning? What words did you use to explain your child's condition to the doctor?
 6. What support, advice, and/or information were you given by the diagnosing professional at the time of diagnosis? How did you feel?
 7. How do you think the Somali community perceives you when you and your child are out in public? (Mosque, Somali mall, Somali gatherings, etc.)
 8. Can you tell me about your experiences getting services for your child with autism?
 9. What types of services have you received/are receiving?
 10. In what way are you included in the services your child receives?
 11. What do you think is the most important thing that could be done to help Somali families understand their child's diagnosis/Autism?

Appendix B: Telephone Script

Hello, my name is Aragan Samatar and I am a graduate student at the School of Social Work, St. Catherine University/ University of St. Thomas. I am conducting a research study regarding how Somali parents experience, perceive, and understand their child's diagnosis, the diagnostic process, and treatment services. You were selected as a possible participant because you are Somali and a parent of an individual with autism spectrum disorder. I am hoping to interview 8-10 Somali parents.

If you agree to be in this study, I will ask you to answer a series of interview questions in which you will answer to your comfort level. The interview will take place at your desired location and should take approximately 60-90 minutes, and will be recorded with a digital audio recorder.

Do you have any questions about the study or for me at this time? Also you have the right to back out of the study at any time.

If you are still interested, the next step would be to set up an in person interview. Are there particular days and times that tend to work better for you? For confidentiality, the interview will need to take place in a private location. I would like to find a location that is convenient for you. At the time of our meeting, I will review the informed consent form with you and give you the opportunity to ask any questions of me prior to starting the interview.

Thank you for your time. Please call me with any questions or if you need to cancel or reschedule. Thank you.