

12-21-2018

Effects of Cultural and Language Barriers on the Outcome of Autism Spectrum Disorder Amongst Children from the Somali Immigrant Population of Minnesota

Amal Farah
Augsburg University

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A Literature Review Analysis: Effects of Cultural and Language Barriers on the Outcome of
Autism Spectrum Disorder Amongst Children from the Somali Immigrant Population of Minnesota

By: Amal Farah

Faculty Advisor: Doug Brock

Paper Submitted in Partial Fulfillment

Of the Requirements for the Degree

Of Master of Science

Physician Assistant Studies

Augsburg University

12/21/2018

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Abstract

Autism Spectrum Disorder (ASD) is a devastating developmental disorder with a decline in both neurological and behavioral functions. ASD can present with delays in language development, social skills, and restricts behavioral patterns. The prevalence of ASD has been on the rise in the United States with a rate of one in 69 children. Moreover, the prevalence of ASD has been drastically increasing in the Somali community of Minnesota affecting one in 32 children. Many research studies associate the rise of ASD in the Somali community with the elements of culture, tradition, and language barriers. This research paper will explore how different cultural beliefs, perceptions, and the language barrier affects the diagnosis and treatment of ASD in the Somali community of Minneapolis, MN. The findings discussed in this research paper are compiled and extracted from peer-reviewed articles, systematic reviews, and meta-analyses published between 2010 and 2018. This research paper examines the strengths and limitations of the reviewed articles and discusses recommendations and indications for future and ongoing research.

Keywords: Autism Spectrum Disorder, Somali Immigrants, Language Barrier, Cultural Competency, Health Disparities

Introduction

The prevalence of Autism Spectrum Disorder (ASD), a complex neurological disorder presenting with impaired social, behavioral and communication skills has been rapidly increasing in the US.¹⁻⁴ Minnesota has the largest population of Somali refugees making up 45% of all primary refugees in the state (figure 1).⁵ The state of Minnesota has provided opportunities and encouragements to Somalis resettling in the US.^{5,6} Somalis have thrived and assimilated in many ways; however, the cultural and language barriers with healthcare providers have led to an unfortunate outcome of late diagnosis and treatment of ASD in the Somali community.⁷⁻¹³ The diagnosis rate for children in the Somali community is significantly higher than for their African American and Hispanic counterparts while also displaying a concerning upward trend.^{8,9,11-13} The objective of this research is to address how the Somali culture and language barrier results in less than the optimal therapeutic outcome in children with ASD, especially to those born to mothers who lack proficiency in the English language.

A summarized history of Somali immigration:

Minnesota is home to the largest Somali community in the United States of America, estimated to be 46,693 and constituted about 0.9% of the total Minnesota population in 2016.^{5,6} Somali refugees began immigrating to the US and other countries in 1991 after a devastating civil war occurred, resulting in political turbulence and the fall of the central government.⁵⁻⁷ Somalia is located in Eastern Africa on a large peninsula that protrudes into the Arabian Sea known as “The Horn of Africa.”⁵⁻⁷ Somalia was considered a civilized country from the time they received their independence from Great Britain and Italy in 1960, up until the start of the civil war in 1991.⁵⁻⁷ The power struggle between various armed rebel groups led to a widespread occurrence of rape, hunger, and killings which prompted more than 250,000 Somali citizens to flee the country.^{6,7}

Refugees often arrived in the US without their families. Once they settled, they petitioned the U.S. government for visas to bring those family members.⁵⁻⁷ The civil war also contributed to the low literacy amongst Somali refugees by destroying the established education system.^{6,7} According to the Center for Disease Control and Prevention (CDC), among adults who are 15 years of age and older, the male literacy rate is approximated 49.7% and the female rate is approximately 25.8%.⁷ Acknowledging the low literacy rate is important for understanding the challenges these individuals face when navigating the American healthcare and education systems (figure 2).¹⁴

Somali refugees choose Minnesota as their new home

Minnesota's reputation for taking in refugees and helping them resettle gained wide popularity amongst Somali refugees.^{5,7} Minnesota displayed a positive image by hosting non-profits such as homeless shelters and food banks thus making survival and adaptation easier for new immigrants. According to Chambers, in the book *Somalis in the Twin Cities and Columbus: Immigrant Incorporation in New Destinations*, “Minnesota’s generous social service benefits, strong public school and university systems, employment options, and reasonable cost of living played comparatively positive roles for Somalis who settled in the state”.⁵ In addition, Minnesota's increased employment rate, and abundant charity services led to the constant arrival of new coming immigrants including Somalis, Ethiopians, and Kenyans .⁵⁻⁷

Despite facing the challenges that come with adapting to a new cultural setting, Somalis in Minnesota have made substantial efforts to create a positive influence.^{5,6} Today, these residents contribute to many aspects of the economic, social, and political incorporations in the Twin Cities.^{5,6} The Somali community of Minnesota has opened a substantial amount of businesses, religious centers such as mosques, and educational centers such as charter schools throughout the state.^{5,6} Their political and leadership roles further show their ability to strive and assimilate to a new country; this is evident from the 2018 election, in which the first Somali American legislator,

Ihan Omar, was elected to the U.S. House of Representatives.^{5,6} However, despite these gains, issues of healthcare disparities have been identified in this population, including the disproportionate rate of autism diagnosis and the recent measles outbreak that resulted from vaccine refusal.⁷

Autism spectrum disorder (ASD) signs and symptoms:

Autism Spectrum Disorder (ASD), is a lifelong developmental disorder affecting neurological and behavioral functions.^{2,15} According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), those diagnosed with ASD typically suffer from impairments in social interactions and communication, a restricted pattern of behavior, interests, and activities, and other symptoms that hinder the one's ability to function properly in everyday life.^{15,16} Prior to the DSM-V, ASD diagnosis were divided into two subcategories of autistic disorder: Asperger disorder, and Pervasive Developmental Disorder (PDD-NOS).^{16,17} Combining the subcategories of autism and defining the diagnosis on a spectrum is due to the variations of severity, ranging from mild to severe, and the wide range of possible symptoms experienced by different individuals.¹¹ Parents may observe key characteristics of the disease including a lack of social or emotional exchange, lack of eye contact or socially directed smiles, and the failure to respond to the parent's voice.^{1,16} ^{15,16} Individuals with ASD have difficulties relating to others due to social inhibiting symptoms of atypical language, repetitive behaviors, and abnormal sensory and motor processing.^{1,15,16} ASD can manifest in challenging behavioral patterns such as trouble understanding other people's feelings, talking about their feelings, giving unrelated answers to questions, becoming upset by minor changes in routine (e.g., taking a different route home from usual), and having obsessive or strong interests in particular objects. Other behavioral patterns that can occur include flapping hands, rocking back and forth, spinning in circles, and reacting unusually to the way things sound, smell, taste, look or feel.^{1,15,16} Furthermore, Autistic children often exhibit behaviors of impulsivity,

hyperactivity, abnormalities in mood and affect, and heightened responses to sensory stimuli.¹⁶

Impaired communication skills are often displayed through repetitive speech, delayed speech, lack of language development, and unusual patterns of high pitch or monotone speech.^{1,15,16}

Autism spectrum disorder (ASD) diagnosis:

In the primary care office, ASD is usually a diagnosis of exclusion and assessments occur when parents report developmental concerns.^{16,18} ASD is diagnosed by observing a child's communication abilities, behavior, and developmental level. Since medical biomarkers or laboratory diagnostic tests do not exist for ASD, the diagnosis depends strictly on the behavioral and psychological observation as well as the ability to communicate.^{4,16,18} The onset of Autism occurs within the first three years of life and disease can be detected as early as 18 months of age.^{4,16,18} The earliest possible diagnosis of ASD is crucial for effective treatment.⁴

Autism spectrum disorder (ASD) epidemiology, risk factors, and causes:

Epidemiological studies conducted over the past 50 years have shown a global increase in the prevalence of ASD.¹⁸ The CDC's Autism and Developmental Disabilities Monitoring (ADDM) network estimates that one in 69 children are autistic in the United States.¹⁸ Environmental and genetic factors both contribute to the rise of ASD. Males are found to be affected at a rate of ASD four times that of females.¹⁸ The contributing factors in the increase of ASD include advanced maternal age, overexposure to environmental toxins, poor nutritional diet, prenatal stressors, gestational diabetes, low maternal folate, and the consumption of valproic acid and thalidomide during pregnancy.^{2,11,16,19} Higher risk of ASD is seen in individuals who have siblings with ASD, individuals who have Down syndrome, fragile x syndrome, and tuberous sclerosis.^{2,16} Despite contrary beliefs that the measles, mumps, and rubella (MMR) vaccine causes the disease, scientific studies have concluded that there is no evidence of a causal association between the vaccine and ASD.^{18,20,21}

Autism spectrum disorder (ASD) therapeutic management:

Interventions including behavioral modifications and skills training programs for parents or guardians during early childhood can significantly improve difficulties with communication and social behavior, thus bettering an individual's quality of life.¹⁸ Symptoms of impulsivity, hyperactivity, and mood disturbance can be further managed with medications used for Attention Deficit Hyperactivity Disorders (ADHD) and antidepressants.¹⁶ The FDA has approved the use of risperidone and aripiprazole in treatment of aggression, severe tantrums, and self-injury behaviors in ASD.¹⁹ Many families also report seeking complementary medicine treatment and elimination of gluten, protein found in barley, rye wheat, oats, and casein (protein found in dairy) has shown to reduce behavioral symptoms in ASD.^{16,9} Vitamin D-deficiency is linked to worsening symptoms of ASD which is evident by the improvement of symptoms in ASD after restoring vitamin-D through supplements.¹⁹

The socio-economic impact of ASD:

The complexity of ASD brings on social stressors including both emotional and economic burdens that afflict many families in the US.¹⁸ Inadequate support and access to services can place substantial social and emotional burdens on the families and individuals with severe ASD.¹⁸ ASD can negatively impact an individual's ability to function properly in activities of daily living which can further isolate them from society.¹⁸ Individuals with ASD suffer from discrimination and stigma that contributes to limited educational and employment opportunities, and difficulties receiving adequate healthcare.¹⁸ The CDC notes that insufficient knowledge of ASD and misconceptions of healthcare providers creates healthcare barriers that put these individuals at a further disadvantage.¹⁸ Furthermore, lack of promotion of preventive medicine in this population makes them more susceptible to acquiring non-communicable conditions.¹⁸ Behaviors of physical inactivity and choice of poor dietary products predispose them to risks of violence, injuries, and

drug abuse.¹⁸ Research studies have further emphasized that there is a positive correlation between the prevalence of ASD and socioeconomic status across ethnic minority groups.^{9,22} The findings are explained by the fact that families with higher socioeconomic status have the financial resources and can more readily access information that can guide them to seek the appropriate medical attention.²²

Methods

A comprehensive systematic literature review was conducted by employing PubMed and Augsburg University Library databases, Google Scholar, and the UpToDate website for the purpose of extracting and compiling relative data, implications, and clinical recommendations. Databases reporting health statistics at the state (Minnesota Department of Health), national (Center for Disease Control and Prevention), and international (World Health Organization) levels were utilized to assess potential risk factors, the prevalence of disease in certain ethnicities, and population-based statistics. Key search operators included following terms separate and in combination: Autism Spectrum Disorder (ASD) with and without the addition of key terms “Somali population in Minnesota”, cultural competency, the language barrier in ASD, health disparity in ASD, and the cultural impact on ASD. The search was further expanded to include any other descriptive words relating the prevalence of Autism Spectrum Disorder or Healthcare disparity, specifically the language barrier. The listed citations of each study were further explored and traced to their original source. Various study designs including systematic reviews, meta-analyses, peer-reviewed articles, observational studies, and qualitative studies were deliberately chosen to optimize the quality of the literature review. The criteria for inclusion was set as the following: 1) Peer-reviewed articles that were published within the past 8 years (2010-2018), 2) Studies investigating the ways that cultural differences, communication barriers,

and environmental exposures correlates with a worsening disease process, 3) Articles published in English examining human subjects.

Background

A Snapshot of ASD in Minnesota:

The CDC's Minnesota-Autism and Developmental Disabilities Monitoring Network has released a community report to help the general population understand and acknowledge the increased rates of ASD.^{10,11,18,23,24} One in 42 children aged eight were found to be diagnosed with ASD and males had 4.6 times higher incidence than females. Data of intelligence quotient (IQ) was available for 79.9% of all children diagnosed with ASD; 28.1% of those children were reported to have an intellectual disability (IQ < 70). The CDC reports a late diagnosis of ASD in Minnesota, in which they state, "In Minnesota, we identify autism much later than when first concerns are reported. The lag between first concerns and diagnosis is concerning due to what we know about the importance of early intervention."¹⁸ Half of all children diagnosed with ASD received a late diagnosis with an average age of 4.8 years.^{10,11,18,23} This is highly concerning as early intervention of ASD is linked to the improved outcome of disease prognosis.¹⁸

The prevalence of ASD and co-occurring ID the Somali community of Minnesota:

The increased incidence of ASD in American children born to Somali refugee mothers has led to many forms of research studies to investigate ASD in this population. The state of Minnesota encompasses the largest Somali refugee immigrants totaling 45% of all primary refugees in the state, in which the majority resides in Minneapolis (figure 1).⁵ After the Somali communities expressed concerns regarding the increasing rate of ASD diagnosis, the Minneapolis Somali Autism Spectrum Disorder Prevalence Project (MSASDPP) in collaboration with the University of Minnesota decided to conduct a study to investigate the matter.⁹⁻¹¹

The study adopted the CDC's ADDM network consisting of a single-site, multi-source, records-based public health surveillance methodology.⁹⁻¹¹ Records were collected from medical and school systems for children with ASD aged seven to nine. The study found that there was not a significant difference in rates of ASD between Somali (one in 32) and Caucasian children (one in 36), however, they were both found to have rates higher than their Hispanic (one in 80) and non-Somali black (one in 62) counterparts.⁸⁻¹¹

Somali children with ASD have increased rate of co-occurring ID:

The rate of co-occurring intellectual disability (ID); meaning an IQ score of 70 or less, was found to be significantly higher in Somali children with ASD compared to all other ethnic groups.¹¹

Despite the small sample size with Somali children representing 8.2% of the total population studies, 100% of Somali children with ASD in the study had a co-occurring intellectual disability.¹¹

Another study that took place in Stockholm Sweden in children born in the years of 1988-1998 found the prevalence of ASD with ID to be three to four times higher in children of Somali descent compared to all other ethnicities in Stockholm. The study was repeated in children born between 1999-2003, the findings implicated that prevalence of ASD in children of Somali background remained elevated with incidence rates being four to five times higher compared to other ethnic groups in Stockholm.^{25,26} Similarly, another study in Western Australia noted that immigrant families from East Africa had three and a half times probability of having ASD + ID compared to their white counterparts.^{9,27} The exact explanation behind the increased prevalence of ASD in the Somali communities is not yet known. Multiple research studies have identified potential risk factors of ASD in the Somali communities including maternal migration, exposure to trauma, lower socioeconomic status, lack of education, and sociocultural dynamics such as health disparities.^{2,8,9,11,28}

The late diagnosis of ASD in Somali children:

The MN-ADDM reported that the average age of ASD diagnosis across all ethnicities was 4.7 years old.¹⁰ The study concluded that there is a lag between when a parent first notices developmental delays and when the child is diagnosed with ASD. In Minnesota, 73% of children diagnosed with ASD were found to show signs of developmental delay at the age of three. Although the diagnosis can be made as early as 18-24 months, only 34% of those children diagnosed with ASD received a comprehensive developmental evaluation by the age of three.^{10,18} Findings indicated that Somali children were diagnosed later than white children with average diagnosis age of 5.9 years compared to 3.7 years for Caucasian children.¹⁰ This corroborates findings from prior studies which reported that children from diverse communities often receive a later diagnosis of ASD.^{22,28-30} This suggests the need for clinical providers to attain a level of awareness that can allow them to distinguish different cultural views and perception of child development.¹⁰ One study explored the association of late diagnosis with the lower socioeconomic status of the community.⁹ A low socioeconomic status was reported for Somali Minnesotans, with 40% of the population aged 16-64 is unemployed and median household income is estimated at \$18,600. The study implied that the failure to seek early intervention in ASD children can possibly be caused by the lack of economic resources.⁹ The study also explained that the reported abnormal eating/drinking habits observed in Somali children can potentially be the cause of increasing the severity of behavioral symptoms.⁹ A population-based study also noted the increased risk of ASD diagnosis as well as the co-occurrence comorbidities of mental retardation in children born to foreign mothers. Those children were also at higher risk of displaying severe behavioral symptoms including severe emotional outbursts and impaired expressive language compared to Caucasian children.³⁰ Overall, these findings highlight the need for an early developmental screening tool in children from diverse communities.¹⁰

The perception of mental illness and cultural acceptance:

Mental illness is highly stigmatized in the Somali community and individuals dealing with mental disorders are often not acknowledged.^{12,14,31} Non-acceptance of mental illness was shown in studies exploring views of mental illness in the Somali community.^{4,12,31} The stigma surrounding mental illness in the Somali community leads to a lack of acceptance and denial of the existence of certain disorders.^{4,12,114,31} Studies have found that individuals who were perceived to have a mental illness in Somalia were shunned and alienated from their community.^{4,12,14,31} This notion is explained by the fact that Somalis conceptualize health differently from Western medicine.^{12,14,31,32} Disorders such as anxiety and depression are viewed as a general lack of health or illness by Somalis, described by symptoms like not feeling like themselves or feeling distracted. Symptoms of a headache, insomnia, and forgetfulness are not viewed as serious in this community. In general, Somalis attribute mental illness to either spiritual factors or explain these symptoms as God's will; thus, implying that there is nothing they can do to change the outcome, further leading to a failure to seek mental health support and increased isolation of these individuals.^{12,14,31,32}

Autism is a new concept in the Somali community:

Somali children have been shown to have an increased incidence of ASD with an atypically severe presentation.^{9,11} Although the reasons for the higher prevalence rate remains unknown, it's evident that this community needs assistance with identifying the appropriate tools and resources to navigate healthcare services (figure 2).^{8-14,33} The concept of identifying autism as a new word and disorder in the Somali community was a common theme that emerged in numerous research articles (figure 3).^{8-14,33} Somali parents in North America refer to ASD as the "Western disease" as they claim that the disease was never heard of nor seen prior to migrating from Somalia.^{12,14,33} In an ethnographic case study consisting of two focus groups, Somali mothers shared their perception of ASD as a new disease stating "ASD is an American or European disease".⁹

And the mothers blamed reasons for ASD incidence on the vaccinations, environment, and processed foods.⁹ They also believed that the stress associated with experiencing the trauma of the civil war and their journey of migration contributed to etiology of ASD.⁹ This phenomenon was explored in multiple studies. In a recent evidence-based review investigating environmental risk factors for autism, six out of ten population-based studies showed higher rates of ASD in children born to migrant mothers compared to the general population. The findings were further supported by another meta-analysis.² A qualitative study using community-based participatory research (CBPR) method was conducted in the United Kingdom in an attempt to identify and improve health inequalities in Somali families experiencing ASD.¹⁴ The study highlighted factors contributing to the delayed diagnosis of ASD in the community. The first identified problem was the lack of having a word to describe autism in the Somali language and the poor understanding of ASD as a mental disorder. Somali parents discussed feeling confused, shocked, and isolated when their child is diagnosed with ASD. Participants felt isolated because not only were they uncertain of what ASD was, but the idea of Autism being a new word and disorder prevented them from finding ways to relay diagnosis to their families and community. Another confusing aspect for Somali parents to understand is the normal appearance of a child with ASD because they believe that a serious disorder should be apparent by signs of physical impairment.¹⁴

Autism is culturally not accepted and poorly understood in the Somali community:

The challenging behaviors exhibited by the children with ASD such as running from parents and having violent outbursts were deemed intolerable in the Somali community, thus creating feelings of shame amongst parents.¹⁴ Several studies have implicated that mental illness is perceived in a negative manner as it's poorly understood and often not acknowledged in the Somali community.^{1,13,31-33} The negative perception of mental health subjects many Somali families to stigma and social exclusion.^{31,33} Furthermore, Somali mothers feel the need to hide their children as

ASD is not culturally accepted and this further delays the process of seeking medical evaluation.¹⁴ A similar UK study, explained how the stigma surrounding the lack of wording for autism and the poor understanding of the disorder led to many children with ASD to be labeled as sick, crazy, naughty, or different.³³ Additionally their parents were blamed for not controlling their combative behaviors, which often led the children to suffer from social rejection and isolation.³³ This study concluded that the stigma of autism was associated with a lack of comprehension of the disease, lack of vocabulary related to autism in the Somali community, and the overall prejudice and “taboo” that surrounds the topic of mental illness in the community. Furthermore, parents that participated in the study revealed a need to find their own descriptive words and language to define their child’s diagnosis.³³ Another compelling aspect found in the study was the conflicting messages Somali parents received from their providers and their communities. Participants expressed the false reassurance that was given to them by the Somali community such as beliefs that their child would grow out of the symptoms and behaviors of ASD.¹⁴ This resulted in one of two things, either the father consistently provided false reassurance to the mother that the child would outgrow it thus delaying seeking intervention, or they would stray away from the family altogether leaving the mother alone.¹³ Another study that was conducted to understand the cultural impact on ASD, found that many fathers failed to acknowledge developmental issues of ASD because it is not culturally acceptable.¹³ In the study, all the participants declared that the male figures in their lives whether it’s their husband, father, or brother were less inclined to believe that symptoms of ASD would persist and they strongly believed that it would fade away as the child grows.¹³ Within the Somali community, taking care of the children and household is considered a mother’s main responsibility while the father is responsible to bring home the income. A common misconception experienced by Somali mothers is that the diagnosis of their child with ASD will, in turn, be a reflection on them as a mother. This stigma and misperception often outweighs the

disorder itself and leads to either silence or a false hope that one day their child will outgrow ASD.¹³

The belief that ASD can be outgrown:

The perception of outgrowing ASD was identified in an exploratory study conducted in the Somali community of Minnesota by Kuenzli as a theme of denial by the community.¹² In the study, Kuenzli found that upon initial diagnosis of ASD Somali families responded with denial since ASD was perceived as a new disorder that would be outgrown in the community. The Somali community understands the concept of childhood development differently from the Western world.¹² Additionally, the word “delay” does not directly translate to the same meaning in the Somali language which creates space for the misconception of the ASD diagnosis.¹² The Somali community understands developmental delay to mean slower learning in which the child will eventually catch up and they fail to understand that the word implies sustained and persisting delay in development.^{12,13} This misunderstanding leads to failure of seeking medical attention because they believe that ASD will be self-limiting overtime.^{12,14} The last concept identified in the UK study were the challenges Somali parents experience with accessing healthcare services.¹⁴ An inadequate comprehension of the educational and health systems led many Somali parents to feel overwhelmed and unsure of where to begin the process of intervention.¹⁴ This unfamiliarity with services and language barriers led to the delay in accessing services in some families.¹⁴ This illustrates the difficulties parents experience in understanding there is a strong support system and services for mental health and individuals are not isolated and ostracized like they were back in Somalia.¹²

The impact of the Somali cultural beliefs and language barriers on diagnosing ASD:

Effective communication skills and cultural awareness in multicultural healthcare settings is an essential factor in receiving adequate care.³¹ Increasing patient diversity requires healthcare

systems across the United States and in the Twin Cities to implement a culturally diverse healthcare workforce, but also train more culturally competent providers.^{1,31} Numerous studies have identified the impact that cultural beliefs and language proficiency have on the perception and acceptance of ASD amongst Somali families.^{8-12,14} The term culture is defined as “the values, beliefs, language, rituals, traditions and other behaviors that are passed from one generation to another within any social group.”⁸ The perception of healthcare in Somali refugees is shaped by their cultural beliefs, traumatic experiences, and their broken education system.^{8,9,13,31} Culture differences have been shown to play a role in the understanding of childhood development and perception of ASD diagnosis. Notably, language barriers have contributed to the late diagnosis and failure to seek follow-up care in Somali children with ASD.^{13,14} This is a significant concept in understanding the prognosis of ASD in this community. Early recognition and treatment of ASD is the most optimal evidence-based therapy according to the World Health Organization (WHO) “intervention during early childhood is important to promote the optimal development and well-being of people with an ASD.”⁴ Early diagnosis is crucial as it defines areas of development need and tailors treatment towards teaching skills that improve an individual’s quality of life.^{8,18} A case study conducted to find how the elements of culture affect ASD, it was found that children from non-English speaking families were diagnosed later with ASD compared to children from English proficient families.¹² They also identified that Somali refugee mothers believed that the language barrier inhibited them from communicating with their providers and in turn, they felt that the providers were more likely to dismiss their considerations and opinions.¹³ A similar study found 28% of parents of children with ASD from non-English speaking households reported severe ASD compared to 13% of parents from English speaking households.³⁴ Additionally, due to the language barrier, many Somali refugee mothers lack awareness of the resources that are available to their children with ASD putting their children at a disadvantage.^{8,9,12,13,33} The language barrier has also

been associated with shaping the perception of healthcare in the community. The mothers from the case study focus groups expressed low expectations for treatment due to “service providers and clinicians failing to understand their culture and as a result are unable to communicate with them both literally and figuratively.” They were also under the impression that the prevalence of ASD would decline if the community was to go back to Somalia where their children would have more access to sunlight, organic foods, and fewer vaccinations requirements.¹³ These communication barriers persist despite the use of interpretation service systems.³¹ This notion calls for a culturally aware health care systems where providers integrate patient’s experience and cultural views into their treatment plan to produce a quality, culturally competent care.^{31,35}

Measles Outbreak in Somali community of Minnesota:

The misconception of the MMR vaccine causing ASD led many Somali families to avoid routinely scheduled vaccinations for their children. Community members are sometimes provided false information promoting such misconception according to the CDC “Anti-vaccine proponents reached out directly to the Somali community, bolstering fears that MMR vaccine caused autism, and encouraging Somali parents to refuse vaccination.”⁷ The CDC also found a decline in vaccination with rates dropping from 91% in 2004 to 54% 2010.⁷ The first case of measles since eradication by vaccination occurred on April 10, 2017, in the Somali community. The Minnesota Department of Health (MDH) and Hennepin County Human Services and Public Health started a thorough investigation to identify the cause.^{6,36} A total of 65 cases across varying schools, daycare, and healthcare facilities were confirmed by May 31, 2017.³⁶ The CDC found that there were 79 confirmed cases in the Twin Cities as of August, 2017 with 64 cases being reported in the Somali community.⁶ Parents opting out and declining the MMR vaccinations for their children were observed over an eight-year period (2007-2014). The study concluded the misunderstanding that the MMR vaccine causes ASD and the concerns regarding the increased prevalence of ASD led to

the decrease in vaccination rates further leading to susceptibility to measles. An intensive community outreach program and accelerated distribution of MMR vaccine amongst children 12 months and older was established during the outbreak.³⁶

Another study was conducted to answer whether Somali parents are more likely to refuse vaccination compared to non-Somalis. The study was conducted in 2011 after an outbreak of measles was traced back to a Somali child who was unvaccinated.²⁰ The study found that Somali parents were more likely to decline the MMR vaccine for reasons such as hearing about adverse effects relating to the vaccine and their strong belief that ASD is caused by the vaccine. Multiple vaccines at a single clinic visit worried parents regarding possible side effects that could occur in their child.²⁰ The findings of these studies further emphasize the crucial need to eliminate communication and cultural barriers in the healthcare system with culturally competent healthcare providers and highly skilled interpreters. The CDC recommends that clinicians should respect concerns expressed by parents and should approach discussions regarding immunization with cultural humility and empathy.⁷ In addition, healthcare providers need to adopt a better model in educating patients from different cultures and find ways to overcome barriers by aiming to build a strong rapport with patients and their families.⁷

Discussion

The purpose of this research paper was to determine if cultural and language barriers result in a less than optimal therapeutic intervention for children with ASD born to Somali immigrant mothers. As the prevalence rate of ASD continues to rise, a multitude of research studies have been conducted and have identified the significant role that culture, tradition, and communication barriers have played in the diagnosis and treatment of ASD. Cultural beliefs, attitudes, and goals influence the type and level of behaviors that are deemed concerning when parents choose to seek medical guidance.⁸

One common concept emerges from the review of the research; ASD is a new word and disorder in the Somali community. From Sweden to the UK, and across the US, all Somali participants claimed that they had never experienced or seen anyone experience ASD in Somalia. In my literature review, I have found that there is no word in Somali or even a name for the disorder. This alone has raised concerns and confusion for Somali mothers dealing with a new ASD diagnosis. There is a disconnect between what Somali mothers view as a new disease and the reality of the situation, which is their lack of understanding of the etiology and origin of ASD. Throughout the research, all interviewed Somali participants claimed that this was a new disorder or a disorder of the Western world. I disagree somewhat with this claim. As I have found in my research, mental illness is not acknowledged and is highly stigmatized in the Somali community. From my perspective, it's difficult to claim that ASD was never seen or heard of before in Somalia because any individual showing any signs of mental illness was immediately designated as "Crazy" and individuals were alienated from the community without any further investigation.

Language barriers have been a recurring issue throughout many of the reviewed research studies and have further been linked to the late diagnosis of ASD in Somali children. The language barrier has led to a misunderstanding of the etiology and prognosis of ASD amongst the Somali community. For instance, community members were passing on lay advice that encouraged parents to believe that their child would improve and outgrow the symptoms brought on by ASD. This false reassurance led many parents not to seek necessary medical help.

From my own experiences volunteering in this community to raise awareness for ASD, I have come across several interesting perceptions. Parents of autistic children shared their struggles and beliefs of ASD with me. I found that language and cultural differences do play a role in the late diagnosis of ASD. In Some Eastern and African cultures, direct eye contact is seen as disrespectful while the opposite is true in the Western world.¹² In the Somali culture, lack of eye contact is not

viewed as a problem as it's both a cultural and religious practice. In the Somali culture, avoiding eye contact is perceived as a sign of respect and in the Religion of Islam, it's a rule of practice that one should lower their gaze when interacting with the opposite sex.³⁷ How can Somali mothers, therefore, notice that their child's behavior of avoiding eye contact is a sign of a clinical problem? Therefore, leading to a later diagnosis as the mothers continue to wait until they feel it's concerning or problematic. Also, the delay in speech poses another concern as most Somali mothers associate delayed speech with the confusion children experience when they need to learn both English and Somali. This ties in what I found in my literature research, which is there no direct translation for the word "delay" in the Somali language. The word "delay" translates in Somali to mean "delayed but will eventually catch up", so many fail to understand that ASD means a sustained persisting delay that can only improve but will not go away. This makes it very difficult for Somali mothers to understand the prognosis of ASD. Many mothers are already under the false assumption that ASD can be outgrown, so when they hear a word such as "delay" that further reassures them. The failure to understand ASD, combined with the conflicting messages provided by community members, lead many parents to come up with their own understanding of ASD in order to accept their diagnosed children.³¹ Delayed diagnosis means a later start to intervention which puts these children at disadvantage. The earlier a child can receive intervention for ASD symptoms the better their overall health outcome will be.

The challenging behaviors exhibited by children with ASD lead many Somali mothers to feel ashamed. The stigma surrounding mental illnesses in the Somali culture causes many parents to hide their children from the community and avoid seeking early medical help. This supports the need for more ASD awareness amongst the Somali communities and to increase outreach efforts. Information about ASD could be delivered through radio, websites, or community channels in an effort to spread awareness. There is also a need for mental health professionals to overturn mental

health stigma through proper education in the Somali community. Awareness of different cultural views of ASD should be raised among healthcare providers. Primary care providers should also educate parents with the use of interpretation services on early signs of ASD. In addition, access to multilingual screening tools should be made available in primary care clinics.

Strengths and limitations of reviewed articles & future recommendations:

The strengths of the reviewed research articles is that they were culturally sensitive and the studies were designed specifically for the local Somali communities. The studies aimed to answer specific questions pertaining to ASD in the Somali community with actively engaged Somali participants. And inductive analysis was done to reflect the views and experiences of the participants by using participants interviews and their answers to questionnaires. Many of the reviewed articles were qualitative studies with small sample sizes. The findings from studies consisting of small sample sizes impose a limitation because they may not generalize to the entire Somali population. The results of the studies can be strengthened by repeating the studies with larger sample size.

There is also a need for more appropriately-level trained Somali interpreters to help close the gap between Somali parents of ASD children and English speaking providers. For instance, in my literature review, I have found that many parents struggled to connect with their providers even with the use of an interpreter. Interpreters who can effectively relay information between a patient and a provider despite cultural differences is highly in need. For future research, an ideal study should investigate whether there are similar outcome and diagnosis of ASD back in Somalia. Further comparison between those who did not migrate away from Somalia and children born to Somali immigrant can help answer the question whether the change in cultural setting has a larger or smaller impact than what's expected.

Conclusion

The prevalence of ASD has been found at an increasing rate in the Somali community of Minneapolis, MN. Somali children with ASD have also been found to have a later diagnosis with an average age of 5.9 years old compared to their Caucasian peers which put them at a greater disadvantage. There are many contributing factors that have been found to play a role in the late diagnosis of ASD in the Somali children of Minnesota.⁹ The misunderstanding of the etiology and origin of ASD, the lack of wording for ASD in the Somali language, the inability to access proper healthcare services, and the misunderstandings between healthcare providers and mothers have all attributed to the late diagnosis of ASD. Overall, children with ASD from different ethnic backgrounds lack access to resources, miss their opportunity to early interventions, and have less of a chance to have a positive outcome while living with ASD. Early identification and Early start of intervention are crucial in the overall outcome of ASD. Yet, the majority of these children miss out on early intervention due to language barriers and cultural misunderstanding of ASD. A combined effort by parents and service providers needs to be placed in the healthcare system to eliminate barriers that can affect a child's life. Healthcare providers and other service providers need to make a conscious effort to understand different cultural, traditional, and religious beliefs amongst diverse communities. Somali parents need to be provided more services such as broadcasting information through a community channel to eliminate their misconceptions about ASD and other mental illnesses. Also, a screening tool for the earliest possible diagnosing age of ASD needs to be implemented and used more often especially with newly arriving immigrants. Finally, proper patient education regarding the signs and symptoms of ASD needs to be given to all parents with young children.

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Appendices

REFUGEE ARRIVALS IN MINNESOTA, 2016

Source: MN DHS

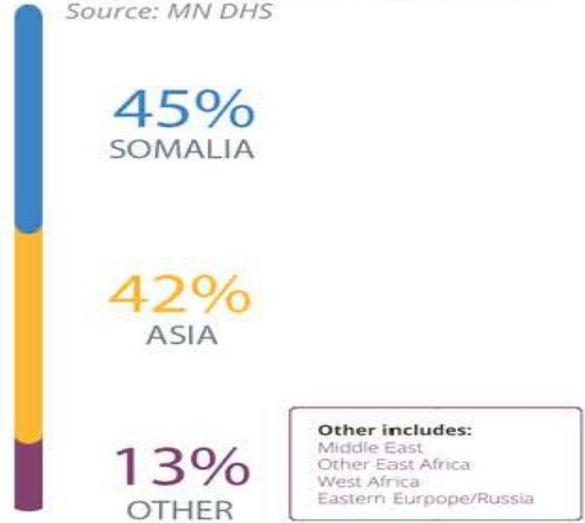


Figure 1. Primary Refugee Arrival.⁵

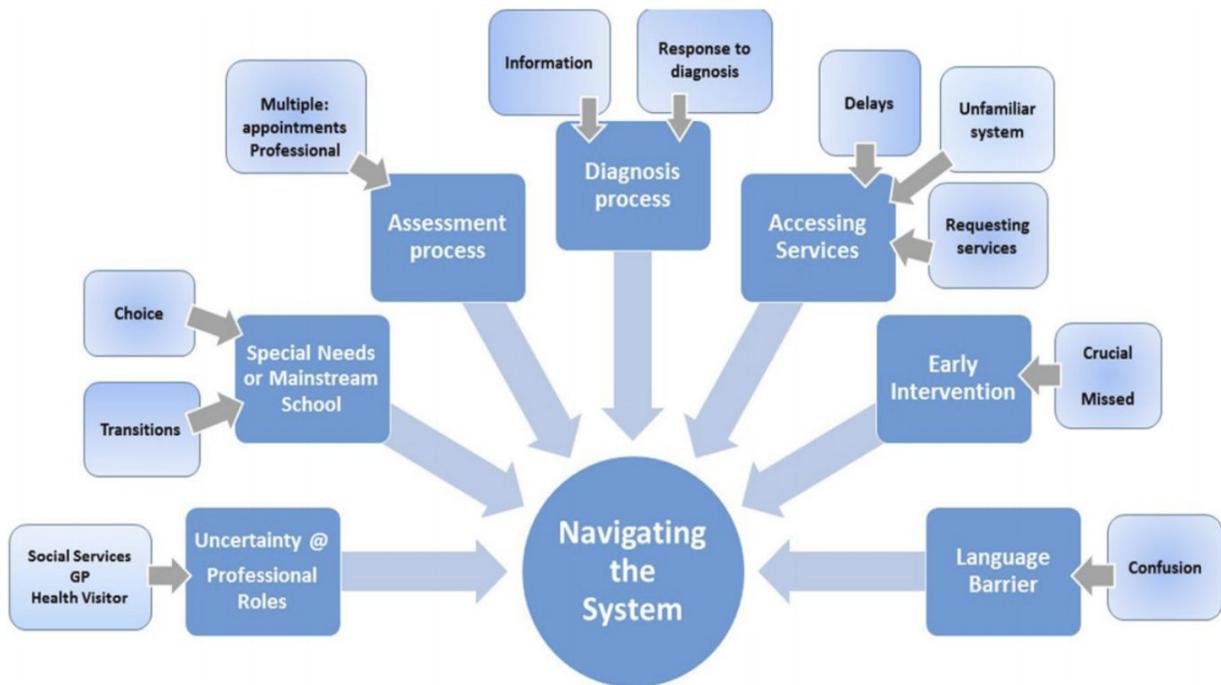


Figure 2. Navigating the System.¹⁴



Figure 3. Perceptions of Autism.¹⁴



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