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Aishwarya Sasidharen Date

Factors of Acceptance and Quality of Life: the experience of Autism Spectrum Disorder (ASD) in the Asian Indian community

By

Aishwarya Sasidharen

Behavioral Sciences and Health Education

Dawn L. Comeau, PhD, MPH
Committee Chair

Jessica M. Sales, PhD, MA
Committee Member

Colleen McBride, PhD
Department Chair

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By

Aishwarya Sasidharen
Bachelor of Arts, Global Health
Mercer University
2016

Thesis Committee Chair: Dawn L. Comeau, PhD, MPH

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Abstract

Factors of Acceptance and Quality of Life: the experience of Autism Spectrum Disorder (ASD) in the Asian Indian community

Background: Autism Spectrum Disorder (ASD) is a neurological disorder that impedes the social and communication development of a child. According to the Centers for Disease Control and Prevention, 1/59 children in the United States (U.S.) were diagnosed with ASD based on 2014 data of 8-year-olds. Although numerous studies indicate the benefits of early interventions for children at risk for ASD, many families access these services after the child has surpassed critical developmental milestones. ASD impacts all racial/ethnic groups equally; however, few studies assess the role of cultural beliefs on the family's experience with having a member with ASD. Due to stigma in some cultural communities, some families are less likely to share their concerns with others to avoid shame and humiliation. Limited studies assess the influence of culture on Asian families who have a family member with ASD. However, numerous findings indicate that stigma towards mental illness exists in many Asian communities. Furthermore, a paucity of literature exists regarding the implications of culture in the process of acceptance and the day-to-day life of Asian Indian families in the U.S. affected by ASD.

Objectives: This study aims to explore the impacts of cultural perceptions on Asian Indian mothers' acceptance of the child's diagnosis, lifestyle choices, and relationship with the cultural community.

Methods: Semi-structured qualitative interviews were conducted with Asian Indian mothers who have ASD-diagnosed children (N= 20). Interview domains focused on mothers' experience of having a child with ASD, day-to-day life experiences, and experience with Indian culture. All audio-recorded interviews were transcribed verbatim to implement a thematic analysis via MaxQDA software.

Results: Three main themes emerged from the data: *family as a central role, the role of social expectations*, and *lack of awareness*. All participants considerably followed some level of kinship, and this priority towards family made them act on their child's best interest. Moreover, this priority of the child overshadowed these participants' need to fulfill societal expectations and changed focus from developing their child's academic abilities to improving their child's independent living skills. Contrarily, some mothers expressed that many Asian Indian families affected by ASD are concerned about meeting societal expectations that are measured by academic achievements, job opportunities, and income. Therefore, participants discussed how families of the Indian community might not share their concerns about their child due to fear of ostracization. Additionally, these mothers stated that lack of awareness in their healthcare, cultural, and social community discouraged them from sharing their concerns and finding adequate resources for their child.

Conclusion: These findings support the need to expand further current outreach models to incorporate cultural context to spread awareness of ASD in various cultural communities. Future research can assess the indication of cultural perceptions and stigma in the choices of families from multicultural communities in the U.S. who are affected by ASD.

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Chapter I: Introduction

1. Introduction

Autism Spectrum Disorder (ASD) is a neurological disorder that hinders the social and communication abilities of a child (Zwaigenbaum, Lonnie, Bryson, & Garon, 2013). Due to the lack of understanding regarding the nature of ASD, professionals have difficulty defining its' etiology (Lyall et al., 2017). Despite this ambiguity, the Centers for Disease Control and Prevention (CDC) estimates that about 1 in 59 children are diagnosed with ASD, emerging as an epidemic (CDC, 2018). Males are four times more likely to be diagnosed than females (CDC, 2018; Lyall et al., 2017). Although non-Hispanic white families are more likely to receive an early ASD diagnosis than non-Hispanic black or Hispanic families, all racial/ethnic groups are equally susceptible (CDC 2018). Additionally, ASD is prevalent among children with higher socioeconomic backgrounds. Due to the increased level of responsibilities, families are faced with severe emotional and financial burden (Horlin, Falkmer, Parsons, Albrecht, & Falkmer, 2014; Weiss, Robinson, Fung, Tint, Chalmers, & Lunsky, 2013). Findings depict the importance of early intervention in alleviating symptoms of ASD, but many parents access these services after their child has surpassed many of the developmental milestone markers (Maenner, Schieve, Rice, Cunniff, Giarelli, Kirby, Durkin, 2013).

Despite the equal susceptibility of ASD across various ethnic groups, few studies explore the factors of the family's process of acceptance and understanding of ASD. Since parental involvement is essential in accessing interventions, parental beliefs, and perceptions impact the child's quality of life (McConachie & Diggle, 2007). Few studies have that assess the barriers to accessing early interventions examine the role of culture. Culture can be described as beliefs and ideologies of a social group that define a way of living. Since disability and illness are defined differently in several cultures, these varying definitions could impact a family's process of acceptance and quality of life in the context of ASD (Ravindran & Myers, 2012). Social interactions and belief systems may influence the family's life choices (Ravindran & Myers, 2012). During the initial years of a child's development, the communities that child interacts with may influence his/her developmental projection. Social/communication issues may be missed as distinctive in various cultures (Sarrett, 2015). Additionally, as the stigma of mental illness is prevalent in many cultures, families may be influenced by the interactions from their cultural community (Kinnear, Link, Ballan, & Fischbach, 2016).

Few studies have been implemented to understand the influence of ASD on the lives of families from the Asian communities. Although the statistics note that the rates of ASD are much less in the South Asian communities, the prevalence of ASD is increasing by 1% globally (Hahler & Elsabbagh, 2015). Although few studies examined perceptions of ASD in the Asian community, findings elucidate the apparent stigmatization of mental illness labels (Ravindran et al., 2012). One qualitative study employed in India and Pakistan noted mothers who had difficulty accepting their child's condition due to the lack of acceptance from their community (Minhas et al., 2015). Additionally, the stress families mainly face regarding their child's future after their demise and families indicating difficulty accepting their child's diagnosis. Families at that stage have accepted their child's diagnosis, but have trouble finding activities to engage with their child. Furthermore, families stated a paucity of services and facilities available for their children. To understand the influence of geography and culture in acceptance of children with ASD, Sarrett implemented a qualitative study to compare home environment of families with Autism in Kerala, IN and the Atlanta, GA, USA which evaluated the family environment to indicate the level of acceptance and quality of life of the families (Sarrett, 2015).

Additionally, few studies have examined the impacts of cultural hybridization on families of children with ASD. As individuals from various cultures assimilate to another country, exposure to another culture could reshape their perceptions and internal beliefs (Stockhammer, 2011). As anthropologist Arthur Escobar suggests, cultural communities are continually shaping and reshaping their views and gathering information from outside and practice along with existing cultures and communities (Sarrett, 2015). Currently, two studies incorporated cultural hybridization to understand Asian Indian immigrants' process of understanding ASD. Ravindran and Meyers employed a quantitative study to explore the quality of life of Indian families of children with ASD living outside India. The findings suggest that families who were more assimilated to the American culture were more accepting of their child's diagnosis (Ravindran & Myers, 2013). However, due to the nature of the study, the data cannot provide insight into the various factors that shaped their perceptions. Additionally, a qualitative study explored parenting styles of Asian Indian families with developmental disabilities in Washington, D.C (Zechella & Raval, 2016). In this study, their parenting style changed, as families put less emphasis on academic success and focused on what was considered best for their child (Zechella et al., 2016). By incorporating the role of culture, researchers could then understand how cultural exposures influence a family of a child with ASD's process of acceptance and the quality of life. Furthermore, public health professionals can utilize this knowledge to create interventions that account for different cultural principles.

Purpose:

As the rates of ASD cases are increasing exponentially, current interventions should imperatively question the internal and external barriers that encourage or discourage a family from seeking resources. Qualitative research is essential in obtaining in-depth information on cultural perceptions. This study aims to examine the cultural perceptions of Autism Spectrum Disorder (ASD) in the Asian Indian community. The research questions guiding the study are:

- What impact do Indian cultural values have on the family's process of accepting their child's diagnosis?
- How do Indian cultural values inform the lifestyle of Indian families with ASD children?
- How does an ASD diagnosis impact a family's relationships with their cultural/familial community?

By understanding the cultural perceptions of ASD, public health professionals can further expand outreach models to incorporate cultural principles to reach racial/ethnic minority groups.

Chapter II: Literature Review

This study will examine the influence of cultural beliefs in Asian-Indian families of Autism Spectrum Disorder (ASD)'s process of acceptance and quality of life. Furthermore, this chapter will delve into current literature on ASD, impacts of early interventions, the prevalence of ASD globally and in South Asia, the relationship of culture and ASD, cultural hybridization, and the gaps in the existing literature to further inform the development of the research.

Autism

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that impedes social and communication abilities and provokes the repetitive behavior of a child (Zwaigenbaum et al., 2013). Some children develop symptoms before 24 months, whereas some children developmentally regress after the age of 2 years (CDC 2018). Children can have sensory issues and medical conditions such as epilepsy and gastrological problems (CDC 2018; Zwaigenbaum et al., 2013). The pervasiveness of symptoms, such as communication and other behavioral components, varies with each child. With much uncertainty, the etiology of autism is claimed to be a combination of genetic and environmental factors (Shaw, Sheth, Li, & Tomljenovic, 2014). Regardless of the ambiguity of ASD's etiology, 1 out of 59 children are diagnosed with ASD, with males four times more likely to be diagnosed (CDC 2018). This prevalence has been noted by the Autism and Developmental Disabilities Monitoring Surveillance system (ADDMs) of the Centers for Disease Control and Prevention in 11 sites (CDC 2018). The ASD prevalence worldwide has increased from 20 to 30-fold since the earliest ASD epidemiological reports in1960s (Boat & Wu, 2015). Some of this could be due to the increased awareness of ASD symptoms and changes in definition of diagnosis. In the United States, non-Hispanic white children are more likely to receive a timely diagnosis than non-Hispanic black Hispanic, and Asian children (CDC 2018; Zechella et al. ,2016). However, ASD is more prevalent amongst higher socioeconomic status families (Christensen et al., 2018). With these findings, families of children with ASD have more healthcare visits and prescription drugs, with higher healthcare and school costs. Leigh et al. states the economic burden of ASD service utilization to increase from $268 billion in 2015 to $461 billion in 2025 (Leigh & Du, 2015). Furthermore, the costs for ASD services might surpass the cost of diabetes and ADHD due to an alarming increase in cases (Leigh & Du, 2015). In addition to the increased financial cost, families may experience more isolation and limited social support due to the high demand for attention towards the child (Weiss et al., 2013; Weiss, 2002).

Early Interventions:

Although the etiology of ASD is unknown, early intervention can significantly improve the development trajectory of an at-risk child (Bradshaw, Steiner, Gengoux, & Koegel, 2015; Zwaigenbaum et al., 2013). Regardless of ethnicity, early intervention has repeatedly illustrated significant improvement in a child's overall life quality (Hahler & Elsabbagh, 2015). Early intervention is primarily targeted before the beginning of preschool (3-4 years old) (Zwaigenbaum et al., 2015). A child accessing interventions by the age of 2 would drastically decrease ASD symptoms, as the neural plasticity at this age is vulnerable to brain development (Bradshaw et al., 2015). To support the necessity of accessing interventions by the age of 2, Bradshaw compiled literature to examine interventions implemented from 2000 to 2012. Findings stated that interventions implemented before three years old could show a significant reduction of ASD symptoms after the age of 5 (Bradshaw et al., 2015). Additionally, the studies emphasize that children should continue practicing the skills learned in interventions outside of treatment sessions. McConachie et al.'s study shared the importance of family involvement while implementing interventions to improve the social and communication outcomes of the child (McConachie & Diggle, 2007). After assessing the quality of their involvement in their child's development, the study highly encourages parents to incorporate these therapeutic skills from these interventions into their familial daily life (McConachie & Diggle, 2007). Furthermore, some interventions are incorporating parents in the model to increase the child’s ability to build social relationships. One intervention, known as the Early Start Denver Model (ESDM) that utilizes Applied Behavioral Therapy (ABA), helped at-risk children gain their overall ability to communicate and interact with the world in two years in comparison to children in community intervention (Dawson et al. 2010). Another type of intervention called Early Behavioral Intensive Therapy (EBIT) has shown significant improvement in the child’s communication development of children at-risk (Reichow, 2012). Nahmias et al.’s study showed that children who were in inclusive EBIT had better cognitive scores after the intervention compared to children in community setting EBIT, and the interventions were more successful with children who had severe behavioral and ASD symptoms (Nahmias, Kase, & Mandell, 2014). Through the Individuals with Disabilities Education Act, the families are permitted access to services for a child at risk for developmental disabilities and should request for development evaluation (Christensen et al., 2018). However, most families receive the diagnosis after the child has surpassed the age to develop key milestones (Maenner et al., 2013).

ASD Globally

Although limited research has been conducted regarding ASD internationally, this developmental disability is becoming prevalent globally (Hahler et al., 2015). In 2010, the surveillance system estimated about 52 billion cases of ASD worldwide (Baxter, Brugha, Erskine, Scheurer, Vos, & Scott, 2015). After implementing a systematic analysis, ASD was shown to be the leading developmental disability amongst children under five years (Baxter et al., 2015). Additionally, ASD was listed among the 20 leading causes of disability in the 2010 Global Burden Disease (Murray et al., 2013). With increasing awareness, countries' surveillance systems are trying to obtain more accurate estimates of ASD cases to understand the current rates (Hahler et al., 2015). However, healthcare professionals in developing nations have difficulty providing an ASD diagnosis, as the instruments used to diagnose ASD are created by healthcare professionals from developed countries (Hahler et al., 2015).

ASD and Culture

The expression of ASD symptoms is significantly influenced by the environment the child interacts with (Sarrett, 2015a). Most narratives of families with disabilities are mostly non-Hispanic White families, and these narratives may not be representative of all racial/ethnic groups who have different cultural interactions (Casco, 2015; Perepa, 2014; Ravindran, & Myers, 2012). Culture can be defined as values and beliefs held by one social group that are passed on for generations (Hahler et al., 2015). The perspectives of physical and mental disability vary by cultural understanding and interpretation of the symptoms (Hahler et al., 2015). Although ASD is prevalent amongst all racial groups, limited research delves into the cultural implications of a family having a member with ASD.

Researchers and scholars are slowly acknowledging the implications of cross-cultural viewpoints in the decisions of racial minority families with ASD. International Association of Marriage and Family Counselors suggests that many families believe ASD is caused by genetics and birth outcomes (Carlson & Dermer, 2017). In some cultures, a child's developmental delay may not seem like a risk factor, as some parents believe he/she will outgrow it (Hahler et al., 2015). To examine the perspectives of ASD in Brazil, one ethnographic study interviewed families of children with ASD and inquired on issues, such as the identity, the role and activism of parents, and the perceptions of healthcare facilities (Rios & Costa Andrada, 2015). Due to the lack of support for individuals with disabilities in Brazil, parents of children with ASD encouraged to support and activism to promote inclusivity for individuals with ASD and other disabilities (Rios et al., 2015). Another qualitative study interviewed African American families, who blamed the cultural stigmatization of mental disabilities for the delay in receiving timely diagnosis of ASD and effective treatment (Burkett, Morris, Manning-Courtney, Anthony, & Shambley-Ebron, 2015). Hahler et al.'s review of cultural perceptions explicated how some African Americans believed that ASD was impacted by diet and food contamination. In contrast, Latino mothers thought that the child was a gift from God (Hahler et al., 2015).

Cultural perceptions may impact the decisions made by families. For example, some Latino mothers were likely to seek other forms of nontraditional treatment for their child (Carlson, J., & Dermer, S. B., 2017). Secondly, some families may not consider lack of direct eye contact as a concern, as some cultures find it inappropriate to stare or give direct eye contact while speaking (Gershoff et al., 2010). Therefore, the cultures perceptions of specific communication skills may influence the families' decisions to access treatment (Perepa, 2014). Daley's qualitative study in northern India informed that those families of children with ASD were likely to notice symptoms of ASD due to Indian cultural emphasis on emotional-social closeness with people (Daley, 2004). Sarrett's study compared the lifestyles of those family members affected by ASD in Kerala, IN and Atlanta, GA, to assess household arrangements (Sarrett, 2015a). The households in Atlanta catered more for the child's development, whereas the houses in Kerala were described as "custodial," as they had more individuals living together. Furthermore, Sarrett suggested the possible impact of geographic location and cultural factors on families' priorities and their process of acceptance.

Regardless of the varying perceptions of ASD, stigma towards mental illness is prevalent in many cultures (Sarrett, 2015a). Some of these stigmas stem from negative interpretations of mental illness; as an example, some Asian individuals interpret mental illness as a punishment from God (Jegatheesan, 2014). Due to these negative connotations of having mental illnesses, children with ASD may be ostracized and shamed from their communities (Lu et al., 2015; Jegatheesan et al., 2014; Zechella et al., 2016). One qualitative study assessed Taiwanese families of ASD process of acceptance, and the families were negatively influenced by cultural stigma, as many were less likely to share concerns and access treatment for their child (Lin, Orsmond, Coster, & Cohn, 2011). Moreover, these cultural indications may influence the likelihood of families accessing treatments.

ASD in South Asia:

The South Asian region contains more than 20% of the world’s population (Hossain et al., 2017). Due to the inability to accurately capture the ASD population in these areas, few studies have examined the influence of ASD diagnosis and acceptance in the Asian culture. Kang-Yi et al. employed qualitative research regarding the impact of Korean Culture on families of children with ASD's attitudes, beliefs, interactions, and coping mechanisms (Kang-Yi, C. D., Grinker, R. R., & Mandell, D. S., 2013). From this study, Kang-Yi et al. discussed how Korean mothers were overwhelmed by their child's lack of communication and improvement. These mothers also stated about receiving little to no support regarding their child's needs from clinical and other healthcare professionals (Kang-Yi et al., 2013). Contrarily in this study, family support served as a protective factor for many of these mothers (Kang-Yi et al., 2013). Furthermore, if professionals are aware of cultural beliefs and appropriation, developmental interventions can be successful in these countries. One study employed a systematic review of community-based research projects of ASD diagnosis and understanding in South Africa and South Korea (Grinker et al., 2012). These studies exemplified the significance of community engagement while implementing culturally acceptable methods (Grinker et al., 2012). Additionally, the studies elucidated the cultural meanings of mental illness, as it is highly stigmatized (Grinker et al., 2012).

Moreover, findings suggest that the prevalent stigmatization of mental illness in Asian culture can perpetuate shame and ostracization. One comparative qualitative study employed in India and Pakistan explored families' attitudes and beliefs of ASD (Minhas et al., 2015). Families of children with ASD expressed their concern about their child's future after their demise and denial of their child's prognosis due to negative support from their community (Minhas et al., 2015).

ASD in India:

To further understand the influence of the Indian culture on the experience of having a child with ASD, this study must discuss elements of the Indian culture. Like many other Asian cultures, the decisions in the Indian community are centered around family, following a collectivistic model (Chadda & Deb, 2013). Traditionally, women serve as caretakers and take responsibility for household chores and family management (Rao, McHale, & Pearson, 2003). Since the culture follows a patriarchal structure, the paternal figure employs most household decisions and they are known to manage the financial aspects of their households (Rao et al., 2003).

In India, individuals with mental illness are discriminated against due to being perceived differently by societal standards (Ravindran & Myers, 2012). People may regard disabilities as a personal tragedy or negative indications of an individual (Buckingham, J., 2011). Buckingham suggests that these perceptions derive from the religious texts elucidating the concept of Karma, as one’s past life determines his/her current life (Buckingham., 2011). He further explored historical documents of the Indian culture to understand some of the roots of stigma (Buckingham., 2011). Buckingham provided an example of a Hindu script elucidating about a blind Brahmin boy, who did not have the ability to inherit, as he was unable to perform mandatory rituals and adhere to social responsibilities (Buckingham., 2011). In contrary to this Hinduism text, a study implemented by Jengatheesan et al. found that Sunni Muslim families viewed their child as a gift from God regardless of their developmental disability (Jegatheesan, Miller, & Fowler, 2010).

Furthermore, the culture stresses much on "ability" as a determinant of success (Buckingham, 2011). Therefore, individuals with disabilities are perceived as a burden due to the extra accommodations to thrive (Buckingham, 2011; Mehrotra, 2011). These stigmatizations and negative perceptions may influence family members' likelihood of going outside their homes. In some capacity, parents may have witnessed and endured adverse treatment towards individuals with a disability. One study assessing South Indian mothers who had children with "mental retardation" indicated the lack of acceptance by family members and experienced shaming by society (Gabel, 2004). Additionally, the paucity of religious support acted as a barrier for these mothers (Gabel, 2004). Due to limited access to community support, parents may become overprotected or neglectful of their family member with disabilities. Daley employed one mixed-methods study to assess the quality of life of families who have an adult family member with ASD living in Delhi, India (Daley, Weisner, & Singhal, 2014). Some members have expressed concern, as the number of facilities and care services is limited in India, some families expressed concern regarding the lack of awareness of ASD in the medical community, and the ongoing stigmatization of mental illnesses that restricts family's choices and social gatherings (Daley et al., 2014).

In addition to the demands of individuals of the Indian community, the product-demanding capitalistic economy could perpetuate negative labels on individuals with disabilities. Mehrotra examined disability through the current capitalistic economy in India (Mehrotra, 2013). Due to the high demands of producing efficient and effective outcomes, individuals with disabilities are devalued due to their inability to follow the vigorous needs of a competitive corporate workforce and provide monetary value (Mehrotra, 2013). Additionally, substantial costs are associated with individuals with a disability, so families have more difficulty accepting the numerous responsibilities (Mehrotra, 2013). Therefore, these families are more likely to avoid participating in this society due to shame and humiliation.

Findings of ASD and other mental illnesses have been more prominent in India than in other Asian countries (Chauhan, Sahu, Jaiswal, Kumar, Agarwal, Kaur, & Singh, 2019). However, the absence of a sustainable surveillance system hinders India from capturing an accurate approximation of its' ASD prevalence. Although the information on ASD in India is scarce, some findings explain parents’ perception of ASD. For example, Daley's qualitative study shows detection of ASD was easier for parents in Northern India, as social communication is vital in Indian culture (Daley, 2004). However, findings show that India lacks the resources to support these children (Minhas et al., 2015). Families have indicated experiencing a high level of stress, as the uncertainty of their child's future and their inability to facilitate their child's needs (Brezis, Weisner, Daley, Singhal, Barua, & Chollera, 2015; Daley, Weisner, & Singhal, 2014; Minhas et al., 2015). To understand the quality of life of adults with ASD, Daley employed a mixed-methods study of adults with ASD living in New Delhi (Daley et al., 2014). The responses of parents varied, as the priorities for their child of ASD changed. For the higher-functioning children, the parents had an easier time commuting and managing their household responsibilities (Daley et al., 2014). Additionally, parents mentioned how their focus is not on their child's skills development, but their child's happiness (Daley et al., 2014). Finally, in Brezis’s evaluation of the 3-month Parent–Child Training Program (PCTP) at Action for Autism, New Delhi, she discovered that despite differences in income, families did not have different narratives regarding their perceptions of their child’s ASD diagnosis (Brezis et al., 2015).

Cultural Hybridization:

Globalization exists in a long process. As the years are progressing, the United States is growing in a diversity of racial/ethnic groups (Hahler et al., 2015). As previously stated, ASD diagnosis is increasing drastically, and current statistics in the Centers for Disease Control and Prevention's ADDMs data show no difference in prevalence in racial/ethnic groups. Despite this, limited studies have examined the impacts of environments, cultural, and social factors on a family's way of life in the United States. As individuals from various cultures assimilate to another country, cultural hybridization explains that exposure to another culture could reshape their perceptions and internal beliefs (Stockhammer, 2011). As anthropologist Arthur Escobar suggests, cultural communities are constantly shaping and reshaping their views and gathering information from outside and practice along with existing cultures and communities (Sarrett, 2015). As Sarrett suggests, incorporating cultural hybridization is essential to evaluate, as behaviors are shaped continuously by cultures and the social interactions around, and ASD is a communication and behavioral disorder (Sarrett, 2015). Although these immigrants are exposed to many cultures, many of them still hold on to their traditions and beliefs (Kang-Yi et al., 2018). These cultural belief systems may influence how they interact with the healthcare systems in the United States (Kang-Yi et al., 2018).

Although there is a paucity of information about the Asian population and developmental disability, Asian population is growing significantly in the United States (Jegatheesan, 2009). One study assessed in Korean- Americans found that the stigma and negative connotations of disability has influenced the way caregivers and other cultural associations interact with them. Another study additionally followed-up and interviewed Korean Americans. Although the parents have learned to adopt a new mental framework, newly immigrated parents had difficulty and faced more dire vulnerabilities. Limited studies have assessed the influence of cross-cultural beliefs and the likelihood of acceptance and love. One qualitative study employed the parent-provider relationships of Asian Americans and their primary care providers. In this study, mothers expressed frustration due to language and cultural barriers and uncomforted by the negative implications of having a child with disabilities (Jegatheesan, 2009).

Furthermore, Asian Indians immigrate to the United States for employment and financial opportunities, in which 63.9% have obtained a bachelor's degree (Zechella et al., 2016). Due to the importance of financial success and employment, Indian communities strongly emphasize academic success and endeavors. Although academic stress may indicate a barrier for a family with disabilities as their children may not be able to uphold academic standards, these families might mold their traditional views after exposing themselves to other cultures (Zechella et al., 2016). One qualitative study assessed Asian Indians in Washington, D.C., to understand parenting styles towards children with developmental and intellectual disabilities (Zechella et al., 2016). Due to being exposed to the American culture, these Asian Indian families have diverted from strictly emphasizing academics. Raveendran and Meyer's quantitative study collected information from families of ASD in the U.S., Kuwait, and Canada via an internet survey. From the data, parents mentioned deviating away from defining ASD via religious or cultural lens (Ravindran & Myers, 2013). However, this study does not provide an in-depth understanding of the parental perceptions of families living outside India.

The risk of ASD is equivalent amongst all racial/ethnic groups, but limited research examines the experience of ASD from the various cultural lens. To understand the effectiveness of the U.S.'s healthcare system in providing a diagnosis and navigating families to receive treatment, studies must evaluate the influence of cultural factors in these families' choices. Research is beginning to assess the implications of culture in the quality of life and the process of acceptance for families of ASD. Still, limited studies assessed Asian Indian families of ASD living in the United States. Furthermore, by understanding the various processes of accepting, understanding, and living with ASD, these findings can help future public health officials, and private organizations to create outreach materials and interventions for Asian American families that tailor to their cultural ideals.

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(N.d.).

Chapter III: Student Contribution

Currently, no studies have examined the cultural perception of ASD in the Asian Indian community via a theoretical lens. This study was conducted by the Principal Investigator (PI), Aishwarya Sasidharen. In spring 2019, the PI implemented a pilot study of this research topic in her Qualitative Research Methods course at Rollins School of Public Health at Emory University; this pilot study informed the feasibility and logistics of conducting a larger study. The tools from the pilot study, such as the research question and interview guide, were used to implement this study. The interviews from the pilot study were not included in the sample for the larger study.

Recruitment

The PI obtained Institutional Review Board (IRB) approval on June 21, 2019. After the study was approved, the principal investigator sent recruitment materials, such as the individual recruitment messages approved by IRB, to the study's gatekeeper to forward to various mothers from the Tough Kids, Tough Moms (TKTM) and Super Teens WhatsApp group. These WhatsApp groups connect mothers of Asian Indian descent in Georgia who have children with a disability. Furthermore, this WhatsApp network provides these mothers support system of other mothers who have a child with (a) disability. The recruitment message included the purpose of the study, the methodology of the research, and the eligibility criteria of participants. The study purposefully recruited mothers of Indian descent who have at least one child with a primary diagnosis of ASD. Additionally, the participants must be fluent in English and have lived in the United States for at least one year. In addition to recruiting participants via the WhatsApp platform, the researcher used snowball sampling to recruit participants. One of the earlier participants shared the study information with other ASD WhatsApp groups. The mothers who expressed interest shared their contact information with the principal investigator either directly or via the gatekeeper. Furthermore, to schedule the interviews, the principal investigator contacted the potential participants to elaborate on the research project, answer any questions regarding the study, screen for eligibility, and confirm the day, time, and preferred location to conduct the interview. The recruitment process occurred concurrently with the interview process.

Data Collection

For this study, the interviews were conducted with 20 participants from July 1, 2019, to September 8, 2019. Nine interviews were conducted at the participant's house, and five interviews were conducted at Starbucks, Panera, & coffee shops within the Metro-Atlanta area. Additionally, six interviews were conducted via phone call, as some participants preferred this method. The duration of the interviews ranged from 35 - 65 minutes. Before conducting the interview, the researcher obtained oral consent. During the consent process, the researcher explained the purpose of research, the sensitivity of the topic, confidentiality, privacy, and the voluntary nature of this study. To ensure confidentiality, the principal investigator asked the participant for preferred pseudonyms and assured de-identification of all information linking to the participant. Additionally, during the consent process, the principal investigator requested permission to audio-record the interviews via the Voice Recorder app on the PI’s laptop and Android phone and explained that all audio-files would be destroyed after transcription.

The interviews followed a semi-structured interview to guide the participant through the research domains. The interview guide included opening questions about the experience of having a child with ASD, descriptions of their community and social support system, experiences with the Asian Indian culture, and some closing questions. Some examples of questions include: “How would you describe your experience of having a child with ASD?”

"How often does your child attend public events/places?" "How is ASD perceived in the Indian culture?" During each interview, the principal investigator wrote field notes and memos to note subtle body language changes of the participant and general observation regarding the participant's environment. Seventeen interviews were transcribed by the researcher and three by a professional transcription service. After transcription, all audio-recordings were destroyed.

Data Analysis

To develop the codebook, the lead researcher analyzed seven of the transcripts to identify emerging codes. The codes were compiled into a codebook that included the definitions, inclusion/exclusion criteria, and examples of quotes that support each code. Some codes were derived deductively from the literature on ASD and the Asian Indian culture, whereas inductive codes were created based on responses from the interviewees. Afterward, all 20 transcripts were open coded and then recoded based on prevalent themes. Additionally, two researchers who were familiar with the study's topic coded few transcripts to discuss similarities and discrepancies in coding and analysis. The analysis was conducted with MaxQDA 2018.2 software.

Modified grounded theory was used to generate a theoretical framework. Grounded theory is a cyclical process in which codes, concepts, and categories are continuously compared and analyzed. (Strauss & Corbin, 1997). The analysis focused on robust themes and concepts that inform the process of accepting the ASD diagnosis, likelihood to access services, relationship with culture, and quality of life of Asian Indian families with children with ASD. While applying grounded theory, this study deductively and inductively examined repetitive codes and themes that emerge from the data (Strauss & Corbin, 1997). The study utilized thick, rich information from the data to support the creation of these codes. The concepts present in the data were compared and organized into categories, and memos and field notes provided an in-depth understanding of the categories. Multiple categories were organized into a theory (Strauss & Corbin, 1997).

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Chapter IV: Manuscript Submission

Abstract: Objectives: This study aims to explore the impacts of cultural perceptions on the acceptance of child with ASD's diagnosis, decision-making process choices, and social networks of Asian Indian mothers. **Methods**: Semi-structured qualitative interviews were conducted with Asian Indian mothers who have ASD-diagnosed children in Atlanta, GA (N= 20). Interviews were audio recorded and transcribed verbatim. Data were analyzed with modified grounded theory via MaxQDA software. **Results**: Three main themes emerged from the data: *family as a central role, the role of social expectations,* and *lack of awareness*. All participants considerably relied on kinship to make decisions for their child's best interest. Contrarily, participants expressed that Asian Indian families affected by ASD are concerned about meeting societal expectations that are measured by academic achievements, job opportunities, and income. Mothers discussed how families of the Indian community might not share their concerns about their child due to fear of ostracization or to protect their child. Additionally, participants stated that the limited awareness of ASD in their healthcare, cultural, and social community discouraged them from sharing their concerns and finding adequate resources for their child. **Conclusion**: These findings support the need to expand current ASD outreach models to incorporate cultural context to spread awareness of ASD in various cultural communities. Future research can assess the indication of cultural perceptions and stigma in the choices of families from multicultural communities who have family members with ASD.

1. Introduction

Autism Spectrum Disorder (ASD) is a neurological disorder that hinders social and communication abilities of a child (Zwaigenbaum, Lonnie, Bryson, & Garon, 2013). Due to the lack of understanding regarding the underlying mechanism of ASD, healthcare professionals have difficulty defining its' etiology (Lyall, Croen, Daniels, Fallin, Ladd-Acosta, Lee, Newschaffer, 2017). Despite this ambiguity, the Centers for Disease Control and Prevention (CDC) Autism Development and Disability Monitoring site (ADDMs) recent surveillance estimates in 2014 about 1 in 59 children in the United States are diagnosed with ASD total, emerging as an epidemic (CDC, 2018). Males are four times more likely to be diagnosed than females (CDC, 2018; Lyall et all, 2017). Although non-Hispanic white families are more likely to receive an early ASD diagnosis than non-Hispanic black or Hispanic families, all racial/ethnic groups are equally susceptible (CDC 2018). Due to the increased level of responsibilities when having a child with ASD, families can be faced with severe emotional and financial burdens (Horlin, Falkmer, Parsons, Albrecht & Falkmer, 2014; Weiss, Robinson, Fung, Tint, Chalmers, & Lunsky, 2013). Research studies have demonstrated the importance of early intervention in alleviating ASD symptoms; however, many parents access these services after their child has passed the age of essential developmental milestone markers (Maenner et al., 2013). Since parents are responsible for accessing interventions, their beliefs and perceptions impact the child’s treatment for ASD and his/her quality of life (McConachie & Diggle, 2007).

Despite the equal susceptibility to ASD across various ethnic groups, few studies have explored cultural factors that impact a family’s process of acceptance and understanding of ASD. Since disability and illness are defined differently across cultures, these varying definitions could impact a family’s process of acceptance, quality of life, and their ability to seek and engage in intervention services (Ravindran & Myers, 2012). Cross-cultural social interactions and belief systems may differentially influence the family’s life choices and caretaking of their children with ASD (Ravindran & Myers, 2012). During the initial years of a child’s development, the communities that a child interacts with may influence his/her developmental projection. ASD is seen as a social/communication disorder, therefore engagement from the cultural community may influence the social development of the child (Sarrett, 2015). Additionally, as stigma is prevalent in certain cultures, families’ choices to share concerns and seek treatment may be influenced by stigma from their cultural community (Kinnear, Link, Ballan, & Fischbach, 2016).

Few studies have been implemented to understand the influence of ASD on the lives of families from Asian communities. Although the research shows that the rates of ASD are much lower in South Asian communities compared to non-Hispanic White, non-Hispanic Black, or Hispanic communities (ranging from 7.9 to 19.2 per 1000 8 year-old children) the prevalence of

ASD is increasing by 1% globally (Baio et al., 2018; Hahler & Elsabbagh, 2015). While few studies have examined perceptions of ASD in the Asian community, these limited findings indicate that stigma towards mental illness is apparent in these communities (Ravindran et al., 2012). One qualitative study conducted in India and Pakistan noted that mothers had difficulty accepting their child's ASD due to the lack of acceptance from their community (Minhas et al., 2015). Additionally, families reported feeling stressed about accepting their child's diagnosis and facing the uncertainty of their child's future. However, in this study, families who had accepted their child's diagnosis had difficulty finding activities to engage with their child. Furthermore, families reported a paucity of services and facilities were available in India and Pakistan for their children. To understand the influence of geography, culture, and acceptance of children with ASD, Sarrett implemented a qualitative study to compare the home environment of families with Autism in Kerala, India and Atlanta, GA, USA (Sarrett, 2015). The goal of this study was to evaluate the family environment to indicate the level of acceptance and quality of life (Sarrett, 2015). The households in Atlanta were "therapeutic" and catered more for the child's development due to the availability of resources and medical-centered approach, whereas the households in Kerala were described as "custodial", as more family members lived together and less resources were available. Furthermore, Sarrett suggested the possible impact of geographical and cultural factors on the priorities, choices, values, and acceptance process of families affected with ASD.

Additionally, few studies have examined the impacts of cultural hybridization on families of children with ASD. As individuals from various cultures assimilate to another country, cultural hybridization explains that exposure to another culture could reshape their perceptions and internal beliefs (Stockhammer, 2011). As anthropologist Arthur Escobar suggests, cultural communities are constantly shaping and reshaping their views and gathering information from outside and practice along with existing cultures and communities (Sarrett, 2015). Currently two studies incorporated cultural hybridization to understand how Asian Indian immigrants process their understanding of ASD. Ravindran and Meyers employed a quantitative study to explore the quality of life of Indian families of children with ASD living outside India. The findings suggest that families who were more assimilated to the American culture were more accepting of their child's diagnosis (Ravindran & Myers, 2013). Additionally, a qualitative study explored parenting styles of Asian Indian families with developmental disabilities in Washington D.C (Zechella & Raval, 2016). In this study, participants' parenting style changed as they assimilated to the culture in the United States; these participants decreased their emphasis on academic success and focused on developing vocational and independent skills that were necessary for their child (Zechella et al, 2016). Clearly, cultural exposures and geographical locations have a large impact on the process of care-seeking for families with children diagnosed with ASD and the quality of life. Furthermore, public health professionals can utilize this knowledge to create interventions tailored to cultural principles.

*Purpose***:**

As the rates of ASD cases are increasing, there is a need to understand cultural barriers and facilitators that impact a family's ability to seek resources for children with ASD that improve the child's life. Qualitative research is essential in obtaining in-depth information on cultural perceptions of mental illness or disability (Hennink, Hutter, Bailey, 2010). This study aims to examine the cultural perceptions of Autism Spectrum Disorder (ASD) in the Indian Asian community. The research questions include:

- What impact do Indian cultural values have in the family’s process of accepting their child’s diagnosis?
- How do Indian cultural values inform the lifestyle of Indian families with ASD children?
- How does an ASD diagnosis impact a family’s relationships with their cultural/familial community?

By understanding the cultural perceptions of ASD, public health professionals can further expand current intervention models to incorporate cultural principles and dynamics.

II. Methods

Recruitment

Following Institutional Review Board (IRB) approval, the Principal Investigator sent recruitment materials, such as the individual recruitment messages approved by IRB, to the study’s gatekeeper, an individual who has access to the ASD Whatsapp and email groups, to forward to various mothers from the WhatsApp groups connecting mothers with other mothers of Asian Indian descent who have children with a disability in Georgia. The recruitment message included a short description of the study, the methodology of the research, and the eligibility criteria of participants. The study purposefully recruited mothers of Indian descent who have at least one child with a primary diagnosis of ASD. Additionally, the participants were required to be fluent in English and have lived in the United States for at least one year. The principal investigator used snowball sampling to recruit participants. Furthermore, to schedule the interviews, the principal investigator contacted the potential participants to share more details about the research project, answer questions regarding the study, screen for eligibility, and confirm the day, time, and preferred location to conduct the interview.

Data Collection Procedures

Interviews were conducted with 20 participants from July 1, 2019 to September 8, 2019. Nine interviews were conducted at participant's house, and five interviews were conducted at coffee shops within the Metro-Atlanta area and six interviews were conducted via phone call. The duration of the interviews ranged from 35 - 65 minutes.

The interviews followed a semi-structured interview guide to lead the participant through the research domains. The interview guide included opening questions about, - the experience of having a child with ASD, descriptions of their community and social support system, experiences with the Asian Indian culture, and closing questions. Some examples of questions include: "How would you describe your experience of having a child with ASD?" "How often does your child attend public events/places?" "How is ASD perceived in the Indian culture?" During the interviews, the principal investigator wrote field notes and memos to document subtle body language changes of the participant and observations of the participant's environment. Seventeen interviews were transcribed by the researcher and three by a professional transcription service. After transcription, all audio-recordings were destroyed.

Data Analysis

To develop the codebook, the study team analyzed seven of the transcripts to identify emerging codes. The codes were compiled into a codebook that included the definitions, inclusion/exclusion criteria, and examples of quotes that support each code. Some codes were derived deductively from literature on ASD and the Asian Indian culture, whereas inductive codes were created based on responses from the interviewees. Afterwards, all 20 transcripts were open coded and then recoded based on prevalent themes. Analysis was conducted with MaxQDA software.

Modified grounded theory was used to generate a theoretical framework. Grounded theory is a cyclical process in which codes, concepts, and categories are continuously compared and analyzed. (Strauss & Corbin, 1997). Analysis focused on robust themes and concepts that inform the process of accepting the ASD diagnosis, likelihood to access services, relationship with culture, and quality of life of Asian Indian families with children with ASD. While applying grounded theory, this study deductively and inductively examined repetitive codes and themes that emerge from the data (Strauss & Corbin, 1997). The study utilized thick, rich information from the data to support the creation of these codes. The concepts present in the data were compared and organized into categories, and memos and field notes provided an in-depth understanding of the categories. Multiple categories were organized into a theory (Strauss & Corbin, 1997).

Ethical Consideration

The Principal Investigator obtained Emory University Institutional Review Board (IRB) approval on June 21, 2019. Before conducting the interview, the principal investigator obtained oral consent. During the consent process, the researcher explained the purpose of research, sensitivity of topic, confidentiality, privacy, and voluntary nature of this study. To ensure confidentiality, the principal investigator asked the participant for preferred pseudonyms and assured de-identification of all information linking to the participant. Additionally, during the consent process, the principal investigator requested permission to audio-record the interviews via Voice Recorder.

III. Findings:

The researcher completed 20 interviews; all personal information was deidentified, and participants were provided pseudonyms for the purpose of this study. The study derived three themes that were supported by the data: the importance of family, societal expectations, and lack of awareness of ASD.

Family as a central role:

All participants mentioned valuing family and family connection, such as their husband, parents, and their child. The participants mentioned that family relationship is integral in the Asian Indian culture, and this cultural value is integrated in their daily life. These kinship values encouraged mothers to sacrifice personal wishes for their family's need. Furthermore, from the Asian Indian culture, the child's development is the number one priority, as families from the community will make decisions based on the child's best interest. Although many participants had initial difficulty accepting their child's diagnosis, their core value of prioritizing their child facilitated in eventually reshaping their perceptions about ASD and noticing their child's gifts and abilities. To elaborate on their caretaking practices for their child, five mothers mentioned protecting their child from people who may not be understanding and empathetic about ASD. For example, Sanya, whose oldest son was diagnosed with ASD, stated that the Indian values of prioritizing children's needs deeply influenced the decisions and sacrifices made in her life. She became incredibly protective about her child and shielded him from people who may speak negatively.

> *"Uh…we can go to any level to uh…do what's right for our kids. And…um…so, I have tried to be like that with my kids. … Even though we had to make some sacrifices, like I had my post-grad from India, but I- once I got to know about Madhav's diagnosis, and*

> *um…I knew I could not manage everything together, so I sacrificed everything just for my kids that, they, they need more of my time. They were the height- they were the higher, highest pedestal for me. Then my own life." - Sanya*

Additionally, participants stated that support from family members helped them emotionally, physically, and mentally during their ASD journey. Mothers shared that their parents have been unconditionally supportive and compassionate to their child throughout this journey. For example, often, family members take care of the child whenever the mother needs a break. Overall, their family members were immediately willing to assist whenever these mothers needed support. For example, Urvashi, a second-generation Asian Indian mother, shared how her family had unconditionally assisted her and her son in facing challenging, finding resources, and being an emotional support:

> *"I would say my parents are like second parents to my son, I'm so thankful to have them. Um…and I rely a lot on parents for support, and I feel like they've been…instrumental in helping me over the years. You know, uh…face the…uh…my son's disability and handle the challenges and really give me a break when I need a break, and just, um, be there for me for moral support" – Urvashi*

As an additional aspect, mothers emphasized marriage and building relationships as a huge component of the Asian Indian culture's kinship values. Therefore, some mothers discussed that some couples stick together despite difficult circumstances to adhere to cultural norms. Moreover, the husband's role in the child's lives emerged from the interviews. Those mothers, who shared about their spouses, indicated that their husband's support helped alleviate some stressors of caretaking. Overall, twelve mothers who mentioned their husbands had relatively positive experiences, whereas the rest of the participants did not mention their husband within the context of their child. When asked about the values from the Asian Indian culture, Michelle mentioned the culture's emphasis of having a reliable partner and believed that imbibing her values and having her husband's support helped her raise her child.

> *"..going back to the values that I just talked about, like the marriage, it's very important for me, because marriage with the right person- marriage has helped me with, I would say, keep shouldering the responsibility of a special needs person." - Michelle*

Alternatively, eight mothers mentioned distancing themselves from families due to their inability to empathize with their child who has ASD. Since these family members, who were commonly elder members, were unaware about ASD, mothers shared how these family members would ask questions regarding their child's diagnosis and provide unsolicited advice regarding next developmental steps. To exacerbate the lack of understanding, participants shared that relatives blamed mothers for their child's diagnosis, believing that the diagnosis was due to the mother's poor attention during and/or after pregnancy. These reprimanding comments discouraged mothers to discuss with others, particularly extended family members, about their child. Sanjana, a mother who has one son with ASD, described the family's reaction to uncertainty of the diagnosis and its' impact on her relationship with them.

> *"I mean, your psyche is to….and the Indian psyche is to, when the news comes out and you're telling your parents and your in-laws, the idea is that, "how did this happen?" It's not like, "where do we go from here?" Like, "how did this happen? Why did this happen?" I mean like, "Who made this happen?" kind of- you know. It's like giving the blame. Like, but…that was all happening in India. Fortunately, we were away from all that because we were here." - Sanjana*

Due to criticism from their family members in India, some mothers expressed appreciation for living in the United States. These mothers had redefined their friends as their family members, as friends were more empathetic about these participants' emotions and circumstances and helped them express their concerns about their child. For example, Tina became more distant from her family because they encouraged her and her husband to hide the diagnosis. Furthermore, her definition of family has changed and reshaped to include her friends.

> *"The only support…family…is my husband. So…I guess I can't blame them, they don't understand. They've never understand what autism was, and I can't be mad at them for that. But over the years, my brothers…I've kind of told* them because my kids are older *and you can't keep hiding all of that. They understand but they don't understand. So…my only support is my husband. And that's why I always feel like Georgia…my friends…they're like my family. I think they understand the struggles I go through."*
> *– Tina*

The Role of Societal Expectations

From the interviews, societal expectations emerged as influential in these participants' experiences. These expectations of success are described by academic achievements, job opportunities, and income-level. Mothers mentioned that meeting societal demands can make coping difficult due to the dearth of external support. Furthermore, these mothers described this issue further by explaining how individuals from the Asian Indian community focus on academic and occupational success, how families mask their child's diagnosis, and how limited attention is given to developing the child's independent living skills. Rima, a full-time employed Indian mother who has one son with ASD, explained the expectations she experienced within the Asian Indian cultural community:

> *"So…one, and I think for most Indian parents, they're competing with each other on how successful their children are, that they're going to be doctors or engineers, how much money they are making, their children are making. In that case, if you have an autistic child, like you know, family's kind of fallen off the spectrum for them (laughs)." - Rima*

Although some mothers did not include academics and competition as a part of the Asian Indian cultural values, all participants stressed its' significance in the Asian Indian community. Some mothers mentioned how the Asian Indian cultural environment measures academic achievement as an indicator of individual success. Mothers explained that this significance placed on academics is due to the belief that academic achievement is equated to occupational success and monetary value/income potential. Some mothers stated that individuals from the community force their children to focus on mathematics and sciences, as jobs related to those subjects tend to flourish financially. Mothers mentioned how monetary success can earn respect from society that ensures a sense of security. Michelle was explaining how the Asian Indian community in the United States emphasize academics, as strong academic achievement is linked to occupational success:

> *"But everybody still believes that having these big education medallions on their things, it's a big deal for them! Hmmm…when you ask me why, the only thing I can think of is that's how it was! And how it is. And it'll take a while for it to section to change. I mean people actually get jobs based on that. THAT's the key right. I think, it's directly related to the amount of money you earn (laughs)." -Michelle*

However, participants stated that children of ASD have difficulty competing academically since they require numerous accommodations. Therefore, mothers explained that some Asian Indian parents are likely to hide their child's diagnosis and their personal concerns about their child’s development. Expanding upon the significance of societal perceptions, participants described this desire to be perceived as “perfect” in society’s eyes. This sentiment in turn discourages parents from sharing any information that depicts their child or their family as inferior to others.

> *“Indian culture, the one thing that comes, is that, the idea is perfection. You know? If you want to sum it up in one word. I think it’s perfection. I think people seek perfection, in every…in everything. It’s like, it has to be perfect. The family has to be perfect. The house has to be perfect. The uh…grades have to be perfect. The uh…the…uh…the values have to be perfect, etc. The question of how…perfect you are. And uh, the more perfect you are, the better your parents look.”* - *Sanjana*

All of the mothers interviewed advised families affected by ASD to find support groups to help their child’s ASD journey. However, the negative reactions from their cultural community might affect the likelihood of mothers of children with ASD to share their concerns with others. Moreover, compared to Asian Indian families living in the United States, mothers stated that families who recently immigrated to the United States might have greater difficulty sharing their concerns and seeking effective treatments for their child due to their limited awareness about ASD and the United States’ healthcare system. As Parvati elaborated, these recently immigrated families might not be familiar with the United States’ healthcare system, so they may be unaware about which healthcare provider to seek for an evaluation or to obtain services. As the quote below highlights, these recently immigrated families might initially seek advice from their cultural community because of familiarity, but many cultural organizations implement limited outreach and awareness programs to educate families about ASD or any disability. Additionally, these mothers expressed that some families have difficulty accepting their child's diagnosis of ASD due to the negative perceptions of disabilities in their cultural community. To increase awareness of disabilities within the Asian Indian community, three mothers suggested that cultural community organizations should conduct more activities to promote more inclusivity.

> *"You don't really discuss about it. And…you don't make it a big issue. Yeah, and if you do it, you should be able to get support from your community, especially living here in a foreign land. You know, that's where you first seek for support right?" – Parvati*

After understanding their child's needs, some participants shifted from focusing on their child's academic endeavors to focusing on their child's independent living skills. Although some of these children with ASD are precociously competent and intelligent, participants emphasized that these children need additional assistance to use the restroom, take a shower, and fulfill other independent tasks. Additionally, mothers mentioned that these children have difficulty developing and maintaining social relationships. However, the participants stated that some families may overlook their child's lack of independent living skills because of their children's academic achievements. Therefore, some participants implored families to change their focus to improving their child's independent skills to be more integrated in the general society.

> *"Otherwise, if it's going to be a person who is absolutely brilliant but you still have to feed them, you know, then that's not going to work. So…focus on the functional areas where they can be very independent, cause it really improves the quality of life of all parties in order, not just for one person!" - Michelle*

Some mothers expressed that if the child depends on fewer accommodations, the more likely he/she will be accepted into society.

Lack of Awareness about ASD

When asked about factors that discourage mothers from discussing their child’s needs, these mothers stated that lack of awareness in the community was a huge barrier. In all interviews, mothers indicated they did not know about ASD at the time of the diagnosis. Some mothers mentioned seeing many cases of ASD in family members or friends but stated never knowing the etiology or the name of the developmental disability. Furthermore, mothers shared their initial difficulties of finding effective services for their child and support groups of families who share similar issues. During the interviews, mothers elaborated that the prognosis of ASD was understood after their receiving the diagnosis.

> *“Well, I didn’t know what autism was! I normally know illnesses like cold, fever, and maximum illness that you know was cancer. This was something which was different.”*
>
> *- Priya*

Mothers acknowledged that individuals in their cultural community have varying levels of knowledge regarding ASD. Due to the ambiguity regarding ASD’s etiology, a few mothers said that individuals from the community would provide different interpretations as to why ASD manifested. When these mothers were introduced to ASD, they mentioned that individuals from the cultural community, particularly family members, defined it as a mental/cognitive disability. However, in the context of religious beliefs, some mothers shared examples of families being blamed for their child’s developmental delay and reasoned the diagnosis as “bad *karma”*. In addition to the religious beliefs, some participants’ family members attributed the mothers’ actions during and/or after pregnancy to their child’s developmental delay. Ultimately, these moms dismissed these reasons and stated that their explanations were due to their lack of knowledge about ASD. Madhuri, a mother who recently moved to the United States, stated that certain individuals in the Asian Indian community derived various theories to explain the child's diagnosis due to their lack of understanding about ASD's etiology.

> *"I think, you know, at least they don't have that exposure, they really don't know how to treat or…or..you know..go about with it. Like now I think in our small extended family circle, uhh now that they see Aryan, I think they're getting to know more about it. And otherwise, they don't have that kind of kids, they have zero exposure, because zero, you know, knowledge. You know, the more they get exposed, the more they will accept it and more they will know." – Madhuri*

Additionally, the role of other families who are affected with ASD or any other disability emerged as a protective factor from the data. Some participants claimed that reaching out to families who have children with ASD provided information, insight, and connection. Mothers described that having a child with ASD can feel very isolating, so connecting to families via ASD support groups could alleviate the feeling of loneliness, as others may find have difficulty empathizing with these experiences. This connection reaffirms families that they are not alone. In addition to connecting with other families who have children with ASD or other special healthcare needs, few mothers indicated the benefits of connecting these same families from similar cultural backgrounds. When asked about her social networks, Chandana stated only being close to the Indian ASD social support groups, as these families were extremely accommodating. When probed why, she elaborated that these Asian Indian mothers could relate and recognize cultural behaviors and belief systems that influences her experiences of having a child with ASD.

> *"Yes. It definitely, you know why? Because…um, the things that we, on a day to day basis that we do, the way …we are in our house and mainly the food. So…when I have some issues or, you know, when we are there. You know? Our cultures like…you know, half of*

> *us though, we are here. They would be able to understand better, relate better, where we are coming from."* - Chandana

However, according to some participants, Asian Indians living in United States are becoming more aware of ASD due to acculturation and assimilation to values practiced in the United States. Additionally, assimilating to different cultural communities provides mothers the confidence to disregard societal obligations that do not serve their lifestyles. Therefore, mothers mentioned that living in American society helped them discuss openly about ASD, reflect on their belief systems, and chose values that are beneficial to their quality of life. Shireen, who has lived in the United States for decades, said living outside of India has helped her experience of having a child with ASD, as she has the liberty to incorporate effective values from the Asian Indian culture and exclude the values/beliefs that were not helpful to her.

> *"Um…so I was fortunate to bring up my child here in U.S.. There was not a taboo, right? So it worked out just great. So I was able to enjoy the richness of Indian culture, the family oriented and good food and all of that without external factors, such as status and power of Indian, Indian culture, right? So for me…it was much easier to raise my kid here in the U.S., so I could focus on his development more, versus hide him from the society. Um, if I were in India, I don't think I would be taking him to those many places in the society." – Shireen*

Although these mothers stated that more awareness of ASD is present in the Asian Indian community living in the United States, they believed more outreach needs to be done to increase inclusion of ASD families in the United States. When asked about the initial diagnosis process, mothers said that at the time of their child's diagnosis, pediatricians were not completely familiar with the medical and behavioral symptoms of ASD. Additionally, during their child's initial diagnosis years, these mothers mentioned having difficulty navigating healthcare systems to obtain effective services, and this constant search for treatment resulted into spending considerable money over unsuccessful services. Therefore, mothers mentioned that even social networks, such as healthcare providers, educators, outside of their cultural community have limited awareness about ASD. Specifically, two participants added that resources may be available for children, but families might not have access to this resources/information on available treatments. Furthermore, participants suggested that more action should be done to spread awareness and knowledge of ASD in the community.

> *"I'm talking about all other parents who don't have the financial means to take their kids to all these things and be able to do all of that. That is what is lacking is where do they find that exposure? Where do they find that information that…these things are even available? You know, that they can do all these things? And…they may have a lot of ability, but the parents either don't have time or resources or finances to support their child to do- to be successful. And then they just end up, you know, saying- you know, doing not, not doing it, not able to do to their potential." – Parvati*

V. Discussion:

The purpose of this qualitative study was to explore the role of Indian culture in the experience of mothers who have a child with ASD. Although few studies have assessed the role of Asian Indian culture and ASD, a dearth of studies have evaluated cross-cultural perspectives of raising a child with ASD. Furthermore, this study assessed how personal, cultural, geographical, and social experiences impacts the decisions of Asian Indian mothers who have a child with ASD. These findings can be supported by the Social Ecological Model, as this theory explains how the interaction of intrapersonal, interpersonal, and community levels informs the experiences of these participants. The Social Ecological Model pieces together missing constructs from sociology and anthropology in current public health behavioral models, so professionals create interventions that focus on specific levels of community to help these families. (Anderson, Roux, Kuo, & Shattuck, 2018).

Overall, these findings indicated that kinship factors from the Asian Indian culture is instrumental in the living experience of these Asian Indian mothers. The root of collectivism obligates family members to care for one another regardless of circumstances, as informed by the literature (Chadda, RK, et al, 2013). Participants interviewed in this study expressed varying levels of comfort in communicating about ASD with extended family members and larger social network, but their close relationship with nuclear family members, such as husbands and children, served as a protective factor by having close-proximity support. Although participants had difficulty raising their child who has ASD, those shared closer, intimate relationships with nuclear family members reported having more confidence in their child's life-trajectory. Furthermore, these results indicate that interventions should focus on including nuclear family members and building on these supportive bonds. Additionally, professionals should create interventions that encourage and empower family members to participate in their child's activities and treatment.

Although kinship relationships significantly impacted the experience, mothers reported that societal expectations from the Asian Indian cultural community, such as academic achievement, income-level, and social status, can act as an obstacle in raising a child with ASD. According to some participants, academic achievement is linked to financial prosperity, which then affects the family's societal position. However, many children with ASD cannot thrive in a standard academic environment, as they need numerous accommodations to facilitate their daily responsibilities. Consistent with previous work, these academic markers of success have elicited shame and ostracization to those with intellectual disabilities from this cultural community (Minhas et al, 2015; Tait et al, 2014; Lin et al., 2011; Sarrett, 2015). Therefore, parents affected are less likely to share their concerns with others to protect their child from shame and humiliation. Even though religion is not overtly seen as a barrier to ASD stigma in this study due to acculturation (Ravindran & Myers, 2012), some religious undertones may shape how people see and understand ASD or any disability (Ravindran & Myers, 2012; John 2012). Rather, societal expectations, specifically financial prosperity, were identified as more salient contributing factors to stigma. Similar to Zechella & Raval's study, some mothers have shifted their focus to improve their child's independent living skills rather than focusing on academic skills (Zechella & Raval, 2016). These participants expressed that parents who have children should make choices in the best interest of the child rather than following standards imposed by society.

Ultimately, the lack of awareness about ASD in society overall may limit families' capacity to navigate the healthcare system and obtain resources. Overall, these mothers noticed symptoms of developmental delay prior to receiving the diagnosis but were not knowledgeable about the prognosis. In addition to the mothers' limited awareness, other individuals in their community, such as family members, friends, and healthcare professionals, were not informed about the risks of ASD and resources available to mitigate symptoms. Due to the lack of encouragement from the community, most mothers were in a period of denial and isolation. However, some mothers mentioned that more support from cultural communities and more representation of Asians working with the disability in the community can help in increasing acceptance and awareness (Ravindran et al., 2012). Finally, improving awareness in the community can encourage more research to be implemented as there is a paucity of evidence explaining the cause of ASD.

Overall, participants expressed gratitude for living in the United States, as they easily can choose values better suited for their child and family's well-being. As mentioned in previous literature about cultural hybridization, these participants assimilated to cultural values and beliefs of individualism and egalitarianism that are followed by individuals living in the United States (Stockhammer, 2011). Although these participants faced impediments daily in the United States, they acknowledged that raising their child would be more challenging if they were living in India. Navigating the healthcare system in the United States requires going through multiple steps, but resources for children with ASD are more accessible in the United States in comparison to India (Bobal, Brown, Hartman, Magee, & Schmidt, 2007; Minhas et al., 2015). In addition to acculturation, these participants have acclimated to the disability culture for the best interested of their child.

Limitations

There are several limitations associated with this study. Due to the recruitment strategy and sampling only Asian Indian women living in the Metro-Atlanta area, these results may not be indicative of all Asian Indian mothers living in the United States. Finally, the researcher did not collect much demographic information in order to maintain privacy and confidentiality of the mothers, and this could limit the researchers' ability to draw conclusions across subgroups of participants. Additionally, the relationship with the gatekeeper might influence the transparency of these participants' responses. This research focused on cultural values and their experience with their child, and the participants might have provided answers that are more socially acceptable due to the sensitive nature of the topic. With one exception, rest of the participants in this sample have acknowledged their child's diagnosis, therefore these results may not be representative of all Asian Indian mothers who have children with ASD.

Implications

This study focused on Asian Indian mothers living in Atlanta, GA, so future studies should evaluate this research question with Asian Indian mothers residing in other areas of the United States to draw more comparison. This study only provided the mother's perspective of having a child with ASD, as mothers were the primary caretakers in the Asian Indian culture (Rao, McHale, & Pearson, 2003); therefore, future studies should include the perspectives of Asian Indian fathers. Since family is a major contributor in the Asian Indian culture, researchers should incorporate the perspectives of other household members (other caretakers) to examine how each perspective informs the Asian Indian families' overall experiences. Since the Asian Indian population is growing in the United States, researchers need to assess the role of acculturation in these families' ASD journey. Furthermore, results from this study should encourage more social models of disability to include cultural beliefs to inform the experience of having a child with ASD. This understanding will provide evidence for public health professionals to create interventions that incorporate cultural values and beliefs. Additionally, more culturally oriented organizations should create outreach programs to their cultural community that combats stigma of disability and increases awareness of ASD, for more inclusion of children with disabilities. Finally, future studies should explore the role of capitalism and it's impacts on the experiences of individuals who have ASD, as this will encourage programs to focus on developing families' advocacy skills, improving vocational and independent living skills of individuals with ASD, and creating more facility centers for more integration.

Conclusion

Overall, ASD rates are increasing through the years, and CDC's Autism Development and Disability Monitoring site (ADDMs) indicates that all racial/ethnic groups are impacted. Therefore, more public health professionals should be proactive in creating effective solutions that cater to diverse racial/ethnic communities. The findings from this study should encourage more researchers studying ASD to incorporate culture in their future studies or interventions. By understanding the experiences of these impacted individuals, families can then obtain timely diagnosis and services.

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Chapter V. Public Health Implications

Discussion:

The purpose of this qualitative study was to explore the role of Indian culture in the experience of mothers who have a child with ASD. Although few studies have assessed the role of Asian Indian culture and ASD, a dearth of studies have evaluated cross-cultural perspectives of raising a child with ASD. Furthermore, this study assessed how personal, cultural, geographical, and social experiences impacts the decisions of Asian Indian mothers who have a child with ASD. These findings can be supported by the Social Ecological Model, as this theory explains how the interaction of intrapersonal, interpersonal, and community levels informs the experiences of these participants. This theoretical model pieces together missing constructs from sociology and anthropology in current public health behavioral models, so professionals create interventions that focus on specific levels of community to help these families. (Anderson, Roux, Kuo, & Shattuck, 2018).

Overall, these findings indicated that kinship factors from the Asian Indian culture is instrumental in the living experience of these Asian Indian mothers. The root of collectivism obligates family members to care for one another regardless of circumstances, as informed by the literature (Chadda, RK, et al, 2013). Participants interviewed in this study expressed varying levels of comfort in communicating about ASD with extended family members and larger social network, but their close relationship with nuclear family members, such as husbands and children, served as a protective factor by having close-proximity support. Although participants had difficulty raising their child who has ASD, those shared closer, intimate relationships with nuclear family members reported having more confidence in their child's life-trajectory. Furthermore, these results indicate that more interventions should include family members and educate them about ASD prognosis and emphasis on social support. Additionally, professionals should create interventions that encourage and empower family members to participate in their child's activities and treatment.

Although kinship relationships significantly impacted the experience, mothers reported that societal expectations from the Asian Indian cultural community, such as academic achievement, income-level, and social status, can act as an obstacle in raising a child with ASD. According to some participants, academic achievement is linked to financial prosperity, which then affects the family's societal position. However, many children with ASD cannot thrive in a standard academic environment, as they need numerous accommodations to facilitate their daily responsibilities. Consistent with previous work, these academic markers of success have elicited shame and ostracization to those with intellectual disabilities from this cultural community (Minhas et al, 2015; Tait et al, 2014; Lin et al., 2011; Sarrett, 2015). Therefore, parents affected are less likely to share their concerns with others to protect their child from shame and humiliation. Even though religion is not overtly seen as a barrier to ASD stigma in this study, some religious undertones may shape how people see and understand ASD or any disability (Ravindran & Myers, 2012). Rather, societal expectations, specifically financial prosperity, were identified as more salient contributing factors to stigma. Similar to Zechella & Raval's study, some mothers have shifted their focus to improve their child's independent living skills rather than focusing on academic skills (Zechella & Raval, 2016). These participants expressed that parents who have children should make choices in the best interest of the child rather than following standards imposed by society.

Ultimately, the lack of awareness about ASD in society overall may limit families' capacity to navigate the healthcare system and obtain resources. Overall, these mothers noticed symptoms of developmental delay prior to receiving the diagnosis but were not knowledgeable about the prognosis. In addition to the mothers' limited awareness, other individuals in their community, such as family members, friends, and healthcare professionals, were not informed about the risks of ASD and resources available to mitigate symptoms. Due to the lack of encouragement from the community, most mothers were in a period of denial and isolation. However, some mothers mentioned that more support from cultural communities and more representation of Asians working with the disability in the community can help in increasing acceptance and awareness (Ravindran et al., 2012). Finally, improving awareness in the community can encourage more research to be implemented as there is a paucity of evidence explaining the cause of ASD.

Overall, participants expressed gratitude for living in the United States, as they easily can choose values better suited for their child and family's well-being. As mentioned in previous literature about cultural hybridization, these participants assimilated to cultural values and beliefs of individualism and egalitarianism that are followed by individuals living in the United States (Stockhammer, 2011). Although these participants faced impediments daily in the United States, they acknowledged that raising their child would be more challenging if they were living in India. Navigating the healthcare system in the United States requires going through multiple steps, but resources for children with ASD are more accessible in the United States in comparison to India (Bobal, Brown, Hartman, Magee, & Schmidt, 2007; Minhas et al., 2015). In addition to acculturation, these participants have acclimated to the disability culture for the best interested of their child.

Limitations

There are several limitations associated with this study. Due to the recruitment strategy and sampling only Asian Indian women living in the Metro-Atlanta area, these results may not be indicative of all Asian Indian mothers living in the United States. Finally, the researcher did not collect much demographic information in order to maintain privacy and confidentiality of the mothers, and this could limit the researchers' ability to draw conclusions across subgroups of participants. Additionally, the relationship with the gatekeeper might influence the transparency of these participants' responses. This research focused on cultural values and their experience with their child, and the participants might have provided answers that are more socially acceptable due to the sensitive nature of the topic. With one exception, rest of the participants in this sample have acknowledged their child's diagnosis, therefore these results may not be representative of all Asian Indian mothers who have children with ASD.

Implications

Future Research

This study only focused on Asian Indian mothers living in Atlanta, GA, hence future studies should evaluate this research question with Asian Indian mothers residing in other areas of the United States for more comparison. In addition, only the mother's perspective was provided, as mothers are the primary caretakers in the Asian Indian culture (Rao, McHale, & Pearson, 2003). However, few participants mentioned gender roles of the Asian Indian culture and its' influence in caretaking behaviors, so future research should include Asian Indian fathers' perspectives for a more holistic conclusion. Finally, since the Asian Indian population is growing in the United States (Jegatheesan, B., 2009), researchers need to assess the role of acculturation in these families' experience to design effective outreach models and interventions.

Intervention: Incorporation of Nuclear Family Members:

Since kinship factors immensely influenced these Asian Indian mothers, researchers and other public health professionals should conduct more studies that include perspectives of other household members to informs these families' overall experiences. Although some current interventional designs focus on fostering parental relationships, more interventions could incorporate other members of the nuclear family and provide tools to improve their communication and interaction with their family member who has ASD. From these interviews, family members served as the most influential advocate for their child with ASD, so interventions could focus on developing and disseminating tools to improve advocacy skills of family members and other community members that can help spread awareness about ASD, create more grassroot organizations, promote more effective policies, and develop more social networks. Overall, family relationships are protective factors that can help individuals with ASD and other disabilities flourish.

Partnership with Cultural Organizations:

ASD organizations, such as Autism Speaks, Behavioral Health and Development Departments of each state, small nonprofits, and other early intervention programs, should partner with various Asian cultural organizations to encourage more creation of outreach programs increasing awareness and addressing stigma of ASD. Providing information about ASD within cultural communities could increase inclusion of children with disabilities. Additionally, stakeholders working with the ASD population should encourage future events in cultural organizations to incorporate policies that are accommodating for individuals with disabilities. Early intervention programs that focus on increasing awareness and resources to individuals with ASD should include an individual who can act as a "cultural broker", a mediator between different cultural groups, to disseminate tools and material that provides information on

ASD symptoms, child development, and available resources (Jezewski & Sotnik, 2005). These resources could present alternative opportunities besides academia that could support their child's development. Additionally, these cultural brokers could provide these families the option to connect with other families from the same cultural community who are affected with ASD, as these individuals could better relate to their experiences.

The Disability Model: Inclusion of both the Medical and Social Model

These findings could suggest merging the social and medical models of disability to better inform methods of increasing awareness and accessing timely treatment. Originally, the medical model was most used to describe experiences of individual with disabilities. This medical model focused on individualistic and biomedical characteristics to explain experiences (Szasz,1956). These methods of disability have assisted epidemiological studies to collect data and estimate prevalence, but these parameters of disability are mainly based on the clinicians' perceptions (Hogan, 2019). Therefore, this approach ceases to provide a holistic depiction of multiple external factors that influences individuals' lifestyles, social networks, and culture. Additionally, the medical model may promote a unified definition of "normality" that could induce stigma and shame (Hogan, 2019). Therefore, advocate Mike Oliver created the social model to incorporate external factors such as infrastructural barriers, social norms, and organizations that hinder or assist individuals with disabilities' ability to thrive (Oliver, 1990). This social model emphasized the importance of targeting outreach and programs to specific societal systems, so individuals from the disability community can be active members of society (Hogan, 2019).

Then, both models could consider the World Health Organization's International Classification of Functioning, Disability, and Health (ICF)'s definition of disability as an umbrella term that represents both positive and negative aspects of functionality influenced by individual or environmental factors (World Health Organization, 2002). ICF's definition emphasizes that individuals, who share similar diagnosis, might have varying functionality levels due to severity (World Health Organization, 2002). Additionally, professionals could use the social ecological model to vividly explain the internal and external experiences of living with any known disability. By obtaining this information, professionals could create programs that target the policy-level, service management-level, or individual level (World Health Organization, 2002).

Explore the Role of Capitalism

In addition to future studies and incorporation of ICF model, professionals should explore the impediments of capitalism for individuals with ASD. From this study, participants were more concerned about their child's survival in a demanding, capitalist economy. Emerged from the data, some cultural norms and value metrics were influenced greatly by capitalism. Furthermore, researchers should assess the impacts of capitalism in the Asian Indian communities' social structure spanning from multiple generations; these investigators can collect information from Asian Indian communities residing in and outside India. By collecting this information, families and advocacy groups can encourage current organizations to create more programs that improve individuals' vocational and independent living skills, advocate for more job opportunities, and develop more facility centers to integrate more individuals with disabilities in society.

Conclusion

Overall, ASD rates are increasing through the years, and CDC's Autism Development and Disability Monitoring site (ADDMs) indicates that all racial/ethnic groups equally are equally impacted. Therefore, more public health professionals should be proactive in creating effective solutions that cater to all racial/ethnic groups. These findings from this study should encourage more researchers studying ASD to incorporate culture in their future studies or interventions. By understanding the experiences of these impacted individuals, families can then obtain timely diagnosis and services.

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Appendix 1: Interview Guide

Question: What are cultural perceptions of Autism Spectrum Disorder (ASD) in the Indian community?

Sub-questions:

1) What impact do cultural values have in the family's process of accepting their child's diagnosis?
2) How do cultural values inform the lifestyle of Indian families with ASD children?
3) How does an ASD diagnosis influence a family's relationships with their cultural/familial community?

Eligibility criteria:

- Mothers
  - Identifies as Asian Indian
  - Has child with (only) ASD diagnosis
  - Has a child diagnosed with ASD for about a year
  - Speaks English

Purpose of this Study:

The purpose of this study is to discover the cultural perceptions of ASD in an Indian community. Furthermore, this study will understand how cultural beliefs impacts an Indian family's process of accepting their child's ASD diagnosis and their overall quality of life. At this stage in the research, culture will be defined as a set of beliefs and ideologies that define a way of life.

INTERVIEW GUIDE:

Opening questions:

1) Tell me about yourself:
   - i. **Where are you from in India?**
   - ii. **What language do you speak?**
   - iii. **Born or brought up in US? If not born here, when did you come to the US?**
   - iv. **How many children do you have? How engaged are they in your family life?**
   - v. **Do you go to work? What made you decide (not) to work?**

Key Questions:

1. ASD
   - a. **How would you describe your experience of having a child with ASD?**
     - i. At what age was (s)he diagnosed?
     - ii. What are some obstacles you face?
   - b. **Did you notice any symptoms of your child developmentally regressing? Why or why not?**
     - i. What mannerisms did your child display that made you doubtful about his success?

        - ii. What made you initially go
    - c. How did you feel while receiving the diagnosis?
        - i. What were your initial reactions?
        - ii. Describe how you physically felt and processed this?
        - iii. How did your family process the diagnosis?
    - **d. Tell me how you felt when you heard the diagnosis**
        - i. What did you know about ASD at the time?
        - ii. How did you learn about ASD?
        - iii. How did you come to terms with your child's diagnosis?
        - iv. What helped or hindered your process of acceptance?
        - v. What were your immediate concerns?
    - **e. What are your main concerns for your child?**
        - i. Regarding the future?
        - ii. Why does that concern you?
    - f. How do you feel about your child's diagnosis today?
        - i. What has helped or hurt you currently in this process?
    - g. Tell me about a time when you felt you weren't able to support your child with ASD
2. Quality of life
    - a. Describe your day to day life with your child with ASD
        - i. What activities does your child enjoy?
        - ii. What activities does your family enjoy?
        - iii. How are his/her days at school?
        - iv. Does (s)he attend private or public school?
    - **b. Does your child attend public events?**
        - i. Why or why not?
        - ii. How often?
        - iii. Does your child participate in school activities?
        - iv. Who spends the most time with your child?
    - **c. Describe the community you most closely associate with**
        - i. Who is in your immediate community?
        - ii. How influential is your family in your decisions?
        - iii. How influential are they in your life?
        - iv. What roles do they play in your life?
        - v. How important is your community when you make decisions?
    - **d. How often does your child attend cultural events or functions?**
        - i. What encourages you to attend these functions with your child?
        - ii. How does your child behave (positively or negatively) during these events?
        - iii. How do you react to your child's behavior?
    - **e. What are your most important values?**
        - i. Give me an example of how these values play into your life

        ii. Please describe how your desire to uphold your values affects how you support your child

3. Core Cultural Values
    a. **Describe some of the main values of the Indian culture**
        i. What do these values mainly encompass?
        ii. How often do you make life decisions based off these values?
        iii. What is your opinion of these values?
    b. **How did these values influence your experience of having a child with ASD?**
        i. Sharing your concerns?
        ii. How did it impact your quality of life?
        iii. Relationship with your family members?
        iv. Likelihood to visit India with your child?
        v. Tell me about a time when your community didn't understand your experience
        vi. Tell me about a time when someone from your cultural community supported you in your journey
    c. **How is ASD perceived in your culture?**
        i. Why is it perceived that way?
        ii. How did this play a role in your acceptance of ASD?
    d. **How would you describe your interactions with the Indian community?**
        i. How often do you associate with the Indian community?
        ii. Who from the Indian community do you associate with?
        iii. Tell me about a time when your community didn't understand your experience
        iv. Tell me about a time when someone from your cultural community supported you in your journey
        v. How often do you visit India with your family?
        vi. Tell me about a time when your family misunderstood your child
    e. **How do you feel when you are around Indian people?**
        i. When you are with your child with ASD?
        ii. Tell me a time when someone misunderstood your child
        iii. What were their reactions?
        iv. How has it helped or hurt you in your journey?
    f. **Tell me how you feel when you take your child to India?**
        i. How often does your child visit India? Why or why not?
        ii. Why do you visit India? How are their reactions to ASD?

Closing Questions:

1) **What message would you like to share with the Indian community regarding having a child with ASD?**
2) What hopes do you have for the future of children with ASD?
        i. Regarding culture?
        ii. Treatment?

    iii. What about for the families who have children with ASD and are having difficulty accepting it?
    iv. Families who are worried about the future?

3) **Is there anything else you would like to discuss that wasn't covered in my previous questions?**

These are all the questions I have for you today. Thank you so much for your time and energy in taking part of my study. Your responses have been incredibly valuable in understanding the influence of culture with the addition to having a child with ASD.

Appendix II: Consent Form

Emory University
Oral Consent and Information Sheet
For a Research Study

Study Title: Acceptance and Quality of Life: The experience of Autism in the Indian culture
Principal Investigator: Aishwarya Sasidharen, MPHc, B.A., Department: Behavioral Sciences and Health Education

Introduction and Study Overview

Thank you for your interest in our qualitative research study. We would like to tell you everything you need to think about before you decide whether or not to join the study. It is entirely your choice. If you decide to take part, you can change your mind later on and withdraw from the research study.

1) The purpose of this study is to discover the cultural perceptions of Autism Spectrum Disorder (ASD) in an Indian community. Furthermore, this study will understand how cultural beliefs impacts an Indian family's process of accepting their child's ASD diagnosis and their overall quality of life. At this stage in the research, culture will be defined as a set of beliefs and ideologies that define a way of life.
2) This study will take about 60 minutes to complete.
3) If you join, you will be asked to to participate in one interview that is semi-structured, and the I will ask you open-ended questions related to ASD, your community, and the Indian culture. These questions will provide you an opportunity to express your opinions while engaging in a conversation. In addition, the I will request permission to audio-record these interviews, and all recordings will be stored in my password-protected laptop. After transcribing these interviews, these recordings will be destroyed.
4) In this study, some possible risks include loss of privacy, breach of confidentiality, and discomfort to sensitive topics. Your personal information will be de-identified, as I will use alternative names to replace your name and your child's name. That said, all de-identified data will be included in the final product of this study. Furthermore, all interview transcriptions will be stored in my password-secured laptop. Since this study will ask questions regarding sensitive topics, you can choose to opt out of answering some questions if it causes you any discomfort. If at any point of the interview you feel incredibly uncomfortable, we can pause the interview. Additionally, if you desire to end the interview early, you may do so at any time during this process.
5) This study is not designed to benefit you directly. However, this study is designed to learn more about the role of culture in your journey of having a child with ASD, therefore these results may be used to help others in the future.
6) Your privacy is very important to us.
7) You may withdraw from the study, as your participation is voluntary.

Contact Information

If you have questions about this study, your part in it, your rights as a research participant, or if you have questions, concerns or complaints about the research you may contact the following:

Aishwarya Sasidharen, Principle Investigator: [(404) 861-9150]

Emory Institutional Review Board: 404-712-0720 or toll-free at 877-503-9797 or by email at irb@emory.edu

Consent

Do you have any questions about anything I just said? Were there any parts that seemed unclear?

Do you agree to take part in the study?

Participant agrees to participate: Yes No

If Yes:

Signature of Person Conducting Informed Consent Discussion Date Time

Name of Person Conducting Informed Consent Discussion

Appendix III: Recruitment Templates

My name is Aishwarya Sasidharen, and I am a first year Master of Public Health Student at Emory University. I am messaging you because I am employing a study that focuses on cultural perceptions of Autism Spectrum Disorder in the Indian community. Due to the lack of information regarding the influence of culture in autism, I am implementing a qualitative study that explores a deeper understanding of culture and community in the acceptance and quality of life of Indian families affected by autism. To recruit for my study, eligible participants must be Indian mothers who have at least one child with a primary diagnosis of autism, who have resided in the United States for at least a year and can speak fluent English. These interviews will take no longer than one hour and will take place at your preferred location. If you have any further questions, please feel free to contact me at (404) 861-9150 or email me at asasidh@emory.edu. Thank you all so much, and I hope you have a great week.

Sincerely,

Aishwarya Sasidharen
MPH Candidate '20| Behavioral Science and Health Education| Maternal and Child Health
Rollins School of Public Health | Emory University|
asasidh@emory.edu| 404.861.9150