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African-American Parents' Cultural Understandings of the Concept of Autism and Implications for Parental Communication and Health Management

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AFRICAN-AMERICAN PARENTS' CULTURAL UNDERSTANDINGS OF THE CONCEPT OF AUTISM AND IMPLICATIONS FOR PARENTAL COMMUNICATION AND HEALTH MANAGEMENT

by

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ABSTRACT

AFRICAN-AMERICAN PARENTS' CULTURAL UNDERSTANDINGS OF THE CONCEPT OF AUTISM AND IMPLICATIONS FOR PARENTAL COMMUNICATION AND HEALTH MANAGEMENT

Kellie J. Fennell
Old Dominion University, 2023
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In 2023 the Centers of Disease Control reported that around 1 in 36 children are diagnosed with Autism in America and that the prevalence has increased by 178% since 2000 (CDC, 2023). Despite increases in awareness and diagnosis past research finds that the discussions of ASD in African American communities is minimal (Fombonne, 2003; Yeargin Allsopp et al., 2003). This disparity is important considering that African American children receive an ASD diagnosis years later than their white counterparts and are much more likely to be misdiagnosed (Mandell et al., 2009, 2002).

Given the history of a lack of representation of African Americans in the ASD literature and disparities in its diagnosis, treatment, and management, this thesis reports an exploratory, qualitative communication study of African American parents' understandings of ASD and their associated experiences. A purposive sample of 10 African American parents of ASD children were interviewed and analyzed using analytical induction and NVivo-12.

Overall, the primary findings this thesis discovered is that many African American parents of children with ASD reported meanings associated with ASD as being neurologically "different," but not neurologically "disordered" (as understood in the medical community). Also similar to other parents ASD is seen as something that is a "danger" to their child requiring parental protections. However, to the extent institutionalized racist patterns are perceived to

exist in a given context, unique among African American parents is the perception that ASD also means a heightened need to protect the child from “yet one more way to experience discrimination” by exercising heighted caution when interacting with white medical providers. African American parents shared their difficult experiences communicating with white service providers that led to the development of a “fighting” spirit within them to advocate for their children and protect them even more. Finally, the parents expressed their difficulties of raising a child with ASD highlighting family members reactions, lack of support, cultural conflicts, and the need for more education about ASD in the African American community.

This thesis of work is dedicated to all the African Americans who are parents of children on the Autism spectrum. As they may have felt and or currently do feel alone as special needs parents. It takes strong and resilient individuals to be special needs parents and despite all the challenges that come with it, we as a community have one another and share similar stories. You are not alone.

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I would like to give a special thanks to my husband who was deployed throughout this journey but still managed to show and display continuous love and support from a far. My mom has also been a huge part of this journey with me as she has backed my degree choice and prayed for me during my many struggles of obtaining a master a degree. I would like to give a grand thank you to my dearest son Kru, this thesis topic would have not been of choice if it were not for him allowing me to experience motherhood.

Most importantly, I would like to thank God for leading the way and allowing me keep pushing throughout the many personal obstacles that life has thrown my way. Life has not been perfect but with him by my side things will always come together.

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CHAPTER I

THE PROBLEM

In 2020, during the COVID-19 Pandemic, I started to suspect that my 14-month-old son, Kru, had Autism (Autism Spectrum Disorder, ASD). His communication was primarily nonverbal. He experienced a lot of sensory struggles and lived in his own world. I am an African-American mother. My husband is in the Navy and currently deployed. I had so many concerns, but like most mothers I did not know where to start. I had not seen many autistic kids in my community and was unsure if my community was even familiar with ASD. Countless times I would bring up my suspicions to family members and friends. They would brush them off, assume I was overreacting, and tell me to “give it time.” Well, instead of “giving it time, “I trusted my motherly instincts, expressed my concerns to Kru’s primary care physician, and scheduled Kru to be evaluated for ASD. Sure enough, at the age of 2-years-old, Kru was positively diagnosed.

Sitting in the evaluation room for over an hour, being given pamphlets, brochures, stacks of papers with websites to visit, and phone numbers to call were overwhelming. When I got home from Kru’s evaluation, that same day, I read through everything and noticed that all of the information given to me was for a highly generalized and ethnically homogenized audience. It assumed that everyone’s experiences with ASD were all the same. It did not speak at all to my African American community, or any other under presented community. The pamphlets did not depict children that looked like Kru. The websites for ASD mothers did not display photos of parents who looked like me. My initial impression was that the black community (like so much of our mediated worlds) was being underrepresented concerning ASD. This gave me the impression that many black Autistic individuals may be overlooked.

As time went on, and without much support, I enrolled Kru into Applied Behavioral Analysis (ABA), speech therapy and occupational therapy. I learned how he could benefit from these services on my own. After enrolling Kru into all the required services, I also started to notice that explaining my son's diagnosis and services to Black family members and friends was difficult. Even after reading reams of material, I did not feel very educated enough about Autism. I felt alone. My African American peers could not relate or understand. I became guarded about Ku having Autism. I did not disclose his diagnosis for months to anyone or share his progress, and hated it. During this time, I started to wonder about other African American parents that have children on the spectrum. Were they feeling the way I felt? Were they noticing a lack of resources for our community? Were their children diagnosed later in life due to "giving it time"? Did they notice the signs as early as I did? These questions led to this Masters' Thesis that begins to address my initial concerns by exploring foundational cultural understandings of the concept of "autism" among African American parents. "Autism" is commonly understood around the world as a "medical diagnosis." However, peoples' understandings and experiences with "autism," like all human experiences, are rooted in cultural understandings and practices. Although humans do share a lot in common, each and every culture is also unique. Yet, in my experience with my son, any cultural understandings and uniqueness of ASD within African American culture were being hidden by homogenization. Are there unique cultural understandings and meanings of autism among African Americans? And if there are, to what extent, if any, are these understandings shaping parental communication?

Today, I advocate for my black Autistic son publicly, as I am extremely open about both his regression and progression, his experience with services offered, and my experience as an

African American ASD mom. This thesis is dedicated to the African American ASD parents who have experienced lack of communication about what ASD is and what it looks like in our community - and my black ASD son Kru.

CHAPTER II

LITERATURE REVIEW

AUTISM BACKGROUND AND MEANING

Autism Spectrum Disorder (ASD) is a social disorder. Some causes of ASD are proven to be genetic and some environmental (CDC, 2022). However, there is not a clearcut cause for ASD (CDC, 2022). People with ASD often have problems with social communication and interaction. When it comes to autism, most of the public health communication and knowledge comes from parents doing research of their own and relying on the large amounts of packets given to parents from health care workers during the diagnosis process. Most of these packets explain the signs that represent ASD such as, social communication, an impaired use of nonverbal behaviors such as eye contact, facial expressions, body postures and even gestures (Babera, 2019) Additionally, there can be difficult social interactions that can be recognized by others such as, lack of interest in many individuals including their family and friends. These particular behaviors are known as neurodivergent characteristics and conditions that fall in the large spectrum of ASD (Rudy, 2023). Some other neurodivergent conditions are Attention Deficit Hyperactivity Disorder (ADHD), Attention Deficit Disorder, Sensory Processing and Disorder, which can be diagnosed with ASD or confused for ASD (Cashin and Barker, 2009). Children with ADHD, like children with ASD, may have trouble staying focused, paying attention, managing impulsive behaviors and they may be overly energetic as well. Children with SPD, like children with ASD, may experience great amounts of sensory when it comes to loud noises, certain food, and clothing textures (CDC, 2022).

ASD is a broad concept that includes many elements of disability and/or impairment, and certainly involve functioning communication skills (Cashin & Barker, 2009). One of the earliest signs of potential ASD impairment can include the delay of or failure to develop language during the most common age of language development (Cashin & Barker, 2009). In reference to language development, some may consider a 3-to-6-month-old not babbling a language delay. Furthermore, most 12 to14 month-olds showing signs of ASD may have trouble or do not say those first common keywords such as “Mama and Dada " or “Hi and Bye” by age 2-year-old (e.g., Socha & Yingling, 2010). Most ASD children who in fact develop spoken language, may still find it difficult in keeping up with expressive language or maintaining interest in conversations. In fact, some verbal children and adults with ASD experience neologisms and echolalia, which are repetition of phrases and delayed language (Cashin & Barker, 2009). Most times neologisms and echolalia are language quoted from close peers but are predominantly copied from most movies and TV shows and songs of interest.

Many children and adults with ASD often experience huge difficulties with receptive and expressive language and restrictive repetitive behaviors (RRB). In short, RRB is restricted or repetitive interests of a child with ASD who shows interest in a song and/or a tv show and may play it repeatedly (Ravizza, Solomon &, Ivry, 2017). ASD children may also have trouble adjusting to minor and large changes in their day-to-day routine. For example, a simple change in the car route home or to school can be extremely upsetting, or a change in schedule throughout the day such as snack time or bath time. Lastly, there may be noticeable physical movements that are repetitive such as hand stimming, hand flapping, walking on their tip toes, rocking back and forth, and covering their ears. Most of these movements are sensory management related and they appear to happen when children with ASD experience loud noises, get excited, tired or become overstimulated. Parents who are aware of what ASD is and what it looks like generally take their child to get diagnosed with ASD by a medical professional.

DIAGNOSTIC HISTORY

The first ASD diagnosis, known as *Case 1* was in 1943 and was examined at Johns Hopkins University in Baltimore by Leo Kanner, an Australian Child Psychiatrist. The child who being examined was, Donald Tripplet, who was born in 1933, in Forest Mississippi and he became the first person in America to receive an Autism diagnosis (Donovan & Zaucker 2010; Pallardy, 2022). He experienced delays, lack of social skills, lack of interest of others and fixated on objects (Donovan & Zucker, 2010; Pallardy, 2022). Although Tripplet was Diagnosed in 1943, his first time being examined by Kanner was in 1938. Kanner struggled to understand the signs and had even compared them to signs of schizophrenia but was initially unable to diagnose him. By 1943, Kanner examined Tripplet several times, and encountered about 10 other cases of children that shared the same signs and symptoms as Triplet. In the same year of 1945, Kanner published an article called *Autistic Disturbances of Affective Contact*, that discussed the signs and symptoms of autism (Pallardy, 2022). At the time, Autism was rare and continued to be a rare condition with only about 10 other kids to diagnose. However, in the 90's the number of children and adults being diagnosed with Autism grew rapidly (Donovan & Zucker 2012; Pallardy, 2022).

The diagnostic criteria for ASD involve health care workers identifying all the signs listed above. Most parents are asked to identify the signs that they tend to recognize and are given long assessments, interviews and rating scales full of questions about their child's social skills, speech/language, occupational skills, milestones and personal traits. The child is also observed by several health care workers and therapists/specialists who analyze the child's behaviors through play and interaction. These diagnostic sessions can typically last anywhere from 4 to 6 hours depending on the health care workers, therapist/specialist, and child and parent. Research has been done using the *Diagnostic and Statistical Manual of Mental Disorders-IV* (DSM-IV) and *Diagnostic Manual of Mental Disorders-5* (DSM-5), that classify disorders as well as define diagnostic criteria of many disorders that fall into the general category of Pervasive Developmental Disorders (PDD). PDD refers to a group of disorders that are then characterized by a number of delays in development, social and communication skills factor. Today, not many studies have looked at the validity of the DSM-5 criteria that is released for individuals who are currently diagnosed with a PDD (Young & Rodi, 2014). One study conducted by Worley and Matson (2012) specified that a group of children that have a current diagnosis of PDD did not fall into the DSM-5 criteria even though they had signs of ASD when they were compared to other children who had similar signs with a greater severity and continued to meet the DSM-5 criteria (Worley & Matson, 2012). In short, these ASD children who did qualify to be in the DSM-5 criteria were presented to be more verbal and social at the time of the study. Today, the severity of signs has been taken into consideration to determine the child's classification when receiving an ASD diagnosis. Therefore, the spectrum has been increased (Young, 2014). Although a child is verbal and appears to be social, does not mean that the child does not have ASD, as they may show other signs and have learned how to mask.

For the past two decades, ASD diagnosis rates in the United States. have increased. In America, according to the Centers for Disease Control and Prevention (CDC) surveillance sites, in 2018, 1 in every 44 children were diagnosed with autism by the age of 8 years old (CDC, 2018), with more than half being boys ASD appears to be less prevalent for girls (Centers for Disease Control and Prevention, 2018). However, in 2023 the CDC reported that around 1 in 36 children are diagnosed with Autism and that the prevalence has increased by 178% as of 2023 (Centers for Disease Control and Prevention, 2023). In the United States, diagnostic delays, and barriers in access to developmental therapy are mostly seen among children who are a part of ethnic groups (Centers for Disease Control and Prevention, 2018). Specifically African American children typically face longer diagnosis times than white children (Centers for Disease Control and Prevention, 2018).

In America, most African American children do not receive a diagnosis until they are about 5 to 8 years old. And if African American children are diagnosed during early childhood, they are about 2 ½ to 3 years old, while most white children are diagnosed as early as 2 years old—about 6 months earlier than African American children if they are diagnosed early (Centers for Disease Control and Prevention, 2018). Many African American parents do not even express concerns about their child's delayed language, development, or behavior until more than 4 years of age (Junco, 2020). Within the African American community, most children whose parents are concerned about ASD saw multiple professionals—the average number of professionals being 6—before being diagnosed as having autism (Junco, 2020). Also, according to the CDC, a proper and faster diagnosis turnaround time is the highest among white children as well (Centers for Disease Control and Prevention, 2018). However, some might say that this is because different ethnic groups are either more likely to have children who are not diagnosed or do not recognize the signs (Junco, 2020). Previous research has also depicted that African American parents are also afraid of labels.

CROSS CULTURAL CONSIDERATIONS

When discussing Autism and African Americans, it is necessary to consider three important concepts: race, ethnicity, and culture. Race is a socially constructed system of categories that groups people according to genetically influenced characteristics such as hair texture, facial features and of course skin color (Artlies, 2010). Oftentimes the words “race” and “ethnicity” are not used properly. Ethnicity focuses on a group of people who share the same particular behaviors, culture, and language. For example, an individual who may identify as Hispanic, (which is known to be ethnicity) can also be Black or White. Also, a Chinese individual or a Chinese American may share the same physical features (which is known to be race). However, they are a part of two different cultures. Lastly, the characteristics of a particular group can be identified by things such as language, religion, music, food, and social behavior is known to be culture (Artlies, 2010). According to Berry and colleagues’ (2002) model of cross-cultural psychopathology, some form of ASD exists in every culture. There is some evidence to support this theory, as ASD organizations exist in over 100 developed Despite global recognition of the disorder, there is evidence of a lack of understanding of ASD within and between cultural contexts, specifically within the US (Ravindran & Myers, 2012). As more research focuses on ASD within varied cultural contexts, new data will contribute to a broader picture of ASD that will influence classification of this group of disorders and improve cross-cultural service provision.

In conceptualizing a disability from an ecological-behavioral framework, Danseco (1997) indicates that parent beliefs about child development reflect cultural values, as do perceptions about cause of the disability, prognosis, and treatment. Beliefs are the “medium by which culture affects child development” (Danseco, 1997, p. 123). It is reported that some minorities may fault a medical explanation for their child’s disability by substituting cultural interpretations of the symptoms. For example, a parent may strongly believe that their child’s disability is the result of a vaccine shot and/or believe that their child’s disability stems from past parental sin or punishment (CDC, 2018). In his review of internationally diverse families Danseco noted that beliefs about the cause of a disability were also related to beliefs about treatment and intervention, where parents addressed the disability with many strategies while still maintaining a value of cultural remedies to “cure” the disability. These associations between culturally influenced beliefs about child development and parent behavior emphasize the importance of understanding the culturally influenced attitudes and beliefs about ASD, a group of disorders that affect all families and communities.

GAPS IN RESEARCH

Literature examining multicultural differences in children diagnosed with ASD is minimal. The existing research typically focuses on the prevalence rates across various racial/ethnic groups, leaving many questions unanswered about the role of other cultural variables and how Autism is talked about and translated to different cultures. In particular, many aspects of culture can influence the perception of ASD within cultural groups, which has the potential to influence diagnosis, parent decision-making about interventions, and coping skills among families raising a child with ASD. Considering the lack of racial differences and conversations in the prevalence of ASD (when comparing African American and Caucasian communities), researchers have highlighted the need for research involving racially, ethnically, and culturally diverse individuals with ASD and how it’s communicated and talked about (Dyches et al., 2004; Hilton et al., 2010). Although not many studies have discussed racial differences in the ASD community (e.g., see Fombonne, 2003), research has indicated that racial minorities are diagnosed with ASD at a later age than their white counterparts (as stated earlier) and are also more likely to receive an alternate diagnosis prior to ASD diagnosis when compared to White children (Mandell et al., 2009, 2002). Discrepancies have also been identified in the special-education system. Mixed findings have been reported in regard to the over or underrepresentation of ethnic minorities in the special-education category of autism

(Donovan & Cross, 2002; Morrier et al., 2008). It appears that most cultures feel comfortable talking about certain topics that appear to be common and relatable, however, an ASD diagnosis is not (Daley, 2004).

HEALTH LITERACY

Evidence of racial and ethnic disparities in health care are found throughout the spectrum of health care, that is, health access, utilization, and health care insurance. Language and health related cultural variables serve as major barriers for access to health care for racial and ethnic minorities. For example, a report of the Commonwealth Fund examined the quality of care for minority Americans (Collins, 2002). Conducted by the Princeton Survey Research Associates, the telephone survey of 6,722 white and ethnic minorities (Africans Americans, Hispanics, and Asian Americans) focused on several aspects of health care. The final sample consisted of a 72% response rate in which 25-minute interviews were conducted in English, Spanish, Mandarin, Cantonese, Korean, and Vietnamese. The results showed inequality in health care in four major categories. These included: patient–physician communication, cultural competence in health care services, quality of clinical care, and access to care. More specifically, in comparison to white counterparts, the minority groups were less likely to consider themselves to be in excellent or very good health and have insurance. With regard to provider communication, the various racial and ethnic groups were less likely to: be able to communicate with the physician, follow the doctor’s advice due to cost constraints, have confidence in their physician, be treated with respect, feel that the provider understood them, inform their physician of the use of alternative therapies, report satisfaction with care, receive clinical services essential for monitoring chronic diseases, and have a regular doctor. These results provide substantial evidence that society must address cultural and financial barriers to health care for racial and ethnic minorities (Collins, 2002). A consequence of these results is that in the African American and Latino communities, poor blood pressure control is related to having a lack of health literacy (Panditl, 2009; Schillinger, 2002).

According to the Literacy Project Foundation, 45-million Americans read below the 5th grade level and most medical paperwork have reading requirements that meet college level (Literacy Foundation Project, 2019). Functional health literacy is the ability to read and comprehend prescription bottles, appointment slips, and other essential health-related materials required to successfully function as a patient. Health Literacy also defines a patient's ability to obtain and understand basic health information, services and health decisions (American Medical Association, 2004; Cameron, Wolf, & Baker, 2012). According to The World Health

Organization, health literacy includes both social and cognitive factors that can affect someone's ability to intake information for health promotion.

Research conducted by Jager, in 2019, Patient Perspectives to Inform a Health Literacy Educational Program: A Systematic Review and Thematic Synthesis of Qualitative Studies, demonstrates that health literacy influences African American health consumers' understanding of informed consent, understanding of diseases, self-efficacy, perceived susceptibility, adherence to medical protocols, medication and administration. While the effect of health literacy is not limited to these specific influences, health literature has an impact on health outcomes and contributes to health disparities (Jager, 2019).

CULTURE AND HEALTH LITERACY

There has been some literature to support the hypothesis that parents and caregivers have different experiences with healthcare professionals based on their ethnic identity.

Specific to ASD, Cuccaro and colleagues (1996) reported that a child's race did not serve as a significant predictor when professionals (e.g., speech pathologists, school psychologists, and physicians) were asked to read a vignette and rate the most likely problem area. However, they did report that Socioeconomic Status (SES) had a significant influence on professional perceptions of ASD. due to lack of income and educational attainment. A significant limitation to the interpretation of this finding is the differentiation between the completion of hypothetical vignettes and actual behavior in practice. In considering parent contributions when interacting with professionals, Guinchat and colleagues (2012) suggested that variation in parent reported concerns reflects differences in perception and interpretation. For example, African Americans can meet a medical provider that they feel may genuinely care for them as a patient, but the reality of the medical sphere can become instantly more hospitable due to the medical language used. Furthermore, the vocabulary used to describe behavior affects how a clinician is oriented towards the concerning problem and may lead a clinician to explore cognitive problems as opposed to autism related problems. It can be assumed that among parents who are not familiar with appropriate developmental milestones, or symptoms of ASD there may be a greater chance of parents using language that does not signal developmental concern for clinicians. In addition, clinician knowledge and attitudes, and the interactions between clinicians and families, may facilitate the influence of inherent clinician bias to behave differently with families according to race, which may contribute to the present diagnostic disparities (Mandell et al., 2002). For example, researchers suggested that the delayed and inappropriate diagnoses of African American children prior to receiving an ASD diagnosis may be associated with clinicians' expectations about treatment needs, which may lead to not screening for ASD in African American children as quickly as White families.

Mandell and colleagues emphasized the need for additional research in these areas, stating that exploration in this area may “require methods outside of those traditionally used in mental health services research” in order to obtain a better understanding of clinician and family behavior as it relates to cultural differences and ASD (Mandell et al. 2002, p. 1452). In 2020, only about 26% black Americans that are 25 (the average parental age) and older have college degrees (Becerra, 2015). This is unfortunate because education is also correlated with health literacy and educational opportunities correlate with the relationship between race and health literacy (Wallace, 2015).

The limited access for some African Americans to understand health information and obtain effective health care appears to be due to discriminatory policies and practices in the medical field (Wallace, 2015). Most African Americans also experience health literature that predominantly caters to White Americans. Most of the time when African Americans are given medical paperwork and pamphlets about disabilities, they are unable to relate in part due to the lack of examples and pictures of black children or parents. African Americans also lack support resources as well when it comes to ASD diagnosis, such as ASD parenting groups, black ASD groups and black autistic mental health groups for the autistic children and their parents (Wallace, 2015).

Schools are a vital venue when it comes to services for ASD students or students with mental health needs. For example, school psychologists often tend to recognize the implications of understanding the cultural beliefs and mindset when working with African American families of children with ASD (Rivera-Figueroa, 2022). School psychologists take on the responsibility of advocating for the needs of African American students. Autistic individuals and their families who experienced or witnessed someone close to them lack access to services offered in the community tend to want to help improve the outcomes for ASD children and their cultural families and to help create relationships with their families that they may lack. However, stigmas can tend to change the need to want to educate (Power, DuPaul, Shapiro, & Kazak, 2003). In urban communities the schools are so overlooked the students lack updated materials such as updated and new textbooks and their schools are under-represented in general. Therefore, as these children become older and become adults, they tend to lack literacy. Overtime, as they have children that may show signs of ASD there are significant racial disparities from the age of the diagnosis and the time between visits for African American children (Mandell, 2009). These initial disparities in both clinical and education systems of African American students with ASD today continue to prove that the urban communities still do not serve as a primary source for positive treatment and remain overlooked (Mandell, 2002). According to Cummings, Ponce and Mays (2018), African Americans are listed as one of the largest ethnic groups to experience low-income households where diagnoses can be overlooked due to lack of finances, and due to a fear of no affordance for outside treatments and therapies (Cummings, Ponce, & Mays, 2018). However, it is important for the medical communities to share other resources that can potentially help. Outside of treatments provided by hospitals and community clinics, schools play an important role and help provide mental health services to groups of children that are unlikely to access services that are expensive (Cummings, Ponce, & Mays, 2018). Narendorf et al. (2017) mentioned and researched the racial differences in school including mental health services for youth with ASD, where African American and low-income youth are more likely to receive some form of affordable help. The results proved the assistance of school psychologists and advocates is much needed. School psychologists are in an ideal position to assist meeting the needs of children and families and connecting families with appropriate services and referrals, and generally pointing these families in the right direction (Narendorf et al., 2017).

Most health literacy research has primarily been on adult populations. It is important to consider parent health literacy as a factor that could really increase children’s health in early childhood children. For years there has been a significant gap in not only African American parents understanding health literacy but also their perspectives about autism and services. For both parents and medical examiners, learning about the lack of health literacy today is vital information. This information can help take steps going forward to better help and support children with autism and their parents how to access and receive services sooner than the average age that children are receiving help today. A previous study (e.g., Lindley, 2021) provided a list of steps on how to improve the understanding about what health literacy is to parents. Starting with medical examiners they can describe and explain the key health literacy dimensions of autism to parents, examine how health literacy has an impact and influences autism services for young children, and lastly, identify health literacy improvement strategies related to autism services use from the perspectives of parents whose young children have autism (Lindly, 2021). Medical examiners such as doctors and nurses can also aim to use these four steps in short to help parents understand autism and the services offered which are access, understanding, evaluation and use of health information and services for health decisions (Lindly, 2021).

According to Wolf, in Literacy and Learning Outcomes (2009), medical examiners and workers do not necessarily know when a patient or the parent of the patient is lacking health literacy. Most patients or parents tend to not express their lack of knowledge about certain subjects and do not share their lack of literacy skills with other family members and friends either (Keyes, 2020). Because of this, most patients and/or parents of the patient may appear to be non-compliant due to missing appointments, not signing up for services, or just overall failing to follow through with doctors' orders (Keyes, 2020). An example of poor literacy skills are the patient or the patient's parents making up excuses when directed to read specified medical subjects such as "I will read this when I get home," signing documents without reading them, or not being aware of their past medical history (Keyes, 2020). Nearly 40% of patients and their families with low health literacy stated their feelings and admitted to being ashamed of not understanding the medical knowledge communicated which can then lead to depression (Keyes, 2020).

Most researchers have stated that cultural factors reveal a lot of information that needs to be both explored and addressed with African American families in order for them to discover their cultural differences when it comes to caring for children with ASD among ASD professionals (Burkett & Manning, 2015). Also, previous studies that examine and focus on the delayed diagnosis and specified treatment of African American children with ASD have no doubt implicated that most of the influences inhibited are due to culture. The research that has been enforced thus far has analyzed and developed that the cultural values, beliefs, and practices of families caring for a child with ASD have not been undertaken. (Burkett & Manning, 2015)

There is lack of research on autism literacy when it is in reference to African Americans. Therefore, African Americans themselves can sometimes be unaware that they lack health literacy and may feel like not knowing medical terms is just the norm for everyone because their peers in their community share the same experience. The goal for health literacy should be for all cultures to understand health literacy and leave the doctor's office educated on the medical issues they are dealing with. For African American families the underrepresentation received is concerning due to the health and long list of diagnostics disparities that African American children with ASD are known to have (Thomas, 2007). Some health care workers can be biased towards African American families and families of color, this can negatively impact the process of receiving an ASD diagnosis or screening (Burkett, 2015). Because of this and because of how the African American community communicates to one another Black parents are less likely to bring up their concerns to their child's doctor about ASD-related signs and symptoms (Donohue, 2017). Unfortunately, when African American parents do decide to report their child's ASD related signs and symptoms, health care workers and providers may not be receptive and disregard or rule out a screening as they search for major milestone delays (Neuhaus, 2018).

However, some doctors may just diagnosis some children based on race using stigma tactics without even communicating properly with the African American parent (Neuhaus, 2018). This can potentially lead to a child being misdiagnosed, affecting the child's confidence, impacting their willingness to learn, and causing them to question their learning capabilities (Burkett, 2015). Unfortunately, it is not only the healthcare workers and providers that give into stigma. African American parents do as well. Like any parent, the words ‘special needs’ can be scary and not something parents may have been prepared for because ASD cannot be determined during pregnancy. The ASD stigma from the African American community’s point of view is that ASD can inhibit the black community even more and make them seem even less intellectual and possibly violent (Burkett, 2015). In the research conducted by Shaia (2020), where she utilized qualitative methods in order to explore the involvement of African American families and ASD by interviewing them, quoted one of the participants: “The gentlemen who shot up their children have autism. Maybe somebody could think that my child could be like that” in reference to a shooting that took place in the year of 2012 in Newtown, CT (Shaia, 2020, p. 50). In continuation, the research that Shaia conducted showed that a lot of African American parents would rather not deal with the ASD diagnosis solely due to fear of contributing to a stigma and lack of health literacy overall. Other barriers also influence African American families to overlook an ASD diagnosis such as shame, interest and lack of time. Overall, good communication skills, more research and knowledge given to both African Americans and health providers in medicine are essential and improves health outcomes and health literacy and can break the pattern. African American stigma can also be found in mental health. Historical beliefs (and myths) play a big part in lack of interest as understanding health literacy generates certain attitudes and lack of trust (Ravindran,2012). Treatments, attitudes, and beliefs in regard to health are all attributable to cultural expectations and experiences. Previously shared stories from the past can influence parenting practices today in the African American community (Stein, 2003).

African American parents of children with ASD may not completely understand a number of diagnoses as well as worry about insurance, the cost of therapies and the child and family's overall needs. Parents of children with ASD in general may find themselves in a depressive state that heavily involves therapy, doctor visits and therapy for themselves. African American patients-children themselves (in their own ways) also struggle with financial burdens and communication which impacts seeking help for themselves.

BELIEFS

In 2004, Dyches and colleagues explained the lack of research about culture and the way families, and their communities look at ASD and the cultural variables could possibly contribute to differences of ASD as well. They suggested that cultural beliefs, attitudes, and upbringings influence a family's willingness to have their child tested, assessed, and diagnosed for disabilities such as ASD (Dyches et al., 2004). In many cultures disabilities are not acceptable because of the way the term 'disability' is defined. It is also hard to tell the difference between ASD and developmental delays so instead due to their beliefs, developmental delays is something that is not manifested (Myers, 2016).

Burkett (2020), a black autistic woman explains her inability to relate to many autistics as she was the only black autistic she knew. She also explains how Autism appeared to be so foreign to African American culture. She would often get told "black people are not Autistic" and insinuating that ASD was only a white diagnosis was told to pray about it and to ask God for "healing" (Burkett, 2020). African American culture enforced disciplinary actions that involve corporal punishment when a child's behavior does not align with "behaving properly"

(ObeySummer, 2018). This particular form of discipline comes from a belief system and decades of generational teaching methods. And for African Americans' cultural assumptions and beliefs about white parents is that they allow their child(ren) to interact disrespectfully and raise disrespectful children (ObeySummer, 2018). In addition, the African American culture has beliefs that corporal punishment retrains the behavior of children and forces them to become respectful adults.

The beliefs of corporal punishment have been implemented for decades. African Americans have cultural values that are childrearing and are shaped by the systems of slavery, Jim Crow laws (Thomas, 2000). Most African Americans enforce discipline their children using some form of punishment, mostly corporal, when a child's behavior does not align with behaving properly. This form of discipline comes from decades of what some may call “generational curses” and a legacy belief system. According to research, African American culture tends to find their self-esteem and identity from their parents emphasizes on being clean, having close family ties, independence, obedience, heavy religion and morals and personal values (Thomas 2000). Because all those qualities tend to define Black culture, in many ways, neurologically different children may lack independence or interest in family which can be difficult for African American parents to accept.

Oftentimes, African American culture also has a system of beliefs when it comes to prayer. Additionally, some African Americans have a hard time trusting the healthcare system due to negative past experiences and do not seek treatments and therapies suggested by hospitals after their child has been assessed and diagnosed but instead result in heavy prayer (Wallace, 2015). Around 95% of African Americans believe in God or a higher power. Within this 95%, the majority of identify as Christians. Therefore, they believe God has the power to determine what happens in the world and that God will judge people for their actions. Being a moral person and praying is the way to receive a desirable life. Many African American

Christians seek prayer, and a change in morals when their child is first diagnosed rather than therapy or advocating (Cox, Diahmant, Gecewicz & Mohamed , 2021). Sources also show that 64 % of black women are Christians and 54% of Christians are black men. In addition, black women are more likely to raise their children in the African American community and are more likely to abide by generational teachings. According to Religious Beliefs Among Black Americans (2015) states that some Christians often seek prayer and religious practices before generalized therapy for their child with ASD. However, this does not mean that they do not seek therapy at all for their child.

Researchers who have studied African American cultural beliefs have stated that cultural factors reveal a lot of information that needs to be both explored and addressed with African American families in order for them to discover their cultural differences when it comes to caring for children with ASD among ASD professionals (Burkett & Manning, 2015). However, some researchers such as Burkett and Manning (2015), who wrote, African American Families on Autism Diagnosis and Treatment: The Influence of Culture Previous studies that examine the delayed diagnosis and specified treatment of African American children with ASD have no doubt implicated most of the influences come from culture (Burkett & Manning, 2015). The research that has been explored thus far has analyzed and developed the cultural values, beliefs and practices of families caring for a child with ASD has not been undertaken (Burkett & Manning, 2015). The delayed diagnosis and specified treatment of African American children with ASD have no doubt implicated most of the influences come from culture (Burkett & Manning, 2015). The research that has been enforced thus far has analyzed and developed the cultural values, beliefs and practices of families caring for a child with ASD has not been undertaken (Burkett & Manning, 2015). Because the numbers of Autistic children are rising today, older generations such as grandparents are more likely to have grandchildren with (ASD).

Therefore, they too have to learn how to communicate and build relationships with their grandchildren that differ from raising their immediate children.

Because the ASD diagnosis is still considered to be “fairly new” in the U.S, grandparents adjusting to the wants and needs of their grandchildren with ASD may be found challenging as changing their beliefs can be foreign. For African American grandparents, accepting a grandchild with ASD may be much harder than for an African American parent. However, a grandparent’s negligence and unacceptance can impact the parents’ decision to seek services and create a lack of communication about ASD. According to a news article by BBC News and the researchers Donovan and Zucker (2016). The first person who was technically diagnosed was 78 years ago in 1943 (Donovan & Zucker, 2016). From 1943 to the year 2000 only about 45,000 people were diagnosed with autism as the diagnosis and even the name changed. However, even then the awareness about autism was not widespread and a lot of African Americans, especially those who are elderly today, lack knowledge about Autism. According to Prendeville (2018) learning how to communicate with people who have ASD can be found much more challenging for those age range from 65 years old and up. As their experiences with ASD children and people with ASD in general have been so limited and they form strong beliefs. According to Penderville about 10 out 30 African American grandparents stated that in their lives, they have only met maybe one or two people with ASD while the remaining believed that they have never even come across 1 person with ASD and that if they did, they were not aware (Prendeville, 2018). About half of the grandparents acknowledged that their adjustment to learning how to communicate and build a relationship was more challenging due their beliefs. While it appeared that some grandparents struggled to enjoy their relationship with their own children due to their unfamiliar ways of parenting (Prendeville,2018).

Desiningrum (2016) states that African American grandparents tend to worry about their own adult children’s well-being with having a child with ASD are coping. Grandparents may also wonder how having a grandchild with ASD may affect their retirement as they have worked pretty much all their lives (more than their white counterparts) and how they may have to be a caregiver themselves if something where to happen to their adult child. This also causes lack of support for the child with ASD as their African American grandparents are too overworked to help support their adult child.

Presenting symptoms of ASD and family interpretations of symptoms may also differ by cultural group. Some investigators maintain an uncertainty about the differences in symptom presentation for African American children (Cuccaro et al. 2007; Valicenti-McDermott et al. 2012), while others believe the heterogeneity of ASD symptom presentation to be affected by cultural norms (Grinker et al. 2011; Lord & Bishop 2010; Mandell et al., 2007; Tek & Landa 2012). Recent studies reported that more Caucasian children than African American children were diagnosed on the milder spectrum of ASD, suggesting that cultural differences may potentially confuse the severity of the diagnosis (Baio et al. 2014; Jarquin et al. 2011). African American family beliefs and interpretations of symptoms have been relatively unexplored, despite some ASD investigators noting that the diagnosis may be assigned differentially by the child’s culture due to misinterpreted HCP and family interactions (Barton, 2012, Bhasin and Schendel 2007, Jarquin, 2011, Mandell, 2007)

THE PERCEPTION AND MEASUREMENT OF ILLNESS

There is currently no one medical test to determine the presence of ASD, which means the diagnostic burden relies heavily on observation and reporting of behavioral characteristics to identify the disorder. Experts in the field of autism have developed an array of screening questionnaires, multi-informant rating scales, interviews, and task-based assessments with respectable psychometric properties for assessing ASD behaviors. However, measurement tools do not account for differences in informant *perception*; the influence of this latent factor is present in both parent report and clinician judgment. Perception of a disorder is the culmination of beliefs and behaviors that are related to the etiology of the illness (Kleinman, 1980), which ultimately influences the way an individual interprets symptoms and makes decisions about interventions to pursue.

In particular, Kleinman (1980) describes an interdisciplinary theoretical framework that highlights the relationship between social and clinical sciences, and culture in the development of illness perception. Kleinman's theory is based on the assumption that healthcare systems have five central functions: construction of disease as a psychosocial experience, establishing general criteria to guide help-seeking behavior and treatment, management of disorders by being able to label and explain them, treatment, and managing treatment outcome (i.e., cure, recurrence, impairment). These functions influence the way a society's population interprets a disorder, yet Kleinman asserts that there is great variation in the ways these functions are performed. For example, the construction of how disease is experienced is guided by cultural schema of recognizing, expressing, and assigning value to symptoms. Kleinman argues that this experience of a disease varies at an individual level and is sustained because it is socially adaptive. He states that the psychosocial experience of a disease, which includes variables such as cognition, affective response, communication, and interpersonal interactions within the context of family and social interactions, contribute to the meaning an individual associates with the disease. Subsequently, he refers to this integrated experience as "illness." For the remainder of this thesis, this concept of experiences related to a disorder is referred to as *perception*. A person's perception of a disorder includes his/her response to the disorder, which Kleinman views as something that is maintained because it is psychosocially and culturally adaptive.

Kleinman (1980) and Pachter (1994) argued that beliefs are influenced by latent ethnocultural variables. Culture represents the intersection of experience and worldview, which is exhibited through predictable patterns of beliefs, attitudes, and behaviors. It is apparent that culture and perception are intricately intertwined and equivocally important in understanding the actions and behaviors of a group. It is necessary to be cognizant of the fact that culture and perception are not isolated constructs; they are constantly altered through interactions with the surrounding environment. Bronfenbrenner and Morris (1998) indicate that development is constantly influenced by a multi-directional interaction with the systems in which individuals live. This suggests that, in addition to the perceptions of disease that are influenced by the greater infrastructure of health care, the presence of an individual with a disorder within families, communities, and organization's influences the perceptions of people with whom they interact. The significant influence of perception on beliefs and actions warrants necessary exploration of the interaction of culture and beliefs about ASD.

INFLUENCE OF CULTURE ON PERCEPTION

By definition, perception is a fluid process that varies across individuals and is influenced by location, education, family, access to health care, financial status, current events in society, and more. Within the African American community, family ties and extended family, identified as kinship bonds, are central in daily lives, beliefs, and decision-making (Hines & Boyd Franklin, 2005; McAdoo, 1997). African Americans with chronic health conditions tend to utilize support from social networks through the use of experiential knowledge obtained from family members as a way of assessing their own risk for disease

(Warren Findlow & Issel, 2010). Furthermore, this intergenerational transmission of information has been shown to have an influence on beliefs regarding parenting practices (Stein, 2003). Therefore, family and community are major contributors to the development of the beliefs regarding concerns of childhood development, parenting, and disability.

In addition to the centrality of family and extended family, religion is an important cultural component in the African American community that has been associated with many behaviors. Koenig and Cohen (2002) reviewed the relationship between religion and health related beliefs. Their findings indicated that African Americans often rely on religious beliefs and traditions to influence their perceptions and behaviors regarding health conditions. Religion, spirituality, and church affiliation are important variables in the lives of African American families. For example, the belief in the ability of prayer to resolve any issue leads many African American to value mental health guidance from religious leaders such as ministers (Bolden & Wicks, 2005). King (2001) reported that African American parents and caregivers attributed their child's disability as having a meaning and a purpose determined by God. King and colleagues (2005) found that approximately two-thirds of the multigenerational African American family members in her study reported active participation in their religious faith as a method for caring for a health condition. Although participants reported religious faith and God as having the ultimate control over health conditions, they reported the need to also take personal responsibility for their health concerns. This personal responsibility often involved prayer and faith that God was working on their healing through the work of health care providers, and that they still needed to utilize health care services to address conditions. This religious cultural influence affects help seeking behaviors.

Finally, socioeconomic status (SES), a measure of economic and social status, is a variable that has a significant influence on perception, but it is difficult to discuss in isolation because race, ethnicity, and SES are complexly combined. Many African Americans live in social environments where the effects of factors such as education quality, employment, home ownership, crime, and health care settings are compounded and negatively influence health behaviors (Acevedo-Garcia, Osypuk, McArdle, & Williams, 2008). Acevedo-Garcia and colleagues explored the role of geographic location and health disparities and indicated that when compared to White children, African American children are more likely to be poor and live in disadvantaged neighborhoods. They indicate that these living conditions contribute to the health disparities with African American children that are the result of unequal access to neighborhood structures that prevent health improvement. The culmination of SES and related factors that affect quality of life, as well as the discrimination and marginalization that minorities and people of lower SES experience, results in a unique set of circumstances that influence the world view of this group of African Americans.

This examination of illness perception through the worldview lens of cultural influences reflects an important aspect of culturally competent practice that is outlined by the National Association of School Psychologists (2016). It is important for school psychologists to be aware of the ways that cultural diversity influences child development and learning in educational environments. This awareness of cultural variables contributes to a school psychologists’ ability to provide assessment, intervention, and consultation in a manner that meets the needs of students and parents. Therefore, it is critical that school psychologists understand how parent perceptions of disorders may affect how they interact with school personnel, report behaviors, and seek resources for their child’s problems.

SPIRITUALITY

The vast majority of African Americans are Protestants, have descendants and ancestors who were slaves that were largely Baptists resulting in many African American being Christians today. It follows that the beliefs for African Americans would be fairly similar pertaining to death and life struggles. Most African Americans believe that belief in God is a prerequisite for morality. Just over half of existing Christians stated that believing in God is necessary for a person to be moral and have good values. They also believe that a form of seeking a blessed life is through prayer and communicating with God. Therefore, for Christians a way to address having a special needs child is to pray and discuss the triumphs of having a special needs child in church. Most African Americans believe prayer can help the parent overcome the grief that is felt when their child has a special need as well as they believe that the child can be cured or changed because of prayer. When African Americans think about God or some other higher power, clear majorities of Black Americans think of a powerful entity with a presence in earthly affairs. Most say they believe in a God who has the power to direct or change everything that goes on in the world. There also is widespread agreement among African Americans, across religious affiliations, that God or a higher power, judges all people and some Christians can associate certain situations such as having a special needs child or health issues as God given for a particular reason.

Today, while African Americans in the two youngest generations (Millennial and Generation Z) are generally less likely than those in older generations (Baby Boomer and older) to express their religious beliefs, prayer still does play a huge part of their spirituality for a better outcome in life. However, therapy is much more common and the idea of change and not “being a good person” is not a thought.

In contrast, according to Watts (2003), most African Americans have strong beliefs but do not really know how these beliefs reach back or can identify their ancestry history. While most African Americans understand that their family's heritage reaches back to Africa, a number of African Americans do not know which part of Africa they are from enough to claim a specific African descent (Watts, 2003). Furthermore, African American parents know that the generation reaches back to African but may still lack trust in their African roots when it comes to medication, natural herbs and African rituals that are claimed to help medically (Bobo, 2001; Watts, 2003). Because most African Americans are primarily and culturally American, their African qualities can seem foreign and out of the norm as some of the African rituals and herbs can be seen as uncanny to Americans.

According to Mohamed (2021), Nigerians shared a low level of knowledge and awareness about ASD as well (Bobo, 2001; Watts, 2003). South African parents also tend to diagnose their children with ASD late because they believe that if their child is somewhat verbal, he or she may not be Autistic (Bobo, 2001; Watts, 2003) When it comes to trusting medical staff, Nigerians may prefer to dive deep into their religious beliefs and seek religious methods to help reverse a diagnosis or receive heath miracles. Therefore, this also applies to a lot of African Americans as it was passed down for centuries based on their ethnic backgrounds.

AFRICAN AMERICANS’ CONSCIOUSNESS

When it comes to African Americans there are many assumptions and stigmas that people make about African Americans. Black Americans with serious psychological distress are less likely to receive health treatment than whites. It is believed that African Americans do not believe in receiving psychological help or they fear that they will be viewed as crazy. African American adults 20% more likely to report serious psychological distress than white adults.

Seeking mental health care is stigmatized within many black communities, and just one in three African Americans who struggle with mental health issues will ever receive appropriate treatment (USC, 2019). In addition, other psychological health is not the only label that African Americans are at higher risk of receiving compared to their white counterparts. African Americans are generally at higher risk for heart diseases, stroke, cancer, asthma, influenza and pneumonia, diabetes, and HIV/AIDS, according to the Office of Minority Health, part of the Department for Health and Human Services.

When it comes to medical labeling, race conciseness plays a part. For many generations, dehumanization and exploitation of black Americans in the health system has occurred (Smedley, Stith, & Nelson, 2002). During the "Bellum" years (Smith, 1990) and the early 20th century the health care facilities separated the medical system, and their delivery was "separate but equal". However, even though the message tried to push equality, African Americans experienced higher birth rate deaths, lack of prescriptions, wrongful diagnosis and longer wait times during emergencies. In comparison to white counterparts, the minority groups such as African Americans and Hispanic were less likely to consider themselves to be in excellent or in very good health. It was also very common for minority groups to be able to communicate properly with their health care provider and health workers or have insurance, which greatly impacted their abilities to follow the doctor's orders and health advice given. Cost constraints along with lack of communication also affected many African Americans' abilities to have confidence in their doctors and nurses. This caused them to feel that the provider would have no respect or care for them. Cost constraints also caused African Americans to disregard information given to them about therapies, satisfaction reports (because there is no therapies being taken), received clinical services essential for monitored health, and even had a regular doctor (Watts, 2003). These results provide evidence and results that society must address cultural and financial barriers within health care for minorities (Watts, 2003). These factors still take place today and are affecting the African American children with ASD (Prendeville,2018).

GRIEF: WHAT IS NOT TALKED ABOUT

According to research conducted by the University of Arizona, the average lifespan for African Americans is 78 years old, which is six years less than it is for white Americans (Blue, 2022). Mental health dipartites in the black community are less understood and the emotional toll involving loss of a loved one is more likely to take place than any other ethnic group. Therefore, African Americans show a much higher prevalence of prolonged grief disorder when compared to white Americans (Blue, 2022). African Americans experiences less knowledge when it comes to health literacy, they are not aware that grief can be accompanied by both mental and physical health causing them to have increased high blood pressure, and lowered immunity. Therefore, due to lack of health literacy in the black community, mental health is not discussed among African Americans as they are unaware of the negative health contributions it can cause.

African Americans have 5 stages of grief known as “black grief”. Those 5 stages entail, despair, self-blame, move to action, endurance, and survival (Forbes, 2020). As African Americans tend to experience constant existing trauma that include loss to homicide, a diminished lifespan, a history of sociological disadvantages, poverty, racism, oppression police brutality, civil injustices, incarcerations and drug and alcohol abuse, the survival stage happens to be their most utilized coping mechanism as it has been enslaved in the black culture for decades (Forbes, 2020)

African American parents of ASD children may not be subjected to discuss grief about their child's diagnosis because they are more likely to experience denial that usually stems from deep rooted fear of their child being rejected by others. In addition, black parents of ASD children may also feel that discussing their emotional state may cause rejection within their family members and peers as well (Neimeyer, 2008). For many decades the African American culture have has views of physiological therapy being for the weak or the mentally ill. Phycological therapy in the Africa American culture is also deemed to be beneficial for white people as well, as African Americans tend to depict themselves as emotionally and phytologically stronger individuals (Bryant, 2022). To the African American culture, therapy is not a realistic or viable option for help as mental health is not seen as an issue or something to predominantly focus on in the black community (Bryant, 2022). However, this is the result of White grief being assumed as the norm, based on white experiences and black grief never being addressed (Forbes, 2020).

SOCIAL CHANGE IN AFROCENTRISM AND AFRICAN AMERICANS

Afrocentrism is a term that generally focuses on the influences by Africa or African origin and cultures such as Afrocentric ideas, attitudes, beliefs, and emphasis. According to Asante (1985), "Afrocentricity is not the black version of Eurocentrism. Eurocentricity is based in white supremacist notions whose purpose is to protect white privilege and advantage in education, economics, politics and so forth" (p.34). From an Afrocentric perspective, a black person cannot truly speak for all Americans because black people are culturally African. Additionally, African culture and European cultures are presumed to be fundamentally different, antagonistic and partake in many different beliefs today.

The Afrocentric perspective is a culturally grounded practice-based model that affirms, codifies, and integrates common cultural experiences, values, and interpretations that cut across people of African descent such as African Americans. Asante, an author who has a base focus on Afrocentrism, often discusses carrying African ancestry and how tradition plays a role in their day to day lives. Asante also compares African American culture to Afrocentrism and how both experience race identity when it comes to social change (Asante,1985). African Americans experience race identity in a form of living in a country where they are the minority, and their traditional values are not familiar to everyone but only those among one another. While South Africans are trying to adjust to the modern-day traditional values that their ancestors have passed down for generations. As a whole, when trying to understand someone with Autism both south African and African Americans have to learn a different approach than what has been taught. While some African Americans Christian beliefs still stem from African culture, modern beliefs and change is needed to treat ASD (Omaize, 2021). However, white Americans have greater resources that allows them to learn and accept ASD while Africans Americans depend on cultural beliefs and are more subject to want to change ASD. Africans may feel as though African Americans have lost change. Therefore, it will take Africans much longer to learn about ASD and how to treat it (Omaize, 2021).

CODE SWITCHING

Code switching has typically been defined as the use of two or more linguistic varieties in the same conversation or interaction (Garner & Rubin, 1986). The idea of using both black and standard English has been termed “code switching”. Language is one cue that seems to provide a basis for inter- personal judgments. In 1978, Hoover, a former researcher at the University of Georgia, interviewed African American parents and asked whether they would subject their children to hearing, speaking, reading or writing black English known as “code-switching” and the results showed that parents stated that they would prefer their children be exposed to and speak standard English in most situations, because it was not acceptable in formal situations. Some educators believe that certain programs that require only Black students to shoulder the burden of acquiring a second language reflect racist tendencies (Garner & Rubin, 1986). These views characterize negative reactions to Black English as symptoms of biased attitudes and tend to lean toward other options in addressing the “problem” of black English. Because of this, African American parents wanting their kids to utilize black English has decreased (Garner & Rubin, 1986). Due to the stigma that African Americans experience regarding their overall language being seen as looked down upon, makes it hard for African American parents to accept their Autistics child’s speech delay and want to seek help.

When obtaining information and visiting the doctor's office African Americans may often feel the need to code switch and change their demeanor or personality. Because to other races, they may not be seen as a professional or known to use “proper etiquette” they may feel the need to break the stigma and find themselves code switching. Oftentimes, this results in them not understanding health literacy or information given and not wanting to speak up.

Furthermore, because ASD children tend to have a speech delay, most speech therapy clinics direct the parents of their ASD to communicate effectively by talking at a good pace, using full sentences, cutting out “baby talk” and slang. This way the ASD child learns to verbally pronounce words correctly and can be understood as he or she develops language skills. However, in the African American community this can be found challenging as African American parents may feel the need to code switch to prove to therapists that they are communicating with the child properly (Myers, 2020). Growing up, most African Americans learned to use slang words and may pronounce certain words and sentences much differently than other cultures. These slang words and pronunciations become a part of their being sometimes and can appear unnoticeable with their own community but stand out to other communities. The feeling of African Americans having to code switch feels needed due to stigmas of all blacks being uneducated and black slang being deemed as “ghetto” and “unprofessional” (Koch, 2016 & Myers 2020).

DISABILITY JUSTICE AND INTERSECTIONALITY

Disability inclusion describes approaches to increase access, inclusion, and awareness for disabled people. Overall, disability justice is significant to prioritize and approach those most historically excluded groups such as women, people of color, immigrants, and people who identify as LGBTQ+. ASD needs to be talked about essentially because within the Disability Justice topic families of Black autistic people are being left out and are not being informed about ASD or the signs. Disability Justice has the advantage of bringing community bonding, solidary and family together and informing.

In social groups, people with disabilities are oftentimes either not represented or misrepresented, especially neurodiversity (Hughes, 2013). Disability groups themselves have been known to leave out neurodiversity groups simply because some neurodivergent people do not have a voice of their own and may be nonverbal like some in the Autism community. Neurodivergent people are routinely excluded from key conversations that impact their lives especially in minority communities. In many discussions involving, social justice and disability rights activism, autism awareness campaigns, contemporary ‘mainstream’ media discourse, and everyday conversations, autistics and other neurodivergent people are often erased, silenced, and derailed (Hughes, 2013). In addition, not only do disability justice groups and minority groups fail to discuss neurodiversity, state agencies and the bodies of policy-making fail to include neurodivergent representatives, regulations and policies as they are not as well-informed from the disabled communities and others with neurodivergent family members, as they otherwise would be (Huges 2013). Autistic activists must be the voices of their own community. According to Hughes, the writer and researcher of *Increasing Neurodiversity in Disability and Social Justice Advocacy Groups* (2013) states that, “Autism activists have been particularly successful using digital tools to fight exclusion in public discourse but utilizing blogs, Twitter and Facebook feeds, message boards, and other online spaces, autistic neurodiversity advocates make their voices heard and pushed back against stigmatizing messages” (Hughes 2013, pg.6). Generally, these online spaces allow them to offer educational messages, break stigmas about disability, build community outside of neurodiversity, and help neurotypical people understand their world a little better (Huges, 2013).

In the year of 2014, the hashtag, #StopCombatingMe, created by the Autistic Self Advocacy Network (2014), was used in blog posts, tweets and other social media tactics encouraging others to call out Congress to reform the Combating the Autism Act. This bill was renamed the Autism CARES (Collaboration, Accountability, Research, Education, and Support) Act in response to the online hashtag (which is considered a form of protest). From there, many legislators increased the way representation of autistic adults were viewed and overlooked in programs funded by the act (Autistic Self Advocacy Network 2014). However, many people still wonder about the children within the Autism community and their families who could not afford therapy weekly for their ASD child/family member (Huges, 2013).

Today, many disability rights groups are still being called out, criticized for their inability to support the disabled community. In 2015, Patty Berne mentioned that disability groups and community members fail to “challenge any structural oppression except for disability” and continues pointing out that even these groups are run by predominantly white people heterosexual males (Lamm, 2015, p. 2). The exclusion of neurodivergent perspectives is particularly striking within advocacy around autism. For example, one of the world's largest autism advocacy organizations called, Autism Speaks, has faced sustained protests from autistic self-advocates and their allies for more than six years due to their inability to include Autistic opinion and create methods of support that actually contributes to helping Autistic individuals (Hughes, 2015). While, Autism Speaks mission statement expresses that their goal is to help benefit the Autistic community, most ASD individuals and their families believe that the non-profit organization does not actively offer support. For example, sources like Autistic Advocacy have stated that that very little of the money donated to Autism Speaks goes toward helping Autistic people and their families, the organizations discuss ASD without including ASD individuals, and their fundraising strategies often promotes ASD stigmas rather than decreasing the fears of the ASD community (Hughes, 2015).

While a neurodiversity perspective focuses on difference and promotes positive messages about disability, it is important to note that neurodivergence is both difference and disability. Disability Justice has only progressed in certain communities. Therefore, many African American parents of ASD children are not aware of many resources and Autism is foreign to them. Leah Beckham, an African American adult who is now a discusses her surrounding areas as a child who grew up in an urban area in Chicago and mentions that there was not many behavioral clinics, therapist, therapies, focus groups or any information such as posters or magazines about neurodivergent people in her area. She also mentions having to cross the tracks in order to receive resources for her daughters and go to the suburbs where she sees many speech pathologist centers, and Autism Speaks posters. However, it appears that children who live in deprived communities are 59% more likely to be diagnosed with autism than are children in upscale and suburban neighborhoods (Centers for Disease Control and Prevention, 2018). This is because the justice system tends to predominantly leave out blacks, queers and other ethnicities when implementing accessibility for disabled people. Disability inclusion is a broad term to describe approaches to advance access and inclusion for disabled people. A disability justice approach centers the priorities and approaches of those most historically excluded groups, such as women, people of color, immigrants, and people who identify as LGBTQ+. ASD needs to be talked about essentially because within the disability justice topic families of Black autistic people are being left out in a sense of becoming informed about ASD. Disability justice has the advantage of bringing community bonding, solidary and family together and informing. Because disability justice tends to leave out certain communities, it deprives these communities such as the African American community from being informed, learning that ASD is common and communicating about ASD. Not being informed about ASD also prevents the African American community from discussing many differences to enhance resources in their community and prevent them from noticing a lack in accessibility (Geggel, 2014).

In 2005, a few disabled activists of color Patty Berne, Mia Mingus, and Stacey Milbern launched the framework of “disability justice.” They did this to expand upon the “disability rights" movement, which established civil rights for people with disabilities. Disability Activism typically helps people with disabilities gain accessibility rights and the goal is to combat the oppression that people with disabilities face every day. The World Health Organization states that about one billion people worldwide suffer from neurological disorders and that 6.8 million people die annually from these disorders (Math, 2016).

In the work world, most Disabilities have typically been viewed as a useless. Most individuals with medical conditions or impairments experience being equality in their workplace, reduced employment opportunities and poor physical access. Because of this, The Rights of Persons with Disability Bill and Neurological Disorders was re-created in 2014 to include both neurological illness and social model for disability conceptualization, which was excluded in the first bill of rights of persons with disabilities bill (Math, 2016). Unfortunately, neurologically diverse individuals tend to still be left out (even with an active bill) in public places and even during disability activism. While most people who have physical disabilities can demand what changes need to be implemented, some neurological individuals lack the ability to speak for themselves and think for themselves as well and cannot necessarily demand the change that they need and are unaware of their rights.

However, intersectionality focuses on social categorizations groups such as, gender, class, race and sex and focuses on the discrimination and disadvantages that are noticed and helps a lot of disabled individuals and their families be aware of their rights and alert. For example, African American parents of ASD children lack health literacy more than white counterparts, not because they choose to, but because they lack many education resources in their areas. For example, most urban areas do not have posters, large billboards or flyers describing autism, what it is and the signs. Therefore, for most urban Black communities ASD is foreign to them, and some African American parents may have never even heard of the word Autism and cannot identify their child's lack of social skills and sensory. African American parents may also mistake signs of ASD and delays for misbehaving. While we are aware that children with ASD specifically experience challenges with communication in general, rather they are considered delayed or nonverbal. Some children with ASD cannot communicate what they want verbally or even use some of their words. According to Wright, strong relationships and various conversations with parents and family members benefit children with ASD.

Unfortunately, according to Wright, DeAstous, and Diene (YEAR) most African Americans tend to have to work harder and work a number of jobs in order to maintain services and everyday affordances. Therefore, most African American parents stated that due to work they lack being present, communicating, and experience many gaps in their relationships with their ASD child. African American parents also stated that due to work, and not being able to be present as much they have not gotten a chance to grow accustomed and learn about their ASD child’s experiences and how much their child is overlooked by society. Not being present and not being able to implement change in their black autistic child's life causes African American parents to become stressed, shut down and lose hope for their ASD child's future.

Autism and intersectionality have been communicated through the media due to law enforcement. The media often displays police brutality and the common racist and unfair treatment that African American men and women experience during their interactions with law enforcement. In most cases African American parents are different from their white counterparts in general when thinking about their child's future due to discrimination. Ball and Wilensky, researchers and writers for *Spectrum* news, mentioned that in 2015, New York Police Department officers injured Troy Canales, a Black autistic teen who was sitting outside his home by beating him, according to a lawsuit. In 2017, Lindsey Beshai Torres called for an ambulance when her autistic son was having a meltdown. Instead, two Worcester, Massachusetts, officers arrived, and a 10-year-olds boy was handcuffed, another lawsuit alleges. In 2018, a school resource officer in Statesville, North Carolina, handcuffed a 7-year-old autistic boy in a restaurant who was agitated after switching to a new medication. And in 2019, police in Brooklyn Center, Minnesota, shot and killed Kobe Heisler, an autistic 21-year-old (Ball, Jerfferery-Wilensky, 2020). Therefore, this topic is a huge consideration for African

American parents of Autistic children, as they tend to worry about their black neurodivergent child's interactions with the police. During police training sessions, police are offered a “one and done” training class where they learn about neurological disorders. However, many ASD advocates tend to believe that the police receive too little education about autism to recognize the signs or time to absorb information given about ASD (Ball, Jefferery-Willensky, 2020). The administrative director, Lauren Gerdner at the Autism Program at John Hopkins All Children's Hospital in St. Pertersburg, Florida states said, "You cannot just get rid of these knee-jerk assumptions in these “one and done” training sessions. People don't learn thing from one session” (Ball, JeffereryWilensky, 2020, pg.8). Many advocates today are still trying to push for law enforcement to receive constant training throughout their time as police officers and are trying to inform the law that their job is not to diagnose but to recognize and notice the signs of ASD (Ball-Jefferey-Welinsky, 2020).

SUMMARY

The above literature review explores the reported research concerning ASD such as the signs and symptoms of similar neurological conditions like ADHD and more. This literature also reflects on the issues that African American parents with ASD children may experience such as late diagnosis for children either due to lack of information or discrimination as opposed to their white counterparts who seem to have access to receive both a diagnosis and help for their child at much earlier ages. Intersectionality plays a large role in African Americans receiving late diagnosis as the urban communities are less likely to have proper educational resources, clinics or therapies that cater to children on the spectrum or disability access. Therefore, the literature pieces together the ethics on lack of medical knowledge in the African American community but also discusses African Americans culture and Health Literacy. For years African Americans have had a negative notion about medical staff based on their own personal experiences and cultural beliefs that reach back for decade and decades.

CHAPTER III

METHOD

OVERVIEW

Qualitative methods were utilized were for this study to provide a unique, in-depth understanding of experiences and perspectives which is difficult to gain from a questionnaire or survey. Qualitative methods were used to track thoughts, feelings and to compare different responses from individuals who share similar roles – in this case, ASD parents. Overall, qualitative methods allow African American parents of ASD children to open-up and utilize their voices.

This is an exploratory study of meanings and understandings of ASD among African American parents. As such its purpose is to begin to surface preliminary meanings and understandings by means of in-depth interviews. Its purpose is not to advance generalizations but rather to begin to create culture-specific conceptual foundations for future research. The interview method was chosen in order to gain increased depth of understanding about how autism is communicated to black parents of children with autism and how their cultural upbringings, medical experiences and more generally culture have an impact on how they understand and communicate about ASD. During these interviews, questions about medical treatment, possible discrimination and cultural beliefs were asked as well, in order to depict what initially impacts the way they communicate and understand Autism.

RESEARCH QUESTIONS

Below are four research questions addressed in this thesis and the interview questions that were used to elicit data to address them. See Appendix A for the interview questions used in the study.

RQ 1: How do African American parents define and understand autism?

Interview question 1. What does the word "Autism" mean to you? Is there a difference between the meaning you have today, from when your child was first diagnosed?

Interview question 2: How did you learn about what Autism is? Did you watch TV Shows, Google, or Read books?

Interview question 3: What do you think the public's perception of "Autism" is?

RQ 2: How do African American parents experience an autism diagnosis?

Interview question 4: When your child was first diagnosed, can you describe how Autism was explained to you by the doctors? Nurses? Other health care professionals? Can you recall how these conversations made you feel? What were your thoughts back then? How did you process the information, for example, talking with others? Who?

Interview question 5. After receiving the diagnosis, what did you do? Were you hesitant? Did you do your own research?

RQ 3: How do African-American parents communicate about autism to others inside and outside of family?

Interview question 6. What is your approach/philosophy of parenting a child with Autism? Does it differ from parenting children who are not on the autism spectrum?

Interview question 7. What was it like explaining Autism to (a) your family, (b) close friends, and acquaintances? How did they understand it?

Interview question 8. As your child gets older, what do you foresee changing about how you communicate as a parent of a child with special needs? What do you see changing for your child with his/her communication?

Interview question 9. Have you experienced episodes of regression/progression? How have you communicated about these episodes?

Interview question 10. Do you think African American parents and the African American community in general understand "autism" as you do?

RQ 4: What do African American parents with children with autism report might be done to improve communicating in the future?

Interview question 11. As an African American, do you think that your communication experiences with healthcare practitioners are the same as other ethnic groups? Different? How?

Interview question 12: What do you think can be done to help educate the African American community about Autism? What changes do you think it will make?

Interview question 13. How do you think society, medical staff and others can help make change?

Interview question 14: What do you think the medical community can do better to help African American parents with their diagnosed children?

SAMPLE

Because this is an exploratory study, I also chose to gather a purposive sample of African American parents who have a child diagnosed with ASD. The sample is also a convenience sample of individuals (n = 10) that I have access to at my ASD child's school and therapy clinics. The study, interview questions, and approach were reviewed by Old Dominion University (ODU) College of Arts & Letters Human Subject Review Committee and were found to be compliant with all rules and regulations for the protections of human research subjects (ODU File 19811390-1, see Figure 1). Privacy of the participants were protected by not revealing any identifying personal information (use of pseudonyms) and general demographics.

Table 1. Summary of Participants' Demographics

Participants' Pseudonym	**Sex of Participant**	**Marital Status**	**Age**	**Age of ASD Child**	**# of Siblings ASD child has**	**Multi-Generational Household?**	**Highest Level of Education**
Camille	Female	Married	41	9	1	Grandparents	Master's Degree
Meleeka	Female	Separated	33	4	0	No	Highschool
Terrell	Male	Divorced	26	5	0	No	Highschool
Kevion	Male	Married	30	4	0	No	Some College
Corinna	Female	Married	31	10	3	No	Highschool
Angela	Female	Married	42	7	4	Grandparents	Highschool
Adrianna	Female	Single	28	3	0	Parents	Master's Degree
Ashley	Female	Cohabitating	30	4	0	Parents	Bachelor's Degree
Jaree	Female	Single	34	10	1	Great-grandparents	Highschool
Gwen	Female	Widowed	66	15	1	No	Master's Degree

DATA GATHERING APPROACH

Participants were recruited where parents were more likely to have ASD children such as ABA, speech and occupational therapies. Upon approaching, parents were recruited based on their race and the signs of ASD that their child may have physically shown and under the age of

18. From there they were informed of the purpose of the study, informed of their rights as participants, and asked to be interviewed soon. Each participant was sent an email to confirm their demographics and child's age to determine qualifications before the interviews.

DATA ANALYSIS APPROACH

After interviews were transcribed (manifest content), I used analytical induction (Bulmer, 1984) to discern themes for each of the interview questions that were then further analyzed using the qualitative data analysis computer program, NVivo-12. Analytical induction and Nvivo were used to gain a better understanding about how African American parents of children with ASD understand ASD and how they communicate what ASD is to one another. As an African American mother of an ASD child myself, I learned that a lot of my peers and family members have heard of the term Autism but do not communicate what Autism is and/or are unaware of its diagnostic signs.

Here is an example of the general data analysis pattern followed in this thesis. To address the first research, what does the word "autism" mean to you? I used repeated readings for all of the 10 responses to this question to begin to identify preliminary candidate themes. I next submitted the 10 responses to Nvivo-12 to ascertain a count of how often a given theme occurred as well as noted themes that might be unique or idiosyncratic. Responses and themes were also reviewed with my advisor (Dr. Thomas J. Socha) to assess the reliability of my initial codlings. Unlike content analysis that requires an 80% category by category reliability comparison, preliminary qualitative analysis using analytical induction requires informed readers' conjoint identification and discussion of candidate themes and illustrations via exemplars that are then validated in future research.

CHAPTER IV

RESULTS

To address the four research questions (RQ) in the study, I conducted a qualitative analysis of responses to 14 interview questions. I transcribed their responses for each interview question and identified the themes using analytical induction. I then used Nvivo-12 to assess the frequencies of themes found in the responses. I organized the results according to research questions and the interview questions used to address each RQ.

RQ 1: HOW DO AFRICAN AMERICAN PARENTS DEFINE AND UNDERSTAND AUTISM?

Interview Question 1. What does the word "Autism" mean to you? Is there a difference between the meaning you have today, from when your child was first diagnosed?

After repeated readings, I identified 3 themes. These themes are (in order from most frequent to least): different, smart, and special. Across all response, the word "different" figured prominently. They understood that ASD children have "different" experiences. Their responses were a positive reframing of the medical framing of neurological disorder as reviewed in Chapter 2. For example, Camille stated, "When I think of the word Autism, I think Ausome. But of course, I also think 'different'. But personally, I enjoy it differently today. Before my son was diagnosed, I felt as though different meant strange or unusual. And while it still means unusual to me, I no longer view it as strange. There is nothing "strange" about my child. He just learns differently and socializes differently".

Camille defines ASD as "Ausome" to imitate the term "awesome" followed by defending her child not being strange. While using Nvivo-12 the frequency count identified the most frequent theme in the responses "different" and had a word count frequency of 14 and weighed a total percentage of 10.82.% when responding to research question #1. The next theme, “Special” in responses to research #1 had a word frequency of 12 and weighed a total of 2.74%. And the last theme of responses, “smart” had a frequency of 6 and weighed a total of 4.24%. Based on these three themes in Nvivo-12 it shows that African American parents are more likely to display ASD in a positive light and are classifying ASD as an individual difference (not as a disorder). This is different from the research literature potentially creating barriers to communication. That is, when communicating about ASD these African American parents might take exception when their child is referred to as a being “disordered.”

Interview question 2: How did you learn about what Autism is? Did you watch TV Shows, Google, or Read books?

Interview Question # 2 asked, how did you learn about what Autism is? Did you watch TV Shows, Google, or Read books? Majority of the participants highlighted that they took the time out to really learn about ASD when their child was diagnosed. During the Analytical induction, most of the participants reported to not receive from information from TV or Google because African-American with autism are not represented in the media. For example, Kevion stated, “I honestly didn’t know what autism was until my son was diagnosed. I fall under the category of if it affects you or someone close to you to learn about it. I didn’t really see Autistic individuals represented in the media. Especially not in African American movies and shows.” The frequency counts created using Nvivo-12 showed that “diagnosis process” had the highest frequency of 43 and a weighted percent of 1.70%. The theme “no understanding” had a word frequency count of 30 and weighted a total percentage of 1.56%. These particular responses show that African American parents are receiving little to no education about Autism unless their child is being diagnosed or someone close to them has been diagnosed.

Interview Question 3: What do you think the public's perception of "Autism" is?

During the analytical induction for this interview question the participants responded that their insights about the public's perception of ASD is completely the opposite of their definition of Autism. As the majority tend to believe that the public has a negative outlook or notation about ASD and used words such as slow, incapable, not smart, dumb, and so on. For this sample of parents, I identified three themes concerning their understanding of the how the public understands autism: disabled, negative notation, and misunderstood. Nvivo-12 showed that, "disabled" had a word count frequency of 46 occurrences and weighted a percentage of 1.68%. "Negative notation" had a word count frequency of 20 occurrence's and weighed in a total of 1.52%. While "Misunderstood" had a word count frequency 15 occurrence's and weighed a total of 1.02%. Based on the themes utilized as responses the participants seem to believe that the perception of others is incorrect and are overall misunderstood. For example, Corinna's response to research question #3 was, "As stated before, not capable. But children with autism are very capable; they just experience and view the world differently than the everyday average person."

RQ 2: HOW DO AFRICAN AMERICAN PARENTS EXPERIENCE AN AUTISM DIAGNOSIS?

Interview question 4. When your child was first diagnosed, can you describe how Autism was explained to you by the doctors? Nurses? Other health care professionals? Can you recall how these conversations made you feel? What were your thoughts back then? How did you process the information, for example, talking with others? Who?

The results of analytical induction of participant responses to interview question #4 identified the following themes: "social disorder", "lack of information", "time", "discrimination" and "stigma." Many of the participants highlighted that they had negative experiences during their child's diagnosis process and all shared similar experiences such as feeling rushed, not receiving enough information, feeling as if they were treated differently from their white counterparts and judged about their knowledge. They all highlighted that ASD was explained to them as a social disorder or neurological disorder. A key example is Terrell's response, "The longest part about the diagnosis was the actual examination. I feel like the explanation was very brief from doctors and nurses. I was just told he wouldn't be able to socialize and that he had a social disorder." In Nvivo-12, "social disorder" had a frequency of 33 which weighed in a percentage of 0.86%. "Lack of information" had a word frequency count of 20 and weighed a total percentage of 0.14%. While "time" had a word frequency count of 10 and weighted a total percentage 0.7%. Although the participants mentioned lack of time and knowledge majority of the participants understand that ASD is defined a social disorder.

Interview question 5. After receiving the diagnosis, what did you do? Were you hesitant? Did you do your own research?

The participants mentioned that their experiences made them hesitant and motivated them to seek research about ASD on their own. The participant Angela responded with, "I had to do my own research for sure because the doctor assumed that a booklet was all I needed to understand Autism. I was extremely hesitant when my son was first diagnosed because I didn't know much about it". Responses shared some the same themes from interview question 4 as the participants experiences had an impact on how they felt and their need to do their own research." The themes identified for interview question #5 were: "label", "stigma", "resources" "uncertain". Most of the participants highlighted that after their child's diagnosis they were hesitant and but still managed to do research and seek resources for their child. Angela mentioned, “I had to do my own research for sure because the doctor assumed that a booklet was all I needed to understand Autism and to move forward. I was also extremely hesitant when my son was first diagnosed because I didn't know much about it, and it felt like another label.” Many participants also pointed out their hesitations were not only due to lack of information but also due to their child being black and receiving another label of judgment. For example, Kevion’s response was, “I was in denial, I didn't believe it. I didn't think this would happen to me or my son. But the doctors did assure that my wife and I would get through it and stuck to a protocol I would assume, very brief and gave us a lot of packets and papers. I felt nervous, scared, anxious and worried about my future as a parent and my sons because now he's not only black but he's autistic too.

In Nvivo-12, “label” had a frequency of 15 and weighed a total of 0.9%. “stigma” had a word frequency count of 14 and weighted 0.8%. “Resources” had a word frequency count of 10 weighing at 0.5% and lastly, “uncertain” had a word frequency count of 8 and weighing in 0.3%.

RQ 3: HOW DO AFRICAN-AMERICAN PARENTS COMMUNICATE ABOUT AUTISM TO OTHERS INSIDE AND OUTSIDE OF FAMILY?

Interview question 6. There are lots of parenting philosophies and approaches. What is your approach/philosophy of parenting a child with Autism? Does it differ from parenting children who are not on the autism spectrum?

The themes identified during the analytical induction for interview question #6 were: “change” and “advocate.” The participants reflected on having to change their parenting styles and what their visions of what parenting would look like. They also mentioned changing their communication styles by learning sign language, how to slow down when speaking and being direct. A lot of the philosophies the participants mentioned were advocating by listening to their ASD child, acknowledging their feelings and being cautious about what their child's needs. As an example, Meleeka's responded with saying, "My son is an only child so I can't compare those differences but as someone who had nieces and nephews that are not on the spectrum, I would assume that the approaches are extremely different. As a special need parent, you have to change your overall perception of parenting. The parent you envision yourself being must change, you have to make accommodations that are out of the norm and learn along the way in many ways that the average parent doesn't have to. For example, most parents must accommodate in ways such as what their children learn but a concern for special needs parents is how our children learn and will they. I would say my approach is adjusting to change for sure."

In NVivo-12 the theme "change" had a frequency of 51 and weighed a total of 2.74%. "Advocate" had a word frequency count of 22 times and weighted a total of 1.29%.

Interview question 7. What was it like explaining Autism to (a) your family, (b) close friends, and acquaintances? How did they understand it?

In their responses to this question. It appears that the participants are breaking cultural upbringings and are no longer trying "to fix" their child. However, their solution is to protect their ASD child by not communicating what ASD is to their family and peers about ASD. This too contributes to the communication barriers about ASD. For Corinna, "Most of my family are still trying to understand Autism. They don't tend to understand when my daughter is experiencing sensory issues. They want to touch and hug her and often even just stare at her because they love her, but they realize how uncomfortable it makes her feel. Trying to explain it is hard because my family is discipline based so when they reach her hand to hold it and she rejects them they think she's misbehaving and try to “correct” her.” Overall, I kind of stop discussing Autism to my family members specifically. However, trying to explain my son's autism diagnosis is challenging. My son cries a lot and I'm told by the’ that he's spoiled an’ that he's like that because of me. My family told me that I need more God in my life to help with my son's behavior and I don’t really bring my son around much because of those comments.”

For this research question NVivo-12, “culture” has a word frequency count of 43 and weighted total of 2.06%. “Lack of communication has a word frequency count of 22 and weighed 1.06%, “protection” has a word frequency count of 11 and weighted 0.11% “no support” has a word frequency count of 8 and weighted 0.09%.

Interview question 8. As your child gets older, what do you foresee changing about how you communicate as a parent of a child with special needs? What do you see changing for your child with his/her communication?

Responses to Interview question #8 share the same themes as question #6, “change” and “advocate” (Question #6 the participants highlighted that they see themselves changing how they communicate and are willing to learn sign language and slow down their speech.) They also shared positive visions about their ASD child’s communication changes and how they foresee their child future. An example is Angela’s response, “I see myself and my son having better understanding with one another when it comes to communication. I see myself acknowledging where he struggles with communication and being his voice.” Corinna’s response was, “My daughter is non-verbal but often smiles when she wants something. She's very smart and knows math very well for her age. I see my daughter utilizing numbers and education as a way to communicate her abilities and I see myself learning how to communicate in ways that make her comfortable and supporting her communication needs.” This reflects to question #1 as the parents tend to only focus on the positive aspects of ASD. Although their children have speech delays, they reframe from saying that he or she may be non-verbal or lose language. In NVivo-12 the theme “change” for this research question has a word frequency count of 12 and weighed a total of 0.35%. “Advocate” has a word frequency count of 10 and weighed total of 0.33%.

Interview question 9. Have you experienced episodes of regression/progression? How have you communicated about these episodes?

The themes for interview question 9 were: “culture”, “discipline” and “stigma”. Majority of the participants responded that they do not discuss their ASD child’s regressions. However, they within their responses they managed to communicate their ASD child’s progressions. Which again supports the participants likely hood of wanting to point out their positive aspect rather than negative to break stigmas and the public’s perception of ASD like the responses in interview question #1. Participants also choose not to discuss regression within ASD due to beliefs of regression being seen as bad behaviors and suggestion on how to fix those behavior’s such as, corporal punishment and other forms of discipline. For interview question # 9 in NVivo-12, the theme “culture” has a word frequency count of 30 and weighed a percentage of 1.03%. “discipline” has a word frequency count of 11 and weighed a percentage of 0.92% and the theme “stigma” has a word frequency count of 7 and weighed a percentage of 0.18%.

Interview question 10. Do you think African American parents and the African American community in general understand “autism” as you do?

Similar to interview question #9 and #10 responses to interview question 10 share the same themes such as, “culture”, “discipline” and “stigma”. The participants highlighted their isolation from family members and friends due to all three themes. For example, Terrell responded, “Nope. Some blacks in our community don’t even believe in autism. They see it as just another label or they are in denial and refuse to understand Autism. Discipline, where I'm from is the only thing understood. I think because blacks in our community took the time to research Autism and learn more, we'd have more people in our community understand Autism. Even those who don't have children with autism.” While Angela’s response was similar as she stated, “No, I do not. Based on my experience with being told I was too gentle and that I needed to go to church I don't think they understand because visually they see a normal child.”

In NVivo-12 for this research question, “culture” has a word frequency count of 36 and weighed a total percentage of 1.63%. “Discipline” has a word frequency count of 20 and weighed 0.96%. “Stigma” had a word frequency count of 8 and weighed a total percentage of 0.89%.

RQ 4: WHAT DO AFRICAN AMERICAN PARENTS WITH CHILDREN WITH AUTISM REPORT MIGHT BE DONE TO IMPROVE COMMUNICATING IN THE FUTURE?

Interview question 11. As an African American, do you think that your communication experiences with healthcare practitioners are the same as other ethnic groups? Different? How?

During the analytical induction the themes I found within the responses were “discrimination” and “stigma”, as the participants touched based on their child’s diagnosis and own personal medial experiences and identified the differences that health practicians have made between them and their white counterparts, Camille responded with, “Absolutely not, I have Autism mom friends of different races and mostly my white Autism moms have much better experiences, have never complained, and received speedy diagnosis. I had to see my son's pediatrician 3 times before I was given a referral to neurology for my child and one of my white autism moms was given one the first time.”

Discrimination" was theme for this research question that had a word count frequency of 22 and weighed a total of 1.22%. "stigma" yet again was also a theme for this research question as it has a word frequency count of 15 and the total weighted percentage of 1.05%.

Interview question 12: What do you think can be done to help educate the African American community about Autism? What changes do you think it will make?

Responses to this interview question shared similar themes analytical with interview questions #13 and #14, That is all shared the same primary themes: "educate", "time increase", "accessibility." Responses to research question #12, stated that raising awareness about signs and benefits of early intervention can potentially help. One participant Gwen mentioned that more resources in black communities will also help as she responded, "I also think that creating my resources and therapy clinics in our communities would be amazing. Our people will have much more access to resources and time and may be more willing to seek therapies for their children if the clinic are just a few minutes away from their homes. Gwen also said, "as a special education teacher and special needs mom. I think more education about Autism in schools can make a difference in all communities. I also believe that special needs parents and educators can come together and help inform the black communities about Autism by meeting with community youth leaders and educating them so that they can know the signs and pass them on. While participant Camille said, "I think advertisements on TV and social media will help. And predominantly black schools can hand out brochures to parents to help be informative about Autism. And black communities can perhaps have gatherings discussing and information their community."

All of these responses support the research in the literature on intersectionality and accessibility. For this research question, In NVivo-12, the theme "educate" had a word count frequency of 12 and the total weighed percentage of 0.92%. “Time increase” had a word frequency of 9 and weighed percentage of 0.85%. “Accessibility” had a word frequency of 6 and weighed total of 0.74%.

Interview question 13. How do you think society, medical staff and others can help make a change?

The responses to this interview question mostly reflected the theme “time increase.” As the participants mentioned medical staff having more patience and allowing more time African American parents more time to ask questions and retain information during the diagnosis process. Adrianna’s response was, “Based on my experience and what I went through. I personally think that diagnosis appointments should intentionally be longer to help prepare both the parent and the child. During those kinds of appointments medical staff need to prepare for longer visits so that parents can ask questions and accept the change.”

Although this research question shared the same themes as research question #12, the frequency of the themes was different (highest to lowest): “time increase”, “educate” and “accessibility”. “Time increase” had a word count frequency of 27 and weighed a total of 1.23%. “Educate” had a word count frequency of 21 and weighed a total of 1.19%. “Accessibility” had a word count frequency of 15 and weighed a total of 1.10%.

Interview question 14: What do you think the medical community can do better to help African American parents with their diagnosed children?

Lastly, most of the responses to interview question #14 highlighted themes of solutions such as “education” and “raise awareness” and “accessibility”. Camille responded to this research question by saying, “I think in the medical world the stigma is that African Americans are in denial or dumb founded about neurological disorders such as autism. But even then, if medical workers believe that the idea should be to be more informative and provide resources." Participant Gwen responded with, "I think the medical staff can raise more awareness by displaying more black patients with Autism on their brochures and resource paperwork. I also think that having more African American medical staff in clinics will allow black parents to feel more comfortable in medical settings and trust the resources given and take their time to learn." This supports the literature in chapter about the uncomfortable medical settings being uncomfortable haven for them and that they are less likely to trust or even process the health information given due to being focused on how they are looked at and perceived. In NVivo-12 for this last research question, "education" had word frequency count of 16 and weighed a total of 0.98%. "Raise awareness" had word frequency count of 11 and a weighted total of 0.89%. "Accessibility" had a word frequency of 9 and a weighted total of 0.78%.

As mentioned earlier, the participants' responses to solutions for interview questions #12, #13 and #14, were similar but all based on their own personal experiences. Many participants felt as if the black community needed more advertisements and resources so they can learn more about ASD and notice the signs. The majority of participants mentioned that there is hardly any representation of individuals like their children on television especially on African American shows and movies. Their responses to solutions involving society and medical staff stated that can make a change by implementing more time and information to patients along with practicing methods on how to avoid stigmas discrimination as majority of the participants shared, "discrimination" as similar themes. However, these words are not just pertaining to medical staff but also school, as some participants feel as if schools should raise awareness as well. These response solutions support the literacy above in chapter 2 as previous researchers have found that once cause of health literacy is lack of trust due to African American patients feeling discriminated against.

CHAPTER V

DISCUSSION

OVERVIEW

This thesis was an exploratory study that aimed to conduct research on the impact of African Americans parent of children with ASD when it comes to culture and medical experiences. The interviews conducted resulted in black parents of ASD using words such as “different” and “smart” to define ASD and what it means to them as a protective mechanism to lower the stigmas that their family members, peers and the public have about ASD. Furthermore, these family members cultural responses and discipline natures over certain behaviors may influence African American children being overlooked. However, African American parents may no longer hold on to cultural values of disbelief and discipline, but instead chose to protect their ASD child by changing their parenting styles and isolating themselves from their African American family members and peers. The African American parents interviewed do not realize that by isolating themselves and refusing to communicate about their child behaviors that they are also creating communication barriers within the African American community about ASD.

PRIMARY FINDINGS

Among the many findings of this study, there are least four primary that add to the literature on parent-child communication, culture, and parental communication, as well as parental-health communication about ASD. First, when communicating with African American parents about their child’s ASD there is a need to consider that African Americans’ parental fears are prompted by layers of stigma (e.g., “just another thing used to discriminate us”).

While conducting interviews and analyzing the research questions, I noticed common patterns that were indicating an unwillingness to consider other areas of difficulty that may be closely related to the stigma associated with ASD that is added to layers of stigma management of being a minority group. Those areas entail the specifics of African American parents wanting to associate ASD and intellectual disability with being “different” more often than anything else but still want to emphasize that their child is smart because most of their family members, friends, and society deems ASD children as “incapable.”

Second, when communicating with African American parents about their child’s ASD there is a need to consider potentially differential informational starting places due to culturally differential experiences with health care systems. Hesitation after diagnosis, in continuing the interviews, there were many responses that highlighted common patterns that showed most were hesitant about seeking help for common concerns about their child’s development. African American parents tend to indicate concerns with the behaviors that seem out of the norm than the delays, even when the child exhibits atypical social-emotional reciprocity and behaviors. (Ogundele, 2018). The interviews also displayed more of their personal experiences and the lack of knowledge their families have regarding their ASD children which then causes them to second guess ASD and refuse to communicate about ASD.

Third, when communicating with African American parents about their child’s ASD there is a need to recognize the unique cultural and generational complexities of the meanings of an ASD diagnosis. During the interviews, most parents described their journeys of raising a child with ASD by highlighting culture being the center of their parenting methods especially when around family. Most expressed that cultural beliefs, family reactions and lack of knowledge as a source of frustration that led to isolation or lack of communication about ASD with family members and wanting to reach out. Family members also had a difficult time accepting the medical definitions, preferring to create their own versions that bordered on myth. One of the interviewees of an ASD child described her difficulty with explaining her child's behaviors to her family and her family's feedback that she should discipline harder to "fix" her child behaviors. Therefore, her philosophy like most of the interviewees was to "change your parenting style." This causes the parent to no want to further explain ASD to themselves and others as well. This creates a major opportunity for the way to incorporate more information, resources, and programs for providing family support that help extend and grow family members and their culture. These efforts providing family support, can potentially have positive outcome on the wellbeing of the African American parents involved in caring for children with ASD.

Fourth, and last, when communicating with African American parents about their child's ASD, their personal histories of negative medical experiences need to be considered. As seen in the review of literature, health care is differentially experienced by African Americans from other cultural groups. Based solely on the interviewee's experiences during their child's diagnosis with medical staff, African American parents of ASD children reported to not receive enough information in order to properly communicate what ASD is to their family members and peers resulting in poor communication and misunderstandings. The interviewees did mention that medical staff attempted to explain that ASD is a neurological disorder and/or a social disorder. However, more in depth information about the unique signs and behaviors of ASD among African Americans are not typically explained well enough for the parents to understand and be able to communicate this to others. African American parents of ASD children are often left to educate themselves about using media sources (mostly white and mainstream) about

ASD. Medical clinics and therapeutic centers are also not within close radiuses of black communities which does not allow African American ASD parents to see other children of the same skin color on the spectrum or their communities. These findings also show that African American parents of ASD children are in uncomfortable during the diagnosis process and have the notion that ASD is another label to deal with combined with being black.

LIMITATIONS OF THE STUDY

The first limitation of this research study is the small number of participants recruited for data analysis. With only 10 participants, the findings cannot fully capture the diverse perspectives of both African American mothers and fathers and diverse age groups within parenting. A larger sample size would have provided a more comprehensive understanding of how they perceive their ASD children based on their sex and generation.

As second limitation of the study pertains to the fact that the sample used is a convenience sample. Thus, the findings cannot be generalized beyond the sample. It is left to future research to determine if the qualities of the sample are shared with the population of African American parents with children with autism.

A third limitation in this research is a lack of validation of potential parental biases. With only interviewing African American ASD parents, and not their children, or other African American family members, peers of ASD children, or health professionals the study may not fully reflect actual perceptions, cultural beliefs, and medical experiences of African American parents. Responses may be biased based on parents discussing their own children.

SUGGESTIONS FOR FUTURE RESEARCH

This research documents a positive halo effect operating in African American parents' responses when communicating about their child's ASD as they seek to communicatively manage what they see as “yet-another-stigma-to-manage” with their child having ASD. This needs to be examined more fully in future research. Africana American parents can become defensive (perhaps more so that parents of other cultural groups, although this remains to be assessed) when communicating about ASD, as they seek to protect their child from negative characterizations. This circumstance is reflected in these parent’s basic definition of autism as a “difference” rather than a “disorder.” Instead of defining autism in medical terms, or stating their child’s struggles, parents interviewed were on guard about their choice of words and emphasize their child’s capabilities and highlighting their intelligence in a positive way. That is, instead of giving a direct explanation of what ASD means, the interviewed parents provided a positive haloed response and emphasized the positives about their child.

Going forward future studies should recruit more diverse samples of African American parents in terms of ethnicity, age and sex because this study reported the responses of more females than males and more millennials than any other age group. This will help gain greater understanding the perceptions of knowledge about ASD across the board. This would also provide their outlook on their own personal influences of parenting style and generational upbringings they decided to pass or to not pass down.

A second suggestion would be to seek African American parents of adult children with ASD to gain developmental understandings as well as to interview ASD children to get their perspectives. This way studies can more accurately depict and include African American ASD parents and their extensive efforts to foster positive communication styles as they help their child with ASD adjust to their education, manage their social needs, and most importantly manage what African American parents report as yet one more potentially stigmatizing cultural quality.

As cultural beliefs are often passed down for decades a third suggestion would be to seek research about the perspectives of older African Americans would be beneficial. Conducting interviews to gather results about the ASD grandparent-grandchild relationships and how they communicate what ASD is to them would reflect on their impact of parenting styles and the generational differences.

A fourth suggestion would be to study the success stories of African American parents of ASD children who are fostering positive communication styles and successfully adjusting to their child needs. And to conduct research to further understand the day-to-day communication struggles of African American parents as they parent their child with ASD over time.

By incorporating the perspectives of both children and parents, future research can offer a more balanced understanding of the communication dynamics within ASD parent-child communication. This would help to further explore the interplay between cultural values, generational differences between the parents and ASD children and whether they are fostering healthy and effective communication about the meaning of ASD.

Lastly, future research should analyze communication concepts and relationships between gender and sex differences within African American and ASD. Unlike this research, there should be more fathers and other caregivers than mothers. The point of these studies would be to better understand the different communications practices of mothers and fathers and how they understand ASD, particularly because black males are 5 times more likely to experience health discrimination than any other race (Meng-Chuan, 2015, p. 11). All five of these suggestions can help to understand the effects that cultural upbringings or health experiences effects how ASD is communicated.

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APPENDIX A

INTERVIEW QUESTIONS

1. What does the word “Autism” mean to you? Is there a difference between the meaning you have today, from when your child was first diagnosed?

2. How did you learn about what Autism is? Did you watch TV Shows, Google, or Read books?

3. What do you think the public’s perception of “Autism” is?

4. When your child was first diagnosed, can you describe how Autism was explained to you by the doctors? Nurses? Other health care professionals? Can you recall how these conversations made you feel? What were your thoughts back then? How did you process the information, for example, talking with others? Who?

5. After receiving the diagnosis, what did you do? Were you hesitant? Did you do your own research?

6. There are lots of parenting philosophies and approaches. What is your approach/philosophy of parenting a child with Autism? Does it differ from parenting children who are not on the autism spectrum?

7. What was it like explaining Autism to (a) your family, (b) close friends, and (c) acquaintances? How did they understand it?

8. As your child gets older, what do you foresee changing about how you communicate as a parent of a child with special needs? What do you see changing for your child with his/her communication?

9. Have you experienced episodes of regression/progression? How have you communicated about these episodes?

10. Do you think African American parents and the African American community in general

understand “autism” as you do?

11. As an African American, do you think that your communication experiences with healthcare practitioners are the same as other ethnic groups? Different? How?

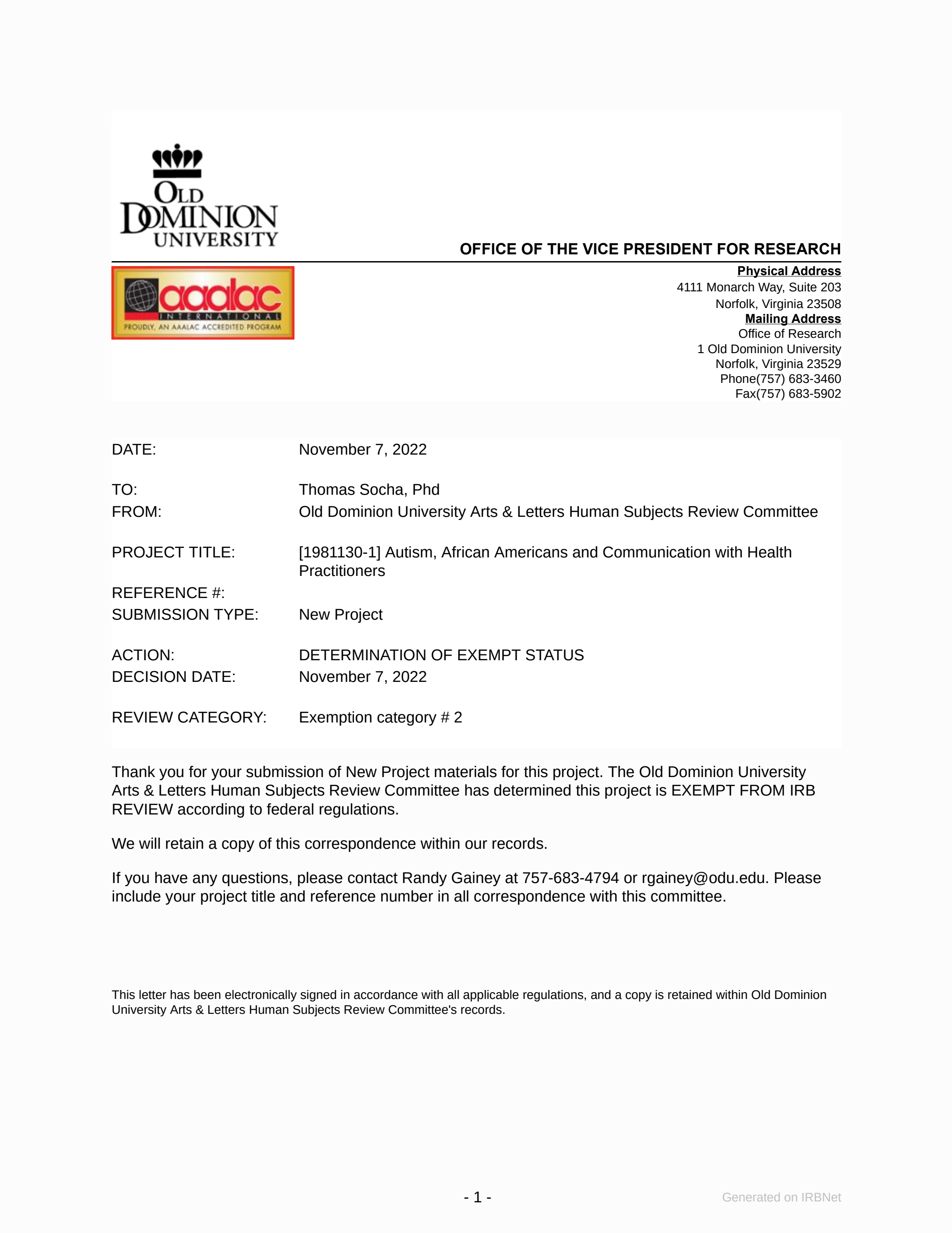
12. What do think can be done to help educate the African American community about Autism? What changes do you think it will make?

13. What do you think the medical community can do better to help African American parents with their diagnosed children?

14. Is there anything else you would like to add that we might not have covered that would help me to better understand health communication about autism and African American parents of children with autism?

APPENDIX B

HUMAN SUBJECTS REVIEW LETTER



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DATE:	November 7, 2022
TO:	Thomas Socha, Phd
FROM:	Old Dominion University Arts & Letters Human Subjects Review Committee
PROJECT TITLE:	[1981130-1] Autism, African Americans and Communication with Health Practitioners
REFERENCE #:	
SUBMISSION TYPE:	New Project
ACTION:	DETERMINATION OF EXEMPT STATUS
DECISION DATE:	November 7, 2022
REVIEW CATEGORY:	Exemption category # 2

Thank you for your submission of New Project materials for this project. The Old Dominion University Arts & Letters Human Subjects Review Committee has determined this project is EXEMPT FROM IRB REVIEW according to federal regulations.

We will retain a copy of this correspondence within our records.

If you have any questions, please contact Randy Gainey at 757-683-4794 or rgainey@odu.edu. Please include your project title and reference number in all correspondence with this committee.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within Old Dominion University Arts & Letters Human Subjects Review Committee's records.

VITA

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THESIS:

African-American Parents' Cultural Understandings of the Concept of Autism and Implications for Parental Communication and Health Management

ADVISOR: Dr. Thomas J. Socha

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