

A PHENOMENOLOGICAL STUDY:
LIVED EXPERIENCES OF BLACK PARENTS THROUGH
THE AUTISM SPECTRUM DISORDER IDENTIFICATION PROCESS

by

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This dissertation was prepared under the direction of the candidate's dissertation advisor, Dr. Valerie Bryan, Department of Adult Education, and has been approved by all members of the supervisory committee. It was submitted to the faculty of the College of Education and was accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

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ABSTRACT

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This study is an informative, phenomenological inquiry, investigating the lived experiences of Black parents and guardians through the autism spectrum disorder (ASD) identification process. Through semi-structured oral interviews, parent questionnaires, and parent journaling, the researcher identified participants' lived experiences. Data were collected, participant interview responses, parent questionnaires, and parent journal entries were analyzed, a list of significant statements was categorized and grouped into meaning units, and textural, structural, and composite descriptions of the phenomena were identified (Moustakas, 1994). Categories and themes, as well as perceived facilitators and barriers were identified. Review of the literature indicates little research has been conducted in investigating the lived experiences of Black parents through the autism identification process. Recommendations from the study are provided to inform parental training needs and supports, to assist in the facilitation of effective identification, as well as necessary recommendations for how educators and health care professionals

can better support Black parents through the ASD identification process.

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CHAPTER 1: INTRODUCTION

This study is an informative, phenomenological inquiry, investigating the lived experiences of Black parents through the autism spectrum disorder (ASD) identification process. All of the parents who participated in this study self-identified as Black, but culturally referenced their African American, African American and American Indian, Jamaican, and Haitian heritage. For the purpose of this study, Black is identified as a person having origins in any of the Black racial groups of Africa, including people who indicate their race as "Black or African American," or report entries such as African American, Kenyan, Nigerian, or Haitian. (U.S. Census Bureau, 2020)

Through semi-structured one-to-one oral interviews, parent questionnaires, and journal analysis, the researcher identified participants' lived experiences. The sample consisted of 16 parents, 15 mothers and 1 father, with a total of 19 Black children (ranging in ages from 6-26 at the time of the study), of which only 2 were female and 17 males, all identified with ASD. Four of the 15 families interviewed had two children with autism in their family. Although all the parents self-identified as Black, 11 of the 16 parents identified as African American, 1 as African American and American Indian, 3 as Jamaican, and 1 as Haitian.

Purpose of Study

The intent of this study was to better understand the lived experiences of Black parents and guardians through the ASD identification process and to identify the barriers

and facilitators mediating parental success in ASD identification, both within the educational system, as well as the health care system.

Statement of Problem

Much research has been conducted documenting underrepresentation, misidentification, and delayed identification of Black children with ASD. However, little research has been conducted in investigating parental lived experiences through the ASD identification process, to better identify the facilitators and barriers for effective ASD identification. Parents and guardians serve a critical role in ensuring their child is properly identified and effectively educated. It is important for educators and health care professionals (HCPs) to understand the lived experiences of Black parents and guardians through the identification process, in order to better support parents and families more efficiently and effectively in identifying Black children with ASD.

Research Question

This study was a phenomenological inquiry, investigating the lived experiences of Black parents and guardians through the ASD identification process. The researcher, through semi-structured, one-to-one oral interviews, participant completion of a parent questionnaire, and parent journaling, identified Black parents' lived experiences. The sample consisted of 16 Black parents, with 15 mothers and 1 father, of 19 Black children of which 2 were females and 17 were males, ranging in ages from 6 through 26 years of age (at the time of study) identified with ASD. Four of the 15 families had multiple children with autism within the family. Although all the parents self-identified as Black, 11 of the 16 parents identified as African American, 1 as African American and American Indian, 3 as Jamaican American, and 1 as Haitian American.

Data were collected, participant responses were analyzed, a list of significant statements was categorized and grouped into meaning units, and textural, structural, and composite descriptions of the phenomena were identified (Moustakas, 1994). The main research question was: What are the lived experiences of parents and guardians of Black children through the ASD identification process?

Research Sub-Questions

1. How do parents and guardians of Black children describe their experiences and the effects of the identification process for ASD on their children?

2. What meaning do parents and guardians of Black children attribute to the identification process for ASD for their children?

3. How do parents and guardians of Black children understand the effects of the identification process for ASD for their children?

Research Design

This study utilized a qualitative research design, employing an informative, phenomenological approach for collecting insights, personal stories, memories, and understandings through semi-structured, one-to-one interviews, parent questionnaires, and parent journaling, to better discern the lived experiences of Black parents and guardians through the ASD identification process, and to determine the perceived most effective practices and barriers within the ASD identification process for Black children. This approach emphasized inductive processes, contextualized knowledge, and human intention, which is suited well to this study (Merriam & Tisdell, 2016). The study, through the collection of oral interviews, parent questionnaires, and parent journaling, identified perceptions of Black parents regarding the most effective strategies and

practices, as well as perceived barriers and facilitators, employed by educators and HCPs within the ASD identification process.

Role of Researcher

The primary role of the researcher was to gather, analyze, compare, categorize, and identify themes, in order to fully understand the lived experiences of Black parents through the ASD identification process for their child. Additionally, the study identified Black parents perceived most effective practices and barriers employed by educators and HCPs, through the ASD identification process.

The researcher is a full-time White staff member working for a university autism center, a parent of an adult child with a disability (not ASD), and an adult child with a serious medical condition; therefore, the researcher must be aware of their own personal biases. The researcher as a White person must also be aware of the potential impact of their race in interviewing Black parents, especially given the particularly potential emotional nature of the interview and any unrealized biases. The researcher met with each participant either via phone or Zoom, prior to the interview to discuss the study, answer any questions the parent might have about the study, to explain the process and the safeguard of data, to secure the consent to participate, and to schedule the interview. Time and care was taken to ensure a level of comfortability, transparency, and honesty, with the researcher sharing up front my race. It was the researcher's intent to promote full disclosure and to facilitate an environment whereby the parent felt free to share fully their feelings and experiences, despite the researcher's race. As a researcher, it is important to ensure to the extent possible, that personal bias is minimized in data collection, analysis,

interpretation, and reflection. This is particularly important given the sensitivities in race and potential bias and discrimination that was uncovered.

As such, researcher bias was managed through multiple levels of comparisons of data utilizing a spreadsheet and color coding to identify any emerging and divergent themes. Additionally, a secondary coder who was Black was solicited to code responses, to cross correlate responses and themes, and to actively seek divergent and convergent understanding, that did not fit emerging themes. Findings were compared to past research to examine areas of overlap and divergence. Memos of the coding and decision-making process are maintained to document the analysis.

Limitations and Delimitations

The purpose of this research was to better understand the lived experiences of Black parents and guardians through the ASD identification process. This study attempted to identify the lived parental experiences through the ASD identification process, and determine parents' and guardians' perceived barriers and facilitators mediating identification through the ASD identification process. It is this researcher's assumption, while all respondent data will be kept confidential, all interviewees responded to oral interview questions, the parent questionnaire, and parent journaling with honesty. All respondent data were restricted to a sampling of 16 Black parents, 15 mothers and 1 father, all of Black children ranging from ages 6 through 26 years of age with autism, across a four-county region, from both urban and suburban areas of the southeastern United States.

Limitations are influences that the researcher cannot control. Some of the limitations of the research are the race of the researcher, time allotted for the study, the

sample size, and generalizability of information learned, due to the small sample size.

The researcher's race did not appear to be a limitation to the research, but must be noted, given the concerns about race, discrimination and unrecognized bias in our society. The researcher however, did afford significant time and effort prior to the interview in meeting with each participant, sharing the purpose of the study, confidentiality protocols, and race of the researcher in an effort to develop a level of trust with the participants.

Delimitations are choices made by the researcher and describe the boundaries that have been set by the researcher for the study. The researcher's selection process utilized a snowball sampling process, whereby parents, school district staff, community therapists and providers, as well as university autism center staff were requested to share the study recruitment flyer with parents meeting study criteria. Additionally, university autism center staff shared the study's recruitment flyer with eligible parents to assist with recruitment. Another delimitation was the criteria for inclusion developed by the researcher: Black parents and guardians with children identified through the ASD identification process. The researcher purposely chose not to limit the ages of the respondents' children, nor the gender of the children with ASD. Additionally, the researcher chose to not limit the respondents to mothers or fathers, or intact families or divorced or separated families.

Significance of Study

The exploration of the beliefs, attitudes, lived experiences, and meaning attributed to the ASD identification process by Black parents and guardians may contribute to the body of knowledge and practice in the field. Understanding the first-hand experiences of Black parents through the ASD identification process will inform educators and HCPs in

developing culturally sensitive and effective practices to better support Black parents and guardians through efficient and valid identification of ASD. It is important for educators and HCPs, to implement strategies and practices deemed most effective by their parent consumers. This study attempted to understand the lived experiences of Black parents through the ASD identification process and to identify what parents and/or guardians perceive to be the barriers and facilitators mediating their success, through the ASD identification process.

CHAPTER 2: REVIEW OF THE LITERATURE

ASD is a developmental disorder that includes deficits in social communication, social interaction, and the presence of restricted, repetitive patterns of behavior, interests or activities, that tend to persist across the age spans (Centers for Disease Control and Prevention [CDC], 2018). ASD is diagnosed at a rate of 1 in 54 children in the United States (CDC, 2020). The prevalence of ASD, however, occurs four times more in males than females. ASD is not thought to differ by race, but the prevalence differs across racial groups (Grinker et al., 2011; Mandell et al., 2009; Valicenti-McDermott et al., 2012; Yeargin-Allsopp et al., 2003), with Black and Hispanics identified at a lower rate than White children (CDC, 2018). ASD is often characterized across a spectrum, varying in symptom presentation and severity.

The causes of ASD are unknown and likely to be varied. Scientists contend that ASD is most likely the combination of heredity, environmental factors, and brain functioning (Ruble & Gallagher, 2004). Current thinking is that there are many different environmental and genetic risk factors, such as children who have a sibling with autism; children who have genetic or chromosomal conditions such as fragile X syndrome or tuberous sclerosis; children born to older parents; and children who have been exposed to the prescription drugs valproic acid and thalidomide during pregnancy (CDC, 2018).

ASD has no known biomarkers, and diagnosis relies entirely on professional observation and parent report of child behaviors (American Psychiatric Association [APA], 2013). An ASD diagnosis is made from a detailed history and observation of

behavior in structured and unstructured situations (Blaxill, 2004; Mandell et al., 2002). Symptoms of the disorder may vary significantly depending on the age and developmental level of the individual (American Psychiatric Association, 2013). However, ASD can be reliably diagnosed by 2 years of age (Stone et al., 1999), while screening measures can identify children at risk for ASD by 12 months of age (Turner-Brown et al., 2013).

Early diagnosis of ASD is critical to ensuring children receive access to early and evidence-based intervention. Multiple studies have concluded early autism identification and treatment leads to better cognitive and language abilities (Rogers et al., 2014). Early intervention has a significant impact on the long-term successful outcomes through childhood and on into adulthood. Research suggests that beginning intervention early can greatly improve outcomes for children at risk for ASD (Stahmer et al., 2017). Substantial gains in functioning are demonstrated by very young children with ASD, who received early behavioral intervention (Dawson et al., 2012, 2010). Effective early intervention can greatly decrease the costs over the lifespan for supporting a person with ASD (Jarbrink & Knapp, 2001; Penner et al., 2015).

In addition to providing early intervention as early as possible, it has been long established that parent involvement is critical for positive child outcomes (Maglione et al., 2012). General developmental guidance offered in many early intervention programs is not an intervention approach that has shown positive effects for children with ASD (Ingersoll et al., 2012). Several recent studies of parent-implemented Naturalistic Developmental Behavioral Interventions (NDBIs) for ASD have shown positive impact on the core symptoms of ASD (Kasari et al., 2014; Rogers et al., 2014 Wetherby et al.,

2014). NDBIs combine behavioral and developmental strategies to address core symptoms of ASD, in addition to building targeted communication and cognitive skills (Dawson, et al., 2010; Schreibman et al., 2015; Stahmer, et al., 2017). Parents learn to use specific strategies from a therapist and are taught to utilize evidence-based strategies into their daily routines, in parent-implemented treatment. Parent-implemented treatment not only promotes the use of effective evidence-based strategies, but engages parents in the intervention process early and increases parent feelings of competence and empowerment (Stahmer, et al., 2017). Research looking at the effectiveness of NDBIs implemented by parents indicate they can learn the strategies with a high level of fidelity when coached by highly trained staff (Aldred et al., 2004; Kaiser et al., 2000).

The American Academy of Pediatrics' (AAP) guidelines support universal screening for ASD at 18 months and 24 months, and at any age when parents express concerns (Johnson et al., 2007). Ideally, all children should be screened at age 2 and those identified at risk would promptly receive a comprehensive evaluation (Juarez et al., 2018). For a variety of reasons such as inability to identify characteristics of ASD and lack of medical professional training, many children are not screened for ASD, and wait times for diagnostic assessments are lengthy (Christensen et al., 2016; Hyman & Johnson, 2012). Despite parents' expressed concern to their pediatrician about their young children's delays before the age of 2 (Chawarska et al., 2007), on average U.S. children are not diagnosed with ASD until they are over the age of 4 years old (Baio et al., 2014).

Racial differences reported in the literature are identified in the timing and type of ASD diagnosis among White and Black children (Sell et al., 2012). Although ASD is not

thought to vary by race, the prevalence differs across racial groups (Grinker et al., 2011; Mandell et al., 2007; Valicenti-McDermott et al., 2012; Yeargin-Allsopp et al., 2003). The CDC reported the prevalence of ASD among Black children continues to be lower than the ASD prevalence among White children (Baio et al., 2014). Children from traditionally underserved communities are less likely to be identified at young ages, including children from families of lower socioeconomic status, children whose parents report lower levels of education, and children from racial and ethnic minority groups (Christensen et al., 2016; Durkin et al., 2010; Fountain et al., 2011). Up to 40% of children and families from low socio-economic communities struggle to access evaluation services, even when universal screening procedures are implemented (Chlebowski et al., 2013). These diagnostic delays contribute to substantial family stress (Warren & Stone, 2011).

Black and White parents raise concerns about their child's development to their health care providers when their children are at similar ages (Jang et al., 2014). But, compared to White children, Black children are diagnosed at later ages (Mandell et al., 2002; Mandell et al., 2007). Black children are less likely to receive a developmental evaluation before age 3 (Christensen et al., 2016). Black children meeting ASD diagnostic criteria are less likely than White children to have a prior ASD diagnosis, but more likely to have a co-occurring ASD and intellectual disability diagnosis (Baio et al., 2014; Bhasin & Schendel, 2007; Mandell et al., 2009). Black children are more likely to be diagnosed with ASD rather than Aspergers, a higher functioning form of ASD, when compared with White children (Baio et al., 2014). Aspergers Syndrome is currently classified under the global classification of ASD under the American Psychiatric

Association [APA] 2013, as Mild-Level One, Requiring Support. Even when controlling for socioeconomic status, racial disparities in ASD diagnoses and services exist (Feinberg et al., 2011; Jarquin et al., 2011; Mandell et al., 2007).

Black children are not only diagnosed later, obtaining a diagnosis for ASD 1.6 years later than White children (Mandell et al., 2002). Additionally, Black children are 2.6 times more likely to be misdiagnosed and are identified with more severe forms of ASD than White children, suggesting under-diagnosis of Black children with milder forms of ASD (Jarquin et al., 2011; Mandell et al., 2007). Black children are 5.1 times more likely to receive a misdiagnosis of adjustment disorder (Mandell et al., 2007). Black children are also 2.4 times more likely to receive a misdiagnosis of conduct disorder (Mandell et al., 2007).

Multiple cultural factors have been theorized as affecting delayed diagnosis, misdiagnosis, and lack of timely interventions for the Black child with ASD, such as HCP diagnostic bias, health care accessibility, symptoms presentation, and family interpretation of the child's symptoms (Kalb et al., 2012; Liptak et al., 2008; Mandell et al., 2002, 2005, 2007, 2009). Primary health care providers, including pediatricians, nurse practitioners, and other medical professionals play a critical role in facilitating timely ASD diagnosis and access to early intervention (Pinto-Martin et al., 2008). Despite the stigmatization of ASD, Black families persevered to secure services for their child (Burkett et al., 2015).

Cultural factors can complicate obtaining an earlier diagnosis for Black children with ASD. For the Black child with ASD, diagnostic deliberations may be confounded, if a HCP believes there is decreased likelihood of ASD, and may not screen or interpret

symptoms as quickly (Mandell et al., 2002, 2007; Smedley et al., 2002). HCP bias has been defined as fluctuating HCP behaviors, with patients of unlike cultures, and HCP expectations about diagnosis and treatment that differ by culture (Mandell et al., 2002; Smedley et al., 2002). Poorer health care access for Black children has also been proposed as a factor in ASD diagnostic delays; however, findings are conflicting as to whether biases of HCPs or socioeconomic factors are more contributory (Liptak et al., 2008; Mandell et al., 2002; Montes & Halterman, 2011; Ruble et al., 2005; Sansosti et al., 2012). Studies that examined socioeconomic status (SES) and ASD diagnosis reported Black children from low income families were consistently associated with delayed diagnoses, but when controlled for SES, Black children with ASD were less likely to have adequate access to health care across incomes (Bhasin & Schendel, 2007; Fountain et al., 2011; Jarquin et al., 2011; Liptak et al., 2008; Magana et al., 2012; Mandell et al., 2007; Rosenberg et al., 2011; Thomas et al., 2012a; Valicenti-McDermott et al., 2012). Potential health care provider-related enabling factors contributing to ASD racial disparities, include inadequate professional training and provider bias (Mandell et al., 2002); distrust of clinical care (Burkett et al., 2015); and strained partnerships between primary health care providers and Black families raising children with ASD (Magana et al., 2015; Montes & Halterman, 2011; Pearson & Meadan, 2018; Zuckerman et al., 2015). Dababnah et al. (2018) investigated Black caregivers' perspectives of ASD screening and referral practices in primary health care settings, and identified four broad themes: (a) Primary health care provider's inattention to caregiver concerns; (b) Perceived racism and poor caregiver-provider interactions; (c) Stigma in the Black community; and (d) Legal and custodial issues. This study recommended training for

primary health care providers to include values clarification, awareness of biases, improving relationships, and addressing the importance of communication, as key in dealing with the perceived racism, caregivers expressed (Dababnah et al., 2018). A comparison study of ASD and associated features among Black and White children in Philadelphia County identified a higher frequency of White children compared to Black children with non-functional routines and rituals, persistent preoccupations with parts of objects, and abnormal motor development (Sell et al., 2012), suggesting that these hallmark characteristics of ASD may manifest differently in Black children in comparison to White children. Sell and colleagues however, did not find significant differences among Black and White children in externalizing behavior or reciprocal social interaction, other key characteristics of ASD. More research is needed in this area.

Black parents are not only challenged in having their children identified early, but also experience significant difficulties in accessing high quality intervention services for their child with ASD (Lord & McGee, 2001). Black families regardless of their economic standing or educational attainment suffer reduced access to ASD treatment services (Gourdine & Algood, 2014; Longtin & Principe, 2016). Accessing high quality diagnostic and intervention services for children with autism requires a high degree of parent advocacy (Lord & McGee, 2001). The experience of parenting a child with a disability requires parents to call on allies on their behalf, to obtain access to supports and services for their children (Shepherd et al., 2018). Black families report experiencing distinct biases and stereotypes serving as barriers for Black mothers, in accessing school resources, services and during the Individualized Education Plan (IEP) process (Stanley, 2015). Research on Black mothers' relationships with special educators provides

evidence that Black mothers do not receive the same level of participation and partnership as White parents (Stanley 2015).

Students with autism are at risk for social challenges, anxiety, and underachievement (Auger, 2013). ASD diagnosis and identification are a passport to not only evidence-based therapies and intervention for the child, but much needed parent education and training, as well as necessary behavioral strategies to manage their child and maintain safety for their child with ASD in the home and community. ASD identification can ensure appropriate family education and the provision of services to assist with coping (Bennett et al., 1996). Delays in the diagnosis and treatment of children with ASD can produce added stress (Burkett et al., 2017). Gourdine et al. (2011) found obtaining good resources for children with autism is difficult. Many clinicians are unaware of the scope of behaviors and problems that children with autism display (Gourdine et al., 2011).

Parents are the single most significant contributors to the care of a child with ASD, across the life span. Black parents express that caring for their child with ASD is emotionally stressful and faith in God and their family help alleviate the stress (Burkett et al., 2017). Parenting a child with autism has been identified as more stressful than parenting a child without autism (Hartley et al., 2016). Parents of children with ASD typically experience higher levels of stress, depression, anxiety and anger (Hayes & Watson, 2013). Eighty-five percent of persons with ASD have needs requiring parental care and support, across the life span (Volkmar & Pauls, 2003). Some of the stressors impacting parents are problem behavior, costs of care in both financial and impact on career choices, restricted access to child care and community activities, greater barriers in

accessing education, time in obtaining and providing ASD treatment, and worry that indecision and uncertainty can compromise time-critical therapy (van Steijn et al., 2014). Parents reported, having a child with a disability requires intensive efforts to ensure their child receives appropriate intervention (Gourdine et al., 2011). Specific autism symptoms (i.e., social challenges) have been identified as triggers for parental stress and can contribute to negative interactions between the child and parent (Davis & Carter, 2008). Uninformed clinicians are a source of frustration for the family, and often complicate the family's ability to obtain quality services (Gourdine et al., 2011). Parents are also frustrated in their research efforts to find literature on behavioral interventions for Black children with autism (Gourdine et al., 2011).

The teaching of coping strategies in relation to parent stress has been studied. Coping strategies may impact the level of stress, as well as the level of parental resilience experienced by parents raising children with ASD (Shepherd et al., 2017). Problem-focused coping strategies are identified to improve parental adjustment, while emotion-focused coping strategies are linked to poorer mental health outcomes for parents of children with ASD (Abbeduto et al., 2004). Positive reframing however, a type of emotion-focused coping strategy was found to be helpful in lowering parental depression levels (Shepherd et al., 2017). Four coping strategies were identified to be utilized by parents with children with ASD: engagement (strategies directed at the stressor); disengagement (strategies to avoid or deny the stressor); distraction (strategies to direct thoughts away from the stressor); and cognitive reframing (assessing the stressor less negatively) (Obeid & Daou, 2015). Benson (2014) reported that cognitive reframing strategies were connected to lower levels of parental stress.

Two cultural studies were conducted comparing White and African American mothers, as identified in the studies. This study contrasted African American and White mothers' well-being with regard to caring for their children with ASD (Burkett et al., 2015). Both studies found that African American mothers perceived less negative impact on their well-being, expressing fewer social, emotional and physical burdens than White mothers (Burkett et al., 2017). Additional threats have been described in parenting an African American child growing up in two worlds—African American and the White world. Socialization in the African American culture focuses on self-care skills and discipline at a young age, that may differ from the White worldview and may add to existing pressures (Dixon, 1971; Peters & Massey, 1983).

There exist differences in available services and access to services for Black children (Mandell & Novak, 2005; Thomas et al., 2012b). Professionals working with different cultures need to be aware of any preconceived attitudes toward a particular race or culture and that those preconceived notions impact their treatment of their clients, in their practice and or services provided or recommended (Wilder et al., 2004). Dababnah et al. (2018) also stressed the importance of the dissemination of early warning signs of ASD to the primary health care provider, to ensure more families receive access to ASD interventions. Burkett (2017) conducted a study with African American parents. Respect from HCPs was identified as a major factor in parenting the African American child with ASD (Burkett, et al., 2017). Parents did not always feel that HCPs demonstrated respect toward them and their child with ASD (Burkett, et al. 2017).

Respect from the community and professionals was another theme identified by Burkett et al. (2017). Black parents often felt judged in public, for their child with ASD's

behavior and some parents shared how family members and friends believed their child's behavior was as a result of their poor parenting (Burkett, et al., 2017). Parents further stated that they often felt judged by HCPs and if families believed that HCPs respected their parenting, they would seek out those professionals for additional information to help them better parent (Burkett et al., 2017).

Black families with younger children and less education tend to be identified with autism by school sources (Yeargin-Allsopp et al., 2003). Educators play a critical role in not only supporting and educating children, but also in educating the parent. Engaging parents as stakeholders in their child's education and in the implementation of research-based, early intervention practices is much needed, especially for children with ASD (Sansosti et al., 2012). Parental engagement is critically important for students with disabilities, who often experience gaps in educational opportunities and outcomes, compared to students without disabilities (Rock & Leff, 2007). Dababnah et al. (2018) also stressed in their study the importance of developing Black caregivers of children with ASD as important facilitators in gaining access to ASD services. More research on the challenges Black families confront in raising a child with autism is needed (Gourdine et al., 2011).

Culture plays a significant role in how parents view the disability of their child (Tincani et al., 2009). The researchers found that the African American families they studied experienced a positive adjustment in the raising their child with autism. This approach is attributed to their strong extended family network and the role of religion and the church in the life of the family (Daly et al., 1995; Gourdine et al., 2011; Neeley-Barnes & Marcenko, 2004; Rogers-Dulan & Blacher, 1995). ASD and other

developmental disabilities have been found to enrich the Black and African American family system by fostering deep family cohesion, developing resilience among family members, and nurturing a greater appreciation for diversity (Reichman et al., 2008). Black caregivers report lower levels of depression, anger, and hostility in their role as caregivers for a family member with a disability (Pruchno et al., 1997). Taylor (1983) in studying African American family culture stated African American families are in general optimistic and believe that all children are important; life challenges can be dealt with better through belief and participation in religious rituals, because religion helps interpret the meaning of a life event; having a child with a disability is a way of helping others; and religion helps parents grow individually, maintain a sense of hope, and help them with acceptance of their child's fate.

There has been little research to identify the relationship between religious coping and parental stress for parents raising children with ASD. Shepherd et al. (2017) identified a significant relationship between religious coping and parental stress. Caring for a child with ASD, is a significant challenge and appears to raise questions and quandaries for parents, such as why was my child afflicted with ASD, and the essence of suffering and hardship. Affiliation to a religious belief may provide a shield and make sense or give meaning to a life altering experience and provide a mechanism for positive reframing (Shepherd et al., 2017). The researcher in studying African American families identified faith in God and faith in the family is an important value in the African American community (Burkett et al., 2017). Their faith was a mechanism to gain strength, obtain support, and cope with the everyday stresses of managing behavior (Burkett et al., 2017). While African American parents of children with ASD did not

always attend organized religion, they felt that their spiritual connectedness to God was critical for their personal growth, ability to cope with stress, and remain hopeful (Burkett et al., 2017). In Burkett's study (2017), all of the African American parents stated they felt blessed to care for their child with ASD, many further stating it led to spiritual and personal growth.

The process of securing ASD identification and treatment has a significant impact on the child, family, and parent. It is essential for parents throughout this process to research autism identification and treatment, seek supports from other parents and professionals, and rally family members in support of their child. The parent throughout this process serves as a transformational leader within their family as identified in Senge's Five Disciplines (Senge, 2006). Transformational leadership is the process whereby a person interacts with others to create a connection that increases the level of motivation and ethics, in both the leader and the follower (Northouse, 2013). Individuals who manifest transformational leadership often exhibit high internal values and ideals, are able to motivate others to support the greater good, rather than their own self-interests. Transformational leaders manifest the following characteristics: establishing a clear vision, motivating others to work as team, creating a sense of trust through implementing a consistent direction, and through understanding their strengths and weaknesses immersing themselves into the tasks, along with the goal of meeting their child's needs.

Through the parent's efforts the family becomes a learning organization. Senge (2006) introduces and defines the concept of the Learning Organization and the pivotal role of the individual learner in achieving the status of a learning organization. Senge

identifies the five disciplines of organizational learning as systems learning, personal mastery, mental models, shared vision, and team learning (Senge, 2006).

The principles of adult learning are utilized by the parent through the securing of ASD identification and treatment for their child. Knowles identified six assumptions of adult learning which is the ability of the adult to self-direct his or her learning (Merriam et al., 2007). Adult learners gather a variety of experiences that serve as a resource for learning (Merriam et al., 2007). There is a direct correlation between the adult's social role and readiness to learn (Merriam et al., 2007). Adult learners tend to be more problem-centered versus subject-centered (Merriam, et al., 2007). Finally, adult learners focus on the importance of internal versus external motivations and the rationale for learning (Merriam, et al., 2007). Parents can be classified as transformational leaders, not only within their families, but within their community. Parents engage as adult learners throughout the process of securing ASD identification and treatment for their child.

Burkett et al. (2015) studied African American families with ASD and found the following two emerging themes in their study on the influence of culture on the identification of ASD among African American families: Theme 1 was identified as providing protection for their child with autism; and Theme 2 was depicted as taking action for their child with autism. Theme 1, providing protection, is evidenced through promoting independence in self-care. Parent participants in the study protected their child with autism, by pushing their child to be independent in daily activities such as dressing, cleaning up, completing family chores, and by treating their child as normal (Burkett et al., 2015). Theme 2, taking action for their child, family, and community involves

making choices for their child with autism, such as seeking an accurate diagnosis to procuring ASD resources, and therapeutic treatments (Burkett et al., 2015).

Increased understanding and awareness of ASD is needed in the Black community (Lovelace et al., 2018). Additionally increased awareness, appreciation and respect is needed in understanding the journey Black parents encounter through the identification of ASD, challenges in finding and obtaining resources and treatment for their child with ASD. Culturally competent educational programs for parents of Black children with ASD must be developed and implemented to inform parents about treatment programs and methods for working with children with ASD (Gourdine et al., 2011). Additionally, there is a need to develop and implement more culturally responsive practices by educators and health care providers in working with Black children and their families with autism (Lovelace et al., 2018). Future research is also warranted on pharmaceutical trials and behavioral interventions to include Black children with ASD (Gourdine et al., 2011).

CHAPTER 3: METHODOLOGY

Research Design and Methods

With the intended purpose of this study, the use of a qualitative research design was deemed to provide a depth of the participants' experiences that would not otherwise be found, within the context of quantitative methodology. The research questions drove the design, informing a phenomenological approach, which seeks understanding about the essence and the underlying structure of the phenomenon (Merriam & Tisdell, 2016).

Sampling Plan

According to Sousa (2014), in a descriptive-based phenomenological methodology, the intent of the research is to describe, understand, and clarify human experiences; participants should be chosen to better inform and assist in understanding the intent. With this in mind, a sampling plan was developed to solicit names and contact information from clinical support staff from a local university autism center to share information on the study and the recruitment flyer. Additionally, recruitment flyers were distributed to four urban and suburban school district staff, community therapists and service providers, and community HCPs to share with parents and guardians of Black children, who successfully mediated the ASD identification process. The snowball sampling technique was also utilized to identify interviewees to inform the study. Participating parents were asked to share the recruitment flyer with other eligible parents. The advantage of utilizing this sampling technique lies within the need to obtain participants who met the study criteria, as well as to share information with the university

staff, educators, and HCPs and to better inform effective parent training and support for parents and guardians, aiming toward effective and efficient identification of Black children through the ASD identification process.

Sampling Plan: Data Sources

Multiple data sources were collected, reviewed, and analyzed in order to triangulate data collection and better inform inquiry. Bowen (2009) states that the qualitative researcher is expected to draw upon multiple (at least two) sources of evidence, to seek convergence and corroboration through the use of different data sources and methods. The researcher collected, reviewed, and analyzed three sources, including parent interview transcriptions, parent questionnaire data, and parent journal data. Additionally, the researcher completed a journal of thoughts and understandings throughout the process.

Interviews, Parent Questionnaire, and Parent Journal

Interview protocol (Appendix A) was developed and edited based on feedback from colleagues, as well as a prior pilot study completed in December 2020. Fifteen interviews were conducted with 16 Black parents, 15 mothers and 1 father, of which 13 were married and 2 were single parents. The 16 parents interviewed had a total of 19 children with autism, 17 males and 2 females, with ages ranging from 6 through 26 years of age. Four of the parents interviewed are raising multiple children with ASD. All of the parents who participated in this study self-identified as Black, but culturally referenced their African American, African American and American Indian, Jamaican, and Haitian heritage. Although all the parents self-identified as Black, 11 of the 16 parents identified as African American, 1 as African American and American Indian, 3 as

Jamaican American, and 1 as Haitian American. For the purpose of this study, Black is identified as a person having origins in any of the Black racial groups of Africa, including people who indicate their race as "Black or African American," or report entries such as African American, Kenyan, Nigerian, or Haitian. (U.S. Census Bureau, 2020). Ten of the families interviewed are registered at the university autism center that employs the researcher of this study. The remaining five families not registered with the local university center were subsequently referred to the center, in order to receive additional supports and resources.

The children as reported by their parents were identified with ASD by either a HCP or the school district between the ages of 17 months and 13 years old. The age range of the children at identification were as follows: 1 child at 17 months, 1 child at 19 months, 3 children at 2 years, 1 child at 2.5 years, 5 children at 3 years, 1 child at 3.5 years, 1 child at 4 years, 1 child at 5 years, 1 child at 6 years, 1 child at 8 years, 1 child at 10 years, and 2 children at 13 years. Of the four families with multiple children identified with ASD the second and younger child with ASD was identified significantly younger, than the older child with ASD. In all four cases the older sibling with ASD was identified, due to the younger child being identified. All four of the older children were prior identified with Intellectual Disabilities, Attention Deficit Hyperactivity Disorder, or not identified with a disability (Table).

Table

Characteristics of Participants at the Time of Study

Participant	Characteristics							
	Mother/ Father	Race and Culture	Reg'ed. w/Autism Center	# Child'n w/ASD	Marital Status	Child Age	Child Gender	Age of Child at Identification
1	M	B-AA/AI	Yes	2	M	26	Male	8 years old
						8	Male	3 years old
2	M	B-AA	Yes	1	M	23	Male	2.5 years old
3	M	B-AA	Yes	1	M	10	Female	2 years old
4	M	B-AA	No	1	M	6	Male	2 years old
5	M	B-AA	No	1	M	10	Male	3 years old
6	M	B-AA	Yes	1	M	7	Female	3 years old
7	M	B-AA	No	1	M	9	Male	2 years old
8	M	B-AA	Yes	1	M	9	Male	3 years old
9	M	B-AA	Yes	2	S	17	Male	13 years old
						13	Male	17 months
10	M	B-AA	Yes	1	M	10	Male	old
11	M	B-AA	No	2	M	25	Male	10 years old
						15	Male	13 years old
12	M	B-J	Yes	1	S	10	Male	5 years old
13	M & F	B-J	Yes	1	M	15	Male	19 months old
14	M	B-AA	Yes	2	M	8	Male	3.5 years old
						6	Male	6 years old
15	M	B-H	No	1	M	10	Male	4 years old
								3 years old

Participants were identified through referrals from the university autism center staff, school district officials, community therapists and providers, as well as from other Black parents who participated in the study. The interview protocol consisted of 10 open-ended questions examining lived experiences of Black parents and guardians through the ASD identification process for their children. The structured interviews conducted via the

Zoom platform took between 45 minutes and 70 minutes to participate, depending on the extent of information shared.

Participants additionally were requested to complete a Parent Questionnaire with nine open-ended questions, and a Parent Journal with five open-ended questions. The intention of these tools was to solicit more in-depth thought, after the interview was conducted. Twelve of the 16 parents interviewed completed and returned the Parent Questionnaire and Parent Journal. Multiple attempts were made via phone call and email to secure the additional tools from the remaining four participants. One of the parents shared that she was in the hospital, and the other three parents did not respond to emails and voicemail messages. The Parent Questionnaire and Journal activity were provided as a Word document via email to each of the participants permitting parents to complete the document and return via email within a week or two dependent on the need. The researcher provided each of the parents a week to complete the Parent Questionnaire and Journal. The 12 participants who completed and returned the forms did so within 2 weeks after the interview was conducted.

Participants were contacted through email and/or telephone to discuss the study and schedule the interview. Telephone conferences or Zoom calls were conducted with each participant, prior to scheduling interviews. The purpose was to provide parents an opportunity to meet the researcher, to share the study and process, to review confidentiality protocols, and to obtain parent consent to participate in the study. Appointments were made, and one-to-one structured interviews were conducted through Zoom, at a convenient time for each of the participants. Some interviews were conducted during the day, others in the evening, and others on Saturday morning between February

through June of 2021. Permission to record interviews was requested via the Parent Consent form, but also verbally prior to initiating the Zoom audio recording online. The Zoom audio recording feature was utilized to record interviews. All data were saved to a password-protected USB under the numbered participants folder on the USB.

Transcriptions were secured through numbered recordings and were saved in the participant folder by participant number with the participant consent document, notes, audio recording, transcription, and completed Parent Questionnaire and Parent Journals, to a dual password protected USB. All participants requesting an opportunity to review the transcript were provided the transcript via email, with an opportunity to review and provide any corrections. Within 2 weeks an email was sent requesting feedback on any requested changes. Two parents out of the 16 participating parents provided feedback requesting their child's name be removed from the transcript. The name was crossed-out in the original transcription, the edited transcription was subsequently saved, and the original transcript was deleted.

Data Collection and Analysis

Data were collected via oral, in-vivo semi-structured, one-to-one interviews through the audio component only on the Zoom platform. Additionally, parent questionnaires and parent journals were completed by recruited parents, reflecting on their feelings and lived experiences through the ASD identification process. These varied methodologies for data collection were identified and selected to obtain a thoughtful detailed inquiry. Parental information about the process, thoughts, and feelings of the ASD identification process were noted. Special attention was noted of the impact of the process on the child, parent, and family. It is believed that through the use of these varied

and descriptive collection tools and analysis, rich, insightful data were provided, to better understand the lived experiences of Black parents through the ASD identification process, to better inform effective parental supports and interventions.

All data and documents were analyzed to gain understanding and meaning (Corbin & Strauss, 2008). Transcriptions of the oral interviews were coded individually by the researcher who was White and a secondary coder. The secondary coder chosen was a Black person knowledgeable about autism. The primary and secondary coder developed a spreadsheet of important comments and themes, across participant responses; barriers and facilitators for identification were noted and color coded. Coders met to identify, review and determine barriers and facilitators through the identification process for the participants. Various groupings and themes were developed across the data. Participant responses were analyzed, a list of significant statements was categorized and grouped into meaning units, and textural, structural, and composite descriptions of the phenomena were identified (Moustakas, 1994). The researcher opted for four cycles of coding and two aforementioned analytic methods for this study.

In order to reliably answer the research question: What are the lived experiences of parents and guardians of Black children through the ASD identification process? and interpret the data related to this investigation, the researcher identified significant parent interview, parent questionnaire, and parent journaling statements, then categorized, color-coded, cross correlated with a secondary coder, and further categorized these statements for four cycles of coding, in order to identify the phenomenon, broad themes, and sub-themes that served as barriers and facilitators for securing identification and treatment for Black children with autism.

CHAPTER 4: FINDINGS

Through the process of analysis, categorization, and theme identification (Moustakas, 1994), the researcher identified the phenomenon, broad themes, and sub-themes. Additionally, the researcher identified characteristics that may serve, as both facilitators or barriers in the valid identification of ASD for Black children. Facilitators (catalysts to perceptions of success) and barriers (impediments to perceptions of success) are identified for all participants. One global phenomenon was identified along with five themes all found to either contribute to facilitating or creating barriers for expeditious identification of ASD for Black children. The phenomenon of Unrelenting Fighter-Black parents fight, advocate, and persevere in meeting the needs of their children with ASD. Additionally, the following five themes were identified: Theme One: Black parents seek and create allies to support them in securing ASD identification and treatment for their child. Theme Two: Black parents experience numerous challenges in seeking ASD identification and treatment for their child. Theme Three: Black parents experience unequal treatment in seeking ASD identification and treatment for their children. Theme Four: Black parents often feel isolated in seeking ASD identification and treatment for their children. Finally, Theme Five: Faith in God helps Black parents positively reframe their experience in parenting their child with autism. See Appendix D: Phenomenon and Themes.

Phenomenon: Unrelenting Fighter

The term *Unrelenting Fighter* captured the essence and lived experiences of each of the parents interviewed, across all participants, married and single parents, mothers and father, parents of young children, as well as parents of young adults. An unrelenting fighter depicts an individual who will not give up and will not stop fighting, until his/her mission is realized. The fight is very personal; it is a battle for their child, for their child's future, for the person they are and will be. One parent shared, "As a parent of an ASD child you have good days and bad days. On your good days take it, enjoy it and love it. On the bad days, step outside, take a deep breath, cry if you have to. Pull yourself back together, because your child needs you, more than you need them. They are looking to us to show them the way."

The motivating factor for the parents interviewed is their deep love, unwavering care and concern for the future of their child. This love propels them to fight, advocate, and persevere through securing identification, resources, and effective treatment for the child with ASD. One parent put it into perspective, this way: "You have to see your child, I am bringing up a woman, I am. And I am proud of her. I am not trying to cure her autism, but make her the best person she can be."

Each of the parents interviewed described their need to equip themselves for battle with research, information, skills, and allies, to come alongside them to fight and advocate with them, for their child's needs. Numerous parent statements were made expressing their love for their children and their commitment to fight, advocate and persevere through early identification, securing resources and access to effective treatment for their children. Throughout this process they discussed dismissing all those

such as pediatricians, educators and therapists, who did not come alongside them in their fight and did not align with their mission to advocate for their children. Participants shared statements such as: “You have to advocate for your child”; “If they don’t have an advocate you won’t get anything accomplished”; “So everything you literally have to fight for”; “You learn you have to stand up for your child”; “Be persistent, you have to be, it’s for your child”; “If you feel your child is not getting the services he needs, or you are getting the run around, don’t be afraid to speak up”; “It is totally on you to get involved in your child’s education, and advocate every step of the way”; “I’ve learned that not every door is going to open. I am going to have to find another way in”; “The school district and pretty much the world in general, pretty much brushes you off”; “Advocate and continue to advocate. Change doctors as frequently as you need to”; and “Don’t underestimate your child. They are capable. Keep pushing.” All of these statements by parents of Black children identified with ASD describe a call to action. One parent summed it up this way: “It is important to stand up for yourself, especially as a Black parent and to push back against biases you are encountering, by pointing them out.”

All of the parents interviewed expressed commitment, dedication and immense love for their children. One parent stated “You have to stand up for your child. Keep trying. Your child needs you to push people to get her there. Don’t settle and don’t give up!” Another parent summed it up well: “This journey has and will be my legacy and I hope my legacy is to show that anything is possible. I believe I was put on this earth for my daughter, because the skills I have and the needs she has, I am able to give that to her. And I believe no one else would be able to do that.” The phenomenon of unrelenting

fighter serves well, as a facilitator for the identification of Black children with ASD and beyond.

Theme 1: Black Parents Seek and Create Allies to Support Them in Securing ASD Identification and Treatment

The first broad theme is *Black parents seek and create allies to support them in securing ASD identification and treatment*. Black parents with children with autism describe the importance and need for parents, to seek and create allies. Allies are individuals that will come along-side them, to help fight and advocate with them for their child. Parents found and sought allies in other parents further along in the journey. Allies also included other family members, support groups, counselors, university autism agencies, and professionals such as developmental pediatricians, therapists and educators that mentored and taught them how to work with their child.

Parents stressed the importance of soliciting, creating, and assembling a team of people that can help them through navigating the many pitfalls in parenting and educating their child with autism. One mother stated, “My husband and I work hard to ensure that all the “village” of support surrounding her is unified. The most helpful tool I have found in my quest to find my daughter’s village is the experience of parents who have already found theirs or are further along in their journey. They have no ulterior motives. They aren’t looking for new patients.” Another parent stated, “I realized I have a child that needs a team, so I realized I have to step outside what works for me and find a team.” Other parents stated, “I find it helpful for parents to have a mediator, like FAU CARD”; “Having another parent to be able to support you too is important”; and “Find a support

group or mothers who culturally understand what you are going through, because those mothers can provide insight into what to do, with working with the school.”

All the parents interviewed spoke about the importance of seeking support, information and resources from seasoned parents or parent support groups. One mother described it as “When I linked up with other parents there was something powerful about that.” Another parent stated “Having a parent, another parent to be able to support you is important. Other parents help, they’re in your shoes. They understand exactly what you are going through.” Another mother shared, “I would recommend parents join a parent support group. We meet, share information, help and support each other. Sharing with others lightens the load.” A parent or a parent support group serves as an ally for parents with children with autism, in navigating through the very complex system of identification and obtaining effective services.

Some parents shared the importance of finding another professional to serve as an ally, a professional that “looked like them” to help advocate. Parents underscored the importance of seeking out Black professionals, such as pediatricians, therapists, and other professionals for guidance and support. One parent stated, “I should have gone to an African American pediatrician, as they are more keen to identifying what is going on in our children,” while another parent stated, “Always seek a second opinion. If you can, try to find a Black provider. I think if they look like you, you may get more information.”

Other parents shared that it was important to find a “White knowledgeable professional” to serve as an ally to help advocate for their child’s needs with other White professionals. One mother stated it is important to identify a White professional as “someone in the room who doesn’t look like you, who believes your experience, who

helps you advocate, and be in a room of people that look like them, and tell them they are wrong.” Black parents felt that White professionals would listen to other White professionals, rather than Black parents in advocating for their children. As this one mother noted, “Sometimes no one listens to us unless there is someone that looks like you in the room, who is able to vouch and say This is not okay! This is not right! This is not how you treat people.”

Parents also shared the importance of reaching out and creating allies for their child across professionals. Parents offered the following, “Have a good relationship with your child’s providers. Bring them into IEP meetings. Sign a release so they can share information”; “It is helpful for me to stay in communication with the professionals working with my son”; “Use parent-teacher conferences and open houses to share information about your child”; and “My son’s Speech and Language therapist not only works with my son, but she works with me. She helps me to communicate better with my child. They give me homework, so I can work with my son at night.” Black parents seek and create allies to support them in securing ASD identification and treatment; this serves as a facilitator to identification and treatment of Black children with ASD.

Theme 2: Black Parents Experience Numerous Challenges in Seeking Identification and Treatment for Their Child with ASD

The second theme depicted in the data identifies the numerous challenges Black parents face in securing an ASD identification and effective treatment for their child. Many of the challenges have to do with lack of knowledge and understanding of ASD, on the part of pediatricians, therapists, and educators, lack of community and school resources, and access to resources and evidence-based treatment. Black parents also are

uniquely required to address a variety of cultural barriers to identification of ASD that the broader White culture may not have to combat.

All of the parents interviewed shared their frustrations in securing an assessment, and referral for an ASD assessment from their child's pediatrician. Despite multiple, periodic, required well-visits, pediatricians failed to screen and early identify ASD in all of the children of the parents interviewed. Many of the parents changed pediatricians in order to access a referral for an ASD pediatric evaluation. A common concern that the Black parents shared is that their pediatrician did not listen to them, take action based on their stated concerns, minimized their concerns, and delayed providing a referral to rule out ASD. Parents stated the following, "I was not listened to, from the very beginning"; "I found my experience (with my child's pediatrician) minimized"; "I feel like my pediatrician did not listen to me. I feel like they did not have enough time, they were rushing off to the next patient"; "I kept pushing the pediatrician to give us a referral, to get the answers we needed"; "I changed pediatricians. The new pediatrician also was saying we needed to wait"; "Each time we had a different doctor from the group. They kept on saying he is fine, let him grow up, and we will see"; and "They wanted him to grow up and see, rather than give me a referral." One parent summed up her frustration like this: "Many of my friend's kids are being identified with ASD at 8 or 9 years old. Why didn't they catch it earlier? The parents have given up." Another parent shared, "I told my pediatrician, something is different about my kid, and I know something is different, and I need answers. It is not okay for you to keep sending me home, saying boys will be boys, and it will get better over time." A parent shared her frustration as follows: "His first pediatrician gave me a very hard time. He said, oh that is typical, oh

that's nothing. I said, don't just brush my baby off." I had a really difficult time. It got so bad, that I, literally, in the middle of an appointment, got up and left. He was not listening. He was not trying to understand or listen to what I was saying about my son." One parent appealed to pediatricians as follows: "Listen to parents. Parents know their children better than anyone. Most parents focus on the positives of their child. If a parent is sharing concerns that should be a huge red flag."

Parents reported not only those pediatricians were hesitant to refer their child for an ASD evaluation, they did not screen their child, and were not knowledgeable about the red flags of ASD. Parents shared the following: "My pediatrician did not say anything. I did not know to say anything. Pediatricians are not knowledgeable about autism"; "I was told my child could not be diagnosed with ASD until he was two years old"; "My pediatrician said he didn't know about autism to say yay or nay"; "I don't believe all pediatricians understand what autism is. They go by the look. The look is nothing"; and "Pediatricians think that if they are verbal, they can't have autism. They do not see ADHD [attention deficit hyperactivity disorder] co-morbid with autism." Parents offered the following solutions: "Pediatricians should be required to take continuing education units in autism and neuro-disorders in children," and "Pediatricians should be conducting mandatory regular screenings for ASD." None of the children of the parents interviewed were screened for ASD, despite the American Academy of Pediatrics's (AAP) recommendations for universal screening for ASD at 18 months and 24 months, and at any age when parents express concerns (Johnson et al., 2007).

Parents also reported that educators are also hesitant to evaluate and identify children with autism. Parents share the following experiences with schools, "I feel there

is a stigma associated with ASD”; “I asked the school to test him and they stated no, if he is not failing. Unless he failed they would not put in interventions or test him. I heard it for years, but no one would help”; “The school district will not accept an ASD diagnosis. They put my child through RTI [response to intervention] and tried to label him ADHD”; “The school district very rarely wants to identify people as being autistic, unless they are non-verbal. Pretty much they are never going to say a child is autistic. Once my oldest child was diagnosed with ASD, I brought it back to the school district. The teachers said he scored high on an ASD indicator. But they never wanted to identify him ASD through the school district”; “The ESE [exceptional student education] Coordinator a Caucasian woman tried to talk me out of placing autism on his IEP”; “A teacher told me I am using autism as a crutch”; and “I asked the school for an evaluation, they said there is no need.” One parent summarized it all this way, “The whole process of identifying my son with ASD has been hard, and frustrating on every level, the kid level and the parent level. I had to fight every step of the way, for them just to listen and to test my children.”

Additionally, parents shared their frustrations in receiving evidence-based services for their children: “Some teachers are trained, but I don’t think they are trained behaviorally. I have yet to meet a teacher trained in ABA”; “So many people are uncertified, untrained to deal with children and do not know about autism”; “I see for my little one no differentiation of curriculum and that concerns me, because he is always getting it wrong. I worry because when children experience too much failure, it’s not that they failed, but that they are a failure. I do not want my son internalizing something that is not true”; and finally, “More training is needed for special educators and general educators in working with children with ASD.” The numerous challenges Black parents

describe in securing an ASD identification and effective treatment for their child serve as a barrier.

Theme 3: Black Parents Experience Unequal Treatment in Seeking ASD

Identification and Treatment for Their Child

Black parents experience unequal and different treatment by HCPs and educators through the ASD identification and treatment process for their children. This area is particularly damaging to the identification of Black children and the development of trusting and collaborative relationships, between parents and professionals. Black parents share that they feel not listened to, minimized, dismissed, rushed out of meetings, misinterpreted, judged, and treated differently than White parents, by pediatricians, HCPs, therapists, and educators. One parent shared: “I have learned that people of color do not get the same treatment when it comes to health care, navigating the school system with IEPs, and when it comes to the lived experiences as a parent with a child with special needs.” Another parent stated, “I have learned that the system is flawed, in terms of identifying needs and listening to parents, and empowering parents to have agency over their child’s educational experience, not just the schools, but medical providers too.” Another parent summarized, “I have seen the most educated, the wealthiest Black women fight for their kid and they still get labeled that way.” Other parents noted that Black parents are asked questions such as “Does your child’s father live in the same house?” Another mother further explained, “I experienced some things that I thought were a little racist, just some of the questions they asked. It is important to point out assumptions such as, “Do you think because I am Black, I must be poor or a single parent?” Another mother illustrated, “Upon walking into a room, it has been automatically assumed that I

am an uneducated “welfare mom,” who is either lost or does not know what activity or event she signed up for. I have no desire to address America’s ignorance.” A mother further stated, “Wealthy Black women, middle class and low-income and all of their experiences are the same. It didn’t change based on economics. It didn’t change. Believe us. Give us the same benefit of the doubt you give Caucasians. If you believe us and validate us, we will trust you.” Another parent shared after the diagnosis of her child, “I did not feel I was seen as a young mom who doesn’t know what resources are available. I felt I was viewed as a young Black mom who isn’t going to be interested in finding resources.”

Black parents noted their experiences and observed different treatment of Black and White parents by professionals. Many parents stated that it is important for them to stand up for themselves, especially as a Black parent and to push back against biases they are encountering by pointing them out. One mother related, “White parents’ stories and concerns are taken more seriously than Black parents. I have a Master’s degree, so I wasn’t going in there fumbling my words. There is always an issue of, you are exaggerating your symptoms.” Another mom shared “When you see certain behaviors, don’t assume that because there is a Black child doing whatever, that it’s a behavioral thing and they have ADHD. Take them out of the box, take off the glasses and look at them as a child.” Another parent explained, “I watch doctors and other professionals interact with White families. I always have my ears open, because I am all about fairness, and always seem to give a little more information to the White family.” A mother further stated, “I hear the speech talking to White families is different than talking to Black families. I am not a racist, but I do believe professionals have biases. I don’t think they

are aware of their biases.” Another parent further identified, “I feel doctors give more information and an extra flyer to White families than to Black families. They also talk differently to Black families than White, almost like they expect the Black family to be uneducated or won’t be able to understand the terminology.” Another mother interviewed shared, “When we come into the school and we are emotional, our passion is seen as anger, but we are passionate about our children. We care! We want them to succeed! We want to have equality in the school system.” One parent summarized the different treatment as follows: “There definitely exist biases and I don’t think there exists a bias with just the lady at the front desk, but with the physicians. I think that is why concerns are not listened to and heard because there is an assumption that mom must have done something during pregnancy. I won’t feel like I can trust the institution, if this is what is happening. I know better so I continue to go and advocate, but for the mom that doesn’t it confirms their biases “Oh doctors don’t like Black people. You don’t go to the doctor.” Different treatment is also evidenced in access to therapeutic community resources as one parent shared, “I kind of know this to be a fact, in some cases when they are creating waiting lists for therapies. The kids that they feel more comfortable with are pushed through on the waiting list. I always find the majority of the kids on the waiting lists are minority children and they are on the waiting list longer than kids who are Caucasian.”

Parents overwhelmingly stated that pediatricians, therapists, and educators need training in diversity, how to engage with parents that do not look like them, and are from different cultures. It is also important for professionals to understand the data as it relates to children of color and autism. One parent summarized, “It is important for more education to be offered in the beginning in undergraduate and graduate programs, as well

as medical school. It is important for educators in the school district to be trained especially with ESE Coordinators, and those that are making decisions concerning our children.” Unequal and different treatment of Black children presents as a significant barrier to identification and treatment of Black children with ASD.

Theme 4: Black Parents Feel Isolated in Seeking ASD Identification and Treatment for Their Child

The fourth broad theme identified is Black parents feel isolated in seeking ASD identification and treatment for their child. Black parents often feel isolated in parenting their children with autism. In the beginning of the journey, they often feel isolated from their spouses, their other children, grandparents, and extended family members for their choices in seeking identification and treatment for their child; time utilized in fighting for identification and resources and taking their child to medical and therapy appointments; as well as judgment and lack of understanding by extended family members. Parenting a Black child with autism brings numerous challenges and pitfalls to navigate, that a White person may not even recognize or consider.

Black parents, mainly mothers interviewed expressed the following: “Some of my friends and family members never understood”; “Some family members help us, and others stay clear of us.” One mother explained: “We have tried to get my daughter out in the community. At times, you want to hide her because she hand flaps, she doesn’t talk, she makes noise at times and people stare at her. You are afraid what people will think and as a Black person, I already feel like people are looking at you in one way.” Another parent stated, “She goes to a predominately White school and I have no problem with that. But as much as I have a connection, I feel like I have a missing connection.”

Another parent shared, “It’s been a long journey. At times, it’s lonely even within the marriage.”

Culture often further serves to isolate Black parents, requiring parents to choose between identification of their child and support of extended family members. The parents interviewed expressed the following impact of culture on the identification of their children: “There is a fear among Black families of not wanting your child to be diagnosed with something that is different or to be labeled with something different”; “Some Black families are fearful of their children being labeled”; “It is easier for a Black person to attribute not meeting milestones as a behavioral thing, than it is from something we should seek out support for. So, if a child isn’t speaking, he is dumb and lazy, as opposed to a speech delay and we should go get services”; “In the Black culture, when your child shows a weakness or areas that will stop them from progressing, you are taught to fix it. So, we are taught from a young age, if there is something that’s going to put you at a disadvantage, we need to get it better, so it places you at a level with everyone else”; “People perceive autism as bad. I think a lot of Black parents do not want the stigma. So, they don’t want to seek out ESE or mental health services because that must be a bad thing. They feel people will judge them by the disease, that someone is going to catch”; and “My mother and sister accused me of being a bad mother for allowing “White people” to put a label on my child, and scorned us as parents to protect our children, and help them fight the system of oppression instead of helping them to label them.” These cultural norms along with trust issues with professionals, cause many Black parents to be conflicted. One parent stated, “I have not allowed behavior from my culture to affect how I treat my son. It is important for me to give him every opportunity

to be successful.” Black parent’s feelings of isolation and forced navigation through cultural norms serve as a barrier for ASD identification and treatment.

Theme 5: Faith in God Helps Black Parents to Positively Reframe Their Experience in Parenting Their Child with ASD

The fifth identified theme is Faith in God helps Black parents to positively reframe their experience in parenting their child with ASD. Many of the parents interviewed shared that faith is critical to their personal well-being, in their role as mother or father, and to the continuity of their family. One parent stated, “We believe in God. We pray as a family together.” Another parent stated, “We have God as our foundation. God has been there throughout this journey.” They shared that their faith in God provided comfort, encouragement, and hope. It provides meaning and assists them in positively framing their parental challenges such as this statement, “I would not have made it without faith and believing that things happen for a reason.” Another parent further illustrated, “When you accept God is in control and has a good plan for your child, you do your best for your child.” Another parent credits God, and her faith as follows: “My relationship with God has helped me to be a good mother.” Another parent thanked God for providing her the strength for the fight, and she stated, “It’s challenging. It’s hard, but I am grateful that God created me with a fight in me.” Other parents spoke to God’s provision in their lives, such as, “I felt God sent me people in my life at the right moment to get me to the next level”; and “I believe God will send angels in your path to help you through this journey.”

Parents not only emphasized the benefits of faith in their journey, but what their children have taught them about faith and love. One mother stated, “There are things that

the faith community can learn about faith, forgiveness and love. Nothing bothers my son. He loves, he forgives quickly, if he thinks he is wrong, he will apologize, he will come and give you a hug. So for me, I have learned a lot about things biblically from my son, and his attitude toward life as a whole.” Another mother stated, “We really need that time, and peaceful place, where you feel you will not be judged, you can hear some good music, and praise God.”

The parents interviewed differentiated between faith in God and religion. When parents were asked about their attendance and involvement in their faith community and how their faith community supported them, all the parents interviewed expressed that they desired the involvement and support of a faith community. None of the families were currently attending services citing behavioral challenges, that the behavioral expectations placed on their children could not possibly be met, and the stares and perceived judgement they received from other members of the congregation over their child’s behavior at services were seen as barriers. Parents additionally shared the difficult decisions they needed to make when forced to choose between faith and community and the needs of their child’s identification and medical treatment. One parent shared, “Personally, I do not have a faith-based community. The faith-based community was not receptive of my decision to get as much medical support as possible, and that was just my experience. That experience diminished my desire to wholly surround myself with another faith-based community support system.” Another parent stated, “We are not attending church now. They wanted to support and assist, but created more harm. They required him to act and behave in ways he is challenged, by asking him to sit at a table. They would call me to calm him down. It was never let me learn strategies to help him to

calm down and help him regulate, and I saw that as harmful.” Another parent explained, “I feel that most of the faith-based community is accepting and supportive of children with disabilities, but they don’t have the resources. It really is dependent on the church. It is dependent on the individuals taking the time to get to know these children and bring them to the table.” Another mother further stated, “I stopped doing it (attending church) because everything stops and they are waiting for me to get this child under control, and I see the eyes and I don’t want to place people in an uncomfortable position, and I refuse to apologize for my son. This is him, and if you want me, you want all of me.” Faith in God serves as a facilitator to identification and treatment, but lack of acceptance and willingness to serve children with autism and their families creates a barrier for families in parenting their child with ASD.

For the purpose of this study, the researcher investigated the lived experiences of Black parents through the ASD identification process. The researcher identified the Phenomenon: Unrelenting Fighter: Black parents fight, advocate, and persevere through ASD identification and treatment. The noted themes identified, also serve as facilitators and barriers in the identification of ASD in Black children. The following themes were noted: Theme 1: Black parents seek and create allies to support them in securing ASD identification and treatment for their child; Theme 2: Black parents experience numerous challenges in seeking ASD identification and treatment for their child; Theme 3: Black parents experience unequal treatment in seeking ASD identification and treatment for their child; Theme 4: Black parents feel isolated in seeking ASD identification and treatment for their child; Theme 5: Faith in God helps Black parents positively reframe their experience, in parenting their child with autism.

CHAPTER 5: CONCLUSIONS AND RECOMMENDATIONS

This study highlighted the following Facilitators for ASD identification and treatment: Unrelenting Fighter: 1. Black parents fight, advocate, and persevere in meeting the needs of their children with ASD; 2. Black parents seek and create allies to support them in securing ASD identification and treatment for their child; and 3. Faith in God helps Black parents positively reframe their experience, in parenting their child with autism. Additionally, the following Barriers were identified to impede effective and efficient identification of ASD: 1. Black parents experience numerous challenges in seeking ASD identification and treatment for their child with autism; 2. Black parents experience unequal treatment in seeking ASD identification and treatment; and 3. Black parents feel isolated in seeking ASD identification and treatment for their children.

A major conclusion derived from the findings of this study is the conceptualization of the phenomenon of the Unrelenting Fighter, a persistent and determined combatant, never giving up, continually fighting for the needs of their child, with single-minded determination, while seeking and creating support from others to assist in the battle. Each of the parents interviewed are Unrelenting Fighters for their children. Additionally, in order to sustain the fight, these parents have sought out and created an army of allies to assist them in advocacy and support. These allies consist of other family members, other parents, support groups, counselors, and university autism center staff, as well as like-minded and trusted professionals.

This study highlights the differentiated and unequal treatment Black children and their parents must endure through the ASD identification process. Black parents, throughout this process, are challenged to secure and seek high quality treatment for their children. The scope and immense difficulties in obtaining early and effective identification and treatment are highlighted through the telling of the lived experiences of the Black parents interviewed.

All the parents in their parental roles demonstrated the qualities of empowered adult learners, served as a transformational leader for their families, and exemplified Senge's Five Disciplines (2006). Andragogy, the study of adult learning, differentiates the learning of adults from that of children, which is pedagogy. Knowles identified six assumptions of adult learning that are demonstrated by all the parents interviewed (Merriam, et al., 2007). The first assumption spoke to the ability of the adult to self-direct his or her learning (Merriam, et al., 2007). Before the birth of their children with ASD, the parents interviewed did not have any prior knowledge about autism, its characteristics, how it manifests, and strategies for parenting and educating. All of the parents stressed the importance of educating themselves, family members, friends and others in order to advocate and better meet their child's needs. The second assumption for adult learners is that adults gather a variety of experiences that serve as a resource for learning (Merriam, et al., 2007). All of the parents took it upon themselves to consult with educators, therapists, and behavior analysts to learn strategies and evidence-based practices from these professionals, in order to assist their child. The third assumption is that there is a direct correlation between the adult's social role and readiness to learn (Merriam, et al., 2007). All of the parents were motivated to expand their knowledge base

about autism in order to better help their children. The fourth assumption about adult learners is that they tend to be more problem-centered versus subject-centered (Merriam, et al., 2007). Each of the parents was focused on learning strategies and techniques to address the current problems manifested by their children. All of the parents were focused on advocacy, others on academic and behavioral strategies, while others were focused on transitioning from school to post-secondary employment strategies. The fifth and sixth assumptions focused on the importance of internal versus external motivations and the rationale for learning (Merriam, et al., 2007). All of the parents were motivated by their love for their child, desire to meet their child's needs, and for their children to progress educationally, socially, and behaviorally in order to fully participate in society. All of the parents interviewed demonstrated criteria for exemplary self-directed learners and advocates for their children.

Transformational leadership is the process whereby a person interacts with others to create a connection that increases the level of motivation and ethics, in both the leader and the follower (Northouse, 2013). Individuals who manifest transformational leadership often exhibit high internal values and ideals, are able to motivate others to support the greater good, rather than their own self-interests. All the parents interviewed, were able to enlist, educate and gain support from family members, friends, like-minded professionals, community supports, and resources to align with them, to address their child's needs with ASD. All of the parents interviewed, despite numerous challenges and unequal treatment from professionals, desired to engage in the system to make it better for those parents following behind them.

These parents can be classified as transformational leaders, not only within their families but within their community. Four common strategies of transformational leaders are establishing a clear vision, motivating others to work as team, creating a sense of trust through implementing a consistent direction, and understanding their strengths and weaknesses. All four of the characteristics of transformational leaders were manifested by all the parents interviewed. All parent participants identified a clear vision and a direction for their child that evolved as their child grew. Additionally, all of the parents motivated family members, friends and other professionals to align with their vision and sought out other parents and professionals who accommodated their weaknesses and capitalized on their strengths.

Senge (2006) introduces and defines the concept of the Learning Organization and the pivotal role of the individual learner in achieving the status of a learning organization. Senge identifies the five disciplines of organizational learning as systems learning, personal mastery, mental models, shared vision, and team learning (Senge, 2006).

Each family interviewed was a full functioning learning organization, with the lead parent in 14 out of the 15 families the mother, firmly established in the leadership role of guiding their child's education. Each of the families interviewed participated in ongoing education, training, and experiential learning to support their child with ASD. They learned with the mother, at a family-systems level, developing their personal mastery, changing their mental models, as their loved one's ASD changed and manifested differently across the age span with a shared familial vision through team-family learning.

This study supports prior research identifying the challenges Black parents experience in identifying accurately and early their children with ASD, as well as the difficulties accessing evidence-based interventions (Gourdine & Algood 2014; Longtin & Principe, 2016; Lord & McGee 2001). This study confirms the biases of many HCPs and educators, in identifying and treating autism in children of color and the importance of understanding how these biases can be recognized and dealt with. The importance of education, recognizing biases, and open dialogue between parents and professionals on how we can better work together to support Black families through the ASD identification and treatment process is highlighted.

Prior research highlighting the resiliency of Black families was identified. Despite all the challenges endured by the families interviewed, all of the families remain optimistic and believe that all children are important (Taylor, 1983). More than half of the parents reported they rely heavily on their faith to carry them through challenging times.

This study also supported the premise that autism enriches the Black family system, by fostering deep family cohesion, developing resilience among family members, and nurturing a greater appreciation for diversity (Reichman et al., 2008). Twelve of the 15 families interviewed stated they had a stronger and more cohesive family unit, as the result of the challenges they have experienced together as a family.

Current literature on the benefits of developing and supporting parents as Unrelenting Fighters in their battle through ASD identification and treatment for their child with ASD is extended by this study. Previous research identifying the benefit of creating systems of support across home, school and community for not only

generalization of skills across environments, but for supporting parents of Black children with ASD is additionally extended by this study.

The strength of this study, however, can be found in the sharing of parental voices, reflecting the lived experiences of Black families challenged through the ASD identification and treatment process. This study, through the capturing of voices, contributes to the understanding of the first-hand lived experiences of Black parents through the ASD identification process. This study also informs educators and practitioners in the importance of development and use of culturally sensitive practices, to better support Black parents and families through the ASD identification process.

Future studies are needed to explore the impact of delayed and unequal treatment of Black families through the ASD identification process and the securing of ASD treatment. Additionally, more research is needed to explore the impact on Black children and parents of delayed and unequal treatment. Future impact studies and modeling studies are needed.

APPENDICES

Appendix A: Interview Protocol

Participant #: _____

Interviewer: _____

Date: _____ Start Time: _____ Ending time: _____

Introduction: Thank you for volunteering your time and participating in this study. The intent of this study is to better understand the beliefs, attitudes, experiences and meaning attributed by Black parents and guardians, through the autism spectrum disorder identification process.

If at any time, you would like me to repeat or clarify a definition or any questions, please request that I do so. Your identity will be kept secure and confidential. For accurate representation of information shared, I will record this interview through Zoom and save the recording on a secured passcode protected USB. May I have your permission to record? [start recording] Thank you for permitting me to record this interview. This interview will take approximately 45 minutes and should be completed by _____. Do you have any questions before we begin?

Questions:

1. Tell me about your loved one with autism?
2. What were your initial feelings on having your child identified with autism spectrum disorder (ASD)? How have your feelings changed over time?
3. How did you first become aware of ASD?
4. Tell me how your child was identified with ASD?
5. What have you learned through this process?
6. What would you like to share with educators to assist other parents?
7. What recommendations would you provide pediatricians to improve the identification process?
8. What would you like to share with diagnosticians to assist other parents?
9. What suggestions would you provide other parents to assist them through the process?
10. What other thoughts would you like to provide about your journey?

Conclusion: Thank you for participating in this interview and contributing to our research, to better understand the beliefs, attitudes, experiences and meaning attributed to

the autism spectrum disorder identification process. If I have any questions after the interview, may I contact you to seek clarification.

Appendix B: Parent Questionnaire

Participant #: _____ Date: _____

1. Are you registered with FAU CARD? If so, how did you learn about FAU CARD?
2. If you are registered with FAU CARD, how helpful are the supports and services provided by FAU CARD? What recommendations would you provide to improve services?
3. How helpful are the supports and services provided by your child's educators? What recommendations would you like to share with educators to help other parents?
4. What if any therapy is your child provided? Are the therapies provided by the school or privately? How helpful are the supports and services provided by your child's therapists (behavioral, speech and language, occupational therapy, etc.)? What recommendations would you provide to improve services?
5. How helpful are the supports and services provided by your child's pediatrician? What recommendations would you make to your child's pediatrician?

Appendix C: Parent Journal

Participant #: _____ Date(s): _____

1. What were you thinking and feeling when your loved one was identified with autism spectrum disorder?
2. Reflecting on your autism journey, what do you think of when you hear the word autism spectrum disorder?
3. What has your child with autism taught you? What has the journey taught you?
4. What were the challenges you faced through the autism identification process?
5. What did you find helpful in the process? Why was it helpful?
6. How has having a child with autism, impacted you, your spouse/significant other, your other children, and your extended family?
7. How has your family and friends assisted or hindered you, in raising your child with autism?
8. How has your cultural background assisted or hindered you, in raising your loved one with autism?
9. What additional information would you like to share with others, that might assist us in supporting parents through this process?

Appendix D: Phenomenon and Themes

Phenomenon: Unrelenting Fighter- Black parents fight, advocate, and persevere in meeting the needs of their children with ASD.

Theme One: Black parents seek and create allies to support them in securing ASD identification and treatment for their child.

Theme Two: Black parents experience numerous challenges in seeking ASD identification and treatment for their child.

Theme Three: Black parents experience unequal treatment in seeking ASD identification and treatment for their children.

Theme Four: Black parents often feel isolated in seeking ASD identification and treatment for their children.

Theme Five: Faith in God helps Black parents positively reframe their experience, in parenting their child with autism.

Barriers and Facilitators to Identification and Treatment for Black Children with ASD

Facilitators: **Unrelenting Fighter:**

1. Black parents fight, advocate, and persevere in meeting the needs of their children with ASD.
2. Black parents seek and create allies to support them in securing ASD identification and treatment for their child
3. Faith in God helps Black parents positively reframe their experience, in parenting their child with autism.

Barriers:

1. Black parents experience numerous challenges in seeking ASD identification and treatment for their child with autism.
2. Black parents experience unequal treatment in seeking ASD identification and treatment.
3. Black parents feel isolated in seeking ASD identification and treatment for their children.

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