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Exploration of the Cultural Perspectives of Caregivers of African American and African Children with Delayed Diagnosis of Autism Spectrum Disorder

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Abstract

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by

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of the Requirements for the Degree of

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Abstract

Through the lens of Bronfenbrenner's bioecological theory, the purpose of the study was to explore African American and African caregivers' perceptions of autism spectrum disorder (ASD), child development knowledge, religious/traditional beliefs, and fear of stigma within the context of their culture. African and African American children with ASD are identified at later ages than Caucasian children by 1 1/2 to 2 years. Disparities in educational and social outcomes of African and African American children with ASD may be related to this identification delay. Current literature regarding African and African American caregivers' perceptions of children with ASD is sparse. An ethnographic research design methodology was used in the study to explore five African American and four African caregiver's cultural values, norms, beliefs, and practices that may influence the timeliness of identification of children with ASD. Semi-structured interviews were conducted and transcribed. The descriptions of the multiple perspectives of the participants were coded and analyzed. The resulting data generated the following themes: (a) caregivers' knowledge of ASD symptoms, (b) healthcare and educational professionals' knowledge of ASD, (c) religious/ cultural/ traditional belief influence, (d) stigma and shame influence, (e) family support influence, and (f) perceived bias influence. Results of the study should contribute to positive social change by increasing understanding of African and African American caregivers' perspectives that can enhance screening, identification, and diagnostic processes, potentially improving educational and social outcomes for children with ASD.

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Dedication

Thank you to my husband, Larry Taylor, for being so supportive and encouraging me to never give up and continue with my goals. Without your support and motivating words, I would have quit.

To my wonderful daughter, Thalia; you and your oldest child were my inspiration for starting this doctoral journey and studying influences in our communities that contribute to delays to early identification of ASD.

To Dr. Tracy Masiello, thank you for your patience and guidance. I am thankful you were there with me from the beginning of this endeavor.

Additionally, I acknowledge the guidance of my second committee member, Dr. Livia Gilstrap, and URR, Dr. Robin Friedman, for your input and for challenging me to do my best.

Finally, I thank God and my parents in heaven for creating me and supporting me all of my life, both physically and spiritually.

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Chapter 1: Introduction to the Study

Introduction

Autism Spectrum Disorder (ASD) is understood to be a brain-based disorder with genetic origins that is characterized by the early onset of a serious, social learning disability. It is a disorder in which children's symptoms are exhibited and manifested differently, and their communicative, academic, and social functioning may be impaired (APA, 2018). Caregivers are an intricate part of the process of identifying ASD. African and African American children are identified with ASD at later ages than Caucasian children. The literature reviewed has revealed similarities between the experiences of African and African American caregivers of children with ASD as far as awareness, understanding, and knowledge of ASD that might be attributed to cultural influences.

Despite separation due to a history of slavery, colonization, and oppression, both groups continue to share cultural perspectives, beliefs, and practices as members of the African Diaspora that may have influenced the delay of identifying their children with ASD. A frequent assertion of researchers was that the existing research on ASD is based on participants from Western and/or European cultures. They noted a need for more examination of cultural factors for African and African American populations with ASD. An example asserted by Natasi et al. (2017) was that 95 % of psychological research has primarily been conducted of the Western populations.

According to Oregon State University's definition of anthropological terms, cultural constructs are the attribution of characteristics to social categories, common beliefs, values, and practices constructed within cultural contexts and transmitted and passed down through generations. Research has indicated that the cultural constructs influence how ASD, symptom presentation, child development, social and communication norms, religious/traditional beliefs, and fear of stigma, are perceived. (Burkett et al. 2015, 2017)

This study was a qualitative exploratory study of the perspectives of African and African American caregivers of children with ASD when identification was delayed beyond six years of age. I used a qualitative design with an ethnographic paradigm to explore how the caregivers' cultural perspectives on their religious/traditional beliefs, social and communication norms, symptom presentation/concerns, and fear of stigma influenced the delay in identifying their child with ASD. This chapter includes the background of the study, as well as the problem statement, study purpose, research questions, theoretical framework, nature of the study, definitions, assumptions, limitations, scope, delimitations, and the significance of the study.

Background

Burkett et al. (2015, 2017) found the cultural practices of African American parents of children with ASD influenced the timeliness by which they sought a diagnosis for their children, which is about 1.6 years later than White parents. They found that the assessment process was not capturing the concerns the parents have of their children's development and behaviors (Burkett et al. 2015, 2017). Bello-Mojeed et al. (2017) found that of children in Nigeria diagnosed with ASD, only 33 % were diagnosed before age 6. In that same Nigerian study, the late diagnosis was attributed to limited knowledge of ASD, as well as to a diagnostic process that may be incongruent with the cultural norms and beliefs about child development of African parents (Bello-Mojeed et al. 2017). It was posited that if assessment processes are not culturally relevant and aligned with the cultural norms for children in Nigeria, it could be a contributing factor to the misdiagnosis of children as having other mental health or behavioral issues, thus delaying the correct diagnoses of ASD.

Ratto et al. (2016) also speculated that African American children with ASD in the United States were being misdiagnosed, and similarly to those in Nigeria, not being correctly identified during the assessment process. Providers' ability to diagnose can be impaired because African American parents indicated fewer restricted and repetitive behaviors and social concerns of autism of their children than White parents. It was also found that providers' bias influenced their interpretation of symptoms as those of a conduct disorder for African American children who were later identified as having ASD (Donohue et al. 2019). It may be the case that ASD and other developmental screening instruments need to contain multiple sets of norm determinants to better align with the communication, social development, norms, and concerns for children of diverse cultures (Bello-Mojeed et al. 2017), as perceived and presented by their caregivers. This study addressed speculations that cultural perspectives influence the screening process and delayed identification to fill a gap in the literature on caregiver's perspectives. This study is needed to contribute proper and timely identification of ASD in African and African American children, and hopefully improve functional outcomes.

Problem Statement

Research regarding identification of autism spectrum disorder (ASD) in African and African American children is sparse (Bello-Mojeed et al. 2017). The existing research has indicated that there are disparities and delays in the identification and diagnosis of ASD in African American and African children when compared to children of other ethnic and cultural groups. Although research is sparse, the delays and disparities in identification are consequential for the future of those children. Caregivers complete ASD screening tools and engage in the screening process and are often the first step in the identification of ASD. There is a clear difference in the age of diagnosis between African and African American children and those of other cultures and races, which indicates the need to explore how caregivers' perspectives and knowledge about child development, ASD, and additional cultural constructs such as common beliefs, values, and practices may influence their contribution to the process of ASD identification.

Children with ASD must be identified as early as possible to improve developmental outcomes. For example, Clark et al. (2018), in their study of school outcomes for children diagnosed early and later with ASD, found early intervention improved children’s cognitive abilities, and that they required less support once in school. In their meta-ethnography research review study, which sought to understand factors contributing to autism differences in the United States marginalized communities, Singh and Bunyak (2019) found the racial, economic, and social disparities associated with autism are familial, cultural, and structural. Likewise, Harrison et al. (2017) asserted in their research that race, ethnicity, and gender impact symptom presentation variability, which highlights the need for increased understanding of the disparities and differences in autism diagnosis within racial and ethnic groups. Pearson and Meadan’s study (2018) of African American parents' experiences accessing services for their children with autism supported earlier literature finding one of the barriers to the identification and consequently, diagnosis, was limited knowledge of autism disorder on the parts of parents and caregivers. Exploring through a cultural lens how African and African American caregivers perceive developmental screening, and child development provided insight into some of the reasons for the delayed identification of ASD in their children, with implications for improving the process of identification of ASD and increasing children’s ability to succeed academically and socially in the future.

The extant literature indicated that the influence of caregiver's perspectives of autism concerns, as well as the cultural congruence of the screening tools used by the caregivers, might not be taken into consideration by providers and health care professionals in the identification process of ASD for African and African American children. A study by Donohue et al. (2019) found that the diagnostic process is impacted by racial and cultural contexts; African American caregivers reported fewer concerns regarding the typical social and restrictive and repetitive ASD behaviors than White parents. As such, the differences in perceptions of behavioral concerns may account for the diagnostic disparity in the age of diagnosis of African and African American children with ASD in comparison to other children.

Donohue et al. (2019) suggested future studies should investigate the possibility that African and African American parents and White parents may have different threshold levels at which they perceive concerns about their child's development, or the presence of autism, asserting that research was needed to determine if differences in parent perceptions are culturally based. Some cultural-based constructs to be examined include lack of knowledge of child development, autism, and symptom presentations masking ASD symptoms and delay recognition of developmental concerns by the caregivers. Additionally, African and African American caregivers' perspectives about religious and traditional beliefs, as well as fears of stigma within their cultural constructs, may influence the typical ASD identification process (Burkett et al. 2015) and will be explored as well. To fill the gap in the literature, this study examined the perspectives of caregivers of African and African American children, particularly of those previously stated cultural constructs relevant to ASD screening and identification that might influence the delayed process of identification of ASD.

Purpose of the Study

The purpose of this ethnographic study was to explore the ramifications of cultural constructs, understandings of child development, ASD concerns and symptom presentations, religious beliefs, and fears of stigma on the delayed identification of ASD in children from the perspectives of their African and African American caregivers. I used the data collected to identify patterns and themes regarding African and African American caregivers' perceptions of autism, typical and atypical communication and social development, religious and traditional beliefs, fear of stigma, and the screening process itself. The results of this qualitative study are intended to add to the understanding of the cultural perspectives of caregivers of children with ASD in African and African American cultures.

Research Questions

RQ 1: What are the African and African American caregivers' perspectives about child development, autism, and symptom presentations that might have delayed the process of identification of their children with ASD?

RQ 2: What are the African and African American caregivers' perspectives of their religious/traditional beliefs that might have delayed the process of identification of their children with ASD?

RQ 3: What are the perspectives of African and African American caregivers about fear of stigma that might have delayed the process of identification of their children with ASD?

RQ 4: What are the perspectives of African and African American caregivers of social and communication norms of their culture that might have influenced the delay of identification of their children with ASD?

Theoretical Framework

The theoretical framework used as the basis for this study was Bronfenbrenner's bioecological developmental theory, which was chosen because it considers the child within a cultural context. Bronfenbrenner's theory views development as influenced by process, characteristics of the person, contexts of micro, macro, meso and exosystem, and time. African and African American children's micro and meso systems are their homes, families, their schools, intersection with their communities, the healthcare systems, as well as their culture and countries (macro systems). Exploring the phenomena of delay in the identification of ASD from a cultural perspective and the experiences in particular societies (Norbury & Sparks, 2012) fit the conceptual framework of the bioecological theory. The theory provides insight into the process across cultural lens with an awareness of the bioecological influences (Newman & Newman, 2016). This research explored how a caregiver's culturally based perspectives and concerns of ASD were developed within the micro, macro, meso, and exosystem and time, and might have influenced timeliness in the identification and diagnosing unique to African and African American children.

Nature of the Study

This study used a qualitative design to gain a richer understanding of caregiver's perspectives in the identification process of ASD in African and African American children and to better understand the delays in diagnosis for this population. ASD is explored via the cultural lenses of the African and African American populations, particularly of their perspectives of child development/ASD symptoms/concerns, social and communication norms, religious and traditional beliefs, and fear of stigma in the process of identifying the disorder in children. The themes emerging from the exploration are discussed within the context of culture (Norbury & Sparks, 2013). Using an ethnographic research paradigm is the more appropriate qualitative approach to explore cultural groups' values, beliefs, and practices as opposed to a less immersive qualitative approach as the ethnographic qualitative design explores the culture and society of a cultural group or groups. The research design enhances the data collection by observing the culture members' perspectives and experiences (Rubin & Rubin, 2012).

The participants were caregivers of children with ASD identified after the age of 6 years old, all recruited from online groups for African American and African caregivers of children with ASD. The data was collected via semi-structured interviews. I contacted the moderators and facilitators of the groups requesting to post a flyer on their group page to recruit caregivers. Once contacted, I called to make appointments for interviews that were conducted by telephone or video conference. recorded and transcribed the interviews. The transcripts were segmented initially into two sections. One section was interviews of African American caregivers, and the other was interviews of African caregivers. The transcripts were further segmented by the cultural constructs explored in the interview. There were interview questions addressing the constructs being explored in the study (i.e., ASD symptom presentations, social and communication norms, religious/traditional beliefs, and fear of stigma). The themes and patterns of perspectives that emerged were sorted by cultural group, either African or African American. The data was coded and analyzed as related to the research questions.

Definition of Terms

African: A Black person born and raised on the continent of Africa and currently residing in a country on the African continent (Agyemang et al. 2005).

African American: Applies to people and their offspring with African ancestral origin (many are descendants of persons brought as slaves) (Agyemang et al. 2005).

Black Person: A person who identifies as being Black, even if of mixed race, and does not identify as just Caucasian, Asian, Native American, Hispanic or Latina, or any other ethnicity (Blay, 2021.)

Autism Spectrum Disorder (ASD): A condition related to brain development that impacts how a person perceives and socializes with others, which causes problems in social interactions and communication. The disorder also includes limited and repetitive patterns of behavior (Mayo Clinic, 2021).

Caregiver(s): A person who attends to the needs of and aids someone else who is not fully independent, such as an infant or an ill adult (APA, 2020). For this study, an adult family member in the parental role is responsible for raising and caring for their child with autism. The caregiver will not be a paid caregiver, residential home employee, or foster parent.

Assumptions

The initial assumptions were African and African American caregivers of children with ASD are consciously aware of and can articulate child development concerns, ASD symptom presentations, religious and traditional beliefs, and their fears of stigma when their child is identified with ASD (Dababnah et al., 2018). I assumed that they would complete the study. I also assumed caregivers would have some documentation that their child was identified with ASD after the age of 6. Lastly, I assumed there were caregivers open to the interview process and able to articulate their perceptions of certain cultural constructs and their influence on the identification of their child with ASD.

Scope of the Study

The scope of the research was limited to African and African American caregivers whose child was identified with ASD at, or after, the age of 6, largely because research identifies those cultural groups' children are identified at later ages often when they enter school (Bello-Mojeed et al. 2017). African caregivers were recruited from online groups from West African regions. Participants were fluent in English. There was an attempt to have 4-6 participants from each cultural group. The outcome of the exploration goal was to provide some transferability of knowledge for professionals identifying, treating, and diagnosing African and African American children as well as increasing knowledge of ASD for caregivers participating in the screening process.

Delimitations

This study was delimited to African and African American caregivers of children identified with ASD after the age of 6 years old. African and African American cultures are not monolithic, and there could be a variety of influences that contribute to the delay in the identification of their children with ASD. The participant perspectives do not represent nor were intended to represent all African and African American caregivers of children with ASD. The findings are not directly transferable to other populations as the goal of qualitative research is to understand the perspectives of the participants of the specific study; however, aspects of the findings may be informative in other contexts and compared to other populations (Ravitch & Carl, 2016).

Delimitations

Potential limitations and challenges of this study were recruiting participants for interviews of African American and African caregivers with children whose ASD identification was delayed to interview. Additionally, completion of the process would be impacted if participants dropped out of the study. Other limitations were the cultural barriers of the participants from Africa. The results of the study are not generalizable as qualitative studies are an exploration of the participants involved to serve to provide insight into some perspectives from a population of people who belong to a particular culture, rather than a wider population (Gibbs, 2018). I recorded accurate information gathered from participants and conducted member checking to reduce bias, as I am an African American and former caretaker of a child with ASD. Walden University Institutional Review Board (IRB) and the faculty review committee also screened for researcher bias to ensure the quality of the study.

Significance

This research adds to the knowledge base about caregivers' cultural perspectives in the process of identification and diagnosis of African American and African children with ASD. The study investigated the possibility that African and African American caregivers may have different thresholds at which they perceive concerns of autism (Donohue et al. 2019). This project is unique because it is a cross-cultural study of the under-researched population of children of African origin with ASD in both the United States and Africa (Bello-Mojeed et al. 2017), which adds to the scarce body of cross-cultural research on the topic of autism spectrum disorder. The study's findings enhance awareness about the cultural constructs that influence caregiver perception of children of African origin on both continents with ASD. The study also shares perceptions of both cultures. Exploring caregivers' perspectives of ASD symptoms and presentation, religious/traditional beliefs, and fear of stigma could be consequential in improving the process of for earlier identification, diagnosis, treatment, resulting in improved outcomes for children with ASD who are of African origin in the United States, Africa, and Europe. Contributing to positive social change could lead to improved outcomes for those children whose identification with ASD was delayed (Burkett et al.2015).

Summary

There are disparities and delays in the identification and diagnosis of ASD in African and African American children when compared to children of other ethnic and cultural groups. The delays and disparities in identification are consequential for the future of those children (Bello-Mojeed et al. 2017; Burkett et al. 2015). The diagnostic process is impacted by cultural constructs, and these constructs may account for the diagnostic disparity in the age of diagnosis of African and African American children with ASD when compared to other children (Donohue et al. 2019). Research has shown that delays in ASD identification impact functional outcomes. This study explored the perspectives of caregivers regarding those influential cultural constructs.

This concludes the background, problem statement, purpose, research questions, framework, and nature of the study. I also provided definitions of terms used in the study and the assumptions, limitations, scope, delimitations, and study's significance. In

Chapter 2, the relevant literature, the framework of the study, the cultural constructs addressed in the research questions developed are discussed.

Chapter 2: Literature Review

Introduction

The purpose of this ethnographic study was to explore the ramifications of cultural constructs, understandings of child development, ASD concerns and symptom presentations, religious beliefs, and fears of stigma on the delayed identification of ASD in children from the perspectives of their African and African American caregivers. This chapter lists the databases and search engines used to gather the background literature. Also included in this chapter is the theoretical foundation for the current study.

Existing research indicates that children who are identified with ASD by age two have better developmental outcomes than those identified later. For example, Clark et al. (2018) found that participants who were diagnosed earlier with ASD had better language and cognitive outcomes. African and African American children in the United States and Africa are diagnosed, on average, two years later than Caucasian or European children; in Sub-Saharan Africa, ASD identification can occur as late as school-age (Bello-Mojeed et al. 2017; Burkett et al. 2015; Wannenburg & van Niekerk. 2018). Currently, there is sparse research on African and African American caregivers' perspectives on the role cultural constructs, norms, and practices play in the screening process of ASD identification. Related subject matter research is reviewed and synthesized in this chapter.

Literature Search Strategy

Information was collected from peer-reviewed sources using the databases of Academic Search Complete, ERIC, SAGE, PubMed, Medline, PsycArticles, and PsycInfo, and a Google Scholar search was used to locate and access articles not available on the previously mentioned databases. The keywords and phrases used to search the databases included *autism, autism spectrum disorder, qualitative study, identifying autism, developmental disability African, Africa, child, children, assessment process, parental concerns, etiology of autism, African American, Bronfenbrenner bioecological theory*, and *neurological developmental disorders*.

Theoretical Framework of the Study

Urie Bronfenbrenner originated the bioecological theory. He offered a theoretical perspective that human development is defined by evolving interaction between the environments. Bronfenbrenner compared the ecological environment to a set of Russian dolls, or nested settings, with the individual in the center (Bronfenbrenner, 1979). He labeled those settings as a microsystem, mesosystem, exosystem, and later chronosystem. Bronfenbrenner's theory views development as directly and/or indirectly influenced by those systems. The definition of microsystem is the system where a developing person is experiencing and perceiving the setting and themselves in their family, school, social or religious group (Newman & Newman, 2007). The mesosystem is the interrelationship between microsystem settings as the developing person moves between two or more settings (Newman & Newman, 2007). Activities in one setting can impact experiences in another setting. In the exosystem, the developing person is not an active participant but is affected by that setting, such as a child being indirectly affected by a parent's workplace (Newman & Newman, 2007). The macrosystem is the ideologies, belief systems, subculture, culture that the micro, meso, and exosystem consist of (Newman & Newman, 2007).

In the 1990s, Bronfenbrenner revised his theory and criticized his original theory for focusing on the context in which a person develops and not enough on the role the person’s genetic characteristics and interactions contribute to their development (Bronfenbrenner, 1995). The process-person-context-time model (PPCT) became the essence of his revised theory. In his evaluation of the application of Bronfenbrenner’s theory in research, Tudge (2009) alluded that the PPCT model requires study over time to measure the proximal processes and regular interactions of individuals, such as between parent and child. Bronfenbrenner's (1995) reconceptualization of his theory stipulates that the proximal processes are engines of development. It can be said that Bronfenbrenner’s theory has always considered the interrelatedness of context-person impact on development (Tudge et al. 2009). For this study, the later “mature” version, PPCT, informed the framework in how religious/traditional beliefs may have influenced caregivers’ perspectives of ASD, whereas Bronfenbrenner’s original theory was more useful for this study’s framework. This study explored groups of participants' perceptions of the cultural contexts or systems influences on identifying the developmental disorder, ASD as opposed to individual proximal processes’ influence on the development of the disorder.

Within each society, the socioeconomic, religious, ethnic differences, and contrasting beliefs form the ecological environment specific to groups. As such, it was important to study the ecological environments and perceptions of caregivers of African and African American children whose identification with ASD was delayed within the systems of Bronfenbrenner’s theory. A study by Mabhoyi and Seroto (2019) of at-risk students in Zimbabwe, South Africa, was informed by Bronfenbrenner's ecological systems theory, using it to confirm that several environmental systems, such as a more inclusive educational model, family support, enhanced socio-economic conditions, and larger systematic factors, influenced each other and the development of at-risk youth. Predescu et al. (2018) used the ecological theory to develop a model for ASD assessment, intervention, and understanding of the disorder. They asserted that their ASD model can be compared to a photo with the closest objects affecting the child is their family, the social networks, and the comprehensive system, including government policies and social issues. This microsystem was described as the child's family, therapists, parents' jobs, and community, whereas the mesosystem was the interrelationship between them; in the background, or exosystem, was their educational system and government, embedded in the larger picture, or the macrosystem, inclusive of the values and norms of the culture or subcultures (Predescu et al. 2018).

A study by Derguy et al. (2015) took the ecological theoretical approach to identify predictors of stress in parents of children with ASD. They found family variables such as parental stress that were specific environmental factors important to consider. Predictive of higher parental stress were poor interactions between systems (Derguy et al. 2015). Regarding the current study, stress could influence the interactions and perceptions of caregivers who seek to identify ASD in their children. African American and African parents generally have more stress than other racial and ethnic groups.

In a commentary on the development of child mental health policy in Sub Saharan Africa (SSA), Aitolia (2014) asserted that a multi-level and holistic approach is needed.

The insights of Bronfenbrenner's theoretical model are useful to prioritize and identify intervention strategies for the SSA region to respond to the problems of child mental health that exist there. In an examination of the assessment and treatment of ASD, La Roche et al. (2018) found that symptoms were better understood within the context of an individual's culture, as the cause of ASD is unknown. Their examination concluded that overlooking cultural beliefs contributes to the delay in the identification of the disorder in African American children compared to White children (Roche et al. 2018).

Literature Review

A conference about autism in Africa (Ruparelia et al. 2014) recognized that children with ASD are not generally identified, as their illness is not perceived as life-threatening. Many places on the African continent are low-resource areas characterized by a lack of understanding or acceptance of the disorder. The researchers at the conference asserted that negative stigma was a predominant struggle for families with children with ASD. Consistent with this assertion, the literature indicates that there are differences between African and African American children with ASD behaviors, as well as in their caregivers’ concerns, beliefs, and knowledge regarding child development and symptom presentation. Researchers of the studies reviewed here have recommended that future studies investigate the possibility that African and African American parents have different thresholds of perceiving or communicating concerns of autism symptoms, and that those differences in perception could be culturally based.

Symptom Presentation, Perspectives, and Child Development Knowledge Influence on ASD Identification

Previous literature indicates that ASD symptom presentation, knowledge, and perceptions of child development, might influence the identification of ASD, as caregivers' observations are significant factors in the diagnostic process. For decades, autism has been difficult to define, identify, diagnose, and treat. Leo Kanner (Cohmer, 2014) described autism as a disorder that resulted from abnormal development of children's brains (Cohmer, 2014). In those early years of research, autism was a singular diagnosis rather than the current American Psychiatric Associations' (APA, 2018) diagnostic characterization of autism as neurodevelopmental disorders on a spectrum. The symptoms are expressed in a variety of ways unique to each individual and within the sociocultural construct of their environment. Thus, it is difficult to identify a child whose behaviors fit on that spectrum, and the child's communicative, academic, and social functioning becomes impaired to add to the difficulty, identification is made primarily by observation of atypical social communication patterns and restrictive patterns of behavior. Some of these observations are via secondary reports from parents and educators. The research that has contributed to what are now considered to be atypical social communication patterns and restrictive behavior patterns have primarily been conducted in Western, industrialized, and wealthy democratic cultures (Beck, 2018). According to current research, ASD is understood to be a brain-based disorder with genetic origins characterized by the early onset of a serious, social learning disability. Therefore, by extension, early intervention is important to help children to decrease symptom expression (Van Schalkwyk & Volkmar, 2015) and to improve social and academic functioning.

Rao et al. (2016) considered several theories in attempting to explain autism, and while they concluded that no one theory can fully explain the disorder, they focused on three neuropsychological theories upon which intervention strategies have been based: theory of mind (ToM), executive function theory, and central coherence theory. ToM posits that children with ASD may not possess the ability to empathize or to put themselves in others' shoes, read others' intentions, or pick up on social cues (Beck 2018). In studies reviewed by Rao et al. (2016), 80 % of children diagnosed with ASD failed ToM tasks such as making eye contact. The absence of eye contact can be considered a manifestation of the inability to decipher information communicated by eyes, which can lead to social difficulties. ToM deficits also include difficulty recognizing vocal cues and the emotional content in language. There are differences in the development of the theory of the mind (ToM) in typically developing children and children with ASD. The differences are related to deficits in executive functioning, face processing, and social motivation, which are some of the symptoms of ASD. The theory, however, does not explain the characteristics of restrictive and repetitive behaviors and savant abilities often found in a child with autism.

In addition to ToM, Rao et al. (2016), examined executive function theory, defined as the ability to guide behavior by reference to mental models or future goals or, in other words, to think abstractly, have cognitive flexibility, and attention control. Studies reviewed and discussed by Rao et al. (2016) suggested that children with ASD, with and without intellectual delay, may have impairment in flexibility and efficient planning not causally related to language ability. The third theoretical examination by Rao et al. (2016) was that of the central coherence theory, which is the tendency to construct higher-level meaning in context by drawing together diverse information characteristics of normal information processing. Children with ASD have a weakened ability to integrate pieces of information into a whole picture. Central coherence theory suggests that persons with ASD who are savants, have special talents, or exhibit repetitive behaviors serve as illustrations of impaired normal information processing and integration (Rao et al. 2016).

In recent years, a self-advocacy movement posed a theory that ASD and other neurodevelopmental disorders are due to neurodiversity. In this sense, they are not diseases in need of a cure. It has been postulated that ASD symptoms are characteristics of an individual whose brain functioning is not neurotypical. Research studies have not been able to determine with certainty what genetic, biological, or social conditions influence or cause the development of ASD (Beck, 2018). ASD symptom expression is within the construct of an individual's unique sociocultural environment and biology, indicating the importance of studying the major cultural constructs influencing the process of identification of ASD of African and African American children (Beck 2018). More specifically, there is a need to examine the cultural influences on the perceptions of caregivers regarding ASD, as they play a key role in identification and diagnosis. Thus, a relevant theory that serves as the foundation for this study is Bronfenbrenner's biopsychosocial theory.

Pearson and Meadan's (2018) qualitative study on African American parental perceptions of services and the diagnostic process included interviews of 11 mothers. In the data analysis, several themes emerged, including that parents needed more knowledge and awareness of ASD. Decreased awareness of concerns indicative of the autism spectrum disorder also seemed to influence the timeliness in the identification and early intervention for the mothers of children with ASD. In the study, a participant noted that an African American celebrity mother's description of her child's behavior and diagnosis of ASD influenced the participant to seek help. Other participants revealed that barriers to identification included family views of their child's behaviors as typical, and the family members' passive responses to ASD characteristics. The participants also admitted having limited knowledge of disability and child development in general. The study highlighted that health care professionals' lack of knowledge of African American family perceptions of ASD symptoms was an additional impeding factor to early identification. Finally, the researchers asserted that the limitations of the study were a lack of fathers interviewed, and the need for a larger sample of caregivers from across the country.

Ratto et al. (2016) asserted reports used to identify ASD may not capture the functions that are of concern to African American caregivers nor the role of cultural and ethnic factors. Ratto et al. (2016) quantitative study investigated the differences between African American and White parents' reports of impairment in social-emotional, adaptive behavior, and executive function of 64 youth diagnosed with ASD. Executive function was assessed using the parent form of the Behavior Rating Inventory (BRIEF), adaptive behavior was assessed by the Vineland Adaptive Behavior Scales, and the Child

Behavior Checklist (CBCL) was used to assess behavioral and emotional problems. The African American children were found to be less impaired than White children on all measures. A few of the ethnic differences explained by the researcher included higher expectations of African American parents of their children's behaviors, development of their adaptive skills, and an underestimation of the ASD symptoms as not problematic. Another explanation for ethnic differences in the study was the possibility the sample was of highly functioning children correctly diagnosed with ASD. The researchers thought perhaps other African American children were not represented because of misdiagnosed behavioral problems, and/or alternative diagnoses such as ADHD.

A study of White and African American parents of children identified at risk for a developmental delay before an ASD diagnosis had similar findings (Donohue et al. 2019). Diagnostic evaluations were used to examine the effect of race on ASD and disruptive behavior concerns. Two separate analyses of covariance (ANCOVA) were conducted and showed that African American parents presented fewer restricted and repetitive behaviors and social concerns of autism in their children, which lessened providers' ability to identify and diagnose ASD. The African American parents were less likely to report the social concerns characteristic of ASD symptoms, even though their children's symptoms were more severe than the White children in the study. The researchers postulated that African American parents are concerned with protecting their children from racism, prejudice, and discrimination and oftentimes emphasize controlling disruptive behavior. The caregivers may have interpreted delayed receptive language and lack of response to parent directives as "bad" behavior when the directive was interfering with a restricted or repetitive behavior. Therefore, African American parents may emphasize ASD symptoms as disruptive behaviors when presenting them to a health care professional. Children who were later identified as having ASD researchers found had providers that interpreted and diagnosed presenting symptoms as a conduct disorder. Donohue et al. (2019) recommended future research examines if parent reports of fewer ASD concerns and their limited access to knowledge of ASD symptoms are predictive of delayed ASD identification and diagnosis.

The literature on the perceptions and knowledge of ASD and knowledge of child development of African caregivers of children is scarce. Abubakar et al. (2016), in their systemic literature review of ASD in Sub Saharan Africa, found most studies were limited to South Africa and Nigeria, and the studies focused mostly on psychosocial issues and did not examine potential risk factors for African children with ASD, including late identification. Franz et al. (2017), in their comprehensive review of the ASD literature in Sub Saharan Africa (SSA), found a need for large-scale, comprehensive, clinical research programs to enhance the ASD knowledge gap. Of all the studies in the review, most were from South Africa. In their review, one of the many themes that emerged was the need for further research and exploration to increase knowledge of family perspectives of ASD in SSA. In both literature reviews of studies in SSA, the understanding of ASD, in general, was attributed to traditional and religious beliefs, as well as biomedical causes. Researchers attributed the lack of knowledge of ASD in SSA in part due to the lack of development of globally relevant screening tools to identify the disorder and the standardization and validation of those tools.

Mthombeni and Nwoye's (2018) qualitative study of participants from a small special needs school in South Africa investigated eight caregivers' understanding and approaches to securing a cure for children with ASD. The caregiver's perspectives of the disorder were as an illness that is not curable, is rare, and is understood to be caused by external supernatural forces. The parents reported utilizing both western and indigenous approaches with limited effectiveness. The participants expressed frustration by western approaches to treatment that did not provide a cure. Their perspective and understanding of ASD were not that it is a developmental disorder that requires approaches to assist in the management of behaviors and improved functioning. In another study, Kakooza-Mwesige et al. (2014) tested the validity of the 23-question screener for ASD they developed for children in Uganda, Africa. Cultural factors contributed to their finding that if children were able to complete daily living skills they may not be identified with developmental disabilities until school age. Children and caregivers were not exposed to media or outside influences beyond their rural communities. They were not aware of or concerned with developmental disabilities and differences.

In sum, the researchers of the studies discussed in this section of the literature review for the proposed study, consistently conclude that there is a need to increase knowledge and awareness of ASD symptoms by both parents and health care practitioners in Africa and amongst African Americans.

Religious and Traditional Beliefs

In reviewing the literature, evidence exists that religious and traditional beliefs influence the identification, care, and treatment of African and African American children with ASD. The literature reviewed indicates that the delay of 1.5 to 2.6 years in the identification and treatment of ASD amongst Africans and African American children can be due to cultural factors and points to the need for further research in this area. Tilahun et al. (2016) found that participants believed that there are supernatural and religious causes for ASD, as was observed in studies of participants in other SSA countries. Their study trained health extension workers in child development and mental illness to decrease their negative beliefs and to empower them to educate and raise community awareness about ASD. They suggested future research examine maintaining belief in positive outcomes in low resource countries. Another Ethiopian study (Zeleke, et al. 2018), examined how 100 parents, many of whom were highly educated, detected symptoms of ASD in their children and found that early identification of ASD was difficult, in part, due to the parents' cultural belief that ASD is caused by the devil or by a spiritual crisis.

Kakooza-Mwesige et al. (2014), in their Ugandan planning and feasibility study, evaluated a screening tool to identify children with neurodevelopmental disorders. There was the attrition of their sample which they asserted may have been due to cultural perceptions that rejection of traditional taboos, myths, and/or belief of evil spirit possession, resulted in ASD behaviors. The researchers thought some of the participants might have been lost to the clinical assessment due to those perceptions which then impaired further ASD identification. The researchers found in their study that children with ASD are viewed with more negativity than physically disabled children in that region. Similarly, a qualitative study that used interviews and focus groups to examine the perceptions of 101 parents and professionals in Kenya found that they ascribed causes of ASD to witchcraft, curses, and evil spirits, and were inclined to use spiritual healing (Gona et al.2015). Amongst Somalian participants in a study in the UK that examined understanding and awareness of ASD, some parents believed that lack of sun and the use of the MMR vaccine were causes of ASD, and the disorder did not exist in their country in Africa. For some participants, a source of healing and support was religion, which was valued over science (Hussein et al. 2019). Burkett et al. (2017) conducted an ethnonursing research methodology in which they immersed themselves within 28 families to discover their perspectives on caring for their child with ASD. The study found that culturally congruent practice is enhanced by understanding and respecting that faith in God and family was influential for families when it came to the care of their child. Burkett et al. (2015) in an earlier study found that diagnosis and treatment for ASD were influenced by culture as well. The participants of that study believed that encouraging their child's independence and treating them as typically developing had prevented them from discrimination and prejudice. The participants were more likely to seek assistance from family, friends, and church members before seeking help from professionals. This practice is like what is found in SSA cultures that seek out spiritual healers. Lovelace et al. (2018) sought to examine the unique perspectives and experiences of African American mothers of children with ASD to inform service delivery. Their research method was a narrative inquiry. The study referenced within the theme of familial interpretations was participants' beliefs that ASD could be a result of poor parenting and/or drug use or a disorder that can be "prayed away."

Social and Communication Norms

The identification of ASD is based on observable social and communication behaviors with caregivers' input. Perepa (2014) studied the cultural influence on caregivers of children with ASD from four different ethnic groups, including participants from Somali, West Africa, and the Caribbean living in the UK. Perepa concluded that what is perceived as deficit behavior in one culture, typically in a dominant western culture, may not be viewed as a deficit in another culture. They found to be viewed as communicating socially appropriate in the UK, the African and Afro- Caribbean cultural groups caregivers perceived needing to teach their children social behaviors of eye contact, a range of facial expressions, and using gestures such as pointing.

Harrison et al. (2017) researched a widely used ASD assessment tool, the Autism Diagnostic Observation Schedule (ADOS), and concluded there was a need for more research in differences in ASD presentations that are influenced by cultural constructs to aid in more accurate diagnosis amongst different ethnic and racial groups. In the Perepa (2014) study parents rated what behaviors were important for their children with ASD to learn. The results were similar in the literature cited in a study on the behavioral differences of cultural expression in play, language, eye contact, facial expression, and recognition (Harrison et.al (2017). Behavioral interaction differences and the cultural variability impact on ASD assessment were examined and the results were those caregiver perceptions of what are "normal" social and communication behaviors are not consistent across cultures. In the Harrison et. al. (2017) study, African Americans scored in the atypical range at a higher rate in the domains of unusual eye contact, stereotyped or idiosyncratic word use, and immediate echolalia. The authors encouraged further research to increase understanding of the impact of cultural variability on ASD assessments. There is a hesitancy in the African American community to label children, and some caregivers experience their family and friends minimizing social and communication characteristics of autism, such as stuttering or delayed information processing and responsiveness, as behaviors they might outgrow or as a defiant behavior (Lovelace et al. 2018). The resistance and delay in seeking assistance and identification of ASD in the African American and African cultures may thus be highly influenced by fear of stigma.

Fear of Stigma

A review of the existing literature regarding ASD indicates that fear of stigma has been examined as an impediment in seeking identification of ASD for children in African and African American cultures. Burkett et al. (2015) found timely autism diagnosis was affected by cultural influences of fear of the stigmatization of having a disability in the African American community, with the possibility of stigmatization delaying the identification of ASD. Dababnah et al. (2018) study on barriers to ASD screening found that caregivers feared stigma from the African American community, including their family members for having a child with autism. Children were left out of gatherings and were not integrated with the rest of the family out of shame or fear of judgment. Fear of stigma and denial delayed parents' seeking developmental referrals or following up with referrals. Hussain et al. (2019) found in their study that nicknaming and labeling by community members was a deterrent that impeded awareness and understanding of ASD for caregivers from Somali, Africa who were living in the UK. A study by Tilahun et al.,

(2016) sought to increase the understanding of caregivers of children with ASD in low-resource countries. They found that in Ethiopia a high level of stigma was perceived, especially for those who seek help through traditional institutions, i.e., churches, priests, or religious healers. Guler et al. (2018) study explored caregivers' perspectives of early intervention for young children with ASD in South Africa, and found stigma was one of ten factors to consider. Stigma was experienced in all sectors of the population. As with the African American community, the child with autism was sometimes kept secret or isolated from other family members and the community, (Dababnah et al. 2018) hindering identification, diagnosis, and treatment.

Summary

In this literature review, background literature regarding autism spectrum disorder and associated theories were discussed. Specifically, three theories were reviewed, and it was noted that none of the three serves to completely explain the disorder. Rather, ASD is a disorder that must be described within the socio-cultural context of the individual. I chose and discussed the appropriateness of Bronfenbrenner's biopsychosocial theory as an appropriate foundation for the current study to explore the perceptions of two cultural groups and the possible influence of culture on the identification of ASD in their children. The literature review revealed similarities in African and African American caregivers of children with ASD in their awareness, understanding, and knowledge of ASD that might be attributed to cultural influences. Research on the presentation of the social and communication concerns and symptoms of ASD that examined it within the context of African and African American cultures was reviewed. Both cultures religious/traditional beliefs informed how parents in these groups care for their children and influence whether they seek out professional services. The literature review discussed the fact that research indicates caregivers in both cultures may seek help from both spiritual and traditional resources. The literature also illustrated how social and communication norms might influence the assessment tools and practices used to identify ASD in both cultures. Finally, the fear of the stigma that befalls their children when identified with a disability, especially ASD, was shown to impede caregivers' seeking help within both cultures. The studies reviewed were primarily conducted in urban areas in the United States and Nigeria, Ethiopia, and Uganda in Africa, and included was a study of African immigrants from Somalia, Africa living in the UK in Europe. The researchers of the studies presented in this chapter suggest further examination is needed to increase understanding of the differences and disparities in the identification, diagnosis, and treatment for African and African American children with ASD (Dababnah et al. 2018, Kakooza-Mwesige et al.2014, Burkett et al. 2017). Such understanding could contribute to increasing knowledge, awareness, and earlier assessment and interventions for this population of children. As most of the existing research on ASD is based on participants from western and/or European cultures, a frequent assertion by the authors of the studies reviewed was the need for more examination of cultural factors for African and African American populations with ASD. The current study will examine perceptions within the cultural contexts and expand our knowledge of African and African American caregivers’ perceptions of ASD, child development, and the influence of those perceptions on the identification of ASD in their children. The study fills a gap of knowledge of the perceptions of caregivers on cultural constructs influencing the delay of identifying African and African American children with ASD. The methodology of the current study including data collection, analysis, and explanation of settings, instrumentation, and participants is discussed in Chapter 3.

Chapter 3: Research Method

Introduction

The purpose of this qualitative ethnographic study was to explore the ramifications of cultural constructs, understandings of child development, ASD concerns and symptom presentations, religious beliefs, and fears of stigma on the delayed identification of ASD in children from the perspectives of their African and African American caregivers. I used the data collected to identify patterns and themes related to African and African American caregivers' perceptions of those constructs and the ASD process itself. The findings of this study add to the existing research related to understanding what may contribute to the delay in the identification of African and African American children with ASD. The study expands the understanding of the cultural perspectives of African and African American caregivers of children with ASD. In this chapter, I discuss the research design and rationale, recruitment and selection of participants, trustworthiness issues, data analysis plan, and ethical considerations.

Research Design and Rationale

Employing a qualitative research tradition with an ethnographic design for this study was appropriate to explore the perspectives of caregivers directly involved with African American and African children with ASD when identification was delayed. Qualitative researchers using ethnographic design conduct research in a natural setting face-to-face with interviewees to gather information directly from participants (Creswell & Creswell, 2018). Qualitative research uses multiple types of data gathered from interviews, surveys, and/or observations (Creswell & Creswell, 2018).

When using the ethnography design, a researcher looks at culture, society, or a cultural group. In the early 1900s, Bronislaw Malinowski helped found modern anthropology in Britain, establishing principles or key concepts of ethnographic fieldwork still used today with the goals of describing traditions, customs, institutions, and what he called the "skeleton of the tribe" (O'Reilly, 2009). He sought to gain insight into cultures other than his own by describing their daily life and their feelings and ways of thinking (O'Reilly, 2009). Around the same time in the United States, Franz Boas, a German Jewish scholar who immigrated to the United States, was also considered the father of anthropology (Vermeulen, 2015). He was labeled a liberal due to his antiracist views, such as for using the word *cultures* to refer to groups of people who were not white, instead of *savage* as Malinowski and other anthropologists of their time did. Boaz was a catalyst for a paradigm shift toward initiating antiracist anthropology. In his work to study human diversity, Boas used a descriptive approach by focusing on language and historical relations between people (Vermeulen, 2015).

As a naturalistic, interpretive constructionist, I believe that reality is complex and can be best understood by people's experiences (Rubin & Rubin, 2012). This research is enhanced by utilizing a postmodern ethnographic qualitative paradigm of gathering data of the culture's norms, values, traditions, beliefs by observing the culture members' perspectives and experiences (Rubin & Rubin, 2012). In this study, I specifically explored the perspectives of persons belonging to African and African American cultures. African and African American children are identified and diagnosed with ASD at least 1.5years or more later than are White and European children (Donohue et al. 2019). The existing literature has indicated that African and African American ASD identification and diagnosis are delayed due to many influential factors (Harrison et. al.,2017). In this study, caregivers' perspectives of some of the cultural constructs that might have influenced the delays in identification were explored.

Research Questions

The following research questions were used to explore some of the cultural constructs that previous literature identified as influential in the delayed identification process of African and African American children with ASD.

RQ 1: What are the African and African American caregivers' perspectives about child development and autism symptom presentation concerns that might have delayed the process of identification of their children with ASD?

RQ 2: What are the African and African American caregivers' perspectives of their religious/traditional beliefs that might have delayed the process of identification of their children with ASD?

RQ3: What are the perspectives of African and African American caregivers about fear of stigma that might have delayed the process of identification of their children with ASD?

RQ 4: What are the perspectives of African and African American caregivers of social and communication norms of their culture that might influence the delay of identification of their children with ASD?

Role of the Researcher

I am an African American who was previously involved in caring for an African American child with ASD that was delayed in being identified. As a researcher, my role as an observer and interviewer will be broad in exploring African American and African caregivers' perspectives. The two groups share some cultural perspectives and experiences that I identify in the study. Additionally, I have a personal relationship with the topic as a grandmother of a child with ASD. Professionally, I am a licensed clinical social worker who has previously treated at-risk families with children with ASD. My bias is my concern for African American and African children, especially males who are often misdiagnosed and do not receive early intervention for ASD (Ratto et al. 2015). Their behaviors are misunderstood by their caregivers and professionals, which may contribute to the overrepresentation of African Americans in the penal system and poorer academic and social outcomes (Bello-Mojeed et al. 2017). In conducting this study ethically, I was cognizant of not exploiting a vulnerable population of caregivers of children with developmental disabilities.

Methodology

Eligibility Criteria and Participants

African and African American caregivers of children diagnosed with ASD after the age of 6 years old living in rural or suburban areas in the United States and West African countries were eligible and fit the criteria to be participants in the study. To participate in this study, the caregivers were adults, at least 25 years old, with a child with ASD who is at least 6 years of age. The child's age was important for the study as

African and African American children in the United States and Africa are diagnosed, on average, two years later than Caucasian or European children; in Sub-Saharan Africa, ASD identification can occur as late as school-age (Bello-Mojeed et al. 2017; Burkett et al. 2015; Wannenburg & van Niekerk. 2018). The mean age that women have their first child in African countries is between 19 and 22 years old (CDC, 2016). In contrast, the mean age that African Americans have their first child in the United States is 25.1 years old (CDC, 2018). To ensure the criterion for selection in the study was met, the participants reported their child was identified with ASD by an educational facility or by a health care provider. African and African American caregivers were fluent in English.

Recruitment Strategy

My literature review revealed that most of the research related to ASD in African and African American populations has been conducted in urban areas in the United States, Nigeria, and South Africa. I specifically recruited from African and African American online groups for caregivers of children with ASD from the United States and West African countries to expand research in those regions. Online social communities have birthed new ethnography research methods of immersion (Caliandro, 2018). There are online groups, whose participants are African and African American caregivers of children with autism, that I reached out to for recruitment into the study. I also targeted on-the-ground organizations with an online presence for recruitment included organizations in West African countries and clinics in the southeastern United States that service children with autism. I also used a flyer on the virtual sites to recruit caregivers (See Appendix A).

One characteristic of qualitative research and ethnographic studies of a cultural group is a small population size (Creswell & Creswell, 2018). In a qualitative study, an adequate sample size is reached when saturation occurs or no new insights or data emerge in the themes deduced from the data collected (Creswell & Creswell, 2018). In a study by Burkett et al. (2015) on the influence of culture on ASD diagnosis, the researchers reached saturation and found recurrent patterns with 24 participants. I recruited at least five African American participants and four African participants. Two African participants withdrew from the study. I analyzed patterns in their responses until no new patterns or themes emerged, which indicated that I was learning nothing new and had reached data saturation (Ravitch & Carl, 2016).

I contacted online group moderators with e-mails and flyers. The respondents were able to respond to a flyer posted online in group forums targeting caregivers of children with ASD in those populations, as well as organizations serving them. A preliminary demographic questionnaire (Appendix B) was used to assess if the participants who responded to the flyer fit the study criteria. The demographics of the participants were gathered, including the age at which their children were identified as having ASD, the age of the caregivers, the caregiver’s nationality (i.e., African, or African American), and the caregiver’s relationship to the child. The participants were the primary caretaker of the child identified with ASD. I also asked participants how they knew their child has ASD, and if their child was identified with ASD at the age of six or later.

Instrumentation

The primary instrument in a qualitative study is the researcher as I collected data from participants via interviews. Participants shared their perspectives on the cultural constructs that may have influenced the identification of ASD in their children via semi-structured, open-ended interview questions that I developed for each construct based on relevant literature. I created the semi-structured interview questions for use via video conference call technology or telephone (Appendix: C). I also took field notes on what I observed in the social media group interaction.

Procedure of Recruitment and Participation

I recruited African American and African caregivers of children with ASD through online forums found through sites, such as Facebook, Instagram, and Twitter, and through on-ground, ASD-serving agencies and educational programs' websites. Recruitment through online groups continued until enough participants were recruited to reach data saturation. Each participant was scheduled for a 45–60-minute semi-structured interview that was both audiotaped and transcribed via cell phone or computer recording app. I conducted follow-up via email and follow up phone interviews with the participants for member checking and debriefing.

Data Collection

I informed the participants recruited via social media support groups within the community and educational organizations that serve those with ASD that the purpose of the study was to explore their perspectives on the cultural constructs that may have influenced the age of identification of their African and African American children with

ASD. I scheduled appointments with the participants to individually interview those who fit the inclusion criteria. Before the interview, I e-mailed the participants a consent form to complete, and they returned them via e-mail (Appendix: D). The interviews were private telephone conversations, and one was a secure meeting over teleconference/video technology. The choice of which technology used was made by the participants. In the interviews, I asked semi-structured questions related to the research question. The participants were informed that the interviews were being audiotaped and transcribed. Data collection began with the notes of individual recorded interviews of individual participants. Data collection included notes of my impressions of participants' perspectives of the constructs related to the research questions, the audiotaped semi-structured interviews, and online group interactions I observed. The data collected from interviews and group observations would fall under the category of qualitative audio and visual material (Creswell & Creswell, 2018).

Data Analysis

In qualitative research, analysis of data is simultaneous with the data collection procedure (Ravitch & Carl, 2016). I transcribed the audiotapes of the interviews verbatim and compared the transcription to the audiotape for accuracy (Ravitch & Carl, 2016). I did not take out natural speech patterns so as not to imply interpretive authority. The transcripts were segmented initially into two sections. One section contained interviews of African American caregivers and the other contained interviews of African caregivers. The transcripts were further segmented by the cultural constructs explored in the interview. There were interview questions addressing the constructs being explored in the study (i.e., ASD symptom presentations, social and communication norms, religious/traditional beliefs, and fear of stigma).

My study was exploratory, and therefore, it was appropriate to use exploratory methods of coding (Saldana, 2016). I developed codes and operational definitions of those codes with some guidance from earlier studies as an origination point. I first pre-coded the transcripts using a large unit or holistic coding for African American perspectives and a second large code for African perspectives. I was able to describe the participants and groups interviewed and the settings with established codes (i.e., interview or observation) as I organized the data, winnowing it down to focus on the perspectives I explored for the study and the elements of Bronfenbrenner's theory. Provisional coding was used by listing the cultural constructs within the micro- macro-, meso-, and exosystem elements of the conceptual framework of Bronfenbrenner's theory. I analyzed all the data by reading, questioning, and engaging with it as it was collected (Ravitch & Carl, 2016) and hand-coded (Creswell, & Creswell, 2018). Quotes from the participants' interviews were viewed through the lens of Bronfenbrenner's ecological framework. The coding generated themes and displayed the multiple perspectives of the participants. I support the themes by using quotations from the interviews as evidence of the themes (Creswell & Creswell, 2018).

Issues of Trustworthiness

Trustworthiness is a word used interchangeably with validity to ensure the quality and rigor of qualitative research (Ravitch & Carl, 2016). In quantitative research, specific methods based on scores, research designs, or instrumentation are used (Ravitch & Carl, 2016). In contrast, qualitative research validity or trustworthiness is established through the lens of the participants, external individuals, and the researcher (Ravitch & Carl, 2016). There is a set of standards or concepts for qualitative research to adhere to concerning validity (Ravitch & Carl, 2016). I compared the transcription to the audiotape for accuracy of having captured participants' speech verbatim.

Credibility

Multiple strategies are recommended to establish credibility in qualitative research. To establish credibility in the accuracy of the findings of this study, I triangulated data from the interviews and observations and the convergence of perspectives of the participants (Creswell & Creswell, 2018). As an African American and prior caretaker of a child with autism as previously described in this dissertation, I was aware of my bias throughout the study and took care to capture participants' statements accurately. I conducted member checking by sending participants a summary of their interviews and they provided feedback on the researcher interpretations. A rich, thick description of the findings added validity to the research. In addition, as part of Walden University's dissertation process, the study methods and findings were reviewed by the Walden University dissertation committee members (see Creswell & Creswell, 2018), including the university research reviewer.

Transferability

As the study is an ethnographic qualitative study exploring the perspectives of specific cultural groups, findings may not be directly applied to other individuals, groups or contexts. Qualitative studies are context-specific; however, the rich detailed description of the findings may allow researchers to transfer aspects of the design to different broader contexts (Ravitch & Carl, 2016). Guba (1981) asserted that research audiences can make comparisons to other contexts when descriptions are rich, thick, and detailed.

Dependability

The concept of dependability is when data remains stable and consistent over time (Ravitch & Carl, 2016). The data presented is consistent and focused on answering the research questions. As discussed previously in the dissertation, utilizing ethnographic research methods and design is a rational one for this study. To achieve dependability, I used the triangulation and sequencing of methods that confirms my data collection was appropriate to explore the cultural constructs for the study.

Confirmability

The goal of confirmability is to explore and acknowledge biases that influence interpretations of gathered data in qualitative research. Confirmability was obtained throughout the study period by monitoring my thoughts and feelings throughout the process as well as presenting any self-reflection for reflexivity processes (Ravitch & Carl, 2016).

Ethical Procedures

I emailed, posted, and/ or direct messaged an invitation to the moderators and/or organizers of online groups, and then forwarded invitations to all the participants who met inclusion criteria with instructions for how they would be contacted for interviews or participation in online observations of discussions. I reviewed consent forms with all the participants, and they indicated their consent in an online form. Participants were recruited from online groups to interview individually by telephone or by virtual videoconference. The privacy of the participants was assured and only synonyms or codes were used to protect their confidentiality. Data was stored in a locked cabinet in my home and recordings were stored on a password protected computer file, which will be kept for five years until destroyed by shredding or erasing. The participant demographics are important for this study but are only shared in a manner that will make the participants unidentifiable. I reviewed the international research requirements available for Malawi, Nigeria, Botswana, South Africa and UNESCO (United Nations Educational, Scientific and Cultural Organization). The requirements are comparable to the University's IRB requirements. One of UNESCO's overarching goals is mobilizing science knowledge and policy for sustainable development. Walden IRB directions states when the study is online, and the researcher is in the USA indicate "no" where asked on the application if the study is international. I conducted the study online in the United States, and, therefore, fulfilling the international requirements for this study was not required.

There were not any potential conflicts of interest with the participants or partner organizations. The burdens and risks were reasonable as new knowledge of perspectives of African and African American caregivers of cultural constructs may influence the decreasing the delay of identification of children with ASD. The results may be used to address those delays and facilitate earlier interventions which could lead to improved outcomes in the communities. The methods used to recruit were non-coercive in any way and the participants were not previously known to me. As I am a licensed clinical social worker and mandated reporter, that information was disclosed to participants before the interviews so participants were aware that any disclosure or observation of abuse would have to be reported to the appropriate agencies. No acute psychological state requiring referral arose, but resources were available for participants to access. The research had two groups, and both groups would potentially benefit equally from the study by learning about the presentation and symptoms of ASD in their child and be a potential influencer in their communities and cultures.

The research was approved by Walden Institutional Review Board (IRB), and the research was appropriately qualified and supervised by the Walden committee in all data collection procedures. A consent form was completed and written to be easily understood by the participants and contained an explanation of the research purpose, the data collection procedures and estimated length of time for participation, as well as clearly statements that participation was voluntary. Participants were informed in the consent form that they could decline participation at any time. Before giving consent, the participants had time to study the information and ask questions. The participants had access to a copy of the consent form and how to contact the researcher.

Summary

In this chapter, I outlined the methodology used most appropriate for a qualitative study of an ethnographic nature. The rationale for the research design and methodology was discussed and outlined. Included in the chapter was a discussion on issues of trustworthiness to address the validity and reliability of the study. I reviewed the methods of data collection and analysis that were appropriate for the study. At some length, I reviewed the ethical procedures used to ensure participant privacy and data security. The study was qualitative using an ethnographic research design. In chapter 4, after completing the data collection and coding of data, I describe the data analysis procedures. I will also present the study findings.

Chapter 4: Results

Introduction

The purpose of this ethnographic study was to explore the ramifications of cultural constructs, differing understandings of child development, ASD concerns and symptom presentation, religious beliefs, and fears of stigma on the delayed identification of ASD in children from the perspectives of their African and African American caregivers. I used the data collected to identify patterns and themes regarding African and African American caregivers' perceptions of autism, typical and atypical communication and social development, religious and traditional beliefs, fear of stigma, and the autism screening process itself. The results of this qualitative study will add to the collective understanding of cultural perspectives of caregivers of children with ASD in African and African American cultures. The data collected was applied to answer the following research questions:

RQ 1: What are the African and African American caregivers’ perspectives about child development and autism symptom presentation concerns that might have delayed the process of identification of their children with ASD?

RQ 2: What are the African and African American caregivers’ perspectives of their religious/traditional beliefs that might have delayed the process of identification of their children with ASD?

RQ3: What are the perspectives of African and African American caregivers about fear of stigma that might have delayed the process of identification of their children with ASD?

RQ 4: What are the perspectives of African and African American caregivers of social and communication norms of their culture that might influence the delay of identification of their children with ASD?

Setting

I conducted semi structured interviews via telephone or Zoom video conference call. I ensured all interviews were confidential by being in an office alone while on the phone or zoom call. I also used a Zoom program that is encrypted. The participants emailed consent to me on the day of their interview. There were no distractions during the interviews. Caregivers in the study were also invited to send their posted online interactions in social forums to be included as data in the study. Lastly, I observed interactions on public social media groups for caregivers of children with ASD.

Participant Demographics

Findings were reported in several ways. Table 1 characterizes the African American study sample demographics for age, gender, nationality, caregiver age, and age of child when diagnosed with ASD. Table II characterizes the African study sample demographic for age, gender, nationality, age of caregiver and age of child when diagnosed with ASD.

Table 1

Demographics: African American (AA) Caregivers

AA Caregivers	Gender	Nationality/Race	Age of CC	Age of cx @ dx
CG 1	Female	AA	40	6
CG 2	Female	AA	38	8
CG 3	Female	AA	53	14
CG 4	Female	AA	46	16
CG-5	Female	AA	51	7

Table 2

Demographics: African (AF)Caregivers

AF Caregivers	Gender	Nationality/Race	Age of CC	Age of cx @ dx
CG 1	Female	Sudanese	44	6
CG 2	Female	Ugandan	37	6

Data Collection

In this study, I collected data from five African American caregivers and two African caregivers of children with ASD. I posted digital flyers on several social media sites and websites of groups, schools, and organizations that served children with ASD and their caregivers. Twenty-nine caregivers responded to flyers posted on the sites. Ten African respondents declined screening due to lack of monetary compensation, two respondents did not agree with ASD as a disorder, and eight did not follow up with consent forms. The remaining five African American and four African caregivers fit criteria for the study; however, two of the four respondents living in Africa declined to participate after receiving the informed consent and understanding there was no monetary compensation. The two African caregivers were from the West African countries of Uganda and Sudan. I scheduled appointments with the remaining seven participants to individually interview those who fit the inclusion criteria. Each of their children's identification with ASD was delayed at six years old or older. Before the interview, I emailed the participants a consent form to complete and return via e-mail or postal mail.

I interviewed six of the participants via private telephone and one participant was interviewed in a secure meeting over teleconference/video technology, asking them the same 11 semi-structured interview questions. The choice of technology used was made by the participants. All electronic recorded interviews were stored in password protected files on the researcher's personal computer. Similarly, all written notes were stored in a locked cabinet in the researcher's home office.

The participants were informed that the interviews would be audiotaped and transcribed. Data collection began with my impressions of participants' perspectives of the constructs related to the research questions as I audiotaped answers to the semi-structured interview questions. In addition to the interview data collection, I was a nonparticipant observer of online interactions on the online groups that the participants were recruited from. I was able to observe interactions online but could not include those observations without the consent of the group members, which was not received, and study participants did not send me their online interactions as requested.

I recorded and transcribed all interviews using Microsoft Word and a computer audio application simultaneously. I played all audio recorded interviews repeatedly to ensure the transcriptions were accurate and further transcribed initially misunderstood words and noted any missed audio on the transcription. The interviews lasted 30 to 45 minutes. The final transcriptions were transcribed verbatim, and reliability of the transcription was obtained and confirmed by checking them against the audio recordings.

Data Analysis

All of the interviews were transcribed verbatim and were compared to the audiotape for accuracy, maintaining natural speech patterns in order not to be construed to be social construction or imply interpretive authority. I used exploratory methods of coding (Saldana, 2016) to hand code the data. I initially segmented data into two units. First, I pre-coded a large unit via holistic coding for African American perspectives and a second large unit code for African perspectives. Secondly, each transcription of caregivers' interview responses was further segmented to correspond with the research questions. The responses were coded, and themes emerged for each research question. The themes that emerged corresponded with both the research questions and cultural constructs being explored in the study (i.e., ASD symptom presentations, social and communication norms, religious/traditional beliefs, and fear of stigma). One other theme, perceived racial bias, emerged that did not fit with the preconceived perspectives of the study. All codes were provided with operational definitions. To code the data, I isolated and identified participants' statements by highlighting words, phrases, and statements illustrating the caregivers' perspectives. I then analyzed all the data by reading, questioning, and engaging with it as it was collected (Ravitch & Carl, 2016). I supported the emergent themes in this section by using quotations from the interviews as evidence.

Evidence of Trustworthiness

Trustworthiness is a word used interchangeably with validity to ensure the quality and rigor of qualitative research (Ravitch & Carl, 2016). In quantitative research, specific methods based on scores, research designs, or instrumentation are used (Ravitch & Carl, 2016). In contrast, qualitative research validity, or trustworthiness, is established through the lens of the participants, external individuals, and the researcher (Ravitch & Carl, 2016). There is a set of standards or concepts for qualitative research to adhere to concerning validity (Ravitch & Carl, 2016). For this study, I compared the transcription to the audiotape for accuracy and evidence of trustworthiness. For member checking, I emailed summaries of interview transcripts to participants and requested their feedback, and three participants responded in agreement with the summaries. Three caregivers responded by email and agreed with the summarized transcript of the interview, and the other four participants were reached by follow up phone calls, during which they also agreed with the provided summaries.

Credibility

Multiple strategies are recommended to establish credibility in qualitative research. To establish credibility in the accuracy of the findings of this study, I triangulated data from the interviews and observations and the convergence of the participants' perspectives (Creswell & Creswell, 2018). As an African American and prior caretaker of a child with autism, as previously described, I was aware of my bias throughout the study and took care to capture participants' statements accurately. I conducted member checking by sending participants a summary of their interviews, and they provided feedback on the researcher interpretations. A rich, thick description of the findings added validity to the research. In addition, as part of Walden University's dissertation process, the study methods and findings were reviewed by the Walden University dissertation committee members (see Creswell & Creswell 2018), including the university research reviewer.

Transferability

As the study is an ethnographic qualitative study exploring the perspectives of specific cultural groups, findings may not be directly applied to other individuals, groups, or contexts. Qualitative studies are context-specific; however, the rich, detailed description of the findings may allow researchers to transfer aspects of the design to different broader contexts (Ravitch & Carl, 2016). Guba (1981) asserted that research audiences can make comparisons to other contexts when descriptions are rich, thick, and detailed.

Dependability

The concept of dependability is described as when data remains stable and consistent over time (Ravitch & Carl, 2016). The data presented is consistent and focused on answering the research questions. As discussed previously, utilizing ethnographic research methods and design was a rational choice for this study. To achieve dependability, I used the triangulation and sequencing of methods to confirm my data collection was an appropriate exploration of the cultural constructs for the study.

Confirmability

The goal of confirmability is to explore and acknowledge biases that influence interpretations of gathered data in qualitative research. Confirmability was obtained throughout the study period by monitoring my thoughts and feelings throughout the process as well as presenting any self-reflection for reflexivity processes (Ravitch & Carl, 2016).

Results

I explored perceptions of the caregiver participants to examine the influence of cultural constructs, ASD symptom presentation, social and communication norms, religious/traditional beliefs, and fear of stigma, all within the framework of

Bronfenbrenner's ecological theory. From this framework, interview questions were developed to gather data that would answer the study's research questions. The results of the data analysis emerged from the participants' answers to the semi-structured interview questions (Appendix C), which correlated with and addressed each of the research questions. I used Saldana's (2016) method of structural coding, which applies a conceptual phrase to data segments related to specific research questions. I initially segmented data into two units by developing an initial set of codes (i.e., African or African American), then each of the caregivers' interview responses was further segmented to correspond with each of the research questions. Finally, similar responses were categorized for detailed coding as related to the research questions and Bronfenbrenner's theory. Additional codes were developed from the caregivers' responses to the interview questions. A total of six themes emerged from the data that collectively answered the four research questions. The research questions and their corresponding codes and themes are detailed below:

Theme 1: Caregiver Knowledge of ASD

RQ 1: What are the African and African American caregivers' perspectives about child development and autism symptom presentation concerns that might have delayed the process of identification of their children with ASD?

All the participants, both African and African American caregivers, answered the interview question regarding how much they knew prior to their child's diagnosis of ASD and behaviors of concern prior to diagnosis. Responses were assigned the codes ASD knowledge, media influence on ASD knowledge, behavioral concerns, ASD identification delay, ASD symptom presentation knowledge, hesitancy to identify disorder, and language/communication delays. The theme, caregiver knowledge of ASD, emerged from those codes. The following excerpts are examples of responses that generated the codes and emergent theme.

Two of the African American caregivers said all they knew of autism was from the movie, “Rain Man.” Rain Man was a 1988 film about an autistic-savant man. The following excerpts are examples of responses that were coded for *ASD knowledge and media influence on ASD knowledge.* According to African American Caregiver 1,

> I did not know much about it… the first time it was mentioned to me by his, because he started school, like on his third birthday due to developmental delays. And ... his teacher. when he was like, he had been there about two weeks, and she called me in and said, you know, this is what I think. Um, and the only thing that I knew of it was and it wasn't even knew of it, but I kind of had the frame of reference from the movie. Rain Man like that was it. That was the only idea I had in my head of what autism was.

As stated by African American Caregiver 2, “I knew little to nothing about it, you know. I mean I watched ‘Rain Man.’ That's all I knew about.”

The caregivers related their observations of their child’s behaviors that were concerning and described them as “different,” “weird,” or “odd.” Caregivers also described knowing their child’s developmental milestones were delayed, even if they had no awareness of neurological disorders. The following excerpts are examples of responses assigned to the behavioral concerns, and/or additional codes of *ASD* *identification delay and ASD symptom presentation.* African Caregiver 2 described the symptoms by noting, "…[exhibited] repetitive behaviors, space out in own world…little eye contact, and flapping arms" African American Caregiver 3 stated,

> I didn't like there were some things that, um, were different about him…felt there was some oddity**,** even from like being at couple weeks old....um I knew something was wrong so when I had him diagnosed, he was first diagnosed with ADHD.

African American Caregiver 2 shared additional thoughts.

> He didn't like being touched. He didn't want to be held. He's perfectly fine being in his bassinet or crib with the door closed when he somewhere else. He's like he, you know. So, I did think something was weird. At that point I was just like, well, maybe it's just me. Maybe I'm depressed, maybe he just doesn't like you know that type of thing.

African American Caregiver 1 noticed behaviors and had some concerns but it was not disturbing to her.

> Well, he played independently. Very well. Okay. Yeah. Yeah. And... he, ... he was not…he was never the kid to ask for stuff or ask for help. Like he just, um you know if he wanted a snack, he would go get it…he wasn't. He didn't sleep well. He wasn't a good sleeper…he would respond appropriately to questions, and even, you know, just regular conversation but would very clearly be something he memorized from a show, but it fit.

African American Caregiver 3 went on to say, “I didn't necessarily associate [his behaviors] with autism, I knew something neurological was not right and then I've had him evaluated over and over again.”

Once the children of the caregiver participants entered the school systems, identifying the causality of their behaviors and greater understanding and diagnosis became more important to them. Some of the Caregivers still were hesitant to have their child officially diagnosed seemingly due to lack of knowledge. The following excerpts are examples of responses assigned codes of *ASD symptom presentation and hesitancy to identify disorder.* African American Caregiver 1 stated the following:

> I, I definitely struggled with it in the beginning, like, especially because I didn't understand it… because, um I mean, as soon as the teacher said that to me, [possibility of autism] even though I thought that she was crazy because, you know, he had eye contact with me, and he was very affectionate, and..., I, you know, I tried. I started trying to seek answers at that point…So, as he grew, he was nonverbal. …he liked toys that made a lot of noise. He always pointed at things he wanted instead of talking he would take you where you were supposed to go and point out the fridge and point at things.

African American Caregiver 2 and African American Caregiver 5 described the behaviors in school that became concerning prior to diagnosis with ASD. The following excerpts from African American Caregivers 2 and 5 were assigned code *behavior concerns.*

> And he would have these meltdowns. They were kind of like quiet meltdowns, they weren't verbal meltdowns. But like we would destroy the classroom, or you know, just was not able to like function, then as he got older, What I was noticing once he you know started going to school, just having difficulty transitioning.
>
> So, I guess we were shopping; we were walking in the mall and I decided I wanted to go left, and she had a full on melt down in the store, and I noticed when we would go in stores, and make a change, it would cause her problems, there were other indications, her communication styles, interactions with others… the 2nd grade teacher she would mention [behaviors].

In addition to behavioral concerns that caregivers did not know were indicative of ASD, they described communication and language delays or differences. The following transcript excerpts were assigned the code *language/communication delays*.

> He would respond appropriately to questions, um, and even, you know, just regular conversation. But it would very clearly be something he memorized from a show, but it fit…he had a hard time with socializing... never really connected with people…she was not interacting with others, would isolate and speak in the third person.

Theme 2: Healthcare and Educator Professionals' ASD Knowledge

African American and African caregivers described experiences with health care professionals and educators in which they perceived lacked knowledge of ASD. The following excerpts are examples of responses that were assigned codes *misdiagnosis/delay and healthcare/educator ASD knowledge*, which generated the theme. African American Caregiver 1 stated the following.

> Nobody knew what they were doing … And so, we like. I struggled a lot with, like, his daycare you know, they were constantly trying to put him out because, you know, he would leave. or, you know, I mean, he was not a violent kid, but he was very obstinate, and he would leave in a heartbeat … You know? So, um, so some of the educators weren't aware either what was going on with him… like he saw a pediatric neurologist for two years before he was diagnosed, he didn't want to diagnose him because he would say things like, Oh, well, he's, you know, he's handsome…[we] had to push our, the pediatrician to give us [referral] to our Children's Hospital. At first, they thought he didn't hear well, [he] didn't follow directions.

African Caregiver 2 stated, "For almost two years and she's [the evaluator] like no there's nothing wrong with him 'cause he gives eye contact," Additionally, Caregiver 3 noted having their child "evaluated over and over again and most of the pediatricians were like, nothing" and "so at first, they identified him with ADHD**,** which is common with you know with black kids from what I read."

Theme 3: Religion, Traditional, and Cultural Beliefs and Influence

RQ 2: What are the African and African American caregivers' perspectives of their religious/traditional beliefs that might have delayed the process of identification of their children with ASD?

African American and African Caregivers' responses to interview questions exploring their perspectives of the influence or lack of by religious and/ or cultural traditional beliefs on the delay of identifying their child with ASD generated codes of *religious influence and cultural/traditional beliefs* and led to the theme. The following excerpts are examples of responses assigned code of *religious influence*. African American Caregiver 1 said,

> I don't think, um. I don't think that any anything religious had anything to with... the identification…maybe cultural stuff had more to do. You know what I mean? More to do with it. And then, like anything, religion, like nobody was like, oh, just pray for him or, you know, it wasn't that. But it was more like, you know, just give him more attention…in Uganda a lot…it had something to do with, you know, traditional… past behaviors, curses…God not happy with you."

African American Caregiver 2 also said, "No, not that that would have influenced. That I mean, it might have been secondary in the sense of like pray about it type of things, but it didn't directly influence me." African American Caregiver 3 stated, "… my mom and dad never associated religious things with mental health stuff it just they didn't connect it…not at all." Additionally, African American Caregiver 5 noted, "I don't think being a Christian have anything you know to do with it? No…, if you need assistance of a doctor, we're gonna get it, you know, so that that didn't play the part as far as that." One of the African origin caregivers felt her Muslim religion indirectly influenced her son getting a diagnosis. African Caregiver 2 stated, "I'm in a headscarf and because of the name she's thinking I'm some refugee she just brushed me off."

The following excerpts are examples of responses that were assigned to the code *traditional/cultural beliefs*. African American Caregivers related their family members advise and concerns. One related family members' hesitancy and not wanting child placed in special education, and another felt addressing behavior at home was best. Some of the suggestions made by the caregivers included, "just give him more attention or just be stricter, [you] need to discipline it more…remember, you have black sons… don't get them tested, they're going to put them in special ed…addressing behavior at home was best and regardless of limitations."

Theme 4: Stigma and Shame Influence

RQ3: What are the perspectives of African and African American caregivers about fear of stigma that might have delayed the process of identification of their children with ASD?

The African American caregivers expressed the perspective that delayed identification of their child with ASD was influenced by their shame, self-blame and/ or fear of stigma. The following excerpts are examples of caregiver responses assigned to the codes *stigma, self-blame and/ or shame* shared that generated the codes and the emergent theme. African American Caregiver 2 stated the following:

> [You] don't not wanting to get a label on your child and thinking …Some [of these] behaviors, [and we] were living in the South and so that was big thing of like, don't let these white folks you know tell you what is wrong with your kids…. I was worried that you know kids did get pigeonholed into those classrooms. And then the other shame I think, was you know, being a young mother at the time.

The following excerpts from are examples of responses to interview questions exploring the caregivers' perspectives and assigned code *stigma*. African American Caregiver 4 stated they "had some shame as son got older and went out and other kids looked at him. As it became more apparent as he got older and could not do what other kids do. "African American Caregiver 5 went on to note, "I struggled with just giving the diagnosis for of the disorder because then they wouldn't push her." African Caregiver 1 noted the following:

> Stigma or shame? I don't know if those are the words, I would use maybe guilt that would be part of stigma… You just want to protect the little ones, right? The reality is we're human beings... They should still be loved and cared for, and so there's stigma, yes.

Finally, African Caregiver 2 stated, "In Africa they do not [see autism] as a serious problem overseas and a lot … are in denial about autism… I did [have shame] overseas, [in Africa] not now."

The following responses are examples of responses that generated code of *self-blame* developed from the interview data.

> What did I do wrong? …doctors that were like, oh, let's wait and see. So, who finally, um, did, um. so, his, his final diagnosis after the three years of just kind of everybody else saying, let's wait and see.

Additional notes from caregivers included,

> Maybe it's something that I'm not doing right…more of the guilt for me, the initial emotion I had to deal with is forgive, forgiving yourself giving myself and

> forgiving…forgiveness and acceptance…I can't take back what happens in the womb.

Theme 5: Family Support and Influence

RQ 4: What are the perspectives of African and African American caregivers of social and communication norms of their culture that might influence the delay of identification of their children with ASD?

African American and African caregivers' participants' family members were supportive, but some were hesitant to have their child labeled. Initially family members may have believed their child needed more attention or discipline while being invested in child's care. The following transcript excerpts are examples of caregiver responses assigned to the code: *family influence*.

African American Caregiver 2 responded with the following:

> Yeah, so I have older son who he was diagnosed with ADHD when he was 17, so it was really really late, and I remember, you know I was a young mother with him, and I remember being told like you know you have black sons. Don't get them tested, they're just gonna put them in special education. Don't do it.

The following transcript excerpts are examples of caregiver responses assigned to the code *need more attention*:

> But it was more like, you know, just give him more attention or just be stricter or just, you know, so be stricter…she [caregiver's mother] was like you're gonna keep taking her to the doctor and they're gonna start writing that stuff down. She

> [caregiver's mother] just figured you know she [her child with ASD] was like different…we can address them [referring to child's behaviors] at home.

Caregivers reported family members expressed relief to know what was going on and have an explanation for their child's behaviors once their children were officially diagnosed. The following transcript excerpts are examples of caregiver responses assigned to the code: family support. African American Caregivers 1 stated, "everybody was really invested in what's going on with [child's name] …. And what do we need to do as a as a team." Finally, African American Caregiver 4 reflected that, "the village is big and wide."

A final interview question addressing the research question of social and communication norms influencing delay of ASD identification was "What else can you share with me about the process and the time it took to have your child identified with ASD?" This question was developed to find out were there any cultural constructs not addressed in previous interview questions that the caregiver participants may have found influential in the delay in their child's identification of ASD.

Theme 6: Perceived Racial Bias

African American caregivers expressed a perspective that inherent racism played a part as professionals perceived child as bad or with ADHD. The following excerpts generated codes *racial bias and perceived bias* from which the theme emerged. African American Caregiver 3 noted the following:

> I notice is that a lot I think especially with our [i.e. Black] children I think they get blown over or glossed over and behavior issues that they leave they would

> consider as problematic in school they think is they don't look at that it may be connected to something like autism … they just make them behavior issues, we've lived in areas that … were primarily white, I have to come in there with all my education showing for them to listen to me because they will they have a tendency to try to not listen to me as much even in schools that are that you know, my son primarily goes to schools that are either multicultural or more Black and they listen better.

African American Caregiver 1 also noted,

> He saw a pediatric neurologist for two years before he was diagnosed. We were in Alaska and there were not very many of people of color**…** if maybe. that had something to do with, like, I don't I don't know. I hate to say that that would be it.

Noting the impact of race, African American Caregiver 2 commented,

> I feel like with Black children, especially black boys, it's like, oh they're just, bad and so I feel like he would have been identified as being autistic much sooner if it wasn't just like oh, he's just bad.

One of the caregivers explained due to her experience as a child with racism she was hesitant to have her child assessed due to fear of having child misdiagnosed or pigeonholed in a special education class. The following were assigned code- perceived bias.

> [I live] in one or more racist counties, if there are and my experience… with racism I felt… long standing resentment… and her father is like you're allowing your resentment to what this lady did to you to to rub into what this teacher,

> maybe you know, may or may not be doing with our daughter (perception of racism) you know the consensus was, as with all of us, is that you know we want the best for her and whatever that's best.

Summary

The chapter discussed the setting participant demographics, data collection, data analysis, evidence of trustworthiness and the results of the study. The purpose of this ethnographic study was to explore the ramifications of cultural constructs, understandings of child development, ASD concerns and symptom presentations, religious beliefs, and fears of stigma on the delayed identification of ASD in children, from the perspectives of their African and African American caregivers. Seven caregivers participated in the study and responded to interview questions that were formulated to answer research questions developed within Bronfenbrenner's ecological theoretical framework. Six themes that were generated were consistent with the cultural constructs explored in identifying the disorder as influential in the ASD identification process emerged: 1) Caregivers knowledge of ASD symptoms, 2) Healthcare and educational professionals' knowledge of ASD 3) Religious/ cultural/ traditional belief influence, 4) Stigma, and shame Influence, 5) Family support Influence, and 6) Perceived bias Influence. Discussed in this chapter was how data was collected, coded, and analyzed. In Chapter 5, I discuss the research findings within the theoretical framework, and existing literature. I make recommendations for further research after discussing the limitations of the current study. In conclusion, I provide a statement on social change relative to this study.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this ethnographic study was to explore the ramifications of cultural constructs, understandings of child development, ASD concerns and symptom presentations, religious beliefs, and fears of stigma on the delayed identification of ASD in children, from the perspectives of their African and African American caregivers. The nature of this study was qualitative, and I utilized an ethnographic paradigm design. I conducted interviews and observed online interactions to explore the perceptions of African American and African caregivers of children with autism whose identification with the disorder was delayed. The research problem was the disparities and delays in the identification and diagnosis of ASD in African American and African children as compared to children of other ethnic and cultural groups. The delays and disparities in identification are consequential for the future of those children. A gap in the literature existed of perspectives of African and African American caregivers of children with autism. The key findings from this study were there are ramifications of the cultural constructs explored in this study that are influential in the delay in identifying African and African American children with ASD.

Interpretation of the Findings

The data gathered overall fit with the existing literature discussed in this study. The caregiver participants' children were identified with ASD after the age of six. As researchers in a conference on autism in Africa recognized in 2014 (Ruparelia et al.

2014), the African participants in this study, as well as those who responded but did not participate, expressed a lack of understanding or acceptance of autism as a disorder.

Caregiver Knowledge of ASD:

The data gathered fit the previous literature (Pearson & Meadan, 2018) that African American caregivers needed more knowledge of ASD and its symptom presentations. The caregiver participants noticed different behaviors and developmental language delays but did not initially relate them to a disorder.

Healthcare and Educational Professionals' Knowledge of ASD:

As with Pearson and Meadan's (2018) study, this research also found caregivers perceived health care professionals' lack of knowledge of ASD symptom presentations as delayed identification as well.

Religious, Cultural, and Traditional Beliefs and Influences:

In contrast to reviewed literature (Burkett et al. 2015), the African American caregiver participants of this study denied that religious beliefs were influential when their child was identified with autism. The African American caregivers perceived culture as more influential than religion in the delay of ASD identification. There was the awareness expressed by one of the African participant caregivers, however, that family members may believe that God had something to do with their child having ASD.

Stigma and Shame Influence:

Fear of stigma was found in both African American and African caregivers in this study and the research reviewed (Burkett et al. 2015, Dababnah et al. 2015). Counter to or in addition to influences, this study found that some caregivers blamed themselves for their child’s disorder coupled with the shame as discussed in previous literature (Dababnah et al. 2015).

Family Support Influence

As Lovelace et al. (2018) found, African American caregivers in this study hesitated to label their children based on cultural tenets.

Perceived Bias Influence

This study agreed with research that found African American caregivers were concerned with protecting their children from racism (Donohue et al. 2019). There were participants who perceived racial bias and hesitated to have their child labeled with any disorder. One caregiver participant expressed concern that an educator trying to inform them of the possibility of ASD may be motivated by racial bias.

Theoretical Implications

The theoretical framework used as the basis was Bronfenbrenner's bioecological developmental theory, which was chosen because it considers the child within a cultural context. Bronfenbrenner postulates in his theory that development is influenced by process, characteristics of the person, contexts of micro, macro, meso, and exosystem, and time. Just as the research by Mabhoyi and Seroto (2019) of at-risk students in Zimbabwe, South Africa, which was informed by Bronfenbrenner's ecological systems theory, this study’s findings showed that family support and larger systematic factors influenced the development of and identification of ASD.

The phenomenon of delay in the identification of ASD from both the cultural perspective and the experiences in particular societies (Norbury & Sparks, 2012) was explored as it fits the theoretical framework of the bioecological theory. The theory provided insight into the process across a cultural lens with an awareness of the bio-ecological influences (Newman & Newman, 2016). The current research explored how for the caregiver, culturally based perspectives and concerns of ASD were developed within the micro, meso, macro, and exosystem and time, and have influenced timeliness in the identification and diagnosis of African and African American children.

Microsystem

The microsystem is the system where a developing person is experiencing and perceiving the setting and themselves in their family, school, social or religious group (Newman & Newman, 2007). The study findings were that delayed identification of ASD was greatly influenced by the culture the child’s family lived within. The caregivers had some awareness of autism, but it was limited to movies or specific behaviors widely known as autistic, such as lack of eye contact. An African caregiver interviewed for the study shared that many elders viewed the disorder as the result of God not being happy with them or of past behaviors. Despite an African caregiver being very aware that she was not at fault for her child’s disorder, she still felt the need to forgive herself for whatever may have happened in the womb. Self-blame was also expressed amongst African American caregivers before they interacted with systems outside the home.

The findings from the literature review were also supported in this study and were similar to a study on the behavioral differences of cultural expression in play, language, eye contact, facial expression, and recognition (Harrison et al. 2017). Harrison et al. (2017) found that African American parents of children with ASD may not be as concerned with behaviors initially when the communication practices fit within cultural norms within the microsystem, i.e., immediate family system. A child playing independently, affectionately, and with some eye contact would not be very concerning until the realization that lack of verbalization or social interactions with others were problematic. Two of the caregivers described their children pointing or taking them to the object they wanted rather than verbalizing. The study revealed that due to cultural norms, within microsystems, family members encourage more discipline and attention to manage behaviors, rather than the awareness that the behaviors may be neurologically based and an indication of a disorder. Two caregivers discussed their child having a meltdown when having to make transitions, and that the behaviors were initially viewed as defiant.

Mesosystem

The mesosystem is the interrelationship between microsystem settings as the developing person moves between two or more settings. Activities in one setting can impact experiences in another setting (Newman & Newman, 2007). Once the child and caregivers interacted outside the family system or culture, and the child interacted with others, they began seeking answers and understanding of what was going on with their child. In schools, the identification process began for the children identified with ASD. This revelation from the participants supports the problem explored in this study that African American children are identified many years later than their white counterparts, who are diagnosed more than two years earlier (Bello-Mojeed et al. 2017; Burkett et al. 2015; Wannenburg & van Niekerk. 2018). In two instances, the children were initially misdiagnosed with ADHD and perceived as having behavior problems or described as "bad," further delaying the proper diagnosis and treatment. One of the children was not properly diagnosed until 14 years old. When caregivers were willing to seek help for their child, the interactions with outside agencies, schools, and programs, were still partially impeded due to a lack of professional knowledge and perceived racial bias.

Macrosystem

The macrosystem is the ideologies, belief systems, subculture, culture that the micro, meso, and exosystem consist of (Newman & Newman, 2007). The macrosystem in the United States where a history of racism and bias exists impacted the process of identification of ASD as perceived and expressed by the caregivers that participated in this study as well as those in Africa that declined to participate. One caregiver related that her experiences as a child with racism delayed her getting help from professionals in her child's school district due to fear that labeling her child could be an act of racism. She perceived bias or racism due to her past experiences and not because it was occurring and delayed having her child identified for that reason.

More than one caregiver agreed with the literature review findings that African American children's ASD symptom presentations are initially seen as "bad". The study revealed that even if Western researchers may have intentions of assisting and helping children with ASD, African and African American experiences and perception that they may be victims of bias contributes to their hesitancy in seeking a diagnosis. One caregiver had to be convinced by a coworker and another by their father to not allow their past experiences with racism to delay getting help for their child.

Exosystem/Time

In the exosystem, the developing person is not an active participant but is affected by that setting, such as a child being indirectly affected by a parent's workplace (Newman & Newman, 2007). The background or educational, and governmental systems were influential as caregiver participants relayed that to get help and assistance from systems required the child be identified, labeled, and diagnosed. The caregivers' fear of stigma or pigeonholing their child into a special education system and that they're not reaching full potential was found to be an influence on the timeliness of ASD identification.

Time was influential in the identification of children with ASD. When the children aged and it became more evident that milestones were not being reached, interactions and behaviors were different or odd, caregivers became motivated to seek help to address their concerns.

Limitations of Study

The findings of the study are not generalizable. A qualitative study is an exploration of the participant group. The Covid epidemic limited recruitment to online social media sites and websites. I was not able to recruit the number of African caregivers proposed despite contacting and posting flyers on 15 websites and social media pages that were African based. Respondents did offer their perspectives on Western practices and their hesitancy to participate in studies on Autism. 14 caregivers from Africa responded but did not fit the criteria for age of child diagnoses or did not want to have their child diagnosed or characterized as having a disorder and discussed in Western studies. The literature review discussed a self-advocacy movement that Autism is an identity of neurodiversity and not a disorder in need of a cure. A respondent from Africa declined participation due to the perception that being Autistic is an identity and not agreeing with their child being referred to as having a disorder as described in the recruitment flyer.

One respondent from Africa declined to participate in the study, expressed distrust of academics researching Africans with ASD due to “not getting anything in return”, and not wanting to be exploited or studied as an “other”. Another African respondent said they felt western researchers (i.e., white) were seeking to come to Africa and do to them what had been done to African American children by labeling them and doing “dog training” (aka ABA) treatment on them. Even after explaining I was an African American researcher, it was implied that I was a tool of white western society.

The study results, therefore, are primarily of the perspectives of the constructs by African American caregiver participants whose children’s identification with the disorder was delayed by several years. Additional African Americans responded to the study not included in results as their children were identified at four years old, still later than white children, but did not fit the criteria of diagnosis after age 6. Another study limitation is I was able to observe interactions online but could not include those observations without the consent of the group members which was not received, and study participants did not send me their online interactions as requested. Thus, the data and results of the study are based on data collected from the interviews. Despite the limitations, the results were consistent with findings in previous related studies discussed in the literature review and identified the additional perspectives that racial bias and self-blame are influential in the delay in identification of African and African American children with ASD.

Recommendations

Further studies utilizing more in-person interviews or focus groups on Africa and the United States, would allow for a more expansive ethnographic methodology. The methodology would be beneficial in exploring the cultural constructs that delay the identification of children with ASD and would be more culturally sensitive increasing trust and transparency.

Another recommendation is the conduction of a quantitative study that could enumerate and provide analysis of the cultural factors contributing to the delay in identification of ASD in African and African American children and may illuminate and expand understanding of the delay phenomena.

Implications

Social Change

The findings of this study contribute to social change by illustrating and reinforcing earlier literature (Clark et al. 2018), that early identification and culturally sensitive appropriate intervention in both cultural groups could contribute to improved social and academic long-term functioning in the futures of African and African American children. Reinforced by the findings of this study was the utilization of Bronfenbrenner’s theory as a framework to develop future research as appropriate as systems influence the development of children with ASD. Although the observations of social media were not able to be included in this study, the participants were recruited from online support groups for parents of children with ASD. The implications are that media is influential in the distribution of knowledge of ASD. As one of the African caregivers related, she will be using social media to influence and educate her elders and other members of her family in Africa by talking about her child's challenges with ASD and encouraging early intervention, which could contribute to social change in her community.

Identified and reinforced by this study is existing literature (Pearson & Meadan, 2018) findings that health care professionals and educators may not recognize ASD symptom presentations, especially in African American children coupled with caregiver's lack of knowledge of ASD symptom presentation. Although behaviors and delays were noticed before children entered school, the children were not formally identified and diagnosed until entering school. A social change practice recommendation is to provide training and information to early childhood educators, pediatricians as well to both cultural groups at earlier ages during pregnancy, well-baby visits to pediatricians, and available at childcare centers in communities of color.

Conclusion

The ramifications of cultural constructs, understandings of child development, ASD concerns and symptom presentations, religious beliefs, and fears of stigma on the delayed identification of ASD in children, from the perspectives of their African and African American caregivers was explored in this study.

The findings that African and African American children with ASD are identified later than their white counterparts were identified in this study. The cultural constructs:

fear of stigma, perception of bias, influenced the delay in identifying African and African American children with ASD according to the caregiver participants in this study.

The strongest influence of the cultural constructs was the finding that improving caregivers and health care professionals' knowledge of ASD symptoms presentation in identifying African and African American children with ASD earlier would be beneficial in addressing the delays in diagnosis.

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Appendix A: Invitation Flyer

RESEARCH PARTICIPANTS NEEDED

Are you an African or African American caregiver of a child with autism living in rural or suburban areas in the United States or a West African country? To participate in this study, you should be fluent in English, at least 25 years old and a family member caregiver of a child who was at least 6 years of age when identified with autism spectrum disorder.

If so, please contact:

Deirdre Johnson-Taylor

Walden University Doctoral Candidate

912-332-3011 or deirdre.johnson-taylor@waldenu.edu

Your participation in her research will assist in achieving the study's purpose to explore caregivers' perspectives on cultural influencers that may have contributed to the delay in the process of identifying African and African American children with Autism.

Thank You!

Appendix B: Demographic/Criterion Questionnaire

Code: ____

Phone #____

Email address: _______________________________________

Date:

Caregiver Name and Date of Birth:

____

Age child was identified with Autism Spectrum disorder _______.

Who identified child with Autism Spectrum Disorder___________

What is you and your child’s place of birth and current

state/country_______________.

What is your ethnicity, nationality? __________________________.

Appendix C: Interview Questions

1. Before your child was identified with ASD what did you know about the disorder

2. Can you describe how you felt or thought about your child's behaviors before you learned they were symptoms of ASD?

3. What were the concerns about your child that influenced you to seek out help and have your child identified with ASD? What were some of those behaviors or concerns?

(RQ 1**.** Addressing caregiver perceptions of ASD symptom presentations).

4. How did you feel or think about when your child walked or talked before, he or she was identified with ASD?

(RQ 1**.** Addressing caregiver perceptions of ASD symptom presentations and knowledge of child development).

5. Do you think there were some ways your family's or community's religious beliefs may have influenced when your child was identified with ASD? If so, can you give examples?

(RQ 2 Addressing perceptions of religious or cultural traditions).

6. Did your religion or spiritual beliefs influence when your child was identified with ASD? If so, in what ways?

(RQ 2 Addressing perceptions of religious or cultural traditions).

7. Can you give examples if you think there were some family or community traditions that may have influenced when your child was identified with ASD?

(RQ 2 Addressing perceptions of religious or cultural traditions).

8.Do you have the fear of stigma or shame that may have influenced when your child was identified with ASD?

(RQ 3 Addressing perceptions of fear of stigma in the culture)

9. What were some family values or normal cultural practices that may have influenced when was your child identified with ASD? Can you describe?

(RQ4, Addressing perceptions of social-cultural norms)

10. What were the reactions from family members, community members, educators or others when you shared that your child had been identified with ASD?

11. What else can you share with me about the process and the time it took to have your child identified with ASD?