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Lived Experiences of Mothers Raising Children with Autism Spectrum Disorder in Nigeria

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Abstract

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Abstract

Autism has no cure, but early and appropriate diagnosis and intervention may increase outcomes for individuals affected. The level of awareness, acceptance, and support for autism spectrum disorder (ASD) in Nigeria is very low. There is a gap in the literature regarding a detailed account of the experiences of parents raising children with ASD within the Nigerian environment and culture. The purpose of this phenomenological study was to explore the perceptions and lived experiences of mothers raising children with ASD in Nigeria including the impact of Nigerian culture on their experiences. Bronfenbrenner’s ecological systems theory was the guiding conceptual framework for this study. Ten mothers of children with autism were recruited through purposeful sampling and interviewed using a semistructured interview format. Moustakas’s steps to phenomenological research analysis were used to analyze the data and report emergent themes. The 8 themes that emerged from the data were low societal awareness about ASD, cultural attitudes and acceptance about ASD, neglect and abuse, inadequate services, impact on parents and other family members, refusing to be isolated by society, nature of support, and the way forward. The findings of this study can contribute to ASD awareness in Nigeria through the experiences reported. Positive social change may result from this increased awareness including improved acceptance and treatment, and policy changes or service improvements to support families living with this disorder in Nigeria.

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Dedication

I dedicate this study to my loving husband, Oke, who supported and believed in me even when I felt I could not take one more step. I also dedicate this journey to my five great sons, Justin, Jeffrey, Joshua, Jeremy, and Jacob, who remained patient and understanding when mom needed to spend so much time on her computer and away from family events. I love you, and all your sacrifices and support throughout this long journey kept me going. To my very special nephew and godson, Eamon, whose life inspired my topic, I love you.

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Chapter 1: Introduction to the Study

Introduction

Autism spectrum disorder (ASD) is a permanent condition affecting many children and families around the world. In Nigeria, ASD affects about 200,000 to 380,000 families and is regarded as one of the top three disorders affecting children in the country (U.S. Diplomatic Mission Nigeria, 2015). While concerns over the increasing rate of the disorder in some countries has prompted attempts to improve the wellbeing of individuals affected by autism, in Nigeria the cause of the disorder is attributed to poor parenting and supernatural forces, and consequently, unconventional methods are used to treat the disorder (Frank-Briggs, 2012; Nwokolo, 2010). Nigeria has a high level of ignorance and superstitious beliefs about mental or developmental illness. Contrary opinions and beliefs about ASD in this society may be influencing the level of awareness, acceptance, and support for persons affected by the disease (Bakare et al., 2009). Children and families living with ASD in Nigeria are rejected, discriminated against, stigmatized, and associated with evil, thereby leading to their victimization and abuse (Brandwork Nigeria, 2015; Ojo, 2015). Despite some parents’ early observations of developmental issues in their children, identification and diagnosis of ASD among African children occurs late due to poor knowledge, negative cultural beliefs and attitudes, difficulties in getting help, and lack of qualified professionals and centers for treatment (Bakare, 2014). In order to improve the current situation of ASD in Africa it is crucial to address the factors that hinder its treatment and management (Bakare, 2014).

The lack of treatment and support programs for ASD in Nigeria constitutes a huge burden for families affected by the disorder. Some families with financial privileges go outside the country to get help for their children's condition, while others without such benefits have nowhere to turn for support in Nigeria (College of Medicine, University of Lagos [CMUL], 2014). Parents and caregivers of children with ASD in Nigeria have reported psychological distress associated with caring for a child with ASD (CMUL, 2014). Some parents in Nigeria have reported having to pull their children from public schools, and some have quit their jobs to care for the children (Brandwork Nigeria, 2015). Many parents have also expressed feelings of hopelessness about the situation (Brandwork Nigeria, 2015). One parent in Nigeria described managing a child with ASD as a very slow, difficult, and exhaustive process (Ayansina, 2015).

The Nigerian government is yet to acknowledge ASD as a disability requiring special treatment and has made no special programs or accommodations available to individuals and families affected by the disorder (Nwokolo, 2010). The lack of understanding and poor level of awareness about the disorder negatively impacts families and deprives them of needed support and services (Nwokolo, 2010). There is a great need to increase autism awareness in Nigeria to attract attention and policy changes that will improve the lives of the many families affected by the disorder (Nwokolo, 2010). In July 2015, the U.S. ambassador to Nigeria urged for an improvement in the Nigerian public's awareness of ASD, changes in policies, and better support for individuals and families living with the disorder (U.S. Diplomatic Mission Nigeria, 2015). Individuals affected by ASD deserve respect and better treatment from the society, and increasing social awareness of the disorder is an important step toward better treatment for these individuals and their families (U.S. Diplomatic Mission Nigeria, 2015). Instead of disdain and blame, children with ASD in Nigeria and their families would greatly benefit from the society's support in order to improve their prognosis and lives (Yesufu, 2015).

Increasing the understanding of ASD within different cultural settings is significant to positive outcomes in the lives of individuals affected (Alqahtani, 2012; Kang-Yi, 2013; Ravindran & Myers, 2012). According to Bronfenbrenner's (1977) ecological systems theory (EST), individuals' dwelling environments significantly impact their development and experiences throughout the lifespan. Bronfenbrenner believed that the social and physical environment surrounding individuals influences their functioning and behavior (Thomas, 2014). However, despite the situation of ASD in Nigeria and the high need for more awareness to improve lives for individuals affected, there is a dearth of qualitative literature detailing the experiences of parents raising children with ASD within the Nigerian culture. Therefore, my primary goal with this study was to gain information about how families of children with ASD in Nigeria cope with the disorder by exploring the lived experiences of mothers raising children with ASD in Nigeria. Findings from this study also filled the gap in the literature.

In this study, I investigated the influence of the Nigerian culture and environment on the experiences of mothers of children with ASD. The positive social change implications of this study include contributing to ASD awareness in Nigeria and increasing knowledge and understandings about the effects of negative beliefs and opinions about ASD on parental experiences. Results from the study could also be used to advocate for policies and programs that may improve services and treatment of those affected by the disorder. Furthermore, the findings from this study add to the existing body of literature on the role of culture in ASD and increase knowledge of how different factors at all levels of an environment affect the experiences of families affected by ASD (Bernier et al., 2010). Another implication for social change that could result from this study was that increasing understanding of the lived experiences of mothers raising children with ASD in Nigeria would help clinicians and other providers working with such families to be aware and sensitive and to provide better care to these families.

In this chapter, I will provide information on the background for this study, the identified problem that was addressed with this study, the purpose of the study, and the research questions that I used to address the problem identified. Information about the conceptual framework, nature, and significance of the study to existing knowledge and practice will also be provided. Also included in this chapter will be definitions of key terms in the study, discussions of assumptions, scope and delimitations, and limitations of the study. At the end of the chapter, I will provide an overall summary and a transition to the following chapters of the study.

Background

Several studies have highlighted the significance of raising awareness about ASD to improve diagnosis and treatment of the disorder as well as improve outcomes for individuals and families affected (Fernell, Eriksson, & Gillbery, 2013; Hartley-McAndre, Doody, & Mertz, 2014). Lagunju, Bella-Awusah and Omigbodun (2014) reported that some of the challenges to the management of ASD in Nigeria include low awareness and understanding, delayed diagnosis, lack of structured health-care or supportive services, and lack of special education programs. Lagunju et al. also highlighted that increasing public awareness and creating special programs will help improve the condition of families of children living with the disorder in Nigeria. In Nigeria, the level of awareness and understanding about ASD is low among healthcare workers, teachers, and the general public (Eseigbe et al., 2015; Igwe, Bakare, Agomoh, Onyeama, & Okonkwo, 2010; Igwe, Ahanotu, Bakare, Achor, and Igwe., 2011; Paul & Gabriel-Brisibe, 2015). Poor beliefs and opinions about the disorder in Nigeria negatively impact the acceptance and support available for individuals and families living with ASD in this community (Audu & Egbochiku, 2010; Bakare et al., 2009; Bakare & Munir, 2011b). Okandeji-Barry, Agofure, and Garba (2015) assessed ASD knowledge among mothers in Delta state, Nigeria and reported that most of the participants had poor knowledge and negative attitudes towards children affected with the disorder and their mothers.

Bello-Mojeed, Omigbodun, Ogun, Adewuya, and Adedokun (2013) provided information about ASD and how the associated limitations of knowledge greatly impact the health and psychosocial wellbeing of mothers in Nigeria caring for children affected with the disorder. Bello-Mojeed et al. claimed that apart from the psychosocial burden to families there is also the physical burden of the disorder that is brought on by the lack of facilities or services to provide relief to families. Increasing healthcare staffs' awareness about the health and psychosocial impact of the disorder on caregivers may help improve services (Bello-Mojeed et al, 2013). Nwanze (2012) reported that in urban areas of Nigeria most parents rely on schools or paid caregivers to care for their children while they work; however, for children with challenging behaviors such as those associated with ASD, parents struggle to find care providers who would agree to care for their children, and in most cases mothers end up leaving their jobs to care for their children. According to Nwanze, the scarcity of qualified staff and programs to assist families affected by ASD poses challenges to the management of the disorder in Nigeria. These include financial and emotional challenges, a negative impact on the marriage of the parents of children with ASD in Nigeria, and maltreatment or harm to the children with ASD (Nwanze, 2012). There is a critical need for more studies on ASD in Nigeria to increase awareness and improve treatment and services for those affected (Nwanze, 2012).

Lesi et al. (2014) also reported that due to the scarcity of studies and knowledge about ASD in Nigeria, individuals with the disorder and their families face financial, social, emotional, and health burdens associated with the condition. Parents of children with ASD and other intellectual disabilities in Nigeria are distressed over the lack of awareness and support for ASD in Nigeria (Ajuwon & Brown, 2012). Therefore, there is need for more research on ASD to improve awareness, effect policy changes, and improve the situation of ASD in Nigeria (Ajuwon & Brown, 2012; Lesi et al., 2014).

These negative effects of the disorder on the family can in turn negatively impact children with ASD and result in a negative feedback loop that may hinder positive outcomes. Therefore, treatment evaluation designs for ASD should consider symptoms/diagnosis and functioning of children and families, as well as their points of view, environments, and interacting systems (Karst & Van Hecke, 2012). Due to the severe and extensive negative impacts ASD can have on different aspects of a family's life and functioning, it is crucial to include parents and families when assessing and planning interventions for individuals diagnosed with ASD to increase positive outcomes (Karst & Van Hecke, 2012).

Researchers have suggested that culture plays a critical role in the diagnosis and management of ASD, yet there is a dearth of studies that focus on the disorder from the perspective of different cultures (Elsabbagh et al., 2012; Kang Yi, 2013; Ravindran & Myers, 2012). There is a gap in the literature regarding how parents in Nigeria describe their experiences of raising children with ASD within the Nigerian environment and culture. Also, considering the significance of understanding ASD within different cultural contexts, an in-depth account of how mothers of children with ASD in Nigeria describe the influence of cultural factors on their experience will be a significant contribution to the literature. Results of this study may contribute to ASD knowledge and improve public acceptance and support for those affected by ASD in Nigeria. The results may also increase healthcare providers' understanding and sensitivity to the experiences of families affected by the disorder and lead to better services for these families.

Problem Statement

ASD has lifelong effects on the lives of individuals diagnosed with the disorder and the lives of their families, but early detection and intervention may help improve lives and prognosis for those affected (Hall & Graff, 2011; Igwe et al., 2011). Around the globe, the rate of diagnoses of the disorder is on a steady rise, possibly due to the increase in awareness, quality screening tools, better reporting, and availability of services for individuals with the disorder (Mori et al., 2009; World Health Organization [WHO], 2013). However, in Nigeria there is a low level of awareness and support for individuals with ASD and their families (Bakare et al., 2009; Igwe et al., 2011). Even parents, teachers, and healthcare workers do not have the knowledge to respond appropriately to individuals affected with ASD (Igwe et al., 2011; Okandeji-Barry et al., 2015). The negative perceptions and beliefs about ASD and other developmental disorders in Nigeria influence the levels of awareness and support for the disease (Bakare et al., 2009). Parents in this society delay in presenting their children with ASD to clinical settings, thereby delaying appropriate diagnosis and interventions (Bakare & Munir, 2011b). Parents of children living with ASD in Nigeria experience physical, psychological, social, and financial struggles due to the lack of awareness and support for the disorder in Nigeria (Ajuwon & Brown, 2012; Bello-Mojeed et al., 2013; Lesi et al., 2014). Yet, there is a scarcity of scholarly information that has examined parents' experiences in raising children with ASD in Nigeria.

Purpose of the Study

The purpose of this qualitative, transcendental phenomenological study was to explore the perceptions and lived experiences of mothers raising children with ASD in Nigeria. My goal with this study was to increase understanding of how negative opinions and beliefs about ASD within the Nigerian culture and environment impact the experiences of mothers of children with ASD. I explored the perceptions and experiences of 10 mothers of children with ASD in Nigeria to understand their experiences of what it means to raise a child with ASD in this community. In this study, I focused on mothers because in the Nigerian culture mothers are mostly responsible for the daily care of children with disabilities (Bello-Mojeed & Bakare, 2013). The findings from the study will contribute to the understanding of ASD within the Nigerian cultural setting and perhaps, help to improve the level of acceptance, sensitivity, treatment, and support for individuals affected by ASD.

Research Questions

The main question that guided this study was: What are the lived experiences of mothers in Nigeria raising children with ASD? Secondary questions that I explored within this study were: How do mothers in Nigeria describe the physical, psychological, social, and economic impact of raising a child with ASD? How do mothers raising children with ASD in Nigeria describe the impact of the Nigerian culture on their experiences?

Conceptual Framework

The conceptual framework that guided this study was Bronfenbrenner’s (1977) EST. According to this theory, the lifelong development and functioning of an individual is influenced by four connected environmental systems with the individual existing at the center (Shogren, 2013). The four systems include (a) the microsystem, the individual’s primary environment that consists of elements such as the family, friends, school, and church; (b) the mesosystem,- which involves the interconnections between the microsystems (e.g., a connection between the individual’s family and church or family and school); (c) the exosystem, the interaction and processes of two or more social settings that indirectly impact the individual (e.g., the person’s neighborhood or governmental agencies); and (d) the macrosystem, which is comprised of the individual’s cultural environment, including customs, beliefs, social systems, and resources (Bronfenbrenner, 1997).

The EST was applicable to the research questions that guided this study because the theory focuses on understanding human development and functioning within the context of the individual human environment. I used this framework as the guiding lens in this study to explore the lived experiences of mothers raising children with ASD in Nigeria to understand how interactions, processes, and systems in this environment influence their experiences. More information about Bronfenbrenner’s EST will be provided in Chapter 2.

Nature of the Study

Based on the identified problem, purpose, and research questions of this study, I used a qualitative, transcendental phenomenological approach to explore and understand the experiences of mothers raising children with ASD in Nigeria. Qualitative research gathers quality and comprehensive information about an issue from a small number of participants who have personally experienced or lived the issue (Patton, 2002). A qualitative method provided me with the approach to gather detailed information from mothers regarding their feelings and experiences of raising a child with ASD in Nigeria. This approach provided mothers with an opportunity and a voice to express the everyday experiences and struggles involved in raising a child with ASD within the Nigerian culture. Since the goal of this study was to gather detailed information from those mothers, a phenomenological approach was best suited for the in-depth exploration and details I sought in this study. According to Moerrer-Urdahl and Creswell (2004), a phenomenological approach helps direct the focus of a study on the real experiences of participants while excluding the researcher's reflective interpretation. Therefore, with this approach the focus of the study was on the real perceptions and experiences of mothers raising children with ASD in Nigeria.

In this study, I gathered information from 10 mothers through face-to-face semistructured interviews. The mother participants were required to be living in Nigeria and raising children with ASD in their household. Permission was obtained from participants to audio record the interviews with an efficient recording device. The interview data were then transcribed and analyzed using Moustakas' (1994) steps for phenomenological analysis. I will provide more information about the design and methodology of this study in Chapter 3.

Definitions

I used the following key terms throughout this study; hence, it was necessary to define their meanings in the context of the study:

Autism spectrum disorder (ASD): A group of neurodevelopmental disorders including autistic disorder, Asperger's disorder, pervasive developmental disorder not otherwise specified, Rett's disorder, and childhood disintegrative disorder (National Institute of Mental Health [NIMH], 2011). The disorders are marked by symptoms of repetitive behavior and impairments in communication and social skills (NIMH, 2011).

Culture: The beliefs, attitudes, norms, values, practices, and institutions common to a group of people, that have been passed down from generations to generations (Cohen, 2009).

Nigerian culture: The common values, customs, and belief systems affecting the behavior and way of life of the Nigerian people, which has been passed down from generation to generation (Olatawura, 2010).

Support services: Services to help and improve the life and welfare of children with autism and their families such as special educational, daycare, and therapy services (Maciver et al., 2010).

Assumptions

My goal with this study was to use a phenomenological approach to explore and gather quality information from mothers regarding their true lived experiences raising children with ASD within the Nigeria culture. Since the target population were mothers raising children with ASD in Nigeria, one of my assumptions underlying this study was that as a researcher I would have access to participants who would be willing to share their authentic experiences about the identified phenomenon. Within the context of this study, this assumption was necessary as these specified participants were critical to the purpose of the study. Another of my assumptions was that the mothers recruited as participants would be truthful and honest in their descriptions and disclosures of their lived experience of raising children with ASD within the Nigerian environment and culture. The elements of truthfulness and honesty were necessary to provide a complete picture of the identified issue (Creswell, 2013) and to maintain the quality of the study (Morrow, 2005).

Scope and Delimitations

I used a qualitative design in this study to explore the lived experiences of mothers raising children with ASD in Nigeria. In this study, I focused on mothers because mothers are mostly responsible for the daily care of children with disabilities in the Nigerian culture (see Bello-Mojeed & Bakare, 2013). The scope of this study was limited to 10 participants who were mothers living in Nigeria and raising children with ASD in their household. Using a sample of only 10 participants could limit the transferability of the study's results. These mothers were recruited from established autism organizations in Lagos, Nigeria. I used semistructured open-ended interview questions to gather these mothers' lived experiences of raising children with ASD within the Nigerian environment and culture. Based on the nature of the study, a purposeful sampling strategy was used to select participants for the study.

The boundaries of this study include the participants and the selected location for the study. However, my goal with this study was to increase knowledge of the experiences of raising children with ASD within the Nigerian culture and not transferability of results. Furthermore, since my plan was to recruit only mothers from ASD organizations in Lagos, Nigeria, the general population of parents raising children with ASD in Nigeria may not be appropriately represented by this sample. However, Lagos is a large city in Nigeria with diverse residents from different parts of the country. Therefore, I expected that there would be a diverse group of participants for the study.

Limitations

One limitation of this study was that only mothers raising children with ASD in Nigeria were recruited as participants. Therefore, the results may not be transferable. The limitations of using a phenomenological design in this study included a small sample size, the possibility that participants may not be willing or able to clearly communicate their experiences to the researcher, and the possibility of researcher bias influencing data collection and interpretation (see Creswell, 2013).

As a researcher with a Nigerian background and knowledge of some of the beliefs and opinions of this culture, there could have been personal biases that may have influenced data collection and interpretations. To control for this bias, I was aware of this and took care to stay objective and asked semistructured open-ended questions so participants could provide their responses and express their lived experiences. Other reasonable measures I used to address the limitations in this study included using guiding interview questions, taking down notes during interviews, investing in a good audio device to record interviews, accurate transcription of interview data, and member checking (see Creswell, 2013). I will also provide additional details on the research design and data collection in Chapter 3.

Significance

There is a scarcity of literature on ASD in developing countries (WHO, 2013) including Nigeria. This study was unique because in it I addressed the topic of ASD in a country where little research has focused on it. There are gaps in the literature regarding the in-depth exploration of the experiences of mothers raising children with ASD in

Nigeria from an ecological systems perspective and a qualitative understanding of ASD within the context of Nigerian culture. In this study, I used a phenomenological approach to explore the experiences of mothers raising children with ASD in Nigeria. In this study, I was the first to examine how cultural beliefs and opinions about ASD in Nigeria impacts mothers of children with ASD; therefore, the results of this study may be a significant addition to the culturally-based literature on ASD and increase the existing body of research regarding the role of culture in ASD perceptions, treatment, and experiences. Healthcare professionals may also better understand and respect the influence of culture on the experiences of families of children with ASD in Nigeria and incorporate this into treatment planning for these families (see Ravindran & Meyers, 2012).

Positive Social Change Implications

The positive social change implications of this study are that results from this study will contribute to ASD awareness in Nigeria. Also, the findings from the study could lead to increased understanding of the situation of individuals with ASD and their parents. This knowledge may be used to advocate that the public, healthcare providers, teachers, and even the government be more sensitive, accepting, and supportive in their dealings with all those affected by the disorder. Results from the study could also address mothers’ dissatisfaction with the situation of ASD in Nigeria and motivate them to advocate for changes in policies and laws that would impact positive social change for their children and their families.

Summary

In this study, I explored the experiences and perceptions of mothers raising children with ASD in Nigeria. This chapter covered the background information supporting the need to fill the gap in the literature. A gap was identified regarding qualitative research detailing the experiences of mothers raising children with ASD within the Nigerian culture. The conceptual framework that was used to ground this study was Bronfenbrenner’s (1977) EST. My goal with this study was to increase understanding regarding the impact of cultural opinions and beliefs about ASD in Nigeria on the experiences of mothers raising children with the disorder and increase understanding of the situation of ASD within the context of Nigerian culture. The primary research question that I used to guide this exploration study was: What are the lived experiences of mothers in Nigeria raising children with ASD? Secondary questions explored in this study were: How do mothers in Nigeria describe the physical, psychological, social, and economic impact of raising a child with ASD? How do mothers raising children with ASD in Nigeria describe the impact of the Nigerian culture on their experiences?

In this phenomenological study, I used a semistructured interview to collect the experiences of 10 mothers of children with ASD in Lagos, Nigeria. I assumed that there would be access to participants able and willing to share their experiences with the identified issue in an honest and truthful manner. The small number of participants and the focus on one region of Nigeria (Lagos) bound this study. The limitations anticipated in the study included a small sample size, biases in data collection and interpretation, the direct nature of information, and the possibility that participants may not be able to express their experiences clearly.

The study is significant because it will increase ASD awareness in Nigeria, contribute to literature on ASD in the context of Nigeria culture, add to the body of culturally based research on ASD, and provide valuable information for providers to better work with families affected by the disorder in Nigeria. Results from the study could also be used to advocate for changes in policies and laws in Nigeria that would impact positive social change for individuals affected by ASD. An increased awareness and understanding about ASD could help healthcare providers and others in the public to be more sensitive, accepting, and supportive in their dealings with people affected by the disorder.

In Chapter 2, I will provide information on Bronfenbrenner’s (1977) EST and how it has been applied in previous research to examine the relationship between humans and environmental systems impacting them. I will also review the current literature on ASD, ASD awareness, and ASD awareness in Nigeria. The literature on the relationship between ASD and parents, the relationship between ASD and culture, and ASD in Nigeria will also be reviewed. Finally, I will provide support for the existence of a gap in the literature regarding the lack of qualitative research on the experiences of parents raising children with ASD in Nigeria and the need for more research to focus on the influence of different cultures on ASD.

Chapter 2: Literature Review

Introduction

ASD exists worldwide and raising a child with the disorder can exert a lot of strain on every aspect of a parent’s life. Evidence suggests that parents of children with ASD experience a great amount of psychological distress as a result of their children’s autism condition (Firth & Dryer, 2013; Hall & Graff, 2011; Mount & Dillon, 2014). The prevalence of ASD is on the rise and studies carried out in developed Western countries have helped to increase awareness and support for those affected by the disorder; however, in Nigeria the awareness of ASD and the acceptance and support for those affected is still low (Igwe, Ahanotu, Bakare, Achor, & Igwe, 2011). The purpose of this study was to explore the lived experiences of mothers raising children with ASD in Nigeria. In this study, I examined the impact of the Nigerian culture and social environment on the experiences of mothers raising children with ASD. My goal was to gather empirical data that would contribute to awareness of ASD and how negative opinions and beliefs about ASD in Nigeria impact the experiences of Nigerian mothers of children with ASD. A further goal was to use information gained from this study to improve acceptance, support, and better treatment of those affected by ASD.

This chapter will contain my review of the literature used for this study. The literature on ASD and awareness and knowledge of ASD, including awareness among the general public, healthcare providers, teachers, and parents or caregivers in Nigeria, will be reviewed. In the chapter, I will then examine the literature on outcomes for parents caring for children with ASD, cultural perspectives regarding ASD, and knowledge of

ASD in Nigeria. The chapter will end with an overall summary of the key findings from the literature reviewed and a transition to the next chapter on the research methodology for this study.

Literature Search Strategy

The research strategy I used to gather sources for this review included an exhaustive search of sources using the Walden University online library, the Internet, and Google Scholar. Articles were accessed using several databases including PsycINFO, ProQuest Dissertations & Theses, PsycArticles, PsycBooks, ERIC, SocINDEX, EBSCOhost, SAGE, and Academic Search Premier. Keywords that I used in the search included *autism, autism awareness, autism and parental stress, parents and autism, community, culture, society, ecological systems theory, Urie Bronfenbrenner, Bronfenbrenner, experience, autism and parental experience, autism and parental health, mothers and autism, Nigeria and autism, autism in Nigeria*, *ASD in Nigeria*, and *autism in Africa*. These keywords were used individually or in pairs and then combined to form key phrases. The reference lists of some of the articles located and accessed were also searched, and I identified some of the literature on EST through this medium.

I used a time and language limit qualifier to access current sources in the English language dating from 2010 to the present time. However, due to the dearth of literature on the issue of ASD in Nigeria and the version of Bronfenbrenner’s theory being used, an open-ended time frame was used for keyword searches with Nigeria, Africa, Bronfenbrenner, and EST. I accessed, studied, and selected articles based on their relevance to the study, giving preference to peer-reviewed scholarly articles.

Conceptual Framework

The conceptual model I used for this study was the EST. This theory was first proposed and developed by Bronfenbrenner in the 1970s as a model for understanding human development through the lifespan (Bronfenbrenner, 1994). The theory arose out of the need for mental health practices and research to understand individuals and their functioning within the context of their dwelling environment (Suarez-Balcazar, Balcazar, Garcia-Ramirez, & Taylor-Ritzler, 2014). According to this EST, human development and actions are impacted by ecological environments or settings (Shogren, 2013). The theory covers the circumstances and activities within the context of an individual’s dwelling environment that influences the development of the individual (Bronfenbrenner, 2000). The use of the concept of ecology was necessary to signify how changes in an individual’s environment influence the individual’s development (Rosa & Tudge, 2013). In Bronfenbrenner’s view, the individual and the environment influence one another (Rosa & Tudge, 2013). Bronfenbrenner’s model was influenced by the work of individuals such as Lewin and the psychological field theory; developmental psychologists, Vygotsky, Luria, and Leontiev, and their work on social learning; and sociologists, D. Thomas and W. Thomas, and their notion that individuals’ subjective perception of their situations impacts their behavior (Rosa & Tudge, 2013).

EST

The main characteristics of Bronfenbrenner’s (1994) theory include the concepts that (a) an individual’s development through life occurs as a result of a continuous mutual interaction between the person and the other people, things, and events within that individual’s primary environment and (b) the nature and style of these interactions usually depend on the characteristics of the developing individual, the environment in which they occur, and the developmental effects being examined. EST tries to explain human development and behavior within the environment in which the human dwells. The focus of the theory is on investigating the interaction between individuals and their sociopolitical environment, the cultural environment, and the outcome of this interaction (Suarez-Balcazar et al, 2014). Bronfenbrenner (1997) described the ecological system as consisting of four mutually connected structures called the microsystem, mesosystem, exosystem, and the macrosystem.

Using these interconnected systems, the EST provides a description of how different factors in people’s environment impact their development and lifelong functioning. The theory represents Bronfenbrenner’s (1999) efforts to establish a working theory for studying how environmental systems impact human development. Hence, the focus of EST is to explore the traits and forces of the various settings within a person’s environment that influences development through the life span (Rosa & Tudge, 2013).

Since its formulation, the theory has undergone various transformations and is currently referred to as the bioecological theory. Bronfenbrenner (1999) identified two periods of change. The first period involves the publication of the work, *Ecology of Development*, in 1979, and the second was the evaluation and evolution of this earlier work. Rosa and Tudge (2013), however, noted three phases of transformation for EST. The first phase (1973 to 1979) they identified focused less on the individual as a contributing factor to development and more on the ecological contexts, the social aspect of human developmental processes, and the various ecological environments for development. The second phase (1980 to 1993) involved the rise of several research models, a focus on the significance of the individual in development, and the importance of culture in the macrosystem (Rosa & Tudge, 2013). This second phase also involved the addition of a fifth system, the chronosystem, and its significance in human development (Rosa & Tudge, 2013). The third phase (1993 to 2006) was on proximal processes as a major part of development and involved the evolution of the model from ecological to bioecological to highlight individual traits as a significant factor in proximal processes (Rosa & Tudge, 2013).

Microsystem

The microsystem is the central layer of the ecological environment where the individual and the environment impact one another (Tissington, 2008). Bronfenbrenner (1977) described the microsystem as containing the individual and the many different relations in the primary environment that affects development and behavior. Within this layer of the ecology, individuals experience particular events and roles as their development is influenced by proximal processes (Bronfenbrenner, 1994). The interactions at this level include the individual's direct contact with others in their family, home, neighbors, school, church, and other areas. Each component element of the microsystem comes with its associated culture, beliefs, customs, values, attitudes, and tendencies that further affect individual development (Suarez-Balcazar et al., 2014).

Mesosystem

The mesosystem is the second layer or level of Bronfenbrenner's (1977) ecological model and it consists of the interconnections between the microsystems in the developing individual's environment. Examples of interactions in the mesosystem can include interactions between an individual's family and school, between the individual's family and church, or between the individual's family and neighbors. The mesosystem can be described briefly as an interaction between "a network of microsystems" with each system having its own identity and set of customs (Suarez-Balcazar, et al., 2014, p. 536).

Exosystem

The exosystem includes formal and informal structures that do not directly involve individuals, yet still influence their development by being present in their primary setting (Bronfenbrenner, 1977). Examples of the exosystem can include an individual's neighborhood, government agencies, the workplace, the economy, and communication systems (Bronfenbrenner, 1977). For instance, the decision of a state government to cut off funding for special education programs in schools can impact the development and functioning of individuals in need of such programs in that state.

Macrosystem

The macrosystem encompasses familiar cultural patterns in the individual's environment and consists of things such as laws, rules, regulations, customs, and practices that impact existing events and systems (Bronfenbrenner, 1977). This layer of the ecological system is the "societal blueprint" because it determines the makeup and occurrences of a culture (Brofenbrenner, 1994, p.40). The belief systems and attitudes within a culture impacting human development and functioning will fall under this layer.

EST and Research

The ecological model has been used to investigate the relationships between people and the different environmental systems that may influence them. For example, Berry (1995) presented one of the earliest discussions of EST by presenting the theory as a framework for understanding the experiences of families of individuals with developmental disabilities who were transitioning from an institution to community. The author discussed how counselors working with these families could also use this model to increase their understanding of this population and provide appropriate support to their needs. Abrams, Theberge, and Karan (2005) also referenced how EST could be used by school counselors. These researchers reported that school counselors could use an ecological framework to better understand and address the various environmental elements that influenced students' depression.

In more recent research, Boxer et al. (2013) used the EST to investigate the connection between ethno-political violence and children's development of aggressive behavior in the Middle East. The authors found that violence between ethnic groups contributed to the development of aggressive behavior in children in the Middle East. This study demonstrated how Bronfenbrenner's model has been used to understand the influence of environmental settings on human behavior and functioning. Paat (2013) also used the model to review present immigration literature to gain an improved understanding of immigrant families' influences on the adaptation and social experiences of immigrant children in America. Paat's work emphasized the significance of having a thorough knowledge of immigrant children's family ecological systems to develop appropriate supportive programs and improve the delivery of social work services. Shogren (2013) used Bronfenbrenner's ecological framework to categorize possible environmental systems that influence self-determination in individuals with disabilities. The author's objective was to increase understanding of how ecological systems affected self-determination in people with disabilities so that societies may better understand how to improve supportive programs.

The ecological systems framework is also applicable in community and multicultural psychology research. It has been used to understand the problems of people and develop treatments for those problems within their cultural contexts (Suarez-Balcazar et al., 2014). Lui (2015) used the ecological model to conduct a literature review of the existing knowledge on environmental influences on working mothers' childcare selection. This author's goal was to inform policies and practice to improve childcare services. Ecological theory is a functional theory for grounding research on human development, for proposing the development of policies and programs related to human improvement, and for explaining the link between social systems and human development (Ceci, 2006; Suarez-Balcazar et al., 2014).

Since its origination, EST has undergone significant changes and is now referred to as the bioecological theory (Rosa & Tudge, 2013). However, due to the nature and focus of this study, I used the original version of the theory that highlights the role of an individual's ecological or cultural environment on development and functioning.

According to Tudge, Mokrova, Hatfield, and Karnik (2009), researchers may focus on an earlier version or a particular aspect of a theory, but it is important to state this fact to minimize theoretical confusion. The original version of the theory mostly focuses on the four interconnected environmental systems as conditions for human development and has been influential in the designing of intervention programs (Bronfenbrenner, 2000). In this study, I used the original version of the EST theory to explore how the various environmental systems in Nigeria may influence the experiences of mothers raising children with ASD in Nigeria.

This study addressed the questions: What are the lived experiences of mothers in Nigeria raising children with ASD? And. how do mothers in Nigeria describe the physical, psychological, social, and economic impact of raising a child with ASD? The goal of the study was to understand the experiences of these mothers raising children with ASD within the context of the Nigerian culture and environment. The EST was applicable to the questions in this study because the theory focuses on understanding human development and functioning within the context of the individual human environment.

Literature on Autism Spectrum Disorder

In this section, I will provide brief information about ASD. I will also present a comprehensive review of current literature on ASD awareness, the relationship between ASD and parents, relationship between ASD and culture, and ASD in Nigeria. The diagnosis rate of ASD is increasing in populations around the globe (Hall & Graff, 2011; WHO, 2013). Though the exact prevalence of ASD in Africa is still unknown (Bakare &

Munir, 2011a; Elsabbagh et al., 2012), it is reported that the disorder affects an estimated 200,000 to 380,000 individuals in Nigeria (U.S. Diplomatic Mission Nigeria, 2015). In the United States, it is estimated that 1 in every 68 children is diagnosed with ASD (Centers for Disease Control and Prevention [CDC], 2014a; Nevison, 2014). ASD is an umbrella term for developmental conditions that include autistic disorder, pervasive developmental disorder not otherwise specified, and Asperger syndrome (Blumberg, et al., 2013; CDC, 2014a). ASD is defined as a permanent developmental disorder characterized by a pattern of repetitive behavior and deficiencies in an individual's communication and social functioning abilities (Blumberg et al., 2013; CDC, 2014b). The disorder exists on a spectrum with impairments ranging from mild to severe (CDC, 2014a). Other symptoms that may be experienced by children with ASD include sensory problems, sleep problems, intellectual disability, seizures, gastrointestinal problems, and co-occurring mental disorders (NIMH], n.d.). ASD can be detected very early in children during well-child checks, and referral to a specialist for a comprehensive evaluation and formal diagnosis can be made if necessary (NIMH, n.d.).

ASD is not discriminatory and may occur in any family regardless of race, color, ethnicity, culture, or socio-economic status (Baba, 2014; CDC, 2014a). The disorder is not specific only to the Western or industrialized societies, rather it is universal and has been reported in countries all over the world, including Nigeria. The exact cause of ASD is not yet known, but research reports genetic, environmental, and biological factors as contributing to the risk of developing ASD (CDC, 2014a; Nevison, 2014).

There is currently no known cure for ASD. However, evidence indicates that early identification and diagnosis of the disorder can help ensure individuals diagnosed with the condition receive appropriate care (Fernell, Eriksson, & Gillberg, 2013). Treatment approaches for individuals with ASD may include pharmaceutical or nonpharmaceutical interventions, or both. These treatments may include behavior and communication approaches, dietary approaches, medication, and complementary and alternative medicine (CDC, 2015; Frank-Briggs, 2012). When initiated, early ASD treatments can help manage related impairments in children, reduce emotional impact on families, and promote quality of life for those affected (Frank-Briggs, 2012).

As a permanent disorder with no known cure, ASD has lifelong impacts on individuals, families, and societies worldwide. The management of ASD is costly, especially in Nigeria (Frank-Briggs, 2012). Most families of children with autism in Nigeria are unable to afford the cost of managing the condition, and the few families with the financial means have to travel out of the country to seek treatment for their children (CMUL, 2014). The financial burden to the society for a child with ASD in the United States is estimated to cost over billions of dollars annually (Elsabbagh et al., 2012; Lord & Bishop, 2010). The lifelong financial cost to families in the U.S. is estimated to be between 3 to 5 million (Frank-Briggs, 2012; Lord & Bishop, 2010). In addition to the financial impact, Karst and Van Hecke (2012) cited that additional impact of ASD to parents and families included parental distress or poor mental health, negative family quality of life, family conflicts and marital dissatisfaction. Individuals with ASD experience difficulties in communicating and socially interacting with others, and some of them are unable to function independently in the community (Elsabagh et al., 2012).

Numerous studies have linked a child’s ASD diagnosis and characteristic behaviors to increased level of parental stress, anxiety, depression, and frustration (Firth & Dryer 2013; Lyons, Leon, Roecker Phelps, & Dunleavy, 2010; Neely-Barnes, Hall, Roberts, & Graff, 2011; Zablotsky, Anderson, & Law, 2013). The effect of ASD on the individual and families may be lessened by application of appropriate interventions at an early stage, but this is mostly possible through early identification. Hence raising awareness of parents, healthcare population, and the general public about ASD is a critical starting point to improve prognosis for all those affected by the disorder.

Awareness and Knowledge of ASD

Researchers have shown that parents of children with intellectual disabilities, including ASD, in Nigeria have expressed distress and dissatisfaction over the lack of knowledge and support for the disorders (Ajuwon & Brown, 2012). Solomon and Chung (2012) reported that for most parents of children with ASD one common stressor is the sinuous road to getting a diagnosis for their children’s disorder. They argued that most medical, educational and therapeutic providers may not be well informed enough to identify and diagnose the symptoms of ASD early. There is a dearth of qualitative research that has explored these parents’ experience or the impact of the Nigerian culture on their experiences. There is a need to create and raise awareness about ASD in communities around the world in order to improve acceptance, support, treatment, and better prognosis for all those affected.

In 2007, the United Nations (UN) selected April 2nd as World Autism Awareness Day due to grave worries about the disorder and the resulting burden to those affected (UN General Assembly, 2007). This decision was meant to encourage societies around the world to raise awareness about the disorder in order to improve the lives of individuals with ASD. Thus, the decision sheds light on the global significance of raising awareness about ASD and to promote research on ASD.

Campbell and Barger (2011) used a quantitative approach to explore ASD knowledge among middle school students in order to gain understanding of their views and beliefs of the disorder. Results showed that most of the participants did not have enough knowledge of the disorder. These authors believed that increasing the knowledge and understanding of students about autism may contribute to positive school inclusion experiences for individuals with autism. Tipton and Blacher (2014) assessed ASD knowledge and views of a U.S. college population using an online survey. And even though 76% of the respondents answered the survey questions correctly, he reported that it is important for more research to be conducted to raise the public's awareness and acceptance of ASD. Thus, the results of both of these studies provide support for the need to raise awareness and acceptance of ASD among the public to improve experiences and outcomes for individuals and families affected by the disorder.

Al Jabery, Arabiat, Khamra, Betawi, and Abdel Jabbar (2014) conducted a quantitative investigation of parental perceptions of services provided for children with autism in Jordan. The authors distributed questionnaires to 60 parents to gather from them the nature of services received, how services were obtained and challenges involved in obtaining the services, their satisfaction with the services received, and services needed. The results from the study indicated that the parents expressed poor satisfaction for the general quality of services received and indicated a need for community awareness services, and early intervention and counseling services for their families.

Wang et al. (2012) used a quantitative cross-sectional survey method to assess awareness of autism among caregivers of children with ASD in Harbin, China. Data were collected from 4,947 participants regarding their attitudes towards treatment, factors that contributed to ASD, and their recognition of symptoms of autism. The authors found that only about half of the respondents were able to identify symptoms of ASD. Approximately 57.8% of respondents recognized ASD, 84.6% reported they would seek treatment for the disorder from health organizations while 68.2%would seek help from a psychotherapist. Despite these results, Wang et al. concluded that there is still room to improve knowledge about ASD to increase early diagnosis and treatment. Therefore, it can be argued that raising awareness among parents and caregivers is critical for early identification and intervention and to improve outcomes for individuals and families.

Hartley-McAndre, Doody, and Mertz (2014) conducted a quantitative study which also revealed the need to increase knowledge and awareness of ASD, especially its characteristics, diagnostic criteria, treatment and available resources, among the healthcare population. The researchers conducted an online survey to access the knowledge of the characteristics and diagnostic criteria of ASD from professionals in Buffalo, New York who were likely to have first contact with individuals with ASD. Based on the results from the study, most of the participants had strong knowledge and understanding about the prevalence and nature of ASD, but lacked knowledge about certain ASD characteristics, diagnostic features, and diagnostic criteria. A large proportion of participants showed interest in increasing their knowledge about ASD identification and diagnosis, interacting with individuals with ASD, and available resources in the community for ASD.

Khanna and Jariwala (2012) conducted a quantitative survey of pharmacists in Mississippi, United States, to assess their awareness and knowledge of the symptoms, etiology, myths, prognosis, treatment, and community resources for autism. Results indicated that 23% of the survey participants were unaware that autism was a developmental condition; 32% were not convinced that genetics played a role in the etiology of autism; over 18% were convinced that vaccines can contribute to autism; and about 19% indicated interest in continuing education geared towards increasing their knowledge of autism. Providing the healthcare population with appropriate information and knowledge about ASD and the needs of those affected is necessary to improve planning, care and experiences for patients and their families (Pratt, Baird, & Gringras 2012).

Awareness of ASD in Nigeria

There have been reports of ASD in most parts of the world. Elsabbagh et al. (2012) reviewed studies on the prevalence of autism around the globe and reported evidence of ASD in different geographical areas including Africa. However, while awareness and knowledge of the disorder may have improved in developed societies, Nigeria and other low-income communities are still in need of studies to gain information that can be used to raise awareness, knowledge, and support for individuals affected by the disorder.

Igwe et al. (2010) utilized a quantitative questionnaire to assess knowledge of childhood autism among final year undergraduate medical, nursing, and psychology students in Enugu state, Nigeria. The focus on these students is based on the expectation that they would graduate and become part of a multidisciplinary team that would be working with children with developmental conditions. The knowledge areas assessed included (a) social interactions of children with childhood autism, (b) communication and language impairments of children with autism, (c) behavioral impairments of children with autism, and (d) knowledge about the nature of autism, co-occurring diseases. Results from the study indicated that medical and nursing students who had more clinical training in psychiatry during their education displayed the most knowledge about childhood autism than psychology students who had no clinical field training. The findings of Igwe et al. were in accordance with previous research that knowledge and awareness about autism is low in this environment.

In a qualitative study using a survey design, Audu and Egbochuku (2010) assessed the knowledge of autism among primary school teachers in Benin City Nigeria. Questionnaires were used to gather data from 131 randomly selected teachers from different public primary schools in Benin City. Descriptive statistics was used to analyze the data. The authors found that 71% of the respondents did not believe in the existence of autism in Nigeria, indicating a low level of awareness for the disorder. The study showed the importance of raising awareness and understanding of autism in Nigeria.

In another study, Igwe et al (2011) utilized a questionnaire survey to assess knowledge about childhood autism among pediatric and psychiatric nurses in Ebonyi state, Nigeria, and decided on the possible factors that influence autism knowledge among this population. They found that pediatric and psychiatric nurses in this region, who were supposed to be part of the care team for individuals affected by ASD, lacked needed knowledge about the disorder. The authors reported that factors that influenced knowledge of autism included the nurses' specialization and prior experiences caring for children with autism. The psychiatric nurses were more knowledgeable about the disorder than the pediatric nurses, due to their specialization and previous experience caring for children with autism. In Nigeria, a case of childhood autism increases the probability of being taken to psychiatric centers rather than pediatric centers (Igwe et al, 2011). The findings of this study emphasized the fact that more knowledge and awareness about ASD is needed to increase early diagnosis and intervention for children affected by the disorder and their families in Nigeria.

Bakare and Munir (2011a) conducted a literature review on ASD epidemiology, diagnosis, etiology, and knowledge within the African setting. Results of this review revealed that only two studies dealt with the issue of ASD epidemiology in two Northern African countries. Three articles were found that addressed ASD diagnosis among African children, and two studies focusing on ASD knowledge in Africa revealed a low level of awareness and knowledge of the disorder in Africa. Six articles focused on ASD etiology among African children, out of which only one covered healthcare workers opinions on ASD etiology. In regards to these results, there is scarcity of literature focusing on ASD awareness and knowledge in Africa. The results of this review support what is currently assumed of ASD knowledge and awareness in most African countries, especially Nigeria. Therefore, more research on ASD in Nigeria and Africa will help improve awareness and knowledge, increase early identification and treatment, and influence policies to improve the lives and of those affected by the disorder and other developmental disorders in these environments.

In order to improve ASD prognosis in Nigeria, Eseigbe et al. (2015) used a quantitative questionnaire to evaluate autism knowledge and management challenges among medical doctors in Nigeria. Findings from the study showed that male participants who were specialists and had prior experience with autism evidenced knowledge about the disorder while most participants who were general practitioners had poor knowledge about autism. The challenges to managing the disorder in Nigeria that were identified by the respondents include: poor awareness, negative attitudes and beliefs, lack of professionals to provide specialized services, and the high cost of special care. Though the study only evaluated medical doctors who attended a conference in the state of Kaduna, the results emphasized the need for increased awareness and knowledge of ASD among medical and healthcare professionals. Conclusions drawn from the research also shed light on the challenges of managing the disorder in Nigeria.

In another recent study, Paul and Gabriel-Brisibe (2015) conducted a cross-sectional study to assess the level of autism awareness among elementary school teachers in Yenagoa city in Bayelsa, Nigeria. Data for the study were gathered through the use of self-administered questionnaires, and analyzed with descriptive statistics. Results indicated poor level of awareness and knowledge about autism among teachers in this community which hindered early detection and special intervention.

Outcomes for Parents Caring for Children with Autism

Parents raising children with ASD in Nigeria have had to shoulder all responsibilities and expenses for their children’s condition while at the same time dealing with the society’s ignorance about ASD (Audu & Egbochuku, 2010; Egbochuku & Imoitseme, 2012). The few ASD support organizations that exist in Nigeria were established by parents who got frustrated and tired of struggling to find help and support for their children (Patrick Speech & Language Centre [PSLC], 2014; Thomas O. Women Network [TOWN], 2014). Parents have reported that raising a child with ASD in Nigeria can be very challenging and frustrating. These parents have to deal with delayed identification and diagnosis of the disorder, lack of available professional care, high cost of care, and poor community support (Eseigbe, Taju, & Lateef, 2013; Frank-Briggs, 2012). Caring for a child with ASD comes with challenges and difficulties that impact the life and the mental health of parents (Seymour, 2013). Apart from dealing with the struggles involved in raising a child diagnosed with ASD, some parents may also experience distress, blame, and lack of understanding from families and the public (Baba, 2014; Neely-Barnes et al, 2011).

Lyons et al (2010) conducted a quantitative study to evaluate the effect of autism severity and parental coping techniques on stress in parents of children with ASD. The authors gathered data from 77 primary caregivers of children with ASD using questionnaires and conducted multiple regression analysis of the data. Lyons et al.

reported that the severity of a child’s autism symptoms and behavior plays a huge role in parental stress among families of children with autism. Dabrowska and Pisula (2011) undertook a quantitative study to assess stress and coping styles in parents of pre-school children with autism and Down syndrome in Poland. Questionnaires were used to gather information about parenting stress and coping styles from a total of 162 parents of children with autism, Down syndrome, and normally developing children. Results revealed that parents raising children with autism experienced a higher level of stress than parents of normally developing children and children with Down syndrome. Parental stress in this population was influenced by parents’ level of education and their coping styles. Results also revealed that mothers raising children with autism experienced more stress than fathers due to the fact that mothers tend to be more involved in the care of the child with autism than fathers. Though the researchers used a small sample group consisting only of parents who had access to professional help in Poland, the results highlighted the effects of ASD on the wellbeing of parents.

Mori et al. (2009) carried out a qualitative study to investigate the relationship between parenting stress and Asperger’s syndrome and autism in Japanese parents. Data were collected from 193 Japanese parents through the use of questionnaires, and ANCOVA analysis was performed on the data. These authors found that both parents of children with Asperger’s and autism experienced elevated parental stress. However, parents in the Asperger’s group were found to experience more parental stress than parents in the autism group due to the behavior of the children.

Desai, Diva, Wertz, and Patel's (2012) conducted a qualitative phenomenological study to explore the everyday views, values, culture, and experiences of Indian parents regarding the ASD diagnoses of their children. Results indicated that the parents had little knowledge about the disorder. Analysis of the data revealed four phases that parents experienced when coping with the children's diagnoses. Those phases included: (a) an initial phase where parents considered everything normal in spite of the disruptive behaviors observed in the child, (b) a second phase where parents considered the child's problem to be short-term, (c) a third phase where parents gradually began to consider that their children had some difficulties, and (d) a fourth phase where parents struggled to improve their children's' potential in the society and to get the society to accommodate their children's' needs. This study was limited in that only parents who had professional help for their children were recruited. Findings from the study however highlighted the need for more qualitative studies to understand the perspectives and experiences of parents caring for children with ASD in the context of their cultural environment. My proposed study was different from the study by Desai et al. because I explored how the ecological systems in Nigeria influence the experiences of mothers raising children with ASD. Desai et al focused on understanding Indian parents' views and conceptualizations of their children's ASD related conditions and behavior, but in this study I focused mainly on Nigerian mothers' personal descriptions of raising a child with ASD.

Shtayermman (2013) conducted a quantitative study to investigate the levels of stress and marital satisfaction related to caring for a child with an ASD diagnosis using online surveys. 253 participants completed online web questionnaires for the study.

Results showed 13% of the participants fall under the DSM-IV-TR diagnostic criteria for major depressive disorder (MDD) and 15% qualify for generalized anxiety disorder (GAD). Results indicated that parents reported increased parental stress related to caring for a child with ASD. This researcher also found that parents reported lower levels of marital satisfaction. A limitation of the study was that it consisted of a nonprobability sample of mostly white females and a self-report method was used to collect data. These parameters reduced the generalizability of the results. However, findings from the study, shed light on the relationship between ASD, parental wellbeing, and marital relationships. Thus, it can be argued that caring for a child with ASD was related to increased levels of distress in the lives and wellbeing of parents.

Firth (2013) investigated predictors of distress in parents of children with ASD using a quantitative method. Firth used self-report questionnaires to gather data from 109 parents of children with ASD, and used a one-way ANOVA to analyze the data. Results revealed that the general distress level of the parents was influenced by the emotional and behavioral problems of the child with ASD, and the parenting related stress was influenced by the gravity of the child’s social difficulties. Findings from the study were in line with others about the negative effects of ASD on parental mental health. The study also emphasized the need to support families affected by the disorder by increasing awareness, education, acceptance, and sensitivity to their experiences. The study indicated that it is important to understand ASD from the perspectives of parents.

Zablotsky et al (2013) also conducted a quantitative study to investigate whether a child’s ASD symptoms influenced maternal depression and quality of life for the families of children with ASD. These researchers recruited 2,773 mothers of children with autism from the Interactive Autism Network (IAN) who completed web-based questionnaires. The data were analyzed with the use of multiple logistics regression. Results indicated a link between severe autism symptoms of a child and maternal depression and low quality of life. Mothers of children with severe autism symptoms and comorbid disorders were more likely to be in treatment for depression. The mothers were also more likely to report a lower quality of life if they had children with severe autism symptoms. However, mothers with maternal depression were found to be more likely to report lower quality of life. Zablotsky et al. emphasized that healthcare professionals working with ASD families need to have knowledge of how ASD affects parents, and professionals should consider these effects when working with such families.

Seymour (2013) examined the relationships between maternal fatigue, maternal stress and coping, and the behavioral problems of children with ASD. A total of 65 mothers of young children with ASD completed questionnaires for the study. Seymour completed data analysis through the use of the predictive analytic software (PASW) statistics version. The findings of the study showed that maternal fatigue influenced the relationship between a child’s problem behavior and maternal stress. The results indicated that the characteristic behavioral problems of children with ASD caused fatigue in parents which then negatively impacted the parents’ coping and stress levels. The results of Seymour’s study provided further support regarding the negative impact of ASD on parental mental health.

Mount and Dillon (2014) used a qualitative study to explore the experiences of parents of adolescents with ASD to understand the parents' views of how the child's disorder affected the parents' lives. Data were collected from nine parents of adolescents with ASD through individual semistructured interviews. A thematic analysis method was used to analyze the data. The findings from the study showed that parents indicated that the demands of raising a child with autism brought a lot of challenges that rendered the parents both mentally and physically exhausted. The parents also identified struggles with relationships and family functioning as effects of their child's disorder. Some parents indicated that their children's attendance in regular secondary school sometimes created challenges for parents as the children came home with behavioral problems due to incidents at school. Parents also reported that accepting their children's diagnosis improved their ability to support each other. Mount and Dillon suggested that better communication between families, schools, and other support services may help to improve the prognoses for individuals diagnosed with ASD and their families. It is significant to explore the lives of all individuals affected by ASD to raise society's awareness, understanding, acceptance and empathy. Thus, increasing understanding of the situation of individuals with ASD and their parents may create a more accepting, sensitive, and supportive environment for all those affected.

Cultural Perspectives Regarding ASD

Different cultures have different perspectives, explanations, and response to health and disabilities. The response and reactions of individuals to ASD is influenced by cultural perspectives about the disorder (Ravindran & Myers, 2012). Elsabbagh et al.

(2012) reported the need for more research to focus on the influence of cultural and socioeconomic factors on outcomes of autism for individuals affected, especially in developing countries. Kang-Yi's (2013) literature review of the Korean culture and ASD also revealed a need for more culturally based studies on ASD to raise awareness in societies where the disorder is stigmatized and poorly recognized or responded to.

A crucial part of providing care and support for families affected by developmental disorders includes increasing understanding of such disorders within different cultural settings. Mandell and Novak (2005) conducted one of the earliest studies that focused on cultural understanding on developmental disorders. The authors performed a systematic review of available literature to investigate the relationship between cultural beliefs and ASD-related treatment decisions made by families of children with ASD. They concluded that culture and beliefs may intervene with the families' decision to seek treatments for a child's ASD condition and the type of treatment sought. They reported the need for more research to explore how treatment decisions of families of children with ASD were influenced by cultural disparities in the presentations, symptoms interpretation, prognosis, and treatment. They speculated that a better understanding of the treatment decisions made by families of children with autism within their cultural contexts may have positive clinical implications for professionals working with these families, and in turn increase prognosis for those affected (Mandell & Novak, 2005).

Baker, Seltzer, and Greenberg (2011) conducted a quantitative study using the family systems framework to investigate the predictive relationship between the level of family adaptability and positive outcomes for mothers and their adolescent children with autism over time. Data were collected from 149 families of children with autism through questionnaires and statistical analysis of the data was completed. They found a correlation between family level adaptability and symptoms of maternal depression and behavioral problems of children in families of individuals with autism. The results indicated that the level of family adaptability positively influenced outcomes for mothers and their adolescent children with autism over the period of the study. Family level adaptability predicted the changes in maternal depression and decrease in child's behavioral problems in this population. The focus of Baker et al.'s study was on the influence of family level processes on maternal wellbeing of families affected by autism. It shed light on the significance of raising autism knowledge and family outcomes by understanding the influence of environmental settings and processes on families affected by autism. However, focusing on family processes only dealt with micro-level factors in the environment affecting families with autism. It is important to focus on all levels of the environment, from micro to macro, so as to have a greater understanding of factors that affect the experiences of families affected by ASD (Bernier, Mao, &Yen, 2010).

Bernier et al. (2010) conducted a review of extant literature on cultural disparities in the diagnosis, acceptance, and treatment of ASD. The authors reported that there is a high need for more research to investigate the impact of culture on the diagnosis, treatment, and prognosis of ASD. The authors emphasized the significance of examining micro-level and macro-level cultural factors that may influence ASD diagnosis, treatment, support, and course. Bernier et al. further argued that it is crucial for clinicians and providers working with families affected by ASD to be informed of how different cultures influence the views and experiences of different families dealing with the disorder.

Ravindran and Meyers (2012) completed a conceptual paper using Bronfenbrenner's EST to examine the influence of culture on the public's perceptions of ASD or other developmental disabilities. They reported that different cultures approach health and disability in many different ways. Therefore, for professionals to offer the best services to individuals with ASD and their families it is important to understand and respect the cultural perceptions these families had about the disorder and to incorporate them into treatment approaches.

Alqahtani (2012) used a qualitative study to explore the beliefs of parents of children with autism in Saudi Arabia regarding the causes of their children's autism. Data were collected from 47 parents through semistructured interviews and an inductive method of analysis was used to identify emerging themes. The author wanted to contribute to ASD knowledge and improve management and care of the disorder by providing information of Saudi Arabian parents' beliefs about the disorder. Results showed that most parents in that environment believed autism to be the result of vaccines, while others blamed themselves, evil, or magic as contributing to autism in their children. The results also indicated that parents often sought unconventional and cultural interventions to address their children's autism condition. Alqahtani suggested that to better care for those impacted by ASD, it is important to increase healthcare professionals' awareness and sensitivity to the beliefs and views parents have about the disorder. Collectively, the studies presented in this section provided a background for my study. Research supported the need for additional studies on the experiences and beliefs of parents of children with autism in the context of their cultural environment. Thus, it can be argued that more research into cultural influences on parental experiences of ASD was important.

Knowledge of ASD in Nigeria

There are over 190,000 children with ASD in Nigeria, most of who were never properly diagnosed or received the appropriate treatment for their condition (Frank-Briggs, 2012). The knowledge and support from the community for those diagnosed with the disorder in Nigeria is very poor (Audu & Egbochuku, 2010). Nigeria is a society with a high level of ignorance and superstition when it comes to mental or developmental disabilities (Baba, 2014). As a result, most individuals with mental disabilities may face a life of abuse, neglect, isolation, and lack of support and treatment (Audu & Egbochuku, 2010; Egbochuku & Imoitseme, 2012; U.S. African Development Foundation [USADF], 2011). Audu and Egbochuku (2010) argued that in Nigeria children with autism and other developmental disabilities are often tagged with negative and derogatory names, and they are never really referred for any special services to assist them. The authors reported that the disorder is usually attributed to spiritual factors and most parents isolate children with autism from the community. It can therefore be argued that negative opinions and beliefs about ASD in Nigeria greatly impacts acceptance, treatment and support for those affected.

A number of studies reported on the general lack of knowledge about ASD in Nigeria (Audu & Egbochuku, 2010; Bakare & Munir 2011a; Egbochuku & Imoitseme, 2012; Frank & Briggs, 2012). Bakare et al. (2009) carried out a qualitative study to assess the opinion of healthcare workers in Nigeria regarding the etiology, treatability and preventability of childhood autism. Data were collected from a total of 134 healthcare workers from four tertiary healthcare facilities in the south-east and far south regions of Nigeria. SPSS statistics was used for data analysis. The researchers reported that some healthcare workers in Nigeria were of the belief that ASD is the result of supernatural and preternatural problems such as family curses, enemies, and evil. As a result of these negative beliefs and opinions about ASD parents may be reluctant to seek help for their children's condition from healthcare workers.

Bakare and Munir (2011b) completed a literature review on cases of ASD from Africa to investigate the age at which African children with ASD were first presented to traditional clinical settings. They found a large number of nonverbal cases of ASD that were presented late to orthodox clinical settings. Since these cases of ASD were presented late to clinical settings, diagnoses and interventions for the individuals with ASD were delayed. Bakare and Munir reported that factors which contributed to the late presentation of these cases in Africa included poor levels of ASD knowledge and awareness in Africa, difficulties getting help, and scarcity of mental health centers and specialists to attend to individuals with ASD. Though this study was a literature review of available literature on ASD from Africa, it helped to show the need for more ASD related studies in African countries like Nigeria to improve awareness and understanding about the disorder.

Frank-Briggs (2012) also reviewed literature on the management and challenges of autism in Nigeria and other parts of the world. The author concluded that even though autism awareness is high in developed countries; in Nigeria, it is still very low. The author identified some challenges faced by individuals with autism in Nigeria that included ignorance and poor knowledge of the disorder among the public, late identification of the disorder, lack of appropriate interventions and services for those affected, and the effect of high cost of autism treatment on family finances. Frank-Briggs concluded that there was a need to increase autism awareness in Nigeria in order to improve the condition of those affected.

In reporting on the role of the International Child Neurology Association (ICNA) in Africa, Newton and Chugabi (2013) mentioned that there was a lack of published information on ASD from Africa. The authors reported that in many African countries, including Nigeria, cases of ASD go undiagnosed, are diagnosed late, and unpublished in clinical or educational reports. Poor knowledge and awareness about the disorder, traditional beliefs about its causes, and lack of access to intervention and support services in these regions make ongoing difficulties for individuals with ASD and their families. Based on the difficulties identified in tackling ASD in Africa, the ICNA held a workshop in West Africa to examine the diagnosis and management of the disorder in Africa and to develop helpful recommendations for improving ASD knowledge and management in Africa (Newton & Chugabi, 2013).

Bello-Mojeed, Ogun, Omigbodun, Adewuya, and Ladapo (2010) investigated the late identification of autistic disorders in Nigeria using a qualitative case study approach. The participants were two mothers of adolescent boys with autism. Data were collected through interviews with the mothers and behavioral observations of the children. The authors reported that the children in this case study had serious social, communication, and behavioral impairments. The children's autism conditions were not diagnosed until the age of 17 years and 14 years respectively. Findings also revealed that low autism awareness, late referral to specialist services, and lack of special health centers all contributed to the late detection and diagnosis of the disorder in Nigeria. Bello Mojeed et al. were conscious of the benefits of early diagnosis and intervention, and they wanted to raise awareness about the late clinical presentation and late diagnosis of autism in Nigeria. Though the results of the study could not be generalized to the larger population of children with autism in Nigeria due to its small sample size, findings from the study revealed the poor awareness of ASD as a factor which delayed early diagnosis of symptoms in Nigeria.

Ajuwon and Brown (2012) conducted a qualitative survey to investigate the family quality of life (FQOL) of caregivers of individuals with intellectual disabilities (ID) in Nigeria. They also examined whether the perceptions of these caregivers on ID was influenced by social and cultural beliefs in this environment. The researchers found that families of individuals with ID considered caregiver health, financial well-being, family relationships, support from others, caregiver leisure, and caregiver community/civic involvement to be important for FQOL. The families reported that health, family relationships, and the influence of values brought quality to their lives but that other areas including lack of support from services, lack of support from others, and poor caregiver leisure negatively impacted family quality of life. The authors reported that some of the beliefs about ID in this community as indicated by the caregivers include endorsement of superstitious causes for ID and seeking cure for the disorders from churches or native doctors. Some caregivers reported mental and financial struggles related to their children's condition such as distress over lack of services and support and struggles to pay for special services. Results from the Ajuwon and Brown study briefly sheds light on the struggles, helplessness and distress experienced by families of individuals with intellectual and developmental disabilities (IDD) in Nigeria. The researchers suggested that there was a need for more in-depth exploration of the experiences of families of individuals with disabilities within the context of Nigerian culture, beliefs, values, and relationships.

Egbochuku and Imoitseme (2012) conducted a quasi-experimental study to access the effectiveness of Discrete Trial Teaching (DTT) and observational learning techniques in helping parents of children with autism in Nigeria manage their children's problem behaviors. The authors indicated that the significance of their study was to minimize psychological distress experienced by parents of children with autism by teaching them how to effectively manage their children's problem behaviors. Participants for the study consisted of 20 parents of children with autism in Nigeria. Data were analyzed using independent *t* test. Results of the study indicated that equipping parents with autism knowledge and intervention strategies helps them better able to manage their children's behavioral problems and even reduce their stress. These results supported the importance of increasing autism knowledge in the public especially among parents in order to improve outcomes for the parents. However, this was a quantitative study and did not provide detailed accounts of these parents' experience of raising children with autism in Nigeria. Thus, there was need for a qualitative exploration of the lived experiences of parents raising children with ASD in Nigeria.

Conclusion

ASD has no known or documented cure. The symptoms and effects of the disorder are lifelong for all affected. Therefore, understanding and improving the experiences and lives of individuals affected by ASD is extremely significant for improved health outcomes. In this chapter, I provided information on Bronfenbrenner's EST and how it has been applied in research to understand human development and behavior. The literature reviewed supported the need to increase awareness and knowledge of ASD to improve diagnosis, interventions, prognosis, and quality of life for all affected by the disorder in Nigerian (Bakare & Munir, 2011b; Eseigbe et al., 2015; Igwe et al., 2011; Igwe et al., 2010) and other parts of the world (Al Jabery, et al., 2014; Campbell & Barger, 2011; Hartley-McAndre et al., 2014; Khanna and Jariwala, 2012; Tipton & Blacher, 2014; Wang, et al., 2012).

The literature reviewed also revealed a relationship between ASD and parental distress and experiences (Dabrowska & Pisula, 2011; Desai et al., 2012; Mori, et al., 2009; Shtayermman, 2013; Zablotsky et al., 2013); and some opinions and beliefs about ASD in Nigeria (Ajuwon & Brown, 2012; Audu & Egbochuku, 2010; Bakare et al., 2009). The review further addressed the poor awareness and challenges of ASD in Nigeria (Audu & Egbochuku, 2010; Bakare & Munir, 2011b; Bello-Mojeed et al., 2010; Egbochuku & Imoitseme, 2012; Eseigbe et al., 2015); and the relationship between culture and ASD perceptions, diagnosis, treatments, and prognosis (Alqahtani et al., 2012; Bernier et al., 2010; Elsabbagh et al., 2012; Kang-Yi, 2013; Ravindran & Myers, 2012).

Even though studies emphasized the significance of understanding ASD within different cultural contexts in order to better improve lives of those affected by ASD, there is a dearth of research focusing on the influence of different cultures on the diagnosis, treatment, prognosis, perceptions, and experiences of ASD (Bernier et al., 2010; Elsabbagh, 2012; Kang-Yi, 2013; Mandel & Novak, 2005; Ravindran & Myers, 2012). Also, literature supports the significance of understanding the views and experiences of parents of children with ASD in order to provide better care (Anderson, & Law, 2013; Desai et al., Mori et al., 2009; 2012; Zablotsky,), and evidence found that parents in Nigeria have reported helplessness and distress over the struggles involved in raising a child with ASD in Nigeria (Ajuwon & Brown, 2012). However, I found no qualitative studies detailing the experiences of these parents. Therefore, there was a gap in literature focusing on ASD and culture, and the perceptions and lived experiences of families raising children with ASD in Nigeria.

In this study, I used a phenomenological approach to explore the experiences of mothers raising children with ASD in Nigeria. The aim of this qualitative study was to improve understanding about how ASD impacts mothers’ experiences of caring for children with ASD, increase awareness and knowledge of ASD in Nigeria, and increase the existing body of research regarding the role of culture on ASD perceptions, treatment and experiences. This knowledge could impact positive social change when used to advocate for policy modifications and increase acceptance, sensitivity, and support for individuals affected with ASD in Nigeria. In Chapter 3, I will discuss the research methodology for the study and the justification for the choice. The issues of trustworthiness and ethical procedures related to the chosen method will also be discussed in Chapter 3.

Chapter 3: Research Method

Introduction

The purpose of this phenomenological study was to explore the perceptions and lived experiences of mothers raising children with autism in Nigeria. The level of understanding and support for ASD in Nigeria is poor (Eseigbe et al., 2015; Paul & Gabriel-Brisibe, 2015). According to a human rights report by the U.S. Department of State (2015), in Nigeria there is lack of services for individuals with intellectual and other disabilities and Nigeria does not have laws that protect such individuals from discrimination. Individuals with intellectual disabilities face stigmatization and discrimination in Nigeria (Frank-Briggs, 2012). Despite the current situation of ASD in Nigeria, there is a scarcity of scholarly literature focusing on the experiences of parents raising children with ASD in Nigeria. Therefore, a gap existed in the literature regarding a qualitative account of the experiences of parents raising children with ASD within the Nigerian environment and culture. One goal of mine with this study was to contribute to ASD awareness in Nigeria. An exploration of how the negative beliefs and attitudes about ASD in Nigeria impacts the experiences of mothers raising children with the disorder may lead to the development of strategies for improving support for individuals affected by ASD and their families.

In this chapter, I will provide information on the chosen research design for the study and the rationale behind that choice. The role of the researcher, procedures used for participant recruitment, instruments for data collection, plan for data collection and analysis, issues of trustworthiness, and ethical procedures will also be discussed in this chapter. I will provide a summary at the end of the chapter.

Research Design and Rationale

This study was guided by the following main research question: What are the lived experiences of mothers in Nigeria raising children with ASD? The secondary questions that I explored within the study were: How do mothers in Nigeria describe the physical, psychological, social, and economic impact of raising a child with ASD? How do mothers raising children with ASD in Nigeria describe the impact of the Nigerian culture on their experiences? As emphasized by the main guiding question, the central phenomenon under study was to understand the lived experiences of mothers in Nigeria raising children with ASD. ASD includes a group of neurodevelopmental conditions that impact the life and behavior of children and families (CDC, 2014a).

In this study, I used a qualitative, transcendental phenomenological approach to explore the experiences of mothers raising children with ASD in Nigeria. Phenomenological research describes events based on participants' personal experiences (Creswell, 2013; Kleiman, 2004). The primary focus of a transcendental phenomenological approach is on participants' real descriptions of the meaning of experiences without including the preconceived interpretations of the researcher (Moerrer-Urdahl & Creswell, 2004). Crucial to phenomenology is the process of epoché process which requires a researcher to approach an investigation in a manner free of any presumptions and instead focus on participants' true descriptions of a phenomenon (Moustakas, 1994). By using a phenomenological approach, a researcher can investigate and obtain individuals' descriptions of the meaning of an experience to arrive at the essence of the experience (Moustakas, 1994). The transcendental phenomenological approach was, therefore, the ideal method of inquiry into the phenomenon of interest in this study. Mothers in Nigeria revisited their lived experiences and provided in-depth accounts regarding their experiences raising children with ASD in this environment, and I then analyzed this information to derive the general essence of the experience (see Moustakas, 1994).

Role of the Researcher

My role as a researcher in this study was to function as an open-minded observer, interviewer, investigator, explorer, data collector, and analyzer. Playing the role of a researcher also includes regarding participants as equal coresearchers on the same journey to discover the phenomenon under investigation (Moustakas, 1994). In qualitative studies, a researcher's role involves being the main instrument for gathering, analyzing, and interpreting data (Creswell, 2013). In this sense, a researcher becomes involved in: (a) the location and selection of participants, (b) collection of quality information from participants through interviews and observations, (c) transcribing of the interview data, (d) coding the data to find emerging themes, (e) analyzing the data for common trends, and finally, (f) interpreting and reporting the findings (Moustakas, 1994). The nature of phenomenological research requires a researcher to focus on the participants and their true description of their feelings and experiences about a phenomenon (Moustakas, 1994). Any assumption a researcher may have about the issue being investigated must be put aside so that the focus can be on the participants' truths (Moustakas, 1994).

I have over 16 years of experience working in health and social services as a care coordinator providing support, information, and advocacy for individuals with disabilities and their families. Working with these families brought me insight into the emotional ordeal experienced by families of individuals with disabilities. It became clear to me that when working with individuals experiencing a disability, it was important to be understanding and be conscious of their emotional struggles.

One of my passions is to empower people. This passion contributed to my decision to further my education in clinical psychology. However, my interest in ASD and its impact on families started when the child of a family close to me was diagnosed with autism. Seeing first-hand how ASD could impact families, their relationships, and psychological health led to my passion to understand more about the nature of the relationship between the disorder and families. So, when it came time to select a topic for my dissertation, my first area of focus was autism and the family; however, finding an exact gap in the literature to focus on was a challenge. I had considered topics such as understanding autism and parental stress, causes of stress for parents of children with autism, how parents of children with autism cope with stress, and support services available for families living with autism. While struggling to find the exact gap in the literature on autism and families to focus on for this dissertation, a conversation with a cohort member who is also a Nigerian like me eventually led to my current topic. This individual reminded me that there were so many social issues in grave need of attention in Nigeria. Research into autism in Nigeria, my personal knowledge about the beliefs and attitudes in the Nigerian culture, and the autism diagnosis of a family member finally led me to a topic that I was passionate enough about to explore.

Based on my personal and professional background, I am aware that my exploration and interpretation of the phenomenon in this study may be influenced by my beliefs. However, being aware of my background and personal experiences helped me manage any biases and discriminatory notions that arose about the issue being investigated in this study. Throughout the study, I approached the phenomenon being explored in a controlled and methodical manner to minimize hasty judgements or generalizations (see Moustakas, 1994). Utilizing Moustakas's (1994) process of epoché, I managed my biases, beliefs, thoughts, and prejudgments about the issue by documenting them in a journal to help me set them aside so that I could focus on the participants and their descriptions.

I conducted this study within my country of birth, Nigeria, but in a different state and city from where I was born. During participant recruitment, I spoke with potential participants to ensure no participant selected had any family, friendship, or employment relationship with me. Other ethical issues discussed in the initial conversations with participants included the purpose and nature of the study, potential risks of the study to participants, confidentiality issues, how the information gathered will be kept private, and obtaining participants' informed consent.

Methodology

Participant Selection Logic

The goal of this study was to explore the lived experiences of mothers raising children with ASD in Nigeria. Caring for a child with a disability in Nigeria is predominantly the responsibility of mothers (Bello-Mojeed & Bakare, 2013). Therefore, the targeted population for the study was Nigerian mothers raising children with ASD. It was important to recruit only those participants who fit the desired population and had experienced the phenomenon under study. According to Moustakas (1994), critical factors to consider when locating and selecting participants for a phenomenological study include participants' experience of the phenomenon, their interest in the study, their comfort with detailed interviews, and their willingness to agree to be audio recorded and for the completed study to be published.

I recruited participants using purposeful sampling. This sampling technique entails deliberately recruiting only participants who fall under the category specific to the purpose of the study (Robinson, 2014). Therefore, my rationale for using this sampling strategy was to ensure that only participants that had experienced the phenomenon and had a unique viewpoint were recruited for the study (see Robinson, 2014).

The criteria for participants to be included in the study included the following: (a) must be mothers of Nigerian decent raising at least one child with ASD in Nigeria; (b) mother must be living with the child in the same household; (c) mother could be from any tribe in Nigeria and from any socioeconomic, religious, or educational background; (d) must be fluent in English; and (e) willing to consent to an audio-taped, face-to face interview. I created flyers about the study and indicated that prospective participants should contact me directly at a listed e-mail address and phone number (see Appendix A). When potential participants contacted me regarding the study, I asked them screening questions to determine if they meet the set criteria for the study. The screening questions included:

1. Are you a mother raising a child with ASD in Nigeria?
2. Are you fluent in English Language?
3. Has your child received a diagnosis on the autism spectrum?
4. Does your child live with you in the same household?
5. Would you be willing to participate in an audio-recorded, face-to-face interview with me to discuss your experiences as a mother raising a child with ASD in Nigeria?

I provided more detailed information about the study to those who met the participant criteria and answered any questions they had. I also reviewed confidentiality, including the informed consent form, and informed participants that the consent form would be e-mailed to them or sent by regular mail if preferred by a participant. I discussed potential interview dates with those who met the criteria. Signatures for the consent form were obtained from participants prior to the onset of the face-to-face interview. Two copies of the consent form were signed by the participant and me so that both parties had a copy to keep. I also obtained relevant demographic information using a demographic information form (see Appendix B). The demographic information form gathered information that may influence participants’ perceptions and experiences regarding the phenomenon, such as participants' age, marital status, education, and income.

I recruited a total of 10 mothers raising children with ASD in Nigeria for the study. My rationale for this number was to have a small sample size sufficient enough for detailed and rich descriptions of the phenomenon to be gathered (see Nicholls, 2009). In a phenomenological approach, researchers have to immerse themselves in the rich data provided by participants in order to understand the phenomenon (Connelly, 2010). A sample size of 10 participants was suitable for data saturation. The concept of data saturation in qualitative research means the point during which continuing to interview more participants does not reveal any further themes or information than has already been revealed (Francis et al., 2010). This sample size was adequate for all significant themes to be revealed to ensure data sufficiency, yet small enough to reduce the redundancy in the data for the study (see Mason, 2010).

I recruited participants from established autism organizations in Lagos, Nigeria. I created flyers to describe the purpose and nature of the study and provided my phone number and e-mail address that mothers interested in volunteering as participants could use to contact me (see Appendix A). After Walden University Institutional Review Board (IRB) and the National Health Research Ethics Committee of Nigeria (NHREC) approved the plan for the study, I contacted appropriate personnel of ASD organizations in Nigeria in person at their organizations or through e-mail, phone, or text message to obtain their permission to post the flyers for the study at their physical locations and their websites. I complied with any specific research review or approval requests required by hospitals or schools to post the flyers at these locations. Though the study was not expected to create psychological stress greater than what a person would experience in daily life, I had a list of ASD support networks in Nigeria available for mothers recruited at non-ASD-support facilities who wanted the list. The recruitment of participants continued until the desired sample size was achieved.

Instrumentation

The instruments I used in this study include a demographic information form (Appendix B), a list of guiding interview questions (Appendix C), and a reliable audio-recording device to record all interviews with participants. The main source of data collection for the study was the face-to-face semistructured interviews with selected participants. I purchased the audio-recorder for the study and developed the guiding interview questions. The interview questions were open-ended and addressed the research questions for the study. With open-ended questions participants provide detailed descriptions of their perceptions and experiences of the phenomenon. I asked follow-up prompt questions during the interview as needed to encourage participants' clarifications and expansion on responses.

Procedures for Recruitment, Participation, and Data Collection

I made arrangements for all face-to-face interviews with selected participants to occur in a mutually agreed upon safe location different from the organizations where participants were receiving services. I gave participants the option of having the interview at their home or a prearranged location that was close to the participant's residence. My goal was to ensure that the interview location was free of distractions and attended to issues of privacy. This way the privacy and confidentiality of participants was to be protected. I notified selected participants that the face-to-face interview was expected to last 60 to 90 minutes. At the start of each interview I went over confidentiality and informed consent again, reminded participants of the voluntary nature of their participation, the contact information for me and my committee chairperson's name and contact information. I also reminded participants of their right to withdraw at any time, and then asked them to sign the consent form. Participants and I signed two copies so that one was left with the participant. I conducted all interviews and skillfully questioned participants about their experiences. I listened to the participants' responses with an open mind, free of any biases or presuppositions about the issue. Any response from participants warranting further querying was addressed as they occurred during each interview. Participants were informed that they may be contacted for follow-up phone interviews, if necessary, to address any discrepancies or confirm information.

All interviews were audio-recorded with participants' consent. I also took brief hand-written notes during the interview to record responses, such as body language that could not be captured on an audio recorder. I transcribe all the audio-recorded interview data verbatim. To maintain confidentially and privacy, I replaced all participants' names with their number in the interview process. For example, the name of the first participant interviewed was changed to P1 on the interview transcript to protect their privacy. I retained a list of codes in case a participant chose to leave the study and deleting this data became necessary. I employed a snowball sampling procedure when the initial recruitment process resulted in too few participants, until the desired number of participants were obtained. In snowball sampling, participants were asked if they know other potential mothers that meet criteria for the study that they could refer to me, and any new participant referred was also asked the same question until the desired sample size for the study was achieved (see Knight, Roosa, & Umaña-Taylor, 2009).

Upon completion of semistructured interviews with each participant, I provided debriefing to help address any further information the participant wished to add and to summarize what was accomplished in the interview. Each participant was then thanked for volunteering their time and experiences for the study. I informed participants that a copy of the interview interpretation would be e-mailed to them to check for accuracy. They were also informed that a copy of the study's findings would be provided to them when ready.

Data Analysis Plan

In this study, I used semistructured interviews to gather data specific to the following research questions: what are the lived experiences of mothers in Nigeria raising children with ASD? How do mothers in Nigeria describe the physical, psychological, social, and economic impact of raising a child with ASD? How do mothers raising children with ASD in Nigeria describe the impact of the Nigerian culture on their experiences? I then transcribed the interview data verbatim to help increase my familiarity with the data.

Due to the small number of participants for this study, data analysis software was not needed. I completed data organization and analysis in the study through hand coding using Moustakas's (1994) steps for transcendental phenomenological analysis.

Moustakas reported that the central processes of transcendental phenomenology research include: (a) epoché, (b) phenomenological reduction, (c) imaginative variation, and (d) synthesis of meanings and essences. The epoché process involves suspending all prejudgments and beliefs about an issue in order to carefully and respectfully pay attention to the new way the issue is presented by a participant (Moustakas, 1994). Following the epoché process is phenomenological reduction which involves considering each experience in its totality, but as a separate individual unit of itself in a manner that is open-minded and new (Moustakas, 1994). In phenomenological reduction, a researcher engages in bracketing and horizonalization (Moustakas, 1994). Bracketing involves deliberately abandoning all your preconceptions and beliefs about a phenomenon to focus attention on the experiences and opinions of participants (Moustakas, 1994). Tufford and Newman (2010) encouraged that researchers should engage in bracketing throughout a study. Before traveling to Nigeria and throughout the data collection and data analysis processes I engaged in bracketing by journaling my thoughts and beliefs to help clear my mind regarding the phenomenon so that I was open to only the experiences described by the participants.

Horizonalization requires a researcher to place the same amount of value on each statement presented by a coresearcher about an experience (Moustakas, 1994). As horizonalization is a reoccurring process, participants' statements eventually become repetitive and are thereby reduced to only those horizons relevant to an understanding of the nature and essence of the experience (Moustakas, 1994). I engaged in the process of horizonalization by reviewing each interview transcript several times for familiarity and understanding, and paying equal attention to each statement made by participants. Horizons of each interview were highlighted using a colored font. I then weeded out repetitive and unconnected statements so that only those that were relevant and consistent remained. The horizons from each interview were combined into similar groups and a heading or title was given to each group. Horizonal groups that were similar in content were grouped together. Themes were identified from these clustered groups of horizons. Textural descriptions using verbatim quotes from the interviews was developed to explicate each theme (Moustakas, 1994).

A third process of phenomenological research is the imaginative variation. After the generation of textural descriptions, I engaged in imaginative variation and mentally considered the data from different perspectives or viewpoints in order to attain the structure of the experience (Moustakas, 1994). Through the process of free imaginative variation, I reflected on all possible perspectives in order to arrive at the structural themes of the experience (Moustakas, 1994). The last process in Moustakas' (1994) phenomenological research method is the synthesis of the core textural and structural descriptions obtained to form the common meanings and essence of the experience. A composite description resulted from this process. Due to possible differences in participant's opinions or views of the phenomenon of study, negative or discrepant cases that are contrary to main themes may emerge (Creswell, 2014). Any such discrepant cases in the study were acknowledged and adequately analyzed by comparing them with established confirmed cases (see Morrow, 2005).

Issues of Trustworthiness

In qualitative research, there are four different elements of quality or trustworthiness and those elements include credibility, transferability, dependability, and confirmability (Krefting, 1991). The subject of credibility is significant to findings in any study (Morrow, 2005). In this study, I established credibility by using appropriate strategies that included triangulation, researcher reflexivity, prolonged engagement with research participants and data, and member checks (see Morrow, 2005). Triangulation involves bringing together information collected from different sources to complete or confirm the common data concerning the phenomenon of investigation (Krefting, 1991).

The multiple sources of data for this study include the face-to-face interviews with multiple participants, demographic information gathered from the participants, and any hand-written notes taken during the interviews. I then considered these multiple data sources against each other in order to capture all aspects of the phenomenon described by the participants. Reflexivity was an ongoing activity I used throughout the study. Researcher reflexivity involves approaching the research issue reflexively by being aware of personal assumptions, preconceptions, and biases (Morrow, 2005). I also used prolonged engagement to ensure credibility by spending more time with participants and data through face-to-face interviews, follow-up phone calls, transcribing recorded interviews, and reading interview transcript several times for familiarity with data. Member checking is a strategy that can be used to improve the credibility of a study. Member checks entail presenting the research data to participants to check for accuracy and ensure there are no misrepresentation of information (Krefting, 1991). During the face-to-face interviews, I used probes as needed so that participants clarified or expanded on information. I informed the participants that I would also e-mail them a copy of my interpretation of the data to review, confirm and e-mail back to me. Instructions was provided in the e-mail for participants to review the interpretations, confirm or make any changes or additions in a different font color and then return it to me.

Transferability means the length to which others can transfer or apply the results of an investigation to other situations (Morrow, 2005). I addressed the issue of transferability for this study by providing thick descriptions about the research setting and procedures, participants' characteristics, and my role as a researcher (Morrow, 2005). I established dependability for the study through a detailed documentation of all activities, processes, data, and elements involved in the study. This documentation process is referred to as audit trial, and it would provide readers with an understanding of how the study addressed appropriate research procedures (Shenton, 2003). Information in the audit trial include the study's design and implementation, data gathering and management procedures, and documentations of researcher reflective practices and other activities (Shenton, 2003).

The criteria of confirmability deal with ensuring that the findings of a study would reflect the true experience of the phenomenon being investigated and not the biases or assumptions of the investigator (Morrow, 2005). In order to establish confirmability Moustakas' (1994) phenomenological process was used. Throughout the study, I maintained a documentation of the self-reflective processes used to remain self-aware of biases, thoughts, and preconceptions. I also utilize the technique of member checks to examine for discrepancies and ensure data accuracy.

Ethical Procedures

The American Psychological Association [APA] (2010) provided Ethical Standards to guide the conduct of all psychological activities including research. In regards to conducting research, I adhered to the APA Ethical Standards that include obtaining appropriate institutional approval before conducting a study; obtaining participants' informed consent, including consent for audio or visual recordings; informing participants of the nature of the study, voluntary participation, and the right to withdraw from the study at any time without retaliation (APA, 2010). I obtained the approval of Walden University IRB before conducting the study. The IRB approval number was 08-12-16-0160152 and it expires on August 11, 2017.

Additionally, since data collection for this study took place in Nigeria, I complied with the standards for conducting research with human participants set forth by the NHREC, Federal Ministry of Health. The NHREC provides the governing ethical guidelines and ensures ethical practice for research with animals and human participants conducted anywhere in Nigeria. I submitted the proposal for this study to the NHREC for their review and obtained their written approval before participants were recruited to participate in the study. The NHREC approval number is NHREC/01/01/2007and it expires on July 26, 2017.

To gain access to participants for this study, I created and distributed flyers about the study to ASD organizations and other appropriate community centers in Nigeria. The flyers included information on the purpose and nature of the study, participation criteria, and the confidentiality of participants. My direct contact information was also provided on the flyers so that potential participants could contact me directly. All participants were fully informed of any potential risks involved in the study. Participants were also informed that their participation in the study was completely voluntary and that they had the right to withdraw from the study at any time.

To protect the privacy and confidentiality of all participants, data such as demographic forms, consent forms, audiotapes, interview transcripts, and other materials were locked up and kept confidential in a file cabinet at my residence. Interview transcripts and all other electronic files related to the study were password protected on a computer that was password protected. I was the only person with access to these files. To protect the anonymity and confidentiality of participants, interviews were conducted in a pre-arranged private location. Names associated with interview data were replaced with a number for identification purposes. All phone and face-to-face contacts and interviews with participants were conducted solely by me. After completion of this study, all research data would be kept for a period of 5 years after which they would then be destroyed as set forth in Walden University research protocol. Though this study was conducted in my country of birth, participants had no working or familial relationship with me.

Summary

In this chapter, I provided a detailed description of the research design and methodology, researcher's role, issues of trustworthiness, and ethical procedures for the study. The purpose of the study was to use a phenomenological approach to explore the experiences of mothers in Nigeria raising children with ASD. The goal of the study was to increase understanding and support for ASD in Nigeria. I was aware of possible personal assumptions and biases to the phenomenon of investigation in this study due to personal and professional interests and engaged in the process of epoché to bracket any possible biases.

I discussed the methodology of the study in this chapter and addressed the recruitment procedures, sampling strategy, criteria for participant selection, and sample size and saturation. I also addressed data collection instruments and data management procedures. Moustakas's (1994) steps to phenomenological process were discussed as the data analysis plan that would be used for the study. The semistructured interviews were guided by the research question: How do mothers in Nigeria describe the physical, psychological, social, and economic impact of raising a child with ASD? How do mothers raising children with ASD in Nigeria describe the impact of the Nigerian culture on their experiences? I also covered the issue of trustworthiness and the strategies that were used to establish credibility, dependability, and confirmability for the study. Also in this chapter, I addressed ethical procedures for following APA established standards for conducting research, obtaining appropriate IRB and NHREC approval, and addressing issues related to participants' confidentiality and proper data storage and management. In Chapter 4 I will cover the setting of the study, participants' demographics, procedures of data collection and data analysis, evidence of trustworthiness, and a discussion of findings related to the experiences of mothers raising children with ASD in Nigeria.

Chapter 4: Results

Introduction

The purpose of this qualitative study was to explore the perceptions and lived experiences of mothers raising children with ASD in Nigeria. A goal of mine with this study was to increase understanding of how negative opinions and beliefs about ASD within the Nigerian culture and environment impacted the experiences of mothers of children with ASD. Therefore, I explored the perceptions and experiences of 10 mothers of children with ASD in Nigeria in this study. The main research question of the study was: What are the lived experiences of mothers in Nigeria raising children with ASD? The secondary questions were: How do mothers in Nigeria describe the physical, psychological, social, and economic impact of raising a child with ASD? How do mothers raising children with ASD in Nigeria describe the impact of the Nigerian culture on their experiences? In this chapter, I will provide information on the demographics and characteristic of the participants, the method of data collection, a detailed description of the data analysis process, evidence of trustworthiness, and the results of the study.

Demographics

This study consisted of 10 participants, ranging in age from 34 to 69 years old who volunteered their time and stories. All participants were mothers of children on the autism spectrum and all lived in Nigeria. The ages of the children ranged from 4 to 36 years old. Six participants lived in Lagos, Nigeria, and four lived in Port-Harcourt, Nigeria at the time of data collection for the study. Seven of the participants were married and living with their families and three participants identified as widows. All participants were fluent in English. Nine participants had one child diagnosed with ASD and one participant had three children diagnosed but only shared information about the experience with one of the children. Five of the participants were actively involved in increasing awareness, acceptance, and support for autism in Nigeria. All participants were primary caregivers for their children with ASD.

Participant Characteristics

Participant 1. Participant 1 was a 69-year-old mother of a 36-year-old son with ASD. She identified as a widow and lived with her son and another adult child. She was college educated, had worked outside the home for many years, and was retired at the time of the interview but indicated that she had to pick up work to support her insufficient pension. Her son was first diagnosed with autism in his early adult years.

Participant 2. Participant 2 was a 48-year-old mother of a 17-year-old daughter on the autism spectrum. She was married and lived with her husband and total of three children. She had a master’s level education and was self-employed full time at the time the interview was conducted. Her daughter was diagnosed with autism before the age of 3 years.

Participant 3. Participant 3 was a 47-year-old mother of a 24-year-old son with ASD. She was a widow and was living with her only son and child and one of her sisters at the time of the interview. Participant 3 had some college education and was self-employed full time as her schedule with her son would allow. Her son was diagnosed at the age of 17 years old.

Participant 4. Participant 4 was a 46-year-old mother of a 13-year-old son with ASD. At the time of the interview she was married and living with her husband and two children. She was college educated and self-employed full-time. Her son was diagnosed with autism before the age of 3.

Participant 5. Participant 5 was a 37-year-old mother of a 4-year-old daughter with ASD. She was married and living with her husband and two children at the time the interview was conducted. Participant 5 was college educated and employed full time. Her daughter was diagnosed with autism at the age of 2.

Participant 6. Participant 6 was a 52-year-old mother of an 8-year-old son with ASD. At the time of the interview she identified as a widow and lived alone with her three children. She had some college education and was self-employed full-time. Her son was diagnosed at the age of 4 years old.

Participant 7. Participant 7 was a 37-year-old mother of a 7-year-old son on the autism spectrum. She was married and living with her husband and two children at the time of the interview. She had a master's level education and was self-employed full time. Her son was diagnosed at the age of 3.

Participant 8. Participant 8 was a 36-year-old mother of a 5-year-old son on the autism spectrum. She was college educated and self-employed part time at the time of the interview. Participant 8 was married and lived with her husband and two children. Her son was diagnosed with autism at the age of 2.

Participant 9. Participant 9 was a 34-year-old mother of a 3 year and 9 month old son with ASD. She was college educated and not employed at the time the interview was conducted. Participant 9 was married and lived with her husband and two children. Her son was diagnosed at the age of 2 years and 6 months old.

Participant 10. Participant 10 was a 37-year-old mother of a 9-year-old son on the autism spectrum. She was married and lived with her husband and two children. She had a master's level education and was self-employed full time at the time of the interview. Her son was diagnosed at the age of 2.

Data Collection

I collected data for this study from 10 mothers of children with ASD in Nigeria who volunteered to participate in the study. Flyers were distributed in person and through e-mail or text messages to different autism organizations and individuals working with children with autism in Nigeria. Some organizations helped to post the study flyer on their social media websites, which made the flyer available to individuals in different parts of the country. Participants indicated interest in the study by calling or sending a text message to me or by providing their telephone numbers to individuals from whom they heard about the study and requested that I call them.

I interviewed all participants individually in face-to-face, semistructured interviews which lasted between 60 to 90 minutes. Interviews were conducted in Lagos and Port-Harcourt, at mutually agreed upon locations. Participants were asked 15 guiding open-ended interview questions to prompt a detailed response of their lived experiences as mothers raising children with ASD in Nigeria. Follow-up questions were used as needed during each interview to gain further understanding or clarification from participants about their individual experiences. Each interview was audio recorded with a

Sony digital recorder after signed informed consent was obtained from each participant. I transcribed each recorded interview by myself.

During data collection and other succeeding processes of the dissertation, I was the only one with access to the data. The digital recorder, signed informed consent forms, completed demographic forms, interview transcripts, interview summaries, and other materials relating to the study were kept in a locked file cabinet at my residence. Interview transcripts and all other electronic files relating to the study were on my personal computer that is password protected. All electronic files were backed up in a password-protected external drive that was also stored in a locked file cabinet at my residence. I was the only person with access to these files.

I summarized and provided each interview transcript to the participants by e-mail for member checking. One participant was called and notified when her summarized transcript was e-mailed as she had requested during the interview. Another participant was also contacted to verify her e-mail address as the summary sent to her had returned as undelivered. During the member checking process, one participant provided further data regarding her perception of how the Nigerian culture impacts the experiences of mothers raising children with ASD in Nigeria. A second participant clarified that there were services at her church for younger children with special needs but none for teenage children like her son. This same participant also clarified that her spirituality helped to reduce emotional stress. A third participant clarified some other aspects of her interview responses. No further information was clarified or provided by the other participants.

Participant 7 responded that the summarized interview about her experiences “perfectly captures what I said during our chat.”

One unusual circumstance that I encountered during data collection was that the telephone network connection system in Nigeria was poor at times. Some individuals shared that they attempted to call the telephone number I provided multiple times, but they got no response. I did not receive these calls and neither did they appear as missed calls. The result of this poor telephone network system may have resulted in potential participants not being able to reach me. Sometimes, potential participants provided their telephone numbers to those from whom they learned about the study and requested that I call them. All individuals that provided their telephone numbers were contacted as requested.

Data Analysis

I completed the data organization and analysis for this study using Moustakas’s (1994) steps and processes for transcendental phenomenological analysis. Throughout the processes of data collection and analysis, I engaged in bracketing by journaling my thoughts, beliefs, and any prejudgments to help clear my mind regarding the phenomenon and to remain open to only the experiences described by the participants. I repeatedly listened to the interview recordings; reread interview transcripts; and noted any personal assumptions, preconceptions, and biases I had. Through this process I was able to maintain an open mind and focus on each participant’s true perspective and experience regarding the phenomenon of raising a child with ASD in Nigeria.

Next, following Moustakas’s (1994) steps, I engaged in the process of horizonalization by reviewing each interview transcript several times for familiarity and understanding, while paying equal attention to each statement made by participants. Horizons of each interview were highlighted using a colored font. I then proceeded to eliminate repetitive and unconnected statements so that only those that were relevant to the phenomenon and consistent remained. The horizons from each interview were combined into similar groups and a heading was given to each group. Horizonal groups that were similar in content were grouped together. Eight major themes were then identified from these clustered groups of horizons. The eight major themes I identified were: (a) low societal awareness of ASD, (b) cultural attitudes and acceptance about ASD, (c) neglect and abuse, (d) inadequate services, (e) impact on parents and other family members, (f) refusing to be isolated by society, (g) nature of support, and (h) the way forward. Textural descriptions using verbatim quotes from the interviews were developed to explicate each theme (see Moustakas, 1994).

After the generation of textural descriptions, I engaged in the process of imaginative variation and mentally considered the data from different viewpoints to attain the structure of the experience (see Moustakas, 1994). Through the process of free imaginative variation, I reflected on all possible perspectives and identified the structural descriptions of the participants’ experiences (see Moustakas, 1994). I synthesized the core textural and structural descriptions obtained to form the common meanings and essence of the experience, which led to a composite description of the experience of raising a child with ASD in Nigeria. Additionally, discrepant cases contrary to the main themes identified were noted and adequately analyzed by comparing them with established cases (see Morrow, 2005).

Themes Identified

In this study, I explored the lived experiences of mothers in Nigeria raising a child with ASD. I also explored how mothers in Nigeria described the physical, psychological, social, and economic impact of raising a child with ASD as well as the impact of the Nigerian culture on their experiences. All participants engaged in a semistructured, face-to-face interview about their personal journeys in raising a child with ASD in Nigeria. I identified the following themes in their detailed responses.

Theme 1: Low Societal Awareness About ASD

Nine participants in the study described low awareness about ASD in Nigeria. In particular, the main areas they noted were low medical awareness and school awareness. The participants further shared some of the challenges they experienced as a result of the low awareness.

Medical awareness. Eight participants identified that their child’s doctor had limited knowledge or information about autism. The mothers discussed their challenges and efforts towards understanding the problem, getting a diagnosis, or knowing what to do for their child. Three of these participants highlighted eventually traveling out of the country to get diagnostic clarity.

> P1: When I had my experience, there was no awareness as to what autism was. I took him to the hospital to see the pediatrician but at the time nobody knew

anything about autism, they thought it was nervous problem. We went to a psychiatric hospital, nobody knew it was autism, even there.

P2: Getting to the hospital the big word autism was suggested but not confirmed. From then on, I began really trying to know what actually made her different from the regular child. I was asking so many questions that the doctors couldn't answer. It didn't even seem like the doctors knew much about the autism because the first time it was from a book that the doctor tried to find the word autism to explain to me. Then many hospitals after that, from hospital to hospital, many said she couldn't have autism because she seems to do a lot of things right. Many said it has to be autism, if it is not autism what could it be? So, most of the early stages I spent trying to find out what is actually wrong.

P7: We went to see a pediatrician and he said: madam, he is fine, you are just comparing him with your other son that is why you think there is something wrong. I insisted that I needed to see a neurologist. I needed an evaluation done. He [neurologist] said everything was fine, it was almost like: what is wrong with you madam? He said your child is fine, you can go. We turned to leave and my son just came down and [laughed], and jumped on the doctor’s table and his laptop was on the floor and everything, and the doctor said oh! Okay, madam come back, this is ADHD. I said ADHD there should be at least some level of speech but at that time there was no speech. So, we had to travel with him, we went to the U.K. and we saw a doctor and the doctor said this is autism.

> P9: At first, I thought he couldn't hear well, so I went for audiology test, on getting there after checking it they said he might be autistic. On visiting the neurologist, he said he [son] doesn't look autistic to him. In fact, I had very conflicting results, so I had to take my son to the U.S. On getting to U.S. it was confirmed that he is autistic.
>
> P10: I went to the hospital and I spoke with his doctor and the doctor was like "no, no, no." That most of the time when a child is on the spectrum, the child is born like that, and he didn't even understand its autism spectrum. He said: I have been taking care of him for years so obviously, we don't have a problem.

School awareness. Seven participants described their experiences with schools and/or teachers who lacked sufficient knowledge or experience about working with children with ASD. Some of these participants identified encountering difficulties in finding appropriate schools for their children to attend and changing schools for their children. While two participants described having to teach the schools how to work with their child.

> P1: I took him to a normal school, they didn’t understand him. They put him at the back [of the classroom]. The teachers were not trained, so any child that disturbs them they will get out of the way and concentrate on all the other children. When I found out that they were not even attending to him I removed him.
>
> P2: I didn’t even know we had to get a separate school for her. The first time I had just gone back to the same school where she was, only to be told that they

can’t keep her there because she was really very hyperactive. I went to about two or three schools but they wouldn’t take her. Then I was advised to take her to a special school. Actually, the school is more for the physically handicapped, and they [other children at school] were not talking. So, I don’t know whether it contributed to her [daughter] slowly losing speech.

P5: Her school was not really willing to handle her. They don’t have experience on how to handle her. So, they were not teaching her, basically I was paying school fees and she wasn’t being taught.

P6: He was in a school before, in that school they did not know anything, they will just put him at the back [of the classroom], and the teacher would just hold a cane and anything she would say: sit down, sit down, sit down, sit down. Maybe from fear he will just sit in one place, but a little bit far from others and I didn't like it so I just moved him.

P7: The teachers didn't know what they were doing. So, I had to start printing out from the internet how to treat a child on the spectrum, how to treat a child that is visual. Every time I had to go to the teacher and say okay if you are teaching him how to add it's easier for you to say two oranges plus to oranges than for you to say 2+2.

P10: Till today I still engage with the school. If my son is in a school am like a student in the school because we have to run everything, we do our own IEP [Individualized Education Program], we do our own everything and we follow it

> to make sure everybody is on board. In a mainstream school they don't have support, so am IEP designer, organizer, enforcer.

Theme 2: Cultural Attitudes and Acceptance About ASD

Participants identified common beliefs in the Nigerian culture about ASD or other developmental conditions that influences the community's reaction to the mothers or children. Cultural attitudes were described related to the church and spirituality, and from family members and others. Participants discussed their spiritual faith and its impact on their journey. The issue of stigma was also discussed.

Church and spirituality. Seven participants identified that the typical belief among the Nigerian society is that ASD or developmental disorders are spiritual problems or of a supernatural cause. Participants identified experiencing different challenges at church. Participant 10 provided a brief description about the importance of spirituality and the church in Nigeria: "We are very spiritual in Nigeria, you will hear a lot of people talk about God. Everything in Nigeria is centered around the church. Everybody goes to the church first, including the family of children with special needs." The following quotes exemplify the challenges experienced by the participants related to the spiritual beliefs and the church.

> P1: His father wasn't supportive. When it happened, he thought it was witchcraft, he thought I was a witch, and the [husband's] family rejected me.
>
> P3: I met someone and we went for prayer and that person prayed and said it's a spiritual problem.

P4: I remember one Sunday school we went to when we walked in the first time and the girls were just looking at him, whispering. When we came back the following Sunday they started whispering.

P6. One Reverend Sister asked me: Do you think that boy [child with ASD] is not possessed?

P7: I faced the most challenges in the church. Its church that comes to you and say "sister how nah, ah-ah you should pray a bit more. There was a woman that called me one day and she said I sat like that and allowed the devil to come into my life.

P8: The experience with the church is, most parents will want to sit maybe like two pews away from you, and start looking at you as if you have done something wrong. Our culture don't accept it [ASD]. We see it as demonic, we see it as evil. Some will reject autism and their children will be almost 10, 18 and they are still rejecting autism, they are still praying against it. When you tell them the child is autistic they say: what is autism? Why are you accepting that? Rebuke it! He is not autistic, God forbid!

P10: We have people that are deeply suspicious of the roots of disabilities. The disabilities that are visible they can say okay, but you look at a child on the spectrum and you say okay there is nothing that shows you that the child is on the spectrum. They [people] are just saying: this child, he is mad, it’s spiritual.

All participants also discussed their spiritual faith as affecting their perspectives, as a source of strength and support, and helping them find a purpose for their journey as mothers of children with ASD.

> P1: I put everything in the hands of God. So that's my main support, God.
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> P2: One was always calling on God to help. Am leaving everything to God. Fortunately, I think that God prepares you for what you will be in the future.
>
> P4: I remember myself fighting more than being down. Am spiritual, I knew that whatever it is I wasn't going to waste the pain, it was there for a reason. I wasn't going to let it ride over me and sink me down. God knows that I have the ability to make an impact and my impact would have been wasted if I didn't have this child. I now know why I have him, am so fulfilled at what I do that I would not trade it for anything else and I could not have discovered it if I didn't have him.
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> P5: I have learned to pray. My time with God is at 3:00 am in the morning. So that is why this does not affect me much.
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> P6: You have no choice, because number one I like long life, so I have to now open everything to God to just take control, to give me the grace to bear everything.
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> P10: We had the hand of God there, it was obvious. I have walked that path and I say listen I am spiritual enough to know that there is a God purpose in virtually everything. So, what I do, I do to help other parents like me.

Family member and other attitudes. Participants described experiences of poor acceptance from different members of the society, especially family and friends. Six participants identified and described experiences where members of the society mentioned that the child with ASD was spoilt, bad, or poorly trained. Mothers or parents were blamed for spoiling the child.

> P2: People first were shouting at me and yelling at me, asking me to control my daughter as if it was something that I could do, even if I wanted to.
>
> P3: The culture is that everybody believes since he [son with ASD] is not handicapped he should be able to do some things and once he's not doing it right, they look down at the parents like maybe you did not train him or he is a spoilt child just because most people they do not know what it [autism] is all about.
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> P4: Okay, at first my family didn’t understand what it was, they thought he was just spoilt, that I was indulging him a lot.
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> P7: People see it as bad behavior, they see me as that woman with the badly-behaved child.
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> P9: When they expect, your child is four years and he is not doing this, he is not doing that, [society thinks] you should spank him the more, he is being naughty, without knowing that the child is challenged.

Stigma. Eight participants identified stigmatization of the mothers or the children with ASD as a common occurrence in the Nigerian society. This stigmatization or the fear of being stigmatized was indicated to cause mothers to feel the need to protect, shield or hide their children from the public.

> P1: I was stigmatized. He [husband] would tell my story to everybody that I was the one responsible for my son’s predicament.

> P5: I don't want my child to be stigmatized. I don't want my child to be known as that child that something is wrong with it. So, I don't allow people to come closer.
>
> P7: People don't want to talk about it, they don't want it to look like there is something wrong with the gene; there is something in the family line. The fear of what people would say force you to keep the child indoors. The stigma is still there.
>
> P8: I didn’t really get any support from friends, some of them wouldn't even want your child to play with theirs; they think your child has a problem. So, if you tell them you are coming over they are asking you: are you coming with your child? Some parents in Nigeria here go as far as locking that child in a room, [because] they don't want to be identified with that child. They are not doing it because they want to, but the society is not accepting.
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> P9: I try as much as possible to shield myself and my child from the eyes of people. I don't take him out so much. I shield him from the public because the public don’t understand him. People will be looking at him, “oh, is this little one too mad, is he mad?
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> P10: You have the deep cultural superstition, we have a really stigmatizing society where people hide the children because you don't want anybody to know. You know people can start avoiding you, people start gossiping you.

Theme 3: Neglect and Abuse

Six participants identified the issue of abuse and neglect from others as part of the experiences of mothers raising children with ASD in Nigeria. The abuse and neglect were experienced by mothers and/or the children. Participants identified ignorance and negative beliefs about ASD as sometimes contributing to the abuse.

> P1: You know, since my son came he [husband] has been treating me like a slave, I had no rights. I was brutalized, I was beaten, I was sent packing. Eventually he gave me a divorce and since then he didn’t even care what he [son] was eating, what he would wear or remember him on his birthday. Some people introduced a set of therapists to me [who] always came to the house and I left him [son] in the house with them [therapists] and go to work because I had to make money. I came home one day and my neighbors told me: Ah, this man you say is looking after your child, has been beating him, and using punches and belt to do his own therapy. I felt bad.
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> P6: Whatever I do, the poor boy suffers a lot because they beat him. They beat him so much. So, because of him I now put CCTV [closed-circuit television] in my house. There was a time I was doing something just for us to feed. I was in the shop selling, the house-girl that I had was using this boy to make love. She almost killed him.
>
> P7: Am afraid of abuse, all forms of abuse from caregivers. Physical abuse, sexual abuse, all of that stuff.
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> P8: Children with autism in Nigeria they suffer, they go through a lot because of ignorance.
>
> P10: So, the children that actually suffer the most are the kids on the spectrum. There are different levels of abuse for children with autism in Nigeria. For the

> exceptionally rich families they send the children out, they take them away from the family. Then you have the really low-class indigent families who now segregate the child and torture the child with all these cages and taking them to prayer houses where they cane them, chain them to trees and all sorts of things, and we have a government that is not doing anything. Our mothers go through so much abuse themselves from both nuclear and extended family members who believe the mothers are at fault.

Theme 4: Inadequate Services

Seven participants described inadequate intervention services for ASD. Participants reported encountering challenges in finding or assessing ASD intervention services after their children received a diagnosis of ASD. Four of these participants described eventually having to read or learn how to provide interventions for their children themselves.

> P4: It was tough at the beginning because there was no help, you know, we didn’t find services [ASD intervention services] that were instantly accessible. Whatever was accessible was too far away from where we lived. We took him to the U.S., whilst we were there I enrolled in a training to get to know more about autism myself. I had to go and learn how to work with him.
>
> P5: I didn’t know what to do, I started looking, okay what do you do, how do you help the child? I started reading that there are some children that actually come out of it, you know, and in Nigeria I didn’t know where to go. The government had nothing to offer, the doctor had nothing to offer, I was basically on my own. I

now entered into biomedical treatment on my own. I had no doctor supervising me. I started based on what I have read that it has helped other children. I read all that online.

P7: I met someone here initially and that is why I actually moved here, she was the only person that had a center [ASD center]. She sent me someone who was supposed to be a therapist and because we were not in the same town, I had to provide accommodation. He was in a hotel for three months, I had to pay hotel bills, feed [him], pay outrageous fees at that time and he [therapist] was more like somebody you picked up from the streets. I was asking questions; where were you trained, who trained you? And I didn't get that. What worked for him [child with ASD], I had to learn all of that on my own. I had to start reading up on everything.

P8: We went to the clinic and they told us that he was autistic. So, the problem now was finding a place to take him. There was no center here, the only center [ASD center] we had then was full and the owner was not even there at that time. So, they had to bring somebody from another state.

P10: We didn't have [ASD] centers that I knew of or any government programs. You know how you would have government programs for early intervention? None of that exists. So, I had to go self-train and start providing that service myself.

Theme 5: Impact on Parents and other Family Members

Participants described how raising a child with ASD in Nigeria affected them and others in the immediate family. The mothers identified roles and responsibilities affected to include family, employment, and participation in the community. Participants also described the economic, psychological, social, and physical burdens associated with raising a child with ASD in Nigeria.

Balancing responsibilities. Six participants identified the different ways that raising a child with ASD in Nigeria had impacted their roles in their family and the community.

> P2: So, it was more like I had nothing else to do but just to focus on my daughter. I felt if I gave it [autism] so much attention maybe it would go away or maybe she will get well. So, I stayed almost every time with her. Then it was like I left almost everything else; I wasn’t attending to my husband [and] the other children. So, I think we could have been a closer family if we didn’t have a daughter with autism. Then in the society, at times I think I could have reached maybe what I wanted as self-actualization if I didn’t have a child with autism.
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> P4: His brother is a relatively reasonable young man, but he has his moments where he feels we are partial with him [child with ASD], that we do more things with [child with ASD] than we do with him. I deliberately make time for him [brother] to meet his own needs. I had to find a balance with that.

> P8: It [having a child with ASD] has helped me to be better, to be closer to my kids, because all the time I pay attention, I know what is going on, am always there. I had to give up a whole lot so that I can really take care of him.
>
> P9: I withdrew from everyone, I almost had issue with my husband. It [having a child with ASD] has affected the way I behave towards my daughter. It's like: oh mommy is always taking care of [child with ASD] so much, she doesn't look my way again.
>
> P10: I used to be in the choir. As [child with ASD] got older and required more time with me it wasn't possible to keep to my commitments. So, I don't engage in anything even in the church community. I can tell you easily my time is not mine. But I have time, together my husband and I make sure we have time for each other.

Economic impact. All participants described an economic burden associated with raising a child with ASD in Nigeria which included the cost of providing both everyday basic needs and the special services the child needed. Participants identified spending large sums of money on different services and treatment approaches for the child. Four participants discussed resigning their jobs in order to devote time to care for their child with ASD.

> P2: Raising a child with autism is a very expensive venture. When we started, we were told that the child is supposed to go on a particular diet, and the diet is not cheap. Now she goes to a regular school, I pay the school fees, they now have to

do therapy for her, you need three or four different therapists for her; each therapist has to be paid a fee

P4: Raising a child with autism is very expensive, because you find that you have to pay for services, like speech therapy, occupational therapy. Anything that you are doing with the child is paid for differently and these are things that he needs to even survive, to be able to exist within the community. So of course, you have to balance your lifestyle, things that are some luxury you have to cut them off. You have to put money towards his own development and care. Each month you are doling out so much money over this child.

P7: If we have to calculate what we have spent, sometimes I try not to think about it. We are grateful we have the money to spend, we just have to save a little bit more. It makes our finances tight.

P8: When I realized that if I really want this boy to be out of this I need to give it my best, I had to let my job go, and come back home, sit down and start looking for solutions.

P9: The financial aspect, hmmm. Well in Nigeria here, ah! Let me start with feeding, eating, we kind of do gluten-free casein-free diets, special diet. In Nigeria here, we have just a few people selling gluten-free products, but they are on a very high side. The prices are high! Too high! They [people selling gluten free products] will always tell you: the dollar rate is high, oh we cannot import. So, it's very, very, high. After giving birth to him [child with ASD] I would have loved to go back to work, [but] after seeing that he has a problem I had to give up the search for job.

Psychological impact on parents. Eight participants described experiencing struggles that were psychological in nature in their journey as mothers raising children with ASD in Nigeria. Some of the participants explained that the psychological symptoms were related to concerns for their children as well as the stress of providing the care the child needed.

> P2: Emotionally, many times you are laughing but you are crying, many times you have to talk tough but you are not as tough as your words are coming out. Many times, you want to say it’s alright, but inside you are not sure if it is alright. Many times, you laugh out, you go home you weep. So emotionally it’s made me cry a lot, inside, because you can’t let people know that you feel it, but it is not an easy thing to watch your child be different.
>
> P5: I am actually stressed out, I am stressed out, that is the word I will use. So, it hasn't been easy, it’s stressful. Sometimes I just lock my door, and I sleep, you know as much as I can sleep, I set my alarm so that I don't oversleep. So, I decided to start taking care of myself.
>
> P6: The work load is too much for only one person. I try to work on myself to zero my mind on so many things. I really feel bad most times. In a full day, the times that I am happy it's just few hours, as I see him the happiness is not there.
>
> P9: Psychologically, it is overwhelming. Sometimes my husband is kind of advocating for me to go get a job, to go look for something doing to take my mind

> off it [child’s ASD], because there was this period of time that I cried almost from morning till night, a whole day! My mind is just on that boy.
>
> P10: Just the constant anxiety or the constant thinking about your child’s tomorrow, the society, the child excelling, the child getting everything that they need. I worry about safety. Safety is a big issue, that your child not be taken advantage of by people especially in Nigeria with all these kidnap pings and abductions and things like that.

Lack of social activities for parents. Eight participants described the impact raising a child with ASD in Nigeria has had on their social life. Time was described as limited for these mothers due to being the primary care giver for the child and their devotion to caring for their children. Participants also described not having the liberty to just go somewhere.

> P1: Well, I can’t go everywhere, I have to think of my son’s comfort first. Anywhere I go I have to take him.
>
> P3: I can say am not a social person per say, but initially when his father was alive I don't feel it much because he is used to his father. The fact that he is with his dad, I have total liberty, if I want to go anywhere I can without looking back or thinking of anything. But now that it's only myself that he is looking up to, if I have to go to anyplace I have to think twice. It’s either I go with him or we will not go to that place at all.
>
> P4: With my social life, I can’t go out as much as I want to, I would like to just go to places.

> P5: I have no social life, I don't go anywhere, I go to church, I go to work, I stay in my house. So, my social life is nonexistent, that's what I can tell you.
>
> P6: It affects me very badly because it's not all functions that I can go to. I want to go but I will stay back because of him.

Health problems related to caring for a child with ASD. Five out of the 10 participants identified that they experienced significant physical symptoms in their journey as mothers raising children with ASD in Nigeria. These participants described that due to all that they had to do for their child, their physical health was impacted.

> P3: Sometimes what am concerned about is my health, I don't used to have BP [blood pressure] before, but now I have BP.
>
> P5: At one point my BP [blood pressure] was very high. Sometimes I get so much headache, I get so tired and dizzy and I start asking myself if something happens to me who would take care of this child?
>
> P6: It’s affecting me because I know that is why my blood pressure is increasing.
>
> P7: At the initial stage when he wasn't sleeping I wouldn't sleep and of course I started having migraines, my blood pressure started rising.
>
> P10: The mothers are under the worst pressure. Me myself, even without I didn't have all of that I did have a breakdown, I had a near stroke so there is a lot of physical toll or burden itself. I was running a ridiculous program; he was in school here, he was doing after school here, doing trainings, because what I did was workshops and trainings, going for all of them in the U.K. and Nigeria anywhere I could get a training down, I would do that.

Theme 6: Refusing to be Isolated by Society

Seven participants described refusing for themselves or their children to be isolated by the society. These participants described making efforts to educate the community. Participants further described modeling acceptance and love for the child in the society.

> P1: Anywhere I went, anywhere I go I have to take him, I take him out. I don’t have any problem, if you can’t sit with me, then move, but now I try to explain to them he is not violent, it’s because he has autism that’s why. Then I try to tell them one or two things about autism and they relax.
>
> P2: There are a few events when they invite me I am able to go with my daughter. So, I find a little corner, because I know that she is hyperactive, so that she can be in that end and not bother people. Then what you need to do is to ignore the child, let the child just be, if not you will be uncomfortable.
>
> P4: In terms of awareness or acceptance, maybe the kind of mother that I am and my personality, wherever I am I will talk about it, I am pushing it into everybody’s faces. So, there is no going to a place and I feel like am not going to fit in. He is going to fit in and you are going to accept him. Sometimes, when we have family gathering people still look at him. So those ones I just ignore them or I decide to have a lecture [about autism].
>
> P6: The only way they [society] are accepting him is the way I treat him. If he is trying to disturb I will just put him on my back so you will see the care and want. [Mothers carrying their children on their backs is a common practice in Nigeria].

> P10: Everything I notice in Nigeria, even with people that are illiterate, how you present your child is how they relate to the child. I take my son to the movies and when he starts stimming we come out of the movie theatre and people are like: oh boy why are you making noise now. So, I start explaining to them, he has something called autism. Have you heard about it before? Their attitude changes.

Theme 7: Nature of Support

Nine participants provided accounts of support received and not received from different members of the society. Participants described what they considered to be support, such as acceptance, information, encouragement, prayers, payment of necessary bills, and scholarships for school fees. All participants also identified the significant lack of support from the government.

> P1: His [child with ASD] father wasn't supportive. The only support they [mother's family] gave me was accepting him the way he is. No real support except for my brother, anytime he comes he relates like his father because he didn't have the love of a father. [Son] is on scholarship [at current school], somebody that I have not met is paying his fees.
>
> P2: The support I needed was information. I did get that from people who knew. Sometimes I needed somebody to be with my daughter when am going out, but I know who to ask for that anyway. My siblings were supportive, but they don't live with us. So, they offer their help and they move on. Many people encouraged me, and wished me well, which was quite nice, but just a very few didn't understand it and didn't want to be part of it.

P4: The government providing for families with autism: zero! They provide for children with special educational needs and they lump them all together in one class. There is nothing designed specifically for autism.

P5: My husband knows a little bit based on what I tell him but what I thank him for is that everywhere I said let's go he is with me. He's very supportive with money, whatever I need, he is the one that brings all the money. My mother is supporting me, she is keeping up with me [and] praying with me. The government had nothing to offer.

P8: I know that sometimes if we visit family they try to baby him [child with ASD] a lot because they keep thinking it's all about petting him. So yeah, I received a lot of support from family. For friends, not really, because some people don't believe here in Nigeria there is something like autism. We don't have any support from any government.

P9: My husband accepted his son, he loves his son so much. Anytime he is crying he would do anything possible, everything possibly to calm him down. Any time he is around and he wants to take his boy to church he will forfeit the adult section and go and stay with his child in the children section. I just love him for that. No support from friends and family.

P10: I have a husband like me who is engaged, who is involved. Because I take the time to explain my friends are open and accepting. We don't have any kind of support from the government.

Theme 8: The Way Forward

All participants identified the continued need for awareness, information, and education of the public as a way to improve understanding, support and acceptance for mothers in Nigeria raising children with ASD. Participants described the need to educate parents, churches, children, and law enforcement official about ASD. Participants also highlighted the need for government support, specialized schools, trained teachers, daycare facilities, mental health support for mothers, and well-trained therapists.

> P2: We need to spread as much information and awareness around the society and the nation. If we have more awareness parents will come out with their children. We need to have qualified speech therapists [and] daycare for the child.
>
> P3: If everybody around us are aware of what [ASD] is all about and can feel what we feel, I think half of the problem is solved. Law enforcement should get to know about them [individuals with ASD] so that when they [individuals with ASD] get to their custody, they [law enforcement] should not maltreat them.
>
> P4: There should be support units where mothers come together first and foremost. Maybe things for mental stability. Mothers of people with autism are a little more emotional, a little more erratic, they are more sensitive so it would be nice to have more embracing outlets for mothers where they can actually unwind.
>
> P6: If the government can come in and put [ASD] centers in different places, and [have] the people working in these centers trained to know how to manage them [children with ASD], make the fees friendly for people like us widows to be able to pay, it will help.

> P8: We don't have anything like support group. If we have that support group it will help us, we share experiences, [and] we talk about it. We need the government to help us. Everybody needs that awareness, that knowledge, we all need it. These children are supposed to be loved like every other child, they shouldn't be maltreated [and] segregated. They should be allowed to be in the society.
>
> P9: [Mothers] can be better helped by creating more awareness to tell them that autism is not a death warrant that your child is autistic. If the government can help support us, maybe helping subsidize the school rates for us, it would be very wonderful.
>
> P10: The only thing that can counter discrimination and stigmatization is education. We also need to educate the churches, make them more aware about how families need to be supported. Instead of just talking to adults alone, start speaking to kids because we have this discrimination and cultural stigmatization so ingrained in us that I don't know what we can do for our own generation, but the children are where we can make a difference. Coming to our government, common now! Can our parents have some relief with you stepping up to what you have signed to do?

Discrepant Cases

Discrepant data were provided by Participant 4, Participant 8, and Participant 9. Contrary to other participants, Participant 4 and Participant 9 shared that raising a child with ASD has made them physically fit, while Participant 8 stated that she was not physically impacted in anyway. Participant 4 reported that her child enjoys being active and pushes her to go outside often and Participant 9 explained she is physically fit from constantly running after her child.

Participant 4 also provided discrepant data regarding the psychological and emotional impact of raising a child with ASD in Nigeria. According to Participant 4:

> I don't see him as a child with autism, maybe because I am around people that all know him. Where we go to within the community would be places where we are already known. Am always emotional about him when we are not in Nigeria because that's where I don't have much support. I do better emotionally when I am with him in Nigeria because then I can share the load.

Regarding the social impact of raising a child with ASD in Nigeria, Participant 7 and Participant 8 provided data different from other participants. Participant 7 shared that her social life was not affected because she takes her child with her whenever she has somewhere to go. Participant 8 reported that her social life was not really affected because her child's autism is not severe, she takes him everywhere and people do not really notice anything. These discrepancies cases were noted and considered as insights and differences in perspectives offered by the individual participants regarding their lived experiences.

Evidence of Trustworthiness

In this study, credibility was established through the use of triangulation, researcher reflexivity, prolonged engagement with research participants and data, and member checks (Morrow, 2005). To address triangulation of data I reviewed and considered all interview recordings and transcripts, demographic information collected from participants, and any hand-written notes during the individual interviews. These multiple data sources were considered against each other in order to capture all aspects of the phenomenon described by the participants. Reflexivity was an ongoing activity I engaged in throughout the study to help me be aware of my personal assumptions, beliefs, and biases. I attended to the issue of prolonged engagement to data by conducting an individual face-to-face interview with each participant, transcribing all recorded interviews myself, and reading interview transcripts several times for familiarity.

To address member checking, I used probes as needed, for participants to clarify or expand on information. I also sent each participant, through shared e-mail addresses, a summary of their interview transcript to review, correct as needed, and e-mail back to me. During member checking, one participant was called and notified after her summarized transcript was e-mailed as she had requested during the interview. Another participant was also contacted to verify her e-mail address as the summary sent to her had returned undelivered. One participant provided further data regarding her perception of how the Nigerian culture impacts the experiences of mothers raising children with ASD in Nigeria. A second participant clarified that there were services at her church for younger children with special needs but none for teenage children like her son. This same participant also clarified that her spirituality helped “the most” to reduce emotional stress. A third participant clarified what she meant by “swimming upstream” when dealing with the Nigerian government. This participant clarified that she and her husband “ensure” they make out time for each other. She further added that people in Nigeria tend to hide children with “any form of disability” and that the belief in the culture is that “all disabilities” are contagious. No further changes were made by other participants.

I addressed the issue of transferability for this study by providing thick descriptions about the research setting and procedures, participants’ characteristics, and my role as a researcher (Morrow, 2005). Dependability for the study was established through the use of an audit trail. All required forms, my reflective journals, interview transcripts, audio tapes, and processes of analysis are stored in a locked file cabinet at my residence. In order to establish confirmability, I used Moustakas’ (1994) phenomenological process. Throughout the study, I maintained a documentation of the self-reflective processes used to remain self-aware of my biases, thoughts, and preconceptions.

Results of Data Analysis

The purpose of this study was to explore the perceptions and lived experiences of mothers raising children with ASD in Nigeria. The primary the aim was increasing understanding of how negative opinions and beliefs about ASD within the Nigerian culture and environment impact the experiences of these mothers. Therefore, the main research question that guided the study was: What are the lived experiences of mothers in Nigeria raising children with ASD? The study also explored how mothers in Nigeria described the physical, psychological, social, and economic impact of raising a child with ASD, as well as the impact of the Nigerian culture on their experiences. The mothers who participated in this study varied in their individual ages, marital status, and the age of their children with ASD.

Composite Depiction

The majority of study participants, 90% of participants, described low societal awareness about ASD in Nigeria that constituted challenges to getting a diagnosis for their child or understanding the problem. Participants reported limited knowledge about ASD among healthcare providers, receiving “conflicting” information or wrong diagnosis about the child’s condition, and traveling out of Nigeria to seek diagnostic clarity about the child’s condition. Participants described making significant efforts, visiting their child’s healthcare provider multiple times or going from one provider to another, seeking answers, and trying to understand the problem.

Participants also described poor knowledge and experience about ASD from schools and teachers. The participants shared that the schools lacked experience on how to teach the children and instead ignored them and focused on other students without the condition. Participants highlighted difficulties in finding appropriate schools for their children, changing of schools, or significant involvement in the child’s school to teach the schools how to work with the child. Participant 10 relayed that at her son’s school she is “like a student, IEP designer, organizer, enforcer.”

Participants described cultural attitudes and poor acceptance about ASD in Nigeria related to the church and spirituality, and from family members and others. Most participants identified that in the Nigerian culture a common belief about ASD is that it is the result of a spiritual or supernatural origin. The participants added that this belief influences the community’s reaction to the mothers or children. According to Participant 10, the Nigerian culture is “deeply suspicious of the roots of disabilities.” This common belief in Nigerian about the condition was identified to contribute to the rejection, neglect, and lack of acceptance and support for the child and mother. Participants also described experiences of poor acceptance from different members of the society, especially family and friends, who viewed the child with ASD to be “spoilt,” or “badly behaved” and expected parents to spank or control the child. Participant 8 explained that the Nigerian culture does not accept autism, and rather people waste time “rejecting it, praying against it.” Participants further described different challenges and poor acceptance from churches, such as people staring, “whispering” or sitting “away from” the mother or the child in church. On a positive note about spirituality, all participants described spiritual faith as a major part of their lives in Nigeria and a source of strength and support in the journey of raising a child with ASD. Participants also described spiritual faith as helping them find a purpose for their journey as mothers of children with ASD.

Furthermore, participants discussed the issue of stigmatization of the mothers or the children with ASD as an ongoing occurrence within the Nigerian society. The participants reported that due to stigma, parents sometimes felt the need to “shield” or “hide” themselves and their children from the public. According to Participant 7, “The fear of what people would say force you to keep the child indoors.”

Participants highlighted the experience of abuse or neglect to the children and sometimes to the mothers as well, mostly perpetrated by families and caretakers. Some of the participants identified ignorance and negative beliefs about ASD as contributing to the abuse. Participant 10 explained that abuse also involved affluent families who sent the child with autism away from the family, indigent families who keep the children away from the public or take them to “prayer houses” where the children are usually tortured.

Participants described part of their experiences to include difficulties in locating or assessing ASD intervention services for their children. Participants identified that it was either services did not exist, were too far or not available where they lived, or the services came with added challenges such as the extra expense of accommodating a therapist from out of town as reported by Participant 7. Some participants emphasized eventually having to read, research information, or attend ASD trainings to learn to care for their children themselves.

Participants highlighted that raising a child with ASD in Nigeria affected them and their participation in the community, as well as others in the immediate family. Participants shared that devoting time to understand the condition and care for the child with autism affected other family roles and responsibilities. Some participants highlighted that they had to make deliberate efforts to find a balance and attend to other family roles and responsibilities.

Participants also described the economic, psychological, social, and health problems related to caring for a child with ASD in Nigeria. Regardless of socio-economic status, all participants highlighted that there was a significant financial toll associated with raising a child with ASD in Nigeria. These expenses included the high cost of intervention services and high prices for the special diet items needed by the child due to high dollar rates for importation. Participants asserted Nigeria is expensive, so even the affluent had to make adjustments to accommodate the economic impact of raising a child with ASD in Nigeria. Participant 4 reported “You have to balance your lifestyle, things that are luxury you have to cut them off. You have to put money towards his own development and care. Each month you are doling out so much money over this child.”

Most participants, 80%, described psychological difficulties as part of the experience of raising a child with ASD in Nigeria. Participants explained that the psychological symptoms were related to the struggles of raising children with ASD in Nigerian and general concerns for the child. Participants identified excessive worrying, tears, anxiety, and stress. Eighty percent of study participants also identified that raising a child with ASD in Nigeria had impacted their social lives. Participants mostly identified lack of time for themselves, socialization, or attending events. Participants relayed that being the primary care giver for the child and their devotion to caring for the child often impacted their flexibility. Participant 6 reported “it affects me very badly because it's not all functions that I can go to. I want to go but I will stay back because of him.” Half of the study participants identified significant physical symptoms, such as high blood pressure, as associated with raising a child with ASD in Nigeria. Participant 5 relayed: “at one point my BP [blood pressure] was very high. Sometimes I get so much headache, I get so tired and dizzy and I start asking myself if something happens to me who would take care of this child?”

Participants further highlighted how they refused for themselves or their children to be isolated by the society. Participant 4 shared

> In terms of awareness or acceptance I find that maybe the kind of mother that I am and my personality, wherever I am I will talk about it, you know, I am

> pushing it into everybody's faces. So, there is no going to a place and I feel like oh, am not going to fit in. He is going to fit in and you are going to accept him and if you are not going to then we are not going to be there. If you call yourself my family, then you have to embrace him.

Participants also described making efforts to educate the community and modeling acceptance and love for the child. Participant 10 reported that people usually related to a child based on how the child was presented by the parent. This participated further shared that she noted changes in the attitudes of others after she explained her child's condition to them.

Participants described the nature of support received or not received, and their perception of support which included understanding and acceptance, information, encouragement, prayers, payment of necessary bills, and scholarships for school fees. Some participants identified support from husbands in the form of involvement in the child's care. All participants highlighted the significant lack of support from the government, as a result, families bore all responsibilities for their child. Participant 4 reported "the government providing for families with autism: zero! They provide for children with special educational needs and they lump them all together in one class. There is nothing designed specifically for autism."

As a way to move forward and better support mothers raising children with autism in Nigeria, most participants highlighted the continued need for awareness and education to increase understanding, acceptance, and support for mothers. Participant 10 stated that "the only thing that can counter discrimination and stigmatization is education." Participants discussed the need to spread information about ASD around the nation including to the churches, law enforcement, and young children who could make a difference in Nigeria. Participants also identified the need for special schools with trained teachers, daycare facilities for children with ASD, trained therapists, and support groups or mental health support for mothers. Most of the participants also highlighted the need for government involvement and support.

Discrepant data regarding how mothers in Nigeria describe the physical, psychological, and social impacts of raising a child with ASD. Contrary to other participants, Participant 4 and Participant 9 shared that raising a child with ASD has made them physically fit, while Participant 8 stated that she was not physically impacted in anyway. Participant 4 indicated that she was not emotionally impacted by her child's autism because she has others with whom she "can share the load" of raising a child with ASD. Participant 7 shared that her social life was not affected as she still takes her child with her whenever she has somewhere to go, and participant 8 denied impact on her social life as her child's autism is not severe so she takes him out and people do not really notice anything. These discrepancies in data were noted and considered as insights and differences in perceptions by the individual participants regarding their lived experiences.

Summary

In this chapter, I provided the results of the research study, which explored the perceptions and lived experiences of 10 mothers raising children with ASD in Nigerian. The goal of the study was to increase understanding of how negative opinions and beliefs about ASD within the Nigerian culture and environment impact the experiences of mothers of children with ASD. I also aimed to address an identified gap in the literature regarding a qualitative account of parents' experiences in raising children with ASD in Nigeria. Data organization and analysis in the study was completed through hand coding using Moustakas’s (1994) steps for transcendental phenomenological analysis.

Following these steps, I identified eight major themes that answered the main and secondary research questions for the study. The eight major themes identified were: (a) low societal awareness about ASD, (b) cultural attitudes and acceptance about ASD, (c) neglect and abuse, (d) inadequate services, (e) impact on parents and other family members, (f) refusing to be isolated by society, (g) nature of support, and (h) the way forward. Each theme highlighted the individual and collective essence of the experience of mothers raising a child with ASD in Nigeria.

In Chapter 5, I will discuss the interpretation of the results, by comparing the findings to the literature review. I will provide information on how the results of this study confirm and extend the knowledge in the area of raising a child with ASD. The limitations of the study, recommendations for future research, and implications for positive social change will also be discussed in Chapter 5.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this qualitative, transcendental phenomenological study was to explore the perceptions and lived experiences of mothers raising children with ASD in Nigeria. The gap I identified in the literature was that there is a scarcity of scholarly information that has examined parents' experiences in raising children with ASD in Nigeria. Therefore, I determined that a phenomenological research design was appropriate to the stated purpose of the study and the identified gap in the literature. A goal of mine with this study was to increase understanding of how negative opinions and beliefs about ASD within the Nigerian culture and environment impact the experiences of mothers of children with ASD.

I individually interviewed all participants through the use of face-to-face, semistructured interviews, which lasted 60 to 90 minutes. Interviews were conducted at mutually agreed upon locations that ensured confidentiality and privacy. I completed data analysis in the study by using Moustakas's (1994) steps and processes for transcendental phenomenological analysis. My key findings in the study revealed eight major themes regarding the experience of mothers raising a child with ASD in Nigeria. The eight major themes identified were: (a) low societal awareness about ASD, (b) cultural attitudes and acceptance about ASD, (c) neglect and abuse, (d) inadequate services, (e) impact on parents and other family members, (f) refusing to be isolated by society, (g) nature of support, and (h) the way forward.

Interpretation of the Findings

The majority of the findings of this study were consistent with the results I discussed in the literature I reviewed in Chapter 2. Most of the study participants described low societal awareness about ASD in Nigeria, negative beliefs and attitudes about ASD, and poor acceptance of ASD in Nigeria (see Frank-Briggs, 2012; Paul & Gabriel-Brisibe, 2015). However, participants' identification of spiritual faith as a major part of their lives in Nigeria, a source of strength and support, and an aid in finding a purpose for their journey as mothers of children with ASD was not evident in the literature reviewed for this study. Furthermore, participants discussed the issue of stigma associated with ASD and the abuse or neglect to the children and mothers, which aligned with the findings of Bakare et al. (2009). Participants described inadequate ASD intervention services for their children; the impact of ASD on mothers and their other roles and immediate family; and the economic, psychological, social, and health-related burdens of caring for a child with ASD in Nigeria in agreement with the studies of Frank-Briggs (2012), Lesi et al. (2014), and Mount and Dillon, (2014).

Inconsistent with the findings of the literature I reviewed was that participants in this study described refusing to be isolated by the society and instead making efforts to educate the community and model acceptance for the child. Participants' descriptions of general poor support, especially the lack of support from the government, were consistent with the literature reviewed for this study. Participants highlighted the continued need for awareness, specialized services, childcare facilities, mental health support for mothers, and government support which was consistent with Lagunju et al.'s (2014) findings.

Seven out of the eight themes identified in this study were consistent with the literature reviewed for this study regarding the lived-experience of mothers raising children with ASD in Nigeria.

Theme 1: Low Societal Awareness About ASD

A majority of the study participants described low societal awareness and understanding about ASD in Nigeria among medical providers, schools, and teachers. Participants discussed how this low awareness contributed to the challenges they encountered in getting a diagnosis, understanding their child's condition, understanding what to do about the condition, and finding appropriate schools for their children to attend. This low societal awareness emphasized by participants coincides with the results of studies conducted by Lagunju et al. (2014) and Frank-Briggs (2012) that concluded that low awareness about ASD in Nigeria posed challenges to its diagnosis and management. Also, consistent with this finding of low societal understanding of ASD in Nigeria was the report by Igwe et al. (2011) on low ASD awareness among healthcare professionals. Further, Eseigbe et al. (2015) concluded that there is a gap in autism knowledge among general medical practitioners in Nigeria. Three participants of this study highlighted traveling out of Nigeria to seek diagnostic clarity about their children's condition, which was consistent with research findings by the CMUL (2014), which reported that some families travel out of the country to get help for their children's condition.

Participants reported changing schools as a result of the limited knowledge and experience of teachers about working with children with ASD. Paul and Gabriel-Brisibe

(2015) concluded that there is a poor level of awareness and knowledge about autism among teachers in the Nigerian community, which hindered early detection and special intervention. Lagunju et al. (2014) also reported the lack of special education programs for individuals with ASD in Nigeria. However, two participants identified having to learn and teach the schools how to work with their children. This finding was not reflected in the literature reviewed.

Theme 2: Cultural Attitudes and Acceptance About ASD

Most participants identified common beliefs in the Nigerian culture about ASD or other developmental conditions that influenced the community's reaction to mothers or children with ASD. Participants described cultural attitudes related to the church and spirituality and attitudes from family members and others in the society. Many participants identified that the typical belief among the Nigerian society is that ASD or developmental disorders resulted from spiritual or supernatural problems. The participants described the different challenges and poor acceptance experienced from different members of the society, including family, friends, and church. Six participants also described experiences where members of the society mentioned that the child with ASD was spoiled or poorly trained and blamed the mothers or parents for the child's behavior. This finding was consistent with previous research findings regarding the challenges to ASD created by negative beliefs and attitudes about ASD in Nigeria (Ajuwon & Brown, 2012; Audu & Egbochuku, 2010; Bakare et al., 2009; Eseigbe et al., 2015).

The finding in this study regarding society blaming mothers for child ASD-related behaviors was consistent with the research findings of Neely-Barnes et al. (2011) who found the public and extended family blaming mothers for a child’s autism-related behavior. Furthermore, 8 of the 10 participants identified stigmatization of the mothers or the children with ASD as a common occurrence in the Nigerian society, which often made mothers feel the need to protect or hide their children from the public. This finding is consistent with previous research by Audu and Egbochuku (2010) on parents’ isolation of their children from the community to avoid discrimination, and Frank-Briggs’s (2012) study that mentioned the high level of discrimination against children with invisible disabilities. However, the description of mothers’ spiritual faith identified by all participants as affecting their perspectives as mothers of children with ASD was not evident in the literature I reviewed for this study regarding ASD in Nigeria. These mothers described their spiritual faith as a source of strength and support that helped them find a purpose for their journey as mothers of children with ASD.

Theme 3: Neglect and Abuse

More than half of the participants of this study identified the issue of abuse and/or neglect of mothers of children with ASD and/or the children. Mothers reported the abuse was from caretakers and even family members. There were various forms of abuse, including physical and sexual abuse. In some cases, abuse involved physical torture of children with ASD at churches or prayer houses as well as isolation of the children and sending the children away from the family homes. Participants identified ignorance and negative beliefs about ASD in Nigeria as contributing to the abuse. The finding of this study regarding abuse or neglect to children with ASD in Nigeria corresponds with Nwanze's (2012) report of maltreatment or harm to children with ASD in Nigeria. Though Nwanze only discussed abuse to the children and not to mothers, other researchers reported that children and families living with ASD in Nigeria encounter rejection, discrimination, stigmatization, and abuse because the disorder is often associated with evil (Brandwork Nigeria, 2015; Ojo, 2015). Findings from this study are also consistent with the finding of previous researchers which revealed that individuals with mental disabilities are subject to abuse, neglect, isolation, as well as poor support and treatment (Audu & Egbochuku, 2010; Egbochuku & Imoitseme, 2012).

Theme 4: Inadequate Services

Many participants reported the lack of ASD intervention services in Nigeria. Participants described experiencing challenges in finding or assessing ASD intervention services after their children received a diagnosis of ASD. Services were either nonexistent, too far away, not accessible or available in the mother's geographical location, or the few services available came with additional costs. One participant articulated that she and her family relocated to a different city where there was an ASD center, and despite the relocation, she still had to cover the extra cost of accommodating a therapist from a different town to work with her child. This same participant described dissatisfaction for the poorly-trained therapist that was sent to work with her child. Another participant shared that after her child was diagnosed with autism, she encountered problems locating a center to take her child to for ASD intervention services.

Some of the participants verbalized that due to the lack of ASD centers or services, they had to go learn or read up on how to provide the intervention their children needed. One mother expressed that she embarked on biomedical interventions solo based on information she read on the Internet. Another mother reported that there were no early intervention programs available, and as a result she trained herself to provide services to her child.

These findings corroborated information from previous research. Eseigbe et al. (2015) found that in Nigeria the high cost of special care for children with ASD and the lack of professionals to provide specialized services were among the challenges to managing the disorder identified by respondents of their study. Also, findings from this study confirmed Frank-Briggs’s (2012) conclusion that lack of appropriate intervention services for autism and high cost of autism treatments are among the struggles faced by those affected with the disorder. Laguna et al. (2014) also reported on the lack of structured health-care services and special education programs for ASD in Nigeria. Nwanze (2012) reported that there is a scarcity of qualified staff and programs to assist families affected by ASD in Nigeria. Though Egbochuku and Imoitseme (2012) suggested that equipping parents with knowledge and intervention strategies for autism can help reduce challenges of managing the disorder, they did not specifically report about parents teaching themselves to provide needed services for their children with autism. According to Al Jabery et al. (2014), parents of children with autism who participated in their study expressed poor satisfaction with the quality of services provided to their children and highlighted a need for early intervention services.

However, the participants of their study were in Jordan and not Nigeria. Information that I reviewed from PSLC (2014) and TOWN (2014) indicated that some of the ASD organizations in Nigeria were established by parents of children with ASD or other developmental disorders who got frustrated with trying to find help and support for their children. However, PLSC and TOWN are not researchers; therefore, my finding in this study that due to the lack of ASD intervention services mothers had to learn or read up on how to provide to their children the intervention services the children needed is an original contribution to the scholarly literature.

Theme 5: Impact on Parents and other Family Members

In their responses, participants highlighted the effects of raising a child with ASD on other maternal roles and responsibilities and other immediate families as well as the economic, psychological, social, and physical health burdens associated with raising a child with ASD in Nigeria. This finding is in line with the results of previous research on the effects of ASD on parents. Lesi et al. (2014) reported that individuals with ASD and their families face financial, social, emotional, and health burdens due to the lack of knowledge about the disorder in Nigeria. Results from a study by Seymour (2013) also revealed that ASD has a negative impact on parental mental health. Karst and Van Hecke (2012) also reported that ASD has impacts on parents that included a financial burden, poor mental health, negative FQOL, and family conflicts.

All participants, regardless of socioeconomic status, described a significant economic burden associated with raising a child with ASD in Nigeria, which includes the cost of providing for the child’s needs and loss of employment in order to devote time to the care of the child. One participant emphasized the fact that due to high exchange rates for importation, the prices for the special diet items needed by the child were extremely high. In accordance with this finding is Nwanze's (2012) conclusion that parents of children with ASD and associated challenging behaviors, struggle to find care providers who would agree to care for their children, as a result most mothers end up resigning from their jobs to care for their children. Caregivers in Ajuwon and Brown's (2012) study reported mental and financial struggles related to caring for their children's intellectual disability. Of note, previous research reviewed did not discuss the high exchange rates for importation that influenced the prices for the ASD special diet items that contributed to the high economic burden of raising a child with ASD in Nigeria.

Participants also reported that their physical and mental health, as well as their social lives, were affected by raising a child with ASD. Most participants described mental health difficulties such as excessive worrying, tears, and stress. Participants explained that the psychological symptoms were related to the struggles of raising a child with ASD in Nigerian and general concerns for the child. Previous research findings reviewed reported that parents and caregivers of children with ASD in Nigeria experience psychological distress associated with caring for a child with ASD (CMUL, 2014). Bello-Mojeed et al. (2013) discussed how the health and psychosocial well-being of mothers in Nigeria caring for children with ASD was impacted due to limited knowledge of ASD and lack of services to provide relief to these families. Also, parents in Shtayermman's (2013) study reported increased stress and low marital satisfaction as a result of caring for a child with ASD. Furthermore, results from the study by Mount and Dillon (2014) showed that parents reported mental and physical exhaustion as well as struggles in relationships and family functioning due to the demands associated with raising a child on the autism spectrum.

Theme 6: Refusing to be Isolated by Society

A significant number of study participants, 7 of the 10 participants, described refusing for themselves or their children to be isolated by the society. Instead, the participants highlighted making efforts to educate the community. The participants also reported modeling acceptance and love of the child with ASD to others to increase understanding and support for ASD in Nigeria. One participant expressed that she took her son wherever she went and she tried to explain to people that her child has autism. Another participant verbalized that she talks about autism wherever she goes. She added that she makes sure her child is accepted in the society or she ignores people and places that are not accepting of herself and her child. Two participants shared that people would usually react to or accept a child with ASD based on how parents present and treat the child in front of others. This finding was not consistent with previous research on ASD in Nigeria reviewed for this study. Therefore, this is an original contribution to the literature on ASD. Mothers of children with ASD engaging in behaviors such as revealed by this finding can be commended and empowered, and others can be motivated to behave similarly.

Theme 7: Nature of Support

Participants described the nature of support received and not received from various members of the society. One participant expressed that there was no support from the government and she did not receive support from her friends because most of them lacked awareness about autism. Another participant explained that most people she knew did not understand autism and wanted nothing to do with the disorder. The insufficient support for ASD in Nigeria, including the significant lack of support from the Nigerian government, identified by all participants was consistent with previous research findings about ASD in Nigeria. Bakare et al. (2011) concluded that the negative perceptions about ASD in Nigeria negatively impacted the level of support and acceptance for the disorder. According to Audu and Egbochuku (2010), in Nigeria there is a lack of understanding and support from the public and a lack of governmental programs for individuals with autism and their families. Nwokolo (2010) reported that the Nigerian government has been slow in making special programs available to individuals with ASD and their families due to their lack of recognition of ASD as a disorder requiring special treatments.

Ajuwon and Brown (2012) found that families of individuals with intellectual disabilities listed support from others as one factor relevant to their family quality of life. Also, in 2015 the U.S. ambassador to Nigeria encouraged increased public awareness of ASD, changes in policies and improved support for individuals with ASD and their families (U.S. Diplomatic Mission Nigeria, 2015). However, this low support from the government and others reported by participants of this study indicated that this is still an issue encountered by parents of children with ASD in Nigeria. Therefore, the results of this study help to further highlight that the issue of low support for ASD in Nigeria requires attention to improve outcomes for children with ASD and their families.

Apart from ASD services, participants of this study described their perceptions of what they considered as support to include acceptance, information, encouragement, prayers, payment of the child's ASD related bills, and scholarships for school fees. Participants reported these forms of support sometimes came from their husbands, family, friends, and some unknown individuals in the community. One participant expressed that the support she needed the most was information on what to do, and added she gained that from others with knowledge about the disorder. Another participant described her mother's inquiries about the welfare of her child with ASD and her mother praying with her as support. One participant vocalized that her friends were open and accepting of her child with ASD because she took the time to explain the child's condition to them. Furthermore, two mothers described receiving financial assistance or scholarships to pay for school fees from unknown individuals or the ASD center. The literature reviewed for this study did not report what parents of children with ASD considered to be support, neither did the literature reviewed provide parents' descriptions of the type of support they received from family and friends. Thus, this finding in this study contributes to the scholarly literature and also provides different ways parents of children with ASD may be supported.

Theme 8: The Way Forward

All participants identified the continued need to increase awareness, information, and education of the public as a way to improve understanding and support for mothers in Nigeria raising children with ASD. One participant indicated that discrimination and stigmatization can only be reduced with education. A second participant expressed the belief that half of the challenge of raising a child with ASD in Nigeria would be resolved if everyone in the nation had awareness about autism and understood how mothers of children with the disorder felt. According to Bakare (2014), addressing the challenges to the treatment and management of ASD is critical to improving the current situation of the disorder in Africa. Bello-Mojeed et al. (2013) also reported that increasing awareness about the impact of ASD on parents may help healthcare staff provide better services to those affected by the disorder.

Participants described the need to educate everyone across the country, including parents, churches, children, and law enforcement officials about ASD. One participant articulated that ASD education should also target children since the current adult generation is already deeply rooted in discrimination and stigmatization of those affected by ASD. Participants also highlighted the need for government support, specialized services with well-trained therapists, daycare facilities, special schools with trained teachers, and mental health support for mothers. This finding is similar to the peer-reviewed literature by Al Jabery et al. (2014) regarding a need for community awareness about autism, early intervention services for the children with autism, and counseling services for their families. Though Al Jabery et al. based their study on a sample from Jordan. Findings from this study are also consistent results by Egbochuku and Imoitseme (2012) that indicated the importance of increasing autism knowledge among the Nigerian public in order to improve outcomes for the parents. Additionally, Ajuwon and Brown (2012) highlighted the need to educate the public about ASD and influence the development of government policies to improve outcomes for those affected.

However, unlike previous research, findings from this study drew attention to the unique opportunity present in Nigerian churches as an avenue to reach and educate more people about ASD and how parents of children with the disorder may be supported. This finding is particularly relevant in the Nigerian society that participants described as “very spiritual.” Also, contrary to previous literature reviewed, this study highlighted the need to focus on enlightening the younger generation about ASD in order to effect positive change in the future for individuals affected by the condition.

Conceptual Framework and Finding Interpretations

The conceptual framework that guided this study was Bronfenbrenner’s (1977) EST. The theory particularly deals with the circumstances and activities within an individual’s environment that influences the development of the individual (Bronfenbrenner, 2000). Therefore, EST attempts to understand individuals, their behavior, and their functioning within the context of their dwelling environment (Suarez-Balcazar et al, 2014). The version of the EST applied in this study consists of four mutually connected structures called the microsystem, mesosystem, exosystem, and the macrosystem (Bronfenbrenner, 1977).

An essential aspect of EST is that the development of an individual involves a continuous process of mutual interaction between the developing individual and the other relations and activities within their shared primary environment (Bronfenbrenner, 1994). Also, important to Bronfenbrenner’s theory is the concept that both the individual and the environment mutually influence one another (Rosa & Tudge, 2013). These important aspects of the EST were evident in the descriptions provided by participants as part of the experiences of mothers raising children with ASD in Nigeria.

Microsystem

The microsystem is the level closest to an individual, with groups and activities in the environment directly interacting with the individual (Bronfenbrenner, 1994). These different groups and relations in the individual’s main dwelling can have impact on the individual’s experiences and behavior (Bronfenbrenner, 1977). Some of the groups at this level of the ecological system may include the person’s family, friends, church, neighbors, or paid caregivers. Participants in this study described interactions with and being influenced by different microsystem groups within the Nigerian environment and in turn also influencing the environment due to their child’s ASD. Participants described direct experiences of challenges with family, friends, and churches due to poor understanding of the child’s condition. One participant described abuse, rejection and being divorced by her husband as a result of having a child with ASD. Some mothers indicated that their families and others thought their children’s ASD related behaviors were the result of overindulgence or poor training. One participant relayed that due to her child’s ASD condition she encountered the most challenges at the church where people sometimes suggested she be more prayerful. Another participant shared that she did not receive any support from friends because her friends lacked understanding of autism.

In line with Bronfenbrenner’s (1994) account of a mutual nature of interaction and influence between the individual and others in the same dwelling environment, participants of this study also described making efforts that in turn impacted some of the groups in their immediate environment. For instance, participants described making deliberate efforts to maintain their relationships or responsibilities to spouses or other children. One participant described receiving acceptance from friends because she took time to explain her child's condition. These contacts and interactions between participants and the different institutions described as influencing their experience are consistent with microsystem activities of the ecological systems (Bronfrebrenner, 1977).

Mesosystem

At this level of the ecological system, an individual's experiences and developments are influenced by the interactions between the different microsystem groups in the individual's environment (Bronfenbrenner, 1977). Participants of this study described being impacted by interactions at this level of the ecological system. Two participants reported that the teachers at their children's school placed their children at the back of the classroom because the teachers lacked understanding on how to work with individuals on the autism spectrum. One participant relayed that some people at the Sunday school in her church stared at her child and whispered amongst themselves when they saw her son. Another participant shared that some of her friends did not want their children to play with her child. Consistent with EST, these identified interactions between the children with ASD and different microsystem groups in Nigeria influenced the mother's experiences and subsequently their behaviors or actions. Some participants described changing their children's school or teaching the schools or teachers how to care for the child with ASD, educating family, friends, or people at the church about autism to increase understanding. Many participants refused to isolate themselves or their children and instead modeled acceptance and love for the child in order to increase the community's acceptance and support.

Exosystem

According to Bronfenbrenner (1977), an individual's experiences and development can be indirectly impacted by formal and informal organizational activities occurring in the individual's primary dwelling. These organizations may include government agencies, healthcare centers, the economy, or other neighborhood agencies. Participants in this study described that their experiences and behaviors as mothers raising children with ASD in Nigeria were influenced by challenges with their child's medical providers, schools, lack of well-trained therapists, lack of daycare facilities for children with ASD, and the lack of governmental programs or support for ASD. Most participants described making multiple visits to healthcare agencies seeking answers and understanding of the child's condition. Participants reported encountering challenges in finding or assessing ASD intervention services for their children, and four participants disclosed that they eventually had to learn how to provide interventions services for their children themselves. Six participants explained that they either resigned their jobs, were unable to return to work or devote sufficient time to their business due to the need to devote time to caring for their children's ASD condition. This is an example of an individual impacting their ecological system, because not being able to work can affect household income and the individual's contribution to the economy. Consistent with the ecological systems theory, the interactions of the mothers with these formal and informal programs or the lack of such program in their dwelling environment influenced their experiences and behaviors as mothers raising children with ASD in Nigeria, but the mothers in turn also influenced their environment (Bronfrebrenner, 1977).

Macrosystem

Activities at the macrosystem level of the environment such as cultural practices, beliefs, attitudes, customs, laws, rules or regulations, affect the individual's development and functioning (Bronfenbrenner, 1997). At this level of the ecological system, the major events identified by most participants as significantly influencing the experience of mothers raising children with ASD in Nigeria included poor understanding and typical belief in the culture that ASD and other developmental conditions are spiritual or supernatural problems. Also, the opinion in the Nigerian culture that children with ASD are poorly trained by parents also falls into this level. These negative cultural beliefs and opinions about ASD in this environment contribute to the stigma, discrimination, and other negative attitudes and reactions towards children with ASD and their families. The mothers described efforts to impact this level as well by refusing to be isolated and providing education about ASD to enlighten the community and increase acceptance and support. The spiritual faith described by all participants as affecting their perspectives, a source of strength and support, and helping them find a purpose for their journey as mothers of children with ASD also fits into this level of the ecosystem. However, in this case the spiritual faith identified by the mothers was a positive factor to their experiences.

The macrosystem is termed the “societal blueprint” as it is the layer that tends to dictate what happens in the environment and also impacts activities at other levels (Bronfenbrenner, 1994). It can be argued that the negative belief and low awareness about ASD identified by most participants is the all-embracing event that has determined the occurrences impacting these mothers' experiences of raising a child with ASD in Nigerian. The negative beliefs and low awareness about ASD reported by participants contributes to the poor acceptance and lack of support from different microsystems groups, the nature of interactions at the mesosystem level, the inadequate services and programs at the exosystem level, as well as the cultural attitudes at the macrosystem level. Hence, most participants identified the continued need for awareness about ASD across the nation as a way to improve the situation or outcomes.

The interconnection and mutual interactions between these different systems including the developing individual, as posited by Bronfenbrenner's theory, was also evident in the experiences described by participants. Due to the activities at the four ecological systems, participants reported different challenges such as difficulties getting a diagnosis, low acceptance, negative treatments or attitudes from family/friends/the public, inadequate services, and poor government support. Some of these challenges directly or indirectly contributed to personal, physical, psychological, economical, and social impacts associated with raising a child with autism. However, it is important to note that despite these effects, the participants also influenced the systems through their efforts such as refusing to be isolated, educating the society about ASD, or learning to provide the intervention their children needed.

Summary

The findings of this research study are consistent with Brofenbrenner's (1977) EST that an individual's behavior and functioning is influenced by four connected environmental systems within the individual’s dwelling (Shogren, 2013). Most participants described events or activities in the four different levels of the ecological systems that impacted their experiences as mothers of children with ASD in Nigeria, and in turn caused the participants to engage in activities that influenced their environment as well in regards to ASD. The results of this study identified one or more interacting circumstances and activities in the microsystem, mesosystem, exosystem, and the macrosystem within the Nigerian environment that influenced mothers’ behavior or experiences as mothers of children with ASD in Nigeria.

Limitations of the Study

A limitation of this study was the small sample size, only 10 participants who self-identified and volunteered as mothers raising children with ASD in Nigeria made up the total sample size. The 10 participants who volunteered for the study ranged in age from 34 to 69 and were all mothers of children on the autism spectrum who resided in Nigeria. The ages of the participants’ children with ASD ranged from 4 to 36 years. The individual descriptions provided by the research participants represented their experiences and perceptions on the phenomenon and may not be representative of the general population of parents of children with ASD in Nigeria. Therefore, the study was limited by the small sample size and individual perspectives. All participants were mothers of children with ASD who provided important insights into the experience of raising a child in Nigeria from their personal journeys. Since this study focused mainly on mothers, the general population of parents raising children with ASD in Nigeria may not be appropriately represented by this sample. Another major limitation of the study was that the majority of the participants were college educated to some degree. The fact that they were college educated affected their ability to be active agents in the care of their children. The participants also had the knowledge of how to be advocates for their children.

Also, given my personal and professional experiences, researcher bias was acknowledged as a potential limitation of the study. To control for this bias, I was aware of this potential bias and took care to remain objective. I engaged in bracketing by journaling my thoughts, beliefs, and any prejudgments which helped kept my mind cleared and open to only the participants’ true perspectives and experiences regarding the phenomenon of raising a child with ASD in Nigeria. I also used an interview guide which was a list of semistructured open-ended interview questions that encouraged participants to provide their responses and express their lived experiences as it relates to the phenomenon. The use of a good audio device to record interviews, accurate transcription of interview data, and member checking also helped to attend to limitation issues related to potential researcher bias (Creswell, 2013). A further limitation of the study was the indirect nature of the interview from the participants. Due to the fact that the interview data represented the lived-experience of the phenomenon from each participant’s perspective, the resulting data were therefore a representation of the participants’ experiences and my interpretation through analysis.

Recommendations

In this study, I attempted to address parents' lived experiences of raising children with ASD in Nigeria. The 10 participants who participated in this study were mothers from two major cities in Nigeria, Lagos and Port Harcourt. Thus, further research addressing the experience of fathers of children with ASD in Nigeria is recommended. Insights provided by fathers into the experience of raising a child with ASD in Nigeria may contribute to a more complete picture of parents' experiences in raising children with ASD in Nigeria. Also, future research could focus on indigent families or parents in villages or rural parts of Nigeria raising children with ASD, to gain insight into their experiences and perceptions. Such a study may contribute to a more generalized knowledge of the experiences of families raising a child with ASD. Furthermore, the majority of the participants in this study were college educated to some degree. Therefore, there is a need to investigate the experiences of mothers raising children with ASD in Nigeria who are of lower educational levels. Such a study would contribute to a more conclusive account of the experience of mothers raising children with ASD in Nigeria.

Participants in this study described refusing to be isolated by the society and educating others about autism, with one participant adding that due to her personality she talked about autism wherever she went. Individual personality or traits as a contributing factor to parenting a child with ASD was not a factor explored in the literature for this study. The original version of the EST that focused on the four interconnected environmental systems as conditions for human development was used in this study to explore the experiences of mothers raising children with ASD in Nigeria. However, given the insights shared by participants, individual characteristics or traits as a factor in development and experiences is a recommended area for further research. Therefore, a potential area for future research is the impact of individual characteristics or traits on the experiences of parents of children with ASD in Nigeria. Research in this area could examine the influence of individual characteristics on the management and outcomes of parental experiences of raising a child with ASD. Overall, considering the poor level of awareness of ASD in Nigeria, any additional research into the situation of ASD for individuals and families impacted in Nigeria would contribute to the literature and possibly inform practices leading to improved outcomes for this population.

Implications

Implications for Positive Social Change

The implications of this study for positive social change include contributing to ASD awareness in Nigeria, and an increase in knowledge and understanding about the effects of negative beliefs and opinions about ASD on parental experiences. The study may also contribute to an increase in the knowledge of how different systems within the Nigerian cultural setting influence the experiences of families affected by ASD. Additionally, information from this study could improve understanding of ASD among healthcare providers, educators and other providers working with families of individuals with ASD, subsequently leading to better services. Also, using the knowledge and information from this study, individuals in the general Nigerian community may then improve their levels of acceptance and support for individuals affected by ASD. Furthermore, findings could suggest possible target areas for planning and advocating for changes in policies and programs for those affected by the disorder.

Methodological Implications

The rate of ASD diagnoses is increasing in populations around the globe possibly due to improved ASD awareness, improved diagnostic criteria and tools, better reporting, and availability of service for those with ASD (CDC, 2014; Hall & Graff, 2011; Mori et al., 2009; WHO, 2013). However, in Nigeria the level of awareness, knowledge, and support for individuals with ASD is still very low (Bakare et al., 2009; Igwe et al., 2011). This poor awareness and understanding of ASD in Nigeria negatively impacts the lives of those affected with the disorder, and increasing societal awareness of the disorder is an important step toward improving the lives of those affected (U.S. Diplomatic Mission Nigeria, 2015). Despite the situation of ASD in Nigeria and the high need for more awareness to improve lives for individuals affected, there is a dearth of qualitative literature detailing the experiences of parents raising children with ASD in Nigeria. The participants of this study provided in-depth information, from their perspectives, regarding the experiences of raising a child with ASD in Nigeria that helped to fill the identified gap in the literature. Therefore, the methodological implication of this study is that an in-depth description of the experience of raising a child with ASD in Nigeria was achieved from participants of the study using Moustakas’ (1994) steps and processes for transcendental phenomenological analysis.

Theoretical Implications

Individual development and experiences throughout the lifespan are greatly affected by their main environment (Bronfenbrenner, 1977). Focusing on activities at all levels of the environment is relevant to a better understanding of factors affecting the management of ASD and the experiences of families affected by the disorder (Bernier et al., 2010). Further, an increased understanding of ASD within different cultural settings is significant to positive outcomes in the lives of individuals affected (Alqahtani, 2012; Kang-Yi, 2013; Ravindran & Myers, 2012). The participants of this study provided valuable insight, from an emic perspective, regarding how families of children with ASD struggle and cope with the disorder in Nigeria, and how the Nigerian environment and culture impact their experiences. Subsequently, the theoretical implication of this study is that it contributes to an increased understanding of the different factors and the nature of interactions at all levels of the Nigerian environment impacting the behaviors and functioning of mothers in Nigeria raising children with ASD. Understanding the lived-experiences of these mothers contributes towards understanding how to best support individuals with ASD and their families in Nigeria and improve overall outcomes for them.

Recommendations for Practice

Participants in this study described how low awareness about ASD among the government, medical population, schools, and the general public in Nigeria have made raising a child with ASD in this community a challenging experience. The insights shared by the participants of this study could provide family members and friends, churches, educators, healthcare professionals, the government, and other members of the community valuable information on how lack of support negatively impacts mothers raising children with ASD in Nigeria. According to Bello-Mojeed et al. (2013), increasing the understanding of the healthcare population regarding the health and psychosocial impact of ASD on families or caregivers may contribute to improvement in services provided. Therefore, a specific recommendation of this study for practice is that it could be used to educate and train educators, healthcare professionals, and other providers working with families of individuals with ASD, to improve their understanding, sensitivity, and empathy that would contribute to provision of better care to these families. Also, the findings of this study could emphasize possible target areas for planning and advocating for changes in policies and programs for improved services and treatment of those affected by ASD.

Conclusion

The purpose of this qualitative, transcendental phenomenological study was to explore and understand the perceptions and lived experiences of mothers raising children with ASD in Nigeria. Exploring with participants their descriptions of what it means to raise a child with ASD in Nigeria and how the different systems within Nigerian cultural setting impacted their experiences has provided valuable insights and contributed to further knowledge in the field. This knowledge may contribute to ASD awareness in Nigeria, provide valuable insight to others regarding the situation of ASD within the Nigerian cultural context, and perhaps help to improve the level of acceptance, sensitivity, treatment, and support of family members, friends, churches, educators, healthcare professionals, the government, and other members of the community for individuals affected by ASD. Urging for improvement in the public’s awareness of ASD, advocating for changes in policies and programs, and improvement in services is crucial to effect positive change for children and families affected by the disorder.

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Appendix A: Study Invitation Flyer

Would you like to share your story about raising a child with autism spectrum disorder (ASD) in Nigeria?

You May Qualify for This Study If:

- You are a mother raising a child with ASD between the ages of 3–18 years in Nigeria.
- You currently live in Nigeria.
- You have at least one child diagnosed with ASD who is living in the same house with you.
- You are fluent in English.
- You are willing to take part in a face-to-face interview.

The purpose of the study is to describe the experiences of mothers raising children with ASD in Nigeria. The study will focus on your personal journey, including the struggles and the support you received as a mother raising a child with ASD within the Nigerian culture. Sharing your story may help improve awareness and acceptance for ASD in Nigeria and may lead to changes in policies, programs, and services for individuals with ASD and their families.

What You Will Be Asked to Do:

If you agree to take part, you will be asked to participate in one audio recorded interview that will last about 60–90 minutes. The interview will be conducted at a time and location convenient for you. A follow-up contact with you may be needed and may take place by phone.

<u>All information will be kept confidential and used only for the purpose of the study.</u>

This research project is part of a dissertation study conducted by Joyce Ulofoshio a Walden University doctoral candidate.
If you are interested, please contact Joyce Ulofoshio at xxx-xxx-xxxx or by e-mail at xxxxx.xxxxxxxx@waldenu.edu

Appendix B: Demographic Information Form

1. Participant ID: ______________________________________ Phone: _________________________ E-mail:________________________

2. Age: _________________________

3. Place of birth (City, State, Country): ____

4. Highest level of education completed: ____

5. Are you fluent in English Language? Yes: ______ No: ________

6. Marital Status: ____

7. Are you employed? _____ IF yes: Full time ______ Part Time ______

8. Occupation: ____

9. Current living arrangement? ____

10. Please provide some brief information about your child (ren) with autism

Child 1	**Child 2**
Age __________	Age __________
Sex __________	Sex __________
Grade/School level __________	Grade/ School level __________
Child 3	**Child 4**
Age __________	Age __________
Sex __________	Sex __________
Grade/School level __________	Grade/ School level __________

11. Are you the primary caregiver at least 50% of the time? ____

Appendix C: Guiding Interview Questions

1. Tell me about your experiences as a mother raising a child with ASD in Nigeria.
2. When and how did you first find out that your child has ASD? What was your reaction?
3. What are your perception and experiences of the reactions of family, friends, and the community to your child's ASD?
4. What kind of support have you received from family and friends?
5. Tell me your experiences with your child's school?
6. Tell me about programs that are available to help you and your child.
7. How does raising a child with ASD affect your role in your family and community?
8. Tell me how raising a child with ASD has affected your social life.
9. How has raising a child with autism in Nigeria affected you physically and psychological?
10. Please describe for me, from your personal experience, the economic impact of raising a child with ASD in Nigeria.
11. Tell me about the challenges you encountered as a mother raising a child with ASD.
12. Please describe the type of support you have received as a mother raising a child with ASD.
13. Tell me your perspective of how mothers raising children with ASD in Nigeria can be better supported.
14. Is there anything else that you would like to share with me that would help me further understand your experiences as a mother raising a child with ASD in Nigeria?