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Attitudes of Nigerian Mothers Toward Children With Autism Spectrum Disorder

Valentine Ntoo Chukwueloka
Walden University

Walden University

College of Health Sciences

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Valentine Chukwueloka

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Review Committee
Dr. Magdeline Aagard, Committee Chairperson, Health Services Faculty
Dr. Kimberly Dixon-Lawson, Committee Member, Health Services Faculty
Dr. Vincent Agboto, University Reviewer, Health Services Faculty

Chief Academic Officer
Eric Riedel, Ph.D.

Walden University
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Abstract

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Valentine N. Chukwueloka

MHA, University of Phoenix, 2010

MA, Wilfrid Laurier University, 1993

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Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Abstract

Autism spectrum disorder (ASD) is a form of developmental disability that affects many children in the U.S. and abroad. The Center for Disease Control (CDC) has indicated that 1 out of every 68 children is diagnosed with ASD in the United States. However, there was limited literature about the attitudinal dispositions of Nigerian mothers toward children with ASD and their lived experiences with a child with autism. The purpose of this qualitative study was to explore the attitudes of Nigerian mothers toward their children with autism. The theoretical foundation of this study was the variation of the social relational understanding of disability propounded by Carol Thomas. The research questions that guided this study focused on the attitudes of Nigerian mothers toward their children with ASD and the lived experience of a Nigerian mother living with a child with autism. This study utilized the hermeneutic phenomenological approach to explore the lived experiences of 8 Nigerian mothers with children with autism. Semi-structured interviews were used to gather data from the participants. Data was coded, categorized and themes were identified through qualitative data analysis. Significant findings of this study included that ASD is a developmental disability and there was positive relationship between children with autism and their families. As such, the knowledge about ASD as a developmental disability and the warm relationship among families with children with autism should be extended to members of the community to increase awareness about ASD. This study's implication for social change is that it can assist governmental agencies and important stakeholders develop better programs and services that will help to increase awareness and strengthen positive dispositions toward children with autism.

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Dedication

This dissertation is dedicated to the loving memory of my beloved uncle, Samuel Chukwunyekobam Chukwueloka. You were a great uncle. May your gentle soul continue to rest in peace.

Acknowledgments

Special thanks to my wife, Geraldine and my loving children for all the love and support they have given me during my academic career. I also want to thank my dissertation chair, Dr. Aagard for her guidance and support. Also, I give special thanks to Dr. Kimberly Dixon-Lawson (committee member) and Dr. Vincent Agboto (URR) for their support throughout this dissertation.

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Chapter 1: Introduction to the Study

Introduction

This study explored the attitudes and perceptions of Nigerian mothers toward children with autism spectrum disorder (ASD). This study was necessary given the increasing numbers of children diagnosed with this disorder and the apparent lack of awareness about ASD, its development, and growth in Nigeria. This study's implication for social change is its contribution to the knowledge that public health officials and policy makers could utilize to implement programs and services for children with ASD in Nigeria.

This chapter is divided into different sections including the background of the study, the problem statement, the purpose of the study, the research questions, and theoretical framework of the study and the nature of the study. Additionally, this chapter includes the definition of terms, the assumptions, scope and delimitations, as well as the limitation of the study.

Background of the study

This qualitative research study explored the attitudes and perceptions of the Nigerian mothers toward their children with autism. The focus of this study was primarily Nigerian mothers from the Southeastern part of Nigeria who voluntarily agreed to participate in this study.

A close study of the literature on ASD in Nigeria showed that there was limited awareness about ASD among Nigerian mothers, caregivers, and healthcare professionals (Bakare et al, 2009; Bakare & Munir, 2011; Igwe et al, 2011). There was very limited

support from the government and no laws that recognized ASD as a developmental or neurodevelopmental disorder (Audu & Egbochuko, 2010). In spite of these difficulties, there were few privately owned ASD centers or healthcare facilities in Nigeria that catered to the needs of children with ASD. However, some parents and caregivers were still hesitant to access their services. Instead, some parents took their children to spiritual churches and traditional healers for treatment (Audu & Egbochuko, 2010; Bakare & Munir, 2011). It was notable that the treatments provided by spiritual churches and traditional healers to children with ASD were harmful and have resulted to deaths of some autistic children in Nigeria (Audu & Egbochuko, 2010; Bakare & Munir, 2011).

There was an urgent need to study the lived experiences of the Nigerian mothers who cared for the needs of their children with autism. More importantly, it was crucial to explore and explain the underlying reasons behind the attitudinal dispositions and perceptions held by the Nigerian mothers toward their children with ASD.

Statement of problem

ASD (Autism Spectrum disorder) as a type of developmental disability has not been thoroughly studied in the Nigerian society. There was a great need to increase the knowledge of ASD in Nigeria to help mothers understand better ways to address the ever growing needs of their children with ASD (Bakare & Munir, 2011). It was also necessary to examine the societal and family structures in this culture and to understand their various influences on the attitudes of the Nigerian mothers toward their children with ASD.

It appeared that Nigerian society had not fully comprehended that ASD is a form of developmental disability. As as result, there were limited facilities that parents and care givers could access to provide care to children with ASD. A more comprehensive understanding of the attitudes and perceptions of Nigerian mothers toward ASD was necessary because this was the segment of the population that delivered and implemented care and services provided to children with ASD.

Purpose of the study

This qualitative study explored the attitudes and perceptions of Nigerian mothers toward their children with ASD. The study utilized a hermeneutic phenomenological approach to collect, analyze, and interpret data to explain the underlying reasons for the attitudes and perceptions held by the Nigerian mothers as they were confronted with the challenges of raising children with ASD.

The sample for this research was drawn from Nigerian mothers from the Southeastern part of Nigeria who have children who were diagnosed with ASD. The participants included the Nigerian mothers who were affiliated with ASD centers from the Southeastern part of Nigeria.

Research questions

1. What are the attitudes of the Nigerian mothers toward their children with autism spectrum disorder?
2. What is the experience of a Nigerian mother living with a child with autism spectrum disorder?

Theoretical framework

The theory chosen for this research was the variation of the social relational understanding of disability that was propounded by Carol Thomas. Carol Thomas (1999) indicated that "disability is a form of social oppression involving the social imposition of restriction of activity on people with impairments and the socially engendered undermining of their psycho-emotional well being" (p.60). Thomas further stated that though "impairments" bring about inhibitions, a state of being becomes a disability when the sociey "socially imposed" on the impaired person several barriers that prevents them from growth and full participation in the society (p.581).

This theory has been used to study the lived experiences of and difficulties encountered by disabled persons in the society. It has also been used to study the lived experiences of women in regard to the challenges they have encountered in the society (Thomas, 1999). Overall, this theory has provided the framework neeeded to identify the inhibitions and barriers placed on disenfranchised individuals in the society and has enabled policy makers to introduce inclusive policies.

For this particular study, this theory helped to better portray ASD as form of disability that has not been sufficiently addressed given the lack of awareness, inadequate services, and lack of recognition of this disorder by the Nigerian government. Additionally, this theory helped to explain the underlying factors that have contributed to the attitudes and perceptions held by the Nigerian mothers toward their children with ASD.

Nature of the study

This study adopted a hermeneutic phenomenological approach to better understand and explain the attitudes and perceptions held by the Nigerian mothers toward their children with ASD. The hermeneutic phenomenological approach was useful because it enhanced the ability to obtain sufficeint data needed for description and interpretation of the lived experiences of these mothers and their relationship with their autistic children.

As Ajjawi & Higgs (2007) have indicated,

In hermeneutic phenomenology the interview serves very specific purposes. First, it is used as a means of exploring and gathering of narratives (or stories) of lived experiences. Second, it is a vehicle by which to develop a conversational relationship with the participants about the meaning of an experience (p.619).

I used the semi-structured interview approach to gathering data for this study because it made it easier to elicit rich data. The data collected through interviews were transcribed before analysis. Furthermore, I used to memos taken during the interview to better understand the transcribed interview text. As part of the data analysis and interpretation, I used hand coding for analysis. I coded the data by assigning key words and phrases linked to ideas and units of meaning that were discovered in the interview text. Thereafter, I placed the various codes into categories. I further analyzed the codes and detected seven themes, which constituted the findings of this study.

Definitions

Attitude: The Merriam-Webster (2015) has defined attitude as "a feeling or way of thinking that affect a person's behavior." Attitudes are also acquired through "direct and indirect experiences and interactions with people, objects and events" (Favazza & Odom, 1997, p. 405). Favazza and Odom (1997) further indicated that "attitudes are manifested behaviorally by a predisposition to act in a positive or negative way when the person encounters the attitude referent" (p.405)

Autism spectrum disorder (ASD): Autism spectrum disorder (ASD) is a form of developmental disability that generally manifests in infancy. It is characterized by impairments/deficits in language, communications, and social skills, as well as the presence of stereotypical/ritualistic behaviors (Dawson 2008; Faras, et al, 2010; Lord, 2010; Samms-Vaughn & Franklyn-Banton, 2008; Thomas et al, 2007).

Autism centers/facilities: These are places that are equipped with skilled professionals, services and equipment for training autistic children.

Healthcare facilities: These include medical centers, medical offices, teaching hospitals and designated places that provide healthcare services to people.

*Healthcare professionals***:** Individuals who have received training in the field of health care and are qualified to provide services to the public.

Nigerian mothers: For the purpose of this study, the Nigerian mothers were the biological mothers, foster care mothers, adoptive mothers, and the Nigerian mothers who had legal guardianship over children with autism spectrum disorder.

Assumptions

The participants for this study were mothers with autistic children who were from the Southeastern part of Nigeria. I assumed that these mothers would provide honest and detailed answers to the questions posited to them. To obtain honest answers, the confidentiality and anonymity of the participants were protected, which they were told of in the informed consent process.

Scope and Delimitation

This study focused on the attitudes and perceptions held by the Nigerian mothers toward their children with ASD. There are several topical issues about the growth and development of ASD; these issues were not addressed in this study. However, the topic chosen for this study was useful to provide a much better understanding of ASD and portrayed the attitudinal dispositions of the Nigerian mothers toward their children with ASD.

There were issues of delimitation with the number of participants who were willing to participate in this study. Although efforts were made to recruit participants from the multiple geographical settings in Southeastern part of Nigeria, it was difficult to obtain the desired number of participants. Despite the efforts I made in explaining the purpose of the study and the benefits of the research, some mothers were unwilling to divulge information about their experiences with their children with ASD. Others found this study emotionally disturbing and decided against participation.

Limitations of the study

The overall aim of this study was to elucidate the lived experiences of Nigerian mothers and their attitudinal dispositions toward their children with ASD. However, it has to be emphasized that the data for this study was obtained from the Nigerian mothers who were from the Southeastern part of Nigeria. Consequently, there were issues of limitations regarding the generalization of findings from this research to other geographical settings in Nigeria. However, I applied rigor when conducting interviews by telephone and used open-ended, semi-structured interview questions to obtain detailed information about the lived experiences of the willing participants.

Another limitation of this study was that the participants for this study were mothers who were literate in the English language. There are several dialects and variations of Igbo language spoken in the Southeastern part of Nigeria. To avoid language problems, it was imperative to recruit mothers who were literate in English.

It is also important to note that only mothers who currently utilize ASD services were included in the study; therefore, I gathered only the perspectives of mothers who were already familiar with ASD services and not from mothers who are not utilizing ASD services. The mothers not included in the study may have different attitudes and beliefs since they are not a part of the ASD care system.

Significance

I explored the attitudes and perceptions of the Nigerian mothers toward children with ASD because the mothers in Nigeria are by tradition the primary caregivers for their children. As such, their attitudes and perceptions toward their children with ASD could

make a positive or negative difference in the lives of children with ASD. Nigerian mothers also have considerable authority over their children and determine the types of care and services that are provided to their children.

In addition to offering data that could lead to a more comprehensive understanding of the attitudes and perceptions of Nigerian mothers toward their children with ASD, the information gathered from this study could help public health agencies develop better training programs given to public health professionals and enhance their responses to children with autism in Nigeria.

Finally, this study could have implications for positive social change because the results of the study could help policy makers to develop better programs that could encourage positive disposition toward children with ASD. This could also sensitize Nigerian mothers to the needs for early recognition of the symptoms of ASD in their children.

Summary

This chapter discussed the background of this study, the problem statement and the purpose of the study. Additionally, this chapter discussed the research questions, theoretical framework and the nature of this study. Finally, this chapter discussed the definitions, assumption of this study, scope and delimitation, limitation and the significance of this study. Chapter 2 will discuss the literature reviewed for this study.

Chapter 2: Literature Review

Introduction

ASD is a form of developmental disability that affects many children. The Center for Disease Control (CDC, 2014) has reported that one out of every 68 children is diagnosed with ASD in the United States. ASD generally manifest in early infancy and is characterized by impairments/deficits in language and communications and social skills, and the presence of stereotypical/ritualistic behaviors (Dawson 2008; Faras, et al, 2010; 2008; Lord, 2010; Samms-Vaughn & Franklyn-Banton: Thomas et al, 2007). The understanding, diagnosis, and treatment of ASD have been deeply influenced by various theories on ASD over the past decades. From the earliest descriptions of infantile autism by Leo Kanner and Hans Asperger in the 1940s to the present, there have been various theories on the nature of ASD. Some of these theories included the cognitive theories of autism and the neurological theories of autism spectrum disorder (Denkla, 1996; Premack & Woodruff, 1978; Rajendran & Mitchell, 2007; Wimmer & Perner 1983; Zelazo, et al, 1977).

The debate on the efficacy of the theories and the precise causes of ASD continues to unfold. Many experts, however, usually diagnose children with ASD based on diagnostic criteria clearly itemized in the *Diagnostic and Statistical Manual of Mental Disorders* 5th ed (American Psychiatric Association, 2013) Upon diagnosis, it is imperative to provide children with ASD with quality services to help them overcome their disabilities and live a productive life. It is equally important to provide early intensive services to children with ASD and provide their parent's access to the resources

that they will need to provide effective care to their children. These services are necessary because ASD and the behaviors associated with it causes enormous psychosocial burden and stress to mothers who care for children with ASD (Bello-Mojeed, et al., 2013, pp.1-7). Services should include counseling services because they will offer the mothers the opportunities present their problems to trained counselors and receive helpful feedback.

While extensive literature exists in the United States about ASD (Autism spectrum disorder) and the services that are available for children and their parents, there is very little written about the disorder and the available services in Nigeria. There is a great need to increase the knowledge of ASD in Nigeria to better understand attitudes, perceptions, diagnoses, and responses regarding the disorder. Increased knowledge on these issues will help the mothers and care givers understand how to address the needs of children with ASD effectively (Bakare & Munir, 2011). The purpose of this literature review was to examine the existing literature on the attitudes and perceptions of Nigerian mothers toward their children with ASD. In doing so, various themes on the growth, trends, and the dynamic nature of ASD were also discussed.

In this chapter, I assess and review some of the major literature on ASD to highlight the nature of the scholarly discussions on the historical background, causes, prevalence rates, and diagnostic criteria for the disorder very broadly, and in Nigeria. In this chapter, I also evaluate studies on access to and availability of services for children with ASD, as well as the attitudes and perception of Nigerian mothers and those of

caregivers. Finally, I review the impact of quality services and programs for children with ASD.

I obtained the articles used for this literature reivew from various sources, including PubMed, EBSCOHost, Google scholar, Psych Articles and Psych Info through Walden University. Google scholar was a particularly useful tool and provided articles about ASD (autism spectrum disorder). To obtain better results, I searched for articles with the following terms: *autism spectrum disorder, autism spectrum disorder in Nigeria, prevalence rate of ASD, the impact of services to children with ASD, causes of ASD, criteria for ASD and attitudes of mothers, parents and care givers toward children with ASD,* and *history and background of autism*. My search produced several hundred articles that I sifted through to obtain the relevant articles utilized in this study.

A close study of literature on ASD in general, and on Nigeria in particular, revealed a number of findings. First, there were variations in the prevalence of ASD from one region of the world to another. Second, there was still an ongoing and unresolved debate about the exact etiology of ASD. Third, despite the disagreement over the etiology of ASD, there was a general consensus on the diagnostic criteria that should be used for identifying ASD. Fourth, there was minimal awareness of ASD and how to diagnose it among mothers and caregivers in Nigeria (Audu & Egbochuku, 2010; Bakare & Munir, 2011). This meant that there were negative perceptions and attitudes surrounding this disorder (Audu & Egbochuku, 2010). This has also limited the abilities of mothers to seek the needed services for their children. Instead, parents have improperly classified their children with ASD with other forms of disabilities or mental disorders and have

resorted to harmful treatments (Audu & Egbochuku, 2010;). According to Audu & Egbochuku (2010) "most parents, because of lack of awareness, hide their children at home because of the fear of being stigmatized or discriminated against" (p.259). Fifth, while there were extensive services provided for children with ASD in the United States, services in Nigeria were limited (Bakare et al, 2009; Bello-Mojeed & Bakare, 2013: Igwe et al, 2010; Igwe et al, 2011; Nwanze, 2013). Sixth, the caregivers in Nigeria have limited knowledge of ASD, and lack the training to deliver the relevant services to children with this disorder. There is growing evidence that early detection and the provision of quality services would produce positive outcomes for children with ASD in Nigeria (Audu & Egbochuku, 2010; Bakare et al, 2012; Bello-Mojeed & Bakare, 2013; Nwanze, 2013; Samms-Vaughn & Franklyn-Banton, 2008;Thomas et al, 2007).

A brief historical background of ASD

The study of autism spectrum disorder (ASD) has been an ongoing process. Scholars have been researching ASD for the last 60 years (www.autism uk.com; Trachtman, 2008; Wolf, 2004). Additionally, the description and definition of autism has evolved over a period of time. Autism is currently known as autism spectrum disorder (ASD). The disorder is also clearly identified as a developmental disability in the DSM-V (American Psychiatric Association, 2013).

The early identification of autism is attributed to two prominent scholars, Leo Kanner and Hans Asperger. Before the work conducted by these two prominent scholars, individuals with symptoms typical to autism were generally diagnosed with schizophrenia (www.autism uk.com; Trachtman, 2008; Wolf, 2004). McGuiness (2015)

stated that "the word autism took its modern sense in 1938 when Hans Asperger of the Vienna University Hospital adopted Bleuler's terminology *autistic psychopaths* in a lecture in German about child psychology" (www.autism uk.com). McGuiness (2015) further reported "Leo Kanner of John Hopkins hospital first used autism in its modern sense in English when he introduced the label early infantile autism in a 1943 report of 11 children with striking behavioral similarities" (www.autism uk.com). Kanner and Asperger concurred that the distinctive features of a "triad of developmental deficiencies, recognition, communication and understanding" were prevalent in the people whom they have identified with autism (Trachtman, 2008, pp. 391-396). It is important to note that autism was not recognized as a specific diagnosis prior to 1981 (www.autism uk.com). Additionally, people diagnosed with autism received various forms of treatments including medical and "applied behavior analysis" (Trachtman, 2008, pp. 391-396).

The history of autism is incomplete without the recognition of the role of the *Diagnostic and Statistical Manual of mental disorders (DSM)*. The DSM is published by the American Psychiatric Association "and is the handbook used by health care professionals in the United States and much of the world as the authoritative guide to the diagnosis of mental disorders" (www.dsm5.org). The DSM has undergone seven editions since its first publication in 1952. Each edition approaches the diagnoses of mental illnesses and developmental disorders differently. The present DSM-V preserves "important diagnostic traditions intact while it introduces clinically important paradigmatic shifts" (Tanguay, 2011). Additionally, American Psychiatric Associations (2014) reported that,

Many of the changes in DSM-5 were better characterize symptoms and behaviors of groups of people who are currently seeking clinical help but whose symptoms are not well defined by DSM-IV (meaning they are less likely to have access to treatment (www.dsm5.org).

As opposed to DSM-IV-TR, which has autism and asperger's syndrome as individual categories under the umbrella of pervasive developmental disabilities, all categories of pervasive developmental disabilities are now collectively referred to as autism spectrum disorder.

Prevalence rate of ASD

The prevalence rate of children with ASD varied a great deal from one region of the world to another. The Center for Disease Control ([CDC], 2014) has reported that one out of every 68 children has been diagnosed with ASD in the United States. It was also indicated that the cases of ASD continue to increase with more cases found in children less than 3 years old (CDC, 2014; Dawson, 2008; Faras, et al, 2010; Lord, 2010). The increase in ASD cases has been attributed to increased awareness of the disorder and early reporting of the disorder in developed countries (Miles, 2011).

The rates of prevalence of ASD in many sub-Saharan African countries were unclear because of the absence of reliable data and late detection of the disorder. A recent study of ASD cases in African countries including Nigeria has shown that cases of children with ASD were usually reported late in their childhood (Bakare & Miner, 2011). This late reportage of ASD cases have been attributed to factors including insufficient

knowledge of ASD, lack of appropriate health care facilities, and improperly trained health care professionals (Bakare & Munir, 2011).

Causes of autism spectrum disorder

While progress is being made in establishing presence and prevalence of ASD around the world, there is still a debate concerning the precise etiology of the disorder. The etiology of ASD has not been clearly identified. Some scholars have indicated that ASD is a neurological and developmental problem; others have attributed the disorder to genetic and environmental factors (Bakare et al, 2012; Bello-Mojeed & Bakare, 2013; Dawson 2008; Faras, et al., 2010; Lord, 2010; Samms-Vaughn & Franklyn-Banton, 2008; Thomas et al., 2007). In presenting ASD as a neurological problem, some scholars adduced that symptoms such as epilepsy, inability to sleep, deficits in fine and gross motor skills and "electroencephalographic abnormalities" were possible factors of the disorder among children (Miles, 2011; Spence & Schneider, 2009; Tuckman et al,). In essence, the neurological signs, which obviously delay developmental milestones in children, were major causes of ASD.

It was also indicated that genetic and hereditary factors played a major role in the etiology of ASD. According to Geschwind (2011), "three main areas of evidence support a genetic etiology in ASD: twin studies, comparing monozygotic twins (MZ) and diagnostic twins (DZ), family studies comparing the rate of autism in first degree relatives of affected probands versus the population, and studies of rare genetic syndromes with a comorbid autism diagnosis" (pp. 409-416). While Geschwind's evidence was compelling, it was not conclusive. Further research and genetic testing are

necessary to explain the underlying genetic factors that created these genetic problems

and symptoms of ASD in children.

It was also stated that environmental and socioeconomic factors contributed to the

etiology of ASD. A recent study on race, ethnicity, and nativity among the immigrant

population in Los Angeles County showed a wide disparity about cases of ASD reported

among the children of immigrants (especially from developing countries) and the

Caucasian population. In the study entitled, "Autism spectrum disorders and race,

ethnicity, and nativity: A population-based study" Becerra et al, (2014) attributed the

high percentage of ASD cases among the immigrant population of Los Angeles County

to pregnant immigrant mothers who have exposed their unborn children to the impact of

immigration hardship, unnecessary worries, changes in food pattern and sociocultural

difficulties (Becerra et al, 2014; Elsabbagh et al, 2012). This study was very important

because it provided invaluable data illustrative of disparities in ASD cases. However, I

am of the opinion that a future study should utilize a qualitative approach so as to

interview participants, highlight their lived experiences and provide rich answers to

questions presented.

Diagnostic criteria of ASD

While there is no consensus among scholars on the etiology of ASD, most agree

that early detection and diagnosis allow for better treatment of children diagnosed with

the disorder. In most cases, experts who have the necessary training and experiences

usually make the diagnosis of ASD. In combination with their knowledge and

experiences, these professionals also rely extensively on the diagnostic criteria of ASD

that are clearly prescribed in the *Diagnostic and Statistical Manual of mental disorders,*

DSM-5 *(5th ed.).* These criteria are as follows:

1. Persistent deficits in social communication and social interaction across

   multiple context, as manifested by the following, currently or by history

   (examples are illustrative, not exhaustive) (APA, 2013, pp. 50-51).

2. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by

   at least two of the following, currently or by history (examples are illustrative, not

   exhaustive) (APA, 2013, pp. 50-51).

3. Symptoms must be present in the early developmental period (but may not

   become fully manifest until social demands exceed limited capacities, or may be

   masked by learned strategies in later life (APA, 2013, pp. 50-51).

4. Symtoms cause clinically significant impairments in social, occupational, or other

   important areas of current functioning (APA, 2013, pp. 50-51).

5. These disturbances are not better explained by intellectual disability (intellectual

   developmental disorder) or global developmetnal delay. Intellectual disability and

   autism spectrum disorder frequently co-occur; to make comorbid diagnoses of

   autism spectrum disorder and intellectual disability, social communication should

   be below that expected for general developmental level (APA, 2013, pp. 50-51).

   In addition to the DSM-5, there are other diagnostic tools for early detection,

and diagnosis of children with ASD. These tools include the following; autism diagnostic interview, autism diagnostic observation schedule, the Gilliam autism rating scale and the criteria specified in the International Classification of Disease – ICD (Bakare et al, 2012; CDC, 2014). Despite these valuable diagnostic tools, the *Diagnostic and Statistical Manual of mental disorders, (DSM)* provides a comprehensive diagnostic and is widely used in many countries including Nigeria (Bakare et al, 2012;CDC, 2014).

Attitudes and perceptions of the Nigerian mothers

Despite the availability and use of *Diagnostic and Statistical manual of mental disorders (DSM)* in Nigeria, public knowledge of the disorder or nature of its diagnosis still remained limited. Furthermore, the absence of government support for the development of awareness, detection and treatment of ASD and the limitations of services have had a negative impact on the attitudes and perceptions of Nigerian mothers toward their children with the disorder. According to Audu and Egbochuku (2010) "most parents, because of lack of awareness, hide their autistic children at home because of the fear of being stigmatized or discriminated against. Other individuals with autism are labeled retard, dumb or deaf" (p.259). Even worse, some of the mothers have taken to spiritual healing and healers, which has resulted to death among some of these children with ASD (Audu & Egbochuku, 2010; Bakare & Munir, 2011).

The role that stigmatization, discrimination, or lack of awareness about ASD played in parental response, especially in public advocacy and seeking services for children was crucial. So were the socio-cultural beliefs about the disorder, especially in a country like Nigeria. There were no clear explanations why the mothers could not bond

as a cohesive unit and advocate for their children. One wonders if it has anything to do with the beliefs of the mothers or if there were other unexplained reasons for that? It is a well-known fact that beliefs play a vital role in how people perceive disabilities. As Lamorey (2002) has indicated, "parent beliefs about the nature of disability are related to parent beliefs about and participation in treatment and intervention" (p.67). There were probably more reasons to the negative attitudes and the poor perceptions held by the Nigerian mothers toward their children with ASD. As this study continues to progress, better reasons could be discerned to better explain and understand this phenomenon.

Availability and access to services

In the United States, children diagnosed with ASD received services which included early intervention services, behavior intervention services, speech therapy, occupational therapy, respite care and educational services. Most of these services provided by ASD related agencies were usually tailored to the individual needs of the child and ocurred both at home and in school settings (Brookman-Frazee, Taylor & Garland, 2010; Young, Ruble, & McGrew, 2009). The accessibility to these services assuaged the fears of the parents/guardians and addressed the needs of the children with ASD.

Early intervention was an important services that has helped to reduce abnormalities in behaviors found in children with ASD (Montes, Halterman & Magyar, 2009). Through early intervention, parents and guardians were better prepared for the challenges associated with this disorder It is even more important to have quick access to early intervention services becasue of the increasing need for physician consultations,

treatments, medications, therapies that children with ASD required on continuous bassis (Chiri & Warfield, 2011). Ultimately, an early access to services was helpful in reorientating children with ASD and equipped their parents with the skills to better address their needs.

While high quality ASD intervention and care for children were widely available in the US, they were expensive. Cimera and Cowan (2009) have attributed the high cost of these services to the uniqueness of the disability faced by these children and the need for their consistent training to better prepare them for the future. Despite the high cost of these services, some parents were still unsatisfied with the quantity and shortages of services provided to children with ASD in the United States.

Available services for children with ASD in Nigeria

Unlike the United States, the services provided to the children with ASD in Africa, especially in Nigeria were limited. A survey conducted by this writer through various Internet websites and scholarly databases showed that these limited services were provided through schools, organizations and treatment facilities such as Center for Autism (CADD), Autism Associates of Nigeria, Nigerian Autistic Society, Children's Development Center (CDC), private schools and a few behavior specialists. Many of these services encouraged early detection and diagnosis of ASD. Additionally, some of these programs emphasized the need for early intensive treatment and specialized education services for children with ASD. However, these aforementioned services were situated in urban communities, privately owned and possibly unaffordable to parents (Bello-Mojeed & Bakare, 2013: Nwanze, 2013).

Additional findings from the various Internet websites show that some of these treatment facilities do not have enough funding and the relevant communication technique to support their services and programs. Even worse, the government does not provide funding to them to help finance their programs and services. Consequently, they depended on their limited income and contributions from other organizations to fund their services.

Typically, services meant for children with ASD were supposed to help with early detection, effective and varying forms of treatments, behavioral, educational and speech services provided to children with ASD (Bakare et al, 2012; Bello-Mojeed & Bakare, 2013; Samms-Vaughn & Franklyn-Banton, 2008; Thomas et al, 2007;). Additionally, they also served as resources to parents who want to know more about ASD, provided training on the management of the behaviors and related concerns to children with ASD. The insufficiency of such services often led to frustrations and enhanced the poor perception and negative attitudes held by the Nigerian mothers toward children with ASD.

The problem of insufficient services was further complicated by the limited effort on the part of African governments to help with the development of awareness, detection and treatment of children with ASD. For example, in Nigeria, there were no codified laws that recognize ASD as a disorder. The one bill that would address the needs of people diagnosed with ASD and the services to be provided is yet to be signed into law. The other option left for parents was to consult with their primary care physicians, who in turn may refer their children to a specialist on ASD for diagnosis and treatment (Bakare et al,

2009; Igwe et al, 2010; Igwe et al 2011). However, it has also been noted that there were few facilities that provided such services and some parents are hesitant to avail themselves of such services (Bakare et al, 2009; Igwe et al, 2010; Igwe et al, 2011). Additionally, most of the health professionals have insufficient training on ASD and had little knowledge about the integrative approach needed to provide care to children with ASD (Bakare et al, 2009; Igwe et al, 2010; Igwe et al, 2011). The aggregate impact of these limitations on the services coupled with inadequate training of health professionals and the lack of awareness of ASD constrained the ability of parents to make informed choices about the health of their children and to seek effective treatment plans for them.

Attitudes and perceptions of caregivers

The attitudes manifested by caregivers can make or mar the progress associated with the treatment given to children with ASD. A positive attitude and knowledge of ASD among the caregivers will help to transform and create meanings in the life of children with ASD. In the United States, emphasis is placed on the training and education of caregivers including physicians (Golnik et al, 2009). It is obvious that the increase in knowledge of caregivers about ASD prepared them and puts them in a good disposition to the challenges associated with ASD.

In contrast to the United States, caregivers in Nigeria have minimal knowledge about ASD and face serious socio-cultural issues revolving around developmental disorders. Bakare et al (2009) have indicated the need for a comprehensive training to healthcare workers to familiarize them with the tools of early detection, diagnosis and treatment of ASD. Other studies have highlighted the paucity of knowledge of ASD

among health care students and indicated the need to incorporate ASD in the training program given to students in colleges (Bakare, M.O. & Munir, K.M. (2011). Bello-Mojeed & Bakare, M.O. (2013); Igwe et al, 2011). Overall, it is obvious that insufficient knowledge and lack of comprehensive training on ASD have impacted on the quality of care given to children with ASD and the attitudinal disposition of care providers in Nigeria.

The impact of quality services and programs for children with ASD

There were increasing evidence about the positive outcome derived when quality services and programs were provided to children with ASD. Most scholars have concurred that the provision of early and intensive services was necessary to reduce autistic-like behaviors, improvement on speech and stereotypical behaviors peculiar to children with ASD (Eikeseth, 2009; Granpeeshew, et al, 2009; Matson & Smith, 2008; Zachar & Itzchak, 2010). While the urgency for early services were noted, it was very significant to utilize a better treatment technique to achieve the desired positive outcome. In a study entitled, "Treatment approach, autism severity and intervention outcomes in children" Zachor & Itzak (2010) did a comparison of the applied behavior analysis (ABA) and the "eclectic" techniques used to treat children with ASD. Drawing their population from a group of selected preschool children, the authors found out that there is no significant difference on the outcome of both techniques that were administered (Zachor & Itzak, 2010). They did however point out that certain domains responded better to either the ABA or eclectic technique (Zachor & Itzak, 2010). Furthermore, they also indicated the need for a thorough itemization of areas of handicapping to help

clinicians make a decision about the best treatment technique to use for children with ASD (Zachor & Itzak, 2010). This study was important and should be extended to children or young adults who have late diagnosis of ASD to help them better integrate into the community and live a productive life.

It was also significant to develop a dynamic specialized education plan for children with ASD. Each child's educational plan should include the identified deficits and the techniques for remediating their peculiar handicaps. Sandra, et al (2007) has noted the positive outcomes associated with a well-developed and administered educational plan known as TEACCH. TEACCH is a technique "based on understanding the learning technique of individuals with autism and the use of visual supports to promote meaning and independence" (TEACCH, 2014). In their study on the effectiveness of a TEACCH technique on a group of Chinese children enrolled in a pre-school in Hong Kong, the authors noted a remarkable improvement on their experimental group more than their controlled group and attributed the success to the proper application of the TEACCH technique (Sandra, et al, 2007). Overall, the impact of specialized educational programs to children with ASD seems to be universally noted.

In spite of the difficulties that were experienced by treatment facilities in Nigeria, Patrick Speech & Languages Center was emerging as they emphasized the need for specialized educational plan and early intervention to help children with ASD to cope with the demands of our everyday changing society (Patrick Speech & languages Center, 2012). However, more has to be done by all stakeholders in Nigeria to ensure that quality

services and highly specialized educational programs were provided to children with ASD.

Theoretical framework

While cognizant of the major theories that can be used to study ASD, this study drew mostly from the work of sociologists. It utilized mainly the theory on social relational understanding of disability especially those posited by Carol Thomas. The theory on social relational understanding emanated in the 1960s from the works of Paul Hunt in Stigma and the Experience of Disability (1966) and Victor Finkelstein (1980) who drew attention to the historical relationship between disabled people and the public. Finkelstein was among a group of scholars who deviated from the ideas held by medical sociologists, who indicated, "disability is caused by illness and impairment and entails suffering and some social disadvantage" (Thomas, 2004, pp.569-572).

From this initial efforts made by Finkelstein and Paul Hunt, many scholars have tried to build on or provide variety of their understanding or experiences of social relational understanding of disability. Carol Thomas (1999) in her own variation of the theory on social relational understanding of disability stated that "disability is a form of social oppression involving the social imposition of restriction of activity on people with impairments and the socially engendered undermining of their psycho-emotional well being" (p.60). Thomas further stated that though "impairments" bring about inhibitions, a state of being becomes a disability when the sociey "socially imposed" on the impaired person several barriers that prevents them from growth and full participation in the society (p.581).

Carol Thomas developed this theory by studying the lives of disabled women of multiple backgrounds and examined their lived experiences as they related with the society on daily basis. Some of the women she studied informed her that they have encountered "social barriers" in their places of work (Thomas, 1999, pp.18-23). Other women have suffered discrimination because of their physical infirmities (Thomas, 1999, pp.18-23). Based on her study, Thomas concluded that disabled women were not fully included in communal activities.

This theory has also been used to understand the difficulties encountered by disabled persons in the society (Watson, 2012). Connors & Stalker (2007) have used this theory to study the views and lived experiences of children with disability, how they coped with their disabilities despite the harship imposed on them by the society. Overall, Carol's theory on social relational understanding of disability was important because it highlighted the inhibitions encountered by disabled people in the society, the limitations which societal laws and practices has imposed on people with impairments to the achievement of their optimal objectives in life.

Another scholar, Reindal (2008) have used this theory to advocate for the designation of a comprehensive special education program in Norway that factored into consideration the limitaions, barriers and societal impositions suffered by people with disabilities. Basically, the theory on social relational understading of disability by Carol Thomas could be used in multiple ways because it shedded light on the difficulties people with disabilities experience and could help policy makers to make inclusive policies.

Carol Thomas's theory on social relational understanding of disability provided the needed framework to achieve the purpose of this qualitative study. Essentially, this qualitative phenomenological study explored the attitudes of the Nigerian mothers toward their children with autism spectrum disorder (ASD). The key elements propounded by Carol Thomas were applied to this study. Specifically, I asked questions to find out if autism spectrum disorder was perceived as a social oppression, restrictive and inhibitive to the progress of the disabled persons in the society. I also explored whether the hardships associated with children with ASD emanated solely from the society or multiple factors. Finally, through a well-structured interview questions, I sought to understand the experiences of the Nigerian mothers as they related with their children and the society to find out if it has affected their "psycho-emotional well being" and caused them to be negatively disposed toward their children with ASD (p.60).

Summary

This chapter highlighted the various aspects of ASD that scholars have researched and discussed. It showed the prevalence of ASD and the growing trends of ASD cases among children in the world and Nigeria in particular. It also pinpointed the vibrant debates on the causes of ASD and underlined that there were commonly accepted diagnostic criteria to guide experts on ASD to make proper diagnosis. The attitudes and perceptions of caregivers and the quality of services and programs for those with ASD remain major challenges for Nigeria, and reinforce the rational for this study. Finally, this chapter emphasized the need for early detection and access to quality services for children with ASD in Nigeria to ensure a positive outcome.

Chapter 3 will discuss the research design and rationale, the research questions, the role of the researcher and the methodology. Additionally, chapter three will discuss the instrumentation, data analysis plan and issues of trustworthiness. Finally, chapter three will discuss ethical issues including agreement to gain access, treatment of human participants and treatment of data.

Chapter 3: Research Method

Introduction

The purpose of this hermeneutic phenomenological study was to explore the attitudes and perceptions of Nigerian mothers toward their children with ASD. Additionally, this study explored the lived experiences of Nigerian mothers as they struggled to manage the atypical behaviors of their children with ASD. Furthermore, this study illustrated the themes derived from the experiences of Nigerian mothers and explained the underlying reasons for their attitudinal dispositions and the perceptions they held toward their children with ASD.

This chapter also discusses the research design and rationale, research questions, and the role of the researcher in this study. Furthermore, this chapter discusses the methodology, instrumentation, issues of trustworthiness and ethical procedures that were used in conducting this study.

Research design and rationale

I used the hermeneutic phenomenological approach to explore the lived experiences of the Nigerian mothers who have children with ASD.
As Sloan and Bowe (2013) have indicated,

> In hermeneutic phenomenology one has approaches that recommend to the researcher to interpret the meanings found in relation to phenomena. Often these approaches suggest the analysis of text to find these meanings and allow interpretation. The focus is on understanding the meaning of experience by searching for themes, engaging with the data interpretively, with less emphasis on

the essences that are important to descriptive phenomenology (p.1295).

Overall, I will use the hermeneutic phenomenology to study the lived experiences and attitudinal dispositions of Nigerian mothers toward children with autism, extricate themes from the data and interpret the findings of this study.

Research questions

I used two overarching questions in this hermeneutic phenomenological study to explore and understand the lived experiences, attitudes, and perceptions of Nigerian mothers toward their children with autism spectrum disorder. These two questons were:

1. What are the attitudes of the Nigerian mothers toward their children with autism?

2. What is the experience of a Nigerian mother living with a child with autism spectrum disorder?

Role of the researcher

I played multiple roles as the researcher in this study. One of my key roles involved the establishment of good relationship and rapport with the participants involved in the study. To do this, I had to be cognizant of my personal idiosyncrasies, as well as my level of involvement and any ethical issues. As Creswell (2009) has noted, "with these concerns in mind, inquirers explicitly identify reflexively their biases, values, and personal background, such as gender, history, culture, and socioeconomic status, that may shape their interpretations during a study" p.177. During this research, I was cognizant of my gender and culture. I am a man from the same culture as the participants and interviewed the willing participants regarding their lived experiences and their relationships with their autistic children.

To ensure that my gender and cultural background did not cause any potential issues, I was introspective of my own cultural background and made every effort to ensure that it did not impact on my judgment of other people's experience. I also assessed my personal beliefs and biases to ensure that they did not pose a threat or lead to misrepresentation of facts presented by the participants.

It was also pertinent to present the interview in a conversational style to build rapport and trust when interviewing participants who were of a different gender. As Arendell (1997) has indicated,

> The conversation with the interviewee, a dialogue, has to be followed closely; responses and attempts to change the line and direction of discussion considered, anticipated and guided both in order to talk about topics not yet covered or to return to others in order to flesh them out; and the overall situation monitored, logically and emotionally (p.342).
>
> Overall, conducting the interviews with the participants in their comfort zone was helpful in eliciting information about their lived experiences.

Methodology

Participant selection logic

In this study I used purposeful sampling, specifically, maximum variation (heterogeneity) sampling to explore and understand the lived experiences, attitudes, and perceptions of Nigerian mothers toward their children with autism. As Patton (2002) has pointed out, maximum variation (heterogeneity) sampling is a "strategy for purposeful sampling aims at capturing and describing the central themes that cut across a great deal

of variation" (pp. 234-235). The use of maximum variation (heterogeneity) further enhanced my ability to highlight individuals from various settings, their narratives, shared experiences and unique themes.

The participants for this study were Nigerian mothers who have children with ASD. These mothers were the biological mothers, foster care mothers, and adoptive mothers who possessed legal guardianship over children with ASD. The participants were recruited from various geographical settings and locations from the Southeastern part of Nigeria. The Igbo speaking people mostly inhabit the states in the Southeastern parts of Nigeria. These states included Anambra, Imo, Enugu, Abia, Ebonyi, and some parts of Delta and Rivers State. Although Igbo language is the native language, there are several dialects and variations of Igbo language spoken in the Southeastern part of Nigeria. Most of the time, people interact with the English language to understand each other. For the purpose of this study, I recruited mothers who were literate in English.

An essential criterion for participant selection was that the mothers interviewed for this research study had children diagnosed with ASD. I drew participants with varying marital status, socioeconomic backgrounds, and geographical settings as part of this study.

I planned to use a sample size of about 5-10 Nigerian mothers, drawn from various geographical settings and locations from the Southeastern part of Nigeria. As Miles and Huberman (1994) have noted, "qualitative researchers usually work with small samples of people, nested in their context and studied in-depth …" p.27. Additionally, Patton (2002) has noted, "there are no sample rules in qualitative inquiry" (p.244).

However, it was important to have an adequate sample size to produce quality work and to ensure the integrity of the research, as well as reach data saturation.

It is very imperative to note when saturation or redundancy of information and data began to occur in this research. As Patton (2002) has indicated, "sampling to the point of redundancy is an ideal, one that works best for basic research, unlimited timeliness, and unconstrained resources." (p.246). Another scholar, Mason (2010) noted that saturation occurs when "a point of diminishing return" set in because "as the study goes on more data does not necessarily lead to more information" (p.1). Consequently, I interviewed to obtain rich data but also paid close attention and continued to recruit participants until data saturation occurred.

I researched the Internet for the different facilities that catered for children with ASD and requested for their permission to place flyers as a means of recruitment for Nigerian mothers of children with ASD who receive services through their facilities. The Internet was a useful tool to locate the ASD facilities in Nigeria, due to their limited numbers and limited awareness of their services. I then contacted the participants through different means, including letters and telephone calls. Following this contact to explain the study, I conducted the interviews by telephone.

As soon as I received an expression of willingness or interest from the mothers, I sent them an informed consent form and more detailed information about the research study. I indicated to the mothers in a separate note that the signed informed consent form was an agreement that gave me the permission to interview and obtain relevant information about them and their children diagnosed with ASD. By relevant information,

I meant the rich data and answers that I obtained from the participants when I interviewed them for this study. The interview questions and answers obtained helped me to address the two research questions. As part of the detailed information, I indicated to the mothers that I would interview them by telephone.

Instrumentation

As soon as I obtained permission and consent signed by the willing participants, I began to collect data. Data for this study were obtained through telephone interviews. The initial plan was to use the telephone and Skype to elicit information from the Nigerian mothers; however, most of the mothers interviewed for this study did not have Skype. By telephone, I was able to access and interview participants who were located in the different and remote geographical settings in Southeastern part of Nigeria. As Irvine (2011) has indicated, "telephone interviews allow the inclusion of participants across wider geographical scale and access to individuals in settings which it may not be feasible, or may be potentially unsafe for the researcher to enter" (p.203). Overall, the medium of telephone was useful to facilitate verbal interactions in the process of data collections.

In addition to the collection of data through telephone interviews, I audiotaped the telephone interview and took notes. Creswell (2009) indicated the need for taking field notes because audiotapes may encounter mechanical errors or interview data may not be appropriately recorded (p. 183). Both the audiotaped interview and the field notes were essential when I began to transcribe the interview.

I collected the data within a period of 4 months. During the time of data collection, participants had two formal interviews that focused on their lived experiences with their children with ASD. Most of the interview sessions lasted from 15-30 minutes, depending on the disposition and willingness of the person interviewed. During the first interview session, I asked the mothers the following questions:

1. What are your beliefs and perceptions about autism?

2. How do members of your family and community relate with your autistic child?

3. What are the things that the government and nongovernmental agencies are doing to improve the quality of life of the autistic children in your community?

4. What are the types of assistance you will need to provide quality care to provide quality care and services to your child with autism?

5. In your opinion, what are the factors inhibiting the increase in awareness of ASD in your community?

During the second interview session, I presented the following questions to the mothers:

6. What is your experience raising your child with autism?

7. What are the techniques you use to relate with your child?

8. How accessible are the available services for autistic children in your community?

My third meeting with the mothers was for follow up and clarification of responses they provided after I had transcribed the interview. My fourth meeting with the mothers was member checking that ensured the veracity of information provided by the mothers to ensure that the views expressed by the mothers were adequately presented in

this study. I also debriefed the mothers about the progress of the research, listened to their concerns and expressed gratitude for their cooperation.

I used an interview protocol for this research. Creswell (2009) indicated that an interview protocol was necessary "for asking questions and recording answers during qualitative interview" (p.183). The interview protocol included the name of the interviewee, place of the interview, number of times interviewed, duration of interview and a statement of gratitude.

Data analysis plan

Although there are a plethora of guides available for qualitative data analysis, most scholars conducting qualitative research do not follow specific patterns in doing their data analysis. The data analysis for this study was conducted in various steps. The first step was the transcription of the data into a written format. Basically, I organized and transcribed the interview questions and responses for in-depth study and analysis. I also made efforts to transcribe the exact verbatim of my questions and the responses of the people I interviewed. The second step of the interview was an in depth study of the transcribed materials to have a good knowledge of the responses provided by the interviewees.

The remaining steps in the data analysis were the horizontalization of the data, the assignment of codes to the identified themes, patterns and significant statements. Additionally, the other steps included the use of the coding process to establish relationship between the themes to identify unique or common themes that cut across data and a write up of clear narrative of the phenomena being studied.

Issues of trustworthiness

Issues of trustworthiness were a very pertinent element that I took into consideration when conducting this qualitative research. This was necessary to ensure integrity of the research and the ability of the researcher to produce a high quality work beneficial to all. Some of the issues of trustworthiness that I took into consideration when conducting this qualitative research were credibility, dependability, transferability, and Intra-and intercoder reliability.

Credibility

Credibility helped to make the qualitative research study authentic. To ensure credibility in this study, I applied academic rigor to derive rich data and analyze such data thoroughly. Additionally, I worked on my bias to ensure that it did not impact on this study. To this end, I adopted the suggestion given by Patton (2002) that it was necessary to reduce bias by "discussing one's predispositions, making biases explicit, to the extent possible and engaging in mental cleansing processes (p. 553).

Furthermore, I used the bracketing method to make explicit my preconceptions and predispositions. As Tufford (2012) has written, "bracketing has the potential to greatly enrich data collection, research findings and interpretation to the extent the researcher as instrument, maintains self-awareness as part of an ongoing process" (p.85). Essentially, the bracketing methods that I used included the use of "memo" and "reflexive journals" to record my predispositions and preconceptions (Tufford, 2012, p.85).

Another integral factor that ensured credibility in this study was the use of triangulation and prolonged contact. To ensure triangulation, I used member checks. Member check meant that the interviewees were involved in the analytical portion of this research. As Creswell (2009) has pointed out, "the interpretation of the informant's reality and meaning ensured the value of the data" (p.199). Additionally, I engaged in prolonged contact with the interviewees through the four interviews to obtain thick data and rich descriptions of their experience. It was also necessary to prolong contact with the interviewees in order to clarify information and fill in the gaps that I noticed when transcribing the interview text.

Dependability

One of the goals of this research was to obtain thick data, analyze the data and produce findings that were dependable. I also worked on producing a high quality work that can be a resource to any scholar who is interested in studying the phenomena of autism in developing countries. To do so, I used a research method that was useful in obtaining the data needed for this study. I also applied the recommendation of Malterud (2001) who stated the need to "keep the principles of the research in mind" and stay cognizant of "the assumptions of the research questions" and "present a relevant sampling strategy" to produce a quality research that is dependable. (p. 485). Additionally, I kept a good account of the research and the process involved in data analysis collection and analysis.

Transferability

Another issue of trustworthiness is transferability. Transferability was ensured by the use of thick description of the lived experiences of the Nigerian mothers with autistic children. Natasi and Schensul (2005), have defined thick description as "the detailed depiction of the study's participants, context and procedures; the purpose of which is to permit consumers to make decisions about the transferability of finding" (p.185). Overall, thick description highlighted the experiences of the Nigerian mother with autistic children and enhanced analysis.

Confirmability

An integral part of this research study was the inclusion of thick and textural data derived from the participants, which explained the attitudinal dispositions, and the lived experiences of the Nigerian mother. To ensure confirmability, I kept an audit trail and was reflexive throughout this study. Nastasiand Schenul (2005) pointed out the importance of audit trail because it is "the systematic documentation and record keeping of all the procedures and data relevant to the study, the purpose of which is to permit review (audit) of the study and potential replication of the research process" (p.185). Basically, I presented a sequential account of the data collection and data analysis. Additionally, I reflected introspectively on the account presented by the mothers to present their viewpoints and ensure that my personal bias did not impact on the interpretation of the data.

Intra and intercoder reliability

Intra and intercoder reliability were necessary to ensure standards and conformity to generally accepted codes. According to Kurasaki (2000) intercoder reliability is "a measure of agreement between multiple coders about how they apply codes to date" (p.192). To ensure conformity to intercoder reliability, this research utilized the principles of hermeneutic phenomenology; give "unique labels or codes to text passages" and "ensuring that it conforms with intercoder agreement" (Kurasaki, 2000, p.192; Zhang & Wildermuth, 2009).

Ethical procedures

It is pertinent to follow ethical procedures when conducting qualitative research. This need was even more important when the research involved the interaction and collection of data from human beings. Additionally, compliance with ethical procedures helped to ensure quality and integrity of the research. As part of this research study, I followed ethical procedures, which included the agreement to gain access, treatment of human participants and treatment of data to ensure that the interviewees were treated with dignity and respect.

Agreement to gain access

The proposal of this research study was submitted to the Institutional Review Board (IRB) of Walden University when the appropriate authorities at Walden University gave the permission to do so. The IRB reviewed the proposal to ensure conformity with existing regulations and ethical procedures.

Another integral part of this research was the informed consent process. I developed an informed consent form, which I requested the participants to sign before they were allowed to participate in this research. A participant has to willingly agree to participate in this research before I interviewed them and collected data. It is imperative to state that the privacy of all participants in this research was protected and their confidentiality maintained.

Treatment of human participants

All the participants in this research study were treated with respect and dignity. I did not deliberately manipulate or trick the participants to provide any information that was harmful to their persons. I also informed the participants that that their involvement in this study was voluntary and they have the freedom to quit whenever they so desire. As the researcher, my primary responsibility was the protection of the human participants and the assurance that their persons were not violated.

Although my obligation was to ensure that human participants were treated with dignity, the Institutional Review Board of Walden University also had explicit and implicit standards that a proposal had to meet before permission was given to the student to collect data. According to the Institutional Review Board of Walden University (2010)

> application should be completed by all students and faculty members who are conducting research projects of any scope involving collection or analysis of data from living persons (whether from surveys, interviews, observation, student work, or records of any type). The only categories of research that do not need to be

submitted for IRB approval are literature reviews, hypothetical research designs, and faculty projects that are completely independent of Walden affiliation, resources, participants and funding (Walden university, 2010).

Treatment of data

The treatment of the data for this research was a joint effort of both the participants and myself. From data collection, data analysis to research findings, I involved the participants to ensure that this research study was credible and the integrity of this research was maintained. As an example, I discussed and agreed with participants the findings of this research before it was submitted to my dissertation committee.

It is also necessary to indicate that all the data collected during the interviews will be safeguarded for privacy and confidentiality. Overall, the data collected during the interviews were saved in a specific folder in my computer hardware. I removed the names and contact information of the participants to protect their privacy participants and ensured confidentiality. Lastly, I created specific password to ensure that I am the only one that has access to the data.

Summary

This chapter discussed the crucial elements that were necessary to produce a good qualitative research. Specifically, I indicated that this study utilized a hermeneutic phenomenological approach to explore the experiences, attitudes and perceptions of the Nigerian mothers toward their children with ASD. Additionally, I discussed my role in this research study as the interviewer and an unbiased person. I also discussed the process of data collection and data analysis pointing out that the final outcome of the research

would be a joint effort of both the participant and myself. Other factors discussed in this research included issues of trustworthiness and ethical procedures that were necessary to ensure the integrity of this research.

Chapter 4 will discuss the setting of the study, the demographics, and the data collection. Additionally, chapter 4 will discuss the data analysis and evidence of trustworthiness. Lastly, chapter 4 will present the results of this study including the discrepant case.

Chapter 4: Results

Introduction

This qualitative study explored the attitudes and perceptions of Nigerian mothers toward their children with ASD. I used the hermeneutic phenomenological approach in this study to collect data and interpret and explain the underlying reasons for the attitudes and perceptions held by the Nigerian mothers who are faced with the challenges of raising children with ASD. This chapter discusses the setting, demographics, data analysis, evidence of trustworthiness, and the results of this study.

The two main research questions of this study were:

1. What are the attitudes of the Nigerian mothers toward their children with autism spectrum disorder?

2. What is the experience of a Nigerian mother living with a child with autism spectrum disorder?

Setting

This study was carried out among Nigerian mothers from the Southeastern part of Nigeria who have children who have been diagnosed with ASD. I interviewed the mothers via the telephone using the semi-structured interview technique. The interviews were conducted on the dates and times agreed upon between the mothers and myself. Also, in conformity with Walden University, Qualitative Checklist (2012), there were no known elements or factors "that influenced the participants or their experience at time of study that may influence interpretation of the study results." Some of the mothers

responded to my interview questions from the comfort of their own homes, while others were interviewed in their workplaces or agreed upon locations.

I carried out all the interviews in the study room of my home. The study room was conducive to focus and devoid of noises, making it possible to understand the views presented by the mothers concerning their perceptions and lived experiences.

Demographics

The participants for this study were recruited from different geographical location from the Southeastern part of Nigeria. Their ages ranged between 27 and 38 years old. Table 1 below includes the participants, their ages, marital status, education completed, and the gender of their child.

Table 1

Information of the participants

Participants	Age	Marital status	Education completed	Gender of child
Mother #1	34 years	Married	High School	Boy
Mother #2	36 years	Married	High School	Boy
Mother #3	33 years	Married	College	Boy
Mother #4	27 years	Married	College	Girl
Mother #5	36 years	Single	College	Boy
Mother #6	38 years	Married	College	Boy
Mother #7	29 years	Married	College	Boy
Mother #8	30 years	Single	College	Boy

Data Collection

Upon Walden IRB approval (12-28-15-0341577) on December 28th, 2015, I began the process of data collection. I began to research the Internet for the different facilities that catered to children with ASD and requested their permission to contact the mothers of children with ASD who were affiliated with their facilities. I also made inquiries through healthcare facilities and healthcare practitioners and requested their permission to contact mothers of children with ASD who receive services through their facilities.

Based on the information I obtained via the Internet, I began to send letters and flyers (Appendix E) to the ASD centers, healthcare facilities, and health care practitioners. The content of my letters included an introduction of myself, an explanation of my research, and an invitation to mothers of children with ASD to participate in this study. One of the ASD centers expressed their willingness to cooperate. Consequently, I sent letters of cooperation (Appendix A) and flyers to them to distribute to the potential participants. Further information regarding recruitment and interviewing is described later.

The initial plan was to interview 10 participants for this study. However, despite my efforts to recruit 10 participants, I was only able to recruit five participants for this study. I interviewed the five participants and transcribed their recorded interviews. Afterwards, I presented the transcribed text to my committee chair for her comments. My committee chair reviewed the interview text and indicated that I should recruit more

participants in order to obtain rich data, which are essential for data analysis. As a result, I began to search the Internet for additional ASD centers in Nigeria.

I contacted the ASD centers I found via the Internet and one of the centers expressed their willingness to cooperate. I sent a letter of cooperation and flyers as a means of recruitment for Nigerian mothers of children with ASD who receive services through their facilities. The flyers provided information about the topic of the research study, the name of my institution, and my program of study. Additionally, the flyers included a request for mothers with children with autism to willingly participate in the study, and my contact information. Three mothers contacted me via telephone and expressed their willingness to participate. I sent the mothers my research materials including the recruitment letters (Appendix B) and informed consent forms. Additionally, I explained to the mothers in a separate note that the consent form was an agreement that gave me permission to interview them and obtain relevant information about them and their children diagnosed with ASD. I also explained to the mothers that I would use telephone and/or Skype to collect data from them. After a prolonged period of time caused by the delay in mail correspondences, the three participants received the research materials. This was the same process that the initial five mothers went through as well.

All the participants who agreed to participate in this study signed and mailed back the informed consent form to me. Upon receipt of the signed informed consent, I began the interview processes. I used a semi-structured interview approach for this study. I also used eight interview questions (Appendix D) to elicit information from the mothers.

Data were collected within a period of 4 months. During the time of data collection, participants had two formal interviews. Most of the interview sessions lasted between 15-30 minutes, depending on the disposition and willingness of the person interviewed. In addition to the two formal interviews, I also conducted follow up telephone calls with the mothers. The follow up calls helped to clarify some of the responses the mothers provided. The fourth call that I had with the mothers was member checking, which helped to ensure the veracity of the information provided by the mothers. It was also necessary to ensure that the views of the mothers were adequately presented in this study. I also debriefed the mothers about the progress of the research, listened to their concerns, and expressed gratitude for their cooperation.

The data for this study were obtained by telephone. The initial choice was to use Skype and telephone calls to interview the mothers, but none of the mothers had Skype. So, I resorted to the use of the telephone. In addition to the use of telephone interviews to obtain data from the mothers, I also recorded all the interviews with an audio digital recorder and transferred the recorded interviews to my laptop computer. It was imperative to have the interviews recorded in both the audio digital recorder and my laptop computer to ensure the availability of recorded data in case of any loss of equipment.

I also used memos and an interview protocol (Appendix E) during the interviews. The memos were useful to record pertinent information that was necessary as I began to transcribe the data. The interview protocol was also important to record the name of the

interviewee, the duration of the interviews, the places and times of the interviews, and a

statement of gratitude.

Data analysis

I conducted the data analysis for this study in various steps. The first step was the

transcription of the recorded interview data into a written format or interview text. I made

efforts to replicate the exact verbatim responses I elicited from the mothers during the

interviews. I also studied the transcribed interview and got familiar with the answers

given by the mothers. Smith and Osborn (2007) pointed out the need "to read and reread

the transcript closely in order to become as familiar as possible with the account" (p.69).

Additionally, I used the memos I took during the interviews to document my

predispositions and ensure that the recorded data were thoroughly transcribed (Tufford,

2012, p.85).

Thereafter, I horizontalized the data. As part of the process of horizontalization, I

identified the significant statements about the experiences and narratives of the mothers.

Creswell (2013) indicated that significant statements should be clustered in chronological

format. So, I organized the statements to help with analysis. The process of

horizontalizaton was also useful in understanding the essential details provided by the

participants.

In addition to horizontalization, the interview text for this study was hand coded

for analysis. I chose not to use NVIVO software for analysis. I assigned words and

phrases to ideas, concepts, and units of meaning that were embedded in the interview

text. I did this in order to identify the underlying experiences and perceptions of the participants. As Saldana (2009) has pointed out,

> Qualitative codes are essence capturing and essential elements of
> research story that when clustered together according to similarity
> and regularity – a pattern – they actively facilitate the development
> of categories and thus analysis of their connections (p.8).

To facilitate coding, I created two columns; column one had the interview text and column two had the codes that were derived from interview text (Liamputtong & Ezzy, 2005; Saldana, 2009). The various codes were also color-coded. As I began to identify codes, I started to notice patterns of repetitive similar codes and some dissimilar codes. I then developed categories based on the repetitive codes. I also placed all the codes under their specific categories. Ultimately, seven themes were developed from the categories. The themes that were identified reflected the strong opinions of the majority of the participants.

Finally, I placed the appropriate quotes derived from the interview texts to go with the themes that were identified. The identified themes were as follows:

1. Developmental disability,

2. Relationship with family,

3. Relationship with the community,

4. Teaching and Learning Techniques,

5. Hindrances,

6. Challenges of Nigerian Motherhood with children with autism, and

7. The assistance needed by Nigerian mothers with children with autism.

Evidence of Trustworthiness

The goal of this research study was to provide research that clearly explained the lived experiences and the challenges faced by the Nigerian mothers who have children with autism. To produce authentic work, I focused on parts of the evidence that enhanced trustworthiness, including credibility, transferability, dependability, and confirmability.

Credibility

To ensure credibility in this study, I applied academic rigor to collect and analyze data. I performed two formal interviews; follow up calls, and member checking to ensure that rich data were collected. Overall, having in place a rigorous and flexible process made it possible for the interviews to proceed in a friendly manner.

In addition to the use of academic rigor, I also used the bracketing technique to contain my personal idiosyncracies. As Patton (2002) has noted, "one strategy involves discussing one's predispositions, making biases explicit, to the extent possible, and engaging in mental cleansing process" (p.553). To effectively use the bracketing technique, I purposely kept an open mind and recorded in a memo any personal biases that crept up as I worked on this research study

Another method that helped me to ensure credibility in this study was the use of triangulation and prolonged contact. As part of triangulation, I did member checking and prolonged contact via telephone to fill in the gaps detected during the transcription of the data and ensured the accuracy of the information provided by the participants. Overall, member checking and prolonged contact through the four interviews helped to impress

upon the participants a sense of ownership in the research study and provided opportunity for them to relay vital information that were left out during the formal interviews

Dependability

To ensure dependability, I remained cognizant of the research design, method, and the research questions guiding this study. According to May and Pope (1995),

there is the need to create account of method and data which can stand independently so that another trained researcher could analyze the same data in the same way and come to essentially the same conclusions" (p.110).

So, in this study, I provided a detailed account of the research process, particularly focusing on the process that was utilized in collecting data and analyzing and attaining the results of the study in order for the process to be repeated by other researchers in the future.

Transferability

To ensure the transferability of the data, I provided thick description of the everyday challenges of the Nigerian mothers with their autistic children, their limitations, needs and the relationship of their children with their families and communities. Overall, I was cognizant of the fact that this study could be a resource for any scholar researching about autism spectrum disorder and seeking to generalize the results to other developing countries such as Nigeria. Consequently, I elicited from the mothers the underlying reasons for their lived experiences with their autistic children.

Confirmability

To ensure confirmability, I collected, analyzed and presented authentic data that portrayed the perspectives of the participants involved in this study. Additionally, I integrated the elements of triangulation, reflexivity and audit trail recommended by Lincoln and Guba (1985) as some of key factors that ensured confirmability in a qualitative research study. Consequently, I obtained thick data through a research process that can be repeated by any researcher examining the ASD phenomenon in any given society.

Results

Seven themes emerged providing answers to the two research questions, which formed an integral part of this qualitative study. Additionally, quotations from the interview transcripts are provided to support the themes that were identified. Also, for the purpose of confidentiality, participants in this study were identified as P and assigned the numbers one to eight.

Theme One: Developmental disability

The overwhelming perception among the participants was that Autism Spectrum disorder (ASD) is a developmental disability. They also believed that ASD is caused by several factors including developmental delay, medical disorder, genetic disorder and neuro-developmental problems. P1 and P8 noted that ASD is caused by developmental delays and the onset begins prior to birth or infancy.

What I meant is late development to the brain for the child. Late development of the child to understand things around him. And you know, they do things repetitively. As in they repeat things, their acts (P.1).

My belief about autism is that it is a condition, which affects an individual's relationship with other people and it progresses. It happens from childhood. The child grows along with it (P.8).

P2 and P3 stated that the occurrence of ASD is a due to a medical disorder that resulted from immunizations or the use of a drug when the child was still in the intrauterine.

The say they don't know the reason why? They can't still say what the cause is. But I feel that circumstances surrounding the child's birth. May be, immunization and all these things (P.2).

Ok, my belief about autism is that it is a medical disorder that emm might have arisen from or arose from either the use of a particular drug or brand drug during pregnancy that might have triggered the disorder in the development of the fetus (P.3).

P6 believed that ASD is triggered by genetic disorder, which impacts on the growth and   relationships of the autistic child.

But it can be caused by genetic mutation or developmental problem in a child. So for me, I believe it is a developmental problem that affect's the child's

development or child's growth or child's ability to interact with other people

(P.6).

For P6, ASD is a result of neuro-developmental issues, which affects the manner the child, relates with people.

Ok, my perception of autism is that it has to do with a neuro-developmental

problem. So that affects the child and he or she does not relate very well with

others (P.7).

Overall, it was pertinent to note that majority of the participants concurred that ASD is a developmental disability, which begins in the uterus or early childhood and is caused by varying factors. Also, ASD has some unique characteristics, which impacted on the way the child related with his or her surroundings.

Theme Two: Relationship with the family

All the participants involved in this study indicated that their families have positive relationships with children with autism. These unique relationships were evident in the special care, love, concerns and the learning skills, which they provided to children with autism.. P1 and P3 noted the special care, concern and love the family members gave their children with autism

… they give him special care. They show him love. Nothing like stigmatization.

Nothing like that (P.1).

In the house we relate to him. We try to repeat things with him, tell him things

all over. We correct him (P.1).

But my family show him love because they have a little idea of what it is. So, they still show the same love, try and get him on their side. Like show him love so that they can win him over (P.3).

Furthermore, P6, P7 and P8, stated that their families used various teaching strategies including music, play, dance and drawing to teach their children with autism.

The child normally likes to be isolated. He keeps to himself and doesn't like talking or playing with anybody. Members of my family too don't also like to disturb him. They keep away from him. But when they want to talk to him for anything they play or sing and dance with the child to make the child do what they want him or her to do (P.6).

The family first creates special program for the child like playing music the child likes or something like drawing (P.7).

We play music for the child. The child likes music. Then, at times, we draw images of things in the house and draw other images too (P.8).

To sum up, it was obvious from the participants that the family members had positive familial relationships with their children with autism. These healthy relationships stemmed from the fact that the family members were empathetic to the needs of their children with autism and have better understanding about the conditions.

Themes Three: Relationship with the community

In contrast with the positive relationship given to children with autism by their family members, there were notable differences in the manner the people in the community related with children with autism. Essentially, the participants described as appalling the relationship between the people in the community and autistic children. For P3, the members of the community ignored children with autism.

But for the community, they don't know his condition, so they will just ignore him; he is like a human being (P.3).

P4 and P5 stated that the members of the community see autistic children as people with spiritual problems.

So, at first when they hear the word autism or see some sign, they tend to think that it is may be kind of spiritual (P.4).

It has been so hard and so horrible because of the discrimination. Because of, you know, the way the tag it as demonic things and they look at you as if you are coming from the other side of the world. You are not meant to be here with their kids or with your child (P.5).

P6, P7 and P8 indicated that the members of the community regarded children with autism as abnormal children.

Aaaaaa! For the community? They don't like associating with the child because they see such children or such child as eeeem an abnormal child or as a child that is not meant to live (P.6).

The community acts differently. They don't really understand the child (P.7).

For the community, most times ignore him (P.8).

In summary, it was apparent that the odious relationship exhibited by the community members toward the autistic children stemmed from ignorance, tagging children with autism as abnormal children and further associating them with spiritual forces.

Theme Four: Teaching and Learning Techniques

Raising a child with autism spectrum disorder required techniques and strategies that helped the child to communicate, learn and adapt to everyday challenges. Most of the participants have adopted various techniques to teach, manage the behaviors and enhance the language skills of their children. P1, P2 and P3 used verbal techniques to communicate with their children.

I communicate with him verbally (P.1).

It is just speech, speech. I kept on talking to him. I never used sign language for a day (P.2).

What I use in relating with him is like I use more of playing and praising. He likes praises. To get his attention, I have to sing. He likes song (P.3).

P1, P4, P5 and P6, used gestures, modeling and verbal corrections to teach their autistic children.

Make him to know things that are wrong and right. He loves a particular thing and
you tell him that something is wrong. So, whenever he repeats that I usually ask
him Daniel, what is that Daniel? And he will tell me it is wrong. I will tell him to
stop. And he stops (P.1).

What I do, is I first access the child. I know that these are the things this child
wants. These are the things that irritate this child. I try as much as I can to play
along (P.4).

It is more of gestures, more of gestures. Or and also I understand that when you
use the sign language or they learn more with modeling. Whatever you want the
child to do, you model it. Or use sign, you point to the thing you want the child to
do. Or you kind of do it first, he or she will now follow suit (P.5).

If I want him to learn his 1,2,3. Like numerals I want him to know. I use to
write1,2,3,4,5,6, show the numbers. Because most times, if you say one, he will
learn one and keep saying one, one, one, one. So you have to also reinforce other
numerals (P6).

P4 and P7 used therapy and structured programs as a technique to help their
children with autism to learn.

And again, autistic children, they learn by routine. You know, they like routine. There are programs structured for them to follow step by step. That is the ABA approach (P.4).

Most times I find out when I play music that the child is happy. Then, emmmm. When I join him in his game or when he is learning or when I am around, he just wants me to be around. Those are techniques that I use (P.7).

The child's physical, sorry. The child's OT or any therapist at all. Their instructions have to be followed and there will be consistency in performing their particular assignments (P.7).

Theme Five: Hindrances

There were several hindrances that were identified by the participants. These ranged from the paucity of knowledge of health professionals, poor government intervention, and few qualified professionals, to ignorance, religious and spiritual factors. All the participants agreed that these hindrances have limited the spread of the knowledge of ASD in their communities and have impacted on the health and well being of their children.

P3, P4 and P6 shared their opinions about the insufficient knowledge of health professionals.

Ok, like somebody that is studying medicine. Well, lots of the doctors that are trained in these days are not even aware of what autism is. If you go to them with a child that is autistic, they cannot even detect (P.3).

Number one is lack of awareness. Some people, they don't really get to understand what it is all about… They don't understand what autism is all about even when you explain to them, they still don't get it (P.4).

Because some of the problem is that some health care givers don't even know the difference between autism and some other conditions. So, you keep time and managing until you are able to know that, you will be able to help, give, give the child the helps the child needs (P.6).

For P.2, P.3, P.4, P6, P7 and P8, there were less government intervention on the plights suffered by autistic children and their mothers.

Nothing, nothing, nothing. Nothing, it is a personal issue. Government, they don't intervene (P.2).

The government and non-governmental associations are not doing anything because they are not enlightened about autism (P.3).

Well, first and foremost, the government per se. They are not really aware that autism has gotten to this extent in my community per se (P.4).

They are not doing anything much. Usually in this our environment or in this community you take sole responsibility of taking care of your child that have any disability (P.6).

I don't think they are doing anything in my community. They don't even know

what autism is all about (P.7)

For the government, I have not seen any. Actually, I have not seen any (P.8).

The participants also expressed concerns about the limited numbers of ASD

professionals who provided services to the autistic children and considered it as a major

hindrance to the treatment of ASD. According to P4 and P5,

Another one is getting trainees. We are lacking trainees, professionals to help with

these challenges (P.4).

So, there is not even a special care for children with disabilities. The only thing

is that once in a while you go for hospital check up to see how the child is faring

and you come back home. And most pediatricians will ask you to see a

specialist who is in charge or who takes care of these children. And these

specialists are very difficult to find. And even if you find one, you cant even

afford it. Or if you afford the payment, it will be for sometime. So, their services

are not even available (P.6).

Another hindrance noted by P.1, P2, P6 & P7 are the pervasive ignorance about

ASD in the their communities.

If enough awareness is created, make parents understand that this is what's wrong

with the child (P.1).

In my opinion once the problem comes to you, you fight it yourself. It is not a general issue. It is not a common thing for now. People are not really aware that this is the main issue, the main problems per se (P.2).

Parents with children in this environment who have autism. Emmmm, we don't actually like taking them out so that people will see them. And in such way, it creates lack of awareness (P.6).

The main factor is ignorance. People in this community, they don't really know about autism. So, it is ignorance (P.7).

Other hindrances that were identified by the participants included the negative impact of religious and spiritual factors to the growth of ASD. P3 and P8 expressed the following:

They tend to associate such things to spiritual things. So, we just believe that when anything goes wrong, it has to be spiritually inclined. That is the factors inhibiting the awareness (P.3).

They treat the child with such conditions as having a spiritual problem. And everybody seems to ignore the child. So, it is ignorance. People don't know about it (P.8).

Even religious people, once they see the child acting that way, they believe they

should do deliverance. They don't believe it has anything medically (P.8).

Theme Six: Challenges of Nigerian Motherhood with children with autism

All the participants reported unpleasant experiences, which they have had while

raising their children with autism spectrum disorder. Most of their experiences stemmed

from difficulties coping with the incessant demands of their children and the struggles

involved in integrating the autistic child in the society. P1, P3, P4 and P7 noted some of

the challenging behaviors they had to deal with on day-to-day basis.

It is like, at a time, he comes up with certain habits and after corrections he

forgets and brings up another one (P.1).

I have had so many experience because the most challenging things is their non

responsiveness to when you talk to them, when you try to communicate when

they are not responding it makes your life difficult (P.3).

Experience. I mean raising autistic children presents a lot of challenges. You

know the verbal challenges. In most autistic children making eye contact is

difficult for them and they have restricted behaviors (P.4).

It has been very challenging and sorry to say also embarrassing. Because at times,

we take the child on social functions and the child doesn't want to talk or greet

anybody. It has been challenging (P.7).

In addition to challenging behaviors, the participants noted that working with

children with autism were time consuming, involves finance and tremendous sacrifices.

Time, time and understanding him as in spending more time with him to make

him understand his situation (P.1).

…the time you spend with a normal child is different from the one you spend with

an autistic child (P1).

It will involve your finance, your sacrifice; you have to devote your time (P.2).

…the child needs you most of your times. You cannot even go to work like

continuously until they pay you (P.7).

The participants also noted that autistic children have difficulties adapting to new

people and new changes.

You know, they are aggressive when it comes to adapting to new people (P.3).

He didn't want the helper to touch him or bathe him and because the door was

open, he left the compound and was walking toward the expressway in a bid to

look for mom (P.3).

He can't grow with other of my children. Like they don't relate well (P.8).

Furthermore, the participants reported that catering for autistic children was

energy consuming.

So you have to stop him or her from doing what he has done before and all that.

So, it is actually energy consuming and a difficult task (P.6).

The child requires special care and also you should be there for the child always (P.7).

In sum, it was obvious that all the participants have had difficult experiences in raising their children with autism. Based on the narratives presented by the participants, raising children with autism were challenging, time consuming and energy involving. It also involved a lot of money and making adequate sacrifices to ensure that the needs of children with autism were met.

Theme Seven: The assistance needed by Nigerian mothers with autistic children

A lot of assistance was needed to raise and meet the needs of children with autism. This assistance, when available helped in the education and training, managing behaviors, creating awareness, and helping children with autism to acquire skills they would need to live a normal life. However, all the participants pointed out there were very limited assistance available for them. P3 noted the need for skilled professionals who could assist with training of children with autism

Emmmm, number one is that they will need to train people so that they will know how to treat such children (P.3).

P2, P4, P6 and P8, pointed out the need for financial assistance to purchase the things needed by the children and providing for their education.

Finance, just finance, just finance (P.2).

You know, and again assistance from government to help create awareness to assist in, to assist financially and helping in creating awareness for these children, getting materials to help these children overcome their challenges (P.4).

I think the basic thing in taking care of my child is funding. Emmmm, we need a lot of finance to take care of my child because some of them they love toys (P.6).

And if I have the finance, I will actually want him to go to a very good school where he will find special teachers to help him with his condition (P.8).

In addition to assisting the participants with their financial needs, the participants also pointed out the needs for establishment of special schools and ASD centers that will provide learning and skills development to their children.

But what I will love is if they can provide a school for them whereby they will teach them normal things as in what other children are learning in their own way. They should be able to know what the child is good at and develop that part of him (P.1).

... learning facilities that aid the understanding of. Just educational facilities that are tailored to, that are designed specifically for autistic children. I think that's basically what I need. Educational facilities that is designed for autistic children (P.3).

Well, the basic, the basic need for now is to; you know have a center, a kind of hostel where these children can be accommodated (P.4).

They need, may be a therapy center that can accommodate a child. Let me say a boarding therapy center. And again, if the government can subsidize on the amount because it is an agency that runs it. Or, if the government can build a state of art school for the autistic children that will be free of charge (P.5).

The participants were also asked about the overall knowledge and awareness of ASD in their communities and all of the participants pointed out the need to provide resources to help increase the awareness about ASD in their communities.

You know, and again assistance from government to help create awareness to assist in, to assist financially and helping in creating awareness for these children, getting materials to help these children overcome their challenges (P.4).

And then support group. And also you create environment for them. You go with them to functions. You take them to special school where they will communicate with others (P.7).

Overall, there is a strong need to provide assistance to the participants to help them grapple with the challenges and difficulties their autistic children exhibit on regular basis.

Discrepant cases

There was one discrepant case that was evident from the study. One of the mothers initially believed that spiritual forces caused autism spectrum disorder. As P5 indicated,

> Initially, I thought it was a demonic thing. Emmmm, initially. It was when I came in contact with this organization that I was able to know that it is not demonic (P.5).

> However, her involvement with an organization, which catered for children with ASD, increased her understanding about the causes of ASD and dissipated any spiritual concerns about ASD.

Summary

This chapter discussed the settings, demographics, data collection, data analysis, evidence of trustworthiness and the results of the study. Efforts were made to answer the research questions, which served as a basis of this study. Codes, categories and themes were identified in the process of data analysis. It is important to note that the identified themes and supportive data were crucial and provided answers to the research questions.

A close study of the data provided by the participants shows a number of findings. First, there are extensive perceptions held by the Nigerian mother that ASD is a developmental disability. Second, there are evidence of positive familial relationship between children with autism and their family. Third, there are unpleasant relationships between autistic children and the community. Fourth, the Nigerian mothers utilize varying teaching and learning techniques to instruct their children with autism. Fifth,

there are in existence several hindrances that have obstructed the growth and treatment of ASD in the communities. Sixth, there are several challenges confronting the Nigerian mothers with children with autism. Finally, there are the needs to provide assistance to the Nigerian mothers to help them provide quality care and services to their children with autism.

Chapter 5 will discuss the interpretation of the findings, the theoretical framework and the limitations of the study. Additionally, it will discuss recommendations and the implications of the study. Finally, chapter 5 will present a conclusion of this research study.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this hermeneutic qualitative study was to explore the attitudes of Nigerian mothers toward their children with autism.. The hermeneutic approach was useful in eliciting thick data from the participants and in understanding the underlying meanings of the experiences depicted by the participants.

The Nigerian mothers interviewed for this study had the perception that autism spectrum disorder (ASD) is a developmental disability. I noted that there were positive relationships between children with autism and their family members. However, the relationships between children with autism and the community were depicted as unpleasant. This study identified the different teaching and learning techniques used by the Nigerian mothers to train their children with autism. This study also identified the hindrances preventing the growth of treatment options for ASD in various communities. Furthermore, this study pinpointed the different challenges of Nigerian motherhood with children with ASD. Lastly, this research study identified the various assistance needed by Nigerian mothers with autistic children.

Interpretation of the findings

The participants for this study were interviewed by telephone and the data were collected and analyzed to derive the findings. The findings were discussed under seven themes. In this section, several interpretations of the findings will be discussed. I will also explain the ways the findings of this study confirmed or did not confirm existing knowledge prevailing in the peer-reviewed literature.

Theme One: Developmental disability

The general perception of the Nigerian mothers was that autism spectrum disorder (ASD) is a developmental disability. The mothers also adduced several factors regarding the etiology of ASD. While some of the Nigerian mothers attributed the causes of ASD to developmental delay or a medical disorder, other Nigerian mothers believed that ASD was caused by a genetic disorder or neurodevelopmental problems.

The perception of the Nigerian mothers interviewed was that there was no exact cause for autism spectrum disorder (ASD). These perceptions were based on a combination of factors that included their experiences, acquired knowledge, and diagnostic recommendations made by professionals or organizations in the field of ASD treatment. P1 summed these up when she noted that,

> But at a time when he got to 5 years, at three he was not communicating with his siblings, with his brother, and me. That was when I started noticing. I did not call it autism at first. It was when I registered with CADD that they said it was autism. I didn't really believe it. But with books, I read something about it (P1).

The understanding of Nigerian mothers regarding autism as a developmental delay is aligned with the atypical behaviors in children that Leo Kanner and Hans Asperger—the pioneers of autism treatment—depicted in their studies (Kanner, 1946). Prior to the development of the theory of autism, children with atypical behaviors were often diagnosed with schizophrenia (McGuiness, 2010; Trachtman, 2008; Wolf, 2004). However, Leo Kanner and Hans Asperger pointed out that "a triad of developmental

deficiencies, recognition, communication, and understanding" were common traits prevalent in children with autism (Trachtman, 2008).

Autism was recognized as a disability with a diagnosis in 1981 ((www.autism uk.com). Since then, the study and diagnosis of autism has undergone many progressive changes. Some of the tools that have helped diagnosticians to properly diagnose autism include the uses of autism diagnostic interview, autism diagnostic observation schedule, the Gilliam autism rating scale, the criteria included in the International Classification of Disease – ICD and the *Diagnostic and Statistical Manual of mental disorders* (DSM) (Bakare et al, 2012; CDC, 2014).

The categorization and classification of autism spectrum disorder (ASD) as a developmental disability and the characteristics of ASD depicted by the Nigerian mothers conform to the definition of ASD in the *Diagnostic and Statistical Manual of mental disorders*, DSM-5 (5th ed). Specifically, the DSM is published by the American Psychiatric Association "and is the handbook used by health care professionals in the United States and much of the world as the authoritative guide to the diagnosis of mental disorders" (www.dsm5.org).

There are seven editions of the DSM. At one point, autism and Asperger syndrome were separated as two forms of disabilities in the DSM. However, in the present DSM-V, both autism and Asperger syndrome are listed under the broad classification of autism spectrum disorder (ASD).

Although they did not identify an exact etiology of autism spectrum disorder (ASD), the causes of ASD adduced by the Nigerian mothers were in tandem with the

etiology of ASD currently shared by scholars in the field of ASD. While some scholars have depicted ASD as a neurological and medical disorder, other scholars have attributed the causes of ASD to genetic and environmental issues.

As a neurological and medical disorder, scholars have argued that issues like seizures, sleep problems, deficiencies in motor skills, and "electroencephalographic abnormalities" could be some potential causes of autism (Miles, 2011; Spence & Schneider, 2009; Tuckman, 2010).

Geschwind (2011) traced the genetic compositions of "monozygothic twins and (MZ) and diagnostic twins (DZ)" and identified genetic causes of ASD (pp. 409-416). In regard to environmental causes of ASD, Becerra et al. (2014) conducted a study on the immigrant population in Los Angeles and concluded that the hardship suffered by pregnant immigrant women impacted their unborn children and potentially caused ASD (Becerra et al, 2014; Elsabbagh et al, 2012).

Overall, there was no generally accepted consensus on the exact etiology of ASD. However, the opinions of the Nigerian mothers were valid and were geared toward understanding the nature and causes of ASD as a developmental delay.

Theme Two: Relationship with the family

All the participants interviewed for this study indicated that their families had good and cordial relationships with their children with autism. The families gave children with autism special care, concern, and love. Developing the skills of children with autism expressed these special relationships. It was obvious that these positive traits expressed

by family members stemmed from true feelings of empathy, compassion, and knowledge about ASD. As P1 pointed out,

> In the house we relate to him. We try to repeat things with him, tell him things all over. We correct him. Even the younger sister tells him Daniel that is bad, what you are doing is bad and corrects him. If you ask him if what he is doing is good or bad. He will tell you it is bad and I will tell him to stop and he will stop (P1).

This findings of this study showed that the increase in awareness about autism spectrum disorder has helped the families of Nigerian mothers with children with autism to better understand their condition. This awareness about ASD has probably filtered from the Nigerian mothers to their families and has resulted to better treatment and positive dispositions toward children with autism.

However, this finding was not in total agreement with the literature reviewed for this study. Notably, one of the articles reviewed for this study specified that children with autism have been maltreated or hurt by their parents because of their ignorance about ASD. Specifically, Audu and Egbochuko (2010) stated that:

> Most parents because of lack of awareness hide their autistic children at home because of the fear of being stigmatized or discriminated against. Other individuals with autism are labeled retard, dumb or deaf (p.259).

Other studies showed that some of the parents have inadvertently hurt or killed their children by taking them to spiritual healers for treatment (Bakare & Munir, 2011).

Theme Three: Relationship with the community

Overall, the participants described the relationship between the members of the community and their children with ASD as negative and unpleasant. The participants stated that members of the community ignored children with autism and believed they had spiritual problems. Additionally, members of the community treated children with autism as abnormal. I wonder why these negative attitudes and discrimination still existed despite the incremental awareness about children with autism. P1 noted this problem and responded that:

> But when you talk about outsiders, the people in the environment, they don't understand it. They don't know what is autism per se. And we have to explain to them (P1).

Clearly, a lot remains to be done in order for members of the community to be aware of ASD. For now, the prevalent negative attitudes by members of the community were reinforcing the barriers against children with autism. As Baffoe (2013) noted,

> Public attitudes and beliefs on disabilities in Africa, which are often based on fear and misunderstandings, stereotype individuals with disabilities exposing them to prejudice, discrimination and ultimately to the denials of rights and resources that are afforded to all citizens (p.188).

In conclusion, it is obvious that the attitudinal dispositions held by members of the communities and the beliefs systems have worked in favor of children with autism and this is evidenced by prevailing barriers, denial of full participation in societal activities and stigmatization.

[Please conclude this with a summary of the meaning of this quote]

Theme Four: Teaching and Learning Techniques

All the participants stated that they have used several learning and teaching techniques to teach and develop latent skills in their children with autism. These techniques were presented through verbal communications, teaching and therapy, and training and consistency in the applicable use of techniques identified by the participants. Lessons can be drawn from the use of multiple teaching and learning techniques by Nigerian mothers, as they showed their apparent flexibility and willingness to use any proven technique to help their children learn. It is also important to note that these teaching and learning techniques were used at the early stage of childhood

This finding conforms to the opinions expressed in the peer-reviewed literature about the efficacy of different teaching and learning techniques used at an early age. Essentially, scholars have noted that teaching and learning interventions administered to children with autism at early age of their life have helped in reducing negative behaviors (Montes, Hatterman & Magyar, 2009). Additionally, early and intensive services given to children with autism at an early age have helped their improvement in speech, language development, and rectification of stereotypical behaviors (Eikeseth, 2009; Granpeeshew, et al, 2009; Matson & Smith, 2008; Zachar & Itzchak, 2010).

Theme Five: Hindrances

The participants indicated that there were several factors hindering the spread of awareness of autism spectrum disorder (ASD) that had negatively impacted the treatment and services provided to their children with autism. Some of these hindrances included

insufficient knowledge of healthcare providers, expensive cost of available treatments

and services, and little involvement of the government. Other factors identified by the

participants included the limited numbers of ASD professionals, ignorance, and

spiritual/religious issues.

These issues mean that despite the realistic efforts made by the participants to

cater for the needs of their children with autism, there were several barriers frustrating

their efforts. Clearly, it is difficult for children with autism to thrive in any given

environment, which poses multiple barriers to their growth and development. It is

therefore important that individuals, organizations, corporations, and governments make

maximum efforts to create a helpful environment that will allow children with autism live

to their full potential.

This finding is in line with the works in the literature review, which pointed out

that factors that indicated the need to train and improve the knowledge of health

professionals in Nigeria about ASD. According to Bakare et al, (2008),

> Knowledge and awareness about childhood autism is low among health workers
>
> and the country in general and Sub-Saharan African countries. Poor knowledge
>
> and awareness about childhood autism, especially among health workers can
>
> compromise early recognition and interventions, which had been known to
>
> improve prognosis in children with autism (pp.4-17).

In conclusion, it is important to raise the level of awareness and knowledge of

health care professionals given that they key people that most parents consult especially

when they are confronted with the atypical behavioral challenges posed by children with autism.

Theme Six: Challenges of Nigerian Motherhood with children with autism

All the participants reported that they have had challenging and difficult experiences in raising their children with autism. Specifically, the participants indicated that children with autism exhibit challenging behaviors. Additionally, providing for the needs and demands of children with autism was time consuming and energy sapping. Furthermore, the participants noted that children with autism have difficulties adapting to change or new situations. P3 noted the difficulties her son had adjusting to the new helper in the family because of the difficulties of the difficulties he has getting used to new people.

> You know, they are aggressive when it comes to adapting to new people. After being with them without a help for 8 months, I said let me go out. I left only for me to come back and saw people gathered in front of my compound. So, I was like what is happening here. They said I should just go in. And when I went in people were gathered. He didn't want the helper to touch him or bathe him and because the door was open, he left the compound and was walking toward the expressway in a bid to look for mom.

Clearly, the challenges depicted by Nigerian mothers were in sync with the behaviors and characteristics of autism spectrum disorder *Diagnostic and Statistical Manual of mental disorders,* DSM-5 *(5th ed.).* Raising autistic children presents significant challenges and difficulties. Most autistic children have routines and have

difficulties adapting and transitioning to new things (Audu & Egbochuko, 2010; Kanner, 1943). Therefore, there is an urgent need to increase the numbers of ASD centers that will cater for autistic children and provide counseling services to their mothers to reduce "psychosocial burden" and stress (Bello-Mojeed et al, 2013, pp.1-7).

Theme Seven: The assistance needed by Nigerian mothers with autistic children

There was a general consensus among the participants concerning the lack of assistance available and what assistance is needed to provide quality care to their children with autism spectrum disorder. The assistance identified by the Nigerian mothers included the provision of skilled professionals and financial assistance to the mothers. Furthermore, the mothers pointed out the need to establish special schools and ASD centers where autistic children will learn and acquire skills. Additionally, the mothers pointed out the need to create and increase the awareness about ASD in their communities.

The Nigerian mothers indicated that there were insufficient services available for children with autism. Even where the services were available, they were unaffordable given the Nigerian mother's limited finances and the high cost of such services. Obviously, the various assistance needed by the mothers were genuine and will help them to attend to the growing needs and challenges posed by their children with ASD. Most importantly, the mothers noted that the Nigerian government should get more involved and provide resources, services, and the human power that are needed to spread awareness about ASD in the communities.

This finding is consistent with the views expressed by some scholars. Audu and Egbochuko (2010) did a study on the school in Benin City Nigeria and recommended, "that awareness levels of parents be increased to prevent problems at home and school environment" (p.265). In the same vein, Paul and Gabriel-Brisibe (2015) discovered from their study on the awareness of schoolteachers about ASD and the possible presence of ASD among pupils in schools in Yenogoa and recommended the need to establish special schools and employ teachers who are properly trained to educate autistic children. In their own words, "teachers should be trained and retrained on how to handle the developmentally challenged child" (p.49).

Theoretical framework

The theoretical framework that was used to analyze and interpret the findings of this study was Carol Thomas's version of the theory of social relational understanding of disability. Specifically, Carol Thomas (1999) posited "disability is a form of oppression involving the social imposition of restriction of activity on people with impairment and the socially engendered undermining of their psycho-emotional wellbeing" (p.60). Additionally, the theorist stated that though "impairments" bring about inhibitions, it becomes a disability when it is "socially imposed on the impaired person" (Thomas, 1999, p.581).

Carol Thomas's version of the theory of social relational understanding of disability aligned with the findings of this study. Based on the narratives of the participants, there were various types of oppression that were imposed on the autistic children and their mothers that have impacted negatively on their wellbeing. A classic

example is the negative attitudes of the community members. All the participants indicated that they have suffered oppressions from the members of the community, who have ignored their autistic children, tagged them as having spiritual problems and considered them to be abnormal children that should be avoided. Although a defense can be made about the limited knowledge about ASD in the communities, it is not enough to excuse the oppression and negative treatment of autistic children in the communities. It is a form of oppression that shows lack of acceptance and intolerance, which is consciously carried out against another human being because of their infirmities.

Additionally, Carol Thomas's statement on "the socially engendered undermining of their psycho-emotional wellbeing" of the disabled person can be applied to the situation of the autistic children and their mother in the community. It is hard enough for those autistic children who are saddled with their conditions and their parents who cater for their welfare that they have encountered difficult experiences. The situations of the mothers are made worse by the paucity of trained ASD professionals, the financial burden on the parents, few ASD facilities and not enough governmental involvement. These difficulties can create stress and "psychosocial burden" (Bello-Mojeed et al, 2013, pp. 1-7.). As Bello-Mojeed et al (2013) indicated,

> Compared with other types of disabilities, mothers of children with autism have
> to manage and cope with the various forms of severe impairments present in the
> condition. They have been observed to be prone to social isolation, 'burn out
> syndrome' and at higher risk of developing psychosocial disorders such as
> depression and anxiety (Bello-Mojeed et al, 2013, pp.1-7; Damas et al, 1991, 97-

110; Bouma R & Schweitzer, R, 1990, pp. 722-730; Montes, G & Halterman, J.S., 2007; Bello-Mojeed et al, 2010, p. 72).

Additionally, one of the postulations made by Carol Thomas though "impairments" bring about inhibitions, a state of being becomes a disability when the sociey "socially imposed" on the impaired person is applicable to the findings of this study (p.581). There are several inhibitions affecting the increase in awareness about ASD and the provision of quality care to children with autism. Most of the hindrances identified by the participants included insufficient knowledge of health professionals, high cost of available services, less government intervention, few ASD professionals, ignorance, spiritual and religious issues. It can be argued that the presence of these inhibitions identified by the participants, the non - removal of the hindrances from the society and no concrete plan to do away with the barriers has given credence to the fact that these inhibitions identified by the participants have become a disability, which is forced upon autistic children.

Limitations of the study

One of the limitations of this study concerned the generalization of findings of this research to other geographical settings. The initial plan was to recruit about ten participants for this study. However, despite my best efforts, I was able to recruit only eight participants who were from different geographical settings in the Southeastern part of Nigeria. To ensure generalizations, I applied rigor and used open-ended questions to elicit thick data about the lived experiences of the participants. The data was thoroughly analyzed and seven themes were identified as part of the findings of this study. It is my

opinion that the findings of this study can be generalized to some geographical settings in Nigeria.

Another limitation of this study was that the participants were Nigerian mothers who were literate in the English language. Igbo language is the native language spoken in Southeastern Nigeria. However, there were several dialects and variations of Igbo language spoken in the Southeastern part of Nigeria. To avoid language issues, I recruited Nigerian mothers who were literate in English language. For future studies, I will suggest that scholars should recruit Nigerian mothers from Southeastern part of Nigeria who speak only Igbo language to understand their lived experiences raising their autistic children.

Finally, another limitation of this study was the concern about the preconceptions, biases and the predispositions of the scholar conducting the qualitative research study. To avoid these problems, I followed the recommendations given by Patton (2002) that biases can be reduced "by discussing one's predispositions, making biases explicit, to the extent possible and engaging in mental cleaning processes" (p.553). Additionally, I adopted the bracketing technique and recorded my predispositions, biases and preconceptions in a memo (Tufford, 2012, p.85). This memo became useful during analysis and helped me to set aside my personal biases and focus on the data presented by participants.

Recommendations

There is an overwhelming need for the local, state and federal government of Nigeria to work collaboratively to provide the needs identified by the Nigerian mothers interviewed for this study. It is very clear that the provision of services and programs will

help autistic children manage their disabilities and assuage the fears and pains experienced by their mothers. Furthermore, the government should work with the non-governmental agencies to spread awareness about autism spectrum disorder and alter the negative attitudes held by the members of the community toward children with autism.

In addition to the involvement of the government, non-governmental organizations and stakeholders, public health agencies should utilize the data and findings of this study to understand of the attitudes, perceptions and lived experinces of Nigerian mothers toward their children with ASD. This will help them to develop more comprehensive training programs for public health professionals and increase their ability to respond to the needs of autistic children in Nigeria.

Finally, I would also recommend that future scholars should use various approaches including qualitative, quantitative or mixed methods to explore the attitudes and lived experiences of Nigerian fathers who have children with autism. This could provide more insights and a comprehensive understanding of ASD in Southeastern Nigeria.

Implications of the study

This study has implications for positive social change because the findings of the study can help policy makers to develop better programs and services that will strengthen positive dispositions toward children with ASD. The services and programs should be made accessible, affordable to parents and tailored to the needs of the autistic children. Additionally, counseling and therapeutic services should be provided to their mothers because it will provide them the avenue to discuss their concerns with professional

counselors, reduce their frustrations and help them to positvely channel their energy toward the overall wellbeing of their autistic children.

Additionally, the findings of this study can help to sensitize the Nigerian government and relevant stakeholders about the need to increase the awareness about autism spectrum disorder in the communities. It is my belief that an increase in awareness about ASD will ultimately help to reduce the negative behaviors manifested by members of the community toward autistic children. To achieve this goal, trained professionals should be engaged on this task and resources should be provided to help the professionals reach the populations in both the urban areas and the hinterland places in Nigeria.

Conclusion

Autism spectrum disorder is a disability that is prevalent among children and is currently on the rise. Center for Disease Control (2014) indicated that one out of every 68 children has autism spectrum disorder (ASD) in the United States of America. However, the rate of prevalence of ASD in Nigeria is unknown because there is no available data.

This qualitative study explored the attitudes, perceptions and the lived experiences of Nigerian mothers with autistic children. Data was collected, analyzed and seven themes were identified as part of the findings. The findings were interpreted for better understanding of the phenomenon. Additionally, the findings were discussed in the light of the literature reviewed for this study and the theoretical framework that was used to analyze the findings.

Overall, it is imperative for the Nigerian government and the various stakeholders to work collaboratively and provide quality care to autistic children sustain the positive

attitudes held by their mothers and alter the negative attitudes disposed toward autistic children by members of the community.

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Appendix A: Recruitment Letter to ASD Centers

Dear …

My name is Valentine Chukwueloka. I am a doctoral student majoring in Health Services at Walden University. I am currently working on a Ph.D. research on "the attitudes of Nigeria mothers toward their children ASD." There are limited studies on the development, growth and dynamic changes about Autism Spectrum Disorder (ASD) in Nigeria. Even more, there is an urgent need to study the lived experiences of the Nigerian mothers who care for the needs of their autistic children. A more comprehensive understanding of the attitudes and perceptions of the Nigerian mothers toward their children with ASD is necessary because this is the segment of the population that will deliver and implement care and services provided to children with ASD.

I am requesting for your permission to contact the mothers of children with ASD who are affiliated with your facilities. I would appreciate it if you could allow me to interview these mothers for this research. I plan to interview the mothers via telephone or Skype, 3-4 times for a time period of 30 to 45 minutes depending on willingness to participate in the research. The information shared by these mothers will be kept confidential.

I would greatly appreciate if you could give me the permission to contact the mothers with autistic children who receive services through your facility. I am waiting patiently to hear from you.

Appendix B: Recruitment Letter to participants

Dear…

My name is Valentine Chukwueloka. I am a doctoral student majoring in Health Services at Walden University. I am currently working on a Ph.D. research on "the attitudes of Nigeria mothers toward their children ASD." There are limited studies on the development, growth and dynamic changes about Autism Spectrum Disorder (ASD) in Nigeria. Even more, there is an urgent need to study the lived experiences of the Nigerian mothers who care for the needs of their autistic children. A more comprehensive understanding of the attitudes and perceptions of the Nigerian mothers toward their children with ASD is necessary because this is the segment of the population that will deliver and implement care and services provided to children with ASD.

I fully understand how committed you are with your own work and greatly plead for your participation in this research study. I would very much appreciate it if you could allow me to interview you for this study. I plan to interview you 3-4 times for a time period of 30-45 minutes depending on your availability of time and convenience. The interview will be conducted through the telephone or Skype. The purpose of the interview is to explore your experiences as a Nigerian mother who lives with an autistic child. It is also important to inform you that you privacy will be respected. Consequently, the experiences you shared with me during the telephone interviews will be kept private.

I will so much appreciate if you can participate in this research study. Please kindly indicate the time and date that I can contact you for the telephone interview.

Appendix C: Interview Questions

1. What are your beliefs and perceptions about autism?

2. What is your experience raising your child with autism?

3. What are the techniques you use to relate with your child?

4. How do members of your family and community relate with autistic children?

5. How accessible are the available services for autistic children in your community?

6. What are the things that the government and non-governmental agencies are

   doing to improve the quality of life of the autistic children in your community?

7. What are the types of assistance you will need to provide quality care and

   services to your child with autism?

8. In your opinion, what are the factors inhibiting the increase in awareness of ASD

   in your community?

Appendix D: Interview Protocol

Name of interviewee:

Place of interview:

Number of times interviewed:

Duration of interview:

Statement of gratitude:

Appendix E: Flyer

PARTICIPANTS NEEDED FOR RESEARCH STUDY.

Name of Study
The attitudes of Nigerian mothers toward children with autism spectrum disorder (ASD).

Purpose of Study
This qualitative study will explore the attitudes and perceptions of Nigerian mothers toward their children with ASD.

Eligibility criteria
Nigerian mothers from the Southeastern part of Nigeria who have children with autism spectrum disorder.

Procedures for data collection
- Telephone or Skype interviews

If you would like to voluntarily participate in this research study, please contact: