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Understanding Use of Care for African Immigrants with Autistic Children

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Walden University

College of Health Sciences

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Leahnata Davies

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Walden University
2018

Abstract

Understanding Use of Care for African Immigrants with Autistic Children

By

Leahnata Davies

MPH, Walden University, 2012

BSN, Felician College, 2009

Dissertation Submitted in Partial Fulfillment

Of the Requirements for the Degree of

Doctor of Philosophy

Health Care Administration

Walden University

August 2018

Abstract

The number of African immigrants in the United States is increasing. The incidence of children diagnosed with autism spectrum disorder in the United States is also on the rise. Despite these increases, little information exists about the adequacy of care for African immigrants with autistic children in the United States. The purpose of this grounded theory study was to understand the factors that affect use of care for African immigrants with autistic children in the United States. Using Aday-Anderson mode of health care utilization framework, this study focused on African immigrants in the United States who had children with Autism Spectrum Disorder from age 2- to 15-years-old. I used open, axial and selective coding to analyze my data and come up with a theory about utilization of care for African immigrants with autistic children. The results of this study showed a need for education to influence African immigrants to use care for their autistic children. Despite cultural strong hold, the use of care for African immigrant with autistic children was influenced by education, experience, need and recommendation. The African immigrant ASD Utilization of Care Model emerged. The positive social change implication of this study is improving the use of care for African immigrants with autistic children. African immigrants with autistic children in the United States will benefit from this study.

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Dedication

Completion of this study has made up for all the wrong decision that I have made throughout my life. My son was four months old when my mother arranged for me to start a Licensed Practical Nursing (LPN) program. The goal was for me to be able to take care of myself and my son. After LPN school, I became motivated to do more.

The topic for my dissertation came from me observing my autistic cousin spit soda on a guest during a wedding ceremony. My aunt was very embarrassed and ashamed. This incident made me wonder if anything could have been done to prevent situations like this.

My dissertation could not have been completed without the support of my family and friends. First to my mother Fatu Ann Davies who passed away September 2017: Thank you for insisting that I go back to school and make something out of my life. I wished you were here to see that I listened to you and went all the way. Second to my only child, Osman Cherinoh Kanu. Thank you for supporting me and allowing me to further my education by being loving and supportive. To my two brothers, Cherinoh Davies and Osman Davies for being a father figure and mentor to my son. Your support gave me time to focus on my studies. To my Sisters, Kultumi Davies, Saiminatu Davies, Bintu Davies, Hawanatu Davies, Rokiatsu Davies, Kadijatu Davies and Fatmata Davies, Thank you for the emotional, physical and mental support.

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Table of Contents

Table of Contents	i
List of Figures	v
Chapter 1: Introduction to the Study	1
Background	2
Problem Statement	4
Purpose of the Study	5
Research Questions	6
Theoretical Framework	6
Nature of the Study	6
Definitions	8
Assumptions	9
Limitations	9
Significance	10
Summary	10
Chapter 2: Literature Review	12
Introduction	12
Treatment Options for Children with Autism	13
Dietary Approaches	15
Medications	15
The Importance of Use of Care for Children with Autism	16
African Immigrants with Autistic Children Use of Care	17

Factors and Use of Care of African Immigrants in the United States	18
Culture	18
Socioeconomic Status of African Immigrants in the United States.....	20
Stigma	22
Programs Available to Autistic Children in the United States and their	
Influence on Utilization of Care.	23
Impact on utilization of care	24
Summary.....	24
Chapter 3: Research Method.....	26
Introduction.....	26
Research Design and Rationale	26
Research Questions.....	26
Role of the Researcher	28
Methodology	29
Participants.....	29
Data Collection	32
Data Analysis	32
Issue of Trustworthiness	33
Ethical Procedures	34
Summary.....	35
Chapter 4: Results.....	37
Introduction.....	37

Pilot Study.....	38
Setting	39
Demographics	39
Data Collection	40
Data Analysis	40
Open Coding	41
Axial Coding.....	43
Selective Coding.....	43
Evidence of Trustworthiness.....	45
Credibility	45
Transferability.....	46
Dependability.....	46
Confirmability.....	47
Results	47
Research Question 1	48
Research Question 2	53
Research Question 3	56
Summary.....	59
Research Question 1	59
Research Question 2	60
Research Question 3	60
Chapter 5: Discussion, Conclusion and Recommendations	62

Introduction.....	62
Interpretation of Findings	62
Cultural Influence as Strongholds.....	63
Benefits of U.S. Treatment	64
Medical Professionals as an Enabling Factor	64
Outcomes	64
Education	64
Framework	65
Theory	65
Limitations of the Study.....	67
Recommendations.....	69
Implications.....	70
Conclusion	71
References.....	72
Appendix A: Interview Questions	80
Appendix B: Flyer.....	82

List of Figures

Figure 1. <i>Codes established during open coding</i>	62
Figure 2. <i>Frequency of factors influencing treatment seeking</i>	64
Figure 3. <i>African Immigrants ASD Utilization of Care Model</i>	87
Figure 4. <i>Countries represented in the study</i>	88

Chapter 1: Introduction to the Study

The prevalence of autism spectrum disorder (ASD) has increased since the late 1960s and early 1970s (Morbidity and Mortality Weekly Report [MMWR], 2014). This increase might be due to the lack of awareness of the disease among African immigrants (MMWR, 2014). The rise in the number of children with ASD has led to increased attention on assessment and intervention for the disorder (Koegel, Koegel, Ashbaugh, & Bradshaw, 2014). Researchers believe that ASD is not necessarily a lifelong and disabling disease (Koegel et al., 2014). Only 10% of children diagnosed with ASD will remain nonverbal with early diagnosis and intervention (Koegel et al., 2014).

African immigrants with autistic children face many challenges that might affect use of care. African immigrants are usually grouped as one culture by other cultures because of their geographic location, similar lifestyles, and health problems (Diaz, Mbanya, Gele, & Kumar, 2017). Although lifestyles and health problems of African immigrants are similar, their cultural norms and health care use patterns are different (Diaz et al., 2017). Sub-Saharan African (SSA) immigrants lived in countries with systems of more self-referral, higher user fees, and generally low use of health services (Diaz et al., 2017). African immigrant response to a different lifestyle and different health system varies because of communication issues and cultural differences (Diaz et al., 2017). Despite the increased incidence of ASD in the United States, there are limited studies on use of care by immigrants with autistic children.

Culture is very important in the health outcome of an individual (Miller-Gairy & Mofya, 2015). Some African cultures believe that having a child with ASD will affect

how people view the mother and the rest of her family (Miller-Gairy & Mofya 2015). In many cases, the fear of the stigma associated with the disease affects the parents more than the disease itself and leads to the parents remaining silent about the illness (Miller-Gairy & Mofya, 2015).

Background

ASD is a group of developmental and behavioral disabilities affecting multiple areas of a person's life (Lin, Harwood, & Yu, 2012). The Health Resource and Service Administration and Center for Disease Control and Prevention reported that an average of 1 child in every 110 is diagnosed with ASD (as cited in Lin et al., 2012). There has been a 17% increase in the incidence of developmental disability between 1997-2008 (Lin et al., 2012). Immigrant children in the United States have also shown an increase in the prevalence of ASD (Lin et al., 2012). Immigrant children are the fastest growing group of children in the United States (Yun, Fuentes-Afflick, Curry, Krumholz, & Desai, 2013). One of the fastest rising groups of immigrants in the United States are African immigrants (Kentucky Nurse, 2015).

Early and intensive interventions by a multidisciplinary team, including educational specialists, are imperative for children with ASD (Farmer et al., 2014). Children with ASD need more medical services, rehabilitation therapies, mental health services and school-based services than other children (Farmer, et al., 2014). Use of care and access to care for African immigrants with autistic children can affect early intervention and intensive intervention. One of the barriers that African immigrants report

in using care is the language barrier (Kentucky Nurse, 2015). Lack of proficiency in English affects the quality of care, satisfaction, and understanding of the medical situation of African immigrant (Kentucky Nurse, 2015). Another barrier reported was the lack of knowledge of eligibility for services. Illegal immigrants may not seek care for their children due to fear of being deported (Kentucky Nurse, 2015).

There are limited studies available on immigrants and use of care for their autistic children in the United States (Kentucky Nurse, 2015). However, children from immigrant families are more likely to report a lack of satisfaction with their physician (Lin et al., 2012). There is a documented increase of African immigrants in the United States, but there are no studies available on their use of care (Kentucky Nurse, 2015). The incidence of ASD among immigrants, including African immigrants, is on the rise in the United States (Lin et al., 2012). There are also limited studies on the perceptions of Africans about ASD and factors that influence use of care. In general, there are limited studies available on issues related African immigrant's health care use (Kentucky Nurse, 2015).

This study could promote social change by bringing awareness about factors that influence use of care for African immigrants with autistic children and their perceptions of ASD. This study could provide insight into factors that could be related to health care disparities among Africa immigrants with autistic children. African immigrants differ from each other in many ways including their country of origin, medical practices, and their beliefs (Kentucky Nurse, 2015). In this study, I focused on immigrants from sub-Saharan Africa with autistic children.

Problem Statement

In the United States, nearly one-quarter of the children have at least one immigrant parent (Lin & Harwood, 2012). There has been an increase in the number of children diagnosed with ASD (Lin & Harwood, 2012). Despite the rise in ASD, little is known about access to medical care and adequacy of insurance coverage for children with ASD from immigrant families (Lin & Harwood, 2012). The African immigrant group is the fastest growing population in the United States (Kentucky Nurse, 2015). The sub-Saharan African immigrant population increased from 130,000 to 1.5 million between 1980 and 2013 (Kentucky Nurse, 2015). According to the Kentucky Nurse (2015), there is limited research on issues related to health care among African immigrants in the United States.

Parents play a role in determining if their child might have ASD and confirming the diagnosis that will lead to the implementation of care. The perceptions of immigrant families about ASD can be related to their cultural beliefs (Ponde' & Rousseau, 2013). There are limited studies on parent's perception of their autistic children (Ponde' & Rousseau, 2013). ASD is a sensitive topic in many cultures due to its stigma (Kayama & Haight, 2013). The shame of ASD not only affects the child, it also affects their families and their decision to use care (Kayama & Haight, 2013).

Use and access to care for sub-Saharan African immigrants with autistic children requires knowledge of services availability and the proximity of a health care facility. Some African immigrants have stated that they do not know where to go for health services (Kentucky Nurse, 2015). In addition, some African immigrants are confused

about the U.S. health care system (Kentucky Nurse, 2015). Cultural beliefs are a predictor of use of care for immigrants with autistic children (Lin & Harwood, 2012). ASD is viewed differently in different societies, leading to various ideas of ASD as a disease across cultures. The background of a family affects the decision the family makes about using treatment for an autistic child.

ASD is considered to be a lifelong, developmental disability defined by diagnostic criteria that include deficits in social communication and social interaction and restricted, repetitive patterns of behavior, interests, or activities (MMWR, 2014). The prevalence of ASD has increased since the earliest studies in the late 1960s and early 1970s (MMWR, 2014). The reason for this increase might be due to raising awareness of the disease (MMWR, 2014). This unexpected increase in ASD has led to public concerns and systematic public health monitoring.

Purpose of the Study

This qualitative, grounded theory study was conducted to understand the factors that influence African immigrants to use health services for autistic children in the United States. I focused on the use of health care services of African immigrants with autistic children in the United States. Early intervention for ASD will build on the child's strength to learn new skills improve behaviors, and identify areas of weakness (Stone & DiGeromino, 2015). This study could help create awareness about the importance of early intervention for children with ASD among African immigrants in the United States, which could improve outcomes and functionalities for their autistic children.

Research Questions

1. How early do African immigrants with autistic children in the United States seek intervention for their autistic children?
2. How does culture influence the decision of African immigrants in the United States to use early intervention for their autistic children?
3. What are the perceptions of African immigrant about ASD and interventions available in the United States?

Theoretical Framework

The theoretical framework of this research study was the Aday-Anderson model of health care utilization. This model is used to view policies that affect characteristics of the health care delivery system and the population at risk to bring about changes in the use of health care services and the satisfaction with those services (Aday & Anderson, 1974). In this study, I sought to understand the timing of parent's seeking treatment for their children with ASD and the cultural belief factor(s) that influence the timing. This framework was used to understand the factors that affect African immigrant parent's decisions to seek early intervention for their autistic children.

Nature of the Study

The study was conducted using qualitative research as it was consistent with understanding the factors that influence the use of care for the autistic children of African immigrants. Qualitative researchers aim to understand aspects of social life by knowing the experiences and attitude of an individual or the community (McCusker & Gunaydin,

2014). In this study, I aimed to understand the perceptions of African immigrants about ASD.

Grounded theory was the research design that was used to develop a theory of use of health care for African immigrants with autistic children. Creswell (2009) described grounded theory as a strategy of inquiry in which researchers derive a general, abstract theory of process, action, or interactions rooted in the view of the participants. Grounded theory is the preferred method for a study where there is little information about the topic under investigation (Quick & Hall, 2015). This approach enabled me to design, test, and generate new theory about African immigrants with autistic children and their use of care. I focused on interviewing African immigrants with autistic children to make sense of the values and beliefs of this population. I also focused on African immigrants and the factors that influence use of care for their autistic children. Answers to the research questions provided insight on strategies that might improve use of care of autistic children from African immigrant parents in the United States

Before interviewing participants, I received permission from Walden's Institutional Review Board (IRB). After the IRB approval, participants read and signed the informed consent before being interviewed. The consent form (Appendix A) contained the purpose of the study. It also ensured confidentiality of the participants, outlined potential risks, and expected benefits of the research. The use of the consent form was to make sure that participants were not coerced into taking part in the study (Quick & Hall, 2015).

In qualitative research, data or theoretical saturation are used to determine the sample size of the study (Walker, 2012). I planned to use theoretical saturation to determine the sample size of my study. Theoretical saturation occurs when no themes can cause the occurrence of redundancy can be identified (Walker, 2012). I contacted community health programs that provide services to families with autistic children. With the help of the staff in these programs, I identified African immigrants with autistic children and requested their permission to become participants in my study. The grounded theory research took place in the New York and New Jersey area because of the proximity to my location.

Definitions

African immigrant: People who migrate to the United States from the continent of Africa.

Autism spectrum disorder (ASD): ASD is a group of neurodevelopmental disorders that result in deficits in social communication and social interaction and in restricted repetitive patterns of behavior, interests, and activities (Harris, 2015).

Concept: An abstraction representing an object, a property of an object, or a phenomenon that scientists use to describe the empirical world (Frankfort-Nachmias & Nachmias, 2007).

Culture: Culture is usually defined as learned values, beliefs, attitudes, and behaviors exhibited by a group of people (Mandell & Novak, 2005).

Research Design: The program that guides the investigator in the process of collecting, analyzing and interpreting observations (Frankfort-Nachmias & Nachmias, 2007).

Informed Consent: The agreement of an individual to participate in a study after being fully in-formed about the study's procedures and possible risk (Frankfort-Nachmias & Nachmias, 2007).

Prevalence: Refers to the number of individuals with the disease in the general populations (Ayton, 2011).

Assumptions

Before beginning fieldwork, I assumed that African immigrants in the United States with autistic children might have difficulty using care because of their cultural beliefs and socioeconomic status. I assumed that immigrant mothers would be more willing to participate in a study for their autistic children than immigrant fathers. In the African culture men usually take the role of the breadwinner, and the women are in charge of the upbringing of the children. Immigrants who have lived longer in the United States were assumed to have adapted to the U.S. health care system; therefore, they more likely to use care for their autistic children compared to recent immigrants.

Limitations

The study was limited to Sub-Saharan African immigrants in the United States who spoke English. The processes of grounded theory required the use of multiple stages of data analysis. The various stages of data analysis might lead to exhaustion and loss of sight of ideas that are emerging from the data (Creswell, 2009).

Significance

This study could provide an understanding of factors that influence African immigrants with autistic children to use care for their autistic children from the view of these participants. Significant cognitive gain, language, and social development are one of the benefits of early intervention for children with ASD (MacDonald, Parry-Cruwys, Dupere, & Ahearn, 2014). Early intensive behavioral intervention for children diagnosed with autism increases behavior in the areas of imitation and decrease behavioral excesses (MacDonald et al., 2014). The results of this study provided insights into the factors influencing the timing of interventions for African immigrants' children with ASD. Insights from this study could aid primary care physicians and medical insurance providers to provide educational programs targeted to African immigrant families with autistic children. Immigrant families might benefit from receiving the necessary information required to seek early access to medical care for their autistic children.

Summary

There has been an increase in the prevalence of ASD among immigrants in the United States, and this increase might be due to the rise in awareness of the disease (MMWR, 2014). ASD was previously considered a lifelong disabling disorder, but scholars have shown that it is not necessarily so (Koegel et al., 2014). Immigrant families in the United States have many challenges that might affect use of care. There are limited studies on use of care for African immigrants in the United States.

African immigrants are the fastest growing group of immigrants in the United States. The purpose of this study was to understand the factors that influence the decision

to use health care services for African immigrants with autistic children. This study was needed because it could help African immigrants, as well as health care providers, understand factors that influence use of care for autistic children with African immigrant families. Qualitative research using grounded theory was used to achieve this goal.

In Chapter 2, I will discuss current knowledge about African immigrants with autistic children in the United States. This will include findings and methodological contributions to factors that influence use of care for African immigrants with autistic children. I will also highlight factors that influence use of care.

Chapter 2: Literature Review

Introduction

ASD is a group of neurodevelopmental disorders that result in deficits in social communication and social interaction and in restricted repetitive patterns of behavior, interests, and activities (Harris, 2015). Autistic individuals have restricted interest with unusual behavioral repertoires. The unique manifestation of ASD in childhood ranges from differences in social behavior to severe disability. ASD is a term used to describe children with multiple disorders associated with autism (MMWR, 2014). Autism has been around for over 60 years, but its etiology is yet unknown (MMWR, 2014). The overall prevalence of ASD among the Autism and Developmental Disabilities Monitoring sites was 14.7 per 1,000 (one in 68) children aged 8 years in 2010 (MMWR, 2014). There are various causes of ASD, and a cure is still unknown.

ASD is the full range of presentation of autism from the severe case of autism with behavioral disturbances, to the mild case of ASD with high communication skills and average intelligence. The diagnosis of ASD depends on the extent to which the persistent deficit of social communication and interaction exist and the isolated repetitive pattern of behavior and activities (Psychiatry and Clinical Neurosciences, 2015). The prevalence of ASD globally in recent years increasing; this increase in the prevalence of ASD may not indicate an actual increase in the disease itself, but raising awareness of illness (Psychiatry and Clinical Neurosciences, 2015). The global increase in the incidence of ASD has mostly been reported from the Western world.

Parents who are raising children with ASD may experience more stress compared to parents who do not have children with ASD (McStay, Trembath, & Dissanayake, 2014). Families must continually adapt after a child has been diagnosed with ASD. The diagnosis of autism not only affects the child diagnosed with autism; it affects the parents, siblings, grandparents, and other family members. A child with ASD usually requires a lot of attention from parents, which will lead to other siblings feeling neglected (McStay, Trembath, & Dissanayake, 2014). There is also the need for multiple treatments and therapy, which can take a physical and emotional toll on the parent as well. ASD and mental illness continue to be a sensitive topic among Africans in the United States and Africa due to the culture and beliefs about the disease.

Treatment Options for Children with Autism

There are different types of treatment for ASDs that have been in scientific and modern literature (Mandell & Novak, 2005). There is limited research on whether most of these treatments have been tested using traditional scientific methods. Many families in the United States with autistic children have used at least one of these treatments (Mandell & Novak, 2005). There is no known cure for autism, but there are treatment and educational approaches that can address some of the challenges associated with autism.

According to the Center for Disease Control and Prevention (CDC, 2016), the treatment for ASD can be broken down into four different categories:

- Behavior and communication approaches
- Dietary approaches
- Medication

- Complementary alternative medicine
- Behavior and communication approaches

The treatment for children with ASD usually requires a multimodal approach (Leskovec, Rowles, & Findling, 2008). The starting point of this method is behavioral and educational interventions that include rehabilitation components, such as occupational therapy, behavioral modification, and speech/language therapies (Leskovec et al., 2008). Autistic children also suffer from dysfunctional behaviors that interfere with the implementation of nonmedical interventions. Some of the dysfunctional behaviors include aggression, irritability, inattention, hyperactivity, and mood/anxiety symptom (Leskovec et al., 2008). Treatments programs that focus on behavioral principles have been instrumental in improving cognitive and adaptive behaviors ((Anan, Warner, McGillivray, Chong, & Hines, 2008). Behavioral approaches are used to measure behavior to identify factors that facilitate the development of skills and reduce the behavioral problem (Anan et al., 2008). The primary goal of behavioral therapy is to maximize the ability of the individual to function independently. Many children with ASD experience an anxiety disorder in a clinical setting (Wijnhoven, Creemers, Engels, & Granic, 2015). The mind game light was developed to focus on decreasing anxiety in autistic children ((Wijnhoven et al., 2015). This game is used mainly in health institutions and individual education schools to reduce anxiety in children with ASD. The mind game light is another form of behavioral intervention for children with ASD.

Dietary Approaches

Vitamins, amino acids, minerals, and other nutritional supplements have been used in ASD disease management and health promotion. The use of vitamins and nutritional supplement in the treatment of ASD is known as complementary and alternative medical therapy (CAM; RuiPing Xia, 2011). Although there have been controversies for over 10 years about the selection of CAM over conventional medicine, scholars have shown the effectiveness of CAM in reducing ASD symptoms (RuiPing Xia, 2011). Vitamins, amino acids, minerals, and other nutritional supplement play roles in reducing the risk of chronic disease and promoting health (RuiPing Xia, 2011). Providing supplements that will increase the serum concentration of Vitamin D may reduce the risk of severity of ASD (Horowitz, 2015). Folinic acid; l-carnitine; and a multivitamin containing B vitamins, antioxidants, vitamin E, and coenzyme Q10 are effective in reducing ASD symptoms in children with metabolic abnormalities (Horowitz, 2015). Luteolin, which is flavonoid in many fruits, vegetables and medicinal, may counter the effects of ASD (Horowitz, 2015).

Medications

Medications are sometimes used to manage high energy levels in children with autism. Medication can also control symptoms associated with autism, such as the inability to focus, depression, and seizures (RuiPing Xia, 2011). There are many medications used to treat symptoms of ASD. The type of medication used depends on the symptoms. Drugs used to treat ASD include psychostimulants, typical antipsychotics, and atypical antipsychotic (RuiPing Xia, 2011). Typical antipsychotic drugs are used to

decrease maladaptive behaviors. Atypical antipsychotics are used to reduce the seizure threshold (RuiPing Xia, 2011).

The Importance of Use of Care for Children with Autism

Knowledge of access to care for African immigrants is limited in the United States due to inadequate studies on health care for African immigrants with disabilities. Immigrants may face challenges in accessing health care that might lead to reduced use of care available to autistic children. Some of the problems immigrants face in accessing health care include uninsured status, limited access to primary care physician, and not being aware of the availability of services (Bogenschutz, 2014). Another factor that influences access to care is limited English proficiency (Bogenschutz, 2014). African immigrants, and other immigrants with disabilities, may lack familiarity with services available to them and their family.

According to the Autism Science Foundation (2015), the earlier in life a child receives treatment for autism, the better the child's prognosis. Early intervention in ASD can help children learn to walk, talk, and interact appropriately. In the 1960s and 1970s before the availability of comprehensive early interventions, the outcome of children with ASD was dismal (Koegel et al., 2014). Children with ASD ended up in mental institutions and locked in wards where they endured undesirable living conditions because ASD was considered a lifelong disabling condition. In recent years, there have been effective interventions that have shown that ASD is not a permanent disabling condition (Koegel et al., 2014). Some positive outcomes for children with ASD were related to educating parents, behavior management techniques, communication

techniques, socialization, and academics. About 25% of children with ASD will be free from the diagnosis and become included in a regular school (Koegel et al., 2014). Fewer than 10% of children with intervention will remain nonverbal (Koegel et al., 2014).

Interventions should be started at the earliest point in time to achieve the best result.

Early identification of ASD is also paramount in the progression and response to the disease. Communication concerns are the primary identifiers because many children who become autistic have language delays (Webb, Jones, Kelly, & Dawson, 2014). The first 2 years of a child's life are imperative in identifying ASD because behavior risk markers of ASD are usually determined when the baby is 12 months old (Webb et al., 2014). Some of the identifiable markers include failure to respond to name, reduced eye contact, and reduced positive affect and decreased communication gestures (Webb et al., 2014). These markers are also linked with other communication disorders. Early intervention can help parents identify the cause of their children's communication issues and seek the appropriate care.

African Immigrants with Autistic Children Use of Care

About 25% of children in the United States have at least one immigrant parent (Yun, Fuentes-Afflick, Curry, Krumholz, & Desai, 2013). Immigrant families in the United States are very diverse in national origin, socioeconomic status, and educational background (Yun et al, 2013). There are also multiple subgroups including documented and undocumented immigrants. The understanding of health issues among immigrant children is limited. Children of undocumented immigrant families are likely to be uninsured, have poor health, and limited access to health care (Yun et al., 2013).

Disparities that affect children of African immigrants play a role in the use of care. Culture can influence the perception of a foreigner about ASD in the United States. A language barrier can also cause misunderstanding, prejudices, and understanding appropriate treatment (Yun et al., 2013).

Many African nations have similar beliefs about the cause of autism. Many people in this part of the world believe that individuals with autism are cursed (Denham, Adongo, Freydbeng, & Hodgson, 2010). Some people think that a child showing signs of autism disorder is an evil spirit and should be cast away (Denham et al., 2010). Culture may play a role in the way families address the development of their children and influence delaying the use of care for their autistic children (Mandell & Novak, 2005).

African immigrants in the United States may delay use of care for a child showing signs of ASD due to their cultural beliefs. Socioeconomic status and language barriers can affect African immigrants with autistic children's ability to understand the importance of early intervention (Mandell & Novak, 2005). The relationship between immigrants' parents and services available for autistic children have not been clear-cut because of misunderstandings, prejudices, and the understanding of appropriate treatment. (Mandell & Novak, 2005)

Factors and Use of Care of African Immigrants in the United States

Culture

Culture is usually defined as learned values, beliefs, attitudes, and behaviors exhibited by a group of people (Mandell & Novak, 2005). Religion plays a role in the meaning parents attach to their child's symptom, causes of the disease, prognosis, and

appropriate course of care. Cultural factors have played a role in thoughts and behavior that can affect the way families address deviation in behaviors and subscription to various intervention strategies (Mandell & Novak, 2005). Africa is the second largest continent in the world (Mandell & Novak, 2005). When it comes to ASD, many African cultures have similar beliefs about its symptoms, causes, and prognosis. Decisions African immigrants make in the treatment of their children with ASD are influenced by their cultural beliefs. Some people in Africa believe in witchcraft and voodoo. When these people migrate to the United States, they hold on to their beliefs (Mandell & Novak, 2005). Someone with this type of thinking may attribute the signs and symptoms of ASD to witchcraft and voodoo (author, year). A parent with this belief might seek the help of a witch doctor and delay use of scientific care such as a pediatrician with experience in taking care of autistic children (Mandell & Novak, 2005).

The culture of the parent plays a role in how the mother interprets the child's disability. African American mothers had a lower level of the perceived negativity of their child with ASD than did European American parents (Tincani, Travers, & Boutot, 2009). The parents of African American autistic children view their children's disabilities differently based on their culture (Tincani et al., 2009). Hispanic American parents have a religious and spiritual culture that makes them more accepting of their children's disabilities (Tincani et al., 2009). Due to cultural barriers, parents may be misinterpreted as resisting care for their autistic children. Parents from non-Western cultures have a varying definition of ASD that does not conform to the clinical definition of ASD by the Western cultures (Tincani et al., 2009). Non-Western cultures may not label the condition

as ASD and severe disabilities. Someone with a learning disability in the African culture is someone who lacks cooperation instead of someone with a disability (Tincani et al., 2009). Because of the cultural interpretation of the learning disability, parents may not seek interventions that might improve the child's learning disability or even provide an early diagnosis.

The first theorist believed that ASD occurred in upperclass European American women (Tincani et al., 2009). However, scholars have shown that the prevalence of ASD is the same regardless of race, ethnicity, or country of origin (Tincani et al., 2009). ASD is uniform across groups, but the uniformity is due to the under identification of ASD in racially and ethnically diverse children (Tincani et al., 2009). African American children received their diagnosis, on average, a year and a half later than European American children (Tincani et al., 2009).

Socioeconomic Status of African Immigrants in the United States

Immigration has been facilitated worldwide by the improvement in transportation and communication. Due to their rich cultures, historical roots, values and practices, immigrants constitute a heterogeneous group (Smith Nielsen, Folman Hempler, & Krasnik, 2013). In many countries, immigrants are at a disadvantage when it comes to health. Immigrants are potentially disadvantaged when it comes to educational levels, employment rates, income, wealth, and deprived neighborhood (Smith et al., 2013). Socioeconomic status has an association with health (Smith et al., 2013). Immigrants often have lower socioeconomic status than native-born persons leading to health inequalities.

Disability has been reported as a morbidity and health status indicator both in the United States and globally (Lin & Singh, 2013). About 15% of the world's populations are considered to have some form of disability (Lin & Singh, 2013). Disability is on the rise in many parts of the world, including the United States. People with a disability are reported to be more likely to have a low socioeconomic status, poor physical and mental health, higher smoking rates, obesity, and alcohol use (Lin & Singh, 2013). A primary determinant of access to health care is health insurance coverage. In many of the industrialized countries, health care coverage is available to all citizens (Lin & Singh, 2013). Uninsured families are more than likely to delay use of care and forego preventive medicine and needed medical services. People with low socioeconomic status have higher mortality rate and are more likely to be diagnosed with an advanced stage disease (Lin & Singh, 2013)

The total population of African immigrants in the United States was relatively small compared to other immigrants (Lin & Singh, 2013). Over the past few years, the total number of African immigrants in the United States has increased. African immigrants are more like to have a bachelor's degree or higher than native-born Americans, but they are also more likely to live in poverty than native-born Americans (Lin & Singh, 2013). There are no studies available on socioeconomic status of African immigrants and use of care for autistic children.

Stigma

Stigma has many definitions that include the occurrence of labeling, stereotyping, adverse emotional reaction, and discrimination (Kayama & Wendy, 2013) In the African culture, disability, mainly mental disability, remains a sensitive topic because of the stigma associated with it. Parents will ignore signs of ASD or delay use of care for the autistic children to avoid stigmatization (Kayama & Haight, 2013). Due to the inappropriate social behavior of children with ASD, parents of autistic children experience stigmatization. Some of the behaviors of a child with ASD breach social norms, leading to the feeling of shame and humiliation for parents (Kayama & Haight, 2013). For example, some cultures in Ghana subject autistic children to infanticide because they are believed to be spirit children from the bush that will cause misfortune and destroy the family (Denham et al., 2010). I stopped reviewing here due to time constraints. Please go through the rest of your chapter and look for the patterns I pointed out to you. I will now look at Chapter 3.

Parents of children diagnosed with ASD experience shame and social exclusion. Parents of autistic children have "spoiled" social identity due to the interpersonal ties with the stigmatized individual (Farrugia, 2009). In some cultures, individuals with disabilities are classified as useless and excluded from society (Kayama & Wendy, 2013). Stigma does not only affect people with disabilities, but it can also affect their families. A situation where both the stigmatized person and their families are treated as negatively valued social unit is known as courtesy stigma (Kayama & Wendy, 2013). Courtesy stigma can affect mothers in some cultures that are considered unfit parents for raising a

child with a disability (Kayama & Wendy, 2013). This type of stigma adds to the stress and demands of raising a child with the disability. There also negative beliefs in some cultures that are having a child with a disability is not right and will bring shame to the family.

Programs Available to Autistic Children in the United States and their Influence on Utilization of Care.

In the United States, many programs cater towards children with ASD and their family. These programs include early childhood education program for children ages 3-9, the school program for ages 7-21, transition programs for ages 14-21, campus and pediatric facility and behavior intervention services. Individuals with ASD suffer significant levels of anxiety due to inhibited temperament, physiological hyperarousal, lack of the ability to navigate social situation and inadequate coping mechanisms (McNally Keehn, Lincoln, Brown, & Chavira, 2012). The Coping Cat program (Cognitive Behavioral Therapy CPT) is one of the beneficial and efficient programs that can reduce clinically significant levels of anxiety in children with ASD (McNally et al. 2012). CPT is the treatment of choice for autistic children with an anxiety disorder (McNally et al. 2012).

The primary characteristics of ASD are the impairments in social and communication functioning and the presence of repetitive behaviors and interests (Faja, Aylward, Bernier, & Dawson, 2008). Individuals with ASD have impairments in face processing including difficulties in discrimination, recognition and memory of faces (Faja

et al. 2008). The inability to recognize faces can contribute to difficulties in social communications. Face training programs are used to help the individual recognize faces.

Movement-based programs that include yoga, dance and music are used to treat behavior and other features of ASD. These programs provide the valuable alternative to pharmacological methods that come with a lot of side effects. A combination of yoga, dance and music therapy triggers a relaxation response that is effective in treating behavioral symptoms (Faja et al. 2008).

Impact on utilization of care

Many of the programs available for autistic children can improve utilization of care if parents are aware of the services and their effectiveness in improving behaviors in autistic children. If the pediatrician of the child does not provide information about these programs, they might not be aware that these programs are available. The possibility of reluctance to talk about ASD among African immigrants might make it challenging to promote awareness of the disease and services that are available to treat symptoms. There are many autistic programs available, but at this point, it is not clear whether there are programs that cater specifically to African immigrants in the United States. Many of these programs might not be aware of cultural differences and its impact on utilization of care.

Summary

The impact of ASD is lifelong and it affects the ability of an individual to interact socially and communicate effectively (MMWR, 2014). There is no cure for ASD at this time, but there are interventions that can treat symptoms associated with ASD.

Interventions used to treat symptoms of ASD can be pharmacological and nonpharmacological. Utilization of care is paramount for children with ASD. Studies have shown that children with ASD that have early access to care show improvement in behavior and functionality (Koegel et al. 2014). The literature on African immigrants with ASD and utilization of care is limited. Many cultures see ASD as a curse and disgrace to the family (Denham et al. 2010). Stigmatization of the disease makes it difficult for the parent to accept that their child has ASD which delays utilization of care (Denham et al. 2010). There are many programs and treatments available to autistic children in the U.S. Programs already available for children with ASD can help improve utilization of care for African immigrant with autistic children if they are made aware of the availability of these programs. The goal of the study is to find out factors that influence utilization of care for African immigrants in the U.S. In chapter 3, I will discuss how the study was conducted to reach the goal of the study.

Chapter 3: Research Method

Introduction

The purpose of the study was to understand the factors that influence U. S. African immigrants' decision to use health services for their autistic children. Early intervention for autism is critical because it builds on the child's strength to learn new skills, improve behaviors, and address areas of weakness (Stone & DiGeromino, 2015). This study could help create awareness about the importance of early intervention for children with ASD among African immigrants in the United States and improve outcomes and functionalities in their autistic children. A qualitative study was conducted using a grounded theory approach. The population for the study consisted of immigrants from sub-Saharan Africa with autistic children.

In this chapter, I focus on research procedures, the method of recruiting participants, and ethical considerations.

Research Design and Rationale

I used grounded theory to generate theory about use of care for African immigrants with their autistic children. The research questions were used to guide the study and data collection.

Research Questions

1. How early do African immigrants with autistic children in the United States seek intervention for their autistic children?
2. How does culture influence the decision of African immigrants in the United States to use early intervention for their autistic children?

3. What are the perceptions of African immigrant about ASD and interventions available in the United States?

I chose the qualitative research method for this study. I chose the qualitative method because it allowed for the exploration of African immigrants' decision to use health care for their autistic children. I did not use the quantitative method because I wanted to understand the perceptions of African immigrants about ASD and their decision to use care. Understanding the perceptions of immigrants with autistic children would have been difficult to do with statistical data and testing of variables. Scholars use the qualitative method to explore and explain the meaning people ascribe to a social or human problem (Creswell, 2009).

There are numerous frameworks within the qualitative method (Nicholls, 2009). The most commonly used are phenomenology, ethnography, case study, and grounded theory. Phenomenology is based on interpretivism, which deals with what it means to be human (Nicholls, 2009). Phenomenological researchers focus on viewing each person as unique and understanding each person's views (Nicholls, 2009). Phenomenology was not appropriate for my study because I was focused on understanding factors influencing use of care for the population being studied. Ethnographic researchers focus on what defines individuals as being part of a particular group (Nicholls, 2009). With ethnography, culture does not pertain only to ethnicity; culture is anything that binds a group of people together, such as shared values and interests (Nicholls, 2009). I did not choose ethnography because my study was not limited to culture, although culture might be a contributing factor that influences use of care for African immigrants with autistic

children. A case study is a qualitative design in which the researcher explores a program, event, activity, process, or one or more individuals in depth (Creswell, 2009). The case study is usually used when the data are to be collected from many sources, such as people, observations, and records.

The qualitative approach I used to explore the perceptions of African immigrants with autistic children and their decision to use care is grounded theory. Creswell (2009) described grounded theory as the qualitative strategy in which the researcher derives several abstract theories of a process, actions, or interactions rooted in the views of participants in a study. I chose grounded theory because I was able to collect data that allowed me to generate a theory about use of care by African immigrants with autistic children. There are limited studies on use of care for African immigrants in the United States. Grounded theory was appropriate for this type of study because it establishes theories in places where sound theory is absent (Nicholls, 2009). Grounded theory also allowed me to study the process of how parents recognize and make decisions about using care for their autistic children.

Role of the Researcher

Doing the qualitative study, I conducted interviews with the participants using open-ended questions. As an observer, I designed my questions to allow the participants to talk openly about their experiences. As an African immigrant living in the United States, I conducted a study that focused on the barriers related to use of care of African immigrants with autistic children. My professional background is in nursing, which provides me with the knowledge of the signs of ASD. I saw many children in my African

community in the United States who were exhibiting signs of ASD, but it was uncertain if these children were using appropriate care, or if the parents had accepted the diagnosis of autism. It was important for me to have clear boundaries about my assumptions of use of care based on my experience with my immediate African immigrant community.

Methodology

Participants

Pilot study. I conducted a pilot study with a small group of participants similar to those who I recruited later in the larger scale for my final study. IRB approval was obtained, and my IRB approval number 06-26-17-0196506. A pilot study was done to assess the effectiveness of my planned data collection and analysis techniques. I conducted the pilot study to detect if there were any problems with my research so that I could make changes before my final research study. The pilot study answered my research questions, guided the development of my research plan, and ensured that my research method worked in practice. Participants were recruited putting up flyers in day care centers and giving out flyers in African functions. Participants were immigrants from Sub-Saharan Africa with autistic children.

Final study. The focus of the study was on African immigrants in the United States who had children with ASD from age 2- to 15-years-old. The age of a child at diagnosis might be associated the child's symptom (Georgiades et al., 2014). Children who are diagnosed at a late age have less severe symptoms, and children diagnosed at an early age have more severe symptoms (Georgiades et al., 2014). I chose a wide age range to be able to determine the factors that affect use of care.

I interviewed at least one parent per child, either the mother or the father. I recruited the parent who was most involved in the care of the child. If both parents were involved and were willing to participate in the study, I was ready to interview both parents. I recruited participants who were immigrants who lived in the United States for fewer than 10 years. I chose t10 years because as an African immigrant in the United States, I know it takes more than 10 years for a person to lose his or her entire cultural perspective. Immigrants appeared to have been integrated into the Canadian society while they maintained their culture, language, and norm (Choi, Kushner, Mill, & Lia, 2014). The selection of participants had a clear rationale and fulfilled the purpose of my research questions.

I determined the extensiveness of my data collection process before selecting my participants. I used grounded theory in my research, which is a task of a systematic discovery of theory from data (Walker, 2012). I used saturation within grounded theory to determine the number of participants for my study. By following the guidelines of the use of saturation within grounded theory, I stopped sampling when theoretical saturation was reached (. In grounded theory, saturation can be determined by the empirical limit of data, integration and density of the theory and the analyst's theoretical sensitivity (Walker, 2012). The sample size for my study was 25, as it is recommended that the sample size for a grounded theory should have 20-30 participants (Creswell, 2009).

My original plan was to recruit participants from Autism Family Service of New Jersey (AFSNJ). I put up flyers in the community programs with permission by the organization with my e-mail address as a point of contact for the participants (Appendix:

B). I was hoping to receive e-mails from the volunteers and then I would provide them with my phone numbers and schedule an appointment to speak with them about my study in detail. This plan did not work because I did not receive any e-mails from this program. AFSNJ is one of the leading providers of family support service to the autism population in New Jersey and is an affiliate of the Family Resource Network (FRN; AFSNJ, 2014). FRN is an umbrella organization that focuses on meeting the growing needs of community-based programs that serve individuals and families with disabilities and autism (AFSNJ, 2014). Although this program provided extensive work with ASD, no one responded to my flyer.

I attended African functions in the New York, New Jersey areas and handed out flyers. I did not require additional IRB approval for handing out flyers in African community programs. I went to Early Start programs in New York city and put flyers in their bulletin boards with permission. Volunteers gave me the e-mail address of other volunteers who were willing to participate in my study. Because of how difficult it was for me to gain participants, I used my initial phone call as my screening call where I found out if they met criteria to be in the study. I asked if they were immigrants from sub-Saharan Africa with an autistic child between the age of 2 and 15 and how long they lived in the United States. After I determined that they met the criteria to be in the study, I scheduled an interview and informed consent was signed on the same day of the interview. I conducted two interviews in a quiet room in a public library, and the rest of the interviews were conducted over the phone.

Data Collection

Participants were asked to sign a consent form before the beginning of the interview. Participants were interviewed via telephone or face-to-face depending on their geographic location. An interview protocol with open-ended questions was used to gather information (Appendix A). Each interview took between 45 minutes to 1 hour. The interview was audio recorded and meeting notes were made and later transcribed.

Data Analysis

Scholars use grounded theory to generate a theory through constant comparison of data (Rintala, Paavilainen, & Astedt-Kurki, 2014). Collection of data in grounded theory is closely associated with data analysis (Rintala et al., 2014). Open, axial, and selective coding are usually carried out concurrently in the analysis of a grounded theory. Data are examined line-by-line in open coding to define actions or events and then reduced to small sets of themes (Rintala et al., 2014). In axial coding, the data are recombined by making connections between categories and subcategories and then specifying the properties of the category (Rintala et al., 2014). One category is selected to be the core category in selective coding, and all the other categories are related to the core category (Rintala et al., 2014).

My study aimed at creating a theory about use of care for African immigrants with autistic children. After completing my interviews, I began the data analysis process. Open coding defined the action of African immigrants with autistic children regarding use of care. Axial coding and selective coding was dependent on the type of data I collected. First, I used open coding to generate categories of information. Second, I

selected one category and positioned it within the theoretical framework and then used selective coding to derive a story from the interconnection of the categories. I used a computer program called QRS NVivo to help code, organize, and sort my information. Using computer software to sort and locate qualitative data is efficient and fast (Rintala et al., 2014). Computer programs are logical because they can facilitate comparing different codes (Rintala et al., 2014).

Issue of Trustworthiness

Trustworthiness is established in qualitative research to assess the reliability and validity of the data (Kisely & Kendall, 2012). The four processes used in determining trustworthiness in qualitative research are credibility, transferability, dependability, and confirmability (Houghton, Casey, Shaw, & Murphy, 2013). Credibility refers to the intensity and value of the study (Houghton et al., 2013). I developed coding schemes and elaborate data in categories, subcategories, and a conceptual framework to promote the credibility of my study (Lasch et al., 2010). The ability of the findings of a study to be transferred into another similar context or situation is known as transferability (Houghton et al., 2013). I provided detailed descriptions of my findings so that the reader can make an informed decision about transferability (Houghton et al., 2013). The stability of the data in qualitative research is known as dependability (Houghton et al., 2013). Confirmability refers to how neutral and accurate data are (Houghton et al., 2013). I used QRS NVivo to ensure dependability and confirmability by outlining decision made throughout the research process and to provide a rationale for my methodology.

In qualitative research, the researcher is never completely objective because the researcher is considered a part of the study (Farrelly, 2013). The researcher takes a holistic view of the subject by including many variables in the study (Farrelly, 2013). This qualitative research validity enhancement uses the words of the participants to name categories and themes (Grossoehme, 2014). To prevent the study from being influenced by my interests and background, my data represented the participants' response and literature reviewed. I was aware that my values and cultural background as an African immigrant in the United States might affect the research process, which is known as reflexivity (Cope, 2014). To address researcher's bias, I maintained a reflexive journal of thoughts and feelings to categorize perceptions and subjectivity. My awareness of my bias at all stages of the research process minimized the bias and increased trustworthiness

I audiotaped two of the interviews and took notes on the notepad for the rest of the interviews. I used the grounded theory approach to gather data while simultaneously analyzing the data and using the emerging theory to inform data collection (Malone, Nicholl, & Tracey, 2014). The cycle continued until there was no more information to be learned. Grounded theory was the best research method for this study because there was no existing theory on African immigrants with autistic children. Grounded theory allowed me to develop a theory on factors that influence African immigrants with autistic children of using care.

Ethical Procedures

The importance of establishing research ethics committees and institutional review boards was emphasized by the Declaration of Helsinki in 1964 (Oye, Nelli, &

Glasdam, 2016). Ethical guidelines were established to prevent researchers from taking ethical responsibilities by themselves (Oye et al., 2016). Before doing research, the researcher must weigh the risk and burden of the study versus the benefit of the study on the participants and others. I recruited research participants on a voluntary basis, and participants freely gave informed consent to participate in the study (Oye et al., 2016).

Before recruiting my participants for my research, I gained approval from the IRB at Walden University. After getting the IRB approval, I recruited participants and Walden informed consent was signed before interviewing the participants. All participants were given a \$5 gift card to Toys R Us in appreciation for their time and information provided. This incentive was offered to increase response rate and willingness to participate. A larger incentive may attract more participants but would not be ethical because it might undermine the freedom of the individual (Cryder, London, Volpp, & Loewenstein, 2010).

Data collected did not include personal information, such as name, phone numbers, and participants' address. Numbers and letters were used to identify participants. This was conducted to assure that the confidentiality and privacy of the individual were protected. I placed the interview in an electronic folder secure with a password. I kept the transcript until I completed my dissertation just in case I need them for further analysis

Summary

The purpose of this qualitative grounded theory study was to understand the factors that influence use of care for autistic children of sub-Saharan African immigrants in the United States. I chose the qualitative research approach because it was more

appropriate in trying to understand the perceptions of African immigrants regarding use of care for their autistic children. Grounded theory was the best method for my study because a sound theory was absent for use of care for African immigrants with autistic children. I gained IRB approval before recruiting participants. After IRB approval and recruiting of participants, the participants signed an informed consent before interviewing. Participants were recruited by attending African functions and giving out the flyer and QRS NVivo was used to help with data analysis and coding. The findings from analyzing the data was used to generate a model for the use of health care for African immigrants with autistic children. The results of the data analysis are presented in chapter 4.

Chapter 4: Results

Introduction

Scholars have outlined the prevalence of ASD. The best choice for this study was to conduct qualitative research using grounded theory to understand the factors that influence African immigrants to use health services for autistic children in the United States. This study could help create awareness about the importance of early intervention for children with ASD among African immigrants in the United States, which could improve outcomes and functionalities in their autistic children.

The research questions that were used to guide the study were

1. How early do African immigrants with autistic children in the United States seek intervention for their autistic children?
2. How does culture influence the decision of African immigrants in the United States to use early intervention for their autistic children?
3. What are the perceptions of African immigrant about ASD and interventions available in the United States?

I conducted interviews, transcribed them, and analyzed data using grounded theory to establish the presence of themes. This chapter details the outcomes of the study to understand the factors that influence use of care for African immigrants with autistic children. This chapter will provide the setting, demographics, data collection, data analysis, and results of this study.

Pilot Study

I conducted a pilot study with four participants similar to the participants recruited for the final study. The purpose of the pilot study is to assess the effectiveness of the planned data collection and analysis techniques (Doody & Doody, 2015). The pilot study was done to detect if there were any problems with my research design so that I could make changes to my final research study. Participants were recruited using the same process as in the final study, even though they were not included in the final study.

Participants were contacted by phone after receiving signed informed consent through the mail. I interviewed four participants on their scheduled time over the phone. Before conducting the interview, participants were read the consent form. The interviews for the pilot study started in July 2017, and I completed in August 2017. Participants declined for me to record the interview, so I took notes by hand and transcribed them into the computer. The average time for each interview was about 45 minutes. I anticipated the 45-minutes time for the interviews on the consent forms.

After the pilot study, I adjusted my interview techniques by adding more probing questions to gain more information from the participants, which led to accurate data collection and analysis. I did not have to change any interview questions. There was a need for a follow-up question to improve the effectiveness of the data collection and analysis techniques. Based on the outcome of the pilot study, there was no need to modify the data analysis process.

Setting

Twenty-five total interviews were conducted for the final study. Twenty-three interviews were conducted over the phone because it was the preferred method of the participants. Two participants agreed to a face-to-face interview, and they chose a library close to their residence. Recruiting of participants was difficult because many of the people who I reached out to at the beginning of the study did not get back to me. I put up flyers and sent e-mails with flyers. The participants who took part in the study were comfortable and willing to share their experiences. The participants spoke openly and honestly to assist with the study.

Interviews were scheduled over the phone and via e-mail. Interviews for the final study started in September 2017 and were completed on November 17, 2017. Notes were taken during the interview because participants refused audio recording of the interviews. About 28 participants volunteered for the study, and 25 were interviewed for the final study. Three participants were eliminated from the study due to their close relationship with me.

Demographics

There were 29 participants interviewed for this study in total, four for the pilot study and 25 for the final study. All of the participants for this study were immigrants from sub-Saharan Africa who lived in the United States for fewer than 10 years. They were parents of autistic children under the age of 15 years. I did not collect demographic data because I did not feel that it was relevant to the study. Volunteers who were qualified for the study, but who have lived in the United States for over 10 years, were

not allowed to participate in the study. Other volunteers were not allowed to participate in the study because of their close relationship to me. Participants in this study lived in the New York and New Jersey area.

Data Collection

Data were collected from interviews with 25 participants and transcribed. I took notes during the interview and type them into a Word document. I conducted 23 of the interviews over the phone. Two of the interviews were done in a library close to the participants. I chose a library close to the participants because it was convenient for the participant and it was safe. We used one of the quiet rooms in the library for privacy. The phone interviews were about 45 minutes long because I was taking notes during the interview due to the refusal of audio recording by participants. The face-to-face interviews were quicker because I was allowed to audiotape the interviews.

The notepad that I used to take notes was in a locked portable organizer and electronic data were kept secured with a password. The notes were shredded using an electronic shredder after the interview was transcribed into a Word document and saved in a laptop hard drive. I used a phone recorder to record the two interviews and deleted the recording after I transcribed the interviews. There were no variations in data collection from what I presented in Chapter 3 and no problems were encountered.

Data Analysis

After interviewing my participants, I removed all information that could be used to identify my participants. I used numbers to identify all of my participants. I developed my preliminary coding scheme guided by the Aday-Anderson model of health care

utilization theoretical framework and the research questions. I used grounded theory to analyze my data, which aims at generating a theory through constant comparison of data (Rintala et al., 2014). I used open, axial, and selective coding because they are usually carried out concurrently in the analysis of grounded theory. I selected treatment seeking as the core category in the selective coding, and all the other categories were related to the core category (Rintala et al., 2014). I examined the data line-by-line in open coding to define actions and events and then reduced them into small sets of themes (Rintala et al., 2014).

Open Coding

I conducted open coding to describe the phenomenon and the coding schemes revised during this process. I read through each transcript without applying codes to understand the data. Then I reread the transcript and began applying codes based on the preliminary coding scheme. Subsequently, I coded the text using open coding where codes are derived from the data to develop the final coding scheme. As new codes emerged, I recoded already coded text as appropriate. Next, I began searching for patterns or themes in responses.

Figure 1 below represents the codes established during open coding.



Figure 1. Codes established during open coding

After completion of open coding, the text was reread to identify and code themes.

Axial Coding

In the axial coding process, I recombined the data by making connections between categories and subcategories and then specified the properties of the category.

The following themes emerged during axial coding.

1. Cultural beliefs: Participants' cultural beliefs about autism and U.S. treatment
2. Cultural practices: Participants' cultural practices related to treating autism, as well as social practices
3. Experiences: Participants' experiences related to caring for or having a child with autism.
4. Perceptions: Participants' stated perceptions of autism and U.S. treatment
5. Treatment seeking: Participants' actions related to seeking a cure for ASD
6. Utilization model: Factors contributing to treatment seeking

Selective Coding

At the completion of axial coding, I began generating larger theoretical themes. Selective coding involves selecting and identifying the core categories and relating it to other categories (Crosby, DiClemente, & Salazar, 2006). Selective coding was the final step of my data analysis process. During this process, I revisited my original research articles to evaluate the developing themes and credibility of the research results. Through the process of selective coding, I was able to identify core categories after reviewing all of the available data thoroughly. The primary theoretical structure is formed by

integrating of the core categories and other categories (Crosby et al., 2006). To aid in this process, I used diagrams as summarizing devices. Figure 2 below shows that need and referral by a doctor are the main factors that led to African immigrants in the United States seeking treatment for their autistic children.

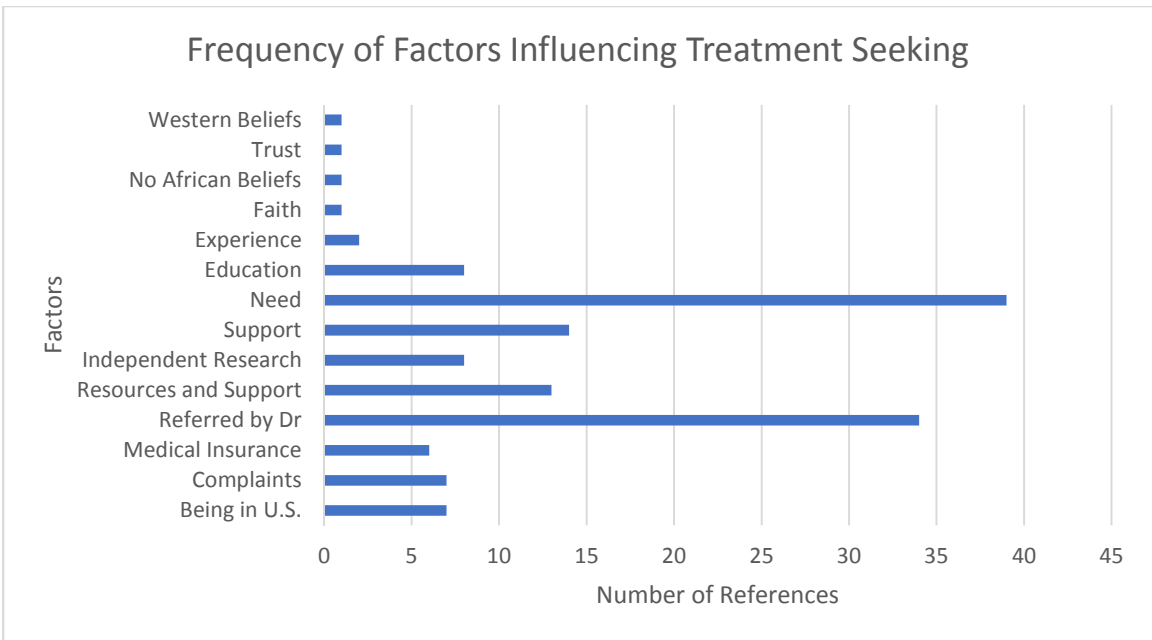


Figure 2. *Frequency of factors influencing treatment seeking.*

Evidence of Trustworthiness

Trustworthiness is established in qualitative research to assess the reliability and validity of the data (Kisely & Kendall, 2012). The four processes of determining trustworthiness in qualitative research are credibility, transferability, dependability, and confirmability (Houghton et al., 2013).

Credibility

In a study, credibility refers to the value and believability of the study (Houghton et al., 2013). Credibility can be obtained by using prolonged engagement and persistent observation, triangulation, peer debriefing, and member checking (Houghton et al., 2013).

Prolonged engagement and persistent observation. I engaged my participants for at least 45 minutes during the interviewing process to get all of my interview questions answered. I asked follow-up questions to gain a full understanding of the answers to my interview questions. The lack of new emerging data was evidence that I had reached saturation.

Triangulation. I used data from my participants to study factors that influence use of care for African immigrants with autistic children. The data that I collected from my participants through interviewing were consistent, which increased my confidence in the credibility of the findings.

Peer briefing. Peer briefing is usually done to confirm whether or not an expert agrees with the coding process (Houghton et al., 2013). During data analysis, my chair,

who is an expert in qualitative research, reviewed my coding and approved my coding process. This enhanced the credibility of my research findings.

Member checking. After interviewing my participants, I took notes and, in two instances, recorded the interview. After the interview, I read the transcript to participant to make sure that I had accurately transcribed the interview.

Transferability

Thick description. To obtain transferability for my study, I ensured that the findings could be transferred to another similar context or situation. I used thick description in this study to determine transferability by ensuring that the original context was adequately described so that judgment can be made. I provided a detailed description of my study so that the reader can make an informed decision about transferability of the findings to their context. I included accounts of the context, provided the research method of my study, and provided raw data of my study so that readers can consider their interpretation.

Dependability

Dependability in qualitative research can be compared to reliability in quantitative research (Houghton et al. 2013).

Audit Trail

I used NVivo software to code and analyzed the data in this qualitative research. NVivo enabled me to enhance the rigor of my study by providing a comprehensive trail of the data that I collected and analyzed. The query tool in NVivo enabled me to audit my findings and guard against rare findings that might suit my preferred arguments.

Reflexivity

I am an African immigrant with family members who are parents of autistic children. I was aware of my bias throughout the research process, making sure that my biases did not interfere with my research process.

Confirmability

Confirmability is the process of establishing neutrality and accuracy of the data (Houghton et al. 2013). To establish confirmability, I compared data from different participants.

Audit Trail

I used an audit trail to achieve rigor by discovering the means. An audit trail was achieved by making thorough and comprehensive notes related to the contextual background of my data and rationale for methodological decisions (Houghton et al. 2013). I also studied the process to which I achieved the answers to my research questions.

Reflexivity

I achieved neutrality and accuracy of data by being aware of my personal biases related to my research study.

Results

The results from collecting and analyzing data from 25 participants through interviewing to address the three research questions are presented below. After reviewing transcripts and codes that evolved through data analysis, six themes emerged. The themes

explained what influences African immigrants with autistic children to seek treatment for their children. These themes also revealed the role culture plays in the utilization of care for African immigrants with autistic children. The information collected demonstrated that need which represents both perceived and actual need for health care services and referral to services by a doctor was reported by participants as the primary reasons for utilization of care for their autistic children.

Research Question 1

How early do African immigrants with autistic children in the U.S. seek intervention for their autistic children?

Theme: Treatment Seeking

This theme refers to the action taken by participants to seek treatment for their children with ASD. The treatments can be either spiritual or U.S. based treatment. Categories for this theme are spiritual, treatment and timing.

Spiritual referred to actions related to seeking spiritually based interventions. Seventeen out of 25 participants noted that they tried spiritual interventions. For some families, it was because of community pressure and for others a spiritual intervention was because of family recommendations. P1 noted that, "I was advised to seek the assistance of a very powerful pastor back home which I did. They prayed for my daughter over the phone when he has his church services back home. I also called him for one to one prayers." P5 engaged in a spiritual ritual based on her family's desire, "My husband family knew someone at the village that can help and we took her there. We killed a

chicken and spilled the blood to sacrifice to demons." However, engaging in spiritual interventions didn't necessarily negate the family seeking U.S. based treatment options.

The next category in this theme is U.S. treatment-seeking behavior, which referred to actions related to seeking U.S. treatments and interventions. Now that they were living in the U.S. some African immigrants felt that it was best to take their child for treatment here. As P10 pointed out, "I decided to take my daughter to a pediatrician because I figure we were now in the U.S. All my efforts in Africa has failed. I was hoping that I would get help to improve her behavior and maybe her speech. Another participant reported that she sought interventions for their children because it was recommended by their doctor. P20 stated, "I follow whatever the doctor tells me."

The final category in this theme is timing relating to when parents sought U.S. based treatments. This category is of critical importance as it directly answers this research question regarding early intervention. The codes for this category are early age and immediate age. Early age represents treatment sought when a child was less than three years old. Immediate reflects treatment started when a child was age three or older but immediately following diagnosis. Nineteen participants reported that treatment was sought at an early age while six participants said they got treatment immediately. P8 Stated, "We started the program as soon as the doctor sent us there. My son was about two years old." Responses from participants show that treatment was sought as soon as it was recommended by the child's physician. Six out of 25 participants noted that they got treatment as soon as the physician recommended it. Parents often wanted to have their child enter treatment earlier, but it wasn't possible. P9 Stated, "I started treatment as soon

as we moved to the States. He was around five years old. I have tried to get treatment earlier, but we could not afford it".

Theme: Utilization Model

The theme Utilization Model encompasses factors that lead to the use of U.S. treatment and health services by African immigrant in the U.S. for their children with ASD. The reasons participants noted for seeking treatment for their autistic child ranged from wanting the best for their child to being required to do so. The categories for this theme are a cultural influence, enabling factors, need and predisposition.

Cultural influence refers to whether or not participants explicitly stated that African culture influenced their decision to seek U.S. interventions. Despite the belief that ASD is caused by an evil spirit, many participants reported that their decision to seek treatment was influenced by their child's pediatrician or their knowledge about ASD rather than their culture. P5 Stated "My decision to seek treatment was not influenced by culture. I chose to seek treatment because I wanted what was best for my child. I knew some families who are resisting treatment because they did not believe that their child has ASD. I was taking my chances; I did not have anything to lose. I have seen great improvement in my child's behavior. He walks independently and functions well in school. There are still some behavioral issues here and there, but he is highly functional, and I am happy". P4 was Registered nurse with a Master of Public health degree. After the ASD diagnosis, she did a lot of research on her own. She stated "African culture did not influence my decision to get treatment for my son. If anything, my level of education and exposure to the western world influenced my decision to seek treatment" Out of 25

participants only two explicitly stated that the decision to seek treatment for their autistic child due to cultural influence. While 13 expressly said that their decision to seek treatment was not affected by culture.

Enabling factors included family support, access to health insurance, one's community and other factors that enabled the use of health care services. Participants reported that referral by their pediatricians enabled them to seek treatment for their autistic child. P2 Reported that her pediatrician told her something was wrong. She stated "I did not know what to expect. This was my first child and my mother was upset that I was pregnant so I moved in with my son's father. He did not care about us so he did not pay attention to anything. I tried to answer the doctor's questions correctly and then he told me to go see another doctor." P13 Reported that she received a recommendation and support from her pediatrician stating that "He told me about autism and that he suspects that my child was autistic. I was interested because whatever he was saying to me made sense. I was not being blamed for my child's illness. According to the pediatrician, it was not anyone's fault that my child is autistic. Living with a sick child was one thing but losing people that you have known and trusted all your life because some native doctor says they contributed to your child's illness was devastating. I was pleased that I won the visa lottery and left Sierra Leone because I was very lonely there. I did not try to make a new relationship because I could not trust anyone." It was reported by 18 participants that the enabling factor for seeking treatment was the referral by the doctor. Next to referral by a doctor was support which was reported by 10 participants. Support was provided by family, friends and pediatrician. One participant reported that she was supported by her

pediatrician by referring her to a psychiatrist and encouraging her to be strong for herself and her child

Need represents both perceived and actual need for health care services. Need also represents parents wanting the best for their child and feeling desperate. P3 Stated "My child was not able to make a complete sentence and she did not behave like normal children. She gets restless and agitated when in an environment with too many unfamiliar people. She repeats her words over and over again. She also made funny hand movement". P3 also expressed the need for treatment as "I was sad because I knew my child was suffering. Her tantrums to me are a sign of pain from not being able to make her needs know and feeling different." A need was reported by 19 participants as one of the factors that influenced utilization of care. Predisposing factors include characteristics such as education, experience and health belief. As noted previously, participants who have had experience with dealing with ASD and education in health care reported their decision to seek treatment was influenced by their knowledge of the disease. In addition to their experiences, P 14 expressed hers, "I have a Master's degree in Public Health. Despite my African background, I am aware of the importance of early intervention in autism. I work in a community health program that caters to the family with children that has a developmental disability. I have seen many children whose family delayed care for their children and the outcome. I did not want to be one of those parents. I am not blaming them for their child's disability. Many did not seek treatment soon enough because they took advice from leaders in their African community. Most of the leaders that gave advise about autism are uneducated. Even the educated ones were still holding

on to the belief that autism is the result of a curse." P18 stated, "I am a Registered Nurse and I went to nursing school here in the U.S. Despite our cultural beliefs, I have education about developmental disability and I knew the earlier I seek care, the better it would be for my child." Out of 25 participants, eight reported that their decision to seek treatment was influenced by education. Two participants referenced that their experience with ASD was a predisposing factor.

Research Question 2

How does culture influence the decision of African immigrants in the U.S. to utilize early intervention for their autistic children?

Theme: Cultural Beliefs

Cultural beliefs refer to beliefs about ASD diagnosis and treatment or U.S. treatment options and their effectiveness or appropriateness. Among the 25 participants interviewed, 23 participants reported that the general belief about the cause of ASD in African culture is that ASD is due to an evil spirit or a curse. Two participants said that a child with ASD behavior was ill-mannered. The categories for this theme are U.S. treatments and Autism.

U.S. treatment refers to the cultural beliefs, effectiveness and appropriateness of U.S. treatment. Seven participants reported that they believed that U.S. treatment was superior to treatment options in their home country. Despite the belief that U.S. treatment was excellent, there was still the belief that diseases like ASD cannot be cured by treatments in the U.S. P1 Responded that "We believe that medical treatment in the U.S. is superior to a certain extent. A disease like Hypertension, diabetes are diseases that can

be treated by the Western medication. When it comes to mental illness, down syndrome and autism, we attribute these illnesses to the evil spirit and can only be cured by a native/witch doctor". P6 also stated that "I was advised that treatment in the U.S only makes the symptoms worst and my child will become dependent. All these people that were giving me this advice did not have a child with autism, how would they know. One thing I learned about being an immigrant is that you have to be very careful who gives you advice. People say a lot of things about issues they do not have a clue on".

Autism in this category refers to cultural beliefs related to children with ASD. 20 out of 25 participants report that children showing signs of ASD are considered to be evil or spiritual. P6 who only found out about ASD after giving birth to an autistic child stated "It was believed to be the cause of the devil. Children who have behavior issues are said to be crazy. They eventually end in the mental asylum. I never heard the word autism until when my son was acting up and the doctor told me about it. With our African people, everything is witchcraft". P16 had no choice but to believe that an evil spirit caused her child's illness. She states "They said it is the work of the devil, so that is what I believed. I have gone through so much suffering and pain in my life that I have no other choice but to believe that it was the work of the devil."

Theme: Cultural Practices

Cultural practice in this theme is traditional African practices and methods used to treat ASD. Cultural practice is also African social practices that influence behavior such as abandoning children showing signs of ASD and avoiding children showing signs of ASD. Abandonment, avoidance and black magic are common practices reported by

participants. 10 participants reported that autistic children were abandoned and isolated in their African community. All 25 participants report that discussing anything related to ASD, including the children and their behavior or disabilities, was avoided. 20 out of 25 participants mentioned the use of black magic in the treatment of ASD. The categories for this theme are Autism and social.

Autism in this category refers to cultural practices used to treat children displaying signs of ASD. P14 "I knew my child was sick but I did not know what it was. I traveled to remote parts of the country to native doctors to seek help. I got the same story that someone placed a curse on me that was why my child was like that. This accusation brought a rift between me and some family members because I was told that it was someone close to me that was responsible for my child's illness." P6 "There is much explanation depending on which witch doctor the parents consulted. Some will say it was because of a family curse. Some will say the child was bewitched while in her mother's belly. There are so many explanations, all pointing to evil spirits, either by the mother's doing or by someone who is mad at the parents."

Social relates to African social practices that influence their behaviors. The codes for this category are gossip and marriage. Gossip associated with the African community gossiping about the autistic child and their family. Gossiping was a common practice in the African community. Marriage relates to the African culture about marriage and the role of a man and a woman in a marriage. Five participants reported that they had arranged marriages. Women are responsible for bringing up of the child. P14 stated "My marriage was arranged by my family and my husband sponsored my migration to the

U.S. In our culture, arranged marriage is common. Because I was a college graduate, my bride price was not low. My parents will have to return the money and face criticism in our community. Even though right now I can afford to pay back the money, my parents are too old for me to put them through that." P8 the situation was unique because she married outside of her culture. She states "My issue is very complicated. My husband is white and people say that white people are sea devils. Having a sick child just confirmed their accusations. I have been asked to take my daughter to our native doctor but I think my husband suspects, so he monitors our movement when we were in Kenya. The people that work for us are hired by him and tells him everything".

Research Question 3

What are the perceptions of African immigrant about ASD and interventions available in the U.S.?

Theme: Experiences

Participants experiences related symptoms, behaviors, feelings and consequences of having a child with ASD. All participants report that having a child with ASD was not an easy experience. Participants who have had experience with dealing with ASD and those with a college education reported having a better experience than the other participants without experience and college education. Categories for this theme are Autism symptoms, treatment by others and broken family.

Autism symptoms are symptoms and behaviors displayed by children with ASD. ASD symptoms reported include the poor appearance of the child, tantrums, inappropriate behaviors and slow cognition. P3 Reports that her child's symptoms and

behaviors were making her feel desperate for help. All she wanted was for her child's symptoms to improve. She stated "I was sad because I knew my child was suffering. Her tantrums to me are a sign of pain from not being able to make her needs known and feeling different." P18 also reported that she would do anything to improve her daughter's symptoms. She states "My daughter was not able to walk or talk at the age of two years. She was comfortable playing by herself. She was excessively calm and slow at everything she is doing. We knew something was wrong. She was also drooling a lot and had episodes of vomiting for no just cause."

How African American parents of a child with ASD were treated by others is the next category. Six out of 25 participants reported that they were treated with kindness while 19 participants reported ill-treatment from people in their cultural community. Aside from all the maltreatment P22 received from her community, she stated "I did not listen to them because they were always laughing at me. They said I am a fool and they laugh and call him crazy and evil spirit. Most of the negativity I got from people in our cultural community is from people that have minimal education. They were stuck in their fundamental ideas and have refused to change despite how long they have spent in the U.S." P22 recalled how people in her community referred to as evil but at the same time got sympathy from other people in her community. She stated "The mean ones referred to me as a witch. They think I used witchcraft to get married to my husband. They say I am ugly and I am fat so it has to be voodoo that let my husband marry me".

Broken family refers to parents that reported that their spouse left them. Three out of 25 participants reported that their spouse left them after having an autistic child.

Out of 25 participants, only six were still married while 19 were single parents. Broken marriages may or may not be because of the diagnosis of ASD. P14 Was one of the participants that reported her husband left her. She stated "We broke up after my daughter was around two years old. Since then I have been the one to take him to all his appointments. I took him to court for child support and he got mad and stopped visiting. I get \$400 every month plus government assistance." P6 Also reported that her husband left her. She stated "My husband left me when my child was three years old. He brought me to this country and dumped my child and me. He and his family back home were blaming me".

Theme: Perceptions

This theme refers to participant's individual perceptions of ASD and about themselves as a parent of an autistic child and perceptions of U.S. treatment interventions. 11 participants reported that they felt terrible about having a child with ASD but do not believe it was their fault that their child was sick. Eight participants stated that they do not have any choice but to think that the cause of their child's illness is due to an evil spirit and it was because of something they or their family have done. Categories for this theme are Autism, self and U.S. treatment.

Autism refers to the participant's perceptions about ASD. Participants reported they grow up believing that children with symptoms of autism were caused by an evil spirit and a curse. Participants reported never hearing about ASD diagnosis until their child was diagnosed with the disease. P6 Stated "They say it is the work of the devil, so that was what I believe. I have gone through so much suffering and pain in my life that I

have no other choice but to believe that it was the work of the devil." P8 Also reported that "In our culture, people showing signs of autism are said to be cursed or possessed by an evil spirit. I do not know why but this has been our beliefs."

Self-refers to respondent's perception of themselves having a child with ASD. Aside from the cultural belief and stigma associated with ASD P17 stated "I am supposed to feel bad about myself but I don't. Having a child with autism to me was God's will. I did not do anything to deserve a sick child. At this point, there is no particular cause of ASD."

Treatments related to Individual beliefs about the benefits, effectiveness, or appropriateness of U.S. treatments. U.S. treatment was reported as helpful to their ASD symptoms by all participants. P21 Stated that "I am very grateful that I came to the U.S. because I have seen a lot of improvement in my child's speech and behavior. In Sierra Leone, we think very highly of the U.S. Anything that comes from the U.S. in our opinion is the best. The U.S. Health Care system was believed to be superior. Coming here, I have all faith in the U.S. health care system." P23 Is also from Sierra Leone reported that "I moved to the U.S. because I was hoping that my son will get better and be able to speak. Healthcare in Sierra Leone was very bad. During my visits to the U.S. before relocating to the U.S., I realized that something could be done."

Summary

Research Question 1

How early do African immigrants with autistic children in the U.S. seek intervention for their autistic children?

Participants reported that they sought treatment as soon as it was recommended by a health care professional. Nineteen participants reported that they seek treatment when their child was below the age of 3 years. Eleven participants reported that they seek treatment as soon as diagnosis was received. Some participants received diagnosis after age 3 years because they were living in Africa and the child was not diagnosed with ASD.

Research Question 2

How does culture influence the decision of African immigrants in the U.S. to utilize early intervention for their autistic children?

Results from the study showed that participants education along with a recommendation from a medical professional influenced their decision to seek treatment for their autistic children. Even though many participants maintained their cultural perception about autism, it did not affect their decision to seek treatment. 2 participants still believe that their autistic children will benefit from both traditional medicine and treatment in the U.S.

Research Question 3

What are the perceptions of African immigrant about ASD and interventions available in the U.S.?

African immigrants believe that ASD is caused by evil spirit and is the result of a curse. Despite these beliefs, interventions available in the U.S. are considered to be superior and successful. Participants reported see improvements in their child's behavior after utilizing recommended treatments.

In chapter 5, there will be an interpretation of results, identification of the study limitation, further research recommendation and implication of the findings. The African immigrant ASD Utilization of care model which emerged during this research will be discussed in detail. The relationship between this theory and theoretical framework that I used to guide the study, will be discussed.

Chapter 5: Discussion, Conclusion and Recommendations

Introduction

The purpose of this qualitative study was to understand how cultural beliefs among African immigrants influence use of health services for autistic children in the United States. I found that despite their cultural beliefs, African immigrants with autistic children seek treatment for their children when needed and when recommended by their physician. Answers to the research questions provided insight on strategies that could improve use of care for autistic children of African immigrants in the United States. This study helps to fill in the gap in research knowledge and scarcity of literature that is specific to African immigrants with autistic children in the United States.

I developed the African immigrants ASD use of care theory to explain the results of the study findings. I was able to develop a preliminary theory through this study that will enable researchers to develop a broader theory. This chapter presents a brief over of the research findings and interpretation of the results. It was difficult to identify how outcomes linked to the literature review because of the limited literature on the subject. Finally, I conclude with limitations, recommendations, the implication of social change, and my concluding thoughts.

Interpretation of Findings

According to this study data and data analysis, the need for services and referral by a health care professional were the two main factors that led African immigrants in the United States with autistic children to seek treatment for their children. The need for services represents both perceived and actual need for health care services. Some

participants reported wanting the best for their child and feeling desperate. In other instances, participants were required to seek treatment by the school district, and treatment was also recommended by the child's daycare center. Participants reported positive outcomes after seeking treatment. Below are the key findings of the study in response to the research questions.

Cultural Influence as Strongholds

Only one participant stated that their African culture influenced their decision to seek U.S. intervention, and 13 participants said that their African culture did not affect their decision. However, perceptions of ASD were rooted in cultural beliefs. Despite higher education, exposure to Western culture, or positive outcomes related to U.S. interventions, perceptions of ASD was associated with evil spirits, religion, shame, and the cause of actions of the parent. This stigma affected the parent's ability or desire to seek intervention or help from family, friends, and the community. Despite having exposure to Western beliefs, practices, education, and interventions, many participants maintained their cultural perceptions about ASD (spiritual, genetic, and shame). Participants also mentioned simultaneously pursuing both U.S. and traditional African (spiritual) interventions.

After my literature review on ASD, African immigrants, and use of care, it was evident that the belief about ASD is similar in many African nations. Many people in these parts of the world believe that individuals with autism are cursed (Denham et al., 2010). Some people think that a child showing signs of autism disorder is an evil spirit and should be cast away (Denham et al., 2010). Culture plays a role in the way families

address the development of their children and influence delaying the use of care for their autistic children (Mandell & Novak, 2005). When Africans migrate to the United States, they hold on to their beliefs (Mandell & Novak, 2005). Some of the cultural views attribute the signs and symptoms of autism to witchcraft and voodoo. Witchcraft and Voodoo cannot be cured by science so a parent with this belief might seek the help of a witch doctor and delay use of scientific care, such as a pediatrician with experience in taking care of autistic children (Mandell & Novak, 2005).

Benefits of U.S. Treatment

Participants stated that immigrating to the United States helped educate them on the nature of ASD and provided better opportunities for treatment options. Many participants believed in the superiority of potential of U.S. interventions. Also, some participants stated that they moved to the United States specifically to seek treatment.

Medical Professionals as an Enabling Factor

Despite cultural strongholds, the advice or recommendation of medical professionals emerged as an enabling factor for seeking intervention.

Outcomes

Although intervention outcomes were mixed, most saw positive gains by seeking interventions early and reported positive results related to U.S. interventions. Some still believed in the benefits of both traditional African and U.S. interventions.

Education

The role or importance of education was central to changing perceptions of ASD and seeking treatment. Education included higher education (college education) and

medical training or work in a health care setting. Also, participants reported educating themselves by conducting their research, reading about ASD, and speaking to others.

Framework

The theoretical framework for this study was the Aday-Anderson model of health care utilization. I chose this model because this framework to demonstrate factors that lead to the use of U.S. health care. This model is designed to view policies that affect characteristics of the health care delivery system and the population at risk to bring about changes in the use of health care services and the satisfaction of those services (Aday & Anderson, 1974). The population at risk were African immigrants with autistic children in the United States. In this study, I sought to understand the timing of parent's seeking treatment for their children with ASD and the cultural belief factors that influence the timing. This framework was used to understand the factors that affect African immigrant parent's decisions to seek early intervention for their autistic children. According to this model, predisposing factors, enabling factors, and need determines the usage of health care services. I used these factors as themes in data analysis and as the foundation for the generation of the theory.

Theory

The Aday-Anderson model was used as the framework for the new theory to emerge. The two main predisposing factors for African immigrants with autistic children to use care was education and experience. Education was mentioned by eight participants, and experience was suggested by two participants as their predisposing factors. Need was presented as the main reason why care was sought for autistic children with African

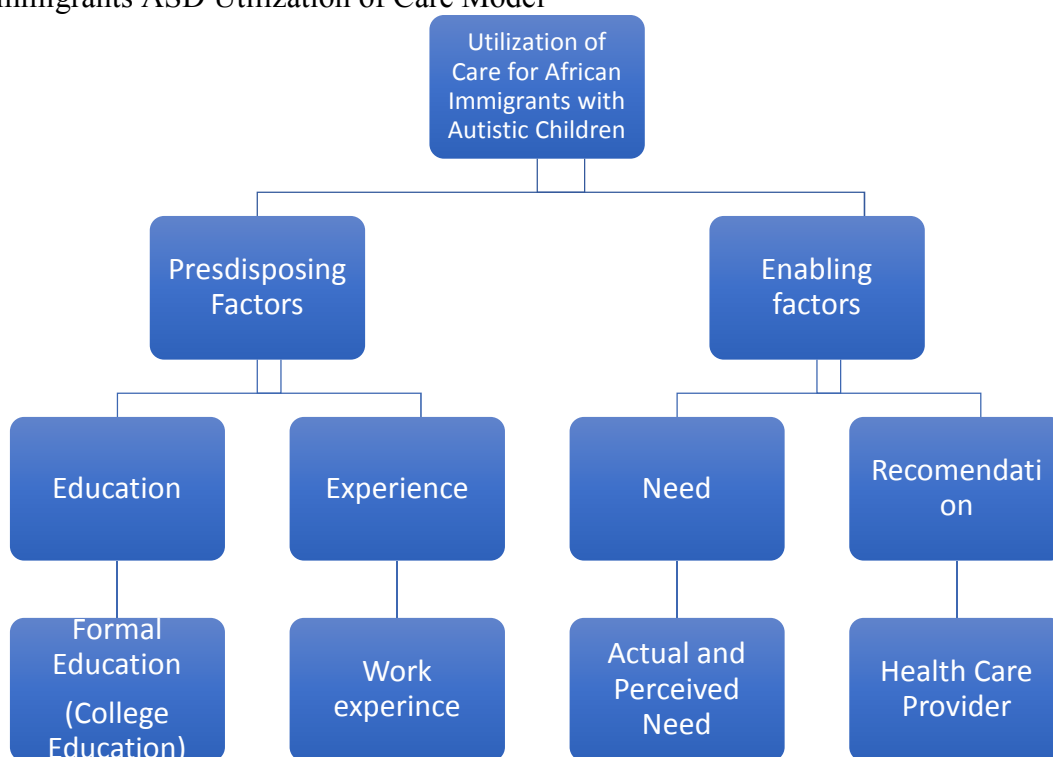
immigrant parents. Need represented both perceived and actual need for health care services by African immigrants with autistic children. Some parents reported wanting the best for their child and feeling desperate. Some of the enabling factors for use of care by African immigrants were the referral by health care professional, support, length of stay in the United States, and independent research. Referral by health care professional was coded 34 times, and support was coded 14 times. Independent research was coded eight times, while a length of stay in the United States was coded seven times. I stopped reviewing here. Please go through the rest of your chapter and look for the patterns I pointed out to you. I will now look at your references.

The themes and responses to the research questions provided an opportunity for a theory to emerge. The theory explains what influences African immigrants with autistic children in the U.S. to seek treatment for their autistic child. The theory is appropriately named "African immigrant ASD Utilization of Care Model" The theory is explained as follows: African immigrants with autistic children seek treatment for their autistic child when the need arises and when recommended by their physician.

The African immigrant ASD Utilization of Care theory describes how need and recommendation of a health care professional are associated with utilization of care for African immigrants with autistic children. This theory is grounded in the responses provided by participants about their cultural beliefs, their perception of self and ASD and their cultural influence on their decision to seek treatment. This theory is surrounded by the themes of what influences utilization of care for African immigrants with autistic children.

The figure below represents the African immigrants ASD Utilization of Care Theory. Need and referral were the number one utilization of care factors. Need represents the extreme suffering of the child that led the parent to seek treatment. Need also represents the requirement by an organization like the school system and day care center for parents to obtain treatment. Many participants reported that their physician recommended treatments and provided information on available services.

African Immigrants ASD Utilization of Care Model

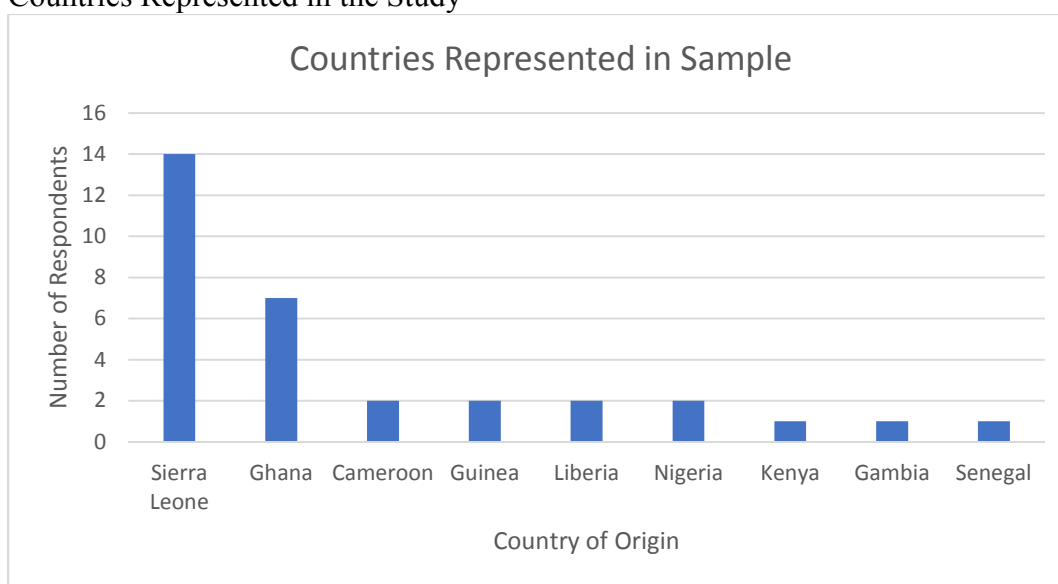


Limitations of the Study

The study was limited to Sub-Saharan African immigrants in the U.S who are English speaking. This is a limitation because it may not represent experiences of African immigrants as a whole. Participants in the study were geographically located in the New

York and New Jersey area, therefore, it represents only their views and not the views of any other geographic population. I had difficulty gaining participants for the study, it took a long time and many avenues of recruitment. The majority of the participants in the study were from Sierra Leone leading to a small sample of sub-Saharan Africa. The diagram below represents participants in the study and their country of origin.

Figure 3.
Countries Represented in the Study



The processes of grounded theory required the use of multiple stages of data analysis. The use of various stages of data analysis might lead to exhaustion and loss of sight of ideas that are emerging from the data (Creswell, 2009). This process produced a significant amount of data that was sometimes difficult to manage. Only two participants agreed to tape recording of the interview. Not tape recording was a limitation because essential details of the interview might have been lost due to not being able to revisit the raw data.

The perception of the African fathers with autistic children and utilization of care might not be adequately represented because of the limited participation of fathers in the study. Participants that volunteered for the study were all mothers except for the two fathers. However, as described in my literature review, mothers are the caregivers for children in African society and their experiences of caring for their autistic child were an important perspective to gather. In addition, several of the participants noted that their families were broken, and the fathers were absent and not participating in the care of the child.

Recommendations

Based on the limitation of lack of participation of fathers in this study it would be beneficial to study the experiences of the family including both parent, siblings and possibly grandparents. ASD impacts the entire family, therefore, understanding the experiences of the family could be important (Kayama & Haight, 2013). In addition, because of the role of the extended family in African society, this type of research would also prove a beneficial extension of this study (Mandell & Novak, 2005).

Recommendations for further research include exploring children showing signs of ASD whose African immigrant parents are not utilizing care and the outcome of those children. Participants for this study were parents with children diagnosed with ASD. There is the possibility of children with undiagnosed ASD with African immigrant parents. The diagnosis tool for ASD that is being used to assess for ASD depends on the parent's perception of their child's symptom. The diagnosis tool for ASD should be

reevaluated taking into considerations cultural influences on a parent's understanding of their child's behavior.

Implications

A study reported that about 25% of children in the U.S. have at least one immigrant parent (Yun, et al. 2013). There are limited studies related to the understanding of health issues among immigrant children in the U.S. Children of undocumented immigrant families are likely to be uninsured, have poor health and limited access to health care (Yun, et al. 2013). This study can serve as a starting point for developing programs that could improve utilization of care for African immigrants with autistic children. Health care providers emerged as one of the leading factors that influence utilization of care for African immigrants with autistic children. Physician and healthcare provider involvement can help improve utilization of care for autistic children with African immigrant parents.

This study implies that it can bring awareness to the importance of health care providers recommendation in the utilization of care for African immigrants with autistic children. Results of this study provides insights into the factors influencing the timing of interventions for African immigrant's children with ASD. Insights from this study could aid primary care physicians and medical insurance providers to provide educational programs targeted to African immigrant families with autistic children.

The individual social change implication for the child is that autistic children with African immigrant parents could get the appropriate treatment as soon as they start

showing signs of ASD. Families of autistic children could be free from stigmatization and access the necessary support services available for them and the autistic child.

Conclusion

This study was done to gain an understanding of the factors that influence utilization of care for African immigrants with autistic children. During the data analysis process, I realized that African immigrant parents with autistic children are reluctant to talk about ASD. This reluctance is mainly due to the stigma associated with the disease. This stigma can affect the parent's desire to seek treatment or help from family, friends and their community.

The perception of ASD is deeply rooted in the culture of African immigrants in the U.S. Despite higher education, exposure to Western culture and positive outcomes related to treatment options in the U.S., they associate it with evil spirit and actions of the parents. Even though the belief among African immigrants about ASD is deeply rooted in their cultural beliefs, the advice or recommendation of medical professionals emerged as an important enabling factor for seeking intervention. Even though U.S. intervention is believed to be superior by many, some still believe in the benefits of both traditional African and U.S. interventions.

The findings led to the generation of a new theory African immigrants ASD Utilization of Care Theory. Need and recommendation are the main factors that led to the utilization of care for African immigrants with autistic children. Need represents extreme suffering as perceived by the parent and recommendation is a referral by a healthcare professional.

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Appendix A: Interview Questions

Research Questions	Interview Questions
<p>1. How early do African immigrants with autistic children in the U.S. seek intervention for their autistic children?</p>	<p>Can you describe how you first realized that your child has autism?</p> <p>What age did you suspect that your child might have developmental problems and what influence that suspicion?</p> <p>Have you started treatment for your autistic child, and if so, when did you seek treatment?</p> <p>What made you decide to seek treatment or intervention for your autistic child at this time?</p>
<p>2. How does culture influence the decision of African immigrants in the U.S. to utilize early intervention for their autistic children?</p>	<p>What are your cultural beliefs about autism and treatment options in the U.S.?</p> <p>What advice have you received from your family and people in the African community about utilizing care for your autistic child?</p>

	<p>How did culture influence your decision to seek treatment for your autistic child?</p>
<p>3, What are the perceptions of African immigrants about ASD and interventions available in the U.S?</p>	<p>What is the perception of people in your cultural community about you having an autistic child?</p> <p>Can you describe the perception of autism in your African culture?</p> <p>How do you feel about yourself, having a child with autism spectrum disorder and what does having a child with autism mean to you?</p>

Appendix B: Flyer

PhD Student at Walden University

PARTICIPANTS NEEDED FOR

RESEARCH IN (Autism and African Immigrant)

I am looking for volunteers to take part in a study of

(Utilization of Care for African Immigrants with Autistic Children in the U.S.)

As a participant in this study, you would be asked to: **(Take part in an interview that will last between 45minutes to 1 hour. Participants information will be confidential)**

Your participation would involve **(At least 2)** sessions, each of which is approximately **(45 to 60)** minutes.

In appreciation for your time, you will receive

(\$5 Gift Card to Toys R Us)

For more information about this study, or to volunteer for this study,

Please contact:

(Leahnata Davies)

(Walden University)

At

Email: (Leahnata.davies-bangura@waldenu.edu)

The study has been reviewed and approved by the Institutional Review Board, Walden University