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African American Parents' Experience Accessing Support Services for Their Autistic Child

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Walden University
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Abstract

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MA, Capella University, 2012

BS, Ashford University, 2010

Dissertation Submitted in Partial Fulfillment

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Abstract

The perspective of African American parents of an autistic child is vital to understanding the experiences and challenges of accessing autism support services for their child. The purpose of this qualitative, generic study was to explore the experiences that African American parents in Philadelphia County, PA had in accessing and maintaining autism services for their child. The behavioral health model and the resilience theory provided the conceptual framework for the study. Semistructured, in-depth interviews were conducted with 10 African American parents accessing autism support services in the Philadelphia County area. The data were analyzed using the six steps of thematic analysis : familiarize, code, generate, review, define and name, and report. The following four main themes emerged: challenges raising a child with autism, accessing autism support services, parental stress, and resilience. Research findings suggested that African American parents can access effective support through programs and services and emphasized the importance of family resilience and family connections as well as community support. Implications for positive social change include professionals understanding the experiences of the African American parent, such as increased autism supports, ASD awareness, advocates, education, and awareness of the stress factors related to everyday parenting.

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Dedication

I would like to dedicate my dissertation to my mother, the late Audrey Jones, and my children, Amya, Payton, and Alisa. I also would like to dedicate my dissertation to my dad, Neville; my brother Ryan, my late Stepmom, Sarah, and my friends who have supported me through all this tedious process, Dr. Kelly Cornish, Dr. Sophelia Kelly, and my best friend, Kyra McFadden. All of you guys have been my living example of what it meant to be a great therapist and a person committed to change and helping others. You all have pushed me out of my comfort zone and still allow me to be me without judgments. I am forever grateful. Lastly, I would like to dedicate this study to the fantastic families that I had the pleasure of interviewing for this study. I have learned a great deal and hope the information within this study serves as a great design to create social change in our communities.

Acknowledgments

I would like to thank the Almighty God for giving me strength, courage, knowledge, and placing all the right individuals in my life who contributed to the completion of this study. I want to recognize and express my sincere appreciation to all the parents who took time out of their day to share their stories for this study. Without their personal contributions and experiences, this study would have remained an idea. You are the true heroes; you have shown great resilience throughout your experiences. I thank the local libraries for allowing me to post my study flyers. I acknowledge my friends and family for their prayers, support, encouragement, and motivation throughout this demanding journey. Last, but not least, I acknowledge my chair, Dr. Dorothy Scotten, and Dr Scott Hershberger for pushing me beyond my limits. Thank you for seeing things in me that I could not see in myself. Your feedback support, guidance, and warm kindness will go with me beyond this journey.

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Chapter 1: Introduction to the Study

Autism spectrum disorder (ASD) is a complex neurodevelopmental disability (American Psychiatric Association, 2013) affecting an estimated 1 in 59 children in the United States (Baio et al., 2018). Because ASD does not have known biomarkers, diagnosis relies entirely on professional observation and parental reporting of child behaviors (American Psychiatric Association, 2013). Detecting autism at the earliest possible age is important to optimize outcomes for children with ASD disorder. Primary health care providers and other medical professionals play a critical role in facilitating timely ASD diagnoses. The role that parents play is important in obtaining the best possible outcomes for their child with ASD by getting a correct diagnosis early so that they can gain access to appropriate interventions and treatments for their child.

Awareness of autism requires that all parties working with a child who may have ASD be able to aid and intervene, including parents (Dababnah et al., 2018). For example, encouragement is given to primary health care providers to listen to caregivers' concerns and refer children with suspected developmental delays to early intervention services or the local school system, even if the children are not yet diagnosed (Dababnah et al., 2018). Part C early intervention services for children younger than 3-years-old are available in every U.S. state through the Individuals with Disabilities Education Act and have aided children to be successful in reaching their milestones despite the diagnosis (Dababnah et al., 2018).

The literature on diagnosis and services for children with ASD has revealed racial disparities in early diagnosis that adversely affect treatment for children with ASD in

African American families. The number of visits for African American children to receive an ASD diagnosis is, on average, 3 times higher than for non-African American children, with a more extended period between initial provider contact and diagnosis (Dababnah et al., 2018). Furthermore, there is a higher probability of African American children being diagnosed with more severe forms of ASD, suggesting the underdiagnosis of children with milder forms. African American children eligible for the public (i.e., Part C) early intervention services are 5 times less likely to receive such services compared to non-African American children. These disparities are of such concern that the American Academy of Pediatrics' Autism Program has developed initiatives to raise awareness among health care providers, as well as parents and school personnel, of the importance of early detection and intervention for African American families.

Background

Although autism can vary in severity and level of functioning across ethnic and socioeconomic groups, autism is characterized by deficits in communication, developmental delays, impairment in social interaction, and repetitive patterns of behavior (National Institute of Neurological Disorder and Stroke, n.d.). Mandell et al. (2009) reported that on average, non-African American children received an ASD diagnosis at 6.3 years of age, compared to 7.9 years for African American children. Racial and ethnic differences in the timely and accurate identification of ASD have been reported whereby African American children were 2.6 times less likely than non-African American children to receive an ASD diagnosis on their first specialty care visit (Liptak et al., 2008; Mandell et al., 2009).

Differences in the timing of the diagnosis are significant because earlier treatment results in improved outcomes (Mandell et al., 2009). According to Mandell et al. (2009), in Philadelphia County, African American children were reported to be diagnosed an average of 2 years later than non-African American children. In addition, African American children were more likely to be given an initial diagnosis other than an ASD at their first specialty care visit, such as attention-deficit hyperactivity disorder, before later being diagnosed with ASD (Mandell et al., 2009). The Autism and Developmental Disabilities Monitoring Network, a population-based public health surveillance network in the United States, reported that when African American children were diagnosed with ASD, they were more likely to be classified as autistic rather than having Asperger's syndrome (Mandell et al., 2002).

Although there is a growing body of literature that reveals racial, ethnic, and socioeconomic disparities in ASD diagnosis, there is limited research on the African American parental experience of accessing support services for their child with ASD.

Problem Statement

ASD is a group of neurodevelopmental disorders characterized by deficits in social communication and interaction as well as the presence of restricted and recurrent patterns of behaviors, interests, and activities (Baio, 2012). According to the Center for Disease Control Prevention (CDC; n.d.), approximately 1 in 59 children overall identify with having a diagnosis of ASD. This is higher than the previous estimate by The Autism and Developmental Disabilities Monitoring Network released in 2016, which found a prevalence of 1.5% or 1 in 68 children (CDC, 2018). A change in prevalence might be attributed to improved autism diagnosis in underrepresented populations, although White children are still more likely to be diagnosed than Black or Hispanic children. The data suggest that early identification of children with autism and referral to appropriate treatments is needed at a young age.

Delays in the diagnosis and treatment of ASD among African American children represent a substantial health care disparity in the United States (Chen et al., 2016). According to Lovelace et al, (2018), African American children are more likely to receive an adjustment disorder diagnosis before that of autism disorder. Access to mental health services for African American families with an autistic child is limited by economic status, differing cultural perspectives on disability, restricted access to evaluation, unfamiliarity with available service options, and service providers' lack understanding of the unique needs of African American families (Furfaro, 2017; Lovelace et al., 2018). These disparities are just a few of the factors that create a barrier to African American families receiving services.

African American parents experience many barriers that prevent adequate access to health care services for their children (Gona et al., 2016). Baio et al. (2018) stated that African American parents might encounter cultural divergence, socioeconomic status, and differential diagnoses in accessing mental health services. Factors contributing to this public health issue consist of primary care model challenges, sociodemographic features of the population, failure by health care systems to incorporate community input in planning efforts, lack of financial resources, and no implementation of quality services (Lovelace et al., 2018). Systems that African American children encounter need to provide better assistance in terms of diagnosis, accessing care services, and retaining those services.

Pearson and Meadan (2018) identified that there is a dearth of information around the diagnosis and misdiagnosis of autism among African American children. Moreover, Sherraden and Gilbert (2016) indicated the need to explore why a delay exists for African Americans regarding diagnoses and unequal access to services. Although autism can vary in severity and level of functioning across ethnic and socioeconomic groups, a gap in the current literature exists on African American parents' experiences with accessing support services for their child with autism.

Purpose of the Study

The purpose of this qualitative, generic study was to explore the experiences that African American parents in Philadelphia County, PA face when accessing and maintaining autism services for their child. Use of the generic approach allowed parents to voice their experiences with accessing autistic support services for their children with autism. The results of this study may bring awareness to mental health professionals, policymakers, insurance companies, mental health agencies, community leaders, and other families experiencing challenges with accessing or maintaining support services to help improve service delivery, treatment, and support to improve the level of acceptance for these families and children being affected by autism.

Significance

There are gaps in the literature regarding an in-depth, qualitative exploration of the experiences of African American parents in terms of accessing and maintaining ASD services for their child from the behavioral health system. Although an abundance of research has been conducted on African American parents and autism (e.g., Dababnah et al., 2018; Lovelace et al., 2018; Pearson & Meadan, 2018; Sherraden & Gilbert, 2016), scholars have not yet focused on the barriers to access to care when it comes to African Americans. Barriers to accessing services include different cultural perspectives of disability as well as limited access to and unfamiliarity with available service delivery options (Pearson & Meadan, 2018).

This section addressed the experiences that some African American families have with maintaining and accessing autism services. This information has the potential to create positive social change by contributing to ASD awareness in Philadelphia. The findings from the study may also lead to an increased understanding of the experiences of individuals with ASD and that of their parents as well. This information may be used to advocate for more access to autism services; more training and education; changes in policies; and increased awareness for the public, insurance companies, other families, health care providers, teachers, and community leaders to be more sensitive, accepting, and supportive in their dealings with all those affected by autism. Results from this study may also address African American parents’ experiences of ASD in Philadelphia and motivate them to advocate for changes in policies and laws that would result in positive social change for their children and their families.

Theoretical Framework

The conceptual framework for this study was formulated based on the resilience theory and the behavioral health model (BHM) to capture the real essence of the experiences of African American parents accessing support services for their autistic child. Resiliency theory was developed by using the strengths of the family to function despite the challenges faced (Zimmerman, 2013). According to Ungar (2013), resilience is defined as the “capacity of both individuals and their environments to interact in ways that optimize developmental processes” (p. 33). Resilience is seen in an individual’s ability to experience positive outcomes despite stressors, challenges, and barriers (Walsh, 1998).

The second concept used as part of the framework was Anderson and Aday’s BHM. Andersen’s behavioral model has been used in studies to investigate the use of health services, health systems, and health conditions (Andersen & Newman, 2005). The BHM facilitates the determination of policies designed to increase access to health care services and increase consumer satisfaction. In this study, I applied the BHM to the experiences of African American families in evaluating how and why they seek and use ASD services for their children. Both elements helped to frame the literature review and the development of the methodology.

Research Question

What are the experience of African American parents with assessing and maintaining services for their child with autism in Philadelphia County, PA?

Nature of the Study

I conducted the study using aa qualitative, generic method. According to Cooper and Endacott (2007), generic, qualitative researchers investigate people’s reports of their subjective opinions, attitudes, beliefs, or reflections on their experiences of things in the outer world. Because the generic, qualitative method is used to explore people's attitude, beliefs, and experiences, I focused on the participants' experiences, allowing them to share their personal stories and perceptions about accessing and maintaining autism services for their child with ASD. Use of this method provided a rich, unobstructed view of participants' experiences that may lead to a better understanding of the impact that autism has on families as they try to obtain autism services. The results of this study highlighted the experiences of African American parents so they can advocate for services that are more inviting, holistic, and culturally competent so that those children with ASD in the African American community will be better serviced.

To obtain qualitative data for this study, I interviewed 10 African American families who have shared their experiences with obtaining a diagnosis and services for their child with autism. I used a semistructured interview approach to gather data for this study because it made it easier to elicit rich data. The data collected through interviews were transcribed before analysis. I also took memos during the interviews to better understand the transcribed interview text. As part of the data analysis and interpretation, I used hand coding for analysis, coding the data by assigning keywords and phrases linked to ideas that were discovered in the text. The various codes were placed into sections and then analyzed to detect themes, which constituted the findings of this study.

Operational Definitions

African American parents: African American parents, foster parents, and adoptive parents who had legal guardianship over children with an ASD.

Autism Services, Education, Resources, & Training Collaborative (ASERT): A statewide initiative that provides support to individuals with ASD and their families through resources, training, and other projects (Autism Speaks, 2016).

ASD: A complex brain disorder typically appearing in early childhood characterized by (a) persistent deficits in social communication and social interaction across multiple contexts and (b) restricted, repetitive patterns of behavior, interests, or activities (CDC, 2018).

Culture: The beliefs, attitudes, norms, values, practices, and institutions common to a group of people across generations (Cohen, 2009).

Socioeconomic status: An economic and sociological combination of an individual's or family's work experience and economic and social position in comparison to others based on income, education, and occupation (Conger et al., 2010).

Support services: Services to help and improve the life and welfare of children with autism and their families, such as special educational, daycare, and therapy services (Maciver et al., 2011).

Assumptions

This study was based on the following assumptions: (a) participants were truthful in all their disclosures, (b) participants were able to articulate their emotional state and experiences, (c) all participants read well, (d) each participant had a sincere and honest interest in participating in this study without any motives, and (e) that readily available literature on the experience being studied would help inform development and implementation of effective policy and program interventions to address the causes of health care access challenges for this population. In a study, it is important to be explicit about any underlying assumptions. Often researchers are not aware of the assumptions that are unconsciously being made that can impact the study's outcomes, so it is important to examine assumptions to ensure that they are valid and consistent with the argument and correct those that are wrong.

Scope and Delimitations

The population chosen for the study were from the Philadelphia area, in which several African American families reside. The populations excluded from this study were parents who are not African Americans with a child with ASD or African American parents whom I may know who have a child diagnosed with autism. I also excluded other races and other disabilities outside of ASD. Parents chosen to participate in the study had one child with an autism diagnosis.

I considered using the social support theory for my theoretical conceptual framework. According to the social support theory, caregivers will need formal or informal support when parenting a child with a disability (Uchino, 2004). Although formal support can be from professional services that provide educational tips and interventions that can be used when raising a child with autism, it does not focus on parental experiences (Renty & Roeyers, 2006). Informal support may be in the form of relatives, friends, and community (Perry, 2008). The social support theory was not suitable for capturing African American parents' experiences with accessing support services for their autistic child.

Limitations

Weiss et al. (2015) identified limitations as areas in the study that the researcher has no control over. One limitation to this study was the use of the generic, qualitative research approach. A limitation of this methodology is the findings usually cannot be generalized to the study population or community (Staller, 2014). The participants within this study were not nationally representative. My sample represents African American parents who are not representative of other ethnicities. This is a limitation that relates to transferability. Qualitative studies are limited on transferability outside of the specific people and places of study (Fletcher, 2017). I addressed this possible transferability limitation by following the research design and providing thorough details of the specific steps taken during the thematic analysis. Transferability was also addressed by providing a rich, detailed description of the participants that will allow for the reader to determine if the findings can be transferred because of shared characteristics to other settings.

Purposive sampling facilitated the selection of participants; however, it can also be considered a limitation. A limitation of using purposeful sampling is that it has a low level of low level of reliability, and it can be highly prone to researcher bias because each sample is based entirely on the judgment of the researcher, leaving room for human error that results in researcher bias (Maxwell, 2005). I addressed this limitation by focusing on the experiences faced by the African American parents and not the ASD child. As an additional precaution, I presented the interview questions in the same order using the exact same wording to all participants and refrained from interjecting comments of any type that could have been misconstrued by a participant. I also reduced bias through member checking and reflexive journaling. All the interviewees were not known to me personally or professionally, which ensured that their responses to the interviews were more valid.

To address the limitation of reliability, I audio recorded each interview session and used a computer program to help with recoding and analyzing the data. I also collaborated with participants to conduct member checking to increase the reliability in interpreting and reporting the data. Reliability concerns may also arise during the data collection phase due to inconsistency in questions presented to the participants; therefore, an interview protocol was used to maintain consistency.

A further limitation was that, in a qualitative study, replication of the findings may be difficult to achieve. I attempted to minimize inconsistencies in questioning by using an interview protocol and facilitated replicability of the study by keeping detailed notes.

Summary

ASD has no known cure. The symptoms of ASD and the effects of the disorder are lifelong and can have an impact on the individual diagnosed with ASD and their family. In this chapter, I provided information on the Andersen BHM and its application in research to understand human development and behavior. Scholars have supported the need to increase awareness and knowledge of ASD to improve diagnosis, interventions, service delivery, autism support programs for both children and families, and quality of life for all affected by the disorder.

A qualitative study was conducted to improve understanding African American parents’ experiences of maintaining and accessing autism services for their children. Understanding the problem of autism service accessibility for young children with autism from the experiences of their parents will help address access problems. This knowledge could improve the experiences and health outcomes for individuals affected by ASD and their families as well as potentially impact positive social change when used to advocate for policy modifications, education, service delivery, and increase acceptance and support for individuals affected with ASD in Philadelphia.

In Chapter 2, I provide details about the research setting; participants; and previous research concerning autism in the general sense, such as prevalence, historical perspectives, ASD disparities, diagnosing of ASD, and service delivery associated with autism.

Chapter 2: Literature Review

ASDs are conditions that cause a developmental delay in necessary skills, the ability to socialize with others, communicate, and use imagination (Baio, 2012). The CDC (2018) estimated that the prevalence of ASD in the United States is 1 in 59 children. African American children are less likely to receive advanced testing to confirm the diagnosis of ASD in comparison to non-African American children (Gourdine et al., 2011). African American children are also being diagnosed with ASD at a later age due to inconsistencies in diagnostic instruments/tools used to make the diagnosis of ASD.

In this chapter, I explored the disparities that African American parents encounter when accessing or maintaining ASD services. First, an overview of the theoretical perspective is presented. Then, I review the history and behaviors associated with autism and ASD (including the prevalence of autism, early diagnosis, and intervention services) as well as the economic cost, diagnostic process, ethnicity, quality of clinician, and school services associated with autism. Additionally, this chapter contains a discussion of factors related to autism and ASD to determine if there are factors that have the potential to impact the rate of diagnosis of ASD in African American children.

Literature Search Strategy

The research strategy I used to gather sources for this review included an exhaustive search using the Walden University Library, the internet, and Google Scholar. The following databases facilitated the literature search for articles published between 2015–2019: PsycINFO, ProQuest Dissertations & Theses, PsycArticles, PsycBooks, ERIC, SocINDEX, EBSCOhost, SAGE, and Academic Search Premier. Keywords used in the search included *autism and African American children, autism and African American parents, disparities among African American children with ASD, accessing services for children with ASD, autism awareness, autism and parental stress, parents and autism, race, culture, society, disparities in mental health service accessibility, Andersen & Aday behavioral health model, experience, autism and parental experience, Philadelphia and autism,* and *autism in Pennsylvania 2014-2020.* Articles selected for inclusion in the literature review were published in the past 5 years, and all articles were derived from peer-reviewed publications, books, and websites.

Theoretical Framework

The conceptual framework for this study comprised the resilience theory and the BHM to capture the real essence of the experiences of African American parents accessing support services for their autistic child.

Resilience Theory

Resilience theory was developed by using the strengths of the family to function despite the challenges faced (Zimmerman, 2013). Resilience is seen in an individual’s ability to experience positive outcomes despite stressors, challenges, and barriers (Walsh, 1998). When considering the African American parents experiences with accessing autism support services for their child with autism and the impact it has on the family, it is also important to consider the parents resilience, or ability to “bounce back” in the face of adversity.

Historically, resilience theory was related to the decrease in the prominence of pathology and an increase in the significance of strengths (Rak & Patterson, 1996). Resilience as a strengths-based construct focuses on providing the developmental supports and opportunities (i.e., protective factors) that promote success rather than on identifying factors that promote failure (Luther & Cicchetti, 2000). According to DuPlessis and VanBreda (2001), resiliency theory examines children, adults, families, communities, and policies. Additionally, Richardson (2002) stated that resilience theory was initiated as a way to explore and examine children's abilities to transcend negative situations. Resiliency theory has been researched across many disciplines. For example, resiliency was defined in the field of psychology as an individual's ability to bounce back and withstand hardship by repairing themself (Higgins, 1994).

The resilient family facing an ASD establishes beliefs and practices that allow them to navigate the most difficult challenges while providing increased family cohesion (Greef & van der Walt, 2010). For example, parents have to navigate supportive services to help their autistic child. These parents also may encounter stressors, such as accessing ASD services, insurance coverage, transportation, availability of services, wait times or disparities. According to Walsh (2007), belief systems are at the core of all family functioning and are powerful forces in resilience. When looking at the African American parents' experiences with the process of accessing support services for their autistic child, their parental perceptions are an important element because parents are a core piece of the family component.

According to McConnell and Savage (2015), parents might benefit from interventions (i.e., support services, parent training and cognitive behavioral therapy), to build adaptability and effective coping strategies as well as establish a positive outlook and solution finding skills. Additionally, Giallo et al. (2016) suggested that parents who engaged in problem-focused coping and solution seeking to help their child resulted in maximized adaptability and coping. To reach this level of accomplished adaptability and coping, Giallo et al. suggested that the parents research treatment opportunities and engage in social supports. According to Dunlap and Fox (2011), the families of autistic children can be some of the strongest support systems. Dunlap and Fox stated that, regardless of the number of professionals that are involved with the child and family, the most influential and significant effects will be achieved by the child's family.

According to Bekhet et al. (2012), families need to acquire knowledge and skills to build confidence and competency when problem solving. When families are coping well, so are their children with autism. Furthermore, Alper et al. (1994) stated that families need to access support to address concerns for their children as well. The availability of a strong support system can assure a more positive family influence (Alper et al., 1994).

The BHM

The second concept used as part of the theoretical framework in this study was Anderson and Aday's BHM. The BHM is a framework used to describe the use of health services among families in the United States (Andersen, 1995). The BHM was initially developed in the late 1960s to provide insight as to why families use health services, define and measure equitable access to health care, and assist in developing policies to promote equitable access (Aday & Andersen, 1974). In the BHM, Aday and Andersen (1974) stated people’s use of health services is a function of their predisposition to use services, factors that enable or impede use, and their need for care. These were relevant factors for the current study because they relate directly to disparities in both needs for care and its availability.

BHM is a tool used to study the use of health services (Andersen, 1995). The model provides a means for evaluating the effectiveness of service policies designed to increase access to health care services and consumer satisfaction (Aday & Andersen, 1974). Regarding societal determinants, Andersen (1995) referred to aspects (i.e., medical technology and social norms) that influence the health care system. In turn, the health care system allocates resources to institutions and ensures an appropriate organizational framework to provide medical services. The individual determinants are controlled by the societal and health care systems and are shaped by the three central population characteristics: (a) predisposing factors, (b) enabling factors, and (c) need.

Andersen’s (1995) model demonstrates the interplay between social and personal characteristics affecting the use of health care services. The BHM model involves variables that facilitate or hinder access, known as enabling resources (Andersen, 2008). In the model, the need for care, commonly known as need characteristics, are further described. The predisposing factors include demographic and social system characteristics, such as socioeconomic status, job position, race, and employment status (Andersen, 2008). Enabling resources include factors (e.g., personal, familial, and community) that must exist for individuals to use health care services (Andersen, 1995). For example, when families have support services available to them (i.e., appropriate insurance coverage, employment, and access to transportation), they are more motivated to use these means to obtain mental health services for themselves and their children.

Although the core components of the BHM have remained constant, the model has been modified several times since its creation to consider additional variables that influence health care use. Andersen (1995) described the model modifications in four phases of development. Phase 1 was the original sociobehavioral model created in the late 1960s that theorized that an individual’s use of health services was based on their predisposition to use the services, the factors that facilitated or hindered use, and the individual’s need for services (Andersen, 1968). Phase 2 was developed by Aday and Andersen (1974) who clarified that the relationship between the core components and the health care system, as well as consumer satisfaction, is an outcome of health services. Phase 3 took place in the 1980s and 1990s, adding the external environment and personal health practices as influences on health outcomes (Alexander et al., 2015). Phase 4 of the model incorporates feedback to depict the core components between contextual and individual characteristics, health behaviors, and health outcomes (Alexander et al., 2015).

For more than 30 years, Andersen’s (1995) model has been empirically applied to multiple facets of medical care across diverse populations. For example, Samson et al. (2015) conducted a study using the BHM to understand how factors relating to a group of HIV patients and their environments impacted their health behaviors and outcomes. They compared patient-identified barriers/facilitators to retention in care and antiretroviral therapy adherence and evaluated how they mapped to the behavioral model (Samson et al., 2015). Some of the barriers that the individuals discussed included stigma, mental illness, colocation of services, lack of transportation, appointment scheduling, expenses, health literacy, and health beliefs (Samson et al., 2015). According to Samson et al., the data support the use of the behavioral model as a framework for classifying factors influencing HIV-specific health behaviors that have the potential to inform the design of interventions to improve retention in care and antiretroviral therapy adherence.

In another study, O'Neal et al. (2014) used the BHM to examine the effects and interactions that health insurance and psychological processes had on the use of preventative services among 200 African American, middle-aged adults. Psychological processes, pulled from the BHM, included competency, or the participants' perceptions of their abilities to complete and participate in care, and vulnerability, or the participants' perceptions of harm that could occur during treatment (O'Neal et al., 2014). O'Neal et al. obtained data from six churches enrolled in a National Institute of Neurological Disorder and Stroke-sponsored program to reduce cardiovascular risk in middle-aged African Americans (with a participant population 73% female and 26% male). Quantitative analyses, including structural equation modeling and correlational analyses, revealed that psychological factors, in addition to having health insurance, influenced patients' likelihood to comply with preventive health services (O'Neal et al., 2014).

I used Andersen's BHM as a model to guide this study because of its many years of empirical support (see Borschuk et al., 2015) and it is currently the most popular model used to predict health care use. The model addresses matters that are of concern for African American parents who may receive less health care compared to the rest of the U.S. population (Borschuk et al., 2015).

Andersen’s BHM was appropriate for this study because it is grounded in the premise that there are personal and external factors that determine an individual’s use of health care services. Additionally, the BHM can be used to examine the population characteristics, the health care system, and external environment. The linear relationship then establishes that the health outcome is an interaction between the perception of health status, evaluated health status, and customer satisfaction (Andersen, 1995).

Aday and Andersen’s BHM model can be useful for describing the health care consumption patterns within the ASD population and the level of consumer satisfaction within the health care system. The use of the BHM model can generate information to determine if individuals with ASD are gaining access to the services that they will need (Babitsch et al., 2012). The BHM can also be used to facilitate understanding related to the parental experiences of African American parents with accessing support services for their autistic child.

Historical View of ASD

The term autism was first used by Bleuler (1961). The terms autistic and autism also were used to describe some characteristics of schizophrenia (Bleuler, 1961). Bleuler applied the term autism to adult patients with schizophrenia; later, Kanner (1943) studied these behaviors in children and formed the foundation of autism history. Kanner theorized the existence of autism in the 1940s and coined the term *early infantile autism*.

Kanner's (1943) first reference to autism concerning abnormal behavior noticeable in early infancy. In 1943, Kanner first defined the disorder as Kanner syndrome or autism disorder. Kanner created the term early infantile autism to differentiate these symptoms from schizophrenia. Kanner also indicated that autism would be noticeable during early infancy by its abnormal behavior. Kanner had an extensive list of features for the autistic syndrome. Some of Kanner's initial key features were adopted and modified for the diagnostic criteria used in various revisions of the Diagnostic and Statistical Manual. Kanner's original work was based on eight boys and three girls between the ages of 2- and 8-years-old (Kanner, 1944) and labeled his patients' condition early infantile autism. Early infantile autism was also known as Kanner's syndrome (Kanner, 1944). Many of these children were severely feeble-minded or had an auditory impairment.

In the 1950s, Bettelheim worked with children diagnosed with ASD and compared them to concentration camp survivors. In 1956, Bettelheim wrote about one of his patients diagnosed with autism named Joey**.** Bettelheim (1967) asserted that his patient's condition was a result of poor parenting**.** Kanner (1943) was the first psychiatrist to use the term "refrigerator moms" to describe mothers who reportedly caused their children's autism by not loving them enough. Kanner and Bettelheim believed that autism stemmed from parents who were cold, unreachable, and who did not want their children (Rudy, 2006). This tendency to blame the parents for their children's disorders was pervasive in the 1950s and 1960s until parents started challenging this belief (Congeret al., 2010).

Historically, people with autism were placed in institutions all over the world (Greenspan, 2018). Greenspan (2018) stated that the ways that individuals understood or thought about autism had, directly and indirectly, formed conceptual responses to autism over the years. Over 50 years ago, people who should have been diagnosed with autism were often misdiagnosed with schizophrenia or other mental conditions and institutionalized (Harris, 2016). Today, ASD is diagnosed with genetic and certain environmental factors that influence early brain development (Harris, 2016). There is a better understanding of the effective treatments for the symptoms of ASD; therefore, more children are getting the help they need to live a more fulfilling life (Harris, 2016).

ASD

ASD refers to a broad range of conditions characterized by challenges with social skills, repetitive behaviors, speech, and nonverbal communication (Burkett, et al, 2015). Autism is classified among neurodevelopmental disorders, which is a group of conditions that commences in the early developmental stage (Christensen et al., 2016). Conditions are identified by some developmental deficits leading to the impairment of social, occupational, academic, and personal functioning (Christensen et al., 2016).

Over the past 30 to 40 years, the prevalence of diagnosed autism has increased not only in the United States, but also globally (Kogan et al., 2018). Although the main cause of such increase is not clearly understood, it may result from the following factors: (a) divergent diagnostic criteria, (b) incremental provider ascertainment during early ages; (c) incremental parent awareness, and (d) an increase in risk factors; especially birth by older couples (National Academies of Sciences, Engineering, and Medicine, 2016).

Additionally, early referral for and enrollment in ASD-specialized services is critical, as behavioral, and educational interventions can improve outcomes for children in cognitive, language, and social domains (Karp et al., 2018). Unpredictable and increased requirements for seeking health care affect most parents, especially in terms of taking leave from their employment, disruptive family routines, and time and financial burdens (Burkett et al., 2015). As knowledge about autism has advanced, so have the techniques used to measure the prevalence of the condition.

Prevalence of ASD

The current ASD prevalence in children in the United States is estimated to be approximately 1.4% but has been reported to be as high as 2.6% (Hansen et al., 2015). The unexplained increase in ASD prevalence has raised public concern, affecting some parents' health care decisions for their children (Hansen et al., 2015). The CDC (2018) reported that the prevalence of ASD among African American children continues to be lower than non-African American children, although the gap has narrowed compared to previous years.

Furthermore, Xu et al. (2018) estimated that the ASD prevalence was 2.47% among U.S. children and adolescents in 2014-2016, with no statistically significant increase over the 3 years. In comparison to the general population, children with ASD experience an increased prevalence of cooccurring conditions (i.e., asthma, behavioral issues, gastrointestinal disturbances, and seizures; Kogan et al., 2018). According to Brian et al. (2016), the onset of ASD symptoms typically occurs by age 3, although symptoms may not fully manifest until school-going age or later. Symptoms can emerge between 6 and 18 months of age (Brian et al., 2016). More severely affected children are more likely to be identified and reliably diagnosed at younger ages than in milder cases (Brian et al., 2016).

ASD in Philadelphia

According to ASERT (n.d.), between 2014-2015, there were 29,273 children between the ages of 3 and 21 diagnosed with autism. In 2011, there were 2,142 individuals with autism in Philadelphia receiving services. By 2014, the rate of autism in Philadelphia had doubled to 4,617 individuals (Autism Speaks, 2016). Among the individuals with autism in Philadelphia who were receiving services, more than three-fourths were children (The Philadelphia Autism Project, 2015).

Consequently, the 2015 Needs Assessment conducted by the Open Minds (2015) found that children with ASD and their families are struggling to find support services. Additionally, it was found that they were often dissatisfied with the services that are provided. According to Open Minds (2015), individuals with ASD grow into adulthood, the need for support and services often increases. For families trying to access autism support services the following services may become less accessible: (a) lack or shortage of providers is the most common barrier to accessing services and (b) there is a lack of effective interventions for challenging behaviors and mental health problems that can also affect people with autism (Philadelphia Autism Project, 2015). ASERT (n.d.) identified that approximately three-quarters of the individuals receiving autism services in Philadelphia are non- non-African American (ASERT, n.d.). The decisions families make about autism diagnosis and treatment are directly influenced by the family’s cultural background. In Philadelphia, many children from multicultural backgrounds face a variety of barriers when trying to access basic health care services (ASERT, n.d.). According to Open Minds, Pennsylvanians of all ages with an ASD and their families are struggling to find the services they need and are often dissatisfied with the services that are provided especially those of minority backgrounds. Some families struggle with accessing services due to their culture, language barriers, poverty, and unsafe neighborhoods (Philadelphia Autism Project, 2015). Therefore, programs and community outreach to individuals with an ASD and their families in Philadelphia will require culturally and linguistically competent approaches for these diverse communities (ASERT, n.d.).

Diagnosis and Testing of Autism Spectrum Disorder

There is no biological test for the diagnosis of ASD. The disorder is usually diagnosed when a psychologist or physician identifies symptoms through direct observation of the child as well as gathering information concerning the child's developmental history (Dababnah et al., 2018). The diagnosis of ASD has historically been influenced by certain demographic variables. Children of higher socioeconomic status (SES) have been overrepresented, and families of lower SES and minority racial and ethnic backgrounds have traditionally been underdiagnosed (Emerson et al 2015) Although community awareness of ASD has begun to reduce these racial and socioeconomic disparities, group differences remain (Centers for Disease Control, n.d.). The most important issue in the identification and treatment of children with ASD is the need for early diagnosis and early specialized intervention (Chiri & Warfield, 2012).

Cidav et al. (2012) stated that getting specialized intervention at an early age can result in significant developmental progress compared to beginning intervention when the child is older. Early treatment results in considerable cost savings to both families and the systems that serve them (Cidav et al., 2012).

For a specialist to help a child, the ASD must be discovered early enough so that the diagnosis can be carried out early and the areas of need addressed (Pierce et al., 2019). Various studies on detecting signs of the disorder exist, but it is still challenging to diagnose a child before they reach the age of 12 months (Nall, 2018). Children develop differently in terms of stage and rate, but it is recommended that parents should consult doctors and check on the presence of autistic behaviors when children are no older than 18 months (Nall, 2018). Symptoms that should be investigated include the following: (a) response to their names, (b) possible deafness, (c) speaking with a questionable tone, and (d) engaging in repetitive motions (i.e., spinning, hand flapping, or rocking; Nall, 2018). Other symptoms of autism that may be prevalent and should be investigated include walking on their toes, upsetting easily when forced to change a routine, and poor eyesight (Children’s Hospital of Philadelphia, 2019).

ASD diagnosis can be improved using various screening tools such as (a) the Autism Diagnostic Observation Schedule, (b) the Child Autism Rating Scale, (c) Autism Detection in Early Childhood (Sappok et al., 2015), (d) the Social Communication Questionnaire (Kennedy et al., 2019), and (e) the Autism Diagnostic Interview-Revised (De Bildt et al. 2015). Testability is a vital issue when investigating or assessing young children suffering from autism in research and clinical settings.

Diagnostic Disparity in African American Children With ASD

According to Donohue et al. (2017), the number of African American children with mistimed autism detection is twice that of other racial populations of the United States. African American children are diagnosed with ASD 1.4 years later than the standard defined period of ASD detection (Donohue et al., 2017). According to clinicians, it is recommended that children should be diagnosed with ASD between 18 and 24 months to help initiate corrective measures (Oswald et al., 2015).

African American and non-African American parents raise developmental concerns with their health care providers when their children are of similar ages (Dababnah et al., 2018). Yet, compared to non-African American children, African American children are diagnosed at later ages (Dababnah et al., 2018), are more likely to be misdiagnosed (Dababnah et al., 2018), and are less likely to receive a developmental evaluation before age 3 (Christensen et al., 2016). Even when controlling for SES, racial disparities in ASD diagnosis, and service persist.

Delayed ASD diagnosis among African American populations has been linked to a wide array of issues (i.e., economic, social, cultural, and parenting concerns). Parenting is an essential element to the sustainable wellbeing of children. Parents and caregivers show different levels of concern towards the growth and development of their children (Donohue et al., 2017). The diagnostic disparity in ASD has been linked to disparities in the levels of parent concerns about how they see their children behaving (Donohue et al., 2017). Many parents show fewer concerns about communication and cognitive skills among toddlers, possibly because they do not know what is normal for this age; however, lower levels of diagnosis are detrimental to children. At the age of 12 months, ASD symptoms are predictive of future ASD diagnosis; therefore, concerns from caregivers and parents influence how early or late the condition is discovered (Donohue et al., 2017).

Matua and Van Der Wal (2015) found that in 2006, African American parents were less likely (82%) than non-African American parents (86%) to report that their health care provider listened carefully to the parent. According to Matua and Van Der Wal, African American parents were 75% less likely to report frustration, and non-African American parents were 85% less likely to report that they did not feel the provider listened more over time. Matua and Van Der Wal also found that between 2006 and 2010, 84% of non-African American parents believed that the provider helped them feel that their concerns were heard and addressed, but 78% and 74% respectively of African American parents shared that feeling in 2006 and 2010. In terms of the attending doctor spending enough time with the child, only 64% of African American parents in 2006 reported that the doctor spent enough time with the child during the visit (Matua & Van Der Wal, 2015). Mandell et al. (2002) conducted a study of Medicaid-eligible children in Philadelphia and found that the average age at first ASD diagnosis for African American children was 7.9, and for non-African American children, it was 6.3-years-old. The difference in age is related to the number of visits the children had until receiving the first ASD diagnosis. Mandell et al. found that the average number of visits before diagnosis for non-African American children was 4.1 visits, and African American children went to an average of 13 visits.

Durkin et al. (2017) conducted a study to characterize the association between indicators of socioeconomic status and the prevalence of ASD from 2002 to 2010. Durkin et al. found that the prevalence of ASD increased simultaneously with SES during each surveillance year among non-African American, African American, and Hispanic American children. In each racial-ethnic group examined, there was a pattern of increasing diagnosis of ASD simultaneously with SES (Durkin et al., 2017). Durkin et al. suggested that, in the United States, autism might be under identified and undertreated in children from low-income families. African American parents with a lower income can be intimidated in the medical setting due to convoluted jargon and differences in worldviews (Reichard et al., 2004). African American parents with a low SES may have barriers preventing them from accessing information and health care professionals to obtain an accurate diagnosis for their child because of the quality of the patient’s health insurance (Reichard et al., 2004).

Disparities in knowledge about ASD symptoms among African American parents have influenced the level of ASD symptom reporting. African American parents have shown underreporting of ASD symptoms, which contributes to delayed or missed diagnosis (Baio et al., 2018). They have limited access to knowledge on ASD symptoms, impacts on a child, and benefits of timed diagnosis (Karp et al., 2018).

Knowledge is an essential component of self-efficacy because a person cannot do what he or she does not know. Non-African Americans are more likely to have a higher level of knowledge about ASD symptoms and the benefits of timed clinical diagnosis. African Americans, on the other hand, are less like to be knowledgeable about ASD, hence the prevalence of missed or delayed ASD diagnosis among their children (Emerson et al., 2016). Despite some improvements in the age of diagnosis, there are still other factors delaying diagnosis, such as health insurance coverage for African American children (Emerson et al., 2015). Doshi et al. (2017) found that non-African American children had better access to coordinated care and family-centered care than their non-African American counterparts. Therefore, access to care is still impacted by the race of the child, and there is more that needs to be done to help these children to gain access to much needed services.

Parental Reaction to Having a Child With ASD

According to Reed et al. (2019), parental reaction to a child's diagnosis of ASD is associated with a range of outcomes for both parent and child. Reed et al. found that unresolved or unaccepted ASD diagnoses predict poorer mental health in parents and poorer child outcomes. Nowell et al. (2017) found that parents of children with ASD reported high levels of dissatisfaction with the diagnosis process itself, often higher than the levels of dissatisfaction with diagnosis relating to more physically obvious childhood problems. Additionally, Reed et al. found that parents of children with ASD have described the diagnostic process as poorly conducted and chaotic (e.g., some parents had concerns that involved the speed of the process, the numbers of professionals that they had to see to obtain a diagnosis, and the knowledge and interpersonal skills of the professionals involved).

Furthermore, Banach et al. (2010) conducted interviews with 10 families about their experience of receiving an autism diagnosis for their child, along with interviewing five diagnosticians about their experience of delivering a diagnosis. Both diagnosticians and families reported anger, sadness, disbelief, and disagreement but also relief, increased closeness, and understanding upon diagnosis (Banach et al., 2010). Hutton and Caron (2005) examined parents' experiences of receiving the diagnosis of autism and found that 52% felt relieved, 43% felt grief and loss, 29% felt shocked or surprise, and 10% felt self-blame. According to Da Paz et al., (2018), when a child is diagnosed with autism, some parents show psychological resilience, defined as heightened wellbeing, and diminished psychological distress. This healthy adaptation might be explained by a caregiver's ability to move past the initial reaction of receiving the diagnosis and advance toward an attitude of acceptance or resolution (Da Paz et al., 2018).

Parenting a Child With ASD

Parenting a child with autism demands time, effort, and patience. Caring for children with ASD is challenging due to the following: (a) severity and chronicity of ASD, (b) the extensive developmental and physical comorbidities, and (c) the difficulties of health services in making the integrated and intensive interventions needed by persons with ASD widely available (Picardi et al., 2018). According to Ilias et al. (2018), parenting children with ASD can be more stressful and challenging than parenting children with typical development, especially in countries where there is a dearth of various support resources. The parenting stress experienced by parents of a child affected with ASD, therefore, appears to pose a greater risk to the parents' psychological and health-related quality of life.

Moreover, increased parental stress is attributed to the need to provide constant supervision and assistance to the daily living skills of the child, as well as ongoing sleep disruption, lack of available respite care, and lack of responsiveness by school personnel and related services (Catalano et al., 2018). The behavior of children affected with ASD may be difficult to manage due to behavioral anomalies (e.g., temper tantrums and aggressive, self-abusive, destructive, obsessive, ritualistic, impulsive, and self-stimulating behaviors) that can pose potential physical harm to the parents as well as siblings or family members and friends (Catalano et al., 2018). Hsiao (2018) found that to cope with having a family member, including a child, with a disability, the parent had to have a healthy psychological quality of life. If a parent was mentally unhealthy, this lessened his or her chances of finding new ways to adapt to the changes that inevitably face them because of their child's disability (Hsiao, 2018).

Sibling Reactions and Relations to Sibling With ASD

Siblings are a critical part of lifelong support for individuals with ASD. Kryzak et al. (2015) also found that siblings face their own social-emotional adjustment needs. According to Kryzak et al., siblings of children with ASD do not show significant differences in adjustment compared to siblings of children with Down syndrome and typically developing children. According to Klaiman et al. (2015), there are positive outcomes upon diagnosis of ASD in children, including siblings' overall positive perceptions of their sibling relationship, recollections of positive experiences with their siblings with ASD, and a close relationship (Kryzak et al., 2015).

For instance, Ward et al. (2016) noted that siblings of children with ASD acknowledged their experiences as both positive and negative. Challenges with communicating with their siblings and understanding other challenging behaviors were difficult for the siblings (Ward et al., 2016). Numerous participants in the study admitted that their siblings with ASD often received additional attention from their parents (Ward et al., 2016). Although there are possible setbacks, having a sibling with ASD made the participants more empathetic (Ward et al., 2016). Williams et al. (2016) noted that siblings of children with autism expressed both positive and negative outcomes associated with being the sibling of a child with autism. Negative feelings reported included frustration, resentment, depression, embarrassment, and jealousy (McHale et al., 2016). The sources of these feelings included both the child with autism’s disability as well as feeling isolation from parents due to the needs of their disabled sibling (Williams et al., 2016). Despite these negative feelings, positive outcomes were also reported such as family closeness, increased sensitivity and caregiving, and personal growth in the sibling with autism that occurred as a result of needing to be more self-reliant as well as helping out with the disabled sibling (Williams et al., 2016).

According to McHale et al. (2016), siblings of children with autism serve a unique role in presenting their brother or sister with numerous opportunities for interaction. Rudy (2006) suggested that aggression was identified as one significant stressor within sibling interactions where one sibling has ASD. Furthermore, the most common reaction to aggressive behavior was anger (McHale et al., 2016). Siblings may have difficulty with internalizing problems and a lack of understanding of how to handle difficult behaviors from their brothers or sisters (Rudy, 2006).

Potential Challenges and Barriers Experienced by African American Parents

Upon diagnosis of a child with ASD, challenges for the family continue to occur. Additionally, parental stress rises as parents strive to meet the needs of their child diagnosed with ASD while also maintaining the positive functioning of the whole family (Conger et al., 2010). Chen et al. (2016) found that parents may face problems in getting information about ASD and accessing the best services for their child when searching for a professional diagnosis. Other challenges that parents may face include accessing speech therapy, difficulty in locating intervention centers, and establishing a good rapport with professionals (Chu et al, 2018). Nowell et al. (2017) noted that family-level variables (i.e., insufficient financial resources, lack of insurance coverage, language barriers, geographic isolation, and limited knowledge or experience with complex health care systems) may be barriers to the timely diagnostic evaluation of an at-risk child.

Social Isolation

Families may also experience severe isolation from others because of their inability to leave home due to their child’s needs (Kurz, 2018). Isolation may also occur through feeling unheard by medical and health providers who lack knowledge about autism and feeling shamed by others when their child’s behaviors are misunderstood (Kurz, 2018). Additionally, parents report feeling isolated from their children because of their lack of communication and developmental delay (Bessette et al., 2016). According to Chen et al. (2016), the sense of loneliness can result from negative attitudes of environment and a lack of understanding for unusual behaviors of a child, which contributes to parents' avoidance of social contacts and social situations. Furthermore, the necessity of care, participation in therapy, and repeating its components at home significantly limits the opportunities for social interaction.

Socio-Economic Status

Work and financial issues are significant stressors for African American parents. SES is viewed as a barrier when financial resources inhibit access to services for this population (Pearson & Meadan, 2018). Some families experience financial difficulties such as (a) the cost of childcare, (b) the cost of time and money in transporting such children to and from health facilities, (c) a lack of enough income due to parents' inability to work full time, and (d) the costs of treatments and therapies (Burkett et al., 2015). According to Proctor et al. (2016), low SES further exacerbates delayed diagnoses and access to services among this population. For example, Liptak et al. (2008) found that families living in poverty had decreased access to getting care from a specialist, having a personal physician, getting acute care, and receiving preventative care for their children.

Stress

According to Miranda et al. (n.d.), the characteristics of the child with ASD have been identified as a possible source of stress for families. However, some families, despite the difficulties, have still managed to achieve successful psychological adaptation (Miranda et al., n.d.). Goedeke et al. (2019) stated that caring for a child with autism can be highly stressful, and it can be associated with a higher incidence of parental mental health issues (i.e., depression and anxiety), the experience of negative emotional reactions (e.g., anger, grief, disappointment, guilt), lower quality of life, and marital or partner relationship strain. Stress can also have an impact on the parents' mental health and psychosocial wellbeing and can make it more difficult for parents to manage the behaviors associated with autism appropriately (Goedeke et al., 2019).

Costs associated with having a child with autism are not, however, limited to the cost of interventions. As is the case with many other forms of childhood disability, parents of a child with autism often face greater outlays of time and money than they would for a neurologically typical child (Kiami & Goodgold, 2017). For example, specialized childcare/daycare/school is costly and often requires care for a longer period than other children would need (Kiami & Goodgold, 2017). An additional cost is also associated with extracurricular activities for children with disabilities. In fact, Rodriguez et al. (2019) found that parenting stress predicted child internalizing and externalizing problems, and, in turn, child externalizing problems predicted later parenting stress, particularly among fathers. Additionally, a reciprocal relationship between ASD symptoms and parenting stress was found such that ASD symptoms led to increased parenting stress, which predicted later increases in ASD symptom severity among children (Gourdine et al., 2011)

Locating and Accessing Services

Access to health care providers appropriately trained in the screening and diagnosis of ASD can be influenced by multiple variables (e.g., race/ethnicity, family income, geographic location, and parental education level; Kiami & Goodgold, 2017).

Blanchett (2009) argued that underrepresented families of children with disabilities face barriers to accessing services such as (a) differing cultural perspectives of disability, (b) limited access and unfamiliarity with available service delivery options, and (c) service providers' lack of understanding of factors (i.e., race, social class, cultural values, and experiences).

Similarly, Blanchett (2009) suggested that when families of color seek services for children with developmental disabilities, they are likely to face systems and structures (e.g., human and community services, special education systems) that are not adequately prepared to help them navigate services. In many cases, this results in families of color receiving culturally unresponsive and inappropriate services and interventions. Reichman et al. (2008) found that many families of children with developmental disabilities reported difficulties finding competent and trustworthy practitioners who were empathetic and understanding of their concerns. In addition, Gourdine et al. (2011) asserted that African American parents are less likely to view certain treatment methods as helpful for their children because of stereotyping, discrimination, and racism that they have experienced when seeking mental health services in the past.

Scheduling

Ofonedu et al. (2017) examined the factors associated with parents not keeping their child's mental health treatment appointments after initially seeking help. Ofonedu et al. found that scheduling conflict and the availability of appointments were barriers affecting parents' decision to participate in treatment. Scheduling conflicts and dissatisfaction with the appointment times offered were reported by 68% of the parents

(Ofonedu et al., 2017). The dissatisfaction of the appointment times was characterized by a lack of evening and weekend appointments, as well as parents and clinicians not having flexible work hours (Conger et al., 2010). Work schedules, domestic demands, and the ability to make the time commitment are contributing factors to the delay in 32% of the parents seeking diagnosis (Conger et al., 2010). Conger et al. (2010) found that parents reported difficulty getting appointments and inconvenient appointment times as a barrier to maintaining support services.

Insurance

The Association of Maternal and Child Health Program (2012) found that children with special needs require a comprehensive array of medical, behavioral, and developmental health services that are often inadequate. This leaves children at risk for missed or delayed care and their families with significant financial burdens. All children need health care coverage that is universal and continuous, adequate to meet their needs, and affordable (Association of Maternal and Child Health Program, 2012). In addition to the number of services, the out-of-pocket costs and gaps in insurance coverage may prevent parents from obtaining mental health services for their children (Cuellar, 2015). Saechao et al. (2012) interviewed a focus group of 30 first-generation immigrants to the United States on the stressors and barriers to using mental health services and found that poverty and low income were identified as a serious barrier to mental health services.

Thus, children and youths with ASD face more serious gaps in coverage as compared to other children, even when compared with those who have other special health care needs (Association of Maternal and Child Health Program, 2012). In addition to problems getting and keeping health care coverage, children with ASD can experience problems with the health benefits that their plan offers. Approximately half of the insured children with ASD (49.4%) have families who report that their child's health insurance coverage is inadequate to meet their needs, and this contributes to the delay in diagnosis (Association of Maternal and Child Health Program, 2012). Families experiencing gaps in insurance coverage are susceptible to increased out-of-pocket expenses related to their child with ASD's medical and therapeutic needs. Increased out-of-pocket expenditures lead to financial difficulties for the families of children with autism (Williams et al., 2010).

According to the Autistic Self Advocacy Network (2019), children with autism and their parents may face coverage denials for required interventions, even when they have health coverage (i.e., both private insurance and state-funded insurance). According to the network, individuals may hear one or more of the following reasons for coverage denials:

- The health plan only covers one kind of autism intervention (i.e., applied behavior analysis).
- The health plan refuses to cover interventions by certain medical professionals (i.e., a board-certified ABA practitioner).
- The health plan rejects a certain kind of autism intervention as experimental or not evidence-based, despite the existence of an adequate evidence base.
- The health plan covers a certain kind of intervention for some other kinds of disabilities but not for autism (e.g., the plan covers occupational therapy for

brain injury survivors but not autistic individuals or the plan covers mental health counseling for people with anxiety disorders but not for people with autism diagnoses).

According to Karp et al. (2018), non-African American children have better access to coordinated care and family-centered care than their non-African American counterparts. Therefore, access to care is still impacted by the race of the child, and there is more that needs to be done to help these children to gain access to much-needed services (Karp et al., 2018). Zhang and Baranek (2016) examined access and use of health services among children with autism needs and found gaps in access and use, due to whether the child had private or public insurance coverage. Children with private health insurance had access to fewer services with their parents paying more out-of-pocket for their health care services (Karp et al. 2018).

Poor Access to Health Care

Ineffective access to health care for African American children can be termed as one of the major factors leading to delayed ASD diagnosis. Burkett et al. (2017) stated that poor access can be representative of institutional factors that present barriers. In a study by Brian et al (2016), they obtained all 50 U.S. state mental health plans and analyzed them for gaps and barriers to mental health services. Their study found that 84% of state plans identified at least one gap in their system. A lack of service providers was the most cited gap in state plans (Brian et al., 2016). A shortage of providers contributes to the many challenges that parents face, such as difficulties scheduling and locating nearby mental health services.

At an organizational level, fluctuating policies and community services for autism locally, regionally missed hospital appointments, and a lack of family based ASD programs are among the obstacles of earlier diagnosis and timely intervention for African American children. Donohue et al. (2017) found that access to mental health care services is a problem for African American children with autism and their parents. Additionally, the American College of Physicians (2020) identified over 175 studies that documented racial/ethnic disparities in the diagnosis and treatment of various conditions, even when analyses were controlled for SES, insurance status, site of care, stage of the disease, comorbidity, and age, among other potential confounders. Among the many root causes of disparities that have been presented and explored are (a) variations in patients' health beliefs, (b) values, (c) preferences, and (d) behaviors have recently garnered attention (Donohue et al., 2017). Among these causes of disparate treatment are variations in patient recognition of symptoms, thresholds for seeking care, the ability to communicate symptoms to a provider who understands their meaning, the ability to understand the prescribed management strategy, and expectations of care (Donohue et al., 2017). Zhang and Baranek (2016) examined the use of health services among children with autism needs and found that gaps in access and use were a result of whether the child had private or public insurance coverage.

Cultural Factors and Access to Health Services

Culture is defined as a set of distinctive patterns of behavior that are shared by a group of people and that serve to regulate their daily living (Ratto et al., 2016). According to Fong and Lee (2017), there is a need to develop culturally sensitive autism intervention programs (e.g., culture may impact the diagnosis of autism and the time of diagnosis, as well as access to services). In the United States, the ASD diagnosis of non-African Americans is on average 1.5 years before their ethnic minority counterparts, allowing non-African American children more immediate access to interventions for autism, in comparison to minority children (Fong & Lee, 2017).

According to Pearson and Meadan (2018), the U.S. health care system is highly characterized by divergence, a perception that there is a poor relationship between African American parents and health experts who attend to their children. Burkett et al. (2017) noted that many cultural aspects have been hypothesized as influencing early diagnostic assessment and appropriate treatments for African American children with autism. According to Burkett et al. (2015), the most common factors affecting diagnosis and treatment for African American children with ASD include (a) clinical professional analytic prejudice, (b) inaccessible medical facilities due to long distances from remote places, (c) symptom display, and (d) parent perceptions of their child's signs.

Also, Emerson et al. (2015) affirmed that professional bias in delivering autism diagnostic evaluation has been associated with changing therapist behaviors with patients from different cultures and physician anticipation regarding diagnosis, as well as interventions that vary by cultural backgrounds. In the United States, the conduct of health care providers varies towards patients of different cultural groups in medical facility relationships (Emerson et al., 2015). These differences in conduct and recommendations, which have the effect of labeling African American children as different from non-African American children, result in barriers to proper diagnosis and intervention for African American families (Emerson et al., 2015). Burkett et al. (2015) concluded that cultural factors reveal a need for exploratory research with African American families to discover their cultural perspectives on caring for children with ASD and the perceptions of family care among ASD professionals. When health care professionals are equipped with knowledge about the effect that cultural influences have on care, it can foster culturally congruent actions that can positively affect the child with autism and reduce the risks faced by the developing child (Burkett et al., 2015).

Summary

Through the literature review, the BHM and resilience theory conceptual framework was evaluated for their suitability with this study. The models were presented separately along with their constructs, then as a whole to explain the rationale and application of this study. This study fills the gap regarding the access to autism support services, specifically African American parents' experiences in obtaining these services in the Philadelphia, PA area. The results will improve understanding of how ASD impacts African American parents’ experiences of maintaining and accessing autism services for their children. Understanding the problem of autism service accessibility for young children with autism from the experiences of their parents is needed to help address access problems. This knowledge will improve the experiences and health outcomes for individuals affected by ASD and their families, while simultaneously resulting in positive social change when used to advocate for policy modifications, education, service delivery, and acceptance and support for individuals affected with ASD.

Research design and rationale will be discussed in Chapter 3, as well as identification of the researcher's role. The methodology of the study will then be discussed in detail, including participant selection, instrumentation, and procedures for recruitment and participation. Finally, a data analysis plan will be provided, and trustworthiness and ethical procedures will be addressed.

Chapter 3: Research Method

The purpose of the study was to explore the experiences of African American parents as they try to access and keep autism services for their children within the city of Philadelphia, PA. Early diagnosis and access to effective therapeutic services are critical because they can make a difference in the outcomes for children who are on the autism spectrum (Autism Speaks, 2016). In this study I employed a generic, qualitative approach using semistructured interviews with participating parents of autistic children to explore their experiences with accessing and maintaining autism services for their children.

Research Design and Rationale

RQ: What are African American parental experience with accessing and maintaining services for their child with autism in Philadelphia, PA?

Following approval from the Walden Institutional Review Board (IRB; IRB Approval # 01-06-21-0352807), I began the data collection process. A generic, qualitative research method was used to explore the experiences of African American parents accessing autism support services for their children. A generic, qualitative study allows for an examination of “people’s attitudes, opinions, or beliefs about a particular issue or experience” (McCusker & Gunaydin, 2015, p. 20). According to Kahlke (2014), generic, qualitative inquiries are best suited for studies in which researchers investigate people’s beliefs or opinions about an issue or experience. The generic, qualitative approach is appropriate for studying perceptions about a topic or issue (Kahlke, 2014). I chose the generic, qualitative research design for this study because I wanted to provide African American parents with the opportunity to express their experiences of accessing support services for their autistic child. This approach allowed me to collect in-depth information as to how these parents access those support services.

I also considered phenomenological, case study, and grounded theory designs for this study. Phenomenology focuses on what and how people experience certain phenomena (Percy et al, 2015). A phenomenological design was not used for this study because I was not looking to understand the lived experiences of a group of people surrounding the phenomenon. A case study approach entails a study of one or more cases to develop in-depth, thick descriptions (Tager-Flusberg & Kasari, 2013). I also contemplated a case study approach with its focus on exploration; however, I considered it inappropriate because I was not examining a specific event. Researchers use grounded theory to develop theories from analyzing the participants' responses (Kahlke, 2014). I did not use the data from the interviews to develop a theory, so the principles of grounded theory were not suitable for this study.

Role of the Researcher

According to Camacho (2016), all researchers have lived experiences and feel emotions. The researcher must take into consideration their preunderstanding, both in the planning process as well as during the analyzing process, to minimize any bias of their influence (Bengtsson, 2016). I assumed the role of the interviewer and the transcriptionist of all data collected for this research. According to Creswell and Clark (2017), in qualitative research, the researcher must show how their experiences or backgrounds shape the interpretations they have made through the coding and theme development process. For over 4 years, I have worked as a psychological evaluator helping diagnose children from all backgrounds. I did not have any personal or professional relationship with the participants or give the participants any incentives to participate.

The process of reflexivity provided me with the opportunity to confront my biases. Reflexivity involves a researcher being aware of how they react to participants and how the information is constructed (Berger, 2015). Keeping a reflective journal requires constant reflection and self-awareness (Anderson & Stillman, 2013). Reflective journals allow for dialogue, self-reflection, and self-analysis (Reid et al., 2018). I was able to keep track of my assumptions, biases, positionality, and personal identity by using reflective journals or analytical memos. In addition to engaging in reflexivity during the research process, I used the reflective journal before and after interviews to document my feelings and thoughts that arose during the interview, as a means of addressing any biases that may have arose.

Methodology

Participant Selection Logic

Population

The study population consisted of five male and five female African American parents from Philadelphia, PA. Philadelphia, PA is considered an urban area. The 2010 U.S. Census (2019) reported over 1.579 million residents. The five largest ethnic groups in Philadelphia, PA are Black or African American (Non-Hispanic; 40.1%), White (Non-Hispanic; 34%), Other (Hispanic; 7.42%), Asian (Non-Hispanic; 7.34%), and White (Hispanic; 5.33%). In Philadelphia, PA, 23.9% of the households speak a non-English language at home as their primary language, and 92.8% of the residents in Philadelphia, PA are U.S. citizens (Data USA, n.d.).

Sampling Strategy

In this study, I used purposeful sampling, which is widely used in qualitative research and appropriate for generic qualitative research (see Patton, 2015). A purposeful sample is selected by a predetermined criterion for the research question (Padilla-Diaz, 2015). This strategy provided me with the opportunity to study the topic in depth since all participants met the criteria to answer the research question.

Inclusion Criteria

The targeted population for the study was African American parents who have undergone the experience of accessing support services for their autistic child in PA. To select a sample of parents who were best suited to answer the research question, I used a purposeful sampling method. To be included in the study, participants needed to meet the following criteria: (a) must be of African American background raising at least one child with ASD in the Philadelphia area; (b) must be fluent in English; (c) will have tried to access or maintain autism services, and (d) must be willing to consent to an audio-taped interview via phone, Skype, or Zoom.

Sample Size

Fewer participants are required for qualitative studies than for quantitative studies. Mason (2010) cited the need for saturation as a reason why large sample sizes become more time consuming to analyze. In saturated research, data collection stops because there is no more information to provide on the topic (Percy et al., 2015).

The way participants are selected purposefully plays an important role in the sample size. Archibald and Munce (2015) found sample sizes that ranged between eight and 50 for single-interview-per-participant designs. In this study, I interviewed 10 participants and reached saturation.

Sample Identification

I recruited African American parents for this study by posting flyers in local libraries in Philadelphia, PA. The invitation letter, the informed consent document, and the reference request were attached to a flyer that was also shared biweekly on social media sites.

Instrumentation

According to Percy et al. (2015), open-ended questions help generate more insightful responses. I developed the first part of the interview guide to collect demographic information, such as the parents, their race, age, marital status, and the number of children in the household with ASD. I referenced Merriam and Tisdell’s (2016) guide to create interview questions. For the development of meaningful and aligned questions, I reviewed qualitative studies that used the BHM and resilience theory as a framework. The review of other qualitative studies helped me visualize how theories generate aligned questions. As a result, I revised the initial questions by merging similar items. I had these questions reviewed for bias and neutrality and received feedback from my peer and professor who are familiar with autism. The African American parents within the study who were seeking ASD support services were interviewed using the specific interview questions developed. As a result, question prompts were incorporated into the interview guide.

Procedures for Recruitment, Participation, and Data Collection

Recruitment

First, I used purposeful sampling to recruit potential participants via email addresses obtained from social media outlets, such as Facebook and Instagram. In addition, I posted several flyers in the local library. I repeated social media postings every 2 weeks and relied on people to share the flyer. I did not request any changes to the recruitment process through Walden's IRB.

Participation

After invitations were distributed via email and the flyer posted in the local library and on social media, I waited for responses. If a parent contacted me about participating and met the inclusion criteria, I requested they review the informed consent document and provide consent, provide availability for the interview, and state their preference for the digital platform. I contacted the parents who did not meet the inclusion criteria for the study by email to thank them for their willingness to help and time.

Data Collection

I asked participants to indicate their availability for a virtual interview. Parents who met the study criteria were notified in advance of the interview that informed consent would be emailed to them. They were instructed to read the document and reply directly to researcher via email within 2 days. A Zoom link was sent to the respondent for the upcoming interview and re-sent the day before as a reminder. I began the approximately 60-minute Zoom meeting by reviewing the study introduction to explain the study and my focus on confidentiality. A standard interview guide was used to ensure consistency and align questions to the conceptual framework. I used prompts to assist interviewees who had trouble answering a question or asked for clarification. Once all the questions from the interview guide were completed, I stopped the audio recording and asked the participants if they had any questions or concerns. The participants were also asked if they would be willing to take part in a follow-up interview if needed. Finally, participants received an email thank you note with my contact information, a reminder about transcript review, and a copy of the study results.

Data Analysis Plan

According to Tessier (2012), field notes, audio recordings, and transcriptions are important to strengthening data analysis. Because I have experience dealing with verbatim transcription for two-person dialogues, I transcribed the interviews prior to analysis of the data. Rather than taking field notes, transcripts are more accurate (Tessier, 2012). Listening to the recordings gives more meaning than reading the transcripts (Tessier, 2012). Following each transcription, I listened to the recording while reading along with the transcript. After reviewing the transcript, I reminded the participant about the transcript review that was discussed at the end of the interview. The field notes were referenced to enhance the meaning of the interview and complete the accuracy check afterwards. For participants who requested to see their transcripts, I emailed them and asked for any changes or approval within a week. For those who did not respond, I sent another email and waited another week to receive a response before finishing data analysis on all 10 transcripts.

To answer the research question, I used thematic analysis, which is a flexible approach that identifies key themes by applying a systematic, methodical, six-step approach to the data (Clarke & Braun, 2017). During Step 1 of the research process, I familiarized myself with the data (see Nowell et al., 2017). I listened to the audio recording and read the transcripts more than once, and I examined my preexisting thoughts and beliefs through reflexive journaling. Saldaña (2016) described coding as a subjective process in which an individual assigns texts or symbols to data to symbolize or convey significance. Codes were manually entered, sorted, and defined using Microsoft Excel. The codes were then recorded using a codebook, which is a tool used in inductive coding. I highlighted key words in transcripts to arrive at preliminary codes. Secondly, using open coding, code names were developed for preliminary codes using line-by-line coding. Lastly, I organized and renamed codes from the first cycle of coding. As I narrowed and grouped codes, I recoded several times, finally forming a final code. Software was not used to sort the data or identify codes.

To generate themes from codes, the third step in TA is to group the data by the theoretical constructs, then identify subthemes within the themes. Accordingly, I grouped my data by the constructs, then identified subthemes within each theme. I reviewed and changed the preliminary themes many times during Step 4, determining whether the theme accounts for the data set or can be combined with another theme (see Clarke & Braun, 2006). According to Barusch et al (2011), triangulation is the use of multiple data sources about the same topic, which adds richness through multiple perspectives. Using researcher triangulation, the final themes were defined and named using the fifth step in the TA process. Finally, I wrote a concise and coherent report based on the data (see Clarke & Braun, 2006). Chapter 4 will include a concise summary of the findings and quotes directly from participants, enhancing credibility.

Issues of Trustworthiness

It has been argued that qualitative research lacks rigor, and the findings are just a collection of people's opinions subjected to researcher bias during analysis (Leung, 2015). Establishing trustworthiness in research is, therefore, key for validating the study. It is recommended that qualitative researchers use field notes in their study because they record their immediate thoughts and help to produce thick, rich descriptions (Phillippi & Lauderdale, 2017). As described by Nowell et al. (2017), trustworthiness is established by showing a coherent, clear, and accurate description of the data in the analysis. Credibility, transferability, dependability, and consistency are the four components of trustworthiness.

Credibility

According to Connelly (2016), internal validity, also referred to as credibility, is the most important factor in establishing trustworthiness. Internal validity refers to the credibility and predictability of the data's findings. This occurs when the researcher represents the perspective of the respondents, not theirs. Popular approaches to address credibility are prolonged engagement, triangulation of data, persistent observation, triangulation of researchers, and peer debriefing (Patton, 2015). During the interview process, I sought clarification from participants to maintain accuracy, and afterwards I attempted to translate their responses verbatim. I also offered the option of transcript review so participants could verify their responses (see Moser & Korstjens, 2018). As Connelly posited, triangulation with peers is necessary to reduce bias and improve credibility. Over the course of the research process, I consulted with my committee chair and peers.

Transferability

A measure of the transferability of the data is its ability to generalize to other situations, populations, or phenomena (Patton, 2015). Shenton (2004) emphasized that transferability occurs during research preparation by identifying similar studies using the same methods in different environments. I kept detailed records regarding methodology, sampling strategies, and recruitment procedures. As a result, I created transferability, so another researcher can easily use my methods in their own study.

Dependability

Dependability contributes to trustworthiness if the research process is transparent so that another researcher may reproduce the study (Nowell et al., 2017). Conducting an inquiry audit, where an outside person analyzes the research process and data analysis for consistency, is an excellent way of ensuring dependability (Nowell et al., 2017). A record-keeping process is essential for guiding future researchers who may be considering conducting similar studies. I kept detailed notes on the research process and consulted committee members and peers to ensure consistency.

Confirmability

According to Nowell et al. (2017), credibility, transferability, and dependability are indicators of confirmability. Confirmability refers to the neutrality of findings by showing how the study found the results from the data (Nowell et al., 2017). The study results should reflect the data and not the researcher's subjectivity (Qu & Dumay, 2011). Audit trails, analytical memos, transcripts, field notes, and the decision-making process will demonstrate transparency during the research process. Reflexivity, on the other hand, is the deliberate process of a researcher reflecting on themselves during the research process (Berger, 2015). The use of reflective journals can be an effective method to address biases, assumptions, motivations, positionality, experiences, and thoughts (Moser & Korstjens, 2018). I kept detailed records, used a reflexive journal, and consulted peers to strengthen my understanding of the study. Berger (2015) indicated that when researchers describe the intersections of the relationships between themselves and the participants, they increase credibility.

Ethical Procedures

Before beginning data collection, I obtained approval from the Walden University IRB approval number 01-06-21-0352807. In order to protect human participants, IRB approval was necessary.

Informed consent allows participants to review the study and decide whether to participate on their own (Manti & Licari, 2018). Informed consent includes participant rights, the purpose and procedures of the study, the risks and benefits of the study, the expected duration of the interview, and confidentiality procedures (Manti & Licari, 2018). Each participant was emailed a letter of consent when they agreed to participate. Prior to the scheduled interview, I emailed the informed consent document to the participant for review and asked for consent to be given by responding to the email. To reduce any language barriers one inclusion criteria is for the participant to be able to understand and speak English (Nijhawan et al., 2013). The participants were informed that they had the right to refuse any questions that created discomfort or withdraw from the study. There were no participant withdraws from the study.

When participants are asked for full disclosure, confidentiality is paramount, so I was the only individual to know the real names of the individuals who participated. Participants were assigned fictitious names, and quotes in Chapter 4 and Chapter 5 were based on those names. Specific demographic information, such as the location of the person's home within the county, was not reported to increase confidentiality. Documents are stored in a lockbox at my home, from which I have exclusive access, and are stored on a password-protected computer in a file nestled amongst two others. According to the IRB, all original data from the study have to be kept for 5 years before destruction. After that period was up, the recording device will be deleted.

Summary

In Chapter 3, the detailed research methodology behind the study was discussed. Major sections included in the chapter were the research design, methodology, and issues of trustworthiness. Participant selection logic was provided for African American parents in Philadelphia, PA. The use of audio-recordings, field notes, and an interview guide were presented and rationalized. In order to show the relationship between the development of the interview guide and the BHM and resilience theory, the original questions were developed using theory. An overview of recruitment, participation, and data collection procedures was provided. Thematic analysis was used to analyze data. In conclusion, I described how I ensured the validity and reliability of my research in Chapter 4 in order to present the data and findings of the study.

Chapter 4: Results

The purpose of this generic, qualitative study was to explore the experiences of African American parents accessing autism support for their autistic children. The contents of this chapter include the description of the interview settings and participant demographic information. The data collection and analysis process are also outlined in detail. Lastly, I provide evidence of trustworthiness and the study results followed by a chapter summary.

Setting

I conducted semistructured interviews with 10 African American parents in Philadelphia, PA. All interviews were conducted through Zoom video conferencing. The date and time of the interviews were determined by each participant. For each interview, I was in my home office alone with a white noise machine on at the door. Each interview lasted between 60 and 70 minutes. To record the interviews, I used the Samsung Voice Recorder application. There were no issues with the recording device or the audio recordings of the interviews.

Demographics

Table 1 provides an overview of participant demographics. The ages of participants ranged from 25 to 44 years of age. All 10 participants reported their race as African American. Five participants were male, and five were female. Six parents identified themselves has single, three were married, and one was divorced.

Table 1

Demographic Information of the Caregiver of the Child With Autism

Participant’s name	Race	Gender	Age	Children with ASD	Marital Status
Participant 1	African American	Female	40	2	Single
Participant 2	African American	Female	37	1	Married
Participant 3	African American	Male	37	1	Divorced
Participant 4	African American	Female	43	1	Single
Participant 5	African American	Male	35	2	Single
Participant 6	African American	Female	44	1	Married
Participant 7	African American	Female	40	1	Single
Participant 8	African American	Female	37	1	Single
Participant 9	African American	Male	29	1	Single
Participant 10	African American	Male	39	1	Married

Data Collection

I received IRB approval on January 06, 2021to recruit eight to 13 participants. After receiving IRB approval, potential participants were recruited using email and social media. The approved invitation letter and flyer) were emailed to email addresses acquired from the Twitter social media site. Potential participants emailed me their interest, and I responded with the prescreening document. Three ineligible individuals were emailed due to their kids having attention deficit hyperactivity disorder and not autism to thank them for their time and consideration and ask them to share the study with friends or family who may be interested. Ten eligible participants were identified. Each participant was sent the informed consent document via email with directions to read the document and reply to their consent directly to me through email within 3 days. Each participant was also asked to provide availability for a Zoom interview on the platform of their choice when responding. Once the date and time was established, a Zoom link was sent to the participant. I recorded the date the email consent was received along with the interview date and time in my field notebook.

I conducted 1- semistructured interviews with the participants from Philadelphia, PA from January 31, 2021, to April 15, 2021using the approved IRB interview guide. Each participant was interviewed once. Their location did not interfere with their ability to participate in the interviews. Interviews lasted between 60 and 70 minutes due to the depth of responses from the participant. The interview was audio recorded using the Samsung Recorder App on my computer. During the interview, notes were taken by hand to document key words and my initial thoughts.

After responding to the last interview question, the participant was notified the recording was being terminated. I emailed each participant the thank you letter the day after the interview. After each interview, I immediately transferred the recording to a folder nestled in another folder on a password-protected computer. I then reflected on the interview by writing my thoughts, questions, and potential biases in my field notebook.

No follow-up interviews were needed. After I transcribed each interview, I contacted the participants to ask if they wanted to review the transcript. All 10 participants declined and wished me well with the study. Transcripts were created in Google Docs and saved with password protection.

Data Analysis

I analyzed the collected data using a six-step TA approach, which enabled me to find repeated meaning patterns among the 10 interviews (see Clark & Braun, 2006). The first step in TA is to become familiar with the data (Nowell et al., 2017). After transcribing the interviews, I listened to them again, took notes, and highlighted words on the printed transcripts using reflexive journaling to address my preexisting thoughts, beliefs, reactions, and reflections (see Nowell et al., 2017). Next, I began to code (see Clarke & Braun, 2006). To prepare for coding, the participant responses were transferred to the interview questions into a Microsoft Excel document separated by interview questions. I began the first cycle coding by assigning words or short phrases to the responses of each participant, which is also known as open coding (see Percy et al., 2015) Next, the second round of coding was completed. During the second cycle, I narrowed the codes by connecting and combining codes (see Saldaña, 2016).

In Step 3 of the thematic analysis, I began to conceptualize and identify themes and subthemes. Table 2 provides an example of the process of open coding, second cycle coding, and theme identification that was used for each interview question.

Table 2

Open Coding

First cycle coding	Second coding	Themes
Having to leave work. Lack of support Routines, no time for myself Run around. Don't know where to turn What to do next Future	Uncertainty	Challenges
Limited support Late diagnosis Unmet needs Lack of awareness	Frustration	Parental stress
Bounce back. Hope Advocating Fall get back up again Call and call I will get it down regardless	Never giving up	Resilience
Limited providers Waiting list Lack of knowledge Limited insurance coverage Not offering or taking any more clients	What's next	Accessing services

As part of the first cycle of coding, I extracted keywords and short phrases from response data. During the second cycle of coding, I grouped like codes to identify four themes: challenges, parental stressor, resilience, and accessing services. The themes were then reviewed to make sure they accurately reflected the data set, the fourth step of TA (see Clarke & Braun, 2006).

Evidence of Trustworthiness

A study's validity is dependent upon the reliability of the data used for its analysis. In qualitative research, trustworthiness is established by demonstrating that the data is precise, consistent, and exhaustive (Nowell et al., 2017). To establish trustworthiness, I used multiple strategies during the research process to ensure credibility, transferability, dependability, and confirmability.

Credibility

Credibility, or internal validity, refers to the trustworthiness of the findings by using the respondents’ own perspectives on the phenomena (Connelly, 2016). To establish credibility, I designed semistructured interview questions based on the conceptual framework, which made it possible for me to seek responses from participants to answer the research question from a theoretical perspective. By asking participants for clarification during the interview and using verbatim translation, I maintained the accuracy of their responses. Transcript review for accuracy is a tool for member checking (Birt et al., 2016).

Employing triangulation and prolonged contact was another method that helped me to ensure credibility during this study. I used triangulation to fill in data gaps uncovered during transcription and ensured the accuracy of the information provided by the participants by reviewing member files and contacting the participants via telephone. This led to the reduction of bias and increased credibility (Nowell et al., 2017). In addition to consulting with my committee chair and peers, method triangulation was employed throughout the research process to help identify themes and draw conclusions (see Reid et al., 2018). During the research process, I made references to previous research, literature, and theory and used previous research, literature, and theory to strengthen the study’s credibility.

Transferability

Normally, data can be generalized to other similar situations, populations, or phenomena only after they are used as a basis for a study (Connelly, 2016). To determine transferability, thick descriptions are commonly used. I provided detailed descriptions of participants, including geographic area, age, marital status, kids in the home with ASD, and demographics. In Chapter 3, the details regarding methodology, sampling strategies, recruitment procedures, and data collection and analysis were provided in detail. Keeping detailed notes on each step of the research process also made it possible for other researchers to use the procedures of my study to inform their own. Shenton (2004) noted there is an ability to transfer research when similar studies are identified with the same methods in different environments. For instance, I used similar studies based on the BHM and resilience theory as a reference for my study.

Dependability

Dependability occurs when the research process is clearly documented for another researcher to duplicate the study and yield similar results (Nowell et al., 2017). Strategies for dependability include keeping detailed records, explaining the research design, providing operational detail, and researcher reflexivity (Moser & Korstjens, 2018). I kept detailed field notes and records of data collection activities. Audit trails allow for transparency in the researcher’s process and decision making (Cope, 2014). I kept an audit trail of decisions I made during coding and theme identification.

Confirmability

Confirmability is the presence of neutrality in the findings by showing steps on how the study's findings emerged from the data (Nowell et al., 2017). By using keywords and phrases from the participant transcripts, I created tables to document how themes emerged from the data. As a mental health professional, the research process required me to deliberately engage in reflexivity to reduce bias and record my thoughts, feelings, beliefs, positionality, and personal experiences (see Moser & Korstjens, 2018). I also reduced researcher subjectivity by using triangulation (Bridges et al., 2015.).

Results

I used the participants' responses to the semistructured interview questions to answer the research question. From the data collected, I used TA to identify the main themes and subthemes from the participants' answers to the interview questions. Detailed information about the themes and subthemes identified during data analysis can be found in Table 3.

Theme 1: Challenges With Raising a Child With ASD

The parents shared their personal experiences with raising a child with autism and their responses at time of the child's diagnosis. Primary caregivers for an autistic child may experience some similarities as well as differences regarding the emotions they experience at any given time. Participant 1 said, "Raising a child with ASD is like looking at the world with a different set of glasses. The whole routine is messed up. So, needless to say it can be challenging more days than others." Participant 4 said, "I would describe my experience raising my daughter as an adventure. I don't see her as someone with autism, maybe because I'm around people in the community who know her. We travel and enjoy other family vacations together." Participant 9 said,

> Caring for my child to me is like a full-time job with double overtime (laughs). I work a full-time job despite the pandemic. I can't always just take off to go to the daycare or school to pick him up when he acts up.

Participant 5 said,

> I quit my job because my wife and I agreed it would be best for all of the children…It was too much of come get him because he would not stop crying at the daycare. You have all of these things that you have to adjust too…because you know they have a routine that if you go off of that here comes those outburst or aggression…and I can't afford to let that happen because I have other children in the home.

Maintaining a schedule, explaining changes earlier, and developing a structure were important factors in minimizing the challenges facing caregivers of children with autism.

Subtheme 1: Emotional Responses to Child Diagnosis

This subtheme referred to how parents reacted after learning their child was diagnosed with autism. Some commonalities and differences will be found in describing the emotions parents experience at any given time when raising a child or children with autism. Participants shared their reactions to their child's diagnosis. Participant 2 said,

> I didn't know what autism was, so I was very shocked, guilty, and at the same time overwhelmed. I wondered if I did something strange during my pregnancy. Am I overlooking something? Then I started thinking about how to take care of

> this child. I have seen times when people were mean to children with special needs. When I told my husband ... he wasn't even upset about the diagnosis ... he was more upset about why it took so long. He felt they would have been diagnosed earlier if it were White.

Participant 8 said,

> I had to admit after all this diagnosis, I had anxiety and frustration because of ASD ... I felt like it was much harder for me now ... because Dad wasn't involved before ... I have to say that sometimes I was upset and said things I didn't like, I said things after which I regret it. Like, I wanted to show her dad's anger.

Participant 4 said,

> When you receive this diagnosis, not only will your life change, but it will also change the child. For me it was joy and acceptance right away. A sense of relief so to speak. When I started to notice something was wrong with my child, with not talking the way she should, not walking like other kids, the first thing I thought was that someone switch my baby. It's like the child some sort of evil roots on her. Crying for no reason, throwing self on the floor. I was completely stressed out, shock, nervous and hopeless until I got that diagnosis.

Although the parents acknowledged experiencing stress, sadness, depression, anger, confusion, or joy, they also acknowledged experiencing good or bad days, relief, worry, and happiness. They acknowledged although the feelings went away, they could resurface at any given time.

Subtheme 2: Structure and Routine

As all 10 parents noted that, after learning of their child's diagnosis, routine changes added to the challenges of caring for their child. A child with autism would need more help depending on whether or not they were low- or high-functioning. To establish a routine for the child with autism, simple things such as making dinner, doing the laundry, and meeting the needs of other family members had to be altered. Participant 1 said,

> In our usual schedule, we go out for a meal at least twice a week. We tend to have to wait 30 minutes before we can be seated about that time my child would become restless and agitated. We would then just have to leave because we know that a meltdown is about to come. So, we just go to a drive through and grab and go.

All parents agreed that structure and routine helped minimize outbursts, loud noises, tantrums, and aggressive behavior.

Subtheme 3: Changes in Lifestyle

Six out of 10 of the parents reported that autism had a negative impact on their careers. They stated that they were unable to combine a full-time job with caring for the child with autism. Some participants felt that this meant they were not providing financial assistance to their child and, therefore, could not ensure that they receive quality specialized treatment.

Participant 9 said, “the income I bring in is not enough to afford additional therapies that make their lives easier.” Participant 5 said, “I have to run a normal life, I have to work, I have to get up in the morning. I have two other children to see to." Furthermore, five out of 10 parents reported having to adjust their daily routines, such as shopping, eating out, family gatherings, and celebrating holidays. For some of the parents they were no longer spontaneous events and activities, and they were unable to engage in activities that they had not planned. Participant 7 said,

> For us, we use to pick up and go to the mall. However, when we take our child, the escalators are dangerous for him, because he starts hitting himself. So, the best thing to do is stop taking him to mall instead and prevent those situations. If you know what triggers them, just steer clear of them.

Participant 2 said,

> Having a child with autism has altered our lifestyle quite a bit. We used to eat out frequently, we used to go and socialize with friends, we used to go out in groups. Our entire lives have changed because our kids' comfort is now what matters to us. The needs of your children have to go first, no matter what, although it can be hard.

Subtheme 4: Social Isolation

Another common subtheme that emerged from the narrative answers was social isolation. Five of the 10 parents reported having difficulties with social isolation. For example, Participant 8 said,

> Often, we restrict the amount of time we spend with the few friends we have and those who aren't familiar with or child because we are not sure what behaviors she

> has and aren't interested in explaining why we are handling her behaviors the way we do.

Participant 2 said,

> People don't invite me to parties or social events anymore because they fear that I won't have childcare or that I may need to bring my son with me. We have lost several friends since our son was born because they couldn't handle him.

While autism often posed challenges to participants, some parents were willing to overcome any obstacles the child's diagnosis presented. In order to cope with a child with autism in the family, some of the parents appear to build a sense of normalcy and meaning out of their experiences.

Theme 2: Parental Stressors

Parents whose children have ASD commonly encounter several types of stress, including the diagnosis of the child with ASD and their ongoing role as caretakers. In addition to their role as parents, these individuals must maintain a structured environment, find providers, have an understanding of treatment, allow time for self-care and attend therapeutic appointments for their child and other family members, and rely on other sources of support (Broady et al, 2015). The following subthemes were related to the main theme of parental stress in relation to having a child diagnosed with ASD. The first overarching subtheme was identified as financial burden, the second subtheme consisted of limited providers, the third subtheme consisted of support systems, and the fourth lack of awareness and understanding of child’s diagnosis.

Subtheme 1: Financial Burden

Some of the parents expressed some form of economic burden related to taking care of a child with ASD. Parents identified spending a substantial amount of money on not only things within the home, but also for services and various treatment methods for their child. Three participants discussed having to take a leave of absence from their jobs to dedicate time to care for their child. The financial burden was an obstacle. However, it did not discourage the parents from seeking services putting the needs of their child first. Participant 8 said,

> We found a few daycares that can accommodate children on the spectrum. However, it's expensive. Essentially, I just do what I can financially, just to make things work, in fact I make bracelets at home." I used the extra money from that to pay for summer programs for the kids.

Participant 3 said,

> To tell you the truth I have no more savings. I used to be able to have some on the side in case of emergencies, but my household only have one income now. It's not like I can't get another job, but what I am I supposed to do with children.

Participant 5 said,

> There's no savings going on…due to a lot of his money being spent on special diets, summer programs and resources for the home to entertain and help my child. Every time I turn around, I have to buy something, like a weighted blanket, a swing and sensory toy (ugh)

Participant 4 said,

> “I had to pay for private speech and occupational therapy and don’t forget about the extra therapeutic resources that we need to have at home to help our children, like headphones to cancel out the noises, tablet, Legos, special soaps, no tag clothing and diaper and wipes” oh might I add babysitters when others are not available. But I was able to do it.

Participant 2 said,

> “I am not rich …But I had some money save from when I was married, and money were given from friends when I was pregnant. I was also able to have various positions throughout a few jobs that I had. I did not have any children then (laughs) I got a late start on staring a family, so I was able to save” “Don’t get me wrong if I am continuing to pay for private lessons, speech and community programs. I am going to run out of that savings within the next year or so.

Participant 7 said,

> I have two incomes coming into the home, although not a lot of savings going on, when we do get the tax returns, we put it up for that moment if one of us have to leave our jobs…. but the daycares and summer programs can easily add up and be awfully expensive. But we must do we can.

Parents did share some commonalities as well as differences regarding the emotions they felt when talking about what it takes to raise their child with autism.

Subtheme 2: Limited Providers

Nine out of 10 of the parents discussed that there were not enough health care providers who specialize in autism in the area. Some parents also felt that since the pandemic began, support services for their children have further been reduced or limited. The ASD service providers in the area often are full. However, 2 out of 10 parents were able to find service providers. Participant 8 said, “I find that the lack of service providers is more in the Urban area where there is a lot of minorities. It’s even harder with COVID being around to seek out even more providers.” Participant 3 stated, “There is a lack of resources and the broadcasting of information including the lack of support groups serving African American families within the community were barriers to providing appropriate care.” Participant 10 said

> Due to the limited providers when it comes to medication is a scary thing. I felt I had to jump through the damn hoops to obtain a prescription from the psychiatrist before I could even take him to see the eye doctor. If he does not get this med, he will become aggressive and hard to control.

Participant 7 said,

> I tried to change my child’s provider so many times, but they are not a lot to choose from. It’s either they don’t accept the insurance, or they are not accepting new patients. I have considered travelling outside of the area just to get my child medications.

Eight out of the 10 parents reported that accessing and using service coordination through the state was extremely stressful. Some reported that they were not made aware of their eligibility for service coordination in a timely manner, nor were they guided properly through the eligibility determination process.

Subtheme 3: Support Systems

Support systems play an important role in parents' ability to cope and manage the stressors when having a child with autism. In response to the kinds of supports, some parents report receiving support from the school, family, friends, and doctors. Others reported no support was given after the diagnosis or during the time that they had to wait for services from either the medical providers, school or family, and community. Four parents indicated that they had great supporters. Some of the supports came from extended family, spouses, friends, school staff, or daycare providers despite the recent pandemic. Participant 1 said,

> My support system is my friend and my older child. I mean it can get crazy that every time my friend comes over, I have to take her temperature, but at least I have the help (laughs). The oldest one models a lot for his sibling and looking at his sibling while I cook or have to take a shower. "Outside of the home I have the support of the speech therapist and special education teacher, they would take the time to always explain to me what they were working on with my child and what I can do at home to help."

Participant 4 said,

> The nurse was my first support system; she was the one that got a referral and give me a few places to check out. She sent that referral to at least five places for me. My best friend was a support for me. I would even add the fact that another support was an online support group.

Participant 2 said, “I had the support of my husband and my in-laws. I also have a few friends that are also my support system.” Linda said, “I had the most help from my husband…. he was the one staying home, and I was the one working. He would take turns doing things with the kids…When I am off from work.” All parents acknowledged the need for social supports. Social support plays a role in health outcomes for parents of children with ASD (Brown et al., 2018).

Subtheme 4: Awareness and Understanding of Child’s Diagnosis

Parents of children with autism within the study reported feelings of frustration due to not only the provider's lack of knowledge of the child's diagnosis, but the lack of knowledge of effective resources available to the child. Participant 5 said,

> There is a lack of understanding and training around autism for providers period even more so during this trying time. They need to understand that all these kids are not the same and if they can’t even get an understanding then how are they going to educate me as a parent.

Participant 8 said,

> I have to say I felt hopeless at one point with this doctor. “I felt they she lacks the knowledge when it came to identifying the reason behind why my child was displaying these behaviors, even though I expressed my concerns with my child lining up things or can’t take the sound noise and the whole aggression and tantrums.”

Participant 1 said,

> “For me, I find a lot of the health care professionals that I encounter during this journey were not trying to understand what the family is going through form their perspective. It would be great if they could put themselves in our shoes.” Think about all that a parent with a special needs child have to go through just for that moment at least.

Participant 2 said, “After doing my own research and talking with a different doctor I felt that this doctor had great knowledge of what was going on with my child.” Parents rely on pediatricians for advice and information about their child's development because they are often the first professionals they reach out to regarding their child's development, so their ability to respond appropriately to parental experiences related to ASD could significantly impact the diagnostic process (Smith-Young et al, 2020). However, some pediatricians believe that they are inadequately skilled and lack adequate resources to educate parents about developmental disabilities, and they reluctance to directly raise concerns about autism to parents (Smith-Young et al., 2020).

Theme 3: Accessing Support Services

According to Zerbo et al. (2019), individuals with ASD demonstrate high rates of accommodation use and usage costs compared to other disabilities.

Subtheme 1: Waiting List

In 8 of 10 cases, parents waited up to 2 years for services or interventions that are critical in the early stages. The resulting unmet needs of their children were due to these delays. Also, six of the children waited more than 2 years for services. Children were waitlisted for autism evaluation, neurological evaluation, and behavioral health services. Participant 7 said,

> For me, the waiting is another stressor for me…It take a while to get a call back or when you get a call back is to tell you they have to put you on a waiting list.
>
> When I finally got my child the ABA services it was like 6 to 7 months.

Participant 8 said, "What drives me crazy yes, the waiting, but you don't even get a call from these providers just checking in on your child… I was on the wait list for personal care and behavioral health services." Participant 3 said,

> For me, the long waiting times was a huge challenge. When we had to wait to get evaluated after a 5 month wait, sitting and waiting for the doctor is like a slap in the face. You get an appointment…mind you took off work and pull your child out of school. You have to take into account that you sit waiting for a person that is supposed to be professional when you can see he has no one in the office and told that he will be with you…and it take him 45 mins to see your child...is disgusting to me…mind you my child was having a meltdown and no help from the staff…I had to keep it together because I needed these services.

Participant 4 said, "It took me about 2 weeks to get my child evaluated and a few days later to get ABA services. I was also able to get speech and physical therapist without any issues." Seeking help was a coping strategy for parents as they attempted to manage the difficulties raising a child or children with ASD. Parents researched online before finding a diagnosis and seeking advice and strategies for their child's challenging behaviors.

Subtheme 2: Insurance

The main issue many parents struggled with was related to insurance and the lack of coverage for recommended services. While caregivers may be covered by insurance, have a medical plan, or qualify for Medicaid, they often have to pay out-of-pocket for specialty activities like social skill development and sensory toys. In all cases, parents felt it would be helpful to learn about alternative funding sources. Participant 5 said,

> It has been a struggle with the insurance company for both my private insurance and struggle with my child state insurance. I was pleased at first that both were able to provide me with a list of places that I can go to get services. However, my frustration came in when some of the providers on the list no longer take that particular state insurance.

Participant 4 said,

> I was able to find some support services for my child. The one of the ladies at the insurance company walked me through the process and provided me with some information for autism social groups for my child. The state insurance has been good at paying for the basic parts of the autism therapy treatment.

Participant 8 said,

> This whole state insurance can be so frustrating at times. I find that the doctors or clinic and even support groups for my child are not the best. I have changed our state insurance more than four times due to the providers not providing effective services. The other problem that I encounter was that once you change the

> providers either change their polices when you are already receiving their services and no longer taking that insurance to only taking private insurance.

Participant 2 said, “Although I had private insurance and state insurance for my child, it was very difficult navigating through the insurance process and knowing what to ask. Often time we thought things were covered, they were not.” A coping strategy for parents struggling to manage the challenges that came with parenting children with autism spectrum disorders was to seek help. They did their research online before receiving a diagnosis and sought advice and strategies for their child's challenging behaviors.

Subtheme 3: Scheduling

Several of the parents within the study discussed their experience with scheduling of support services for their child. All parents indicated that due to work or other commitments with other kids within the home, it can be a challenge to either stick to the appointment to schedule an appointment with options. Participant 1 said,

> They give you a set time and that’s it, it’s fixed, and they don’t want.to change it and that is a huge challenge and stress for me. Additionally, now that we have this whole COVID pandemic it has added to the stress.

Participant 10 said, “You call to get an appointment and the phone just keeps ringing or they put you on hold forever, only to come back on and tell you they don’t have anything for the next 2 months.” Participant 8 said, “It was challenging because I had to take time off or rearrange my schedule to bring her in. I would say it would have been great if it could have been on a weekend, but that’s asking a lot.”

Participant 2 said,

> They were willing to work with me, I was able to either call in for the reevaluation or zoom and they even had a few weekends per month that I was able to schedule.

Participant 9 said,

> What can I say, maybe if I was white, I would have gotten an appointment right away. I mean yeah, I am not rich, but I am educated and yet that they do not get me anywhere in this dame system. I told evaluator, that I could not do that day because I had another appointment that my child needed to attend. This professional person or supposed to be professional told me either I make that appointment, or they will give the spot to someone else.

Participant 4 said,

> Although I had to wait for a week or two, I was able to get a few options when it came to scheduling my child's first evaluation with the psychologist. The lady on the phone (smiles) in fact, listen to me when I told her I needed to give my boss notice.

Most parents felt that they had little or no knowledge regarding the associated resources and support services for their children with autism. This led to them feeling alone, lost, and desperate while navigating the system.

Theme 4: Resilience

Throughout the parental interviews, despite facing certain challenges and barriers for some, all the parents demonstrated tenacity and resilience. The ability to succeed in the face of various obstacles and difficulties shines through in the parents' interview. Participant 10 said,

> I have been waitlisted, yelled at, encounter sleepless nights, arguments in Individual Education Plan meetings, frustration with doctors and providers, but I tell you what. I kept going, nothing was going to stop me from getting the services that my child needed. Giving up was never an option for me and my family.

Participant 3 said, "We went down to one income and despite the challenges and struggles, this did not deter me from getting the help my child needed." Participant 5 said,

> I although there were frustrations and still are this experience has thought me a lot about myself. I have read books, attending conferences and at the end of it, I got closer to my child, because of this I am much stronger, patient and understanding of what other parents are going through. They need to be a little more flexible when it come to a child with ASD.

Participant 9 said,

> At times, yes...I get stressed out and I cry when I am alone and I have lost some friends, but then I tell myself, it could be worst…I look at my child and I see joy, love and a sense of innocence and then I realize that yes times are challenging but I am doing this for us…for him. I turn those negative thoughts into a more. I got this" attitude and keep it moving…(laughs).

Obtaining an ASD diagnosis for their child was difficult for most of the parents in different ways, but the joy brought by their child was the most common sentiment shared by all.

Discrepant Case

Discrepant information helps validate the research process by showing support for different ways to interpret the data (Rose and Johnson, 2020). I considered Participant 4 a discrepant case. Participant 4 said,

> When I started to notice something was wrong with my child, with not talking the way she should, not walking like other kids, the first thing I thought was that someone switch my baby. It’s like the child some sort of evil roots on her. Crying for no reason, throwing self on the floor. I was completely stressed out, shock, nervous and hopeless until I got that diagnosis.

While participating in an organization where her child is treated for speech and occupational therapy, she gained a greater understanding of ASD.

Summary

The chapter addressed the study setting, participant demographics, data collection and analysis processes, evidence of trustworthiness, and the study results. The purpose of this generic qualitative study was to explore the experiences of African American parents accessing autism support services. Ten African American parents answered questions formulated using the BHM and the resilience theory about accessing autism support services. Four themes were generated from the BHM and resilience constructs to include challenges with raising a child with ASD, parental stress, accessing services, and resiliency. Each theme highlighted the individual and collective essence of the experience.

In this chapter information on the data collection process was addressed. The processes used to gather, record, and analyze the data were discussed. A description of the coding process was also included. In Chapter 5, I discuss the findings of the research in the context of existing literature and the conceptual framework. I also discuss limitations of the study and make recommendations for further research. I conclude with a statement on social change.

Chapter 5: Discussion, Conclusions, and Recommendations

The purpose of this generic, qualitative study was to explore the experiences of African American parents accessing autism support services for their autistic children. The existing literature on autism mostly focused on non-African American parents' experience with ASD. The experiences of African American parents with children with autism was absent. The research question was: What are African American parents' experience with accessing autism support services in Philadelphia, PA? To answer this question, I collected data through semistructured interviews with 10 parents of autistic children accessing support services in Philadelphia, PA. The participants took part in the interviews without compensation, and the interviews lasted between 60 and 70 minutes. This chapter contains an analysis of the results, conclusions, limitations, implications for social change, and recommendations for future research.

Interpretation of the Findings

Findings Related to the Literature Review

Findings from the study indicated that there is a problem accessing therapeutic health care services for children with autism. In addition, item analysis of the interview questions indicated that it was easier for African American parents to gain access to speech and occupational therapy for the child with autism than autism support services, such as behavioral therapies, social skills training, sensory integration therapy, respite, nursing supports, and early intervention therapies. Through the item analysis of the research questions, it is evident that parents attempted to access autism support services for their child but found it difficult to obtain those services. African American parents experienced high levels of frustration due to the lack of access to autism support services for their child with autism.

Through data analysis and examination of the participants’ interview transcripts, patterns and common descriptions emerged. A step-by-step analysis identified repetition, codes, and themes. The following subsections contain a review of the research literature as compared to the study findings.

Theme 1: Challenges With Raising a Child With ASD

Parenting a child with autism demands time, effort, and patience. Caring for children with ASD is challenging due to the following: (a) the severity and chronicity of ASD, (b) the extensive developmental and physical comorbidities, and (c) the difficulties of health services in making the integrated and intensive interventions needed by persons with ASD widely available (Picardi et al., 2018). Daily family activities, such as shopping and family meals, were mentioned as challenging activities. Participants found that family activities that usually promote family cohesion became cumbersome chores rather than opportunities for socializing as a family.

In addition, the COVID-19 pandemic has added some stressors to what some of the families that had already been experiencing stress. Many parents find that since the start of the COVID-19 pandemic, they are taking on additional roles within the home. Some parents, for example, find that they are taking on the role of teachers when they have to help their kids with schoolwork or other activities that otherwise will be addressed in the school setting. Furthermore, some parents are even caring for their children while working remotely.

All the parents indicated that there were significant challenges in raising a child with autism. For example, Participant 9 said, “caring for my child to me is like a full-time job with double overtime.” Participant 4 said, “It can be a struggle especially when you are raising three kids on your own. She does require a lot from me.” Seven out of 10 of the parents described feeling physically drained by the experience of raising a child with autism. Two single parents reported an increase in their blood pressure since they became single parents and had become the primary caregiver for a child with autism. This finding is consistent with a study conducted by Esdaile and Greenwood (2009) who reported that both mothers and fathers experienced physical stress because they were preoccupied with worry about their children.

The second subtheme dealt with the parents’ emotional responses after finding out their child had autism as well as the stress the parents experienced. Parenting a child with autism involves a lot of emotions. When dealing with a child’s tantrum or with strangers’ stares, for example, many of the parents became emotionally overwhelmed. The 10 parents reported feeling sadness, guilt, anger, anxiety, and relief. Participant 2 stated, “In the very beginning we never thought that our child had autism, we thought she may have a speech impediment.” Participant 3 added “I have to say it was a relief, on my side it was a relief. It was like, finally this thing has a name. Now I know what is wrong with my child.” Parents spoke about the various challenges they have encountered with caring for a child with ASD; however, many also spoke not just about the negative emotions, such as anger, fear or frustration, but also about the relief that they found in knowing what was medically wrong with their child.

Although no parent reported anger or resentment toward the child for being diagnosed with autism, researchers have noted that parents of children who face such a diagnosis endure stress and perceive it as overwhelming (Hoogsteen & Woodgate, 2013). The parents in the current study reported feeling relieved, but they refused to give up on their children or their success, regardless of challenges. The positive emotions that participants described in this study and the joy of raising children with autism have been reported in other studies, including parents who describe appreciation for “small moments” of progress and connection with their children, which in typical-developing children, this would probably go unnoticed or uncelebrated (Corcoran et al., 2015). Participant 5 told me that raising his daughter was “something you learn as you go.” Participant 2 described it as “an adventure. There is no set rule book for how each kid is going to act.” As reported by MacDonald and Hastings (2010), parents of children with developmental and intellectual disabilities who were actively involved in their treatment reported a positive outlook about their children’s future, provided emotional support to the parents, and had a better family cohesion and well-being for the family.

Parents of children who experience lifelong autism may experience feelings of anger, blame, frustration, and taking on multiple roles as well as a higher divorce rate (Hoogsteen & Woodgate, 2013). Parent participants in the current study were concerned with the delay of diagnosis of their children despite their reporting to the child’s primary care providers. Eight out of 10 of the parents also reported challenges with getting their child diagnosed. Parenting is an essential element to the sustainable well-being of children. Parents and caregivers show different levels of concern towards the growth and development of their children (Donohue et al., 2017). In spite of the fact that primary care providers have frequent contact with parents during a child’s first years, some give false assurances or fail to identify diagnostic resources when valid parental concerns exist (Zuckerman et al., 2017). Zuckerman et al. (2017) suggested that the timing between initial discussions with providers and ASD diagnosis is frequently delayed. Delays may result from a lack of awareness of ASD and the health care system, disability stigma, authorization issues, or long waiting periods for evaluations.

Several parents within the current study discussed their frustration and challenges as their children were diagnosed at a later age. Additionally, some parents reported that because of the late or delayed diagnoses, their children lacked some of the interventions that they needed. Participant 1, for example, said, “I should have gone elsewhere, it’s not like his pediatrician is the only one in the darn city. My child did not get their diagnosis till age 6.” My findings indicated that parents also expressed anger and questioned why their child’s diagnosis took so long. They also attributed blame but not to their child; instead, they blamed themselves for not being aware of the cause of autism. However, none of the parents in the present study reported depressive symptoms as a result of the child being diagnosed with autism.

Theme 2: Parental Stressors

According to Deater-Deckard (1998), parental stress is defined as experiencing discomfort or distress due to the demands of parenting. Stress levels are much higher among parents of children with ASD than parents of typically developing children because of their caregiving roles; the lack of social support and resources; and their children’s poor social skills, abnormal behaviors, and developmental delays (Hutchison et al, 2016).

Eight out of the 10 parents in the current study reported lacking some social supports, especially from family members and friends. Seven out of 10 parents reported that the child’s other parent accepted the child’s ASD but was not involved in caring for the child when they showed problematic behaviors. Participant 7 said, “being out in public is very difficult, as you never know what will trigger her angry outburst. Looks, comments, and eye rolls from all over have become a norm. Everyone (almost) just assumes you're a bad parent.” and P 4said, “I avoid certain activities or outings because it is just too hard.” The findings of the study also indicated that parents experienced abandonment from their friends, many of whom were uncomfortable dealing with children with special needs.

The results align with the findings of previous studies that showed that family members and friends had distanced themselves while their child was diagnosed with ASD and were not knowledgeable about autism (Connelly, 2016). Pepperell et al. (2018) suggested that including extended family members can provide valuable support, especially grandparents who have been educated in autism. Despite the fact that some participants were divorced, separated, or single parents, 7 out of 10 of them were the primary caregivers of their children due to the absence of their biological father.

Parents in the study stated that they needed more support, with special attention given to African American parents. They also stated that support should be increased from medical professionals and at schools. It appeared that awareness and knowledge regarding autism among African Americans are increasing, but awareness and knowledge campaigns do not target African Americans as a whole. Despite the increased awareness, few resources are focused on African American parents. Medical professionals should focus on African American parenting styles rather than on those of non-African American parents. The evaluation of parents' experiences is an important factor for policy development, effective interventions, and other support services (Hsiao, 2018).

Additionally, study participants said they needed support in various ways to raise their children with autism, such as financial resources, family medical leave, and community supports. An ASD is a costly disorder, both financially and personally for those who are caring for the child (Hodgetts et al., 2013). Each individual child requires individualized support. Some children with ASDs may be eligible for government-funded support (e.g., speech language therapy, behavioral support, and educational support are publicly funded; (Hsiao, 2018).

In addition to the financial burden parents are already experiencing, there are costs associated with respite care and access to appropriate resources, such as daytime activities and lost earnings as a parent who has to provide additional care for the child or is unable to work. According to the CDC (2015), the estimated societal cost of caring for children with ASD was over $9 billion in 2011. According to the CDC, children and adolescents with ASD spend on average $4,110–$6,000 more on medical care than those without ASD. It has been estimated that caring for children with autism costs over $62 billion, according to Autism Speaks (n.d.). When engaging with parents of a child with autism, it may be beneficial for professionals to work with the parents from an empowerment standpoint to better identify and understand what support is needed.

Insurance coverage was another concern for all the parents in the study. Some parents in the study (i.e., Participants 1, 7, and 10) cited their insurance coverage as a primary reason for the disparities they faced when seeking care for their autistic children. I found that insurance and economic factors played a role in parental perceptions of autism support services. There is a higher rate of uninsured African American children, and these problems are not limited to children enrolled in private health insurance plans (CITE). Similarly, problems exist for children enrolled in public benefit programs. In the United States, Medicaid reimbursements are historically so low that providers often refuse to treat patients with Medicaid insurance (Thomas et al., 2016). There is an increasing gap in health coverage, making it more difficult for parents to figure out what programs are available (Kenney et al., 2015).

Zhang and Baranek (2016) examined access and use of health services among children with autism using the National Survey of Children’s Health data set. They found gaps in access and application due to whether the child had private or public insurance coverage. Families with private health insurance had less access to services with parents covering a larger part of their health care costs. Williams et al. (2010) found that private insurance clients’ out-of-pocket expenses for children with autism were significantly higher. For instance, Participant 2 said, “Although I had private insurance and state insurance for my child, it was very difficult navigating through the insurance process and knowing what to ask. Often time we thought things were covered, they were not."

Participant 7 said,

> This whole state insurance can be so frustrating at times, the problem that I encounter was that once you change the providers either change their polices when you are already receiving their services and no longer taking that insurance to only taking private insurance. Some parents found that once they start to receive services, the company were no longer taking their insurance and they had to apply for rother state insurance. While others who used private insurance, their insurance company changed their policies to point where they were not covering all of the child's therapy services. Some parents found out that had to use either the combination of state and private insurance if they were able to access those or pay out of pocket for the extra cost.

Theme 3: Challenges With Accessing Support Services

Parents reported difficulty locating resources and being given inadequate assistance by schools or professionals because of their child's challenging behavior. The study findings are similar to Kakkar and Srivastava's (2017) who found a lack of positive relationships with outside assistance may be attributed to a child's behavior problems.

Zerbo et al. (2019) found that individuals with ASD demonstrate high rates of accommodation use and usage costs compared to other disabilities. Despite this, there is evidence highlighting paramount unmet health care needs prepandemic: Patient-level factors, like challenges around appointments and sensory issues; provider-level factors including lack of ASD education and training; and system-level factors, such as accessibility of health care facilities, which constraint accommodation and referral pathways (Narzisi, 2020).

According to Doshi et al. (2017), non-African American children had better access to coordinated care and family-centered care than their African American counterparts. For children recently diagnosed with autism, their parents must go through many challenging forums, including health care policies, requirements with insurances, and long waiting list lack of awareness from the health care providers and limited providers. For example, one parent pointed out that after getting the diagnosis, she encountered a lack of professional guidance on what to do next. Another reported that he encountered long waiting lists and challenges with the insurance company. Additionally, when sharing their experiences with service providers and obtaining autism support services for their children, some parents had both positive and negative experiences. For instance, Participant 1 said, “Waiting times can be a great challenge for us. I think that they forgot these kids are autistic and we don’t always know what to do while waiting. To get ABA services we were on the waiting list for at least nine months.” (P 1)

A lack of communication with service providers was also reported by parents. Participant 10 said, "People do not understand you. They do not listen, they do not care, and maybe they do not know." In addition, parents said they were unclear about aspects of autism and did not know where to find the necessary resources. Participant 10 said, "In actuality, there aren't any resources out there for me and I'm asking for help." Five parents said their doctors dismissed their concerns about the child’s behaviors (yelling, tantrum, stimming, no eye contact, lining up of toys or objects) and told them that it may be due to their ages and that they needed to come back within another year. In the study, 5 out of the 10 parents reported both positive and negative experiences when dealing with professionals or schools. For example, Participant 4 and Participant 8 cited their positive interactions and support from their child's special education teachers with getting an IEP set up and help with names of behavioral health services from the speech or occupational therapist.

Additionally, out of 10 parents discussed that there were not enough health care providers who specialized in autism in the area. Some parents also felt that since the pandemic began, support services for their children have further been reduced or limited. Parents in the study reported that the ASD service providers in the area often are full. Four out of 10 parents felt that best doctors who specialized in autism were located at the outskirts of the urban area and had better accommodations, especially in a time of COVID.

Parents within the study also indicated that scheduling has also been a barrier to them in accessing autism support services. DeRigne (2010) analyzed a subsample of the National Survey of Children with Special Health Care Needs consisting of 1,301 parents who reported the reasons for unmet mental health need of their children. DeRigne found that parents reported difficulty getting appointments and inconvenient appointment times as a barrier. Several of the parents within the study discussed their experience with scheduling of support services for their child.

All of the parents indicated that, due to work or other commitments with other kids within the home, it can be a challenge to either stick to the appointment to schedule an appointment with options. Participant 7 said, I try to give them times that I know will work and that I don’t always have to pull my child out of school or to take off and yet, it’s either take that time and day or we will have to reschedule you and your child will be in lapse and will not be able to get the service. Participant 1 said, they give you a set time and that’s it, it’s fixed, and they don’t want.to change it and that is a huge challenge and stress for me. Additionally, now that we have this whole COVID pandemic it has added to the stress.

Prior research has demonstrated that the severity and level of functioning of autism varied from patient to patient. Autism is an impairment in communication, social impairments, and repeat behavior patterns (National Institute of Neurological Disorder and Stroke, n.d.). In addition, autism awareness and brought to the forefront through the grassroots initiatives of organizations like Autism the Autism Center, the Pennsylvania Autism Action Center, and the Autism Society of America.

In addition, the results of this study suggested that health care practitioners need increased awareness and training regarding children with ASD. Previous research indicated that by increasing awareness of autism in health care, health care providers have increased confidence, delivery of care, and quality of care provided to patients with ASD (Shawler & Sullivan, 2017). By increasing knowledge and awareness, the communication, understanding, and knowledge gap between patients and professionals can form a more successful health care experience. Also, there is a need to increase the number of health care professionals who specialize in working with patients with ASD would help increase access to all youth with ASD in rural and urban areas. Through additional training, health care professionals will be better able to (a) use the alternative strategies to help youth with ASD communicate more effectively, (b) comprehend time more effectively, (c) cope with health care exams, and (d) cope with the overall health care experience. By improving the knowledge and training about ASD, trained health care professionals may be more accessible to parents and help bridge the gap to finding quality care for youth with ASD.

Theme 4: Resilience

Protective factors that buffer against stress, counter vulnerability, and resist negative social adjustment are the components of resilience (Shawler & Sullivan, 2017). These factors promote resilience by buffering against adverse situations and promoting positive adaptation. African American parents involved in this study demonstrated positive perspectives and strong relationships when it came to their children.

Although the challenges described in the previous sections should not be ignored, some positive benefits were reported with regard to having a child with autism. During the interviews, the parents made several references to their personal journey of understanding and acceptance. According to Da Paz et al. (2018), when a child is diagnosed with autism, some parents show psychological resilience, defined as heightened wellbeing, and diminished psychological distress. This healthy adaptation might be explained by a caregiver’s ability to move past the initial reaction of receiving the diagnosis and advance toward an attitude of acceptance or resolution (Da Paz et al., 2018). For instances, Participant 3 said: “We went down to one income and despite the challenges and struggles, this did not deter me from getting the help my child needed.”

Participant 4 said, “God give us this special child for a reason. So, I would say that both of us do try to be optimistic for him, for us so that we can also communicate effectively,” and P 8 said, “I look at my child and I see joy, love and a sense of innocence and then I realize that yes times are challenging but I am doing this for us…for him. I turn those negative thoughts into a more “I got this” attitude and keep it moving. Although family life is not without hardship and conflict, recovery and resilience are possible with a strong relationship, cohesion, problem-solving skills, connectedness, and communication.

Analysis and Interpretation of Conceptual Framework

Aday-Anderson’s BHM and resilience theory were used in developing the framework for this study. They are both used to discuss or predict social behavior and behavioral change interventions.

The BHM

The BHM identifies the access disparities faced by African American parents based on three categories of factors (predisposing characteristics, enabling resources, and perceived and evaluated need). According to Andersen (2005), inequitable access to health care may be caused by elements of societal structures (e.g., ethnicity), enabling resources (i.e., income), as well as predisposing factors.

African American parents were predisposed to suffer significant racial/ethnic discrimination, which makes an African American parent more likely to be faced with disparities in access to care. Eight out of the 10 parents interviewed felt that they were treated differently or unfairly while seeking a diagnosis for their child's behaviors. The major sources of enabling resources identified by participants in BHM included health insurance types and social classes. As an example, the model’s assumption that enablers and impediments (predisposing characteristics, enabling resources, and need factors) influenced the way in which individuals accessed and used health care services has been proven to explain disproportionate access to ASD support services. Additional enabling factors identified in the current study included perception, quality of services, and access. In the next section, I will present how the resilience theory (classified under psychological factors in the Andersen model) plays in African American parents accessing autism support service for children with autism.

The Resilience Theory

Unlike the BHM, resilience refers to a person’s ability to recover from emotional or mental challenges quickly (Aithal et al, 2020). Individuals with resilience experience positive outcomes despite barriers, challenges, and stressors (Rutter, 2013). According to the resilience theory, families attempt to restore order, harmony, and balance when confronted with crisis situations that force a change. A stressor is a demand made of the family that causes changes to the family system (McCubbin et al, 1998). Resilience models emphasize how families adjust to stressors based on the various factors that protect their functioning, such as family appraisals of the stressor, coherence, and paradigms. Among African American families, raising children with ASD caused stress. Parents completed certain tasks as part of the adjustment process. As a result of the stress, African American parents sought the needed support services and accommodation for their families with ASD. In addition to coping mechanisms, African American parents also employ reframing of negative feelings as positive ones to cope with stress.

Additional factors associated with resilience in the family are self-efficacy, optimism, religious or spiritual beliefs, and enrichment. Self-efficacy is the confidence in an individual’s ability to succeed in their goals and challenges (Becerra-Culqui et al, 2018). Broady et al. (2017) illustrated that resilience reflects psychological functions that connect one’s emotions, impulses, and ability to cope (Maltby et al, 2019). For instance, Participant 5 said that he made use of emotional support from his girlfriend, his faith, and reminding himself that his kid needs him has a coping strategy to manage his stress. Participant 2 said, having to deal with the stress that comes along with accessing services for my child and dealing with limited family supports have me resilient. I am stronger, patient, more loving, more caring, I guess more love for my family, and get more connected just to help my child. This phase of the resiliency model emphasizes the importance of appraisals of family members as they cope with stress (McCubbin & McCubbin, 1998).

Limitations

I focused on 10 African American parents in Philadelphia, PA. One limitation of this study was the use of a generic qualitative approach, which has been critiqued for its lack of rigor (Kennedy et al., 2019). All participants were required to be African American parents who served as primary caregivers to a child clinically diagnosed with autism. The individual experiences and perspectives of the parents are not representative of the population of people with children with autism.

The geographical location of the study was a limitation as well. The participation criteria excluded potential participants who lived outside Philadelphia, PA. Burkholder et al. (2016) pointed out that there is a potential for researcher bias during the interview, data analysis, and reporting processes. I am a female African American mental health provider who currently resides in Philadelphia, PA. Reflectively journaling and triangulating sources helped me to address possible personal biases.

An added limitation to consider was the COVID-19 pandemic and the National State of Emergency in Pennsylvania. COVID-19 created issues and changed priorities for the participants. COVID-19 is still active changed my desired location to conduct my face-to-face interviews. The last limitation to consider is the technical issues that were experienced, including limited access to scan and return the consent forms. In addition, face-to-face interviews would have allowed me to observe body language and facial expressions, which were not captured by the video. I was able to use the paper trail of emails, and the written “I consent” attached to the emails to suffice for a stamped date, time, and consent for participation.

Recommendations

Through this generic qualitative study, I sought to address the identified gap in the literature regarding African American parental experiences of accessing autism support service in Philadelphia, PA. The 10 African American parents who participated in the study were from the Philadelphia area and are accessing autism support services for their autistic child. A broader study of the collaborative partnerships between service providers, social workers, educators, community service providers, community leaders, and African American parents could inform all of the parties on the best ways to address the overall needs and the individual needs of autistic children and their parents. As an example, one theme arising from the data was the issue of children with autism gaining access to services. One major subsection of this theme is not having enough information. As soon as it is suspected that a child has autism or when it is confirmed that a child has autism, a packet of information can be sent. During this study, seven caregivers shared that they were not provided with information packets at the point of diagnosis, which demonstrated a gap in the provision of information packets. This package of information would include, but not be limited to, information in layman's terms about the diagnosis, an autism fact sheet with next steps, provider information, basic information on treatment approaches, and doctors or specialists in the region who have the skillset.

The results of a quantitative study looking at trends of autistic children over a period of time might improve the outcomes of all autistic children of color. More research is necessary to investigate the types of autism support families of children with ASD need. In order to provide better services to the African American community, future research should also examine the experiences of African American families, particularly those who were recently diagnosed to obtain more accurate results. Research should focus on how the context of a family's social-economic status impacts the individual's perception of the diagnosis. It should also focus on how acculturation plays a role in an individual's perception of the diagnosis. As a final recommendation, future research should identify ways to assist families from underrepresented backgrounds and to address service and health disparities for children with autism who need services to support their needs.

Implications

The data from the interviews provided detailed information on how African American parents were accessing autism support services for their autistic children. According to the CDC (2018), autism is diagnosed at a rate of 1 in 54. African American children are often diagnosed later than their peers because they do not have access to care. Thomas et al. (2016) argued that access to care is affected by many factors, including lack of resources and differences related to help-seeking behavior.

Burkett et al. (2015) argued that African American families with a child with autism have a harder time gaining access to resources because they have fewer economic resources, lack knowledge about ASD, and make use of different social networks than their White counterparts. There is a need for accessible information from health care professionals because all parents need different means of obtaining an ASD diagnosis. Implications for health care professionals include transferring knowledge and helping parents access the proper resources. For example, pamphlets in various languages with terminology that parents can understand (symptoms of ASD, etc.)

Additionally, the study provided implications for change in how supportive relationships are to be established between physicians, mental health providers, specialists, human service workers, and care managers. Care coordination services would meet the needs of both the child and the parent. A high degree of stress can be experienced by some parents raising children with autism and accessing ASD services. However, some parents reported joy in raising a child with autism. Toomey et al. (2012)

found that quality of care for a child increased with coordination of services. In order for parents to become children's best advocates, they need support too.

Conclusion

This study contributed to literature by addressing the gap in research on African American parents accessing autism support services for their autistic child in Philadelphia, PA. The four themes and respective subthemes that emerged led to the conclusion that parents know how they can best be supported in not only raising a child with autism but what is needed to help support them.

This study indicates that parents of children with autism face great challenges in accessing therapeutic health care. Early diagnosis and treatment are crucial to getting children back on track. Accessing therapeutic health care services was more difficult for caregivers than it was to access health care in general. It is possible to improve access to therapy services for children by focusing social change efforts specifically on this topic. In light of the research conducted by Austin et al. (2016), it is possible that streamlining clinic flows and educating clinicians about autism could have a significant impact on access to care for children who have autism in general. The availability of autism support services will make a positive impact on the lives of children and families who are affected by autism.

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