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Barriers to Respite Care Among African Immigrant Mothers

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This is to certify that the doctoral dissertation by

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Walden University
2024

Abstract

Barriers to Respite Care Among African Immigrant Mothers

by

Yewande Tamara Richards

MPA, New York University

BA, Berea College

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Human Services – Family Studies and Intervention Strategies

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Abstract

African immigrant children living in the United States (US) are highly susceptible to medically complex, life-limiting, and life-threatening conditions, including rheumatic heart disease, congenital heart disease, autism, and other neurodevelopmental disabilities. As primary caregivers, mothers frequently need a break from their caregiving responsibilities to experience normalcy, rest, and regenerate their reserves, which is critical to their families' long-term stability. The purpose of this study was to understand access barriers to respite care services for these mothers and the role of race in potential disparities in access using a critical race theoretical lens. The generic qualitative research design was used with semi-structured interviews using broad and open-ended questions to address African immigrant mothers of children with complex needs (ages 17 and under) living in the US. Purposive sampling was used to select a sample of 5 participants for semi-structured interviews. Qualitative data were analyzed using thematic analysis to interpret study findings. The key findings underscored the imperative to consider the intersectionalities and nuances within the experiences and perceptions of these African immigrant mothers. The more adjacent participants were with American culture, wealth, status, English language, and whiteness, the less hardship they faced when accessing services. Findings may help achieve mandates for positive social change and social determinants of health among African immigrant mothers of children with complex health needs by improving access to family support services and care – ensuring positive health and quality of life outcomes for these mothers and their families.

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Dedication

I dedicate this work and the time on this doctoral journey to my late Mother, Maudeline Alaricia Scere, daughter of Lulu Adelaide Richards and the third great-granddaughter of Vice President of the Republic of Liberia Beverly Page Yates and Willie Ann Payne Yates (sister of President James Spriggs Payne of the Republic of Liberia). Mommy, I cite our lineage to contextualize you in written form, as I never knew these things until you were gone. It finally made sense as service to others is simply part of who we are, not something to change or fight against – given societal expectations and the prevailing emphasis on status and materialism. The "call to serve" in our veins helped build a nation, in a far from perfect manner, but the nation has remained since 1847.

You made a difference in many lives through your work with social change through the arts (Leeway Foundation). You were the encourager of many dreams that continue to bear fruit and will flourish for years to come. It remains a testament to your legacy.

You wanted me to finish this doctoral journey and so I did it even when I lost the will to continue much when I lost you. The trials were many, but you prepared me as my Mother and through your example as a relentless forward thinker. This achievement is as much yours as it is mine. To me, you are Dr. Maudeline Alaricia Scere. I love you beyond eternity.

For the time I have left on this earthly plane, I pray to fulfill every dream you had for me and engage in meaningful work for the betterment of marginalized children and their families. Thank you so much for being my Mother.

Acknowledgments

I want to extend immense gratitude to Dr. Andrew Carpenter for his unwavering guidance and support through this dissertation journey. I also thank Dr. Jeffrey Harlow for his encouragement and time dedicated to guiding my progress in this study.

A special acknowledgment is extended to each participant who generously invested time from their demanding schedules to contribute valuable insights and experiences to this research. It is my sincere hope that this study provokes discussions on the imperative need for family support services informed by critical race and intersectionality theory, not only for African immigrant families with children with complex health needs but also for their other marginalized counterparts.

In addition to my late Mother, I dedicate this achievement and journey to my sons, Iam Forde, Jase Richardson, and Judah Richardson, my brother, Rinde Adebayo and my sister Ireti Thomas-Adebayo. You are the joys in life.

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Chapter 1: Introduction to the Study

This study involved exploring access barriers to respite care services among African immigrant mothers of children with complex needs in the United States (U.S.). African immigrant children in the U.S. are likely to live with medically complex conditions, including rheumatic heart disease, congenital heart disease (Kroenig & Dawson-Hahn, 2019), neurodevelopmental disabilities (Abdullahi et al., 2018; Khanlou et al., 2017), and chronic diseases requiring constant monitoring and care.

Typically, mothers are the primary caregivers of their children (Khanlou et al., 2017). African immigrant mothers of children with complex needs bear excessive and continuous strain involved with their children's care. These mothers contend with chronic fatigue, sleep deprivation, emotional distress, anxiety, depression, pain, and physical symptoms and are in greater need of social support services due to ongoing responsibilities and concerns about physical, mental, and social wellbeing (Koch & Jones, 2018; Kvarme et al., 2017; Page et al., 2020; Wilkinson et al., 2021). A range of peer-reviewed studies - Biber et al., 2019; Bradshaw et al., 2019; Brenner et al., 2017; Carnevale et al., 2017; Carter et al., 2017; Doucet et al., 2020; and Ronan et al., 2020 - further supports findings on the mental, physical, social, and economic challenges impacting parents of children with complex needs. Additionally, when immigration status and complex needs are considered concurrently, restrictions multiply, resulting in challenging experiences for immigrant parents and their families (Alsharaydeh et al., 2019).

For African immigrant mothers of children with complex needs, their dual foreign and Black status further exacerbates challenges involving daily experiences with discrimination, skill devaluation, underemployment, and lower earnings despite high levels of skills and knowhow among this population group (Saasa, 2019). They navigate negative attitudes from and towards healthcare and social service professionals when caring for their children with complex needs (Munroe et al., 2016; Wilkinson et al., 2021). Immigrant mothers especially struggle with social isolation, lengthy battles to access help and information, and prejudice when navigating healthcare and social service systems (Arfa et al., 2020). Quality of care is suboptimal, and disparities remain for immigrant children with complex needs (Zajicek-Farber et al., 2017). Additionally, immigrant families face inequities due to poverty, immigrant status, lack of access to insurance, education, and discrimination based on race and ethnicity (Linton & Green, 2019). While there is a lack of data on the incidence and best practices for immigrant children with complex needs, immigrant children with complex needs historically experience less healthcare access and lower quality care than counterparts in non-immigrant families (McKay, 2019). These findings in the literature support the need for access to respite care among African immigrant mothers as they tend to be at the highest risk for having children with complex health conditions based on their race and ethnicity.

The study is necessary to fill a knowledge gap regarding experiences and perceptions of barriers to respite care among African immigrant mothers of children with complex needs and inform the fields of human and social services. The study involves documenting experienced and perceived barriers to respite care among these mothers in the U.S.

Respite care is well-recognized in the literature and practice as an essential resource for mothers of children with complex needs. Respite care is most effective when accessible with a child and family-centered approach promoting well-being of caregivers, supported by governmental policies and adequate funding (Brenner et al., 2018; Legge & Legge, 2021; Spruin et al., 2018; Whitmore, 2017). When implemented as standard care instead of a form of crisis intervention, respite care helps reduce stress and fatigue among caregivers of children with complex needs, as well as additional intensive and person and family-centered interventions including coordinated care, peer support networks, and psychological services (Koch & Jones, 2018). This holistic approach maintains positive effects over time and optimizes mothers' ability to care for their children with complex needs while maintaining healthy family functioning (Zurynski et al., 2017). Persistent disparities point to the need for systemic change to eliminate system-level barriers that can help best position researchers, practitioners, program leaders, and policymakers.

Findings of this study may inform system-level changes and support relevant program and policy professionals to implement adequate and equitable respite care services for African immigrant mothers of children with complex needs and other minorities.

I discuss background information along with existing literature. The study's problem statement and purpose are also addressed, along with relevant data to guide the research process. I also articulate the research question and theoretical framework as well as the research methodology and nature of the study. I also provide definitions of terms to help understand my topic and conclude with a discussion of limitations and delimitations as well as the significance of the study.

Background

There is limited research on African immigrant health in the U.S. despite the population's growth across U.S. cities from 130,000 in 1980 to 2.1 million in 2015 (Anderson, 2017; Zong & Batalov, 2017). There is a paucity of research on health experiences of African immigrant children living outside of Sub-Saharan Africa.

Salami et al. (2021) indicated a decrease in health among African immigrant children in terms of nutrition, infectious diseases, mental health, birth outcomes, sexual and reproductive health, physical and developmental health, parasitic infections, oral health, respiratory health, preventative health, endocrine disorders, access to healthcare services, and treatment for hematological conditions. Salami et al. recommended further examination of under researched and neglected health concerns of African migrant children, highlighting pneumonia and child maltreatment.

Kroenig and Dawson-Hahn (2019) found the most prevalent chronic diseases among African immigrant children in the U.S. were rheumatic heart disease (10 per 1000 people from central Sub-Saharan Africa), congenital heart disease (19 to 75 per 1000 live births), thyroid disease (5 out of 69 children often in association with Type 1 diabetes mellitus), congenital hypothyroidism, cerebral palsy (2.9 per 1000 live births), sickle cell disease (57% of annual cases diagnosed in newborns), and thalassemia. According to Jivanji et al. (2019), 500,000 African children are born with congenital heart disease annually. Immigrant children have a higher likelihood of acquired or congenital heart disease based on rates of abnormal echocardiograms that are observed during initial consultations. Rheumatic heart disease is a cause of morbidity and mortality among African children (Animasahun et al., 2018). Seventy-six percent of Sub-Saharan African immigrants are likely to have a child diagnosed with autism (Khanlou et al., 2017).

The probability of complex health conditions among African children signifies a need to fill knowledge gaps regarding African immigrant access to support services related to human and social services in the U.S. Filling the knowledge gap will help in terms of building a robust knowledge base to address how these children's conditions and needs are identified, tracked, and supported with family support services including respite care.

The Centers for Disease Control and Prevention (CDC, 2019) acknowledged nearly 60% of children with heart conditions are more likely to require special healthcare services, including respite care services for their mothers, their primary caregivers. There are structural, instrumental, emotional, and perceptive challenges involved with accessing necessary support services and addressing inequalities in terms of access to support services, highlighting the need for respite care, support, and social networks for immigrant parents, particularly mothers, in caring for their children's complex needs.

Parents value respite care for their family relationships, children with complex needs, and other children (Khanlou et al., 2017; Kvarme et al., 2017; Whitmore & Snethen, 2018). Whitmore and Snethen (2018) emphasized the need to tailor respite care to the unique needs of their families. Systems notably excluded parents of color from respite care services.

Bridges et al. (2017) argued to achieve pursuits of health equity, it is necessary to reposition race as central to science and medicine, understanding racialized social, economic, and political forms of governance.

Furthermore, current geopolitical situations around the world continue to drive immigrants toward Western industrialized nations (Turin et al., 2020). It is important to establish mitigation strategies for access to health and social services for minority immigrants.

This study is necessary to document how these mothers describe and perceive access barriers to respite care services. Investigating this problem will help fill the knowledge gap in the human and social services fields related to identifying and tracking African immigrant children's complex health conditions, as well as providing critically needed care for them, their mothers, and their families.

Problem Statement

African immigrant children living in the U.S. are highly susceptible to medically complex, life-limiting, and life-threatening conditions, including rheumatic heart disease, congenital heart disease, and autism (Abdullahi et al., 2018; Animasahun et al., 2018; Fouche et al., 2021; Jivanji et al., 2019; Khanlou et al., 2017; Kroenig & Dawson-Hahn, 2019; Ronan et al., 2020; Rossouw, 2021). Their mothers frequently need a break from their caregiving responsibilities, the chance to experience some sense of normalcy, rest, and regenerate their reserves (Kvarme et al., 2017; Murphy et al., 2021; Whitmore &

Snethen, 2018). This study involved exploring their access to respite care services which can provide intervening support for them and interim care that is critical to their families' long-term stability.

Investigating this problem is significant to the health and human social services fields. It is unclear that African immigrant mothers of children with complex needs have access to respite care in the U.S. According to Omenka et al. (2020), paucity of research and data on access to respite care for this immigrant group stems broadly from a lack of interest in the population and research funding on African immigrants' health status in the U.S. There is also a tendency to view the African immigrant population as a monolith along with African Americans and Caribbean immigrants (Adu-Boahene et al., 2017). Additionally, when considering the role of immigration policy in terms of health and social services access in the U.S., Latin immigrants are assumed to be the only group that is affected, generally excluding experiences of African and other minority immigrants (De Trinidad Young & Wallace, 2021).

There are limited immigrant-specific studies related to respite care conducted in the U.S. The most recent and available studies conducted in Norway, Germany, and Canada suggest a lack of access to respite care services for parents of immigrant children with complex needs exacerbates mental distress, failing health, and poor quality of life and impedes efforts to mitigate these adverse conditions (Biber et al., 2019; Khanlou et al., 2017; Kvarme et al., 2017). These researchers explored what access to respite care services means in the lives of immigrant children with complex needs and their parents in their non-native environments. Khanlou, Haque, Mustafa, Vazquez, Mantini, and Weiss

(2017) identified access barriers to family support and other essential services for immigrant mothers and their children with life-limiting conditions in Canada, however, the data is not necessarily transferrable to the United States given differences in health care systems and the prioritization of immigrants and their care via funding and governmental policies. Given the need to understand African immigrant mothers' access to respite care and experiences accessing such services, this study's findings will inform policies, programs, and practices to better support them in caring for their children.

Eleven percent of the 2.4 million African immigrants residing in the U.S. are under 18 (Echeverria-Estrada & Batalov, 2019; Omenka et al., 2020). There is limited empirical data regarding their health status and access to essential health and family support services, including respite care. With sparse research and data as well as strong evidence of the role of race in terms of access disparities in the U.S. and other western nations, there is a need to add to the body of knowledge in the fields of human and social services. This work includes insights, solutions, and recommendations informed by participants regarding access barriers to respite care services in order to potentially ensure more efficient, effective, and equitable services for these mothers, their children, and families.

Purpose of the Study

This generic qualitative study involved exploring how African immigrant mothers of children with complex needs described and perceived access barriers to respite care services. In addition to gathering their insights, the study involved exploring care coordination and shared plans of care (SPOC) as markers of equitable access for these mothers as evidenced in literature and the role of race in terms of access disparities. This study's findings could inform practitioners, policymakers, insurers, health systems, program leaders, and researchers in terms of developing race-conscious approaches to serving these mothers, their children with complex needs, and their families via a critical race lens. Care models informed by this study's framework and understanding the role of race, racism, and racial power in American society and impacts of inequality and systemic racism will help health and social service practitioners, policymakers, and managers find solutions leading to greater justice and inclusion for African and other minority immigrant mothers of children with complex needs. The study also presents an opportunity for a future quantitative comparative study focusing on comparing access barriers to respite care between African immigrant mothers and their European immigrant counterparts.

Research Question

How do African immigrant mothers of children with complex needs describe and perceive access barriers to respite care services?

Theoretical Framework

The selected theoretical framework for this study was critical race theory (CRT). CRT centers the role of race, racism, and racial power in society and impacts of inequality and systemic racism in finding solutions leading to greater justice and inclusion (Obasogie et al., 2017).

CRT originated from Derrick Bell in the 1970s. The theory holds that racism is deeply embedded in American laws and institutions, including many of those intended to remedy past injustices (Bell, 1992). By accepting and basing research, policy, and program planning on the fact that racism is permanent in the United States and all but indestructible, practitioners, policymakers, insurers, health systems, program leaders, and researchers have the opportunity to institute and implement policies, programs, and other mechanisms that protect and better serve the oppressed and marginalized minority groups in the United States.

Graham et al. (2001) proposed core tenets of CRT drawn from the seminal works of Crenshaw et al. (1995), Delgado and Stefancic (2001), Schneider (2003), and Moran (2004) to use in population health research among ethnic minorities. Under the core tenets, scholars recognized that institutions generally function based on values, principles, and foundations that are not representative or culturally diverse. The dominant cultural customs, mainly Anglo-American, are presented as universal and used to otherize and exclude ethnic minorities from inclusion, opportunities, access, and participation. Individuals also navigate and view racial and ethnic landscapes qualitatively including race consciousness, color-blind liberalism, interest convergence, economic or material determinism, and structural determinism. Qualitative inquiry is also employed when using CRT to ensure that a person or group's position or standpoint is not watered down or marginally taken up. Data must also be rooted in social contexts, drawing on cultural studies, history, and context data collected from study participants. The fifth and final tenet notes that researchers are more honest and forthcoming about their subjectivity in their design of the research study, data collection, analysis, and presentation. Given the tenets outlined which are not exhaustive of all the points that underwrite CRT (Carbado and Roithmayr, 2014), this theoretical framework naturally aligned with my study design.

CRT has not been applied widely to immigrant health in the U.S. or other western nations. A few scholars have used CRT to address general minority health, training of researchers, and achieving health equity in the U.S.

According to Ford and Airhibenbuwa (2010), CRT is a comprehensive framework for connecting research efforts, advancing understanding of racial constructs and phenomena, critical analyses of knowledge creation processes, and praxis that builds on community-based participatory approaches linking research, practice, and communities. In application, CRT is used to understand if and how racism-related factors are potential barriers to minority access to essential services as required by relevant public health or social service institutions.

Butler et al. (2018) focused on CRT training of researchers to confront racism, understand racism, and intervene on its impact on the well-being and health of minority populations. In this commentary, Butler et al. advocated the need for new theoretical frameworks and paradigms to respond to persistent effects of systemic racism on health, health disparities, and research. While the article does not involve CRT's application in a study, it provides insights on how CRT can be used to eliminate ethnic and racial health disparities.

Obasogie et al. (2017) argued for inclusion and wider use of CRT as a framework to achieve health equity. CRT is a cross-cutting and process-based approach that is used to rethink conceptual foundations and facilitate ground actions. CRT is embedded in the research process, including research question formulation, study design, data collection, variable definitions, intervention, and action. Obasogie et al. advocated using community-based participatory research methods, multi-level and multi-sectoral approaches to interventions, and mixed methods studies to address poor health outcomes in marginalized populations.

This study involved using CRT during the research process, including formulation of questions, design, data collection, as well as recommendations for action shaped and informed by participants. I used CRT to address how practitioners, policymakers, program managers, researchers, insurers, and health and social service systems can adopt race-conscious approaches to understanding and working towards providing just and inclusive accessibility to respite care services for immigrant families caring for children with complex needs. Ford and Airhihenbuwa (2010) noted CRT is grounded in social justice and intended to elucidate racial phenomena and equip practitioners to discuss complex racial concepts and challenge racial hierarchies. The role of race in African adult and pediatric immigrant health status, care, and access in the U.S. is not well-discussed in literature. CRT was also used during data analysis to glean potential patterns of discrimination and de-prioritization of African immigrant children with complex needs and their mothers when accessing respite care services due to race.

Nature of the Study

This study used a generic qualitative design. A generic qualitative approach is best suited for this study as the research question does not align with standard qualitative research traditions such as ethnography, grounded theory, case study, phenomenology, and narrative inquiry. Understanding barriers to respite care among participants required a generic qualitative approach to collect rich descriptive data on their subjective opinions, beliefs, attitudes, and reflections regarding such barriers. Participants provided in-depth and detailed information about barriers they perceived and experienced. Participants interpreted their experiences and attributing meanings to their experiences. As experts on their opinions, beliefs, attitudes, and reflections, these mothers would illuminate the areas of need by interpreting their experiences, constructing, and reflecting their worlds, and attributing their meanings to their experiences (Kahlke, 2014).

The generic qualitative approach to the study aligns with my postmodernist ontology (Given, 2012; Maiter and Joseph, 2017) and emic epistemology (Given, 2008) in co-creating knowledge with participants in this study. With a postmodernist perspective on reality, there are multiple valid ways to perceive and describe reality, and there is not one narrative or all-encompassing viewpoint (Maiter and Joseph, 2017). Vaid (n.d.) suggested there is a need to understand systems and hierarchies that inform people's understanding of the world. Emic epistemology involves multiple realities in keeping with positions and perspectives of individuals in any given community (Given, 2012).

In this study, I used the concept of information power to determine sample size, where the more information in sample that is relevant for the study, the lower the number of required participants. While the suggested number of participants for a generic qualitative study was unclear in the literature, the goal of this study was to maximize information; thus, the sample size was determined to be between 15 and 20 participants using purposeful sampling.

The pool of participants who met the criteria was unknown and presumed to be narrow given limited research and statistical data on African immigrants in the US. Recruitment was set to occur through African immigrant community-based organizations, networks, and faith centers, including African mosques and churches.

I used semi-structured interviews and obtained permission to tape interviews to build data using a combination of experience and behavior, background demographic, opinion and values, and feeling and sensory questions to address access barriers to respite care services.

I used an interview guide to obtain data from participants in order to keep structure and consistency during the interview process. Broad and open-ended questions in everyday language, guided by a critical race approach, were used for participants to provide detailed stories. I used a minimum of six primary and probing questions. Questions involved opinions, beliefs, attitudes, and reflections of African immigrant mothers of children with complex needs regarding access barriers to respite care services.

For data analysis, I used thematic analysis to analyze participants’ reports. Thematic analysis can be deductive or inductive. Data were analyzed as they were collected, moving between data that were already coded and clustered into patterns and current data. According to Percy et al. (2015), themes and patterns grow and change as analysis continues throughout the process. I used an inductive approach to perform thematic analysis.

Definitions

Complex needs: According to Ronan et al. (2020), children with complex needs are children with medically complex, life-limiting, and life-threatening conditions. There has been a lack of consensus in the field about the definition of "complex needs" given insufficient data in the literature and the limited visibility of the rising number of children with life-limiting conditions in routinely published national data (Pinney, 2017). For this study, I will adopt the comprehensive definition provided by Ronan et al. which states that children with "complex needs" are children with "medically complex, life-limiting, and life-threatening conditions" - allowing for an all-encompassing model of disability and illness when discussing "complex needs."

Critical race theory (CRT): A theory that is used to explain the role of race, racism, and racial power in society and impacts of inequality and systemic racism on justice and inclusion (Graham et al., 2001; Obasogie et al., 2017). The theory is used for practitioners, policymakers, and program managers to adopt race-conscious approaches to acknowledging service barriers and working towards just, inclusive, and tailored strategies to ensure access to services for minority families.

Respite care: Interim care for children with complex needs that provides relief for primary caregivers, often relieving mothers from their caregiving responsibilities (Kvarme et al., 2016; Whitmore & Snethen, 2018). This may lead to reductions in stress among mothers caring for children with complex needs.

Assumptions

The primary assumption in this study is that African immigrant mothers of children with complex needs may not have equitable access to respite care services due to significant evidence in the literature that race, and ethnicity are primary drivers of disparities in terms of access to critically needed services. Based on a core tenet of CRT, I assumed that racism is deeply embedded in American health policies, systems, and institutions. The findings in the literature on broader health equity challenges within African immigrant communities in the United States (Adegboyega and Hatcher, 2016) support the assumption that racism and discriminatory policies are at the root of health inequity. Additionally, findings of the Center for Disease Control and Prevention, 2019; Misra et al., 2021; Saasa, 2019; Viruell-Fuentes et al., 2012; and Zaidi and Sederstrom, 2018) validate my primary assumption.

Scope and Delimitations

The role of race was central in terms of exploring access barriers to respite care among African immigrant mothers caring for children with complex needs to cogenerate knowledge regarding impacts of race on equitable access to respite care in the U.S. The study did not include discussions on the impacts of children with complex needs on siblings or fathers, as mothers are typically the primary caregivers. I also excluded specific discussions on gender. CRT was the sole theoretical framework in the study to understand the magnitude of the role and dynamics of race in terms of accessing respite care services among participants.

Transferability involved assessing whether findings are applicable in other settings. It is possible to replicate the study, focusing on other minority immigrant and marginalized groups.

Limitations

The primary challenge in the proposed study is lack of research and data on African immigrants in the U.S. Access to participants was also a challenge. Vulnerable populations, including children and immigrant mothers, presented a unique challenge during the data collection process. Bracken-Roche et al. (2017) noted when at-risk populations participate in a study, researchers must have a clear plan for recruitment, obtaining informed consent, and protecting participants from harm as well as show how benefits of the research outweigh risks.

Another limitation involved my positionality and proximity to the issue. I am an African immigrant mother of a child with neurodevelopmental challenges living in the U.S. My lived experiences involving racism across various social, educational, and professional spaces and within healthcare systems also informs my worldview and understandings of broader societal contexts in which immigrants and minority citizens operate. I have also immersed myself in dialogues and scholarly literature on CRT, systemic and institutional racism, and discrimination in America and the developed world.

Steps to limit my biases included using peer review experts to develop the interview survey instrument, employing open-ended questions, and practicing reflexivity to assess my biases and assumptions. Being aware that my approach would set the context in which participants share rich data about their opinions, beliefs, attitudes, and reflections about the topic was paramount to trustworthiness and validity of the study. It was also imperative to refrain from distorting findings to fit pre-established agendas and not lead with emotions versus evidence. Use of reflexivity throughout the research process and documenting how my worldview and beliefs shaped data collection, including prior assumptions and experiences was also necessary.

Social desirability bias was another area of weakness. One proposed remedy was to use participant observation techniques to triangulate other forms of data. Thus, along with interview notes, audio recordings, and reflexive journaling, I also documented observations of participants during the interview process while conducting observations to inform possible follow-up questions.

Significance

This study involved using one-on-one semi-structured interviews to gain understanding and insights regarding access barriers to respite care among African immigrant mothers of children with complex needs in the U.S. Findings will inform potential respite care service policies and program reforms to improve access and support for these mothers, their children, and families.

CRT was used to help frame the study to help inform practitioners, policymakers, insurers, health systems, program leaders, and researchers in terms of adopting a race-conscious approach to addressing access barriers and working towards just and inclusive access as well as tailoring strategies to ensure access to respite care services for these mothers.

The study is also significant as it can help fill a knowledge gap in the human and social services fields and inform the processes of identifying and tracking African immigrant children's complex health conditions and providing essential family support services, namely respite care. The study also involved discussing care coordination, burden of care, and shared plans of care (SPOC) as some indicators of how well African immigrant mothers of children with complex needs can access respite care services.

Summary

This generic qualitative research study involved seeking to understand how African immigrant mothers in the U.S. described access barriers to respite care services in terms of caring for their children with complex needs. This will help inform respite care policy and program reforms to improve access and support for this population. As respite care mitigates high levels of stress and strain among immigrant mothers and improves their quality of life and that of their children, findings from this study will help reduce hardships experienced by this population as they navigate life in the U.S. Findings also includes insights regarding current care models and systems through which multidisciplinary teams provide care coordination in the region.

Chapter 2 includes a review of limited studies that are available on respite care and immigrant mothers of children with complex needs. Following a discussion of the literature search strategy and theoretical framework, I also discuss peer-reviewed articles on respite care services as a part of integrated care and multidisciplinary family support services, children with complex needs and the impact of their care of their mothers and families, CRT related to health and social science research and minority health, the history of respite care services, unmet needs and barriers that are identified in literature, the role of culture among immigrant parents of children with complex needs, and inequitable access to respite care services for immigrant mothers of children with complex needs in other developed countries.

Chapter 2: Literature Review

African children are significantly susceptible to medically complex, life-limiting, and life-threatening conditions (Animasahun et al., 2018; Jivanji et al., 2019; Khanlou et al., 2017). As their primary caregivers, African immigrant mothers of children with complex needs require short-term breaks to experience normalcy as well as rest and regenerate for the benefit of their physical and mental health (Kvarme et al. 2016; Whitmore& Snethen, 2018).

While the importance of respite care for immigrants and broader populations is well-established in other Western nations, it is unclear for African immigrants in the U.S. Lack of research and data on access to respite care for this immigrant group stems from a lack of interest in the population and research funding on African immigrants' health status in the U.S. (Omenka et al., 2020). There is no literature on access barriers to respite care services for African immigrant mothers caring for their children with complex needs in the U.S.

The purpose of this generic qualitative study is to understand how African immigrant mothers in the U.S. describe access barriers to respite care services in terms of caring for their children with complex needs and the role of race in terms of access disparities. This study presents an opportunity to add to the body of knowledge in the human and social services fields and provide insights, solutions, and recommendations informed by African immigrant mothers caring for children with complex needs regarding this topic. Using a critical race lens, this study will help participants inform ways that practitioners, policymakers, program managers, researchers, insurers, and health and social service systems can improve policies and programs to optimally serve these mothers, their children with complex needs, and their families in the region.

In western industrialized nations, children with complex needs or medically complex, life-limiting, or life-threatening conditions are surviving critical illness through technological advances (Ronan et al., 2020). These survival trends are resulting in parents of children with complex needs needing to seek out family support services, including respite care to maintain a quality family life (Boss et al., 2020; Brenner et al., 2018; Carnevale et al., 2017; Hill, 2016). Since children with complex needs have multidimensional health and social care needs, respite care services are essential for families in managing their children with complex needs or medically complex conditions including therapeutic opportunities, quality time, and independence (Brenner et al., 2018). Respite care is a crucial element of integrated healthcare services, coordinated family support, and direct home care programs for families caring for children with complex needs, with nearly 5.6 million children with complex needs in the U.S. receiving 1.5 billion hours of family-provided health care annually (Kuo et al., 2011; Pilapil et al., 2017). Respite care provision also receives substantial national and international research attention, particularly across western nations. Despite being well-discussed in literature, the most significant area of unmet needs among parents of children with complex needs is respite care provision. These unmet needs are often due to gaps involving primary healthcare services for children with complex needs in their local communities as well as lack of care coordination (Spruin et al., 2018).

A combination of integrated healthcare and family support interventions is most beneficial throughout disease management and care of children with complex needs (Bradshaw et al., 2019). However, immigrants and their children with complex needs face increased barriers to accessing healthcare and other family supports, and their needs remain underreported (McKay, 2019; Warden et al., 2019). Moreover, research on foreign-born children with complex needs in the U.S. focuses on children of Hispanic and other ethnic minority backgrounds (Waldman et al., 2017). There is a paucity of research on African immigrant children with complex needs in the U.S. and their families' ability to access healthcare and family support services, including respite care.

There are currently 2.4 million African immigrants residing in the U.S., and 11% are under 18 (Echeverria-Estrada & Batalov, 2019; Omenka et al., 2020). There is not much known about their health status and access to essential health services, including related family support services. Khanlou et al. (2017) found 76% of Sub-Saharan African immigrants are likely to have a child diagnosed with autism. Kroenig and Dawson-Hahn (2019) found the most prevalent chronic diseases among African immigrant children in the U.S. are rheumatic heart disease, congenital heart disease, thyroid disease, congenital hypothyroidism, cerebral palsy, sickle cell disease, and thalassemias. Roughly 500,000 African children are born with congenital heart disease annually, and rheumatic heart disease is another cause of morbidity and mortality among African children (Animasahun et al., 2018; Jivanji et al., 2019). Agrawal et al. (2020) found based on rates of abnormal echocardiograms, immigrant children have a higher likelihood of acquired or congenital heart disease during initial consultations. This points to a need for further inquiry into African immigrant children's heart needs in the U.S.

At the time of conducting the literature review, efforts to identify barriers to respite care among African immigrant mothers caring for their children with complex needs in the U.S. was not evident in literature principally due to the absence of research and funding on African immigrant health and tendency to view all Black populations in the U.S. as monolithic (Adu-Boahene et al., 2017; Omenka et al., 2020). Warden et al. (2019) indicated the most widely used tool to assess prevalence of children with complex needs, the Children with Special Health Care Needs Screener, underidentifies medically complex conditions and needs in immigrant households. Additionally, the Centers for Disease Control and Prevention (CDC) annually fields a cross-sectional address-based survey, the National Surveys of Children with Special Health Care Needs, to assess the impact and prevalence of special health care needs among children in the U.S. and evaluate change over time. Demographic questions include race, primary language spoken at home, country of birth, and how long respondents and their children with complex needs have been in the U.S. However, raw data is not readily available, further pointing to the need for specific research regarding this group.

Furthermore, while discrimination and well-being research among African immigrants is sparse, it is well-established in the literature that this group faces racially stratified constraints, adverse immigrant integration outcomes, and social exclusion tactics. These tactics include material deprivation, limited access to fundamental social rights (including health care), limited social participation, and poor cultural integration

(Saasa, 2019). In recent years, the Trump administration implemented such tactics via the public charge rule, which would deny immigrant families legal permanent residency based on past or potential use of government benefit programs. The rule prompted immigrant families' avoidance of noncash government benefit programs, including Medicaid, the Children's Health Insurance Program (CHIP), the Supplemental Nutrition Assistance Program (SNAP), and housing subsidies (Bernstein et al., 2019). Zallman et al. (2019) found that 5.5M immigrant children with complex needs were at risk of disenrollment from the Medicaid, CHIP, or SNAP programs under the public charge rule. Conditions among the children included asthma, epilepsy, cancer, disabilities, or functional limitations. The American Medical Association and medical practitioners issued warnings about the loss of health and nutrition benefits among children, including those with complex needs, noting that if left untreated, would contribute to child deaths and future disability (Haq et al., 2020; Zallman et al., 2019). Such discriminatory immigration policies increase the vulnerabilities among African immigrant mothers with children with complex needs and their families. Additionally, given the role of race as a barrier to equitable healthcare access in the United States (Ambegaokor, 2012) and other western nations, as acknowledged in the literature, where barriers have been principally examined using social support theoretical models (Khanlou et al., 2016, Khanlou et al., 2017), it may be helpful to examine the problem through a critical race theoretical lens.

This generic qualitative study using critical race theory will identify the access barriers to respite care services for African immigrant mothers with children with complex needs in the United States to inform the work of practitioners, policymakers, health systems, program leaders, researchers, insurers, and health and social service systems to ensure equitable access to respite care and other essential family support services for African immigrant mothers and their children with complex needs.

In recent literature across western nations, respite care is not only thought of as crucial for parents of children with complex needs but most effective as part of a family-centered set of integrated care and family support interventions (Koch and Jones, 2018; Pilapil et al., 2017). Recent empirical findings also indicate a strong correlation between poor socioeconomic and minority racial/ethnic background and ineffective, inefficient, and inequitable access to respite care services for parents caring for children with complex needs (Ambegaokor, 2012; Agrawal et al., 2018; Breneol et al., 2019; Cummings and Hardin, 2016). Parents can often be limited to waitlists, where the ability to incur out-of-pocket costs is not feasible. In addition to the systemic barriers these parents face, the role of culture is also well discussed as an individual barrier for immigrant mothers of children with complex needs in seeking access to respite care services (Sobotka et al., 2019; Breneol et al., 2019; Welsh et al., 2014; Nageswaran, 2009; Cooke et al., 2020; Upshur, 1983; Teo et al., 2018; Palisano et al., 2009; Dybwik et al., 2011; Woodgate et al., 2015; Carter and Bray, 2017; Koch and Jones, 2018).

Chapter 2 discusses the primary peer-reviewed articles centered on existing respite care access barriers identified in the literature for immigrant families caring for children with complex needs. The experimental studies included were conducted in Canada, Norway, the United Kingdom, Australia, and the United States. Theoretical approaches, methodologies, data analysis, and findings are explored to determine what has already been done and established in the literature related to immigrant mothers with children with complex needs and in, some cases, African immigrant mothers with children with complex needs in western nations. For historical and contextual purposes, Chapter 2 also discusses findings in the literature on the evidence of respite care effectiveness, what respite care can achieve as a part of integrated health care and family support programming in helping caregivers of children with complex needs, and the policy implications, as determined across a vast body of literature. Unmet needs and universal access barriers for respite care for children with complex needs identified in the literature are also discussed, as well as, modes of payment and affordability of respite care services, the availability of respite care services for immigrants with children with complex needs, and the availability of respite care services for African immigrants with children with complex needs compared to the availability of services for European immigrants and other minority immigrant groups. The roles of culture and inequity in seeking respite care access among immigrant families caring for children with complex needs are also explored, as discussed in the literature. Lastly, critical race theory (CRT) is discussed as the chosen theoretical framework to support the study and how CRT relates to African immigrant mothers' potential barriers in accessing respite care in the United States.

Literature Search Strategy

I used the following databases: Academic Search Complete, APA PsycArticles, APA PsycInfo, CINAHL Plus with Full Text, MEDLine Full Text, Political Science

Complete, SocIndex with Full Text, Social Work Abstracts, Thoreau, and Google Scholar.

Key search terms were: *African immigrant mothers in the United States*, *African immigrant children with complex needs*, *immigrant mothers and children with complex needs, African children with heart disease*, *emigrants and medically fragile children*, *children with complex health care needs in the United States*, *respite care and children in the United States*, *paying for respite care in the United States*, *public charge and children with complex needs*, *immigrant children and respite care*, *immigrant health*, *immigrant health and critical race theory in the United States*, *African health and critical race theory in the United States*, *family support and respite care and United States*, *policy and respite care and United States*, and *European immigrants and healthcare and United States.*

An extensive literature search was conducted, including both qualitative and quantitative primary and secondary studies. The search included articles between the years 1970 and 2020 published in English (to also capture seminal works due to the limited to non-existent research on this topic in the United States). The search used keywords and index terms across all databases. Diverse terminology, synonyms, and spelling of keywords were also considered to capture articles related to the topic that is principally published in other western countries, including Canada, Australia, the United Kingdom, Norway, Ireland, and Japan.

Theoretical Foundation

CRT originated in the 1970s via lawyers, activists, and legal scholars to address the regressions and shortfalls of the Civil Rights Era's advances of the 1960s. The premise was that newer theories and strategies were needed to address the subtler forms of racism and discrimination (Delgado and Stefancic, 2017). Derrick Bell (1992), known as the father of critical race theory, posited that racism is deeply embedded in the laws and institutions of the United States, including those intended to remedy past injustices. Basing and accepting research, policy, and program planning on the reality that racism is permanent in the United States and nearly indestructible, practitioners, policymakers, insurers, health systems, program leaders, and researchers have the opportunity to develop and implement policies, programs, and other mechanisms that protect and adequately serve groups that are oppressed and marginalized based on race in the United States.

Critical race theorists principally hold two schools of thought on racism – idealist and realist. The idealists view racism as a matter of ways of thought, categorization, developed attitudes, and discourse remedied through the changing of systems, images, words, unconscious feelings, narratives, attitudes, and societal teachings (Curry, 2011; Delgado and Stefancic, 2017). On the other hand, the realists argue that although attitudes and words bear significance, racism is more the means through which society assigns privilege and status. Racial hierarchies determine who receives material benefits, resources, and access to products and services. Realists also stress that any civil rights gains for families and communities of color occur in keeping with white self-interests (Burrell-Craft, 2020; Delgado and Stefancic, 2017).

The prevailing understanding of CRT is that racism is not aberrational and is the traditional way society does business and the shared, everyday experience of people of color in the United States and other western industrialized countries (Bonilla-Silva, 2009; Crenshaw et al., 1995; Delgado and Stefancic, 2017). It is also understood that the universal system of white supremacy over people of color serves material and psychic purposes for the dominant group, and by ignoring the realities of racism and perpetuating white-dominant ideologies, the beneficiaries of racism continue to benefit from socio-structural inequalities (Delgado and Stefancic, 2017; Garcia, 2017). These ideologies rooted in white supremacy, consequently, hinder certain groups from advancing or accessing resources and essential services in the United States. Researchers have noted that a pervasive failure to acknowledge race as a barrier to accessing critical services does not eliminate the reality of racism embedded in US systems (Brainard, 2009; Garcia, 2017). Ford and Airhihenbuwa (2010) identified that systemic racism impacts health outcomes and the production of knowledge about marginalized populations, their health, and health disparities.

Critical race theory has not been applied widely to immigrant health in the United States or other western nations. An initial literature search yielded the Ford and Airhibenbuwa (2010) peer-reviewed commentary on critical race theory, anti-racism praxis, and public health. The article noted that CRT could contribute "a comprehensive framework for connecting research efforts; a lexicon for advancing understandings of racial constructs and phenomena; critical analyses of knowledge creation processes; and praxis that builds on community-based participatory approaches linking research, practice, and communities." In application, CRT would allow the researcher to understand if and how racism-related factors are potential barriers to a minority group's access to essential services as required by relevant public health or social service institutions. Ford and Airhibenbuwa's example also integrated the use of the Andersen access to care conceptual model, a socioecological framework used to examine behaviors in clinical settings, along with CRT concepts.

Additional searches, including the search terms "critical race theory and immigrant health," yielded articles on the use of CRT as a framework and analysis tool for population health research (Graham et al., 2011), the use of CRT training to eliminate racial and ethnic health disparities (Butler et al., 2018), and the use of a critical race intervention to eliminate racial disparities in health in the United States (Obasogie et al., 2017). Graham et al. proposed core tenets of CRT drawn from the seminal works of Crenshaw et al. (1995), Delgado and Stefancic (2001), Schneider (2003), and Moran (2004) to use in population health research among ethnic minorities. Under the core tenets, scholars recognize that institutions generally function based on values, principles, and foundations that are representative or culturally diverse. The dominant cultural customs, mainly Eurocentric, are generally presented as universal and used to otherize and exclude ethnic minorities from inclusion, opportunities, access, and participation. The second tenet involves the ways in which individuals navigate view racial and ethnic landscapes that can be explored qualitatively, including race consciousness, color-blind liberalism, interest convergence, economic or material determinism, and structural determinism. The third tenet advocates the use of narrative inquiry to ensure that a person or group's position or standpoint is not watered down or marginally taken up. The fourth tenet suggests that data must be rooted in social contexts, drawing on cultural studies, history, and context data collected from study participants. The fifth and final tenet notes that researchers are more honest and forthcoming about their subjectivity in their design of the research study, data collection, analysis, and presentation. Butler et al. (2018) focused on CRT training of researchers to confront racism, understand racism, and intervene on its impact on the well-being and health of minority populations. In this commentary, Butler et al. advocated the need for new theoretical frameworks and paradigms to respond to persistent effects of systemic racism on health, health disparities, and research. While the article does not involve CRT's application in a study, it provides insights on how CRT can be used to eliminate ethnic and racial health disparities. Obasogie et al. (2017) argued for the inclusion and wider use of CRT as a framework to achieve health equity given repeated attempts at health equity in the literature and programmatically. CRT is described as a cross-cutting and process-based approach that allows the researcher to rethink conceptual foundations and use it to facilitate on the ground action. Consequently, CRT is embedded in the research process, including research question formulation, study design, data collection, variable definitions, intervention, and action. Obasogie et al. advocated using community-based participatory research methods, multi-level and multi-sectoral approaches to interventions, and mixed methods studies to address poor health outcomes in marginalized populations.

Given that the few researchers of access barriers to health and related services among African immigrants caring for children with children with complex needs in other western industrialized nations have solely utilized social support frameworks, the use of critical race theory to examine such barriers will add to the knowledge in the field and further enhance and support recommendations made in Obasogie et al. (2017).

CRT will be utilized to understand and provide recommendations to address the issues of discrimination, segregation, inequality, and systemic racism that African immigrant mothers caring for their children with complex needs experience in the United States, given that healthcare and support services in the United States are Anglocentric in nature and racism and inequity are fundamentally engrained into laws, policies, and perspectives established as the norm (Algood and Davis, 2019). The use of CRT will not only help to illuminate the challenges that African immigrant mothers face as they care for their children with complex needs but aid in addressing barriers to respite care services that the literature, thus far, suggests they struggle with, in many cases, for years. The use of CRT will also center and contextualize the issues that these mothers and children face related to systemic racism and discrimination in the health and social service sectors.

Literature Review Related to Key Variables and Concepts

As noted, a systematic review of databases proved that literature specific to respite care and African immigrant mothers caring for children with complex needs in the United States, at the time of this writing, was non-existent. The following studies provided an understanding of existing respite care access barriers identified in the literature for immigrant families caring for children with complex needs. Researchers conducted the primary experimental studies included in this study in Canada, Norway, the United Kingdom, Australia, and the United States:

Khanlou, Haque, Mustafa, Vazquez, Mantini, and Weiss (2017) used a qualitative descriptive approach using the House's (1981) conceptualization of the four social support domains. Khanlou et al. conducted in-depth interviews to explore the experiences and perspectives of 21 immigrant mothers of children with disabilities regarding their access to structural, emotional, instrumental, and perceptual support in Canada. The study presented a conceptual framework to understand the range of concerns these mothers raised related to structural, emotional, instrumental, and perceptual support. While study participants only represented the continents of Asia, Europe, Latin America, and the Caribbean islands, the barriers identified in Khanlou et al. can help inform this study. In identifying the access barriers that immigrant mothers face in Canada, Khanlou et al. (2017) took a holistic view of these mothers' challenges in caring for their children with complex needs in their host country. The challenges include being unable to access needed support due to low income, language barriers, transportation limitations, inflexible service offerings in the host community, limited social networks, low employment, and marginalization, which interfere with access. Other disadvantages include the extent to which these mothers have assimilated and understand how to navigate service sectors in caring for their children with complex needs and their understanding of children with complex needs's disability or medical condition. These immigrant mothers often experience social isolation, guilt, and shame affecting their willingness to seek services and support, playing a role in failures to obtain early diagnosis and intervention. Recent studies examining interventions to support caregiver stress (Edelstein et al., 2016); and pediatric care for newly immigrated families (Nicholas et al., 2017) present similar discussions to Khanlou et al. (2017) in their use of a four-domain social support conceptual framework to understand the challenges these mothers face. While Edelstein et al. (2016), conducting a systematic and scoping review, found no conclusive evidence around which interventions or combination of, including respite care, are most effective for stress reduction, the researchers found that with the right support, multiple interventions can effectively mitigate the burdens of care experienced by parents of children with medical complexity. Nicholas et al. (2017) acknowledged that immigrants' needs in pediatric care systems are sparsely addressed in the literature and utilized a qualitative descriptive approach of interpretative description to generate knowledge on the pediatric health care needs and experiences of new immigrants in Canada. In addition to income requirements, transportation access, ability to understand and navigate complex health care systems, Nicholas et al. found that new immigrant families struggled with a lack of social support and emotional adjustments. Having a child with complex needs further compounds these challenges. Saasa (2019) also cited research findings advocating the use of instrumental support and social support in overcoming the discrimination and social exclusion that African immigrants face in the United States. Examining immigrant mothers of children with complex needs' experiences through the lens of social support frameworks is justifiable in that such frameworks allow practitioners, policymakers, insurers, health systems, program leaders, and researchers to develop targeted interventions to best support immigrant families and their children with complex needs. However, without centering systemic and institutional racism and discrimination as a fundamental barrier for immigrant families of color, social support frameworks are limited, outcomes are often limited, and systems remain unchanged. A review of studies on immigrants of color in western nations highlighted the under-reporting and under-addressing of needs consistently in the literature (Javier et al., 2010; Kuo et al., 2011; Linton and Green, 2019; Sritharan and Koola, 2019; Warden et al., 2019). These findings taken together justify exploring and examining the access barriers experienced by African immigrant mothers of children with complex needs in the United States through a critical race theoretical lens.

Kvarme, Albertini-Fruh, Brekke, Gardsjord, Halvorsurd, and Liden (2016) conducted a qualitative study using an exploratory design with individual and focus group interviews on understanding how immigrant parents of children with complex needs manage their family lives, their health, and quality of life in Norway. Kvarme et al. conducted one-on-one and group interviews with 27 Pakistani, Polish, and Vietnamese parents - 18 mothers and nine fathers and the data was analyzed using phenomenological hermeneutic guidelines. In this study, Kvarme et al. discussed caregiving's impacts on immigrant parents, particularly mothers as the primary caregivers, for their children with complex needs and the health and quality of life challenges that they faced citing the lack of respite care, social networks, support, and a persistent struggle to access resources. A single mother of two children with complex needs participating in the study noted that she received respite care for only one of her children with complex needs after applying for respite care for 4 to 5 years despite a national policy that mandates all children with complex needs have an individual plan and a responsible care team and coordinator to ensure each child with complex needs receives follow-up care based on their needs and resources. A common theme among study participants was the lack of information, language barriers, and insufficient knowledge about their rights and resources initiated following their children with complex needs' diagnosis. Kvarme et al. found that most of their sample lacked an individual plan and a care coordinator but lent no understanding as to why. There appears to be a missed opportunity to understand the systemic barriers that these mothers face due to the theoretical approach and preunderstandings of Kvarme et al. as research nurses, a sociologist, and a social anthropologist. Another observation is that according to Statistics Norway (2020), 137,411 African immigrants (99,538 African-born) and (37,873 Norwegian-born to African immigrant parents) at 2.6 percent of the Norwegian population, yet no African parents or mothers are in the sample. While the research questions centered on the health and quality of life experiences among immigrant parents from Pakistan, Poland, and Vietnam having children with complex needs; the factors contributing to their health and quality of life; and the differences between maternal and paternal caregiving burden, the approach to the study and the findings point to a need to understand the systemic barriers impacting immigrant families and apply to immigrants with children with complex needs in the United States.

Kvarme, Albertini-Fruh, and Liden (2017) adopted a phenomenological and hermeneutic approach and self-efficacy and coping theoretical perspective to understand coping strategies identified in analyzing the individual and focus group interviews conducted with 27 Pakistani, Polish, and Vietnamese parents - 18 mothers and nine fathers. In this follow-up study, Kvarme et al. illuminated the physical, mental, and emotional health and sociocultural challenges immigrant parents with children with complex needs face in Norway. While the study did not include African immigrants, it raises questions for the reader regarding the root of inequity and disparity in services for minority immigrants in Norway. A study on Sub-Saharan African's access to the Norwegian healthcare system (Mbanya et al., 2019) noted an ongoing debate whether immigrants in Norway benefit equally from services as non-immigrants. Mbanya et al. recognized that reducing inequity in health between socioeconomic groups in Norway is the government's priority, with targets set at local and national levels. However, a gap remains in understanding the immigrants' experiences with healthcare, and in the case of Africans, as "blacks," they often experience racial discrimination in most facets of life and get treated as second class citizens (Mbanya et al., 2019). Together, these studies provide insight into the challenges that immigrants with children with complex needs face in western nations and apply to African immigrant mothers caring for their children with complex needs in the United States.

Cummings and Hardin (2017) focused on understanding immigrant families' experiences of having children with disabilities, as limited literature tells the stories of immigrant families with children with disabilities. The study utilizes a phenomenological approach and sociocultural theory to explore four immigrant parents' educational and cultural experiences with their children receiving special education or other specialized services in North Carolina, USA. The parents were from Burma, Vietnam, Mexico, and

Peru, and Africans are not participants in this study. However, the study is relevant because it provides additional insights into barriers that immigrant parents with children with complex needs face in the United States. Cummins and Hardin used an in-depth examination of these parents' perceptions of disabilities informed by their experiences with cultural heritage and special education services in the United States and the broader social contexts that shape these immigrant parents' experiences. While the study's focus was on parents' perceptions of their children with complex needs's conditions, it uniquely highlights the role of culture in parents' understandings of their children’s conditions and their subsequent care-seeking decisions. It also highlights the need for practitioners and service providers to have sound understandings of culturally sensitive populations to reduce access barriers to services, including respite care.

Agrawal, Dokania, Allen, Acosta, Caracostis, Havemann, Lara, Riley, and Seery (2020) described the findings of a monthly outreach pediatric cardiology clinic focused on the cardiac needs of immigrant children and resettled refugee children in Houston, Texas, USA. Researchers analyzed the pediatric cardiology clinic data collected from 2014 through 2017 using descriptive statistics. Only seven percent of the sample population (27 out of 366) were from Sub-Saharan Africa, and their specific cardiac care and needs for referrals not discussed and a detailed investigation of specific barriers African and other immigrants face in accessing pediatric cardiology healthcare and related support services deemed beyond the scope of the study. Agrawal et al., however, recognized some of the multifactorial reasons for immigrants’ lack of access to integrated healthcare services, including respite care - poverty, lack of insurance, lack of mobility, language barriers, cultural differences (including issues of the stigma associated with health conditions and disabilities), and challenges with navigating the complex US healthcare system. This study was included based on the findings of studies citing the high prevalence of congenital heart disease in Sub-Saharan Africa and is significantly underestimated (Hoffman, 2013; Jivanji et al., 2019). With nearly 500,000 children born in the region with congenital heart disease (Jivanji et al., 2019), an unknown segment of these children currently residing in the United States and require above average use of medical care, mental health and educational services, and respite care (Chen et al., 2018; Lantin-Hermoso et al., 2017). Agrawal et al. provided insights into the referral process for diagnosis, treatment, and interventions but no discussion of ensuring links to support services, including respite care through Texas Children Hospital, a tertiary referral center for pediatric specialty services.

Munroe, Hammond, and Cole (2016) used an interpretive phenomenological analysis to examine six African immigrant mothers' experiences with children diagnosed with Autism Spectrum Disorder (ASD) in the United Kingdom. The study involved one-off, semi-structured interviews to inform clinical practice and policy related to providing culturally sensitive support for ethnic minority and immigrant communities. Munroe et al. found that western medical explanations were generally at odds with their study participants' traditional and cultural beliefs, which is already well-understood in the literature. Many seminal and recent studies have recognized cultural beliefs as a barrier to health and social support services among immigrant families (Sritharan and Koola, 2019; Decoteau, 2017; Cowden and Kreisler, 2016; Daley, 2004; Cho et al., 2003; Welterlin and LaRue, 2007; Ravindran and Myers, 2013). In addition to recognizing cultural belief systems that can pose barriers to services, Munroe et al. also discussed Heer et al.'s (2012) argument about the minority experience and how it reflects immigrant families' distinctive needs and experiences. Heer et al. posit that immigrant families' religious and cultural background, their minority communities, practices, and institutions shape how they make sense of their children's conditions and diagnosis and often conflicts with the overarching medical model of their host country's healthcare systems' approaches to supporting them. Heer et al. identify discrimination, stigma, material disadvantage, language, lack of social support, minority group pressures, aspects of the migration, and acculturation process as the primary factors that influence immigrants' “minority experience.” The acknowledgment of Heer et al.'s findings is useful; however, Munroe et al. strengthen the study by selecting a design approach used in areas with limited previous research (in this case, experiences of African immigrant mothers) and allows for rich and detailed accounts and understandings of the African immigrant mothers' experiences. Via the IPA approach, the reader can consider the meaning participants give to their experiences and the researcher's interpretations. The IPA approach is meaningful, but there remains a need for a critical race lens to get to the root of systemic barriers that African immigrant mothers with children with complex needs face and limit their access to respite care and other essential support services.

Arfa, Solvang, Berg, and Jahnsen (2020) sought to examine what influences immigrants’ use of healthcare services to inform the Norwegian government’s policy planning and service delivery efforts in achieving the government’s stated goal of equitable healthcare. Taking a qualitative approach, the researchers used semi-structured interviews to examine the experiences of non-western immigrant parents. Parallel with Munroe et al.'s (2016) findings on the "minority experience," Arfa et al. found that the "immigrant experience" shaped how immigrant parents viewed, experienced, or valued healthcare services. While parents appreciated the well-organized and reliable follow-up services provided by pediatric rehabilitation centers, parents reported being exhausted from the years of struggling to obtain access to support and services. Parents also reported feeling otherized as well as viewed and treated stereotypically in their interactions with service providers. Based on the primary themes derived from interviews conducted, the immigrant experience involved feeling alienated, challenging communication between healthcare professionals and immigrant families, appreciation for the healthcare system, the struggle to access help, limited access to information, and facing prejudice while navigating the healthcare system. Five African immigrant parents participated in the study; however, the researchers do not provide specific insights about their experiences accessing support services. As it has been long-established in the literature for decades, systemic barriers highlighted in Arfa et al. point to the persistent gap between the universal ideal of equal access to health and support services and the reality of the everyday lives of non-western immigrant families with children with complex needs. While the study is insightful about systemic barriers that immigrant families with children with complex needs face, findings are not generalizable across all western countries as healthcare and service delivery systems vary and policy priorities also differ.

Kan, Choi, and Davis (2016) utilized data from the 2011 National Survey of Children's Health (NSCH) to compare the prevalence and probability of a parent-reported medical home and five medical home components by immigrant family types in the United States. The bivariate and multivariate logistic regression results indicated that immigrant children with complex needs were less likely than native-born children with complex needs to have a medical home, family-centered care, and care coordination – critical channels to respite care services and other family support services. The study emphasizes the likelihood of immigrant children with complex needs and their parents being Hispanic (Kan et al., 2016, p. 3); therefore, there is not a specific inquiry into those that are African. Nonetheless, the study provides a road map on how to think through and frame various inquiry points that will help illuminate the experiences of African immigrant mothers of children with complex needs in accessing respite care services in the United States. The quantitative and statistical regression approach based on the 2011 NSCH's secondary data is essential and supports broader findings in the literature on minority immigrants' access to healthcare and support services. The primary challenges with this study are that the researchers focus their definition of immigrants around families of Hispanic origin, and they were unable to capture the immigrant status of parents or children as NSCH does not gather such information.

Brekke, Evensen, and Kaldager Hart (2020) used administrative register data to examine the uptake of non-means-tested cash benefits for children with a disability in Norway and whether uptake of attendance benefits varied by socioeconomic status and immigrant background. The study also included a sub-sample of 482 children born with

Down Syndrome to ensure that out of the total sample of 335,415 children, some children met the study's eligibility criteria. Findings indicated that immigrants have a lower uptake of attendance benefits for children with disabilities compared to the remaining population. The study does not discuss or specify immigrants' countries of origin but provides insights into systemic barriers that may limit access to respite care services among immigrant families with children with disabilities and other complex needs in western nations. The researchers also noted that the number of immigrants caring for children with disabilities is presumed to be relatively small in Norway. Consequently, Brekke et al. were unable to differentiate between immigrant groups for the study.

Welsh, Dyer, Evans, and Fereday (2014) employed a qualitative descriptive approach to explore the concept of proper respite care from the lens of parents of children with complex needs and determine the availability of suitable respite care services in Australia at the time of the study. Welsh et al. conducted semi-structured interviews in the parents' homes, and the interview data analyzed with thematic analysis. The researchers identified barriers as well as enablers for families when accessing respite care services. While the study does not focus on African or other immigrant populations in Australia, it provides insights and reference points for baseline barriers that parents of children with complex needs may encounter in western societies. Welsh et al. noted that one barrier to respite care (not widely discussed in the literature) is the complexity of the children with complex needs' condition, equipment required, the need for continued supervision, and the experience and training that staff requires to support the child. Nageswaram (2009) noted that these complexities increase the likelihood of not gaining access to respite care. Funding due to high costs of respite care, staffing issues, strict eligibility requirements, the inflexibility of agencies and policies, lack of privacy, as well as transaction costs (as noted in Brekke et al., 2020) are all barriers to respite care. Welsh et al. note that the study is not generalizable as it focused on a specific and small group of mothers caring for their children with complex needs in Australia. While the findings can inform the formulation of interview questions in this study, they cannot serve as a default representation of what mothers of children with complex needs experience across all western nations.

Javier, Huffman, Mendoza, and Wise (2010) conducted a cross-sectional study using data from the 2003 California Health Interview Survey to compare the perception of the health status of children with complex needs in immigrant families and those of children with complex needs in non-immigrant families and compare their health care access and health service utilization. Javier et al. recognized that compared with children of U.S. native-born parents, children of immigrants face a host of challenges that affect their access to and use of health [and related support services]. Bivariate analyses indicated that children with complex needs in immigrant families were more likely to have no usual source of care, experience delays in getting medical care, report not visiting a doctor in the past year, not likely to report a visit to a hospital emergency room in the last year, and more likely to report fair or poor health. Multivariate analyses showed that the effect of immigrant family status on access was mainly mediated by access to insurance coverage, language skills, and household income. Regarding health care utilization, multivariate analysis results indicated that a non-English speaking parent was more likely to report having no visits to the doctor in the past year. In the sample, both Hispanic and Asian families had greater odds of reporting no doctor visits in the past year. The multivariate analyses also showed that non-English speaking and less educated families were two timed likely to report that their child was in fair or poor health. Findings in Javier et al. are consistent with the studies' findings over the years on health status and access among immigrant families in western nations. It is understood in the literature that immigrants are not a homogenous group (Arfa et al., 2020); however, there is a consistent theme across western nations regarding lack of access to health and support services among non-western and ethnic minority immigrants and their families. Woodgate et al. (2017) found that one-third of the African immigrant mothers witnessed or were the victims of racism and discrimination and felt judged and stigmatized in Canada's healthcare system. Language, lack of interpretation support, cultural differences, lack of insurance coverage, lack of services, isolation, poverty, and lack of transportation were all cited as barriers and challenges for immigrant families (Woodgate et al., 2017). The data is understood, and the problem has undergone examinations using various frameworks including socio-ecological models (Khanlou et al., 2017) and social support models (Khanlou et al., 2017). For decades, the problem has been approached qualitatively utilizing various experimental designs and quantitively using systematic reviews, literature searches of peer-reviewed articles, secondary data, and a range of statistical analyses, yet the challenges that immigrant families of children with complex needs remain systemic. It points to a need to approach the problem via a critical race lens and determine how actual transformative and systemic change can begin.

Sritharan and Koola (2019) conducted a literature search of primarily qualitative peer-reviewed articles using keywords immigrants, minorities, autism spectrum disorder, autism, cultural barriers, immigrant, and access using PubMed and Google Scholar. The authors searched to increase understanding and collaboration between immigrant families and health practitioners in Canada to address barriers already identified in western nations. Findings indicated that, for immigrant families, early diagnosis, factoring parents' cultural beliefs about child development and their children with complex needs' condition, timely access to support and health services required equitable access, often the challenge for immigrant families. Sritharan and Koola proposed a program model in Canada, the South Asian Autism Awareness Center, to address the challenges of early diagnosis, educating parents, treatment planning, and care management skills - the program adaptable for other immigrant groups. The program model suggests a three-prong approach- awareness, education, and intervention. The program model raises an additional question of how critical race theory can inform the development of similar programs to support ethnic minority immigrant families with children with complex needs in the United States.

Cooke, Smith, and Brenner (2020) performed a systematic review of studies on parents' experiences and views of respite care for children with an Autism Spectrum Disorder to gain an in-depth understanding of accessing respite care. Pubmed, CINAHL, Embase, and PsychInfo were searched using predetermined criteria of qualitative data and qualitative portions of mixed-method studies. The data were synthesized using a meta-aggregative approach. Of the seven articles selected, one was conducted in Pakistan and India, two were conducted in Ireland, and the remaining in Sweden, Kenya, Canada, and the United States. The review identified several barriers to respite care that will also inform this study. Cooke et al. found that respite care needs to be affordable, accessible, conveniently located, available at the right times, durations, and frequencies. A recurring theme emerged from one of the studies included in Cooke et al.'s review- lack of cultural sensitivity, parents being made to feel inferior by a healthcare professional when deciding to in-home and family respite support for their children with complex needs and families. Healthcare professionals refusing access to respite care services based on emergent, acute, or complex behavioral or health issues were also identified.

Viruell-Fuentes, Miranda, and Abdulrahim (2012) highlighted that researchers examining the social determinants of health have long emphasized racism's central role in the persistence of health inequalities and have attributed racism to the various forms of oppression and marginalization of immigrants. Viruell-Fuentes et al. suggested the need to explore how day-to-day experiences of racism and discrimination impact immigrants' health, citing the over-reliance on cultural explanations in health literature that obscure the impact of structural factors on immigrant health disparities. Virtuell et al. also recognized the need to shift to frameworks and perspectives that examine how multiple dimensions of inequality converge to impact health outcomes and recommend using intersectionality theory to create a richer understanding of the social determinants of immigrant health. While not explicitly focused on African immigrants, this article provides rich context and findings on the systemic, institutional, and societal challenges and the resultant health impacts that racial minority immigrant groups face in the United

States. Findings will inform interview questions for participants in this study and obtain a holistic view of their day-to-day experiences in navigating health and social support systems in the United States to care for their children with complex needs.

History of Respite Care Services

Macquarie Dictionary notes that the term "respite" means to temporarily relieve from anything difficult or distressing or give a break of relief (O'Brien, 2001). In the United States, respite care concepts began in the 1950s when parents pursued government support for specialized childcare payments. With respite care principally framed around intellectual disability, the first Federal legislation was enacted by Congress in 1963 to assist persons with intellectual disability (Paige, 1970). In the 1970s, professional respite care program models developed through family grassroots efforts, state pilot initiatives, and local area initiatives in the United States, shifting away from segregating and excluding children with disabilities to integrating into community life (Agosta and Melda, 1995; Racino, 1998). Paige (1970) also notes that respite care emerged as an integral part of comprehensive community services and that according to U.S. policy, respite care became defined as appropriate services, in various settings, provided for the care of persons with intellectual disabilities through temporary separation from their family, inside or outside the home, for short, specified periods on a regular or intermittent basis. Respite care would also involve other services as needed on an individual basis to relieve the family of their care to meet a planned or emergency need; restore or maintain physical or mental well-being, or initiate training procedures in or out of the home. Respite care services have since expanded beyond serving persons with intellectual disabilities to serve families with children with other complex needs and terminal illnesses via large social service agencies at both community and state levels (ARCH National Resource Center, 2010).

Carnevale, Rehm, Kirk, and McKeever (2008) note that decades later, although some in-home respite care programs provide coordinated, comprehensive health and social services within children with complex needs's communities, they are not customary. Parents are navigating inadequate support in communities inundated with social, physical, and policy barriers. The availability of funds to support families with children with complex needs varies from country to country (Teo, Kennedy-Behr, and Lowe, 2018; Nishigaki et al., 2016; Spruin, Abbott, and Holt, 2017; Hill, 2016; Sung and Park, 2012; Cantan, Bolger, and O’Donovan 2017) primarily based on how much government view respite care and family support as a policy priority.

Purpose and Effectiveness of Respite Care Services

Evidence of respite care effectiveness is extensive in the literature and widely understood that it serves as a stress-reduction mechanism for primary caregivers and yields positive effects for participating families (Sung and Park, 2012). Aldgate, Bradley, and Hawley (1996) suggested that respite care serves a range of purposes in preventing family breakdown, including providing relief from parental stresses, offering an alternative to long-term hospitalization or institutionalization, and helping with stress from life in cyclical poverty. Respite care services also help parents address their challenges; provide an early diversion from possible physical abuse and provide parents support and ideas in healthy and positive child management.

In a systematic review that integrated the findings of 15 quantitative and qualitative studies of families with children with complex needs receiving respite care services, Strunk (2010) found that irrespective of the severe illness of children with complex needs in participating families, parental income level, or locale, respite care services are needed support for families with children with complex needs. Results also indicated that the need for respite care is high among families with children with complex needs, and respite care is associated with a reduction in parental emotional and psychological stress. Where parents of children with complex needs are more likely to self-report ongoing strain, emotional distress, chronic fatigue, poor health status, higher clinical depression rates, anxiety, high levels of family conflict, disruption, and low-quality marriage, respite care remains pivotal for the primary caregivers of children with complex needs (Boss et al., 2020; Carnevale et al., 2008; Dyches et al., 2015; Pilapil et al.,, 2017; O'Brien, 2001; Norton et al., 2016). Researchers have found that respite care utilization has significant advantages for parents and siblings of children with complex needs, including improvements in psychological adjustment, mental health, fatigue, and quality of life (Cooke et al., 2020; Norton et al., 2016). Findings of a cross-sectional survey conducted in the United Kingdom for family caregivers of children with complex needs who utilized one of three local respite care service agencies also showed that quality of life increased for children with complex needs at 81, 90, and 63% in each service opportunity and decreased by 3, 3, and 11%, respectively. The results imply a net positive effect on children with complex needs and their families receiving respite care services (Spruin et al., 2018).

Several studies have attempted to measure the effectiveness and outcomes of respite care services for families caring for children with complex needs. Aldgate (1998) tracked the progress of a sample population of 60 children with complex needs and their families utilizing respite care services. Employing an exploratory design, researchers gathered data from parents, children, and social workers before utilizing respite care services and from parents, children, and social workers after using respite care services or no later than nine months after the receipt of service. The goal of the study was to measure the outcomes of using short-term respite care in terms of whether families remained intact; whether services ameliorated parents' challenges; whether services met parents' needs; whether social workers met their aims; how children perceived the service at the end; and whether changes occurred in the perceptions of older children. The study results showed that quality of life improved for parents as they felt more in control of their lives and empowered to manage their problems better, and their expectations of the services were met. Ninety-two percent of the families remained intact, considered a successful outcome by all standards. In less complex cases, social workers were more satisfied with their interventions. Children also generally enjoyed their experience with respite care services and the kindness and quality time with their caregivers.

Otsuki, Fukui, Sakaguchi (2020) developed a reliable and valid measure to quantify respite care benefits for families with children with complex needs in Japan. Researchers recruited 465 family caregivers to complete a survey questionnaire responding to items on respite care benefits for themselves and their children with complex needs. Results indicated that respite care plays a critical role in the developmental trajectories of children with complex needs, building a sense of peace and life fulfillment among their mothers as their primary caregivers, provision of mental health support for their mothers, and expanding their perspectives and outlook on the future by measuring their social participation. The measure can be used in observational research to inform intervention studies in determining the respite care needs of children with complex needs.

Sung and Park (2012) examined a family support program that included respite care services for primary caregivers of children with disabilities in Korea. The study measured parenting stress and family quality of life before and after receiving respite care to verify intervention effects. Utilizing an experimental design, 21 primary caregivers of elementary students with disabilities in Buchen, Korea, were selected to participate in the study for six months. Researchers assigned participants to three groups (seven caregivers per group) with Group A receiving 4 hours of respite care twice per week; Group B receiving respite care and additional family support programs, and Group C serving as a waitlist control group. Results showed that Group A and B's parenting stress reduced after receiving respite care and additional family support interventions. Parenting stress increased among Group C; however, the difference between the experimental and control groups was not statistically significant. The study also found that respite care, combined with other family supports, had positive effects on family quality of life; however, respite care on its own did not have any effect. The study results raised two important points for further exploration in this literature review process: 1) recognizing empirical findings that suggest that respite care interventions alone have little effect on caregiver's well-being, and 2) the importance of respite care services working combined with other parts of integrated care and coordinated family support programming to ensure positive effects on parenting stress and family quality of life (Earle and Dadebo, 2004; Kaurstad and Bachmann, 2014; Koch and Jones, 2018; Pilapil et al., 2017; Sung and Park, 2012; Townsley et al., 2004;).

A study conducted in Queensland, Australia (Teo et al., 2018) also concluded that there is little evidence that respite care has consistent or lasting benefits to parents' well-being in caring for their children with complex needs. The qualitative study used Appreciative Inquiry in two phases to understand parents and respite care service providers' perspectives. Findings indicated the importance of flexibility in types of support based on parents and their children with complex needs and better accessibility to funded supports that parents can tailor and design to fit their individual and family needs.

Respite Care as Part of Integrated Health Care and Family Support Programming and Policy Implications

Research studies principally from other industrialized nations have consistently shown respite care effectiveness as a part of integrated health care and family support programming. Early works and reviews of the literature have established the necessity of coordinated, interagency and intersectoral responses to the needs of children with complex needs and their families at local, state, and national policy levels and have recognized the need for systemic change (Kuo et al., 2011; Racino, 1998; University of Washington Center for Disability Policy and Research, n.d.;Young et al., 2004). A consensus reached among researchers to date is that all levels of government should assign higher priority to develop coherent policies for children with complex needs and their families – in their homes and communities to improve service integration and coordination to alleviate gaps and inconsistencies that leave children with complex needs and their families unable to access services (Young et al., 2004; Cantan and Bolger, 2017; Bradshaw et al., 2019; Cooke et al., 2020).

The themes that emerged from the interviews conducted in Young et al. (2004) centered on ongoing support, coordination of services, monitoring, extensive communication, professional development, increased quality of life for children with complex needs and their families, improved access to services, as well as improved awareness and funding of services as the working elements of a successful integrated health care and family support program including respite care services. Reflecting on the findings of the study, which examined an evidence-based integrated health and family support program for children with complex needs and their families in Canada, it is necessary to take an extensive look at how the fragmentation of services between sectors for children with complex needs and their families contribute to unmet needs and access barriers for these families in the United States.

Studies from Nageswaran (2009), Kuo et al. (2011), and a report from Waldman, Compton, Cannella, and Perlman (2013) based on secondary data from 2001, 2005-2006, and 2011-2012 National Surveys of Children with Special Health Care Needs respectively, provide additional insights into how adverse sociodemographic factors, children with complex needs health status, as well as care inaccessibility, lack of care coordination, along with fragmented services between sectors further compound the likelihood that children with complex needs will not receive needed care. Nageswaran explored the link between sociodemographic factors and the health status of children with complex needs that need respite care and have unmet needs for respite care. The study determined that respite care needs were least met among parents with younger children with complex needs, had low maternal education, was of minority race/ethnicity, from low-income households, and had uninsured/having insurance gaps/public insurance/or other types of insurance. Kuo et al. (2011) noted that there was little known on a national level in the United States about the effects of children with complex needs caregiving on families. Consequently, the authors developed a national profile of caregiver challenges of children with complex needs using and analyzing secondary data from the 2005-2006 National Survey of Children with Special Health Care Needs. Kuo et al. found that based on service gaps identified, the optimal approach to providing effective family support for families and their children with complex needs is to ensure enhanced care coordination support, respite care, and direct home care to address the multiple challenges families face.

Reflecting on the complexity of the issues facing children with complex needs and their families, the role of local, state, and national policies is of extraordinary significance. Hill (2016), Nishigaki, Yoneyama, Ishii, and Kamibeppu (2017), and Spruin et al. (2018) recognized that the role of government policy is crucial for children with complex needs and their families in gaining equitable and sufficient access to respite care services. Western industrialized nations including Japan, the United Kingdom, Canada, the European Union, and European Economic Area, Ireland, Australia, and Norway have recognized the necessity for establishing better and more coordinated health and family support services for children with complex needs and their families as a national policy priority (Brenner et al., 2017; Cantan and Bolger, 2017; Kaurstad and Bachmann, 2014; Nishigaki et al., 2017; Spruin et al., 2018; Teo et al., 2018). While many of these governments are well-intentioned in prioritizing respite care and extensive coordinated family supports many pay limited attention to adapting respite care services for the families most in need, due in part to a significant lack of information on how to successfully achieve necessary levels of coordination for children with complex needs and their families in practice (Koch and Jones, 2018; Spruin et al., 2018; Townsley et al., 2004; Zurynski et al., 2017;). Consequently, children with complex needs and their families often fall between the cracks due to exclusionary criteria, ambiguous categories, and service gaps (Carnevale et al., 2008). With the vulnerability of children with complex needs and their families, it is crucial to develop a comprehensive understanding of the host of unmet needs and access barriers identified in the literature.

Unmet Needs and Access Barriers to Respite Care Services

Consistent with previous research, respite care services are available on an ad hoc basis, accessible in some areas more than others, and are often diagnosis dependent (Hill, 2016; Woodgate et al., 2015). The lack of respite care services is a recurring theme across western industrialized nations including Ireland, the United Kingdom, and Australia, with studies in Australia highlighting, for example, the only children's hospice in Brisbane closing down in 2009 due to lack of funding, leaving no pediatric respite facilities available in the region (Hill, 2016).

As previously noted, unmet needs and access barriers to respite care and family support services for children with complex needs and their families are well-discussed in the literature. However, research and data specific to access barriers to respite care services for African immigrant mothers and their children with complex needs in the United States are nonexistent. A review of studies on respite care services for children with complex needs and their families across Australia, Norway, Ireland, Sweden, Canada, the United States, Pakistan, India, and Kenya yield rich insights into unmet needs and access barriers these families face (Breneol et al., 2019; Carter and Bray, 2017; Cooke et al., 2020; Dybwik et al., 2011; Nageswaran, 2009; Palisano et al., 2009; Sobotka et al., 2019; Teo et al., 2018; Welsh et al., 2014;). Parents reported often being dissatisfied with respite care received while others reported needing more support; not having the right frequency; not being to access care at necessary times; not having sufficient length of time during care; not being able to afford care (Cooke et al., 2020; Nageswaran, 2009; Welsh et al., 2014;). Other issues reported included a lack of training of respite care staff with staff receiving, in some instances, training only up to 10 hours (Upshur, 1983); haphazardness of service responses; lack of reliability and continuity of staff; unavailability of services; and insufficiency of services (Teo et al., 2018). In two studies, mothers also noted that while high levels of stress are a primary motivator for accessing respite care, the lack of access to respite care was a significant stressor (Cooke et al., 2020; Dyches et al., 2015). It is unknown that African immigrant mothers caring for their children with complex needs in the United States will share similar experiences or more adverse experiences.

The access barriers identified across the same body of literature are more extensive and individual/sociocultural and systemic in nature (Breneol et al., 2019; Carter and Bray, 2017; Cooke et al., 2020; Dybwik et al., 2011; Koch and Jones, 2018; Nageswaran, 2009; Palisano et al., 2009; Sobotka et al., 2019; ; Teo et al., 2018; Upshur, 1983; Welsh et al., 2014; Woodgate et al., 2015;).

Individual/sociocultural barriers noted by parents included unpredictable and unstable health of children with complex needs creating challenges for planning and accommodating respite care visits; the need for specialized equipment limiting the extent and level of respite care staff support due to complexity of children with complex needs's needs; cost as a barrier to respite care services for most parents without financial or grant assistance; the severity of children with complex needs health status also dictates the model of support that a children with complex needs needs; parents do not trust respite care workers and prefer to not risk their children with complex needs with them for the benefit of a break; and some parents have a lack of knowledge, not knowing what to ask medical professionals which limits them from learning about available support services.

Systemic barriers reported by parents were extensive. Funding sources for respite care services are limited depending on the nation and how much children with complex needs, their families, and the provision of respite care are prioritized in local, state, and national policies and budgets. Funding barriers exist because respite care is often not a required service under private insurance benefits while most U.S. states provide respite care under Medicaid Home and Community-Based Services 1915 Waivers. As waivers are not entitlement programs, families are often placed on waitlists prior to receiving respite care. Wait times can be years long when obtaining respite care support through the government. Additionally, not all children with complex needs families are eligible for respite care funding, and there are restrictions on services for which the funding can be used, and there is no interchangeability for other services. This limits the opportunity to deliver family-centered respite care and family support for children with complex needs and their parents. Processes through which children with complex needs can access respite care funding and services are significantly complex. Documentation and application processes required to obtain funding for respite care are daunting with significantly strict requirements for approval and required routine recertification to remain eligible to receive fund assistance. Variability with rules and regulations across respite care provider agencies which can limit families' ability to access or utilize respite care services. Whether receiving in-home or center-based respite care services, time and date availabilities are inflexible for children with complex needs and their families. The lack of staff and nurse training limits the pool of staff available to support children with complex needs and their families. The challenges with healthcare professionals in the context of seeking support services including respite care and failure of health care professionals to inform children with complex needs parents about the availability of services. The tendency for medical professionals to be ill-informed about some children with complex needs conditions resulting in their limited ability to link parents with appropriate support including respite care. The roles and responsibilities of respite care support workers are poorly defined and there is a lack of agreement on the impact of care, and the feelings of fighting with the community health care systems because despite having one of the world’s best health care systems, care for children with complex needs presents an enormous challenge for service providers.

The scope of unmet needs and barriers to respite care services point to a universal and systemic challenge in optimally supporting children with complex needs and their families. One of the primary barriers to respite care services across western industrialized countries is funding. Several studies discuss the structure and processes of funding for respite care and family support services (Parish et al., 2000; Pilapil et al., 2017; Koch and Jones, 2018). Mclung, Glidewell, and Farr (2018) specifically discussed financial burdens on families of children with complex needs with congenital heart disease- one of the primary conditions along with rheumatic heart disease found among African immigrant children with complex needs (Animasahun et al., 2018; Jivanji et al., 2019; Kvarme et al., 2016).

Parish, Braddock, Hemp, Lakin, and Smith (2000) noted that family support services are financed by state-level MR/DD agencies using vouchers, direct cash payments to children with complex needs families, reimbursement, or direct payments to the service providers identified as family support agencies (includes respite care providers). The most recent national data indicated that in 2004, 1.98 billion was allocated for family support services across the United States. New York State spent $53,957,000 on family support services for 51,231 families, with the average annual spending per family at $1,053 due to an 8 percent reduction in funding and 17 percent reduction in the number of families receiving family support services. The State of New Jersey also spent $57,227,488 on family support services for 9,167 families, with spending per family at $6,243 due to a 25 percent increase in funding and 12 percent increase in the number of families receiving family support services (University of Minnesota-Research and Training Center on Community Living, 2006). A search for current year allocation yielded no results; however, funds are disbursed to families in the form of cash subsidy programs via direct payments or vouchers to manage or control spending for support services received.

With limited funding and subsidies available for children with complex needs and their families, high out-of-pocket costs are often incurred. However, they may qualify for financial support through Social Security Income (SSI), which is funded by tax revenue and serves to cover shelter, clothing, and food for eligible children with complex needs and their families (Pilapil et al., 2017). Some children with complex needs may also be eligible for coverage under their state Child Health Insurance Program (CHIP) or Medicaid programs depending on the complexity and severity of their condition and family income. However, as of 2010, Mclung, Glidewell, and Farr (2017) found that roughly 400,000 children with complex needs remained uninsured. It is unclear in current state policies whether African immigrant children with complex needs can readily be covered under the CHIP, Medicaid, or SSI programs. Policy researchers have suggested that whether these families are citizens, legal immigrants, or undocumented, they face barriers when attempting to access health care or apply for health coverage (Ambegaokor, 2012) – highlighting a definite gap in the literature on the availability of respite care services for immigrant families with children with complex needs in the United States.

Respite Care Services for Immigrant Parents with Children with Complex Needs

Kvarme et al. (2016) found that immigrant mothers of children with complex needs reported significant health problems due to a lack of respite care, support, and social networks. Even as Norway provides families with children with complex needs with extra support through universal and selective welfare services available to all country inhabitants (Kvarme et al., 2017), immigrant mothers of children with complex needs remain most vulnerable and struggle to access resources. This pattern is highly similar across other western industrialized nations irrespective of differences in health and social welfare systems. While immigrants also face challenges accessing health care and other support services due to low socio-economic status, lack of insurance, reliance on need-based programs, lack of transportation, language barriers, cultural beliefs, and difficulty navigating the complex US health care system (Agrawal et al., 2018; Ambegaokor, 2012; Aroian, 2005; Breneol et al., 2019; Cummings and Hardin, 2016), a future point of inquiry may be examining the differences between the levels of access to respite care and other family support services for African immigrants with children with complex needs and those of European immigrants with children with complex needs in the United States.

A US Census Bureau data review on European immigrants has indicated that 71 percent of European immigrants are more likely to have private health insurance than other foreign and native-born populations in the United States. Thirty-six percent are more likely to have public health insurance, and the remainder of the population likely to be uninsured (Zong and Botolova, 2015). Additionally, a critical analysis of four studies examining equitable, effective, and efficient health care and support services across older low-income immigrants and minorities, including Russian and Chinese immigrants, concluded that Russian immigrants did not report inequitable access to health care or limited access to resources. Another study utilizing data from an exploratory survey conducted in 2010 thru 2012 in the Northeast US region found that 67 percent of the 122 families participating that identified as Black or other non-White reported having less family-centered care in the care setting policies, practices, community coordination, and follow-up for their children with complex needs than the families who identified as White (Zajicek-Farber et al., 2017). An assessment of an intensive care coordination program seeking to improve its effects on children with complex needs from an ethnically diverse patient population also supported findings that families of racial and ethnic minority children with complex needs are at significant risk of reporting a lack of satisfaction with medical and family-centered care (Hamilton et al., 2017). These studies provide indicators of potential disparities and challenges that African immigrant mothers face in accessing respite care services in caring for their children with complex needs. While systemic barriers are identified in the literature for families with children with complex needs accessing respite care and family support services, culture also serves as a barrier to immigrants' decisions to utilize such services.

Role of Culture with Parents of Children with Complex Needs Seeking Access to Respite Care Services

A review of the literature on immigrant families and childcare found that it is not unusual, irrespective of health status or ability, for young immigrant children to be under the care of a parent due to part-time work arrangements, cost of care, and concerns about external cultural influences (Obeng, 2007). For many immigrants, including African immigrants, the US health care system is different from what they are familiar with in the native countries and the non-western health care practices they trust more readily than the American health care model (Ambegaokor, 2012; Nishigaki et al., 2017). Researchers have discussed the psychological burden that being separated from their children causes in Japanese mothers as Japanese traditional child-rearing culture requires that mothers be with their children until the age of 3 (Shiozaki and Muto 2006). The feelings of guilt and anxiety limited their willingness to utilize respite care.

Similarly, African immigrant mothers participating in a qualitative study using interpretive phenomenological analysis found that exposure to western, allopathic medical explanations for their children's diagnosis with an autism spectrum disorder create an emotional and cultural dissonance (Munroe, Hammond, and Cole, 2016). Their traditional beliefs, including a high value on privacy, kept them from seeking support or sharing their children's diagnoses with employers or community members, which may have allowed opportunities to build their support networks. The stigmatization of disabilities within African culture also played a role in mothers' reluctance to seek support (Munroe et al., 2016).

Tilahun, Hanlon, Fekadu, Tekola, Baheretibeb, and Hoekstra (2016) conducted a cross-sectional facility-based study explored the experiences of caregivers of children with autism spectrum disorders or intellectual disabilities (ASD/ID) to understand stigma, unmet needs, explanatory models, desired interventions, and their coping mechanisms in caring for their children in Ethiopia. The authors found that of the 102 participants, 43% were worried about being treated differently; 45% felt ashamed about their child's condition; 26% felt it necessary to hide their child's condition in the community; 24% were concerned about potential suitors having the reluctance to marry into their families, and 39% had concerns about taking their child outside their home. Participants experienced challenges explaining to community members that their child did not have a mental illness. Many also attributed their children with ASD/ID's condition to supernatural or biomedical causes, for which 47% of them blamed themselves. Migration to western industrialized nations does not alter such beliefs. African immigrant mothers of children with complex needs generally have strong connections to their African culture (Munroe et al., 2016). Consequently, culture may be a significant barrier to African immigrant mothers with children with complex needs attempting to access respite care in the United States. Inequitable access to services is also a challenge that requires further discussion.

Inequitable Access to Respite Care Services for Immigrant Mothers of Children with Complex Needs in the US

Studies have acknowledged that health care and other family support services are not equitable for immigrants in the United States, particularly African immigrants (Adegboyega and Hatcher, 2016; Aroian, 2005). Contributing factors are well-established in the literature and have been discussed throughout the chapter; however, examining the oppressive link between race, disability, life-limiting illnesses, and complex needs are necessary.

Stuart (1992) suggested that oppressive experiences of being Black and disabled [or caregiver of Black and disabled person] occur all at once as a singular experience. Often judged through a western lens, certain ailments are viewed as inherently a failure of Black people to follow western practices. Consequently, Black families with children with complex needs also contend with unconscious biases in which they endure stigmatizations that impact the extent of funding and resources allotted for their benefit. Their cultural views and beliefs about their conditions are often viewed as primitive and result in their marginalization in the planning and developing services and delivery systems (Munroe et al., 2016; Stuart, 1992; Tilahun et al., 2016).

This approach to Black families remains prevalent today and is emblematic in the paucity of knowledge on African immigrants' healthcare needs and experiences in the US. Research remains limited due to the absence of research and funding on immigrant health on the African population and the view that Africans are the same as all Black populations in the United States (Omeka, Watson, and Hendrie, 2020). Much of the existing literature reviewed in this chapter addressed barriers in the context of general inequities for all children with complex needs or racial and ethnic minorities without acknowledging the deep-rooted and systemic context of the identified barriers and inequities.

Garcia (2017) presented one of the most cogent points in the literature that by ignoring the realities of racism and perpetuating white-dominant ideologies, the beneficiaries of racism continue to benefit from sociostructural inequalities. White dominant-ideologies hinder certain groups from advancing or having access to resources and specialized services in the United States and the failure to acknowledge race as a barrier to accessing critical services does not eliminate the reality of racism embedded in US systems (Brainard, 2009). Ford and Airhihenbuwa (2010) emphasize that systemic racism impacts health outcomes and the production of knowledge about marginalized populations, their health, and health disparities.

Summary and Conclusions

The problem of unequal access to health and support services for immigrant families with children with complex needs has been approached qualitatively using various experimental designs and systematic reviews yet challenges that minority immigrant families of children with complex needs remain systemic. This points to a need to approach the problem via a CRT lens and determine how actual transformative and systemic change can begin. African immigrants are the least studied population in the U.S. due to a lack of interest in African immigrant health as they are viewed along with all Black populations in the U.S. as monolithic. NSCSHCN underreports special needs children in immigrant households (Warden et al., 2019).

The problem has undergone examinations using socioecological models, with emphasis on intersectionality and social support models. There are currently no peer-reviewed articles that examine access barriers for African immigrant mothers caring for children with complex needs using a CRT model. By using this approach, this study may present opportunities to look at systemic ways that African immigrant mothers of children with complex needs in the U.S. can be best supported. It is crucial, particularly for African immigrant mothers, practitioners, policymakers, insurers, health systems, program leaders, and researchers to identify and understand individual and system-level barriers involving researching, developing, funding, implementing, and evaluating respite care interventions, models, and programs in their contexts.

I used one-on-one semi-structured interviews with African immigrant mothers of children with complex needs to identify access barriers to respite care they encountered in the region.

Chapter 3: Research Method

The central phenomenon under investigation in this study is how African immigrant mothers describe access barriers to respite care services in terms of caring for their children with complex needs and the role of race in their potential lack of access to services. I adopted a generic qualitative approach to best address the research question. The primary feature of generic qualitative research is methodological flexibility.

Using CRT, the study is built on the premise that repositioning race and racism as central in the pursuit and creation of health equity is necessary to improve acute pediatric health outcomes and reduce related disparities. Without acknowledging the racial stratifications across social, political, and economic levels of society, outcomes will remain unchanged. Study findings could inform practitioners, policymakers, insurers, health systems, program leaders, and researchers in terms of serving African immigrant mothers, their children with complex needs, and families in the region and lead to for African immigrant communities and similar communities in the U.S. and other western industrialized nations.

Chapter 3 includes discussions of the research design, rationale, theoretical framework, research sample, population, and data collection and data analysis processes needed to address the research question.

Research Design and Rationale

The research question under investigation in this study is:

How do African immigrant mothers of children with complex needs describe and perceive access barriers to respite care services?

In adopting the generic qualitative research approach, my goal was to access subjective opinions, beliefs, attitudes, and reflections of participants while acknowledging race and racism as central to their ability to access essential health and social support services. The generic qualitative design is used to answer straightforward questions regarding practical consequences and useful applications of what researchers and their audiences can learn about a real-world or social problem (Keen et al., 2018).

I collected rich and in-depth information from participants regarding barriers they perceived and experienced accessing respite care services when caring for their children with complex needs. One-on-one semi-structured interviews using broad and open-ended questions with everyday language guided by a CRT approach were used for participants to provide detailed stories. I used an interview guide approach to obtain data from participants to keep structure and consistency during the interview process, and questions generated detailed stories with a minimum of seven primary questions and probing questions.

I used a highly inductive methodological approach with open coding, categories, and thematic analysis.

Role of the Researcher

As an African immigrant mother of a child with complex needs who has lived experiences regarding racism in the U.S. in a healthcare context and is immersed in dialogues and scholarly literature regarding CRT, race, and discrimination in America and the developed world, I was cognizant of potential biases during this study. I understood African immigrants are not a monolith and come from various realities and backgrounds. Acknowledging this fact allowed me to maintain objectivity in addition to using specific bias reduction mechanisms. I was the interviewer, transcriber, and data analyst and adhered strictly to a postmodernist ontology and emic epistemology. Researchers must explicitly identify their biases, values, and personal and cultural backgrounds that may influence their interpretations of data, themes, and patterns (Chan, 2017; Palaganas et al., 2017). In this study, I used a peer review and expert process to guide development of survey questions. I also employed open-ended questions for participants to describe their experiences with accessing respite care services for their children with complex needs. I practiced reflexivity to carefully assess my assumptions. I made my possible biases explicit to my audience and considered those biases in designing, conducting, analyzing, and writing results of my research using reflexive journaling to create transparency during the research process.

To collect data for analysis, I collaborated with local pediatric practices serving African communities across the U.S. as well as African immigrant faith centers (churches and mosques) and community centers. I had no affiliations with any of these entities. I also took precautions to ensure I did not have professional or personal ties with participants who were selected for the study.

Using a CRT lens also involved centering participants as experts on their perceptions and experiences involving accessibility to respite care services when caring for their children with complex needs.

Methodology

Participant Selection Logic

The population under study will be African immigrant mothers of children with complex needs living in the United States. As the African immigrant population in the United States is under-researched (Omenka et al., 2020), there are many unknowns regarding the potential number of participants. The most recent statistical data on the number of children with complex needs out of the United is unknown. There is no verifiable US Census data on the country and age breakdown of the African immigrants in the United States.

Researchers found a high prevalence of chronic diseases among African-born children (Hoffman, 2013; Jivanji et al., 2019; Muhame et al., 2014) and African immigrant children in the United States, with conditions such as rheumatic heart disease, congenital heart disease, thyroid disease, congenital hypothyroidism, cerebral palsy, sickle cell disease, and thalassemias (Kroenig and Dawson-Hahn, 2019), there is limited data on the health status of these children, and their family's access to respite care services. Of the African immigrant children under the age of 18 in the United States, it is unknown how many are living with heart conditions and a range of other chronic diseases that require constant monitoring and care.

According to Liu (2016), generic qualitative research requires purposive sampling, where the sample is derived based on the researcher's discretion, the nature of the study, coupled with the researcher's understanding of the target audience. Under this non-probability sampling method, only participants who fit the research criteria and study objectives are selected, and the remaining are excluded. While results will not be statistically generalizable across similar groups, findings can provide insights for practitioners, policymakers, program managers, researchers, insurers, and health and social service systems. The population under study required only African immigrant mothers caring for children with complex needs in the United States, as they were the select participants that could yield appropriate and valuable information for this study.

Selection criteria are purposed to obtain a manageable sample for analysis (Aspers and Cortes, 2019). Nageswaram (2009) found that the need for respite care tends to be higher among children with complex needs of a younger age, minority race/ethnicity, low-income households, and low maternal education. While African immigrants are not monolithic, it is well established in the literature that African immigrants are at greater risk for racial discrimination, skill devaluation, lower earnings, and underemployment despite the high levels of skills and knowledge, and experience among them (Saasa, 2019). It is also understood in the literature that mothers are often the primary caregivers of children (Khanlou et al., 2017). To meet the criteria, participants in this study were African immigrant mothers caring for their children with complex needs (ages seventeen and under) living in the United States.

Malterud, Dirk Siersma, and Dorrit Guassora (2016) proposed using "information power" to guide a sufficient sample size for qualitative studies. The concept of information power denotes that the more information a sample holds and is relevant for the study, the fewer participants are required. Malterud et al. suggested that a sample size with adequate information power will depend on (1) the purpose of the study, (2) the sample particularity, (3) the use of proven theory, (4) the quality of discussion, and (5) the analysis strategy. Utilizing these elements as guides ensured that sufficient information power was achieved. While sample size guidelines are ambiguous in qualitative research studies, the sample size recommendation to ensure full information is derived was 15 to 20 participants. Data collection would end when the process no longer yields new themes and categories to explore.

Instrumentation

Generic qualitative studies often require more than one data collection method to conduct the study (Keen et al., 2018) and ensure rigor (Cooper and Endacott, 2007). Instruments in this study included semi-structured in-depth interviews, audio recordings, and research/reflexive journaling.

Chenail (2011) noted that qualitative researchers tend to develop study-specific, open-ended questions to allow participants to contribute their perspectives with little to no limitations imposed by close-ended questions. Based on the extensive literature review on the topic of interest, I developed open-ended questions grounded in the literature, different from previous research, and still need to be answered - from the least challenging to the most difficult (Jacob and Ferguson, 2012). The questions produced detailed stories using a minimum of six primary questions and probing questions and focus on gaining descriptive information on the experiences and perceptions of African immigrant mothers in accessing respite care services for their children with complex needs in the United States.

An interview guide approach was used to obtain data from participants but keep structure and consistency during the interview process across all participants (DeJonckheere and Vaughn, 2018). The broad and open-ended questions were formulated in everyday language, guided by a critical race approach, to allow for detailed stories (Obasogie, Headen, and Mujahid, 2017).

Given the limited time available to these prospective participants, planned initial interviews ranged from 60 minutes to 90 minutes face-to-face via Doxy.me and follow-up interviews where necessary for 10 minutes to 25 minutes via telephone or web chat to clarify responses based on participants' availability.

The first interview included questions about participants' background experiences, personal experiences caring for their children with complex needs, and experience with accessing respite care services in the region. These questions would help with gaining understanding of the participants' experiences accessing respite care. I obtained permission to record audio of all interviews to allow for triangulation of the data collected. I also utilized journaling to record vital notes and observations as well as limit bias in the analysis of the data. These instruments allowed for sufficient data collection to determine how African immigrant mothers in the United States describe the access barriers to respite care services in caring for their children with medically complex, life-limiting, life-threatening, or technologically dependent conditions. The interview questions were developed by the researcher and submitted for review by the committee chair and a panel comprised of Walden University School of Social and Behavioral

Science faculty and peers with terminal degrees. The interview guide and relevant questions can be found in Appendix A.

Procedures for Recruitment, Participation, and Data Collection

Selected pediatric practices, faith, and community centers will afford opportunities for targeted access to African immigrant mothers caring for their children with complex needs (ages seventeen and under) and their families. Participants were to also be recruited via snowball sampling and the distribution of flyers on social media platforms. Participants were interviewed one-on-one via Zoom or Doxy.me. Participants were informed that interviews will be recorded. Letters of agreement were obtained with each entity where flyers were distributed to recruit participants. While the recommended sample size is 15 to 20, recruitment and data collection continued to the extents possible and until there were no more new themes and categories for exploration.

Data Analysis Plan

I followed the Lester, Cho, and Lochmiller (2020) guidance for conducting thematic data analysis in these successive steps. I prepared and organized data for analysis by gathering all audio-recorded interview files into one location; created a Word or PDF document of observational notes; and scanned documents obtained in paper form. I developed a structured naming process for each file as well as a catalog system listing each data source, creator, storage location, and the date of creation. I transcribed my own data using verbatim transcription and performed an initial analysis taking notes on ideas and experiences that study participants describe during interviews, via observations, field notes, and my reflexive journal. The initial analysis occurred by detailing my early reactions to the data as part of my reflexive journaling. The process helped me identify the limitations and gaps in my collected data. I also generated memos in electronic format to attach to primary data sources. Memos were suggestive not conclusive.

I followed the Saldana (2016) guidance for coding data in three phases including priming the data and assigning codes; returning to the passages and data segments assigned in the first phase; and coding to make explicit connections to the study's conceptual and theoretical ideas. I then moved codes to categories and categories to themes. I also developed an audit trail in tabular form including information from the manuscript for transparency.

I performed the data analysis manually and developed a coding framework. The analysis was combined for participants, including patterns and themes consistent across the data, and synthesized together to create a composite synthesis of data regarding the question under investigation. Following Percy et al., 2015, the study was strictly data-driven and free of pre-understandings and suppositions.

Issues of Trustworthiness

Credibility

In selecting strategies to ensure rigor, also referred to as trustworthiness, I adopted the Morse (2015) recommendations for achieving rigor in this study. Credibility deals with how well participants' perceptions and experiences of a phenomenon are represented in a study and serves as the equivalent concept of internal validity in quantitative research (Merriam, 1998; Morse, 2015; Korstjens and Moser, 2018; Shenton, 2004).

This study achieved credibility by 1) building thick and rich data across participants (Morse, 2015); 2) utilizing purposive sampling to better match the sample to the study's goals and objectives, improving the study's rigor, and ensuring trust in the data and results (Campbell et al., 2020); 3) establishing a coding system where the meaning of the analysis is the same between coders (Morse, 2015); 4) triangulating the data collecting data from multiple sites, using in-depth interviews, audio recordings, and field notes; and 5) practicing reflexivity providing descriptions of the contextual and connecting relationships between study participants and myself. I also acknowledged my positionality and sensitivities related to the phenomenon under study using a social identity map; observed and better understood my role in creating this new knowledge; diligently monitored the potential impacts of my biases, experiences, and beliefs on the research; and maintained balance and objectivity (Dodgson, 2019; Jacobson and Mustafa, 2019).

Transferability

Transferability or external validity describes the extent to which the findings of a study are applicable in other studies or settings (Merriam, 1998). To achieve transferability, I built detailed and thick descriptions of study participants and the research process to allow future qualitative researchers to assess whether the findings are applicable in their settings (Korstjens and Moser, 2018). Descriptions included the context in which I conducted the research; the settings; the sample population; sample size; sampling strategy; the socio-economic, demographic, and relevant characteristics; the inclusion and exclusion criteria; the interview procedures, topics, and themes;

changes in interview questions; and sections of the interview guide (Korstjens and Moser, 2018). In considering transferability for this study, I subscribed to the views of Stake (1994) and Denscombe (1998), who suggested that while qualitative studies are individually unique, each one is representative of a broader group.

Dependability

Researchers describe dependability as the consistency, reliability, and replicability of a study's data collection, interpretation, and analysis and obtain the same results if repeated (Morse, 2015). Validity (credibility) and reliability (dependability) are generally intertwined where attaining dependability is inherently a part of the process of attaining credibility (Lincoln and Guba, 1985; Morse, 2015). As such, there was a significant overlap between the steps taken to achieve dependability and credibility. Steps included triangulation, as discussed previously related to achieving credibility. Additionally, an audit trail was maintained, including all raw data; methodological processes; products of data reduction; synthesis; analysis; process notes; audio recordings, reflexive journaling; and steps in developing the study survey instruments were detailed to allow for replicability if a future researcher is interested in repeating the study (Lincoln and Guba, 1985; Shenton, 2004).

Confirmability

According to Korstjens and Moser (2018), confirmability involved maintaining neutrality and objectivity. An audit trail and reflexive journaling documenting personal notes and my thinking as the researcher throughout the research process was purposed to achieve confirmability per Lincoln and Guba (1985).

Ethical Procedures

Institutional permissions and IRB approvals were approved, and research ethics planning was completed to ensure compliance with ethical standards.

McLaughlin et al. (2015) recognized that migrant populations, including immigrants, present distinct vulnerabilities pertinent to protocol development and ethics review criteria and procedures. This study involving migrant populations was guided by the principles of (Clark-Kazak, 2017): 1) equity in which participants take the lead in the production of knowledge; 2) the right to self-determination in which the researcher respects the right of participants to make their individual decisions on the degree of participation in the study and access to information about their lives; 3) competence in which the researcher takes care to protect participants, their confidence, respect their time, and ensure that all phases of the data collection process are conducted in a culturally appropriate manner; and 4) voluntary, informed consent in which the researcher obtains necessary participant consents to participate in the study, informed of the benefits and risks of their participation, and ability to withdraw from the study at any time.

The study also complied with the Code of Conduct and Ethical Guidelines of Social Science Research (UNESCO, n.d.). Under these guidelines, the researcher was responsible for ethical issues and procedures related to the study. I conducted my research, maintained the integrity of the research field, and avoided any negative after-effects that could diminish the potential for future research. The choice of the research topic was based on the best scientific judgment and assessing the possible benefit to the participants and society given the risk to be borne by the participants and relate to an essential intellectual issue. Additionally, I considered the effects of my work, including any consequences or misuse, both for the participants and communities among whom I conducted my research and for colleagues and the broader society, among other tenets set forth by the code of conduct mentioned above.

Haram Klykken (2021) noted that ensuring free and informed consent is a primary ethical standard in conducting health or social science research to establish research relationships built on trust and integrity. Through informed consent, I safeguarded the freedom of participants to decide whether to participate in a study. Nussbaum, Douglas, Damus, Paasche-Orlow, and Estrella-Luna (2017) emphasize the importance of successfully communicating the risks and benefits of participating in the study, ensuring comprehension, and being prepared for the role of administering consent. I provided an informed consent form to participants before their respective interviews, allowed participants to review the form, reviewed the form along with them reading it aloud, and asked if they had any questions. Where participants were satisfied with all their concerns, I requested that they sign the consent form, and I provided them each with a copy. Given the nature of the population in this study and the constraints they face, informed consent documents were provided to participants prior to the study derived from research community guidelines and checklists.

Lobe, Morgan, and Hoffman (2020) highlighted the importance of safeguarding participants in the era of social distancing due to the COVID-19 pandemic. Where it was most ideal to meet face-to-face, considerations was given to the health vulnerabilities of participants and their children with complex needs. I utilized Zoom to conduct interviews with participants' consent. I also checked with my committee chair and ethics committee for any additional guidance regarding data collection in this era of the pandemic. The privacy and confidentiality of participants' data was paramount in this study. Data privacy protects participants from personal intrusions and interferences – physical, psychological, social, and informational (Leino-Kilpi et al., 2001). Participants maintained the right to control their personal information and data, and my responsibility remains to protect their information. I utilized fictitious initials in storing their information to protect their identities and maintain their privacy during and after the data collection process.

To comply with IRB requirements, participant data was encrypted and stored digitally on my password-protected computer and backed up on a password-protected hard drive. Researchers are obligated to protect the personal data of study participants, including personal records and proprietary information (Pietila, Nurmi, Halkoaho, and Kyngas, 2020). All physical documents and transcriptions were stored in a locked filing cabinet in my home. I provided my detailed recruitment, consent, and data collection plan, including the roles of local pediatric practices, churches, and mosques. To ensure participants' privacy in the data collection process, I utilized fictitious names in the study and limited all disclosures beyond logistics and arrangements if applicable. I also ensured that the mothers' age and country of origin and their children's medical condition were shared in a manner that will not render them identifiable. The names of partners, if applicable, were also kept private per Walden University standards for research studies.

Additionally, confidentiality agreements were signed by translators where necessary for the study. Lastly, the results of the study would be disseminated to participants and relevant stakeholders in the form of a brief report including recommendations for practitioners, policymakers, program leaders, researchers, insurers, and health and social service systems, as Boss et al. (2020) have noted that these immigrant mothers would be the experts of what works and what does not work in accessing respite care in their regions. Participant data will be kept confidential for five years and disposed of afterward.

Summary

For this generic qualitative study, I set out to recruit 15 to 20 African immigrant mothers in the U.S. caring for their children with complex needs (ages 17 and under) using purposive sampling to understand how they described access barriers to respite care services when caring for their children. I used semi-structured in-depth interviews, audio recordings, and reflexive journaling. Study-specific and open-ended questions were used during semi-structured interviews ranging planned for 60 to 90 minutes face-to-face via Zoom and 10 to 25 minutes for follow-up questions via telephone or web chat, if necessary, to clarify responses based on participants' availability.

I used thematic analysis to achieve rigor and validity by identifying themes and patterns through organizing, clustering, and coding data. Morse's recommendations were used to ensure rigor, credibility, and dependability. Lincoln and Guba (1985) and Korstjen and Moser (2018) guided my steps to achieve transferability and confirmability. I also prioritized protecting participants, ensuring equity where participants lead in creating knowledge, establishing, and guarding their autonomy and freedom to participate or decline participation in the study, emphasizing informed consent and data privacy.

Chapter 4 includes a discussion of the results of the study. I then discuss the population of interest. The data collection process and analysis are discussed in rich detail, followed by a discussion of trustworthiness and strategies to achieve credibility, transferability, dependability, and confirmability. Lastly, I discuss key results, conclusions, and recommendations.

Chapter 4: Results

This generic qualitative study involved understanding access barriers to respite care services among African immigrant mothers of children with complex needs in the U.S. This chapter includes a description of study settings, situational contexts, and demographics, data collection and analysis processes, evidence of trustworthiness, conclusions, and recommendations.

The research question for this generic qualitative study is:

How do African immigrant mothers of children with complex needs describe and perceive access barriers to respite care services?

Setting

I used participant inclusion criteria with an outreach plan for local pediatric practices serving African immigrant communities in the New York metropolitan region. On June 12, 2022, I began outreach to eight pediatric practices and nine African immigrant civic and social organizations across this region. This did not result in opportunities to recruit participants.

On June 24, 2022, introductory emails accompanied by the recruitment flyer were sent to two large African immigrant churches and two large mosques and their affiliated immigrant support programs in this region. I contacted four of the leading local African hair braiding salons, where I distributed flyers. This also did not result in responses from prospective participants.

On June 29, 2022, I reached out to area children’s specialized hospitals regarding policies for external research projects to explore potential partnerships for recruitment.

They responded and advised that their policy is to only recruit or list recruiting flyers for studies that involve their staff people in senior roles. I also contacted 14 other African civic and social organizations via Facebook to explore potential partnerships for recruitment, but there were no responses.

On July 10, 2022, I began outreach to local community leaders with significant African immigrant constituency and community members, including an East Orange, NJ councilperson, Newark, NJ city councilperson, African Society of Newark president, and leadership of the NJ Statewide Respite Care Program. My hope was that contacting community leaders would be a more practical approach to reaching my target population. This step also did not yield results.

On July 24, 2022, it became necessary to modify study criteria to African immigrant mothers of children with complex needs (ages 17 and under) and expand beyond the New York metropolitan area to improve chances for recruitment, given lack of response to the study.

Upon IRB approval of changes, on August 7, 2022, I began outreach with 14 African immigrant listservs and membership groups to distribute the recruitment flyer. I also contacted Pennsylvania-based organizations serving large African immigrant communities in the Upper Darby and Philadelphia areas.

On September 8, 2022, I opted to try keyword searches on social media platforms and found a potential participant. I sent the prospective participant (P1) an introductory email and recruitment flyer and asked if she would be open to participating in the study. P1 consented to participate, and I interviewed P1 the following day, on September 9,

2023. P1 provided two additional prospects who met study criteria. Both expressed interest in the study but opted against participation because they wanted to complete survey questionnaires in written form. The study requires verbal participation and consent to audiotaping.

On September 13, 2022, I conducted a phone meeting with a contact at a Philadelphia-based service organization regarding the prospect of recruiting participants. The connection noted one Ethiopian client has a child with a chronic condition but was reluctant to provide contact information because the client was guarded. The contact proposed I meet the client in-person to decide on participation. This proposal never materialized.

On the same day, I sent an introductory email and recruitment flyer to the lead for an autism program at a regional primary children's hospital. They led a workshop I attended to build my skills involving caring for my child with complex needs. They responded within the day and agreed to a phone meeting.

On September 16, 2022, I held a phone meeting which yielded several insights and suggestions for recruitment that I had yet to consider. Recommendations were for the recruitment flyer to emphasize benefits of the study, address data and privacy measures, and note they would receive a report of the study findings. They also suggested I contact special services, early intervention programs, daycares, schools, and Catholic and Baptist churches with large pools of African congregants.

I incorporated these suggestions into my outreach plan, but no participants resulted from these efforts.

Recruitment efforts continued until I found the next prospect meeting study criteria via my family network. In early to mid-October 2022, the prospective participant (P2) consented to participate in the study. On October 22, 2022, I interviewed P2. She did not have prospects to refer.

Within the following week, via my family network, I found a third prospect meeting study criteria in the early stages of diagnosis (P3). P3 consented to the study, and I interviewed her on October 30, 2022.

Recruitment efforts continued via New Jersey, New York, Georgia, and Minnesota-based case managers. Two prospects arose from this but opted not to participate in the study. I continued distributing flyers via social media groups and local business entities, including supermarkets, restaurants, and laundromats frequented by African immigrants in New Jersey and New York communities. One prospect inquired on behalf of an African immigrant mother with a child with sickle cell disease. Upon followup, the prospect opted not to participate in the study.

On January 7, 2023, I conducted another keyword search on social media platforms and found a prospect (P4). I required a contact to reach her. On January 25, 2023, the contact agreed to link me with P4 to determine their willingness to participate in the study. Following a brief discussion with P4 and explanation of the purpose of the study and terms of confidentiality, they consented to participate. On January 30, 2023, I interviewed P4. She did not have other prospects to recommend for the study.

Recruitment efforts remained underway via family networks, flyer distributions in local neighborhoods, and outreach to the leadership of Minnesota, Philadelphia, and New

York-based civic organizations (centers of large African immigrant communities). Participants did not result from these efforts. On June 12, following another keyword search on social media platforms, I found a fifth prospect (P5). P5 also required going a contact to ascertain her willingness to participate. By June 17, I received their consent to participate. We scheduled the interview for July 24th, 2023. The interview date and time were rescheduled and conducted on July 27, 2023.

Socioeconomic background, locale, education level, professional background, the severity of the child's condition/level of need, family structure, intra-family support, the role of culture, and resource access influenced each participant's responses. Four participants (P2, P3, P4, and P5) raised the issue of racial discrimination - at varied degrees - perceived as having the potential to be impacted by discrimination or being directly affected by it. I will primarily use their participant IDs (P1, P2, P3, P4, and P5) to protect participants' identities.

Demographics

All participants in the study were 21 years or older, African immigrant mothers living in the United States and caring for their children (seventeen years old and under) with complex needs that require respite care and other family support services. Study participants were recruited from across the United States. This section provides a profile of each participant.

P1 is an African immigrant married mother of two daughters (including a thirteen-year-old daughter with autism). Her daughter was diagnosed at age three, but P1 reports that she is fairly independent now, although she will need lifelong care. P1 has an advanced medical professional background, and her husband is a general internist in their locale. She also has a sister in the United States who is a pediatrician and the next of kin in their daughter's advanced and future care planning. She has opted to work independently to stay at home with her daughter, which allows her flexibility to pursue access to necessary services for her daughter.

P2 is an African immigrant single mother of six (including a six-year-old son with autism). He is the second youngest of her children. P2 reports that her child has a high level of need, and they receive an abundance of child-centered services that began with an early intervention program since his diagnosis at age two and a half. P2 reports not having or knowing about services that can help support her well-being as his sole caregiver. She also works outside the home, takes him and his siblings to school, and picks them up without day-to-day support. She also reports having another child- a daughter- with another neurodevelopmental challenge.

P3 is an African immigrant married mother of three (including a two-year-old son with an early diagnosis of autism). P3 and her husband live in an affluent township and are high-profile entrepreneurs. P3 reports concern about understanding her child’s needs and accepting his diagnosis. She reports that she and her husband have the flexibility to pursue necessary services for their son.

P4 is an African immigrant single mother of five (including a fifteen-year-old daughter, an eleven-year-old son, and a seven-year-old daughter with autism). P4 reports that her children each have a high level of need. They have access to respite care services after a long-protracted fight with the service-providing agency but no access to the required day-to-day child-centered support services. She also reports a fourth child (a three-year-old daughter) with a pending diagnosis of autism. She has siblings, a sister-in-law, a nephew, and a home attendant that help in varying degrees to care for her children.

P5 is an African immigrant mother of six children (including a 12-year-old son with pediatric acquired heart disease and autism and a 14-year-old daughter with autism and other mental health diagnoses). P5 reports that her nuclear family has varied levels of disabilities and high complex needs. She also reports that she has used respite care services and has built a diverse and culturally compatible medical team and wrap-around support around her children in their locale. She works in the policy and research fields. Her mother is a former health professional. Her husband is also a professional (see Table 1).

Table 1

Summary of Participants' Family Structures and Support Networks

Participants	Family Structure	Support Networks
P1	Married/Mother and Father/ Two Children	No community support; Siblings (for long-term care plans); Babysitters when needed
P2	Single Mother/Six Children	No community support; Church friends that advocate for her/her son with service providers
P3	Married/Mother and Father/ Three Children	No community support, no additional support
P4	Single Mother/Five Children	No community support; Siblings, Siblings-in-Law, Nephew, Home Attendant, Respite Care Worker
P5	Mother/Six Children	Views pediatric rehabilitation centers, comprehensive medical in-home care, dedicated physician, nurse, and case manager as community and structural support; Mother; Mother-in-Law; Extended Family

Table 2

Summary of Age Range of Children, Conditions, and Complexity of Needs

Participants	Age Range of Children	Conditions	Complexity of Needs
P1	13	Autism	High
P2	6	Autism	High
P3	2	Early Stage - Autism	Early Stage
P4	15, 11, and 7	Autism	High
P5	12 and 14	Pediatric Acquired Heart Disease and Autism (12 yr. old); Autism (14 yr. old)	High

Data Collection

I obtained a sample of five (one pending) participants using purposive sampling required for generic qualitative research. While sample size guidelines are ambiguous in qualitative research studies and Braun and Clarke (2021) note that concrete guidance provided by authors on the subject matter often seems to rely on arbitrary and largely unexplained criteria for what counts as data saturation; saturation should be shaped by the adequacy (richness, complexity) of the data for addressing the research question but with an empirical ‘nod’ to sample size acceptability.

Consequently, this study achieved richness in data to address the research question with a sample size of 5. This sample size does not reflect the approximated sample size in Chapter 3 due to recruitment challenges and a difficult-to-reach population over the year-long period.

Recruitment for this study occurred primarily via searches on media platforms and family networks. In each instance, I sent a recruitment flyer to the prospective participants and inquired about their interest in participating in the study. Upon their agreement, I sent them informed consent forms to review and determine their willingness to participate. Each participant formally consented via email or text message with the words “I consent” to confirm their consent.

After receiving their consent forms, individual Zoom interviews were scheduled with an understanding of a time commitment of up to 60 minutes. Each interview lasted 30 minutes, allowing sufficient time for the seven open-ended questions, and elicited rich responses from the participants. For each interview, I reminded participants of the purpose of the study, the voluntary nature of their participation, the risks and benefits of their participation, the incentive payment for the study, their privacy rights, and the process for potential follow-up. Three participants came to participate in the study due to searches on media platforms. The two remaining participants resulted from recruitment efforts using my family networks. One interview (P1) began with a technical error, and some of the audio was accounted for in my notetaking as she initiated her first response. P2 had a definitive time constraint, having to participate in the interview from her car to avoid disruptions by her son. P4 had frequent disruptions due to her children; however, we proceeded and completed the interview in sufficient time. At some points, there was a need to reiterate or clarify questions for P4. P5 had to be rescheduled two times due to the nature of the participant’s schedule. However, there were no significant issues during data collection for the interviews.

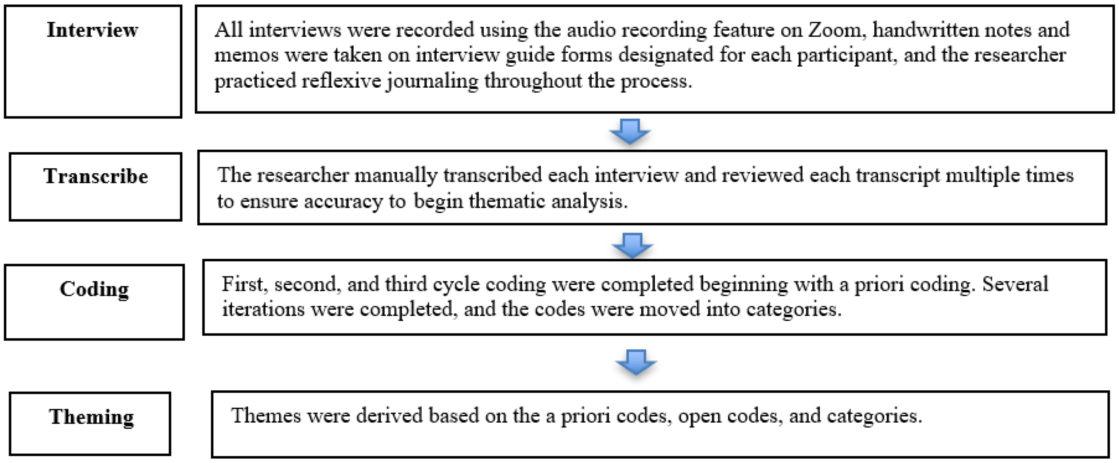
Data Analysis

I conducted all interviews in a private office and recorded them via Zoom with each participant’s consent. I recorded the interviews after enabling audio transcription in Zoom, and the interviews were saved as downloadable transcripts in the Zoom software cloud. I reviewed and manually transcribed each transcript verbatim. I also took handwritten notes on each participant's interview guide forms (Appendix A). The interview guide consisted of seven semi-structured interview questions. Each participant was assigned a unique ID to manage the data and ensure confidentiality (P1, P2, P3, P4, and P5). Figure 1 indicates the steps followed in the data collection and analysis processes.

I utilized an interview guide approach to obtain participant data, maintain structure and consistency, and produce participant experiences sufficient to answer the research question (see Figure 1).

Figure 1

Data Collection and Analysis Process



Interview

All interviews were recorded using the audio recording feature on Zoom, handwritten notes and memos were taken on interview guide forms designated for each participant, and the researcher practiced reflexive journaling throughout the process.

Transcribe

The researcher manually transcribed each interview and reviewed each transcript multiple times to ensure accuracy to begin thematic analysis.

Coding

First, second, and third cycle coding were completed beginning with a priori coding. Several iterations were completed, and the codes were moved into categories.

Theming

Themes were derived based on the a priori codes, open codes, and categories.

Coding

All interviews were conducted using the semi-structured interview guide with the research question in mind: How do African immigrant mothers of children with complex needs describe and perceive the access barriers to respite care services?

I generated first and second-cycle codes using thematic analysis for this study after intuitively highlighting sentences and phrases connected to each participant's experiences pertinent to the research question (Percy et al., 2015). I organized the codes into categories as I observed patterns between the highlighted sentences and phrases. When I established the categories, I organized them into themes combining patterns observed across participants.

A total of 219 codes were generated and organized into 18 categories. The categories established are confluence of factors that shape respite care service seeking and utilization - family structures; confluence of factors that shape respite care service seeking and utilization - intra-family supports; confluence of factors that shape respite care service seeking and utilization - socio-economic and other backgrounds (i.e. professional; social positioning); confluence of factors that shape respite care service seeking and utilization - resource access; confluence of factors that shape respite care service seeking and utilization- child's level of needs; confluence of factors that shape respite care service seeking and utilization - family structures, levels of need, intra-family support, socioeconomic, individual, or professional backgrounds, and resource access, varied complexities of caregiver burden, need for respite care, system efficiencies and gaps, denialism, barriers, knowledge/awareness gaps, advantages that contribute to positive experiences navigating systems of care, privilege and opportunity that limit need to interact with social services, disadvantages that contribute to negative experiences navigating systems of care, markers of intersectionality, emotional, mental, and psychological impacts of discrimination, and role of culture/role of culture in service-seeking decision making.

The research question resulted in four primary themes: confluence of factors that shape respite care service seeking and utilization: family structures, levels of need, intra-family support, socioeconomic, individual, or professional backgrounds, and resource access. the need for respite care, systemic barriers and enablers, and individual barriers.

Discrepant Cases

While I did not come to the study with a foregone conclusion that race would be a primary barrier to accessing respite care services among my study population, my lens and worldview were informed by the consistent findings across the literature on race as a barrier to health and ancillary support services among African immigrant mothers and families with children with complex needs in the developed world. The selected theoretical framework for the study- critical race theory- also informed my worldview.

P4 was most representative of the discussions and findings in the literature regarding race and access to services. She detailed the hardships she experienced in accessing services for her three autistic children and her perception of race's role in those challenges. She was the only participant with access to and use of respite care services. P2 and P3 briefly discussed their senses of race and racism as a barrier to gaining access to services. Neither of these participants accessed or used respite care services. P3 was unaware of the availability of such services.

P1 was one anomaly, only describing the role of culture in her experience seeking services for her autistic child. Race and racism did not emerge as a point of discussion during her interview, and it prompted a need to consider intersectionality in understanding the experiences of African immigrant mothers of children with complex needs in the United States.

P5 was the most unique of the cases, having access to respite care services in different forms, paid and some versions grant-funded with a match arrangement as well as a dedicated medical team comprised of people of color providing continuous care for her children. When discussing social service options, she relayed incidences of racism and discrimination and concerns and discomfort about in-home care providers and feeling policed in her home.

Each participant was unique. Their points of commonality were being African immigrant mothers caring for one or multiple children with autism, significantly influenced by their culture, and principally independent and self-contained with limited to no reliance on social services (P4 and P5 being the exceptions).

Evidence of Trustworthiness

Credibility

I implemented some Morse (2015) recommendations to achieve rigor and ensure that I represented participants' perceptions and experiences in the study, beginning with semi-structured interview questions that generated thick and rich participant data (Morse, 2015). With the limited time the participants had available, I focused on the data quality and obtaining an acceptable number of interviews and participants - albeit the recruitment challenges. I also utilized purposive sampling to match the sample to the study's goals and objectives, enhance the study's rigor, and establish trust in the data and results (Campbell et al., 2020). I also followed Morse's (2015) recommendation to use shadowed data to determine what participants generally knew about respite care services. Through the question, some participants provided insights into their knowledge of the experiences of others.

Since semi-structured interviews were used to collect the data in this study, I also followed Morse's (2015) guidance to establish a coding system to ensure that the meaning of the analysis can be the same between coders and enhance the validity and certainty of the findings. However, I did not have the benefit of peer review or debriefings (Morse, 2015; Shenton, 2004) as planned in Chapter 3.

I also triangulated the data via the study design. While I did not collect data at multiple “sites” (Korstjens & Moser, 2018), the data was collected across four states in the United States. I also used in-depth interviews, audio recordings, and field notes to explore bits of information across the participants to increase the scope or depth of the study (Korstjens & Moser, 2018; Morse, 2015; Shenton, 2004).

I practiced reflexivity, provided contextual descriptions, and connected relationships between study participants and myself. I acknowledged my positionality and sensitivities related to the phenomenon under study but did not utilize a social identity map as planned in Chapter 3. I observed and understood my role in creating the new knowledge; and diligently monitored the potential impacts of my biases, experiences, and beliefs on the research to maintain balance and objectivity (Dodgson, 2019; Jacobson & Mustafa, 2019).

While not stated in Chapter 3, I also clarified questions for participants that needed a better understanding by reframing questions and allowing for reflection to ensure credibility (Shenton, 2004).

Transferability

To achieve transferability, I developed detailed and thick descriptions of study participants and the research process to allow future qualitative researchers to assess whether the findings are applicable in their settings (Korstjens & Moser, 2018). I included descriptions of the context in which I conducted the research; the settings; the sample population; sample size; sampling strategy; the socio-economic, demographic, and pertinent characteristics; the inclusion and exclusion criteria; the interview procedures, topics, and themes; changes in interview questions; sections of the interview guide (Korstjens & Moser, 2018), and a discussion of the recruitment challenges faced with a hard-to-reach population. I still concur with the views of Stake (1994) and Denscombe (1998) that qualitative studies represent broader groups and can therefore be transferable or applicable.

Dependability

As discussed in Chapter 3, the steps to achieve credibility significantly overlapped with those to achieve dependability. Steps included triangulation, developing an audit trail, including all raw data; methodological processes; products of data reduction;

synthesis; analysis; process notes; audio recordings, reflexive journaling; and steps in developing the study survey instrument (Lincoln & Guba, 1985; Shenton, 2004). I detailed these steps to allow for replicability if a future researcher repeats the study.

Confirmability

To limit researcher bias and subjectivity and ensure confirmability, I followed Lincoln and Guba's (1985) guidance by maintaining an audit trail and practicing reflexivity- journaling, documenting personal notes, my thinking as the researcher throughout the research process, and thematic coding. I took each step necessary to maintain neutrality and objectivity to ensure confirmability (Korstjens & Moser, 2018).

Results

This study aimed to answer the research question: How do African immigrant mothers of children with complex needs describe and perceive the access barriers to respite care services? All five participants recognized or discussed elements of systemic and individual barriers to services, primarily centered around their children. Four primary themes emerged from the responses to the research question confluence of factors that shape respite care service seeking and utilization, need for respite care, systemic barriers and enablers, and individual barriers (see Table 3).

Table 3

Themes for the Research Question

RQ	**Themes**
How do African immigrant mothers of children with complex needs describe and perceive the access barriers to respite care services?	**Theme 1**: Confluence of factors that shape respite care service seeking and utilization: family structures, levels of need, intra-family supports, socioeconomic, individual, or professional backgrounds, and resource access.
	Theme 2: The need for respite care
	Theme 3: Systemic barriers and enablers impacting families **based on social position levels of access to resources, zip code, adjacency to affluence, adjacency to Whiteness, and discriminatory practices based on race and class
	Theme 4: Individual barriers - Knowledge and information barriers; Cultural considerations

Two-Parent Households

The roles of family structure and intra-family support in the potential need for access to respite care services became clear with Interview Questions 1 and 2 in which I asked participants to tell me about their families and any community support they receive in caring for their children, and what a day is like for them in caring for their child. While all but one participant (P5) reported having no community support and mainly being self-contained, relying on and sharing caregiving responsibilities within their families, the traditional two-parent households indicated more flexibility for self-care and breaks from caregiving responsibilities.

P1, married with two daughters (one 13-year-old with autism), noted her modes of self-care and caregiving breaks include "hiring babysitters, going to spas, traveling, and going on runs." She also noted, pertaining to her child’s level of need, that her daughter is “fairly independent now, although she used to run away in the hall [of our building]. She mostly stays in her room. She has a routine, comes out to get breakfast, and makes her own food too. She’s into making her own tea. She also likes donuts.”

P3, married with three children (one two-and-a-half-year-old with an early diagnosis of autism), reported on what she does if she can get a break: "I take a break from him.. [and] I would say watch a movie. I love to watch a movie. I love to sleep because I'm always, you know, busy. So whenever I get a chance to sleep, oh, I'm all, I'm all in for it. So I watch a movie, I sleep. And that's really perfect for me." At two and half years old, her child is dependent, while the extent of his level of needs remains emergent as she works with ABA therapists and relevant specialists daily.

P5, married with six children (including a twelve-year-old son with pediatric acquired heart disease and autism and a fourteen-year-old daughter with autism and other mental health diagnoses). P5 reported trading off with her spouse but has a wide definition of community and support. She has the benefit of intra-family support, including help from her older children; she also has the benefit of a “strong sense of support” from her extended family, emotional support from her siblings, and structural support. She views pediatric rehabilitation centers, physical and occupational therapy, and the comprehensive medical team assembled, dedicated physician, nurse, case manager, and transportation services as community and structural support. She also places a high emphasis on self-care as she navigates her neurodivergence and an auto-immune syndrome that requires a low dose of weekly chemotherapy. This is of consequence as her son and daughter are moderately independent. "One of the children has, you know, chronic nightmares and so might need. They already are in bed with us, you know, depending on if that was the situation, you know, or insomnia, and the other one has, you know, sometimes issues with incontinence. [My son] also had Kawasaki disease that caused some fine motor damage, so he can't really [dress himself on his own]." Their needs, along with needs and medical complexities within the family, require a high level of organization.

Single-Parent Households

Single-parent households reported less flexibility for self-care and a break from their caregiving responsibilities, with variations depending on their access to child-centered services (ABA therapy, home attendants, and other services). The number of children with complex needs and the total number of children in the households also compounded their challenges. P2, a single mother of six children (one six-year-old son with severe autism), noted in response to the questions about caring for her child and any opportunity to take breaks: “It’s really stressful. And you know, I have to have a lot of patience like to be able to walk with him. Like I have to take him to a lot of places, you know, take him to all his.. He goes to school, so you have to take him to school and ABA and speech and other services that he received, so it's not easy to cope with a child, you know, with autism. It's not easy because they have a lot of um services and a lot of help that he gets, he receives. I don't get no break. There's no break for me right now because that, that that's not gonna be no break because like I said, he's all over me and he always wanting something, seeking attention and all of that and um being that like he's not the only child I have, I have his other siblings so there is no break.”

P4, a single mother of five children (one 15-year-old daughter, one 11-year-old son, and one 7-year-old daughter with varied and severe levels of autism), did not indicate the extent of reliability of family support but reported sibling and extended family support in caring for her children and when she needs to attend errands or events. “Um, I normally call my sister. [Yeah] I normally call my sister or my brother’s wife to help me take care of them when I go. A lot of program is going on. Like I want to go to the salon, the first one, the home attendant will take care of her, the second one, I take my aunt, um grandma to take care of him, the third one it’s my nephew that come to take him and drive him all around. Like take him out because I fight for them to give them home attendant.” In providing insights into her children’s needs, P4 revealed her challenges with accessing services for her children with complex needs, including speech, physical, and occupational therapy, due to policy changes. “Day-to-day is like God’s doing and being better than before. Day to day are when you go and fight and fight and get the result, is better than what you get fight and you don't have the result. What I mean is that, like the 15 years old is nonverbal, I try to get all the resources that I could give to her. Sometimes the agency, like my insurance will say they will not cover this; they will not cover that. So I lose in a moment like I have a speech OT and PT coming to the house for her. Now, they said it's based on the result they give to them. That they now qualify no more, and they cancel all the services.” It is unclear the levels of severity of her younger son and daughter, but they were also receiving speech, physical, and occupational therapy until they lost access to the services.

Individual, Professional, and Socioeconomic Backgrounds

Each participant had a distinct background. P1 had an advanced professional background in medicine obtained in the United States and opted to become a finance entrepreneur to stay at home with her child. Her husband is a family internist, her sister is a pediatrician as such, she recognized her significant advantages in accessing necessary services for her daughter. She noted that “yes, insurance did cover the service. But also, only because my husband works with the same healthcare provider, his benefits are a little bit higher than the typical ones, so we didn't have to pay out of pocket. But I can imagine the limitation if you have to pay out of pocket.”

P2 has a foreign university background and works full-time while caring for her six children. She did not provide further insights into her economic or professional background.

P3 also has a foreign university background and, with the help of her husband, developed a successful business in the United States that allows her to stay home with her children.

P4 did not provide insights into her educational or professional background but implied that she has a source of income that limits her access to some needed resources.

P5 has an advanced degree in the social sciences focused on persons with disabilities and medically complex conditions. Her husband is also educated, as are the members of her family with advanced degrees. No specifics were provided about her economic status; however, provided insights when asked about social services. “I think they are overburdened, and I am more privileged than others - college educated, married, have a family vs those struggling, on Medicaid, single parent, still learning English, who need a lot more help than I do."

Resource Access

P1 noted that she and her husband have established resources for the care of their daughter. “We have a special needs trust set up for her. We are making a lot of these provisions such that her sister will be able to take care of her, or you know she’ll be able to have a companion. I have a sister here in the US who’s really good with her, and my husband’s sister would be the next of kin if, unfortunately, we pass before age, a good age. But we’ve made all those provisions with the expectation that we are going to have to care for her, she’s gonna need care for probably a lifetime.”

P2 discussed resource access in the form of access to ABA and speech therapy and opportunities for outings in the community for her son. “They recommend a lot of things you know that will help in the community like going on community outing and taking him to places that will be of his interest. You know, taking him out. Maybe, yeah, just socialize, and we go on places.”

P3 also provided insights into her perceptions of resource access in beginning her son’s initial stages of care- given short waiting periods for services. “Of course, like right now, we are waiting. They said it's supposed to be 15 days. I believe we had the final meeting with them two weeks ago, and they said it's going to take; they are going to reach back out in 15 days to a month to now to like finalize. We’re already finalized, but to let us know when the in-person will be coming over because it's supposed to run from Monday to Friday, you know, so every day from Monday to Friday. But right now I would say there was a waiting list and actually we are still on it because we are waiting. Because they said it will take about 15 to 30 days to get someone to start working with us. I would say about six weeks now." "They were pretty nice, they were able to lay the processes down for me."

P4 provided insights into a less positive experience with accessing resources. "They call me give me place to go oh we are waiting list because of COVID she cannot start and based on you don't have…you are not on welfare, you cannot qualify. Blah blah blah. So, if I'm not on welfare, why can't you give something that people that don't live in welfare get? They cannot give me the answer to it."

P5 reported the most fulsome experience across the healthcare and care coordination systems. She reported a range of resources shared with her by her medical team, networks, and by "happenstance", a case manager. The team recommended the use of app reminders; putting technology in place for biomonitoring; pill organizers; recurring appointment scheduling with a high emphasis on structure and organization." She noted that because of her sense of partnership with the medical team, "There aren't a lot of surprises." P5 also utilizes education as a resource. She educates her children on their conditions; the medical terminology; and how their medications can metabolize with other substances - considering their conditions. She uses resources such as diagrams, videos, art, and other tools, and her continued education approach allows for great, open communication with providers.

In response to Interview Question 4, participants discussed their desire to access respite care services but the limitations (P1); their inability to take on the additional service (P2); their lack of knowledge about the services (P3); their current access to the services (P4); or their various experiences with respite care services (P5).

P1 noted that she and her husband sought respite care services and did not qualify for the services due to their income. “Respite was all that was offered to us [via hospital care coordination], but then when we put in for it, we did not qualify because of the income [was too high]."

When asked what she knows about respite care services, P2 stated, “I’ve heard about it, and I haven’t really researched it, and I haven’t used their services yet, so..well, I’ll say no. Because right now, there is no time to fit in any other services because we’re getting a lot, and it's time-consuming. Because I don’t know what it’s like if I have to take him there what its gonna look like because right now, his day is filled up with what he’s getting. There’s no time to fit in any other thing.” I then clarified that the respite care services would be received in-home. She responded, “Yeah like I said, I don’t know much about them. But what I’m getting right now, the help he’s getting, he goes in there, and they come into the home so like they work with him every single day [with ABA therapy], and whenever he’s home, they stay till 6 o’clock and all of that.”

P3 reported, “Oh.. it's my first time hearing about it.” There was little else to glean from the fourth interview question with P3.

P4 was one of the two participants with access to respite care services. She reported, “My experience with that I have a lovely one, and the husband fell victim on the COVID. So she stopped working, and they keep on sending me black, blue, yellow, green and blue, black..boo boo <laugh>. So now I’m stuck with one black now.” I then clarified that I was asking specifically about the services and if she valued the services. She responded, “Yeah, because they take them out, take them to movies, take them to appointments that if I don’t feel like going.” I then asked if she found it easy to access the respite care services, she was receiving. She noted, “It’s not easy; that’s what I’m telling you after I lose my good one. My good one is like my family member. I work with her since, like, she’s a Spanish lady, but she’s like my family member. She has to take care of her... they go driving. They go different placed. So when her husband fell victim, that’s when I lose her. But the other ones, they still send me old person, but I can’t deal with the old lady. Unfortunately, the schedule that she has didn’t fit my daughter’s schedule, so she left. So before they send me this young one, so I try to tell them to go hire my family member that come from Africa so that one I can work with them as a family. But they saying that as far... she’s still working with me. I didn’t complain about her, so they cannot just throw her out like that.” I then asked her if it was a long time to obtain respite care services, and she stated, “Oh ok, to get it…oh my God, it’s a long journey, love.” She went on to describe the processes of accessing respite care services which I will describe in outlining the findings around systemic barriers and enablers.

P5 reported a few different experiences with respite care (the Easter Seals program then a grant-funded option that operated like a bank of hours for respite care). With the latter, she had the freedom of selection from their provider list or her own - which allowed for the option to use family. Through the program, she was able to select her mother as a care provider. The grant lasted a few years but was not renewed. She liked that respite care option most -allowing her to keep her children with her family. “That was a great program.”

Responding to Interview Questions 3, 5, and 7, participants provided insights into their perceptions of barriers and enablers in accessing services as they care for their children with complex needs. Participants alluded to perceived advantages or disadvantages stemming from their social positions and the influences of their access to resources, zip codes, adjacency to affluence, adjacency to Whiteness, or exposure to discriminatory practices based on race and class.

Via Interview Question 3, I asked participants about the types of information that hospital and social service staff shared with them about their child's care planning. The question and follow-up questions were purposed to gain insights into participants' experiences with care coordination with health and social service staff - often the pathway to learning about respite care and other family support services.

P1 reported, “The therapist would come, I think, you know, two or three, three times a week, and they would share a plan with us. They would say, hey, this is what we're going to try with her. We're going to try to ask, ask you know, who, what, where type of questions. So, they would, they would tell us what it is that you know, having her respond to greetings. Have her do, you know, do better with eye contact? So, things like that, she should, you know, they would kind of always tell us, you know, what kind of things can we do to have her engage with, with peers a little bit more or have her engage with us a little bit more. So, they'll leave us a binder, and then we kind of follow along with what they were teaching to the best of our, to the extent that we could.”

P1's direct response regarding obtaining information about respite care overlapped with her response to Interview Question 4, in which I asked, "Did the health or social service staff give you any information about services to help you in caring for your child?" P1 responded: "No, just the respite, just the respite was all that was offered to us..."

P2 reported that the child's pediatrician began the process and recommended an area early intervention program: "They shared that information, and they referred him to the brain center to get a diagnosis, which was done. That was helpful so that, you know, he could get help the help that he needs. So that was really helpful. And here, they also shared information about him getting speech therapy, and that was helpful also."

P3 also noted that a pediatrician initiated the process of an early intervention program but made no mention of other services recommended by hospital and social service staff when asked.

P4 provided a significant insight regarding her children's care planning, reporting: "They cannot coordinate because they don't know anything. Instead of them to refer you like for the PT, the doctor referred me to the PT, and the PT said he's entitled to get PT at home and PT at school, but when I went to the one that takes care of the bones and everything, he said he's not qualified because he did what they tell him to do. So, who is who now? The PT, the one that do the leg, said he's qualified the other one said he's not qualified. So, I don't understand..."

P5 noted that her care coordination arrangement is so unique that she and her husband turned down highly lucrative employment opportunities in other States. "I think this is a Unicorn." "I don't think I'll get this again, I can't." "I cannot recreate this anywhere else." Responding further about social services, P5 reported "There were a few outstanding ones but for the most part it was a huge disappointment; it is not individualized; the information provided is boilerplate". She continued, "It is a waste of time. I could just hit the internet and get more information than they could give me."

Interview Question 5 was purposed to gather information about participants' experiences as African immigrant mothers interacting with the health care system and advocating for their children.

P1 immediately cited her advantages and recognized the disadvantages there can be for others: "I think I have an advantage there because I have a healthcare background myself and being that my husband also is in healthcare, I think I have an advantage there, but I can only imagine how hard it is if you are coming from the African.." She also noted: "My sister is a pediatrician. A couple of things worked in my favor when she sees paid parents, a lot of times, they would complain that they wouldn't be able to even be able to talk to a person at the regional center where they can get free services because #1, you have to call within their working hours and sometimes if they leave you a message then you call back or even taking her to get diagnosed was something that I had to, you know, sometimes repeatedly call for and, you know, get these appointments and all those things. Even getting my daughter to the pediatrician to have this referral done, all of those things would have not been possible had I been working a full-time job at the time I was staying at home. [There] is a limitation in terms of time if you're not somebody who can call and call if you're not somebody who can take your daughter there at whatever time you know your child there, whatever time that they say that is is is possible right that that definitely can be a limitation. You have to have the time to kind of follow up on these things. And then also with the treatment type, sometimes it depends on their availability. Therapist ABA therapist may say, well, we can break free from three to five, you know, but what if you're working? What if you're not able to have somebody at home with your child from three to five, and where do you do these services right?" She concluded: "I could see many broken places. I could see many broken places that I was kind of able to navigate because I think that I have that flexibility. But I can see how it would be difficult for somebody to just say, well, I can't, there's no access, there's no access because I can't, I can't, I don't have the flexibility."

P2 also immediately cited her advantage due to her Caucasian friends and community from her church: "Well, I'm going to say maybe because I have a community, I have friends. I have people that advocate for me. So I don't really have problems with that because I have a community, I have people that always go with me that know more. So it's not like I'm just going there alone by myself. I have a community of people that advocate for me and my child. Like a support system." She noted offline that her friends are Caucasian from her church, and she allows them to do the talking and liaise with various elements of the healthcare system in caring for her child.

P3 reported that when it comes to interacting with the healthcare system, "I would say it's been kind of pleasant because I hear a lot of.. especially with my research on the internet, I've heard a lot of moms complain that they actually noticed things with their child and with their health care professionals you're talking about, and they come in, and they basically tell the mother nothing is wrong with your child. They have to fight it, argue it, and the Mom keeps insisting something is going on with the child, but the health care people tell you they are not seeing it. But fortunately for me, when they came in to kind of assess my son and see what's going on, most of them, I would say 9 out 10 of the things I pointed out, they were able to see the same thing with me, you know. Which made it so much easier because imagine if I was telling them this is wrong and they were telling me that is not wrong. That would be a problem, so I would say from me, from my own part, it's been pleasant because they've been able to work with me and see what I am seeing."

P4 reported her perception of being discriminated against based on race: "The journey to be is uh… with my God that I serve is what I trust every day to give me the strength, to give me the power. Um, to give me the grace to deal with the issue because I'm not sure if you don't have that three things, I'm not sure the journey will continue because when you see the way they treat people..mostly this color that we have, it's kind of nuts.

Because if the blue-black people go to yellow-green, they go there, they gonna get whatever they want. But you that have this color, I think they thought all of us are not speak English, one, not education, two, and third they thought we don't know the system so because of that's why they treat us like that."

P5 addressed Interview Question 5 in her responses to Questions 3 and 4. She reported that her State has issues in terms of equitable care and she has to be "a parent that advocates for sure". She noted the most helpful element has been assembling a diverse medical team. The children's pediatrician is Nigerian, her son's cardiologist is Asian, and she has a medical team of all people of color. She noted her perception that “they are more attentive to the children’s needs and things and they understand cultural nuances differently with disability and not just writing things off”. "[My] children feel comfortable and open" and "[It] creates safety." She also noted “There is racial stuff too. Discriminatory stuff sometimes.” There was resistance to involvement of her mother in the care of her children in her and her husband's absence during the workday. She also perceived a lack of understanding of the multi-generational aspect of families of color and noted that social service providers spoke to her mother in patronizing tones due to her mother's strong accent and the assumptions that her mother is ignorant. She also voiced her concerns about in-home care and visits and the policing her home and family. “I felt this pressure because I just didn't trust them. I know these are supposed to be people who are supposed to work with you, but I was also felt if I made any kind of wrong, any kind of mistake that how do I know you're not reporting me to CPS? So, my children have to be showered. The house has to be clean; you know? So, it's not like it was messy. But, like, you know, you know, normal wear and tear of children things and then again, we have neurodivergent children. They like to write on stuff and climb on stuff, they break stuff, but I felt like I could... I had to keep those things, so I felt like I couldn't really be forthright with some of these people because I didn't trust them.” “Every time to come to your house, you feel worried, and you just feel on edge.”

Interview Question 7 was purposed to gather information on what participants expect to experience as they navigate the health and social service systems.

I captured P1's responses to Question 7 in her discussion of her advantages in navigating the healthcare system. She also noted that she has yet to need social services.

P2 reported: “Social services wise, at first it was really hard for me, at first. It was really hard getting, but once we got help, it got easier. I think during the pandemic, that was the toughest time because offices were not open, and some people were not comfortable coming into the home, and we had to struggle with COVID and all of that. It wasn't really a good thing.” “We got help through the school [during the waitlist period]. So yeah, he started going to school, so he wasn't just out of service. We got help through school…we don’t have private insurance right now it’s still public insurance.”

P3 responded: “I would say we started on a very right foot with them, and you know, I hope the relationship will be the way it has started. I think it has a lot to do with [my zip code] because even when I was talking to… when I started newly, the first thing they asked me was where do I live, you know? I told them they said ok ok, they have some clients over there. So I feel like the zip code or the side where I live, they are more accepting as supposed if was calling from where there is an African-American population, I don’t know if I’m making sense, you know?..That’s what I think.”

For P4, responses to Interview Question 7 were captured across Interview Questions 2, 3, 4, and 5. One response pertinent to Interview Question 7 was about her feeling that she was being lied to because the specialists handling her children's care did not agree about what physical and occupational therapy services her children qualified for - as noted previously (see P4 response - Interview Question 3). “What I’m trying to say is that when they refer you like that as a mother, you see that, know that they are lying, and you want to go for fair hearing.”

She then discussed having to fight for services for her children, “I never know all these things before until I went to the meeting.. somebody tell me oh, you could fight for it. I said how long its going to take to fight? This country, everything is fight, fight, fight. How long? They say no, you request first, and if they deny you go and fight. So that’s why I did..I started knowing about the fighting for this, fighting for that.

She also shared her coping mechanisms for the mental health impacts of the treatment she has experienced navigating the health and social service systems in caring for her children “When they treat you that way with your grace, you can say um <shrug> that is life, you move on. But if you don’t have that grace, you’re gonna be depressed, hurting yourself; you won’t want to see human beings anymore because you think all human beings are the same. So that’s why I say we need three things, God, grace, and peace… to help you move on.”

P4 also mentioned issues with communicating with various health and social service professionals involved in her children’s care, care coordination, and case management: “So except you don’t know what they are talking about, and you don’t know nobody to explain to you like what I told you when you first started I said, please explain again let me know what you are talking about. See, if I didn’t see so for somebody to explain to me like that, I’m not gonna know what they are talking about. I may mad and forget about that child. But if I see somebody that gonna put me through and explain better and I’m ready to go with the person, I will go better. They will tell you, say it so you can get upset and say you don’t want.” “I try to explain to [a] coordinator, that coordinator is not..he’s just telling me when you ready you let me know, when you ready you let me know. Instead of put me through, sit down with me and look for all the information on the computer or call people and ask a question."

P4 also discussed the challenges regarding her children's case management: "That's why I say I'm the one doing my own job, not them." "Sometimes we are the ones that give them the information as [the] parent." "If they qualify, they will tell you they gonna give you Case Manager, and that Case Manager you.. I is going to work more than them because they never pick up their phone when you needed them. Because they will never..when you call them that you find some program, they will tell you…like the program like the one I have, he's the one that telling me I should go to straight Medicaid. I told her I can't go to straight Medicaid because it didn't work for me when I did it before. So that's why I stuck with FS. Instead of him to tell me ok this what you qualify, this is not what you qualify, he didn't tell me until one of the manager from one of the agency come. I explain to the manager I said why everybody telling me to go to straight Medicaid, and when I call Medicaid and tell them that I have 56 hours home attendant they telling me am I crazy to switch. So I don't know who to help me. So he said oh, don't worry about it. What happened? So I said I have a City Pass. Now he is the one that explained to me that because of the City Pass, I have they can not hire me. Because I have a City Pass under my family, and it what they offering me to go to Medicaid will be another agency.. Today, one will come…another one will come…tomorrow, another person will come. I say no, I don't want that. So let me stuck back with my FS and stay with it with my family member. But I try to explain to my Case Manager, he don't understand. He keep on telling me, oh Ms., if you need to get OT at home free, coming back and forth without making the ..what do they call it… the assessment every time, go to straight Medicaid. But when I explain to this man <likely someone else>, he explained it to me better."

She also provided additional key insights: "Like early intervention, they are the ones that will give you early intervention, but after early intervention, you are going to go by yourself from the rest of the thing." "I expected them to pay for it so that somebody come to my home. Instead of going outside in the cold or in the rain. That's why I'm fighting, and that's what I am going to tell them again when I go to the fair hearing. So but my doctor tells me they don't wanna pay no more because they cutting off in budget. But I ask the doctor, I said if they cutting off in budget, how about people that people needed it mostly, for example, let me say [Child 1], since [Child 2] is okay thats 11 and 7 [Child 3] is talking better, how about [Child 1] that is not talking at all? Why they gonna cut off all the services? And her skill motor, her skill motor, they talking they remove, they not using the skill motor from the like her hand. She cannot button little object, button small button. I don't know if you understand me. It's not good. And the PT, they said the one leg... The guy that tell me that one leg is bigger than one leg."

These data points also shed light on the final emergent theme in the study, individual barriers, which include knowledge and information barriers and cultural considerations.

P2, P3, and P4 reported knowledge and information gaps regarding respite care and broader service access opportunities. Each participant cited cultural considerations in service-seeking decision-making (individually or observed). Each also expressed struggles with accepting their child or children’s diagnosis given stigmatization in their cultures.

Knowledge and Information Barriers

P2 repeatedly noted that she did not know much about respite care services, although she heard of the services. To her understanding, respite care services would be an additional time-consuming service for which she could not make room to accommodate in her schedule.

P3 had no knowledge of respite care services, and the opportunity to explore its benefits was limited.

While P4 had access to respite care services, she had the most significant gaps in information and knowledge in successfully navigating the broader health and social service systems, as previously outlined in this chapter.

Cultural Considerations

Each participant alluded to the role of culture in seeking services and in caring for their children with complex needs. P1 noted, “You know we don't talk about this stuff.. we don’t talk about oh my child is something is…they just say oh that child is.. nobody comes outright and talks about it. And then sometimes when you know that something is wrong with your child, right..but people might be saying okay, just pray about it. You know there is God’s timing, or don’t take them, they’re just gonna put them on some medicine, medications, or whatever. These are first world kind of problems, you know, in Africa, we don’t have autism, that kind of stuff. So, which by the way, is wrong. So it can be as an African parent, it can be kind of hard to seek that help when you are fighting that taboo. That stigma. Not taboo that kind of stigma. So you almost have to be more forward-thinking than our culture generally is like to say I know something is wrong with this child, and I'm going to go and see what's going on, and I want to read, and I'm not just going to wait for people to tell me oh you know it's gonna be fine or whatever. No, I'm gonna go out and actually seek it, so I think that it might be hard for an African mom because of the stigma. You don't know, we just don't know how to, where to go to look for help, right? People just say you don't want to put your kid on medication these are diseases that's how come we never had that when we were growing up? Blah blah blah you know, all that stuff. You know, so I think that can be a challenge for sure. But because I think that I have that background, it's for me, I knew, knowing, I knew going into the appointments what I'm looking for."

P2 discussed her resistance to accept her child's diagnosis due to her cultural background, "I struggled so hard to accept that diagnosis. I had to ask questions like why like are you sure about this diagnosis? Are you sure he has this? I was really struggling with it because of my background, where I come from…and all of that." "I didn't want to accept it. I saw it oh my goodness, they are going to label my son. He's going to have this limitation, but I didn't see it as help."

P3 also reported, "As moms, you know, we find it so difficult when especially when we feel like or something is wrong, but we always scared to look for what is actually wrong. You know, most of us, nobody wants to be bothered with a child that maybe when he's supposed to talk, he's not talking. Like you want your child to be perfect." When asked if she was reluctant to follow up with the information obtained concerning her child’s diagnosis due to culture, she responded: “I would say it's a mix of both, right? I come from a background where everybody, you know how people have different things where people will tell you it's from my line, lineage, but I don’t come from my husband's side I don’t think they have anything like that, and then from my side, we don't have anything like that so I was like there is no how my son is just going to manufacture things from a thin air. There has to be maybe somebody has had it in the family. Maybe in my family or my husband’s family, don’t think anybody has autism.”

P4 made a significant observation regarding immigrants and their service-seeking decision-making, “The problem that we have as immigrants we don’t have patience. They don’t, we don’t. If I didn’t have patience for a while, I could not even get the little that I have. Because they will make you miserable for you to drop everything.” “For example, if you live in the Bronx, they can tell me to go to Queens to go get paper. Or they tell you to go to Brooklyn to go pick up a letter. [Some] people will say I don’t care. I don’t need that paper, please. Forget about it. Let me continue my lifestyle. You continue your lifestyle, but it's your children that needed it is suffering, and they are the one that brought them to the world. So that’s why I keep telling everybody, please, if you suffering, please remember the kids they didn't tell you to bring them to the world.”

P5 also discussed culture in the context of the lack of competence in healthcare and social service systems which caused her to build the medical team of people of color around her children while navigating uncomfortable interaction in-home interactions with social service providers.

Summary

The purpose of this study was to understand how African immigrant mothers of children with complex needs describe access barriers to respite care services. To answer the research question, I conducted five semi-structured qualitative interviews with African immigrant mothers of children with complex needs (ages 2 to 17) in the U.S.

Interviews were conducted via Zoom, and participant responses were transcribed verbatim. Thematic analysis yielded 136 codes that were organized into 18 categories: family structures, intrafamily supports, socioeconomic and other backgrounds, resource access, –child's level of needs, complexities of caregiver burden, need for respite care, system efficiencies and gaps, denialism, barriers. knowledge/awareness gaps, advantages that contribute to positive experiences involving navigating systems of care, privileges and opportunities that limit need to interact with social services, disadvantages that contribute to negative experiences involving navigating systems of care, markers of intersectionality, emotional, mental, and psychological impacts of discrimination, and role of culture in service-seeking decision making.

Four themes emerged from participant discussions: confluence of factors that shape respite care service seeking and utilization (family structures, levels of need, intra-family support, socioeconomic, individual, or professional backgrounds, and resource access), need for respite care, systemic barriers and enablers, and individual barriers.

Chapter 5 includes interpretations of findings, limitations of the study, recommendations for future research, and implications for positive social change and social determinants of health.

Chapter 5: Discussion, Conclusions, and Recommendations

This study involved understanding access barriers to respite care services among African immigrant mothers of children with complex health needs in the U.S. I addressed this topic due to lack of research on experiences of this subset of mothers in the U.S. and lack of information in other Western and developed countries.

Previous studies on immigrants of color in Western nations have highlighted underreporting and under addressing of needs and experiences of mothers and parents. However there has been limited exploration of the impacts of systemic and institutional factors on access to services and resulting health outcomes.

Adding to existing literature using a CRT lens can be helpful for program and policy practitioners. It can help ensure equitable access to respite care services for African immigrant mothers in the U.S., supporting advancement of national health and human service institutional goals that are aimed at addressing social determinants of health for such unique populations.

Due to limited available research on African immigrant mothers of children with complex needs in the Western world, and the diverse qualitative and quantitative approaches, study designs, and frameworks of the works underpinning my study, the findings of my study predominantly align with aspects found in Kvarme et al., 2016, Munroe et al., 2016, Arfa et al., 2020, Brekke et al., 2020, Javier et al., 2010, and Viruell-Fuentes et al., 2012. Most studies did not specifically focus on African immigrant mothers of children with complex health needs in Western and developed countries.

Only Agrawal et al., 2020 conducted their research in Houston, Texas (with a sample of n=27 African immigrant families out of 366 immigrant families), Munroe et al., 2016 conducted their study in the United Kingdom (with a sample of n=6), and Arfa et al., 2020 conducted their research in Norway (including a sample of n=5). These studies included African immigrant mothers, parents, or families with children with complex needs in their samples.

Upon further examination of these underpinning works, it became evident that employing a critical race lens is essential to understanding the experiences of African immigrant mothers, who serve as primary caregivers of children with complex needs in the Western world, particularly in the United States.

A significant body of evidence in the literature highlights negative experiences of African immigrant women, families, and communities in their host countries. Furthermore, African immigrants often face risks such as skill devaluation, underemployment, lower earnings, systemic and individual level racism, similar to African Americans in the U.S. (Saasa, 2019).

Upon concluding thematic analysis, I found experiences and levels of access to respite care services varied among participants. Four key themes emerged: factors that shape respite care service seeking and utilization (family structures, child’s level of need, intra-family support, socioeconomic, individual, professional backgrounds, and resource access), need for respite care, systemic barriers (including those related to race and ethnicity) and enablers, and individual barriers.

Additionally, my findings prompted the need to consider intersectionality related to CRT, given intersecting roles of race and class that became evident as themes emerged from participant data. I found African immigrant mothers of children with complex health needs in the U.S. are not without agency. These mothers are not one-dimensional or a monolith, they have multi-dimensions and intersecting identities. Providing adequate services and ensuring equitable access requires intersectional and critical approaches considering impacts of race, ethnicity, and social positioning on their experiences.

I also conducted a supplementary review of recently published literature on broader African immigrant populations in the U.S. This was aimed to contextualize intersections within the population and deepen my understanding of findings.

African immigrant experiences are highly nuanced and influenced by various factors. These factors include predeparture characteristics and class during entry into the U.S. (Chikanda & Morris, 2021). Despite high levels of labor force participation, education, and strategic integration efforts, social exclusion persists among African immigrants (Saasa et al., 2022). African immigrants exhibit higher returns resulting from educational attainment compared to natives and are more likely to be employed. However, they are also more likely to face unemployment and less likely to be in the labor force (Ikpebe & Seeborg, 2018). Discrimination in social and work settings, lower pay, and underemployment persist among African immigrants irrespective of their education level (Nkimbeng et al., 2021).

High income levels act as protective factors against social exclusion, enabling increased participation in social, economic, and political activities (Saasa et al., 2022).

However, it is crucial to recognize the nuanced nature of African immigrant populations in the U.S. Viewing them as a singular group and anticipating solely positive outcomes based on their social and economic standing, education levels, and labor force participation rates leads to oversimplifying their diverse experiences (Chikanda & Morris, 2021).

As a means of appropriately contextualizing the interpretation of the findings in this study, I will present crucial insights derived from discussions on critical race theory (CRT) and intersectionality, the emergence of a new model minority myth around African immigrants, concepts of white adjacency, and the examination of racial and social hierarchies found in the literature (Gillborn, 2015; Ukpokodu, 2017; Rahman, 2021; Magee & Galinsky, 2008; Burrell-Craft, 2020; Delgado & Stefancic, 2017). This discussion aims to illustrate why adopting a critical race lens is instrumental in shaping and informing research, policy, and actions aimed at providing equitable access to respite care services for African immigrant mothers of children with complex health needs. The key points to consider are:

While individual, systemic, and institutional racism in the United States are not aberrations, it is crucial to comprehend how racial inequities are molded by processes influenced by and reflective of other dimensions of identity and social structure, commonly referred to as positioning (Gillborn, 2015). This underscores the significance of intersectionality in acknowledging that African immigrant mothers of children with complex health needs are, on the whole, vulnerable to various forms of racism and discrimination, as established in the literature (Viruell-Fuentes et al., 2012; Ambegaokor, 2012). Importantly, their vulnerability is not solely a result of their racial identity; it is also intertwined with other aspects of their identity, such as class and gender. Consequently, their complex identities play a pivotal role in shaping how they experience, perceive, or do not experience or perceive racism and discrimination.

Rahman (2021) initiated a crucial discussion on white adjacency concerning Muslims in Western nations, a concept relevant to the findings in this study. Participants in the study either implied or directly communicated that white adjacency—manifested through relationships, zip codes, individual and professional backgrounds, and socio-economic status—created a perception or shield of safety from racism and discrimination. This shield of protection felt by high-earning or white-adjacent participants originated from racial and social hierarchical structures, where rank ordering determines who receives material benefits, resources, and access to products and services.

Scholars of Critical Race Theory (CRT) adhering to the realist school of thought stress that civil rights gains for families and communities of color align with white self-interests (Burrell-Craft, 2020; Delgado & Stefancic, 2017; Magee & Galinsky, 2008). Consequently, the challenges faced by African immigrant mothers of children with complex health needs are further obscured by a recent notion in the literature and discourse that labels African immigrants as exceptionally successful and the new model minority in the United States. Ukpokodu (2017) highlights that African immigrants are the most highly educated group in the United States. However, the new model minority myth conceals the significant challenges that African immigrant children and families encounter in the United States.

The ability of a high-earning, well-resourced, networked, and married African immigrant mother of a child with complex needs to access necessary services may give the impression that there is no need for policy changes to ensure equitable access to crucial family support services, including respite care. However, such an assumption is disingenuous.

In Chapter 5, I delve into the interpretation of my findings within the framework of critical race theory, anchoring the discussion in the core peer-reviewed articles that form the study's foundation. I extend the analysis to encompass the broader contexts of the African immigrant community as delineated in the literature, acknowledging the study's limitations, and proposing recommendations for future practice. Additionally, I expound on the implications for positive social change and the social determinants of health, not only for the mothers, children, and families involved in the study but also for other minority immigrant and refugee populations in the United States. The chapter culminates with a concise summary of the study.

Interpretation of the Findings

As discussed in Chapter 4, I methodically organized the patterned and pertinent ideas derived from my interview data into categories and themes. In this section, I present the interpretations of these findings, providing a comprehensive explanation of the identified themes in relation to the literature outlined in Chapter 2. To guide the interpretation of the findings, I restate the research question. Drawing upon both the literature review and the data collected in Chapter 4, I articulate a nuanced understanding of the study's findings and draw well-supported conclusions. Themes were consolidated based on shared meaning, relevance, pattern, and frequency.

All study participants acknowledged or discussed elements of systemic and individual barriers to services and primarily focused on their children. It was notable that they did not equally understand the benefits of respite care services in providing them short-term relief from their caregiving responsibilities. The varied experiences are reflected across the themes identified.

Access to respite care services varied across participants due to their social positioning, family structure, child/children's levels of need, intra-family support network, backgrounds, and access to resources. The two-parent households experienced less hardship and stressors caring for their children with complex health needs due to mothers' coordination with their spouses and extended family members. In the case of P1 and P3, coordination with spouses, the ability to afford temporary childcare to allow for breaks, and schedule flexibility as high earning stay-at-home entrepreneurs in high-income households limited their need for respite care services. P1, whose spouse is a family internist, expressed interest in accessing respite care services but reported that "the income was too high" to qualify. P3 was unaware of the option for respite care and focused on access to early intervention services and reported a "pleasant and easy" experience accessing those services – partly due to her affluent area of residence. P5 was also part of a high-income, advanced degree two-parent household with high levels of coordination with her spouse, extended family, healthcare, and community support; however, respite care services were necessary for her due to the high complex health needs among her six children. Only the two youngest (ages 12 and 14) were included in this study. She reported using several programs, the most recent one allowing her to keep her children with her family members (compensated as the respite care providers). In these cases, social positioning and high levels of income serve as protective factors, to varying degrees, against social exclusion and limited access to needed services (Saasa, 2019).

Family structure appeared to moderate participants' need for respite care and external family support services – with the severity of the child's condition increasing the need for respite care. Researchers have found that structurally diverse families face poor health outcomes compared to families headed by two married parents due to differential and inequitable resource access (Ganong et al., 2015; Russell et al., 2018; WHO, 2010). Consequently, as reflected in the literature, the single-parent households (P2 and P4) experienced significant hardship.

P2 and P4 each had a unique story but some commonalities. P2 was a single parent of six children, with one child with severe autism spectrum disorder; P5 was a single parent of five children, with three children with severe autism spectrum disorder and a fourth child pending diagnosis. P2 relied on her White church community in navigating the health care systems to access the many services her child receives. P4 had family support, in-home care, and respite care services to help care for her children after years of ongoing fights to obtain and maintain services for her children.

There is a through line of race and the intersectionality of each participant, whether in the context of the model minority myth (Ukpokodu, 2017) and social ranking based on levels of education, professions, resource access and flexibility as reflected in the data collected from P1 and P5 – allowing for material benefits, resources, and access to products and services (Magee & Galinsky, 2008; Burrell-Craft, 2020); adjacency to affluence and zip code (Magee & Galinsky, 2008) reflected in interview data from P3; and white adjacency reflected in interview data from P2 (Rahman, 2021). P4's sustained fight for services for her children was the clearest indicator of systemic biases and failures due to race. I will discuss this more specifically in addressing systemic barriers identified in the study.

The need for respite care among participants was primarily determined by the complexities of their children's conditions and the high burdens of care for their mothers and families. As noted in Chapter 2, the need for respite care is more likely among children with complex health needs of a younger age, minority race and ethnicity, low-income households, and low maternal education (Nageswaram, 2009). This study found the need for respite care in high-income (P5) and lower-income (P4) African immigrant households, depending on the complexity of their child/children's conditions. These mothers gained access to respite care services with varied levels of ease. P5 built a diverse and culturally responsive team around her children, and she used her advanced professional knowledge, experience, and skills to source various iterations of respite care services to allow for her short-term breaks. P4, on the other hand, noted years of fighting to get services. When asked how long it took, she responded, "To get it…oh my God, it is a long journey." Hence, ease of access also appeared to be influenced by the level of maternal education, resource capacity, and ability to source information outside of the social service networks independently. Both P4 and P5 discussed the role of race in obtaining access to services or the proper configurations of services; however, the impacts of race on these mothers' comfort levels with using respite care were most evident in their concerns about having non-family members in their homes to provide care - as addressed later in this chapter.

Systemic barriers to respite care services identified among participants included systems, processes, policy making, and program design challenges: unexpected shifts in governmental policies, budgets, and funding (P1, P4); greater systemic emphasis on child-focused support services than caregiver support services (P1, P2, P4, P5); income eligibility and restrictions (P1, P4, P5); inflexible providers (P4); inflexible time options (P1, P4); long wait times (P4); fragmented services and inefficient care coordination (P2, P4, P5) and race-relevant challenges: poor cultural responsiveness and competence and staff issues (P4, P5); poor client education efforts from case managers (P2, P4, P5); accessing help as a battle (P2, P4, P5); and the impacts of race and ethnicity (P2, P3, P4, P5).

P1 noted that the passage of a new law called the Lanterman Act resulted in her family restarting services for their daughter. Services were free regardless of income; however, with the new law, "we had to go to the pediatrician to give us a referral to pediatric, I don't know what they call it psych or something like that, and then they write a referral contract" to restart services again. P4 noted, "My doctor tells me they don't wanna pay no more because they cutting off budget." Researchers have established in the literature that governments do not provide sufficient funds to programs, leading to long wait times (Khanlou et al., 2017; Mirza et al., 2013; Welsh et al., 2014).

P1, P2, P4, and P5 reported receiving robust services for their children with complex health needs but indicated limited options and reliance on external support services for themselves as caregivers. The perception of this barrier was particularly acute with P2 and P4. P2 stated there was no room for additional services to allow for respite care services and short-term relief from her caregiving responsibilities because "we're getting a lot of services for him." P4, on the other hand, noted disruptions in physical and occupational therapeutic services for her three children with severe levels of autism but maintained access to in-home health care and respite care after lengthy periods of waiting and adjudication. Recent works have found that parents of children with complex health needs desire broader mechanisms of support and relief from caring for their children and effective case management (Carosella et al., 2018; Hagvall et al., 2016; Hagerman et al., 2022), however, such options remain limited.

P1, P4, and P5 discussed income eligibility or restrictions with their ability to access services. P1 and P5 reported high levels of income but different outcomes for access to respite care. P1 well-exceeded the income eligibility requirements for state-funded respite care, while P5 found and maintained access to respite care through a mix of self-pay and private grant-funded programs. P4, with a moderate to low income, reported a challenge in resource access, “One [case manager] said I should go to welfare; welfare said I’m not qualified because of my income, so where do I belong? You don’t belong anywhere because your income is not qualified with your income.” These findings mirror those found in literature. Smith et al. (2020) found that lower income families reported less access to services than their higher resourced counterparts.

P4 raised the issue of inflexibility with respite care service options. “I try to tell them to go hire my family member that come from Africa so that one I can work with them as a family, but they saying that as far she’s [the current respite care worker] still working with me, I didn’t complain about her, so they cannot just throw her out like that.” There was inflexibility to change although P4 expressed, she would be most comfortable with a family member with whom she could trust her children’s care. P1 said:

> There is a limitation in terms of time if you're not somebody who can call and call if you're not somebody who can take your daughter there at whatever time you know your child there, whatever time that they say that is possible right, that definitely can be a limitation. You have to have the time to kind of follow up on these things. And then also with the with the treatment [service] type, sometimes it depends on their availability. I could see many broken places. I could see many broken places that I was kind of able to navigate because I think that I have that flexibility. But I can see how it would be difficult and for somebody to just say, well, I can't, there's no access, there's no access because I can't, I can't, I don't have the flexibility.

Limitations of respite care reported in the literature are mainly associated with accessing respite care and can be attributed to, among other factors, inflexibility in services and lack of choice of services (Cooke et al., 2020).

P4 reported long wait times for respite care and other critical care services. She noted that it is a long journey and described, "You gonna go for Open Door. I call it Open Door, but they said **** Door. So, you go for **** Door, they will tell you…they will assess your kids… they will check and see if they qualify. So, to get **** Door, after **** Door, they gonna refer you… after referration, they gonna send you to O*****, it's a long journey, my sistah." Wait times are exacerbated by difficulties reaching staff by phone to obtain information and understand the processes. "If [your children] qualify, they will tell you they gonna give you Case Manager and that Case Manager you and I is going to work more than them because they never pick up their phone when you needed them." P4's experience with long wait times mirrors the findings in the literature on the experiences of immigrant parents of children as a key barrier to services. Immigrant parents described waiting times as long, circuitous, traumatic, and significantly stressful in accessing diagnostic and intervention services with many immigrant mothers not knowing when their child’s turn will come (Habib et al., 2017; Jegatheesan et al., 2010; Khanlou et al., 2017; Leung et al., 2022).

P2, P4, and P5 had varied experiences with fragmented services and inefficient care coordination. P2 described the difficulty of having to take her son to a lot of places and being overrun by the number of services required for her child. P4, on the other hand, reported having an in-home attendant and respite care services but having lost the in-home speech, physical, and occupational therapeutic services for her three children with severe autism. “They said based on the result they give [for] them that they now qualify no more and they cancel all the services.” P5 also acknowledged the challenges of care coordination and that she was fortunate to have assembled what works for her children. She reported “Yeah, I'm very fortunate, like, and it's the reason why we've had some job opportunities out of state in the last few years that were like very lucrative ones. And we've turned them down as much as sometimes that dollar sign looked gorgeous or the place that we could have relocated to the weather looked amazing. Just thinking about having, I'm thinking this is a Unicorn. I don't think I'll get this again; I can't do this. Like I've got these kids to a place with the systems, with the schools. I just don't feel like I can recreate this anywhere else, and I just don't- we can't take the risk.” Khanlou et al. (2017) found that immigrant mothers emphasized their dissatisfaction with the disjointed coordination between the health, social services, and school systems.

Ataro Adere et al.’s (2023) findings overlapped with those in this study regarding systems, processes, policymaking, and program design challenges. The challenges identified resulted in a significant need for access to respite care services and other services among Ethiopian and Eritrean immigrant mothers of autistic children who participated in their study. While the authors referenced previous works on cultural responsiveness and the likely impacts of known racial and ethnic disparities on Ethiopian and Eritrean parents in accessing autism services, the study does not factor in that healthcare and support services in the United States are Anglocentric in nature (Algood & Davis, 2019). Furthermore, the Eurocentric frameworks that underpin these systems are considered universal (Crenshaw et al., 1995; Delgado & Stefancic, 2001; Schneider, 2003; and Moran, 2004) and not intended for immigrant or native ethnic minorities.

Examining each system barrier through a critical race theoretical lens would prove beneficial.

Race-Related Challenges

P4 and P5 observed instances of poor cultural responsiveness and interactions with service providers. The experiences were more acute and direct for P4, citing communication challenges with care coordinators, "See if I didn't see so for somebody to explain to me like that, I'm not gonna know what they are talking about. I may mad and forget about that child [not seek services for the child]. But if I see somebody that gonna put me through and explain better and I'm ready to go with the person, I will go better…I try to explain to [a] coordinator, that coordinator is not… he's just telling me when you ready you let me know when you ready you let me know. Instead of put me through, sit down with me and look for all the information on the computer or call people and ask a question. That's why I say I'm the one doing my own job, not them." P4's perceptions are mirrored in Smith et al. (2020) findings that non-white families have limited receipt of family-centered care, which includes a lack of cultural responsiveness from providers and interferes with the relationship and trust between families and professionals. In this instance of P4, a professional with the capacity to understand her non-standard version of the English language, referred to as Broken English, could have made the difference in her experience. Omenka et al. (2020) note the importance of health care [and other relevant] service professionals understanding the nuances among African immigrants and variances within their languages - in P4's case, the English language.

Similarly, P5 reported challenges with staff when she incorporated her mother into her support team, helping with the children's in-home services. She reported, "So in the beginning, we started doing some of the in-home service. I wanted to alternate them between her [her mother's] home and mine because she's their grandma. She sees them a lot. She cares. She can provide input, or if one and because I have other kids, someone had an appointment or something going on. I wanted continuity, and so I felt there was pushback from the very beginning as to why was I having her involved in things like, you know, like it was just really odd. But my husband works, he couldn't do it. She was there to support me. They didn't really understand, I think the multi-generational aspect of some of our…of some families of color. You know how we work? Some of them would; I don't think my mother noticed that first, but I did; they spoke to her in a really patronizing tone 'cause of her accent, you know. Like my siblings and I, we were born here, we don't have as much of an accent. But my parents still very much have a very strong accent, but they know English better than my brothers and I ever will. You know what I mean? But because they hear an accent, they'd automatically, you know, do that stupid baby talk, wide eye, and loud babyish tone. As if you don't understand. Speaking slowly. And because my mother doesn't know this, some people just speak like that… they're just kind of country, so she's not knowing but me having spoken with these people before on the phone, knowing that's not how they speak to me, I'm offended immediately because they're assuming that she's ignorant. So, there's some of that. Such experiences are reflected in the literature, with African immigrant study participants believing that their accents [and other facets of their identity] trigger unfavorable and hostile provider attitudes (Omenka et al., 2020). Consequently, they would disengage from health and social services because they perceived that services were culturally inappropriate (Alsharaydeh et al., 2019).

P2, P4, and P5 described varied experiences with poor client education efforts with case managers. P2 noted, "I've heard about it [respite care], and I haven't really researched it, and I haven't used their services yet, so…" indicating that case managers did not make much effort to educate her about respite care services and the substantial benefits for her well-being. P4's experience reflects the common failures of case managers to educate and adequately explain services and related processes to immigrant parents. She reported, "They cannot coordinate because they don't know anything…they tell you to call this, call that…I don't understand." Researchers have found that providing poor guidance and information to families regarding available and evidence-based interventions and services is a barrier to obtaining respite care services (Breneol et al., 2019; Fong et al., 2022).

P5 provided an additional insight into inefficiencies with client education and dissemination of information by social service case managers. She reported, "I have to say that there have been a few outstanding ones, but for the most part, that's been a huge disappointment. I feel like the social services care staff maybe, while well intended, weren't… didn't give me very individualized, you know, information very kind of like template cookie cutter type of thing, absolutely detached. Sometimes out of date or inaccurate. Even again not, I don't think intentionally so, and to the point where it seemed like it was just, not to sound mean, but it almost felt like a waste of time. And not because, not to be insensitive or anything like that, I could just hit the internet and get more information than they could give me."

P2, P4, and P5 described various levels of difficulty in accessing services. P2 noted, "At first it was really hard for me, at first. It was really hard getting, but once we got help, it got easier". P4 faced significant hardships accessing services, "This country everything is fight, fight, fight. How long? They say no, you request first, and if they deny you, go and fight. So that's why I did. I started knowing about the fighting for this, fighting for that." P5 also noted the challenge of accessing services, acknowledging that she could not recreate her children's current coordinated and optimal care elsewhere. Arfa et al. (2020) found that immigrant parents struggle for years to get help, consistently have to fight for the help they need, and often feel exhausted, stressed, frustrated, and demanding regarding resources.

P2, P3, P4, and P5 shared insights on the impacts of race and ethnicity on their access to respite care services. P2 reported that her connection to a Caucasian church community shielded her from experiencing challenges with the healthcare and social service systems. “Well, I’m going to say maybe because I have a community, I have friends. I have people that advocate for me. So, I don’t really have problems with that because I have a community, I have people that always go with me that know more. So, it's not like I’m just going there alone by myself. I have a community of people that advocate for me and my child. Like a support system.” P3 also attributed her pleasant experience with service providers to her zip code and adjacency to affluence. “I think it has a lot to do with that because even when I was talking to… when I started newly, the first thing they asked me was where do I live, you know? I told them they said ok they have some clients over there. So, I feel like the zip code or the side where I live, they are more accepting as supposed if was calling from where there is an African American population, I don't know if I'm making sense, you know?" P4 reported her experiences with discrimination and racism while navigating healthcare and social service systems to access respite care and broader services. "They laugh with you the beginning but inside them they're not helping you... when they treat you that way with your grace you can say um <shrug> that is life, you move on. But if you don't have that grace, you're gonna be depressed, hurting yourself, you won't want to see human being anymore because you think all human being are the same." P5 also described her need to ensure that the team around her children's care were diverse and persons of color. "Because I am in [this State], there's a lot of issues here. You know, there's a lot of issues in terms of, you know, equitable care and what not. So, I've also had to be quote-on-quote that parent, you know what I mean, the one who just kind of really advocates for sure. And I've also tried to make sure that we have a diverse team, you know of people…like our pediatrician is Nigerian, like we are we've got you know people of color. For almost all of our services, so you know whether it's South Asian, Asian cardiologist. I just try to surround my children with people because I feel like, first of all, I feel like they're more attentive to, you know, needs and things that are and they understand some cultural nuances a little differently in terms of how things with disability and not just writing everything off as oh, that's because of this. So, because of that so I feel like there's a… that helps with the care. It helps the children feel a little more comfortable and open and lets them see people who look like them in positive, you know, positions of authority and you know, and it and it and. Now I don't have to feel like I have to explain as much about things sometimes, you know right, and it creates safety.” P5 also expounded on her perceptions of potential risks and feeling “on edge” with asking for services needed and utilizing in-home care due to racism and discrimination. “I think like I'm thinking if my child looked different then you know then this, I think he would be fighting for these things or wanting these things but because I'm asking for them it's going to be, you know, don't, you know, irritate people or don't make waves and you know and so and then I also felt this pressure because I just didn't trust them.”

P5 continued, “I know these are supposed to be people who are supposed to work with you, but I was also felt if I made any kind of wrong, any kind of mistake that how do I know you're not reporting me to CPS [Child Protective Services]? So, my children have to be showered. The house has to be clean; you know? So, it's not like it was messy. But, like, you know, you know, normal wear and tear of children things and then again, we have neurodivergent children. They like to write on stuff and climb on stuff, they break stuff, but I felt like I had to keep those things, so I felt like I couldn't really be forthright with some of these people because I didn't trust them that they had my [interest]. I felt like I was being judged. So, you know, I've got it. Yeah, I'm thinking I've got children with sensory issues. Sometimes they don't want to do their hair, you know, I mean, like, sometimes some things hurt, and I don't want to put lotion on it. You know, they just want to be ashy cause it just doesn't feel right. It feels uncomfortable and, or they don't want to put on certain things or they get attached to a certain outfit, you know. And so, you might have like four or five of the same shirt because they're in love with that shirt, but they think that the kids wearing the same thing every time they come to your house, so you're just worried and you just feel just on edge, yes, very much so, yes. And I think sometimes they also if they give advice and you don't take up on it, I think there's also a sense of offense." Participants' perceptions and experiences of discrimination and racism in accessing services are reflected in the literature. Recent studies have found that white-dominant ideologies hindered access to resources and specialized services among African immigrant mothers in the United States, and African immigrant mothers observed or experienced racism and discrimination from others, felt judged and stigmatized, and that their skin color and faith influenced how they were treated and the services they received in Western countries (Brainard, 2009; Woodgate et al., 2017; Arfa et al., 2020; Tekola et al., 2023).

The race-related challenges found in this study aligned with the established findings in the literature that [healthcare and support services-related] laws, policies, and perspectives are fundamentally engrained with racism and inequity (Algood & Davis, 2019) and purposed to maintain socio-structural inequalities (Delgado & Stefancic, 2017; Garcia, 2017). The use of the critical race theoretical lens helped to understand if and how racism-related factors are barriers to accessing health and support services among the immigrant group under study.

Study participants discussed elements of regional policies and programs that indicated systemic enablers for access to respite care services in their locales. P4 and P5 were the only two participants with access to respite care services, while P1 exceeded the income eligibility requirement for state-funded respite care, P2 felt overextended by the number of services received for her son and did not pursue the services, and P3 was not cognizant of the services. Interview data collected with P4 and P5 indicated that the complexity of the children's conditions, regional policies, available funding, and knowledge of and access to various care models and payment mediums for respite care services influenced the likelihood of access to respite care services.

P4 reported a lengthy process and difficulties accessing respite care but was maintaining access to the services at the time of the interview. She noted having an alternative to Medicaid [that covered the cost of in-home care and other services]: "[One told me] I should go to straight Medicaid. I told her I can't go to straight Medicaid because it didn't work for me when I did it before. So that's why I stuck with FS." A variety in insurance plan options helped facilitate her access to respite care. While cumbersome, the network of agencies (**** Door, ****DD, ***** Center, and **I) that P4 interfaced with also aided her access to respite care. The opportunity to pursue fair hearings and adjudication also served as a systemic means of correcting harmful policy-based decisions that affected her family.

P5 reported having "a few different experiences with respite care services… [two of which were paid, with one of them, the county had a grant that would be double matched to cover the cost of care. The program allowed for bankable hours for respite care and flexibility to choose our own care provider, which allowed me to select my mother as the care provider]." She learned about the opportunity through a case manager by chance. The grant ran for three to five years and not renewed; however, P5 valued that the program was "very client-directed," and there was flexibility in the choice of agencies (state and private).

The study findings mirror the literature in that the availability of funds to support families of children with complex health needs varies based on how much [local and federal] governments view respite care and family support as a policy priority (Teo et al., 2018; Nishigaki et al., 2016; Spruin et al., 2017; Hill, 2016; Sung & Park, 2012; Cantan & Bolger, 2017).

Despite the strong correlation between poor socioeconomic and minority racial/ethnic background and ineffective, inefficient, and inequitable access to respite care services for parents caring for children with complex health needs (Ambegaokor, 2012; Agrawal et al., 2018; Breneol et al., 2019; Cummings & Hardin, 2016), system enablers identified in this study allowed for P4 and P5, mothers of children with the most severe conditions, to access respite care services. Following a lengthy period of fighting for services, P4 obtained respite care access to support her in caring for her three children with autism. P5 obtained access to support her in caring for her six children with complex health needs, given her ability to pay and access personal funding and community grant resources to supplement the costs of the services. The flexibility with service options, access to private and public funding, and opportunities to adjudicate service provider decisions made access possible for these mothers in caring for their children. In essence, structural elements of regional policies and programs eventually aided families with the most complex needs.

The individual barrier identified across participants was culture, except P5. However, P5 made mention of culture when discussing her perceptions of providers' adeptness to African immigrants and their cultures in providing services to the population. P1, P2, P3, and P4 voiced concerns about the labeling and stigmatization of the children, given their cultures, and the role that the prospect of labeling and stigmatization played in their care and service-seeking decisions.

The level of maternal education and assimilation into American society also moderated knowledge and information access. The more integrated participants were into American culture, wealth, status, language- and whiteness, the less hardship they faced in accessing services.

Limitations of the Study

A notable limitation of this study was participant recruitment. Although participants were geographically diverse, representing the Northeast and Southwest regions of the United States, the exclusion of participants from the Northwest and Southeast regions limits the generalizability of the findings. Perspectives from these regions might have offered unique insights influenced by region-specific factors affecting access to respite care services. Additionally, study recruitment yielded primarily mothers with children diagnosed with autism, potentially limiting the breadth of the findings. Including more diverse family configurations, intra-family support structures, and a broader range of complex health conditions beyond autism could have enriched the study by capturing a more comprehensive range of experiences among African immigrant mothers of children with complex needs. A more expansive participant pool, incorporating semi-structured interviews, might have facilitated a more thorough exploration of the intersections shaping their perceptions and experiences (Morse, 2015).

Recommendations

Given that this was a generic qualitative study purposed to understand, using a critical race theoretical lens, how African immigrant mothers of children with complex health needs describe their experiences accessing respite care services in the United States, a chance to repeat the study with a marginally larger sample size would prove beneficial to ensure the dependability of the study findings. Expanding the sample size would allow for confirming or disconfirming the validity of the findings when considering the broader population of African immigrant mothers of children with complex needs in the United States. Building a broader sample that represents the many intersections of these immigrant mothers and the complex conditions of their children may help strengthen the external validity of the study (Kahlke, 2014; Percy et al., 2015).

There would also be a benefit to repeating the study to include European and White immigrant mothers of children with complex health needs as a comparative group. Researchers note that immigrants and their children with complex health needs face increased barriers to accessing health care and other family support, and their needs remain under-reported (McKay, 2019; Warden et al., 2019). Utilizing the comparative group will help determine if there are significant disparities in experiences accessing respite care services in the United States. As implemented in this study, the researcher would embed critical race theory in the research process, including research question formulation, study design, data collection, variable definitions, intervention, and action to illuminate if and how racism-related factors are barriers to African immigrant mothers' access to services provided by health and social service institutions. Obasogie et al. (2017) also advocate using community-based participatory research methods, multi-level and multi-sectoral approaches to interventions, and mixed methods studies to address poor health outcomes in marginalized populations.

Implications

Respite care is a crucial element of integrated health care services, coordinated family support, and direct home care programs for families caring for children with complex health needs, with nearly 5.6 million children with complex health needs in the United States receiving 1.5 billion hours annually of family-provided health care (Kuo et al., 2011; Pilapil et al., 2017). As established in the literature, African immigrant mothers are most vulnerable to racism and discrimination (Ambegaokor, 2012; Algood & Davis, 2019; Woodgate et al., 2017) in access health and related services. Utilizing a CRT approach to understanding their experiences allows for a holistic means to connect research efforts; develop a lexicon for advancing understandings of racial constructs and phenomena; ensure critical analyses of knowledge creation processes; and enhance praxis that builds on community-based participatory approaches linking research, practice, and the African immigrant community (Ford & Airhibenbuwa, 2010).

Furthermore, the use of a CRT lens better achieves desired mandates for social determinants of health among African immigrant mothers of children with complex health needs, allowing for both improved health and quality of life outcomes for these mothers, their children with complex needs, and their families (Kvarme et al., 2016; Vaz et al., 2021; Welsh et al., 2014)– irrespective of their levels of agency, professional, and socio-economic backgrounds. In the literature, researchers posit that a CRT approach in the research process best informs ways that practitioners, policymakers, insurers, health systems, program leaders, and researchers (Cady et al., 2020) can improve policies and programs to optimally serve these African immigrant mothers of children with complex needs and their minority counterparts in the United States. In as much as respite care is purported to be enmeshed in governmental policies and health and social service delivery systems (Hill, 2016; Nishigaki et al., 2017, p. 678; Spruin et al., 2018), it is crucial to utilize lenses that allow for course correction – taking into account the Anglocentric nature of the health care and social support systems in the United States – to better serve non-white, immigrant, and marginalized families that irrespective of their intersections and placements in the social hierarchy, are more prone to be at acute disadvantages. The health implications for these mothers and their families cannot be understated.

Conclusion

Expanded research to understand the access barriers to respite care among African immigrant mothers of children with complex needs, using a critical race theoretical lens and validating the findings of this study, has broad implications for the African immigrant community and their other minority immigrant and native counterparts. Considering the intersectionalities and nuances within the groups, the use of the lens and methods can be extrapolated to other human development and social justice areas where inequity remains pervasive to date. This research process allowed for the development of a call to action in achieving equitable access to respite care services. As long as African immigrants, their children, communities, and their minority counterparts remain racialized (Garcia, 2017), the use of CRT is imperative to highlight the inequities they face in the United States. This approach will help to resolve the policy and programmatic impacts of the inequities stemming from practices and neutral frameworks that inform planning and service delivery in the health, human, and social services sectors.

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Appendix A: Interview Guide

Sample Interviewee (M1): *African immigrant mother with x old daughter with cerebral palsy*

Interview duration: 60 to 90 minutes

TRANSCRIPT DATA	**CODE 1**	**CATEGORY 1**	**CODE 2**	**CATEGORY 2**	**CODE 3**	**CATEGORY 3**	**THEORY**
Researcher: Thank you for participating in my study.							
Researcher: The goal of this study is to understand your experience getting help with respite care in your area. Also, please know that you can end this interview at any time if you feel uncomfortable, feel free to ask questions, and let me know how you are feeling as we go along. Can we begin?							
M1 (Response):							
Researcher: (Q1) Tell me about your family							
M1 (Response 1):							
Researcher (Follow-up Question 1): Tell							

me about your community and support networks							
M1 (Follow-up Response 1):							
Researcher: **(Q2):** Give me a sense of your typical day and caring for your child.							
M1 (Response 2):							
Researcher (Follow-up Question 2): If you get to take a break, tell me what that involves.							
M1 (Follow up Response 2):							
Researcher: **(Q3)** Tell me about the types of information the hospital staff share with you about your child’s care planning							
M1 (Response 3):							
Researcher (Follow up Question 3): Tell me about the types of information social service staff share with you to support you in caring for your child							

M1 (Follow up Response 3):							
Researcher: **(Q4)** Tell me what you know about respite care.							
M1 (Response 4):							
Researcher (Follow-up Question 4): What could be better about the service? Share anything about your experiences with the service.							
M1 (Follow up Response 4):							
Researcher: (Q5) Tell me about your experience as an African mother interacting with your area health care systems and advocating for your child							
M1 (Response 5):							
Researcher: (Follow up Question 5)							

Tell me about what it is like interacting with social services to get services you might need in caring for your child.							
M1 (Follow up Response 5):							
Researcher: **(Q6)** Tell me what you expect the rest of your journey caring for your child to be and what you expect your experiences with health and social services to be.							
M1 (Response 6):							

Appendix B: Informed Consent

CONSENT FORM

You are invited to take part in a research study on access barriers to respite care services among African immigrant mothers of children with complex needs in the United States. The researcher is inviting all participants identified by research partner organizations to be in the study. Eligible participants will be African immigrant mothers of children (ages seventeen and under) with complex needs.

This form is part of a process called “informed consent” to allow you to understand this study before deciding whether to take part. This study is being conducted by a researcher named Yewande Richards, a doctoral student at Walden University.

Background Information: This study will explore the access barriers to respite care services among African immigrant mothers of children with complex needs in the United States. Researchers have found that African immigrant children in the United States are likely to live with medically complex conditions, including rheumatic heart disease, congenital heart disease, neurodevelopmental disabilities, and a range of chronic diseases requiring constant monitoring and care. Typically, mothers are the primary caregivers of their children; as such, their mothers bear the excessive and continuous strain of their care. These mothers contend with chronic fatigue, sleep deprivation, emotional distress, anxiety, depression, pain, and physical symptoms and are in greater need of social support services due to the ongoing responsibilities and concerns about their child's physical, mental, and social well-being. Consequently, the study is necessary to fill a knowledge gap on the experiences and perceptions of barriers to respite care among

African immigrant mothers of children with complex needs and inform the fields of human and social services. The study will document experienced and perceived barriers to respite care among African immigrant mothers in the United States – where scholars have empirically researched, identified, and discussed such barriers in other Western and industrialized countries, including Canada, Norway, Germany, and the United Kingdom

Procedures: If you agree to be in this study, you will be asked to:

x Participate in an interview via Zoom, or Doxy.me.

x Total time for the initial interview is up to 30 minutes

The interview will focus on access to respite care services, navigating the health care and social service systems in caring for your child, navigating your communities, and any role race and ethnicity play in your ability to access respite care.

INTERVIEWS WILL BE AUDIOTAPED

Voluntary Nature of the Study: This study is voluntary. You may stop at any time. You can change your mind at any time.

Risks and Benefits of Participating in the Study:

Risks: Participating in this study will pose minimal risk to you, your child, or your family's safety or well-being. You may experience distress due to questions asked or feel some discomfort sharing sensitive information. If you experience distress due to the interview related to their child's care, you can stop, regroup, continue, or not continue. Additionally, you may call the following support hotlines if you need further support:

National Mental Health Hotline - 866-903-3787

Benefits: Your participation will help inform policies and programs to make respite care and other support services accessible. You may not receive an individual report; the summary of the results will be available upon completion of the study.

Payments: The researcher will provide a $100 gift card for each participant in appreciation of the time taken to participate in the study.

Privacy: All information you provide will be kept confidential. Your personal information will not be used for any purposes outside of this research project. Your name and anything else that can identify you will not be included in study report. Data will be kept secure in a password protected folder protected with a protected login and a number identifier solely for your identity to protect your personal information. Data will be kept on file for at least 5 years, as required by the university.

Mandated Reporting: Please be aware in advance that the researcher is mandated to report to child protection authorities, any indications or information about physical or sexual abuse or neglect of a child. According to United States Federal Law, mandatory reporting is a legal requirement of certain groups of people to report a reasonable belief of child physical or sexual abuse or child neglect to child protection authorities.

Contacts and Questions: You may ask questions now or if you have questions later, you may contact the researcher by email. You may also talk privately with the Walden University representative about your rights as a participant. Walden University's approval number for this study is 04-21-22-0568543 and it expires April 20, 2024.

Please print or save this consent form for your records.

Statement of Consent: If you understand the study well enough to participate and wish to volunteer, please reply to this message with the words “I consent.

Appendix C: Participant Recruitment Flyer

Receive a $100 Gift Card for Your Time After the Interview

DO YOU NEED MORE SUPPORT, TIME TO REST, OR WORK?

Help improve policies and programs to access Respite Care and Family Support Services for you and your child with chronic conditions.

Your names and personal information will not be included in the study.

Participants will receive a report of study findings.

REQUIREMENTS:

Must be an African Mom of a Child (age 17 & under) with a Chronic Condition like:

- *Congenital Heart Disease*
- *Rheumatic Heart Disease*
- *Thyroid Disease*
- *Cerebral Palsy*
- *Sickle Cell Disease*
- *Thalassemia*
- *Autism*

**Must live in the United States of America

For more information on participating in the study, contact:

Yewande Richards, Doctoral Candidate in Human Services

at yewande.richards@waldenu.edu or

TEXT - 609-831-4354

Participation Is Voluntary + All Information Is Confidential

IRB Approval # 04-21-22-0568543

Appendix D: Letter to Participants

Dear Participants,

First, please allow me to thank you for accepting the invitation to participate in this study. We know that as mothers of children with significant health challenges, you often face a great deal, including chronic fatigue, sleep deprivation, emotional distress, anxiety, depression, pain, physical symptoms. For this reason, you are often in greater need of social support services due to the ongoing responsibilities and concerns about your child's physical, mental, and social well-being. Participation in this study will help health care leaders, policymakers, and service providers learn what is needed to make respite care and other family support services accessible.

Please also remember that your identities will remain anonymous and personal information kept confidential. You may discontinue participation in the study at any time.

I look forward to meeting with you and learning about your experiences.

Sincerely,

Yewande Richards

Researcher - *Understanding Respite Care Barriers among African Immigrant Mothers in the United States*