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Exploring Lived Experiences of Mothers Raising Children with Down Syndrome in Western Nigeria

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Abstract

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by

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MS, Benedictine University, 2021

BS, Ambrose Alli University, 2011

Doctoral Study Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Public Health

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Abstract

Having a child with Down syndrome (DS) negatively impacts mothers’ health and well-being. Families raising a child or children with DS encounter significant financial burdens, inadequate support services, and cultural influences, which have adverse effects on the families. The purpose of this phenomenological qualitative study was to understand the accessibility and utilization of support services through the lived experiences of Western Nigerian mothers raising children with DS. The study involved 10 mothers who were recruited using a purposive sampling technique. Data were collected through semi-structured interviews via Zoom and observational notes. Thematic analysis was guided by Bronfenbrenner's ecological model. NVivo software and a codebook supported the analysis process. The analysis of the data in this study followed Moustakas' descriptive phenomenological approach. Ten themes emerged, and they evolved around mothers struggling with accessing and utilizing support services for their children with DS, facing stigmatization and discrimination, and receiving no support from the community and government. Based on the identified themes, this study's findings hold promise for positive social change by informing policy formulation aimed at addressing challenges faced by mothers and their children with DS in Nigeria. This can significantly enhance their health, overall well-being, and quality of life.

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Dedication

I dedicate this study to my fantastic daughter, Sarah, who has been diagnosed with Down syndrome. She has been the inspiration behind this research. Additionally, I extend this dedication to my supportive husband, Oluwatobi, who has stood by me every step of the way. To my other children, Jordan, Victoria, Solomon, and Zion, I express my love and gratitude for your understanding and patience while I was engrossed in this study.

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All thanks to God for the strength and grace throughout the process of the study. I would like to express my deepest gratitude to my chair, Dr. Isma Berthline, whose unwavering support, guidance, and expertise have been invaluable throughout this academic journey. Her dedication and mentorship have played a pivotal role in shaping the direction of my research and ensuring its successful completion. Thank you for believing in me and for helping me reach this significant milestone in my academic career. I am also thankful to my committee member, Dr. Hudson Brieah, for her contributions to this work. Her insights and feedback have nonetheless been valuable in refining my ideas and strengthening the overall quality of my study. To my family and friends, I extend my heartfelt appreciation for their unwavering support, encouragement, and understanding. Their love and encouragement provided me with the strength and motivation to persevere through the process of the study.

Furthermore, I want to express my sincere gratitude to the mothers in Western Nigeria who are raising children with Down syndrome. They graciously agreed to share their experiences with me. Their openness and willingness to share their stories enriched my research immeasurably, providing invaluable insights and perspectives that have profoundly influenced my work. Finally, I would like to acknowledge Dr. Morris Bidjerano, a faculty member who offered his assistance and encouragement along the way. Your guidance has been instrumental in my academic journey.

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Section 1: Foundation of the Study and Literature Review

In this study, I explored the lived experiences of how mothers access and use support services when raising children with Down syndrome (DS) in Western Nigeria. DS is a common and the most prevalent neurodevelopmental disorder that is caused by trisomy of chromosome 21 (MacLennan, 2020; Windsperger & Hoehl, 2021). Raising a child with DS poses a significant burden to the mothers. Studies confirmed that the demands of families raising DS children are notably high, and mothers experience numerous challenges in their daily lives (Alam et al., 2021; Mishra et al., 2023). It was not known about the lived experiences of how mothers access and utilize support services for their children with DS. Therefore, I investigated the experiences of mothers in Western Nigeria on how they access and use support services for their children with DS, with the aim of improving these support services and resources. Research suggested burdens that mothers of DS children experience, which include stigmas and discrimination for their children (Deakin & Jahoda, 2020).

Based on research, individuals with DS require enhanced parental involvement, which has significant detrimental implications for the children (Chiracu et al., 2023). DS is a public health issue because of the enormous financial burden on the economy (Daniel et al., 2021). As a result, this study presents positive societal implications by (a) raising awareness about the challenges and resilience of mothers, (b) developing preventative programs that address systemic barriers, (c) providing health education tailored to the needs of families with children with DS, (d) driving changes that better support the critical role of mothers in the care and well-being of their children with DS, (e) improving access to specialized support services such as therapy and special education, and (f) reducing stigma and discrimination associated with DS.

Chiracu et al. (2023) revealed that having a DS child affects the entire family, and the mother, who is often the primary caregiver, bears the full responsibility of offering physical and emotional support. In this regard, I provide insight into the body of knowledge pertaining to Western Nigerian mothers’ lived experiences of raising children with DS.

In this section, I introduce the study by delving into its background, problem statement, purpose, and research questions. I also outline the theoretical framework, study nature, literature search strategy, review of related literature, definitions, assumptions, scope, delimitations, and the study's limitations. The section concludes with a reflection on the research's significance in the domain of public health, a comprehensive summary, and a segue into the subsequent sections of the study.

Background

Various research studies have been conducted to examine aspects related to raising DS children. In one study, Jess et al. (2021) investigated whether the DS advantage—the concept that families of individuals with DS may experience certain benefits or positive outcomes, such as lower levels of maternal psychological distress and higher caregiving life satisfaction compared to families of individuals with other developmental disabilities—would influence maternal psychological distress. They explored how this advantage affects or influences caregiving life satisfaction and the perceived positive outcomes associated with having a child with developmental disabilities when controlling for external variables (Jess et al., 2021). From this study, these researchers noted that there was an insignificant DS advantage and that aspects such as life satisfaction and psychological distress were positively correlated with poverty (Jess et al., 2021). Jess et al. revealed crucial information relating to the experiences of raising a DS child and factors that influence mothers' life satisfaction and psychological distress. Specifically, the study highlighted the role of economic factors, such as financial strain and poverty, in shaping these experiences.

Research findings show that parents of children with DS experience enhanced levels of sadness, worry, fear, and disbelief because of having a disabled child (Daniel et al., 2021). Additionally, research studies have revealed that families or mothers with DS children are subjected to social stigma and are compelled to conceal the frustrations and social stigma from their DS children or even their families (Deakin & Jahoda, 2020). More importantly, and as Duru et al. (2020) posited, mothers of children with DS often face exorbitant out-of-pocket expenses for their children's support services, with a significant number of them, especially those who belong to low socioeconomic status in Nigeria, being unable to sustain the high out-of-pocket expenses.

In another study, Ijezie et al. (2023) conducted a systematic review to gather, consolidate, and combine both quantitative and qualitative data regarding the quality of life among adults with DS, as reported by both themselves and proxies. The review included 39 studies, which collectively suggested that individuals with DS experience a high quality of life, particularly emphasizing aspects such as self-determination and interpersonal relationships (Ijezie et al., 2023). Based on their study's findings, the researchers advocated for the implementation of a more structured approach to improving the quality of life for adults with DS in specific areas (Ijezie et al., 2023). The authors demonstrated the need to ensure that individuals with DS are accorded appropriate support services due to identified discrepancies between self-reported and proxy-reported quality of life. They highlighted inadequacies in current services and assessment methods, suggesting the integration of digital assistive technologies. According to Ijezie et al., enhancing support can address the unique needs of adults with DS and improve their overall quality of life. This move could have positive implications in terms of enhancing the life satisfaction and quality of life of DS children.

In yet another study, Lee et al. (2021) conducted a scoping review to examine the family and child quality of life-related factors that have been studied pertaining to one another in children with DS. In this study, the researchers noted limited focus on a child’s emotional welfare, and none investigated how families perceive a child's emotional well-being (Lee et al., 2021). Based on this finding, they recommended the need for future studies focusing on an in-depth understanding of relationships between children with DS and their families (Lee et al., 2021).

Oduyemi et al. (2021) conducted a mixed methods study to examine knowledge about autism spectrum disorder (ASD) in Nigeria. The authors discussed the negative experiences of families of children with DS. These experiences included enacted and internalized stigma and correlates among guardians or parents of children with ASD. Correlates included factors like the parents' level of education and monthly family income. In this study, the researchers observed poor overall ASD knowledge, with a negligible population (1.3%) having good knowledge (Oduyemi et al., 2021). Additionally, they emphasized the need for better education and community awareness to support parents of children with ASD. Oduyemi et al.’s study raised fundamental concerns regarding the possibility of poor DS knowledge among mothers in Western Nigeria who have children with DS. Conducting the current research helps to determine participants' knowledge by examining their lived experiences with DS.

Based on the previous studies that have been explored, there was a notable knowledge gap. Although researchers have extensively researched this issue, it has not been explored using qualitative studies to explore the lived experiences of how mothers access and utilize support services when raising children with DS in Western Nigeria (Deakin & Jahoda, 2020; Jess et al., 2021). In this regard, it was indisputably vital to address this knowledge gap.

Problem Statement

The problem that I addressed in this study was the lack of access to support services for mothers of children with DS in Western Nigeria. These mothers face significant challenges in obtaining the necessary support services for their children, which include medical care, educational resources, therapy, and social support networks. Understanding the lived experiences of how these mothers access and use these services is crucial to addressing the gaps and improving the well-being of both the mothers and their children. The phenomenon that triggered my interest in examining the literature is that DS is the most common and prevalent genetic disorder (see Duru et al., 2020). Research shows that this health problem affects children and families worldwide (Lee et al., 2021). It is estimated that over 6,000 infants are born with DS, and one in 1,000 to one in 1,100 births result in families caring for a child with DS (Duru et al., 2020; Lee et al., 2021). DS is one of the top three disorders and is projected to occur in one in 865 live births in Western Nigeria (Duru et al., 2020). Families raising children with DS need more extensive physical, environmental, intellectual, emotional, financial, developmental, and social support services to prevent more severe health issues (Chiracu et al., 2023; Daniel et al., 2021; Deakin & Jahoda, 2020; Rahimi & Khazir, 2019).

However, existing research studies have highlighted superstitious beliefs and supernatural forces as factors influencing the increase in the lack of service accessibility and utilization (Jansen-van Vuuren et al., 2022). The most pronounced problem is cultural stigmas of public awareness of raising and supporting children with a disorder in Western Nigeria. Yet, there needs to be more adequate knowledge or information on lived experiences of how mothers access and utilize support services for their children with DS. Consequently, this may adversely affect the child's opportunities to improve their health and quality of life.

Purpose of the Study

The purpose of this qualitative study was to understand the accessibility and use of support services through the lived experiences of Western Nigerian mothers raising children with DS. Data were collected by virtual face-to-face semistructured interviews via Zoom, and observation notes of behaviors, gestures, and mannerisms were obtained during the interviews. Ten mothers were recruited living in Western Nigeria. The problem of the study was addressed by using thematic analysis. This allowed me to compile my data in one place, label and cleanse the data, disassemble, reassemble, and then create a cohesive and comprehensive visual representation of the dataset.

The findings from this study hold significance for policymakers, public health practitioners, and my target population. For instance, in line with the World Health Organization (WHO) recommendations for research-based policymaking in healthcare (Trapero-Bertran et al., 2022), findings from this may inform policymakers' decisions on the issues to address through formulating effective public health policies. Policymakers can design strategies that effectively consider mothers' lived experiences and tailor interventions for children with DS in Western Nigeria to improve their overall well-being and quality of life. This is significant because it ensures that policies are not only evidence based but also context-specific, addressing the unique challenges faced by these mothers. By incorporating the lived experiences of mothers, policymakers can develop more targeted and effective interventions, ultimately leading to better health outcomes and enhanced quality of life for both the children with DS and their mothers. Additionally, this approach promotes equity in medical services, which ensures that marginalized populations receive the support they need.

Similarly, findings from this study can have positive implications for public health practitioners, including promoting awareness, influencing practices of the healthcare systems, and advocating for more tailored support services to the unique norms and customs embedded in the culture of Nigeria for children with DS from policymakers within local government. This is significant because it ensures that interventions are culturally appropriate and effective, thereby enhancing the quality of care and support these children receive.

Finally, findings from this study should benefit my target population, particularly by ensuring that their welfare is addressed or promoted, for example, by ensuring that they have adequate social support to help alleviate the negative experiences of raising DS children. This is significant because the quality of life for both the children and their mothers can be improved, and a more supportive and inclusive community environment can be fostered.

Research Questions

The overarching research questions addressed in this study are as follows:

RQ1: What are the lived experiences of mothers accessing and utilizing supportive services while raising children with Down syndrome in Western Nigeria?

RQ2: How do mothers raising children with Down syndrome describe their experiences with accessing and utilizing support services within the social systems in Western Nigeria?

RQ3: How do mothers raising children with Down syndrome describe their experiences with accessing and utilizing support service resources in Western Nigeria?

RQ4: How do mothers raising children with Down syndrome describe their experiences with accessing and utilizing support services within the customs and cultural beliefs in Western Nigeria?

Theoretical Framework

I used the Bronfenbrenner ecological model as a theoretical framework to support my study. Bronfenbrenner was the original tenet of the ecological model developed in 1977. The concepts of Bronfenbrenner's (1977) ecological model focus on the impact of a person’s surrounding environment on their development. Bronfenbrenner divided the environmental construct into five levels of influence: the microsystem, mesosystem, ecosystem, macrosystem, and chronosystem. Scholars use the ecological model to illustrate how to guide the development and evaluation of interventions that target multiple levels of influence and promote positive behavior changes and health outcomes (Kennedy, 2021). The logical connection between the Bronfenbrenner ecological model and my study approach includes using one of the five levels of environmental influences. The selected ecological level is the macrosystem, which consists of (a) customs and cultural beliefs, (b) resources, and (c) social systems for mothers accessing and utilizing support services for children withDS in Western Nigeria.

The ecological model theory relates to my study in that it highlights various factors influencing human development that can be used to understand the development of DS children, which could influence their mothers’ lived experiences (see Bronfenbrenner, 1977). Additionally, this theory relates to the research questions in the sense that it could be used to base arguments pertaining to the lived experiences of mothers raising children with DS and on the lived experiences of these mothers while accessing and using support services within the customs, cultural beliefs, and social system. Also, families that have more resources are better equipped to adapt to the challenges of raising children with DS.

Nature of the Study

As aforementioned, in this study, I explored the lived experiences of mothers raising children with DS in Western Nigeria. I employed a descriptive phenomenological qualitative research approach. The phenomenological approach was best suited for gathering in-depth, contextualized, open-ended responses, rich details, and deeper insight (Tanwir et al., 2021) into the lived experience of mothers residing in Western Nigeria on how they access and use support services for their children with DS.

Importantly, virtual face-to-face semistructured interviews and observation notes of behaviors, gestures, and mannerisms during the interviews from the participants were used in collecting data on the mothers' lived experiences in Western Nigeria. Additionally, I recruited 10 mothers with DS children in the study. I created 12 open-ended questions for all participants, along with follow-up questions. The interview sessions lasted approximately 30-35 minutes, using my interview protocol as a guide. Following cycles of member checking of the data interpretation to ensure the accuracy of the transcript helped my study reach data saturation. Data saturation was attained when no new data arose from my participants.

The collected data was analyzed using the thematic data analysis technique. I compiled my data in one place, labeled and cleaned the data, disassembled, reassembled, and then created a cohesive and comprehensive visual representation of the dataset that aligns with the interpretation of the findings through a narrative. This process was accomplished by using NVivo data analysis software and a comprehensive codebook. NVivo is a tool that helped me store, organize, identify, code themes, and analyze my data for trends and patterns to understand better the lived experiences of mothers living in Western Nigeria raising children with DS. The study's conclusion and recommendations were based on the identified themes.

Literature Search Strategy

Search for appropriate and relevant research studies and articles in the literature review section was done using various library databases. These databases include the Walden Library, Cumulated Index to Nursing and Allied Health Literature (CINAHL), Embase, Emerald, Global Health, Google Scholar, PubMed, Science Direct, SSRN, Thoreau Multi-Database, ProQuest, and Scopus. These databases were selected because they are relevant and contain vast research articles and other information sources that were used to support the significance of this current study. In their journal article, Oermann et al. (2021) emphasized the importance of using credible databases in public health research by arguing that the quality of literature used as the foundation of a scholarly project is crucial.

An array of relevant key search terms and a combination of search terms was used to search for relevant and appropriate research articles. The search terms include *Qualitative methodology, phenomenology research design, Ecological Model, Down syndrome, support services, service utilization, Nigerian mothers and Down syndrome, attitudes, perceptions and Down syndrome, customs, cultural beliefs, and childhood developmental disabilities, Cultural disability, lived experiences, quality of life, the well-*

being of children with down syndrome, challenges, stigma, discrimination, and *Urie Bronfenbrenner*. The Boolean operators included ‘AND’ and ‘OR.’

The scope of the literature review comprises current peer-reviewed research articles published within the last 5 years. Peer-reviewed public health, education, and health promotion journal articles were prioritized in the literature review because peer review is a hallmark of high-quality journals. Considering this was a scholarly project, high-quality public health journal articles were preferred. In this regard, choosing peer-reviewed journal articles was a crucial consideration when selecting research articles to be included in the literature review section. In another aspect, current research articles, particularly research articles published in the last 5 years (between 2019 and 2023), were included in this study. This consideration was intended to ensure that the information included in the literature review section was current and thus reliable in demonstrating the purpose and significance of this study. Concerning the types of literature and sources that were searched, primary, secondary, and tertiary literature were explored. The essence of searching different types of literature was to obtain vast information about the research topic, including extensive or in-depth information about the research problem and the gaps in the existing literature. Such information helps ensure that the purpose and problem of this study are sufficiently supported with research evidence and, importantly, that the significance of the study was justified. Therefore, the scope of the literature review comprised of current peer-reviewed journal articles related to the study's purpose and problem.

In another aspect, approval to use any peer-reviewed journal articles older than 5 years and any other seminal literature was not needed in the study from the supervisory team as all the journal articles used in this study were published within the last 5 years. Such a move was critical to ensure that the educational project is authentic and aligns with or meets the requirements for an academic project outlined by the institution’s faculty or the research department.

Theoretical Foundation

This study was based on Bronfenbrenner's (1977) ecological model. This ecological theory was developed by Bronfenbrenner between 1973 and 1979 (Bronfenbrenner, 1977; El Zaatari & Maalouf, 2022). Navarro and Tudge (2022) argued that Bronfenbrenner formulated the ecological theory of human development as a response to what he characterized as the study of children in unfamiliar settings. It is important to highlight that Bronfenbrenner's ecological model was developed in three phases. In Phase 1 (1973-1979), Bronfenbrenner posited that an evolving individual happens within five systems: the microsystem, mesosystem, exosystem, macrosystem, and chronosystem (Bronfenbrenner, 1977; El Zaatari & Maalouf, 2022). In the second phase (1980-1993), the theorist focused extensively on the impact of developing individuals on their own development and placed greater emphasis on biological factors (El Zaatari & Maalouf, 2022). In this phase, the theory was named the bioecological systems theory of human development (El Zaatari & Maalouf, 2022). In the third and final phase (1993-2006), numerous changes happened, and greater emphasis was focused on the proximal process, which was considered a vital element of the bioecological systems theory (El Zaatari & Maalouf, 2022). Based on this narration, it is evident that this theory was developed in phases, with several changes being undertaken to make it relevant to the intended purpose.

Bronfenbrenner’s theory is based on specific theoretical propositions. One of the theory’s theoretical propositions is that individuals make up living systems and must be open to enable them to change and adapt to their environments (Crawford, 2020). Additionally, it is hypothesized that systems follow a hierarchal structure, where each system builds upon the other, and that communities develop from the individuals that make up the community, progressing from microsystem to mesosystem to macrosystem (Bronfenbrenner, 1977; Crawford, 2020). The principles of this systems theory can be applied across different cultural contexts (Bronfenbrenner, 1977; Crawford, 2020). More importantly, the theory is based on specific key concepts that focus on the impact of a person’s surrounding environment affecting their development. Bronfenbrenner (1977) divided the environmental construct into five levels of influence: the microsystem, mesosystem, ecosystem, macrosystem, and chronosystem. I focused on using the concept of one of the five levels of environmental influences. The selected ecological level is the macrosystem, which consists of the (a) customs and cultural beliefs, (b) resources, and (c) social systems for mothers accessing and utilizing support services for children with DS in Western Nigeria. Finally, and in line with Crawford’s (2020) assertion, a key assumption of Bronfenbrenner's ecological model is that the relationships children have with parents or caregivers influence their development and that these relationships are impacted by internal and external environments.

Bronfenbrenner's ecological model has been applied previously in ways similar to this study. For example, Lopez et al. (2021) used this theory to examine the existing discussion on the social environment of early childhood concerning health outcomes across different stages of development (childhood, adolescence, and adulthood). They illustrated that employing adverse childhood experiences (ACEs) as a tool to comprehend early life experiences provides a multidimensional view of the various interconnected factors within a growing child's environment (Lopez et al., 2021). Lopez et al. used Bronfenbrenner's ecological model and their research is similar to mine in the sense that it explored public issues relating to early childhood development and the surrounding environment.

The rationale for electing this theory was that it focuses on human growth and development and the influence of various factors in an individual’s environment that influence their growth and development (see Bronfenbrenner, 1994). Mainly, the macrosystem was selected among the environmental influences because it encompasses the overall structure of micro-, meso-, and exosystem within a culture or subculture; it includes belief systems, understanding, tangible assets, traditions, ways of life, opportunities, risks, and life path alternatives embedded within these wider systems (Bronfenbrenner, 1994). As Navarro and Tudge (2022) argued, Bronfenbrenner’s ecological model emerged as a response to the science of children in strange situations. Bringing up a child with DS is indisputably a strange situation that mothers find themselves in and which undermines their ability to provide quality care and to enhance the children’s quality of life and overall well-being.

In another aspect, there are certain strengths in applying theories or models to public health issues. One of these strengths which Beyera et al. (2022) highlighted is that applying theories to public health issues provides the rationale behind the occurrence, method, and/or reasoning behind a particular phenomenon of interest. Additionally, applying theories or models to public health issues helps to delineate the causal pathways which in turn helps public health practitioners to design appropriate as well as research-led interventional strategies to address the public health issues (Beyera et al., 2022). Hence, it can be rightly argued that applying theories or models to public health issues is significantly vital in enabling researchers or public health practitioners to analyze and understand public health issues in-depth and develop appropriate evidence-based solutions to address the problem.

Despite the strengths associated with applying theories or models to public health issues, there are certain limitations as well. Cummins (2022) highlighted some of these limitations. They included the fact that the use of theory in research may be subjected to various factors affecting health-related results, the assessment of theory utilization has not been consistent, and finally, the public health field conflates theories and models (Cummins, 2022). The inability of a researcher to address these limitations can prevent them from effectively applying theories or models to public health issues.

The selected theory relates to the present study, while the research questions relate to the existing theory. For instance, the theory focuses on factors or strange situations that influence human development (Navarro & Tudge, 2022). In line with this assertion, I examined a strange situation involving children with DS. Additionally, the research questions were designed to explore Western Nigerian mothers' lived experiences on specific aspects pertaining to how mothers access and use support services when raising children with DS in Western Nigeria and how specific elements such as resources, social systems, cultural beliefs, and customs affect their ability to ensure enhance well-being and quality of life of these children.

Finally, the constructs of Bronfenbrenner's ecological model are the microsystem, the mesosystem, the exosystem, the macrosystem, and the chronosystem. Notably, the macrosystem, which consists of the (a) customs and cultural beliefs, (b) resources, and (c) social systems that I used, aligns with the executive summary in the sense that identifies or demonstrate how these systems influence child growth and development and how specific interventional strategies, for example, social support systems, cultural awareness, customs, and cultural beliefs, may influence program development and implementation strategies plan to foster the quality of life and well-being of these children with DS.

Literature Review Related to Key Concepts

The literature review is based on specific key concepts. The concepts are divided into three main themes, each with specific subthemes. The constructs of interest are social systems, resources, customs, and cultural beliefs. The subthemes for social systems are family, sociocultural, and gender. Subthemes for resources are financial challenges and support services. Subthemes for customs and cultural beliefs are stigmatization and cultural perceptions of disability.

Social Systems

Social systems are made up of intricate networks that influence the individual life experience (Alon, 2019). Alon explored the social support network influence on post-crisis growth among mothers of children with DS and with ASD. Alon concluded that social support predicted mothers' postcrisis growth, with a particular type of disability acting as a mediator variable between these influences.

Alon (2019) used phenomenological qualitative methods and found that social support network denotes postcrisis growth but only with mothers of children with ASD. An inherent strength of the study is that the researchers highlighted the experiences of mothers of children with ASD and DS, as it provides insights into the challenges faced by these mothers and the coping strategies they used in managing the challenges (Alon, 2019). On the contrary, an inherent weakness is that this article explored the challenges of financial burdens, stigmas, lack of support, and mental issues mothers face while raising children with ASD and DS. Limited information exists about how mothers access and utilize support services (Alon, 2019). Additionally, the research relies on self-reported data, which may be subject to bias (Alon, 2019).

The rationale for the selection of the social system concept is that the study presents an invaluable opportunity to explore the lived experiences of Western Nigerian mothers concerning how they access and use support services when raising children with DS. Similarly, Hielscher et al. (2022) used a phenomenological approach and a thematic analysis to explore the impact of the COVID-19 pandemic on the feeding experiences of mothers of children with DS. In the study, Hielscher et al. investigated the alterations in services, their effects on the support received, and the mothers' feeding experiences during the COVID-19 pandemic and lockdown period. Hielscher et al. concluded that the mothers of infants with DS were dissatisfied with the support they received from health professionals . The mothers felt that their needed support was not being met due to the lack of knowledge about DS among health professionals (Hielscher et al., 2022). The virtual support offered to them further magnified their frustration.

Importantly, findings from exploring this aspect may have positive implications that Western Nigerian mothers with DS children are accorded the necessary support services to effectively care for the children to promote their overall well-being. An inherent strength of the study by Hielscher et al. (2022) is that it highlighted the feeding experiences of mothers. Thus, an inherent weakness of the study is that it does not describe challenges or barriers to positive feeding experiences to enable appropriate mitigation measures to be employed to foster DS children’s well-being and quality of life (Hielscher et al., 2022). Furthermore, an inherent weakness is that the study is based on data provided by the participants, which could be influenced by bias (Hielscher et al., 2022).

On the contrary, Thompson et al. (2020) disagreed with Alon (2019) and used a qualitative multiple case study to understand the lived experiences of individuals with DS and their families. The researchers conducted in-depth interviews with 10 families of individuals with DS and analyzed the data using a thematic analysis approach. Thompson et al. explored the social system by examining the social support networks of individuals with DS and their families. They found that social support networks played a vital role in the welfare of individuals with DS and their families (Thompson et al., 2020).

The researchers approached the problem by conducting in-depth interviews with families of individuals with DS (Thompson et al., 2020). This approach allowed them to gain a more profound comprehension of the experiences of individuals with DS and their families. An inherent strength of this approach is that it provided the researchers with the opportunity to explore the experiences of individuals with DS and their families in their own words (Thompson et al., 2020). However, an inherent weakness of this approach is that it is time-consuming and resource-intensive (Thompson et al., 2020).

The rationale for selecting the social system concept is justified by the broader literature emphasizing the significant role of social support networks in the well-being of individuals with DS and their families. Thompson et al.’s (2020) study contributed to this rationale by highlighting how social environments contribute to thriving experiences. The study by Thompson et al. presented an invaluable opportunity to explore the lived experiences of Western Nigerian mothers concerning how they access and use support services while raising children with DS. Examining the theme of the social system is paramount for a holistic grasp of the challenges and strengths encountered. The next subtheme will discuss family in view that the social system is intricately woven into the fabric of a family.

Family

The family unit holds a central role in shaping the experiences of mothers raising children with intellectual disabilities, especially DS. Literature suggested that familial support structures significantly influence the well-being of both mothers and their children (Juveriah & Gulnaz, 2020). The study concluded that mothers with supportive spouses and extended family members reported higher levels of well-being and satisfaction with their lives (Juveriah & Gulnaz, 2020).

Juveriah and Gulnaz (2020) employed a qualitative phenomenological study of mothers who have children with Autism Spectrum Disorder (ASD) in Pakistan. The study investigated the perceptions and lived experiences of mothers raising children with ASD in Pakistan and the impact of Pakistani culture on their experiences (Juveriah & Gulnaz, 2020). The study uses Bronfenbrenner's ecological systems theory as the guiding conceptual framework. The researchers conducted in-depth interviews with 10 mothers who have children with ASD (Juveriah & Gulnaz, 2020). The researchers found that mothers of children with ASD in Pakistan face significant challenges, including insufficient awareness and comprehension of ASD, limited access to resources and support, and social stigma (Juveriah & Gulnaz, 2020). The researchers also found that mothers use various coping strategies to manage their challenges, including seeking social support, engaging in religious practices, and developing a positive outlook (Juveriah & Gulnaz, 2020).

An inherent strength of this study is its ability to provide rich, detailed descriptions of the encounters of mothers raising children with ASD in Pakistan (Juveriah & Gulnaz, 2020). Additionally, the study captured the complexity and diversity of the human experience (Juveriah & Gulnaz, 2020). The study also provided insights into the challenges encountered by mothers of children with ASD in Pakistan and the coping strategies they use to manage these challenges (Juveriah & Gulnaz, 2020). The study’s use of Bronfenbrenner’s ecological systems theory as the guiding conceptual framework is another strength, as it emphasizes the importance of understanding the multiple levels of influence on human development, including the family, community, and culture (Juveriah & Gulnaz, 2020). Nevertheless, an inherent weakness noted in this study is that the researchers used a limited sample size, which restricts the applicability of the findings and its potential for researcher bias (Juveriah & Gulnaz, 2020). The study also focused on the experiences of mothers of children with ASD in Pakistan and may not apply to other cultural contexts of children with ASD (Juveriah & Gulnaz, 2020).

The rationale for selecting the family concept was that it helped to gain a deeper understanding of the experiences of mothers raising children with DS in Western Nigeria and the factors that influence their access to and utilization of support services. This concept is important because it helped to identify the challenges faced by mothers of children with DS in Western Nigeria and the factors that contribute to their experiences.

Antithetical to Juveriah and Gulnaz (2020) study, Farkas et al. (2019) used a qualitative study that explored the positive and negative parenting experiences of parents of children with DS. The researchers found that parents of children with DS experience both positive and negative emotions in their parenting journey (Farkas et al., 2019). The researchers identified positive experiences, including feelings of love, joy, and pride in their child’s accomplishments (Farkas et al., 2019). The researchers also identified negative experiences, including challenges related to accessing support services, resources, stress, frustration, and anxiety (Farkas et al., 2019). An inherent strength of the study is that it provided an in-depth understanding of parents' experiences of children with DS (Farkas et al., 2019). The researchers used a thematic analysis approach to analyze the data, allowing them to identify themes related to positive and negative experiences (Farkas et al., 2019). However, an inherent weakness is that the study only included parents from one geographical location, limiting the findings' generalizability.

The rationale for selecting the family concept is the broader literature emphasizing the central role of the family in the well-being of mothers raising children with DS. Farkas et al. (2019) study contributed to this rationale by providing a detailed exploration of positive and negative parenting experiences, shedding light on the intricacies of family dynamics. The study addresses insightful perspectives into the complexities of the family, justifying its relevance to explore the lived experiences of how mothers access and utilize support services while raising children with DS in Western Nigeria (Farkas et al., 2019).

Similarly, other researchers have used qualitative methods to explore the experiences of families affected by developmental disorders (Fernández-Ávalos et al., 2020). The study by Fernández-Ávalos et al. is a qualitative study that explored the quality of life and worries of parent caregivers of adult children identified with intellectual disability (ID). The researchers opted for a semi-structured interview format to evaluate 16 parents of adult children with ID (Fernández-Ávalos et al., 2020). The author conducted a thematic qualitative analysis. They also explored the role of family in the lives of parent caregivers of adult children with ID (Fernández-Ávalos et al., 2020). They found that family played a critical role in the well-being of parent caregivers of adult children with ID (Fernández-Ávalos et al., 2020). This is consistent with Juveriah and Gulnaz (2020) study, where the researchers found that family structure plays an important role in the well-being of mothers while raising their children.

The inherent strength of the study is that it enabled the researchers to investigate the experiences of parents of adult children with ID in their own words (Fernández-Ávalos et al., 2020). However, an inherent weakness is that the approach requires time and resources (Fernández-Ávalos et al., 2020).

The rationale for selecting the family concept is well-supported by the broader literature accentuating the central role of the family in the well-being of mothers nurturing children with developmental and intellectual disabilities. Fernández-Ávalos et al.'s study contributed to this rationale by providing insights into the concerns and quality of life of the parents, shedding light on the complexities of family dynamics. By examining the caregiver perspectives, the study addresses detailed insights into the challenges faced by families of individuals with intellectual disabilities. This justifies its relevance for exploring the lived experiences of how mothers access and use support services while raising children with DS in Western Nigeria.

Family holds a pivotal role in the lives of mothers raising children with intellectual disability. The challenges and joy within the family setting significantly impact the overall well-being of both caregivers and children. Next, social-cultural issues will be discussed as subthemes of the social systems.

Social-Cultural

The socio-cultural context introduces a set of customs and beliefs that significantly affect mothers' experiences (Van der et al., 2019). Van der et al. conducted a qualitative study to explore how mothers of disabled children in an urban settlement in South Africa adapted to their circumstances and demonstrated agency. They used a phenomenological approach to understand the lived experiences of these mothers and how they adapted to their situations (Van der et al., 2019). The authors found that cultural and social factors considerably impacted mothers’ experiences and how they adapted to their situations (Van der et al., 2019).

The researchers approached the problem by conducting in-depth interviews with 30 mothers (Van der et al., 2019). An inherent strength of this study is that it allowed the researchers to gain a deep understanding of the mothers’ experiences and how they adapted to their situation (Van der et al., 2019). However, an inherent weakness noted in this study is that it is time-consuming and may not be feasible for larger sample sizes (Van der et al., 2019).

The concept of social-cultural is relevant to my study as it explores how cultural and social factors influence the experiences of mothers raising children with DS. Van der et al. discovered that cultural and social factors significantly impacted mothers' experiences and how they adapted to their situation. The mothers faced challenges such as stigma, discrimination, and lack of support from their communities (Van der et al., 2019). The researchers emphasized the need for support for these mothers. Additionally, this study demonstrated the significance of support services needed to enable caregivers of children with DS, particularly mothers, to effectively care for these children and improve their well-being.

As noted in the preceding sections, the specific problem that this study addressed was that there was a lack of adequate knowledge or information on lived experiences of how mothers access and used support services for their children with DS. In line with this problem, this study provides additional information about the suffering that mothers experience as well as the significance of social support systems, which can be of significant use in terms of enabling mothers caring for these children to provide them with the needed support to improve the children's well-being. Therefore, the rationale for selecting the social-cultural concept is that it was relevant to my research questions and provided insight into mothers' experiences raising children with DS in Western Nigeria.

Cultural intricacies impact perceptions, decisions, and support systems, influencing the caregiving trajectory. Recognizing and respecting these social-cultural dynamics is paramount for developing culturally sensitive interventions and support services. Gender role in mothers' experiences will be discussed as the last subtheme for the social system.

Gender

Within the social system, gender norms and roles contribute to distinct challenges and opportunities for mothers. Malhi et al. (2022) noted that mothers were the primary caregivers for children with autism spectrum disorder (ASD) in their sample. The researchers further posit that mothers bear the challenges and burden of raising their children (Malhi et al., 2022).

Malhi et al. (2022) conducted a qualitative study to explore the parental experiences of children with ASD in India. The study used a phenomenological approach employing thematic analysis and in-depth interviews with the parents of children with ASD (Malhi et al., 2022). The researchers noted that mothers were the primary caregivers for children with ASD in their sample (Malhi et al., 2022). This suggests that gender may be an important factor to consider in the experiences of parents of children with disabilities, including DS.

An inherent strength noted in this study’s approach is that it allowed the researchers to gain an in-depth comprehension of the parental experiences of children with ASD (Malhi et al., 2022). They identified a range of themes related to parents' experiences, including the challenges of obtaining a diagnosis, the emotional impact of the diagnosis, and the need for support and information (Malhi et al., 2022). On the contrary, the study's weakness is that it was conducted in India, which may limit the applicability of the results to other cultural contexts (Malhi et al., 2022). Additionally, the researcher noted that their sample was relatively small, which may limit the representativeness of the findings (Malhi et al., 2022). However, they did note that their study provided a valuable contribution to the literature on the experiences of parents of children with ASD in India (Malhi et al., 2022). The researchers noted that further research is needed to better understand the experiences of parents in other cultural contexts (Malhi et al., 2022).

The rationale for selecting the concept of gender was that it was a crucial factor to consider in the experiences of parents of children with disabilities. As noted by Malhi et al., mothers are typically the primary caregivers for children with ASD. By examining the experiences of mothers raising children with DS in Western Nigeria, my study may contribute to a better understanding of the factors that impact the experiences of mothers of children with DS in this context.

Celik and Kara (2023) conducted a qualitative investigation to examine the stress-inducing experiences and coping mechanisms of 26 parents with young children diagnosed with DS in Turkey. The authors conducted a semi-structured interview applying a thematic analysis approach (Celik & Kara, 2023). More than half of the participants were mothers, which suggests that gender may be an essential factor to consider in the experiences of parents of children with DS (Celik & Kara, 2023). The researchers used the qualitative method to explore the complex and detailed experiences of parents of children with DS (Celik & Kara, 2023). From this study, these researchers noted that the mothers in their study experienced more stress than fathers, which further posits the importance of considering gender in this context (Celik & Kara, 2023). Colton and Paul (2020) confirmed this assertion that mothers are archetypally the primary caregivers for children with disabilities in Nigeria. The researchers further mentioned that mothers are considered responsible when they give birth to a child with a disability, and as a result, they carry the weight of fulfilling the health and education requirements of their children (Colton & Paul, 2020).

Based on the approach employed in this study, an inherent strength that can be noted is that it allowed the researchers to gain a deep understanding of parents' experiences of young children with DS (Celik & Kara, 2023). However, an inherent weakness in this study’s approach is that the researchers conducted the study in Turkey, which may limit the generalizability of the findings to other cultural contexts (Celik & Kara, 2023).

The rationale for selecting the concept of gender was that it was a crucial factor to consider in the experiences of parents of children with DS. As noted by Celik and Kara, mothers of children with DS experience more stress than fathers. By examining the experiences of mothers in Western Nigeria, Celik and Kara's study contributed to a better understanding of the factors that influence the mothers' experiences and how they access and use support services while raising children with DS.

The research conducted by Dewi et al. (2020) used qualitative methods, specifically employing a phenomenological approach to depict the experiences of mothers raising children with DS. The study involved 10 mothers chosen through purposive sampling in Binjai, Indonesia (Dewi et al., 2020). Through in-depth interviews, the researchers gained valuable insights into the perspectives and experiences of these mothers (Dewi et al., 2020). The findings revealed that mothers of children with DS undergo diverse emotional experiences and employ strategies to provide optimal care amidst various physical and social challenges (Dewi et al., 2020). The authors also recognized that mothers of children with DS experience hindrances in caring for their children, which can be influenced by their gender roles and expectations (Dewi et al., 2020).

An inherent strength of the study is that it offered rich and detailed data that can be used to develop a thorough understanding of the phenomenon being studied (Dewi et al., 2020). An inherent weakness could be the reliance on self-reporting through interviews (Dewi et al., 2020). Since the data is based on the mothers' perspectives and recollections, there is a possibility of response bias or social desirability bias, leading them to provide answers they consider socially acceptable, potentially resulting in skewed data.

The concept of gender was relevant to the study because it was one of the concepts that can influence the experiences of mothers of children with DS. The authors recognized that mothers of children with DS experience difficulties in caring for their children, which can be influenced by their gender roles and expectations (Dewi et al., 2020). The concept of gender was relevant because it contributed valuable insight into the experiences of how mothers access and utilize support services for their children with DS in Western Nigeria. The exploration of gender sheds light on the distinctive roles and expectations placed on mothers raising with DS. Understanding the gender dynamics inherent in caregiving allows for a detailed perspective on challenges and coping strategies. The next main theme will address how mothers access and utilize available resources.

Resources/Support for Children with Down Syndrome

Resources play a central role in shaping the daily lives and challenges faced by mothers raising children with DS. Research suggested that mothers of children with DS require additional resources and support to help them cope throughout their parenting journey (Kammes et al., 2022). Resources and support, such as community support through social media platforms, provide essential peer connections, access to information, emotional support, and advocacy opportunities (Kammes et al., 2022). This helps mothers of children with DS cope more effectively and enhances their overall well-being.

Kammes et al. (2022) conducted a qualitative study to explore the birth stories of mothers of children with DS on social media. The researchers employed a phenomenological approach to analyze the data collected from social media platforms (Kammes et al., 2022). The researchers approached the problem by analyzing the birth stories of mothers of children with DS on social media (Kammes et al., 2022). The study found that mothers of children with DS use social media to share their stories and connect with other mothers of children with DS (Kammes et al., 2022). The study also found that social media provides mothers raising children with DS with a sense of community and support (Kammes et al., 2022). The study suggested that mothers of children with DS require additional resources and support to help them cope throughout their parenting journey (Kammes et al., 2022).

The key strength of the study is that it allowed the researchers to collect data from a large sample of mothers of children with DS (Kammes et al., 2022). However, an inherent weakness of the study is that the data collected may not be representative of all mothers of children with DS (Kammes et al., 2022). The concept of resources/support was that there was a lack of adequate knowledge or information on how Western Nigeria mothers access and utilize support services for their children with DS. Understanding the resources available to these mothers is essential to improving the quality of life of children with DS in Western Nigeria.

Rahimi and Khazir (2019) used a qualitative approach, delving into the perceived life problems experienced by parents with a DS child. The researchers focused on parents' experiences with a child with a DS (Rahimi & Khazir, 2019). They used snowball and purposive sampling methods to select 21 parents with a DS child who were members of the DS Association of Iran (Rahimi & Khazir, 2019). The researchers used conventional content analysis on data collected through asynchronous interviews (Rahimi & Khazir, 2019). The researchers found that parents experienced various life problems, such as social isolation, financial burden, and inadequate available resources (Rahimi & Khazir, 2019). The study concluded that there is a need for increased awareness, attention to children with DS, the promotion of suitable social interactions for children, and the implementation of relevant educational and health programs (Rahimi & Khazir, 2019).

The researchers approached the problem by selecting parents with a DS child who was a member of the DS Association of Iran. This approach has the inherent strength of offering a qualitative perspective on the challenges faced by parents raising a child with Down syndrome (Rahimi & Khazir, 2019). Employing conventional content analysis on data gathered from asynchronous interviews enabled a profound exploration of participants' experiences and the associated issues. There is an inherent weakness of being subjective and dependent on the researcher’s interpretation of the data (Rahimi & Khazir, 2019). Additionally, an inherent weakness is the exclusive focus on Iran, potentially constraining the applicability of its findings to diverse cultural and national contexts.

The concept of resources was the fact that there was a lack of adequate knowledge or information on how Western Nigeria mothers access and utilize support services for their children with DS. By exploring mothers' experiences with DS children, my study can provide insights into the available resources and how they access and utilize them. This can help to improve the support services that are available to mothers with DS children and ultimately improve the quality of life of Western Nigerian children with DS.

McDonagh et al. (2022) employed an interpretative phenomenological methodology to explore the experiences of 10 parents of children with Down’s arthritis (McDonagh et al., 2022). The researchers concluded that parents experienced various emotions, including guilt, sadness, and frustration, and felt unsupported (McDonagh et al., 2022).

The researchers approached the problem by conducting in-depth interviews with parents of children with Down’s arthritis (McDonagh et al., 2022). This approach allowed them to gain a deep understanding of the experiences of parents and the challenges they face (McDonagh et al., 2022). A key strength of this approach is that it enabled the researchers to explore parents' experiences in detail and gain a rich understanding of their perspectives (McDonagh et al., 2022). However, a weakness of this approach is that the sample size was small, restricting the generalizability of the findings (McDonagh et al., 2022).

The concept of resources is essential in determining the quality of life of children with DS and their families. Research has shown that access to resources significantly impacts the well-being of children with DS and their families (McDonagh et al., 2022).

By exploring the experiences of Western Nigeria mothers on how they access and use support services, the study provided essential insights into the challenges faced by families of children with DS and support services.

Resources play a central role in the lives of mothers raising children with DS. Understanding the intricacies of resources becomes essential in shedding light on how Western Nigerian mothers navigate the journey of supporting their children with DS.

Support Services for Families of Children with Down Syndrome

Support services play an important role in mothers accessing external assistance while raising children with DS. Finkelstein et al. (2023) emphasized the importance of support services such as educational resources, financial assistance, and counseling for mothers while raising children with DS.

The study by Finkelstein et al. (2023) explored the perceptions of activist Israeli mothers with coping with the diagnosis of DS in their newborns using a qualitative phenomenological study. The researchers approached the problem by conducting in-depth interviews with activist Israeli mothers, allowing for a detailed exploration of their experiences (Finkelstein et al., 2023). The researchers found that mothers of children with DS in Israel experienced several challenging and supportive factors while coming to terms with their child's diagnosis (Finkelstein et al., 2023).

The mothers reported that they experienced a range of emotions, such as shock, sadness, and anxiety when they first received the diagnosis. However, they also reported finding strength and support from their families and friends (Finkelstein et al., 2023). The mothers emphasized the importance of support services such as counseling, educational resources, and financial assistance (Finkelstein et al., 2023). They also highlighted the need for more community awareness and education about DS (Finkelstein et al., 2023). Inherent strengths of the study include the depth of analysis and the revelation of rich narratives of the mothers. However, an inherent weakness lies in the limited generalizability beyond the specific context of Israeli activism.

The concept of support services emerged from the identified gap in knowledge about how mothers in Western Nigeria access and utilize such services for their children with DS. Literature supports this choice by emphasizing the pivotal role of support services in improving the well-being of mothers and children in similar contexts. Finkelstein et al. focused on coping factors that indirectly underscore the significance of support services, aligning with the rationale to explore the lived experiences of mothers in Western Nigeria within the broader framework of coping with DS.

Steffensen et al. (2022) conducted a qualitative study using a phenomenological approach. The researchers explored the experiences of parents raising children with Down syndrome (DS) and how they manage their everyday lives. The researchers approached the problem by conducting in-depth interviews with 25 families of children with DS (Steffensen et al., 2022). They analyzed the data using a thematic approach (Steffensen et al., 2022). The researchers discovered that Danish families with children with DS engage in daily activities intended to create a positive future for the child and manage their daily lives on their terms (Steffensen et al., 2022). An in-depth exploration of the experiences of parents raising children with DS and provides rich data that can be used to inform support services. However, an inherent weakness is that the sample size of

25 families may not represent all families raising children with DS, and the findings may not be generalizable to other contexts (Steffensen et al., 2022).

The concept of support services was that it is a critical factor in the lives of families raising children with DS. Access and utilization of support services can help mothers manage the challenges of raising children with DS and improve their quality of life.

Clark et al. (2020) conducted qualitative research using a phenomenological approach to understand how families in the United States make sense of their experiences after getting a DS diagnosis for their children. The researchers conducted in-depth interviews with 33 parents and 9 grandparents families with a child with a DS diagnosis (Clark et al., 2020). The researchers found that families with DS children face challenges in accessing support services and inadequate services such as early intervention programs (Clark et al., 2020).

The researchers acquired an in-depth comprehension of the experiences of families with DS children in the United States (Clark et al., 2020). However, the weakness is that the sample is small, which could restrict the applicability of the results to other populations (Clark et al., 2020).

Support services are a common challenge faced by families with children with DS. According to Clark et al., families with DS children face challenges in accessing support services. The concept of support services was important to explore as it is a significant challenge faced by families with children with DS in the United States and other parts of the world. By exploring the experiences of mothers of children with DS in

Western Nigeria, the study provided valuable insights into the challenges encountered by mothers in accessing and utilizing support services for their children with DS. Support services hold the utmost significance in molding the holistic welfare of children with DS. Subsequently, financial challenges will be discussed as one of the subthemes under the broader category of resources.

Financial Challenges

One of the primary difficulties mothers encounter while raising children with DS is the constraints posed by financial challenges. Study confirms that parents or caregivers of children with DS encounter notable financial and other economic challenges that adversely affect their ability to provide optimal care to the children (Desimpelaere et al., 2023).

Desimpelaere et al. (2023) conducted a qualitative study to investigate the encounters and behaviors of parents raising a child with DS. This study was informed by the realization that caring for a child with DS presents distinctive obstacles to parents' psychological well-being, and considerable quantitative research revealed that these parents often encounter elevated levels of parental stress and reduced overall well-being (Desimpelaere et al., 2023). Such challenges and negative experiences could have adverse direct and indirect implications on the children’s well-being and negatively affect their quality of life.

The researcher confirmed that parents or caregivers of children with DS experience significant financial and other economic challenges that negatively affect their ability to provide optimal care to the children (Desimpelaere et al., 2023). Fuca et al.

(2022) further confirmed this assertion by arguing that the stress experienced by parents has harmful impacts on both parents and children, as well as on the overall functioning of the family. Such parenting stress may be caused by the economy, particularly the lack of educational opportunities that Western Nigerian women encounter while bringing up their DS children. In line with this narration, Desimpelaere et al. (2023) used the self-determination theory as a broad theoretical framework to investigate the opportunities and challenges associated with meeting parents' psychological needs for autonomy, competence, and relatedness. They also offered insights into how these needs are addressed for their child.

According to Migliorini et al. (2019), the self-determination theory holds that individuals' level of proactivity or passivity can vary depending on the social environments in which they are engaged. Drawing from their findings, the researchers reached the conclusion that caring for a child with DS presents substantial challenges for the caregiver’s familial bonds, personal autonomy, career aspirations, and sense of capability (Desimpelaere et al., 2023).

The researchers used a self-determination theory perspective to explore parents' experiences of children with DS (Desimpelaere et al., 2023). This enabled the researchers to gain insight into how parents’ basic psychological needs for competence, relatedness, and autonomy were met or unmet in the context of raising a child with DS (Desimpelaere et al., 2023). This approach offers a distinctive perspective on the experiences of parents of children with DS and can inform support services that are tailored to meet the specific needs of parents. An inherent weakness of this approach is that the study was conducted in Belgium, which may limit the generalizability of the findings to other countries or cultures (Desimpelaere et al., 2023).

The concept of financial challenges was that it was a critical factor in the lives of caregivers raising children with DS. In this regard, this study confirmed that parents or caregivers of children with DS experience significant financial and other economic challenges that negatively affect their ability to provide optimal care to the children, thus leading to the children's poor well-being. Exploring the lived experiences of mothers raising children with DS in Western Nigeria helps gain a deeper understanding of how they access and utilize support services for their children with DS.

Alabri (2023) employed qualitative phenomenological research that investigated the requirements of 14 families with children who have DS in Saudi Arabia from the point of view of mothers and in a cultural and religious context (Alabri, 2023). The researchers approached the problem by conducting semi-structured interviews with mothers of children with DS (Alabri, 2023). They found that families with children with DS encountered financial challenges due to the high cost of medical care, therapy, and special education (Alabri, 2023). The author also found that families with children with DS face social stigma, lack of support, and inadequate services (Alabri, 2023).

The researcher gained an in-depth understanding of the experiences of mothers of children with DS in Saudi Arabia. The weakness of this approach is that the small sample size restricts the ability to apply the findings to broader populations.

The concept of financial challenges is important due to its prevalence among families raising children with DS. According to Alabri (2023), families with children with DS face financial challenges due to the high cost of medical care, therapy, and special education. Hence, the significance of the concept of financial challenges lies in its prevalence among families raising children with DS in Saudi Arabia and various regions globally. It helps gain a deeper understanding of how mothers access and utilize support services for their children with DS in Western Nigeria.

Bohnstedt et al. (2023) also conducted a qualitative investigation to explore parents' viewpoints on children diagnosed with Down syndrome (DS) regarding their child's treatment, side effects, and involvement during hospital care. This study was based on the understanding that children with DS have higher vulnerability and an enhanced risk for other health conditions, such as leukemia (Bohnstedt et al., 2023). The study involved parents of 10 children with DS, and the study's results demonstrated that parents of these children experienced challenges in bringing up children with DS. Based on this assertion, it can be rightly argued that Western Nigerian mothers with DS children experience disproportionate economic resources characterized by inadequate resources, which undermine their ability to care for their children optimally to enhance the children's well-being.

This study's approach is that the researchers demonstrated the direct negative implications of financial challenges on mothers' ability to care for their children with DS. However, an inherent weakness noted is that the researchers did not provide recommendations or proposals on how such financial challenges can be mitigated to enable the mothers to provide optimal care to their children with DS.

The reasoning behind choosing the concept of financial challenges stemmed from its pivotal role in the lives of mothers raising children with DS. Financial challenges can affect the quality of life of children with DS and can impact mothers' access and utilization of support services.

Examining finances emphasizes the economic dimensions influencing the daily lives of mothers raising children with DS. Next, customs and cultural beliefs as mothers' experiences raising children with DS will be discussed.

Customs and Cultural Beliefs

The experiences of mothers raising children with disabilities are intricately woven into customs and beliefs that shape familial and societal perspectives. Colton and Paul (2020) emphasized the importance of cultural influences on the perceptions and experiences of parents of children with disabilities in Nigeria.

Colton and Paul (2020) used a qualitative study to examine how parents of children with disabilities in Nigeria perceive and experience inclusive and special needs schooling. The research employed a phenomenological methodology to explore and understand the firsthand experiences of parents raising children with disabilities. (Colton & Paul, 2020). They conducted semi-structured interviews with 12 parents of children with disability in Nigeria. The research used thematic content analysis to uncover and comprehend the perceptions and experiences of parents regarding children with disabilities (Colton & Paul, 2020). The study found that some disabilities are considered more acceptable than others in Nigeria; this is based on a cultural belief that places different bodily impairments on a hierarchy. Bakare et al. (2019) confirmed this assertion by highlighting the importance of customs and cultural factors in the experiences of individuals with intellectual disabilities and their families in Nigeria. The researcher approached the problem using a phenomenological method to examine the real-life encounters of parents raising children with disabilities (Colton & Paul, 2020). They highlighted the importance of cultural influences on the perceptions and experiences of parents of children with disabilities in Nigeria (Colton & Paul, 2020).

The researchers approach allowed for an in-depth exploration of the experiences of parents of children with disabilities and provided rich data that can be used to inform policy and practice (Colton & Paul, 2020). However, an inherent approach of this study is that it is time-consuming and resource-intensive, and findings may not be generalizable to other contexts (Colton & Paul, 2020).

Customs and cultural beliefs play an essential role in potentially shaping the experiences of mothers raising children with DS in Western Nigeria. The researchers emphasized the importance of cultural influences on the perceptions and experiences of parents of children with disabilities in Nigeria (Colton & Paul, 2020). By exploring the customs and cultural beliefs of mothers raising children with DS in Western Nigeria, the study provides valuable insights into the experiences of these mothers and how they access and utilize support services for their children with DS.

Jidong et al. (2021) conducted a qualitative study that explored Nigerian cultural perspectives on mental health situations and traditional healing. The study used a qualitative design with critical realist viewpoints to explore mental health-care practitioners' and lay participants’ opinions in Nigeria concerning mental health conditions and traditional healing (Jidong et al., 2021). The researcher discovered cultural beliefs as a spiritual curse (Jidong et al., 2021).

The researchers used a qualitative design that allowed for an in-depth exploration of Nigerian cultural beliefs and traditions (Jidong et al., 2021). However, the weakness is that they used purposive and snowball sampling techniques, which may have resulted in a biased sample (Jidong et al., 2021).

The concept of customs and cultural beliefs was that customs and cultural beliefs are integral to understanding how Western Nigeria mothers access and utilize support services for their children with DS. The study by Jidong et al. can be used as a reference to understand Nigerians' cultural beliefs and traditions, which can be applied to gain insights into the customs and cultural beliefs of Western Nigerian mothers raising children with DS.

The thematic exploration of customs and cultural beliefs unfolds crucial dimensions in the narratives of mothers raising children with DS. Stigmatization will be discussed as one of the subthemes for customs and cultural beliefs.

Stigmatization

Societal judgments regarding DS frequently cast shadows of stigmatization on mothers raising children with DS (Lentoor et al., 2023). Researchers have disclosed that the burden of societal perceptions, along with the barriers and challenges posed by stigmatization, leads to detrimental issues for mothers raising children with disabilities (Lentoor et al., 2023; Watanabe et al., 2022).

In their study, Watanabe et al. (2022) conducted a qualitative study to examine the experience of courtesy stigma and the adjustment journey among 23 parents of children with DS using data collected via semi-structured interviews. The researchers approached the problem by conducting semi-structured interviews with parents of children with DS, allowing them to gain insight into their experiences and perspectives (Watanabe et al., 2022). This study’s findings revealed that parents of children with DS experienced courtesy stigma while bringing up their children with DS. The study highlighted the importance of understanding the experiences of parents of children with DS to improve their well-being and reduce the negative impact of courtesy stigma (Watanabe et al., 2022).

The strength of this study is that it allowed the researchers to collect rich and detailed data about the parents’ experiences (Watanabe et al., 2022). However, the inherent weakness is that the study's small sample size limits the generalizability of the findings (Watanabe et al., 2022).

The concept of stigmatization was that parents of children with DS frequently encounter courtesy stigma, which stems from their close association with individuals possessing stigmatized attributes and detrimentally impacts their interpersonal relationships. By exploring stigma, the study gains a better understanding of how Western Nigerian mothers raising children with DS access and use support services.

In the study by Deakin and Jahoda (2020), the researchers examined how families of children with DS contended with social stigma using a phenomenological approach. Based on research studies, the phenomenological approach is a qualitative thematic approach that is used to examine the subjective lived experiences of target populations or study participants (Love et al., 2020; Mole et al., 2019; Motta & Larkin, 2023). The findings highlighted that children with DS exhibited varying levels of awareness, and mothers played a crucial role in facilitating a positive self-identity for their children. Overall, the study emphasized the dynamic nature of parent-child interactions in shaping awareness and the need for support systems in navigating the challenges associated with DS (Deakin & Jahoda, 2020).

An inherent strength of this particular study and in relation to the current study is that it employed a similar research approach, that is, the qualitative phenomenological approach, which is an emphasis on lived experiences, allowing for rich insights, thus demonstrating its suitability for the current research. With respect to inherent weakness, the researchers failed to explain the shortcomings of the qualitative phenomenological approach to enable the users of their findings to determine the degree of reliability or applicability in practice settings (Deakin & Jahoda, 2020).

The rationale of the concept of stigmatization can be justified based on Deakin and Jahoda (2020) findings. The study indirectly touches upon societal perceptions and awareness of DS, indicating the relevance of exploring stigma within the cultural context of Western Nigeria. Incorporating this concept was justified by the need to understand how stigmatization may influence mothers' access to and utilization of support services for their children with DS. By building upon the existing literature, the current study filled the knowledge gap identified by Deakin and Jahoda, contributing to a more comprehensive understanding of the experiences of Western Nigerian mothers raising children with DS.

In their research, Lentoor et al. (2023) used a qualitative phenomenological methodology to explore mothers' experiences in South Africa. The study involved nine black African mothers who had children diagnosed with Autism Spectrum Disorder (ASD) (Lentoor et al., 2023). The researchers conducted thorough interviews with the participants and analyzed the data using thematic analysis (Lentoor et al., 2023). The researchers approached the problem by exploring the experiences of mothers raising children with ASD and the care burden they face (Lentoor et al., 2023). They found that mothers raising ASD children face stigma, isolation, social exclusion, internalized self-blame, and social judgment (Lentoor et al., 2023). A study by McLean and Halstead (2021) confirmed this assertion by revealing that mothers with children with intellectual or developmental disabilities experienced stigma and that resilience-building interventions could benefit in terms of reducing stigma among these mothers.

The inherent strength lies in the emphasis on mothers' voices, providing a holistic view (Lentoor et al., 2023). However, a potential inherent weakness could be the limited generalizability of findings beyond the specific context of Black African mothers caring for children with ASD (Lentoor et al., 2023).

The rationale for selecting the construct of stigmatization in my study was justified by drawing parallels with the findings of Lentoor et al. (2023). While their study focuses on ASD, the overarching theme of maternal experiences navigating societal perceptions and challenges aligns with the aim of understanding stigmatization in

Western Nigeria mothers raising children with DS. The literature on care burden experiences provides a foundation for exploring how stigmatization might influence the access and utilization of support services for Western Nigeria, contributing to the broader understanding of maternal experiences in caregiving.

Understanding and addressing the prejudices of stigmatization foster an environment that dismantles stereotypes and promotes empathy, ultimately aiding in fostering a greater inclusive and supportive landscape for mothers within the Western Nigerian cultural context.

Cultural Perceptions of Disability

The attitudes and beliefs within the Nigerian cultural context regarding individuals with disabilities can shape the experiences of mothers. According to Babik and Gardner (2021), parental practices, cultural influences, and personality traits can impact how disabilities are perceived.

Babik and Gardner (2021) conducted a qualitative study that explored the developmental perception of factors affecting the perception of disability. The researchers approached the problem by adopting a developmental perspective, emphasizing how parental practices and culture influence disability perception in children (Babik & Gardner, 2021). Cultural influence factors may include societal norms, beliefs, values, and traditional practices. The inherent strength of this approach is found in the comprehensive examination of various factors (Babik & Gardner, 2021). On the contrary, the inherent weakness is the subjectivity in interpretation and challenges of generalizability (Babik & Gardner, 2021).

The rationale for selecting the concept of cultural perception of disability was supported by Babik and Gardner's (2021) findings, highlighting the profound impact of cultural factors on disability perception. Understanding these perceptions becomes crucial given the cultural diversity in Nigeria, particularly in Western Nigeria. The literature justifies this choice by emphasizing the need to explore how cultural beliefs and practices impact the experiences of mothers raising children with DS. By building on the existing knowledge, my study contributed to addressing the gap in understanding how Western Nigerian mothers access and utilize support services for their children with DS.

Ani et al. (2023) employed a qualitative phenomenological analysis approach, conducting semi-structured interviews using a purposive sample of households to explore the perception and coping strategies related to disabilities involving 36 elderly aged 65 years and older from the Saharan African community. The research uncovered three interconnected themes regarding the perception of disability: disabilities are responsible for external factors like witchcraft, disabilities caused by diseases, and the impact of old age (Ani et al., 2023). Additionally, two interconnected coping themes were identified: pragmatic and unpragmatic strategies (Ani et al., 2023).

The inherent strength of the approach is that it provides valuable insights into the subtle understanding of disability and coping strategies employed by elderly individuals within the Sub-Saharan African community (Ani et al., 2023). By delving into their firsthand experiences, the results enhance comprehension of their difficulties. These findings carry significant implications for formulating policies and public health initiatives. However, an inherent weakness is that the sample size is relatively small, and the study only focused on older adults in a Sub-Saharan African community (Ani et al., 2023).

The rationale for selecting the concept of cultural perceptions of disability was that it was a crucial factor in understanding how individuals with disabilities are perceived and treated in different cultures. Cultural perceptions of disability influence the way individuals with disabilities are treated, the support services available to them, and their overall quality of life. Also, the study provides a deeper understanding of how cultural perceptions may impact mothers' access to and utilization of support services while raising children with DS in Western Nigeria.

Another study by Ngozi et al. (2019) explored qualitative phenomenological on coping strategies within Nigerian families, providing a contextual understanding of how cultural perceptions influence families with members facing cognitive challenges. The study revealed that families experienced several challenges, including financial constraints, stigmatization, and lack of support (Ngozi et al., 2019). The researchers concluded that families' coping strategies were influenced by their cultural beliefs, resources, and social support (Ngozi et al., 2019).

An inherent strength of this study is that it provides an in-depth exploration of coping strategies within families, capturing the details of cultural perceptions and their impact on learning disabilities. The study also takes a community-centric perspective, providing a contextualized understanding of coping within the Nigerian cultural setting (Ngozi et al., 2019). This approach adds depth to the exploration of cultural perceptions. However, an inherent weakness is that the subjective nature of qualitative data collection may introduce bias in interpreting coping strategies, as researchers' perspectives and cultural backgrounds could influence the analysis (Ngozi et al., 2019).

The rationale for the selection of the cultural perception of disability concept was that the study provides a deeper understanding of how cultural perceptions may impact mothers' access to and utilization of support services while raising children with DS in Western Nigeria.

Based on the reviewed studies from the literature, it was determined that certain aspects of the quality of life and the well-being of children with DS were known, while others were controversial. In contrast, other aspects of the phenomenon remain to be studied. Aspects that were noted as known about having a child with Down syndrome include experiences of stigmatization for having such a child (Lentoor et al., 2023; Watanabe et al., 2022). Additionally, the lack of support systems and the presence of financial challenges for mothers or caregivers of children with DS (Bohnstedt et al., 2023; Desimpelaere et al., 2023) and negative experiences relating to the burden that the family who form key or primary caregivers of children with DS encounter while bringing up these children (Alam El-Deen et al., 2021; Farkas et al., 2019). With respect to what was controversial about the issue under investigation, it was noted from the literature that people have superstitious beliefs about having a child with intellectual disabilities, such as DS (Ani et al., 2023; Sango & Deveau, 2022). In this modern era, beliefs that are not scientifically proven can be categorized as controversial because there exists vast credible information that explains different public health issues such as DS.

Finally, some aspects of this particular phenomenon remain to be studied. These aspects pertain to the lack of qualitative studies about the lived experiences of how mothers access and utilize support services while raising children with DS in Western Nigeria. This aspect forms the purpose of this study, which was to explore the lived experiences of mothers raising children with DS in Western Nigeria.

As indicated earlier, this study explored four research questions, which are as follows: (1) what are the lived experiences of mothers accessing and utilizing supportive services while raising children with Down syndrome in Western Nigeria? (2) How do mothers raising children with Down syndrome describe their experiences with accessing and utilizing support services within the social systems in Western Nigeria? (3) How do mothers raising children with Down syndrome describe their experiences with accessing and utilizing support service resources in Western Nigeria? (4) How do mothers raising children with Down syndrome describe their experiences with accessing and utilizing support services within the customs and cultural beliefs in Western Nigeria? These qualitative research questions are based on findings from literature studies showing the significance of supportive services (Desimpelaere et al., 2023) and the impact of customs and cultural beliefs on the ability of mothers with DS to ensure that the children have improved quality of life and enhanced well-being (Alghamdi et al., 2021; Bakare et al., 2019; Colton & Paul, 2020; Tomris et al., 2022; Van Riper et al., 2019).

Definitions

The following terminologies were extensively used in this study:

Cultural Beliefs: Refer to factors that affect how people think or feel about their health and health problems (Alam El-Deen et al., 2021).

Customs: Individuals’ or communities' values about health and health-related behaviors that may differ between cultures (Ijezie et al., 2023).

Down Syndrome (DS): Common neurodevelopmental disorders and early intervention and supportive environments can improve the quality of life for individuals with Down syndrome (Duru et al., 2020).

Lived Experiences: The mother’s encounters or experiences as a result of raising children with DS (Rahimi & Khazir, 2019).

Resources: Materials that mothers raising children with DS require to have positive health outcomes and improved quality of life for their children and themselves (Rahimi & Khazir, 2019).

Social Systems: Broader societal and cultural contexts that influence an individual’s development (Bronfenbrenner, 1977).

Stigma: Social disapproval or prejudice directed toward individuals or groups of people (Deakin & Jahoda, 2020).

Assumptions

Certain assumptions were made in this study. One of these assumptions was that all 15 initially selected research goal participants would participate in the virtual face-to-face semi-structured interviews. This is an assumption since participants have the right to withdraw from a study at any time and stage of the research process (Fernandez, 2020). This study was not immune to this possible outcome. Another assumption that was considered in this study was that the participants had adequate or vast lived experiences living with children with DS. Therefore, it was presumed that adequate qualitative data would be collected from the participants.

Scope and Delimitations

This study's scope revolves around Western Nigerian mothers raising children with DS. Additionally, it focused on this population's lived experiences with raising these children. Therefore, to participate in the study, the individuals were mothers who were raising a child or children with DS and living in Western Nigeria. Also, other mothers who were not mothers of DS children were not allowed to participate in this study. Regarding potential transferability, which Munthe-Kaas et al. (2020) described involves assessing the extent to which the context of the review question differs from the context of studies contributing data to the review finding with respect to a priori identified characteristics or the extent to which the study's findings are applicable in another setting. This study's findings may be potentially transferable to other communities or mothers with DS children living in other regions outside Western Nigeria.

Limitations

A possible limitation of this qualitative study is obtaining a sufficient sample size. Sample size may negatively affect the study's findings, limiting the rich data received. As Hennink and Kaiser (2022) and Indrayan and Mishra (2021) reported, adequate sample size ensures saturation, which is a critical guiding principle in qualitative research. The larger the sample size, the more dependable the result. Another limitation is that the data is self-reported by the mothers, which is prone to response bias and careless responses by study participants (Florian et al., 2020; Kreitchmann et al., 2019; Lira et al., 2022). Participants' answers may be exaggerated, or participants may be too embarrassed to reveal personal details. Another limitation is that the population is limited to mothers.

Significance

The findings from this study may directly address the critical aspects of accessing and utilizing support services through the lived experiences of mothers living in Western Nigerian mothers raising children with DS. This study holds the potential for substantial positive social change, including public health intervention within educational centers as well as social support systems (Hendrix et al., 2021) and care coordination (Skelton et al., 2021) that may be tailored to the unique norms and customs embedded in the culture of Nigeria. The findings of this study may contribute to children's overall well-being and quality of life, providing valuable insights into how maternal lived experiences influence their care and health outcomes.

The impact of this research may extend to various stakeholders and offer crucial insights to different stakeholders, including promoting awareness through public health practitioners, influencing practices of the healthcare systems, awareness, and advocating for more tailored support for children with DS from policymakers within local government. These stakeholders can harness this knowledge to design strategies that effectively consider mothers' lived experiences and tailor interventions for children with DS in Western Nigeria.

At the individual level, this study may contribute to social change by providing information that could help public health practitioners ensure mothers raising children with DS from Western Nigeria have proper access to the utilization of support services that Alon (2019) and Jensen et al. (2021) argued fosters the well-being of children with developmental disabilities such as DS. Similarly, at the peer level, mothers raising children with DS will have a better understanding of the problem. Given the specific challenges within this context, the study may have positive societal implications to collaborate and drive changes in public health programs that better address the mother's lived experiences and their influence on the care and well-being of children with DS—ultimately promoting the health and quality of life in Western Nigeria.

Summary and Conclusions

As addressed in the paper, this study explored the lived experiences of how mothers access and use support services while raising children with DS in Western Nigeria. The study was informed by the realization of a knowledge gap regarding the lack of qualitative studies about the lived experiences of how mothers access and utilize support services for their children with DS in Western Nigeria. The study's major concepts include social systems, resources, customs, and cultural beliefs. As noted from the literature review, it was well-known that mothers with DS experience challenges relating to inadequate resources, lack of social support systems, and negative customs and cultural beliefs, which are linked to stigmatization and negative cultural perceptions of disability. However, it was unknown how mothers' perceptions of their children with DS affect the children's quality of life and overall well-being. The study employed a phenomenological qualitative research approach. It involved ten mothers who were recruited from the target study population to address the research gap that the topic has not been explored using qualitative studies about the lived experiences of how mothers access and utilize support services while raising children with DS in Western Nigeria. Notably, the study was grounded in Bronfenbrenner's Ecological theory. Data was collected using virtual face-to-face semi-structured interviews and analyzed using the thematic data analysis approach. This process was accomplished by using NVivo data analysis software and a comprehensive codebook. Section 2 is the next section, which will include the research design and data collection.

Section 2: Research Design and Data Collection

The problem I addressed was that the lived experiences of how mothers access and utilize support services for their child DS were not known. Families raising children with DS need more extensive physical, environmental, intellectual, emotional, financial, developmental, and social support services to prevent more severe health issues (Chiracu et al., 2023; Daniel et al., 2021; Deakin & Jahoda, 2020; Rahimi & Khazir, 2019). Therefore, the purpose of this qualitative phenomenological study was to understand the accessibility and use of support services through the lived experiences of Western Nigerian mothers raising children with DS. The findings of the study may extend to various stakeholders and offer crucial insights to different stakeholders, including (a) promoting awareness through public health practitioners, (b) influencing practices of the healthcare systems, (c) awareness, and advocating for more tailored support services to the unique norms and customs embedded in the culture of Nigeria for children with DS.

In Section 2, details regarding the research design and data collection are addressed. The research questions are restated, and my role as the researcher is discussed. The research methodology is highlighted, as well as the participant selection logic, instrumentation procedures for recruitment, participation, data collection, and data analysis plan. Additionally, issues of trustworthiness and ethical procedures that I followed are discussed.

Research Design and Rationale

The overarching research questions addressed in this study are as follows:

RQ1: What are the lived experiences of mothers accessing and utilizing supportive services while raising children with Down syndrome in Western Nigeria?

RQ2: How do mothers raising children with Down syndrome describe their experiences with accessing and utilizing support services within the social systems in Western Nigeria?

RQ3: How do mothers raising children with Down syndrome describe their experiences with accessing and utilizing support service resources in Western Nigeria?

RQ4: How do mothers raising children with Down syndrome describe their experiences with accessing and utilizing support services within the customs and cultural beliefs in Western Nigeria?

The central concept of the study was the lived experiences of mothers raising children with DS in Western Nigeria, mainly focusing on how they access and use support services for their children with DS. The phenomenon being explored is the intersection of cultural stigmas, customs, cultural beliefs, resources, and social systems (see Ani et al., 2023; Deakin & Jahoda, 2020; Juveriah & Gulnaz, 2020; Oduyemi et al., 2021; Rahimi & Khazir, 2019), impacting the accessibility and utilization of support services for DS children in Western Nigeria.

I used qualitative descriptive phenomenology for this study. Phenomenology is used when a researcher seeks to understand and describe individuals' experiences within a particular phenomenon.(Neubauer et al., 2019). Neubauer et al. argued that phenomenology is a rigorous exploration of the meaning embedded in the firsthand experiences of the lived world. It involves thoroughly examining and portraying phenomena as they are subjectively experienced, devoid of theories attempting causal explanations (Neubauer et al., 2019). Using the phenomenological approach involves temporarily putting aside beliefs or "bracketing" worldly elements (epoché) and directing attention to the phenomenon under investigation itself (Moustakas, 1994; Neubauer et al., 2019). With a phenomenological method, the researcher aims to be as unrestricted as possible from unexamined assumptions (Neubauer et al., 2019). In this case, the goal was to explore the subjective experiences of mothers in Western Nigeria raising children with DS, exploring the intricacies of their interactions with the access and utilization of support services and the broader cultural context.

The rationale for choosing phenomenology lies in its suitability for capturing the depth and richness of individual experiences (see Neubauer et al., 2019). This approach allowed me to explore the lived realities of mothers, providing insights into the challenges, coping mechanisms, and unique aspects of accessing and using support services within the social systems, customs, and culture in Western Nigeria. Descriptive phenomenology aligns well with the qualitative nature of the study, emphasizing a holistic understanding of the participants' experiences (see Moustakas, 1994; Neubauer et al., 2019). To explore and collect individuals’ descriptions of the significance of an experience, I aimed to unveil its fundamental essence (see Moustakas, 1994; Neubauer et al., 2019). By adopting this tradition, I uncovered detailed insights that contribute to a comprehensive understanding of mothers' challenges and opportunities in a cultural context. My research provides a detailed understanding of the accessibility and utilization of support services for children with DS in Western Nigeria.

Role of the Researcher

In this study, my role as a researcher involved being an impartial observer, investigator, and interviewer. My role also included collecting and analyzing data with an open-minded approach. In the role of an observer, my primary responsibility was to objectively document and analyze the lived experiences of mothers raising children with DS in Western Nigeria. This involved maintaining a nonintrusive stance, merely observing and recording without direct engagement. On the other hand, adopting a participant role would mean actively engaging with the mothers, potentially influencing the dynamics of their experiences. Considering the sensitive nature of the study, a more balanced approach as an observer-participant is preferred. This ensures a detailed understanding while minimizing interference in the participants' natural behaviors (see Moustakas, 1994). As a researcher with a personal connection to the topic, namely being a mother to a child with DS, my role takes on a dual perspective of both an observer and a participant. This unique position allows for a more empathetic and insightful understanding of the lived experiences of other mothers in Western Nigeria raising children with DS. By drawing on my personal insights as a participant, I was able to empathize with the challenges these mothers face while maintaining the objectivity of an observer. I was committed to remaining impartial and objective in my role as a researcher. This role as an observer-participant enables a deeper connection with the participants, fostering a richer exploration of their experiences (see Tanwir et al., 2021).

Regarding personal and professional relationships, there were no personal or professional relationships with my participants. My connection as a mother to a child with DS was distinct from my relationships with the study participants. No supervisory or instructor relationships involve power over the participants; I ensured an equitable research environment.

Managing biases is a central consideration. While my personal experiences may offer a unique perspective, I was committed to minimizing biases through continuous self-reflection. Maintaining reflexivity is essential; this involves acknowledging personal biases, preconceptions, and assumptions that could impact the process of data collection (Barrett et al., 2020). Barrett et al. argued that understanding reflexivity in qualitative research can be intricate. Reflexivity is an ongoing practice where the researcher actively interacts with and clarifies their position in relation to the research context (Barrett et al., 2020). This process entails continuously questioning and expressing the impact of social and cultural factors on both the researcher and the research environment (Barrett et al., 2020).

Additionally, by adopting the phenomenological approach, researchers temporarily set aside beliefs or "bracket" worldly elements (epoché) and concentrate on the phenomenon of interest itself (Moustakas, 1994; Neubauer et al., 2019). I handled my biases, beliefs, thoughts, and preconceived notions by recording them in a journal. This practice assists me in temporarily setting them aside, allowing me to concentrate on the participants and their narratives. The goal was to strike a balance between the empathetic understanding gained from personal experience and the impartiality required in qualitative research.

Ethical considerations are essential, especially when conducting research in a community where power dynamics may be at play. Other ethical issues that were discussed were ensuring voluntary participation and informed consent and respecting the autonomy and rights of the participants. In cases where participants felt vulnerable, steps were taken to minimize any potential harm. Furthermore, the study's findings were presented objectively, avoiding any undue influence on policy or practice in the local context. Clear guidelines were established to navigate potential conflicts of interest and power differentials, ensuring the integrity of the research.

Methodology

This section covers the study's methodology, including instrumentation. I also provide an overview of the participant selection logic, data collection procedures, procedures for participant recruitment, data collection methods, and data analysis plan for the participants.

Participant Selection Logic

In conducting this study, I followed a rigorous methodological process to explore the lived experiences of mothers raising children with DS. The target population was mothers residing in Western Nigeria, including biological mothers, adoptive mothers, and foster mothers who were actively raising children between the ages of 2 and 20 years diagnosed with DS. Recruitment was conducted across different geopolitical zones in Western Nigeria, where the predominant Yoruba-speaking population resides. These regions/zones include states such as Lagos, Ogun, Oyo, Osun, Ondo, and Ekiti. While diverse dialects exist in the region, English is commonly used for effective communication; their age was 18 years and above.

The target populations were recruited using a purposive sampling technique aimed at including mothers raising children with DS from diverse socioeconomic backgrounds. Although specific questions about income and educational background were not asked during the demographic data collection, during the selection process I sought to include a variety of community settings including urban, suburban, and rural areas. Purposive sampling was chosen for its ability to select participants purposefully, ensuring a diverse representation of experiences within the specific context of Western Nigeria. According to Andrade (2021), a purposive sample is one in which the qualities are intentionally determined to serve a purpose pertinent to the study. Selecting participants with intentionality becomes crucial, especially when anticipating the influence of sociocultural and other factors on outcomes, highlighting its significance in ensuring a targeted and relevant selection of participants in a study. Given the sociocultural context, where customs, cultural beliefs, and social systems play a significant role, purposive sampling allows me to deliberately select participants who have firsthand experiences within these sociocultural dynamics. Mothers in Western Nigeria with children with DS navigate unique challenges influenced by cultural norms, available resources, and societal perceptions (Bakare et al., 2019; Jansen-van Vuuren, 2020). Purposive sampling ensures that the participants' pool reflects this diversity, providing a rich understanding of how these sociocultural factors impact their lived experiences.

Nevertheless, intentionally choosing participants based on their connection to the sociocultural aspects outlined in my research framework (Bronfenbrenner's Ecological Model) enhanced the relevance and applicability of my findings (see Bronfenbrenner, 1994). This approach allows me to capture nuanced details that might be overlooked in a more random sampling method, providing a more accurate portrayal of the accessibility and utilization of support services for Western Nigeria mothers raising children with DS.

Participants were selected based on the follow criteria: (a) they were mothers actively involved in the care of a child diagnosed with DS in Western Nigeria, (b) they were 18 years and above, (c) they were proficient in English, (d) they coresided with the child within the same household, (e) they resided in the state of Lagos, Ogun, Oyo, Osun, Ondo, or Ekiti, and (f) they agreed to participate in virtual zoom interviews and consented to audio recording. Participants were known to meet the criteria after screening participants prior to the virtual face-to-face interviews. This criteria ensured that participants possessed first-hand experiences relevant to the study's focus. Participants were identified through various channels, including churches, schools, markets, shopping malls, and community networks. These channels enabled me to connect with mothers who actively meet the established criteria.

Ten participants were chosen, aligning with the concept of saturation. This sample size was deemed sufficient to capture diverse perspectives, reaching a point where additional participants could not contribute significantly to the richness of information gathered. I achieved data saturation with a sample size of 10, ensuring a comprehensive understanding of the lived experiences of mothers in Western Nigeria raising children with DS. Saturation occurs when no additional information surfaces during the process of data collection (Alam, 2021). So, where data becomes repetitive helps guide the sample size. The goal was to reach a point where additional participants do not contribute substantially to understanding these mothers' lived experiences on how they access and use support services for their children with DS.

Participants were identified through the distribution of informative flyers across relevant channels, such as churches, schools, markets, shopping malls, and community networks. Relevant channels on the internet were checked for basic information to obtain permission from the organizations/sites to distribute flyers to their physical addresses. These sites posted the flyers on their public bulletin boards. The recruitment process involves interested mothers reaching out to me. Once mothers expressed interest, they were contacted and scheduled through email or their preferred means of communication, emphasizing the virtual nature of the study to ensure safety and convenience. Informed consent forms were then sent via email for them to sign. Subsequently, virtual face-to-face semistructured interviews with probing questions were conducted via Zoom. By meticulously following these steps, I discovered the lived experiences of Western Nigerian mothers raising children with DS, identifying their access and utilization of support services within the cultural, social, and resource-related contexts.

Instrumentation

Semistructured Interviews

Data was gathered through semistructured interviews by posing 12 open-ended questions to all 10 participants during the interview process. Following the creation of the initial set of open-ended questions, a review was conducted to verify their alignment with the research questions, the problem, the purpose, the theoretical framework, and the methodology. The interview protocol was researcher-produced and tailored to elicit responses that explored the lived experiences of mothers in accessing and utilizing support services for their children with DS in Western Nigeria.

Virtual, face-to-face, semistructured interviews with probing questions were done to provide an interactive platform for in-depth exploration, allowing the mothers to share their experiences authentically. Sah et al. (2020) argued that virtual, face-to-face interviews enable researchers to observe participants' facial expressions and body language, providing an opportunity for reflexivity, especially in challenging situations. The interviews were conducted using Zoom, and I provided each participant with the meeting room link and password before the interview. In the semistructured interviews, I posed the same open-ended questions to every participant, with the flexibility to ask follow-up questions for clarification. These interviews lasted approximately 30-35 minutes for each participant, recorded electronically, and transcribed for subsequent data analysis.

Observation Notes

The observation notes were also obtained during the interviews. The notes served as a vital tool in capturing the detailed behaviors, gestures, and mannerisms exhibited by participants during the virtual face-to-face interviews (Shafique et al., 2023). Its purpose was to complement the verbal data obtained through interviews, providing a holistic understanding of the lived experiences of Western Nigeria mothers on how they access and use support services while raising their children with DS. The source was researcher-produced, and I was the primary observer. The observation note was custom-designed by me to document behaviors, gestures, and mannerisms observed during the virtual face-to-face interviews. Observations serve as a complementary data point, capturing non-verbal cues and contextual elements that contribute to a holistic understanding of the mothers' experiences. The observation notes systematically document non-verbal cues such as facial expressions, body language, and gestures (Shafique et al., 2023). This includes noting moments of joy, frustration, or subtleties that may convey emotional states. In connection with cultural context, the observations are made to identify expressions or actions that reflect the influence of customs and cultural beliefs. This provides insights into how cultural factors shaped the mothers' experiences in Western Nigeria.

Additionally, specific features such as tone of voice, pauses, or changes in speech patterns were meticulously noted. The observational data was analyzed alongside interview transcripts to enrich the qualitative analysis process (DeJonckheere & Vaughn, 2019). It added layers of context to participants' lived experiences, allowing for an adequate understanding of the phenomena under investigation. The observation note was designed with ethical considerations in mind. It focused on behaviors and cues relevant to the study's objectives without infringing on participants' privacy or causing discomfort. The observation note was a valuable instrument to systematically document non-verbal aspects (Shafique et al., 2023), contributing depth and context to the phenomenological exploration of mothers' lived experiences raising children with DS in Western Nigeria.

Given the phenomenological nature of this study, historical or legal documents were not used as data sources. The emphasis was on understanding current lived experiences directly from the mothers raising children with DS in Western Nigeria, aligning with the qualitative approach. The combination of virtual face-to-face interviews with probing questions, observation notes, and audio/electronic recordings established a comprehensive approach to answering the research questions. Virtual interviews provide rich verbal data, and observations add non-verbal context (DeJonckheere & Vaughn, 2019; Shafique et al., 2023). Electronic recording preserved the authenticity of mothers' voices, ensuring sufficiency in capturing the mothers' lived experiences. DeJonckheere and Vaughn (2019) argued that the typical procedure for analyzing and interpreting most interviews consists of examining the data, which may take the form of transcripts, audio recordings, or comprehensive observation notes.

Researcher-Developed Instruments

In crafting the researcher-developed instruments for this study, meticulous attention was devoted to constructing tools that align seamlessly with the unique demands of the research objectives. These instruments, comprising a virtual face-to-face interview protocol with probing questions and detailed observation notes, were purposefully designed to delve into the intricate dimensions of the lived experiences of mothers accessing and utilizing support services while raising children with DS in Western Nigeria. The following sections expound upon the basis for the development, the establishment of content validity, and the meticulous steps taken to ensure their sufficiency in addressing the research questions effectively.

The development of the researcher-developed instruments, including the virtual face-to-face interview protocol and observation notes, was grounded in a comprehensive review of relevant literature. This involves an exploration of existing studies related to DS, maternal experiences, and lack of adequate knowledge or information on lived experiences of how mothers access and utilize support services for their children with DS (Daniel et al., 2021; Deakin et al., 2020; Jansen-van et al., 2022; Jess et al., 2021; Rahimi et al., 2019). The theoretical framework, Bronfenbrenner's ecological model, also guided the formulation of questions and criteria based on established concepts and understanding in the literature. Rooted in an extensive review of relevant literature and guided by established theoretical frameworks, these instruments captured verbal narratives and non-verbal cues, providing a holistic understanding of the cultural, emotional, and contextual factors shaping the mothers' perspectives on accessing and utilizing support services while raising children with DS.

A multifaceted approach to content validity enhances the reliability and relevance of the research instruments in this study: (a) expert review, (b) validation by previous researchers' work, and (c) mock interviews with a friend. Content validity assesses whether the instrument accurately represents the constructs under investigation (Roebianto et al., 2023). The interview protocol underwent scrutiny by experts in DS research, qualitative research, and maternal experiences. No alterations were made to my interview protocol. Should changes have been deemed necessary, I would have discussed them with my committee member. However, no modifications were made to my interview questions to ensure alignment with the study. Also, the study benefited from thoroughly examining validated instruments used in previous research within the same domain. By leveraging the established work of predecessors, the research instruments were grounded in existing knowledge, ensuring alignment with best practices and recognized standards within the field.

In addition to expert input and validation through previous research, a mock interview was conducted with a friend who simulated a study participant. This process allowed for a practical assessment of the interview protocol's clarity, question flow, and overall effectiveness. Feedback from these mock interviews played a pivotal role in refining the instruments and addressing any ambiguities or potential challenges in the data collection process once the study was initiated. The strategies feedback ensured that the instruments comprehensively covered relevant dimensions and aligned with the study's objectives (Roebianto et al., 2023). Essential for ensuring alignment with research objectives, content validity involves thorough coverage of relevant dimensions, informed development based on literature and theory, and expert review (Roebianto et al., 2023). By integrating these content validation strategies, this study ensures that the research instruments possess a high degree of content validity, ultimately enhancing the reliability and relevance of the data collected.

The sufficiency of researcher-developed instruments was ensured by aligning them with the research questions. The interview protocol and observation notes were meticulously designed to address the research questions directly. The questions and criteria were tailored to capture the detailed lived experiences of how mothers access and use support services while raising children with DS in Western Nigeria. Also, the combination of virtual face-to-face interviews, observation notes, and electronic recordings was a multi-faceted approach to data collection. This comprehensive strategy captured both verbal and non-verbal aspects, providing depth and richness to the dataset (DeJonckheere & Vaughn, 2019; Shafique et al., 2023). Additionally, the instruments underwent iterative refinement based on ongoing analysis. This iterative process enhanced the instruments' sufficiency by addressing potential shortcomings and ensuring clarity for participants.

The researcher-developed instruments drew on literature sources, underwent rigorous content validity checks, and were carefully designed to align with research questions, providing a robust foundation for the qualitative study.

Procedures For Recruitment, Participation, and Data Collection

In this section, data collection procedures will be discussed, mainly focusing on the virtual face-to-face semi-structured interviews with probing questions that were conducted via the Zoom platform. I served as the primary instrument to navigate the unique challenges of collecting authentic and comprehensive data from participants in Western Nigeria. From the virtual interview setup to the detailed planning of data recording, the methodology set the stage for an in-depth exploration of the mothers' narratives, ensuring sensitivity and rigor in the research process.

Data was collected remotely through virtual face-to-face interviews conducted on the Zoom platform. Participants joined the interviews from the comfort of their chosen locations in Western Nigeria. As the primary researcher, I conducted the virtual face-to-face interviews. This approach ensures consistency and uniformity across data collection sessions. Virtual face-to-face interviews were scheduled individually with each participant. The frequency was determined by the availability of participants, aiming for a comprehensive understanding while respecting their time constraints. Each virtual face-to-face interview lasted approximately 30-35 minutes. This duration was designed to allow for in-depth exploration of participants' lived experiences while maintaining engagement. Prior to each interview, I reviewed the concepts of confidentiality. Additionally, I emphasized that they have the option to discontinue their involvement at any point and subsequently provide them with the consent form for their signature.

To ensure the credibility of this study, several strategies were employed throughout the recruitment, participation, and data collection processes. I ensured prolonged engagement and persistent observation. Prolonged engagement was achieved by in-depth interviews with the mothers to deeply understand their experiences. Triangulation was used by incorporating multiple data sources (Adler, 2022). I employed interviews with probing questions and observational notes to cross-check and validate the findings, ensuring a robust and reliable interpretation of the data. Throughout the data collection process, reflective journaling was maintained to document my reflections, decisions, and potential biases. This practice contributed to transparency and credibility by providing a clear audit trail of the research process.

Rich, thick descriptions are essential for transferability (Bingham, 2023; Cloutier & Ravasi, 2021). I ensured that detailed accounts of the participants' demographics, the geographical and cultural context of Western Nigeria, and the specific experiences and challenges faced by the mothers. Strategies for enhancing transferability include providing thick descriptions (detailed and contextually rich accounts of the study) and incorporating variation in participant selection (ensuring diverse representation for broader applicability). Also, for variation in participant selection, I ensured diversity in participant selection to capture a broad range of perspectives and experiences, enhancing the potential for findings to be applicable in varied settings (Bingham, 2023; Cloutier & Ravasi, 2021).

Data was recorded electronically, ensuring an accurate and comprehensive record of the interviews. These recordings served as primary sources for transcription and subsequent analysis. I took observational notes to capture participants' detailed behaviors, gestures, and mannerisms that could not be captured on the recording during the virtual face-to-face interviews.

In the event of insufficient participation in this study, additional efforts were made to recruit more participants. This involved employing a snowballing sampling approach to ensure an adequate sample size. Snowball sampling included referring other participants who met the study criteria and creating a chain referral process until the desired sample size was achieved (Kennedy-Shaffer et al., 2021). This method is often used in qualitative research to access complex populations (Kennedy-Shaffer et al., 2021). In this study, I asked participants to inquire about their knowledge of other eligible mothers who fit the study criteria, and if so, they were encouraged to refer those individuals. This process continued iteratively with newly referred participants, asking them the same questions until the sample size of 10 reached saturation.

Exist and Follow-Up Interviews

Participants exited the study through a debriefing process. After the Semi-structured interviews, participants received a comprehensive debriefing that included a summary of the study's purpose, a discussion of any potential emotional impact, and an opportunity to ask questions or seek clarification on any aspect of the study during this debriefing phase. Participants were informed during the debriefing that they could contact me for additional clarifications or to express any concerns that may arise after their participation. These procedures are designed to ensure ethical and transparent participant interactions throughout the study, from recruitment and data collection to the exit process.

Member checking, a crucial follow-up procedure, was incorporated into the study. After the initial semi-structured interviews, participants were invited to review the transcripts of their interviews. The member-checking process allowed participants to verify the accuracy of the transcriptions, offer additional insights, or clarify any points (Brear, 2019; Motulsky, 2021). This iterative feedback loop enhanced the trustworthiness and validity of the data, ensuring that participants' perspectives were accurately represented. By incorporating member checking as a follow-up procedure, my study goes beyond debriefing to actively involve participants in the verification and validation of the data I collected, contributing to the overall rigor and credibility of the qualitative research process.

Data Analysis Plan

The data analysis process for the virtual face-to-face semi-structured interviews was qualitative thematic analysis. Described by Kiger and Varpio (2020) as a potent and adaptable method for qualitative data analysis, it was applied in this research. The data directly connects to Research Questions 1, 2, 3, and 4, focusing on the lived experiences of how mothers access and use supportive services while raising children with DS in Western Nigeria. I gathered my data into a single location, labeled and cleaned the data, disassembled, reassembled, and subsequently developed a unified and thorough visual depiction of the dataset. This representation aligned with the interpretation of the findings conveyed through a narrative. Thematic analysis was applied to identify patterns and themes within the interview transcripts (Kiger and Varpio (2020), employing Moustakas's (1994) eight-step-by-step descriptive phenomenological approach. This approach involves (a) listing and initially categorizing data, (b) identifying the invariant constituents, (c) grouping and organizing the invariant constituents into themes, (d) validating the identified constituents and themes, (e) providing detailed descriptions, (f) creating individual structural descriptions, (g) developing individual textural and structural descriptions, (h) synthesizing textural and structural aspects (see Moustakas, 1994). This process was accomplished by using NVivo data analysis software. NVivo was a tool that helped me store, organize, identify, code themes, and analyze my data for trends and patterns (see Dhakal, 2022) to better understand the lived experiences of mothers living in Western Nigeria raising children with DS.

Additionally, a comprehensive codebook was employed to guide the coding process, ensuring consistency and reliability in the interpretation of data. Codebook provides a structured framework for coding, ensuring consistency and reliability in analyzing data (see Giesen & Roeser, 2020). The combined use of NVivo and a codebook facilitates a systematic and rigorous analysis of the lived experiences of how mothers access and use support services while raising children with DS in Western Nigeria. Discrepant cases were scrutinized during coding, considering contextual factors and potential contributing elements to understand variations in participant experiences.

The observation notes contributed to all the research questions 1, 2, 3, and 4. Exploring mothers' lived experiences on accessing and utilizing support services while raising children with DS within social systems, customs, cultural beliefs, and available resources in Western Nigeria. The observation notes supplemented the interview data, providing non-verbal insight into the lived experiences of how mothers access and utilize support services while raising children with DS in Western Nigeria. These observations connect to the research questions by offering a holistic perspective on how customs, cultural beliefs, and social systems manifest in daily interactions. Similar to the interview data, thematic analysis was applied to observation notes, focusing on identifying patterns related to non-verbal aspects of customs and culture. The process involves systematically identifying, organizing, and interpreting patterns within observed behaviors, gestures, and mannerisms, also employing Moustakas's (1994) eight-step-by-step descriptive phenomenological approach. Qualitative analysis software NVivo was used to analyze the observation notes. This ensured consistency in coding procedures and facilitated the integration of observational data with interview data. Nvivo can analyze, classify, and categorize extensive data obtained from interview transcripts and notes (Allsop et al., 2022). Also, the codebook was used; the codebook served as a reference guide that outlines definitions and guidelines for each code, ensuring consistency and transparency in the coding process (see Giesen & Roeser, 2020). It is important to note that the interview transcripts and observation notes were analyzed simultaneously.

This data analysis plan ensured a systematic approach to analyzing both types of data, maintaining alignment with specific research questions and fostering a comprehensive understanding of the lived experiences of mothers accessing and utilizing support services while raising children with DS in Western Nigeria.

Issues of Trustworthiness

Trustworthiness refers to the level of confidence in the data and the overall quality of the study (Jeff & Corey, 2020). In qualitative research, trustworthiness includes four key constructs: (a) credibility, (b) transferability, (c) dependability, and (d) confirmability.

Credibility (Internal Validity)

Credibility focuses on the study's internal validity, emphasizing the extent to which the research accurately and authentically represents the participants' experiences (Jeff & Corey, 2020). To establish credibility, I employed various strategies such as triangulation, prolonged contact, which involve extended engagement with the participants, member checks, saturation, reflexivity, and peer review (Adler, 2022; Jeff & Corey, 2020).

Triangulation involves using multiple data sources (Adler, 2022). This study employed multiple data sources, virtual face-to-face interviews with probing questions, and observational notes to cross-verify findings and enhance the robustness of interpretations. I established a lengthy engagement with the participants to establish trust and gain deeper insights into their lived experiences on how they access and use support services for their children with DS. Member checking enhanced the study's credibility by incorporating the perceptions of those who directly experienced the phenomenon under investigation (Adler, 2022). For this study, I involved the participants in the verification process by allowing them to review transcripts and findings, ensuring accuracy and resonance. I ensured continuous data collection until saturation was reached (Alam, 2021), ensuring comprehensive coverage of themes and reducing the risk of overlooking essential details. Reflexivity is the ongoing process through which researchers critically examine and acknowledge their beliefs, biases, assumptions, and subjectivities that may impact the research process and findings (Adler, 2022). I maintained reflexivity throughout the research process to minimize the impact of preconceptions on the study, enhance transparency, and contribute to the trustworthiness of the qualitative research.

Collectively, these credibility strategies reinforced the internal validity of the study, establishing confidence in the accuracy and authenticity of the collection of data and interpretations.

Transferability (External Validity)

Transferability is concerned with the external validity or generalizability of the study findings. It addresses the question of whether the insights gained in one context can be applicable or transferred to other settings (Bingham, 2023; Cloutier & Ravasi, 2021). I addressed the issue of transferability by providing a detailed depiction of the study environment that is rich in context and procedures to aid understanding and application in different contexts (Bingham, 2023; Cloutier & Ravasi, 2021).

Dependability (Qualitative Counterpart to Reliability)

Dependability pertains to the reliability and consistency of the research process and outcomes (Bingham, 2023; Jeff & Corey, 2020). It aims to ensure that the study's findings are dependable and can be replicated. Strategies for establishing dependability include maintaining audit trails (comprehensive documentation for external scrutiny) and employing triangulation (using multiple sources and methods for data validation) (Bingham, 2023; Jeff & Corey, 2020). For the audit trails, I kept thorough records of the research process, including the collection of data, coding, and analysis, to enable external scrutiny and verification. Also, the study maintained triangulation by consistently using multiple data sources and methods to corroborate findings and establish consistency. These dependability strategies contributed to the reliability of the study, ensuring that the research process was systematic, transparent, and could be traced and replicated.

Confirmability (Qualitative Counterpart to Objectivity)

Confirmability addresses the neutrality and objectivity of the research, emphasizing that the findings are free from bias and represent the participants' perspectives authentically (Bingham, 2023). Reflexivity, a key strategy, involves continuous reflection by the researcher on their biases and subjectivity to enhance objectivity (Bingham, 2023). This study maintained confirmability to ensure that the interpretations were grounded in the data rather than influenced by my preconceptions.

These constructs collectively contributed to the overall trustworthiness of qualitative research, ensuring rigor, transparency, and the reliability of findings. Each construct involves specific strategies aimed at mitigating potential sources of bias and enhancing the quality and integrity of the research process.

Ethical Procedures

Receiving Walden University's Institutional Review Board (IRB) and the National Health Research Ethics Committee of Nigeria (NHREC) approval confirms my ability to uphold ethical research standards (see Appendix A). The study ensured ethical engagement with participants by establishing transparent agreements outlined in both the IRB application and NHREC, particularly due to the recruitment of participants from Nigeria. The consent forms and information provided to participants detailed the purpose, procedures, potential risks, and benefits, fostering informed decision-making. These documents are integral to the ethical foundation, promoting voluntary participation and respect for participant autonomy (Xu et al., 2020). In adherence to ethical standards, the study obtained the necessary institutional permissions and IRB approvals. The IRB approval number is (04-30-24-115398) it expires on (April 29, 2025), and the NHREC approval number is (NHREC/01/01/2007- 01/04/2024), and it expires on March 31, 2025, affirming the ethical clearance obtained for the research. Ethical concerns related to recruitment materials and processes were centered on transparency and informed consent (see Xu et al., 2020). The study addressed these concerns by providing precise and comprehensive information in recruitment materials, ensuring participants understand the nature of the study, their rights, and the potential impact. The consent process emphasized voluntariness and the right to withdraw at any stage (Xu et al., 2020).

Ethical considerations during data collection include participant privacy, power relationships, and potential risks. The study employed virtual face-to-face semi-structured interviews, emphasizing confidentiality and creating a safe space for the participants to share their experiences accessing and utilizing support services for their children with DS. The power dynamic was carefully managed through respectful and equitable interactions, minimizing the potential for coercion or undue influence. Data treatment prioritized participant confidentiality. The study specified that data was confidential, ensuring participants' identities were protected (see Xu et al., 2020). Anonymized data collection and storage procedures were implemented to safeguard sensitive information, reducing the risk of unintended disclosure. Also, confidential data was protected through robust measures. Data storage procedures involve secure electronic storage with restricted access (Mahajan et al., 2023). I was the only one with access to the data. A clear timeline for data destruction has been established, ensuring that data are retained only for the necessary duration. The data will be kept for a minimum of five years in compliance with Walden University requirements.

Conducting the study within my work environment raises ethical considerations. Transparency and disclosure mechanisms were implemented to address this, acknowledging potential conflicts of interest. The study proactively addressed power differentials by fostering a collaborative and respectful research environment.

Transparent communication and active participant engagement empower individuals, ensuring their voices are heard and respected throughout the research process. The use of compensation was justified ethically. The mothers were compensated for their time and contribution, allowing them to choose a quiet location, thereby avoiding coercion and acknowledging the value of their involvement.

A potential ethical issue in public health research involves power differentials between the researcher and participants. I may hold a position of authority, potentially influencing participants' decisions and responses. This power dynamic raises concerns about the voluntariness of participation and the potential for coercion or undue influence. To address power differentials, the research design incorporated strategies to empower participants. This included transparent communication about the voluntary nature of participation, emphasizing participants' right to withdraw at any stage without consequences (Xu et al., 2020). Additionally, I practiced reflexivity, continually reflecting on my own position of power and taking steps to mitigate any imbalances in the researcher-participant relationship (Barrett et al., 2020).

Another ethical issue involved the vulnerability of participants, particularly when discussing sensitive topics related to raising children with DS. Participants shared personal and emotional experiences. Ensuring the emotional well-being and protection of participants becomes a critical ethical consideration. To address participant vulnerability, the research design incorporated measures to minimize risks and provide support. The informed consent process includes a clear explanation of the study's purpose (Xu et al., 2020) and potential emotional impact. I remain attuned to participants' emotional states during interviews, offering opportunities for breaks or emotional support when needed. Additionally, participants were provided with post-interview resources, such as contact information for counseling services, to ensure ongoing support beyond the research interaction. By actively addressing these ethical issues, I created a respectful, transparent, and supportive environment for participants. This upheld the principles of autonomy, beneficence, and justice in the conduct of public health research (Xu et al., 2020).

Summary

Section 2 meticulously outlines the research design, data collection methods, and overall methodology for the qualitative study exploring the lived experiences of mothers raising children with DS in Western Nigeria. I began the section by defining the purpose and problem, restating the research questions and gap addressed by the study, and emphasizing the lack of qualitative studies about the lived experiences of how mothers access and utilize support services for their children with DS in Western Nigeria. Bronfenbrenner's ecological model, particularly at the macrosystem level, provides the theoretical framework, focusing on customs, cultural beliefs, resources, and social systems.

The chosen research design was a descriptive phenomenological qualitative approach involving recruiting 10 mothers through purposive sampling. The research questions examined varied aspects, exploring Western Nigeria mothers' experiences raising children with DS on how they access and use support services within social systems, customs and cultural beliefs, and available resources. I addressed the methodological instrumentation, encompassing virtual face-to-face interviews with probing questions and observational notes, ensuring a comprehensive exploration of lived experiences. I addressed the issue of trustworthiness and outlined the strategies employed to establish credibility, transferability, dependability, and confirmability in the study. This section established a robust foundation for investigating the multifaceted experiences of mothers raising children with DS in Western Nigeria, emphasizing methodological rigor and ethical considerations. Section 3 is the next section, which includes the presentation of the results and findings.

Section 3: Presentation of the Results and Findings

The specific problem that I addressed in this study is that the lived experiences of how mothers access and use support services for their child with DS were not known. Therefore, the purpose of this qualitative phenomenological study was to understand the accessibility and utilization of support services through the lived experiences of Western Nigerian mothers raising children with DS. This study explored four research questions, which are as follows: (a) what are the lived experiences of mothers accessing and utilizing supportive services while raising children with Down syndrome in Western Nigeria? (b) How do mothers raising children with Down syndrome describe their experiences with accessing and utilizing support services within the social systems in Western Nigeria? (c) How do mothers raising children with Down syndrome describe their experiences with accessing and utilizing support service resources in Western Nigeria? and (d) How do mothers raising children with Down syndrome describe their experiences with accessing and utilizing support services within the customs and cultural beliefs in Western Nigeria?

This chapter encompasses study findings, beginning with an overview of the study setting and participant demographics and characteristics, followed by a description of data collection measures and a detailed process of how I conducted the data analysis. Subsequently, I discuss evidence of trustworthiness and present the results.

Study Setting

After obtaining approval from the Walden University Institutional Review Board (IRB) and the National Health Research Ethics Committee of Nigeria (NHREC), this research was conducted among Nigerian mothers residing in Western Nigeria, each of whom has a child diagnosed with DS. I conducted interviews with these mothers via Zoom, using virtual face-to-face, semistructured interviews with probing questions. Confidentiality measures were implemented by furnishing each participant with the meeting room link and password. The interviews were scheduled at mutually agreed upon dates and times between the participants and myself. Participants were able to participate in the interviews from their preferred locations in Western Nigeria. Throughout each participant's interview, I observed no significant distractions that could have hindered data collection. Each participant responded comprehensively to questions, displaying full engagement in the research process. I sought validation from mothers through member checking, where the mothers were invited to review and provide feedback on the interpretation of the data to ensure my interpretations aligned with their experiences. The participants validated their transcripts before the data analysis started. This enabled a thorough understanding of the perspectives shared by the mothers regarding their lived experiences in accessing and using support services for their children with DS.

Demographics

The study had 10 participants. Initially, the target was to recruit 15 participants, but the 10 participants were determined based on attaining data saturation. Data saturation, as described by Alam (2021), is attained when no new information emerges during the data collection process. Participants were recruited from various geopolitical locations in Western Nigeria, including states such as Lagos, Ogun, Oyo, Osun, Ondo, and Ekiti. All participants were proficient in English and possessed diverse demographic characteristics (refer to Table 1).

Table 1

Participant Demographic Characteristics

Participants	Age	Region	Marital status	Age of child	Number of children	Sex
Participant 1	54	Ondo	Married	19	One	Female
Participant 2	47	Ondo	Married	10	One	Female
Participant 3	59	Ondo	Married	20	One	Female
Participant 4	44	Ibadan	Married	18	One	Male
Participant 5	48	Lagos	Married	9	One	Male
Participant 6	40	Lagos	Single	7	One	Male
Participant 7	44	Osun	Married	4	One	Female
Participant 8	50	Ekiti	Married	15	One	Female
Participant 9	41	Ogun	Married	12, 3	Two	Males
Participant 10	45	Ondo	Married	12	One	Female

Participants in the study encompassed a diverse range of ages. They all affirmed their current status as mothers raising children with DS residing in Western Nigeria. Their ages spanned from 41 to 59 years, with an average age of 50 years. Among them, nine participants indicated they were married; one stated she was single. Regarding their children diagnosed with DS, their ages ranged from 4 to 20 years, with an average age of 12 years.

Data Collection

After obtaining IRB (04-30-24-115398) and NHREC (NHREC/01/01/2007-01/04/2024) approval, data was collected from a total of 10 mothers raising children with DS in Western Nigeria, though initially, the plan was to recruit 15 participants. Saturation was reached with this sample size. According to Guest et al. (2020), saturation is achieved during data collection when there is ≤5% new information and no new information (0%) is observed. In the study, saturation was reached during interviews when the mothers provided no new information. Additionally, saturation was identified during the coding process when no new themes emerged from the data. Guest et al. further stated that run length can be used to determine saturation where no new themes emerged. To determine saturation using run length, I interviewed eight mothers and analyzed the consecutive interviews to see if new themes emerged; no new themes were identified. To confirm saturation, I interviewed two additional mothers and again found no new themes during coding. The new data of the two mothers fits into existing codes and themes without needing new categories. This indicated that thematic saturation was achieved, as additional interviews did not yield new information, confirming the completeness and robustness of the data collection process. This dual approach ensures comprehensive data collection and thorough analysis.

Participants were identified through the distribution of informative flyers (see Appendix C) across various channels. Flyers were distributed through channels, including churches, schools, markets, shopping malls, and community networks, all at their physical addresses. These sites posted the flyers on their public bulletin boards. Mothers who expressed interest contacted me via phone or email, requesting a callback due to network issues prevalent in Nigeria.

Virtual, face-to-face, semistructured interviews were conducted with each mother to gather qualitative data on how they access and use support services for their children with DS based on their lived experiences. I assigned participant IDs (e.g., Participants 1, 2, 3, etc.) to track their involvement in the study. These interviews were conducted in a private environment via Zoom, in the participants' homes, to ensure confidentiality and comfort. The frequency of data collection for interviews varied based on participant availability, with each interview lasting approximately 30 to 35 minutes. Each interview comprised 12 open-ended questions for all participants, along with follow-up questions tailored to the participant's responses (see Appendix B). Additionally, during the interview, observational notes were taken to record nonverbal cues, context, and any noteworthy observations. These notes were recorded manually using pen and paper. Data was recorded electronically/audio and transcribed for subsequent data analysis.

The data collection process followed the plan outlined in Section 2, with minor variations to accommodate participants' schedules and preferences. For example, some interviews were rescheduled by pushing the time back by 2 days due to unforeseen circumstances. Throughout the data collection process, efforts were made to maintain rapport with participants and ensure their comfort and confidentiality. Overall, the data collection process proceeded smoothly.

Data Analysis

The data analysis process for the virtual, face-to-face, semistructured interviews with probing questions accompanied by observational notes was qualitative thematic analysis. It is described by Kiger and Varpio (2020) as a potent and adaptable method for qualitative data analysis. I gathered my data into a single location, labeled and cleaned the data, disassembled, reassembled, and subsequently developed a unified and thorough visual depiction of the dataset. Thematic coding was applied to identify patterns and themes within the interview transcripts (Kiger & Varpio, 2020), employing Moustakas's (1994) eight-step-by-step descriptive phenomenological approach. This approach involves (a) listing and initially categorizing data, (b) identifying the invariant constituents, (c) grouping and organizing the invariant constituents into themes, (d) validating the identified constituents and themes, (e) providing detailed descriptions, (f) creating individual structural descriptions, (g) developing individual textural and structural descriptions, and (h) synthesizing textural and structural aspects (Moustakas, 1994). This process was accomplished by using NVivo data analysis software. NVivo was a tool that helped me store, organize, identify, code themes, and analyze my data for trends and patterns (see Dhakal, 2022) to better understand the lived experiences of mothers living in Western Nigeria raising children with DS. Additionally, I employed a comprehensive codebook to guide the coding process, ensuring consistency and reliability in the interpretation of data. A codebook provides a structured framework for coding, ensuring consistency and reliability in analyzing data (Giesen & Roeser, 2020). The combined use of NVivo and a codebook facilitates a systematic and rigorous analysis of the lived experiences of how mothers access and utilize support services while raising children with DS in Western Nigeria.

Following Moustakas's (1994) eight-step descriptive phenomenological approach, interview transcript recordings were transcribed word for word. Transcriptions and observational notes were imported into NVivo software. I set up containers or codes for each of the research questions. This was to generate codes under each respective research question. Informed by Moustakas' Steps 1, 2, and 3 of analyzing phenomenological data, I reviewed the transcripts to identify relevant excerpts. Initial codes were generated based on the relevant excerpts and placed under their research questions. Developing the codebooks, I created an initial list of codes with definitions, adjusted and added new codes as patterns and themes emerged during analysis. The codebook contains the list of codes applied to the data and their respective definitions (see Giesen & Roeser, 2020). I re-examined the data, leading to the refinement of the initial code generated. I used this process to ensure that all relevant data were accurately coded according to the updated codebook. The initial codes were exported from NVivo to an Excel spreadsheet for further exploration to generate themes. I then copied the organized codes from Excel to Microsoft Word to develop and document themes.

For Moustakas' (1994) fourth step, utilizing thematic analysis, I started grouping similar codes into broader themes in Microsoft Word. At the end of the grouping process, two, two, three, and three themes were generated to address RQ 1, 2, 3, and 4, respectively. I then imported the finalized themes back into NVivo for integration and further analysis and put them under their respective research questions.

Following the fifth step of Moustakas' (1994), I then provided detailed descriptions, involving thorough descriptions of each mothers' experiences based on the coded data and identified themes. In the sixth step, I described the underlying structures of the mother's experiences by interpreting the themes based on the mother's background. For Moustakas' seventh step, I combined the textural and structural descriptions of the mothers' experiences to comprehensively understand them. Finally, I developed insights from the identified themes and documented findings, showing how they reflected the mother's experiences in a composite description.

The following 10 themes were identified: (a) challenges in accessing and utilizing support services, (b) creation and utilization of support networks, (c) absence of community and government support, (d) family support and resilience, (e) financial strain in accessing support services, (f) inadequate educational services, (g) successful access to educational resources, (h) stigmatization and discrimination associated with DS, (i) experiencing resilience through religion/spirituality, and (j) parental responsibility to care. These themes addressed all the research questions. Discrepant cases were scrutinized during coding, considering contextual factors and potential contributing elements to understand variations in participant experiences. Additionally, I performed a word frequency query to identify the most frequently used words in the mothers' transcripts. The results were visualized using word clouds and word trees to clearly represent the common terms and their related usage (see Appendix D).

Table 2 provides a comprehensive summary of the qualitative data analysis conducted in this study. The table illustrates the relationship between the research questions, identified themes, corresponding codes derived from the data, and specific excerpts from the mothers' transcripts. This structured approach facilitates a clear understanding of how the raw data was systematically analyzed to extract meaningful insights.

Each research question is linked to several themes that emerged from the data collected. The codes within each theme represent the specific aspects of the mothers' experiences that were highlighted during the thematic analysis, following Moustakas' (1994) eight-step descriptive phenomenological approach. These codes are further substantiated with excerpts from the data. The excerpts provide concrete examples of the mothers' experiences, ensuring that the themes and codes are grounded in actual data. This method enhances the reliability and validity of the findings, demonstrating how the data was inductively analyzed to develop broader representations and insights.

Table 2

Alignment of Themes, Codes, Excerpts, and their Respective Research Questions (RQs)

RQs	Initial codes	Themes	Participants	Excerpts
RQ1	No support services Sense of frustration Difficulties accessing special school Seeking support but not successful Difficulties locating a nearest special center Extreme measures due to lack of support	Theme 1: Challenges in accessing and utilizing support services	P1	“There's no service here at all. I've said there is no help anyway.”
			P2	“The services here are very poor. Let me even put it in the whole Western.”
			P3	“So, there's no special help.”
			P5	“There are no services that are helping parents with children with Down syndrome.”
			P6	“I've been facing many problems, especially educationally.”
			P7	“Very poor, no help.”
			P8	“No support anywhere. It's a bit challenging.”
			P9	“There is no help for him to go to a special school.”
			P10	“There's no adequate care for them. Not adequate at all. It's not good at all.”
	Creating support group for mothers Utilization of specialized services	Theme 2: Creation and Utilization of Support Networks	P4	“I found a home; they have a doctor's service. Doctors are always there. There is a clinic in the school where they get to see doctors.”
			P5	“There are no services that help parents with children with Down syndrome. No, no, I decided, on my little level, to create a little group on a platform to help parents.”
RQ2	Lack of structure related to care for DS children Lack of government and NGO support Perceived lack of interest in helping Lack of community support Lack of volunteerism Government neglect	Theme 3: Absence of Community and Government Support	P1	“There is no government. The government is not making any arrangements to help people in that category.”
			P2	“And they are not able to give us the help we need. Both from the government and the private one, the private schools.”
			P3	“So, there is no help from any other people. So, there's no special help from the community. No special.”
			P5	“We try to find information to have anything someone can do, our government can do for our children, but it was in vain.”

RQs	Initial codes	Themes	Participants	Excerpts
			P6	“There is not any professional or anybody that I can mention now that helped us with the boy.”
			P7	“So, nobody is getting help from anybody.”
			P8	“So, the government is not doing anything. So, you are left alone with your burden, with your cross.”
			P9	“There is no help either from the government or from the community.”
			P10	“They are not ready to help them.”
	Family resilience Receiving family support	Theme 4: Family Support and Resilience	P1	“When people are not ready to relate, at least the immediate family, we are there for her.”
			P2	“So, the little we can do at home is I have a small board for her; I just write. Sometimes, I write it on the sheet of paper, go and repeat it, and she will.”
			P3	“There's no, there's no special help, so only me, my husband, and the other siblings. I'm working, so I made her niece a priority. I used to give her moral support, financial support, and spiritual support.”
			P4	“The dad has been really supportive. So, I think because I think for a child with Down syndrome to go far, he needs a family that is willing to support him. So, the boy got that with us, with the dad, with the uncles, with the grandparents.”
			P5	“We have sacrificed a lot to provide for the needs of the child, and what we can do to help him grow as a child with Down syndrome, we are trying our best.”
			P6	“I'm just managing him in a parlor school because many schools in this place used to reject them.”
			P7	“But I only take care of her. By teaching her with the cartoons that I downloaded and also helping her on my own part.”
			P8	“You do it. The little you have, you put it just to get at least to give a good life. So, everything goes down to you.”
			P9	“Taking care of them is even much, Is even much more than people who have no disability.”

RQs	Initial codes	Themes	Participants	Excerpts
			P10	“As a mother, I will never abandon my child. I will do whatever in my power to give her what she needs.”
RQ3	Access to educational resources	Theme 5: Successful Access to Educational Resources	P4	“There is a clinic in the school where they get to see doctors who speak with them, who engage them; he has really improved. I remember a time that we wanted this particular instructional material, and the dad could not get it, and the owner of the home said Ohh, I have someone that makes them; we can get it for you because she believes that there is ability in disability.”
	Inadequate educational services Lack of therapy services Supplementary support services	Theme 6: Inadequate Educational Services	P1	“It has really affected her because now we can't put her in any of these private schools with therapy to assist. There was a time when she was at home for a year. Here, we can't put her anywhere. She couldn't access it.”
			P2	“I think that on your side, they will have a special school for special people like them. But here, we were unable to get it.”
			P3	“So, there is no help from any people or school.”
			P5	“No. Right now, my son is in a normal school.”
			P6	“It's not so easy like that, and it's not easy to find things to help the boy because the boy even needs special education.”
			P7	“I believe a good school will change her. A good school, a special school that is meant for them.”
			P8	“No special school.”
			P9	“There is no help for him to go to a special school.”
			P10	“There's no adequate school for them. Not adequate at all.”
	Lack of affordability of support service center Financial Strain in Accessing Child's Needs Paying out of pocket for therapy	Theme 7: Financial Strain in Accessing Support Services	P1	“They are just too expensive. Too expensive.”
			P2	“Because of this financial constraint. So that's why we are limited to what we have in our environment here.”
			P3	“There's no special help from any professional to her; I don't think because of the little I earn, I spend it on my children.”
			P4	“But financially, it was not really…. It was not really smooth because we

RQs	Initial codes	Themes	Participants	Excerpts
				had to pay for a lot of stuff, and then we moved to this other school where we could not really pay the fees again."
			P5	"For a child now, the best school that they can go to is #380,000 per term for a child. So, as a parent, if you don't have this type of money, your child can't go to a specialized school here in Nigeria."
			P6	"I abandoned taking care of his health since he was two years old because of financial problems."
			P7	"We did not enroll her for that kind of school. No really help from there because to get to that special school. It is money, It's a big challenge, a big challenge to me."
			P8	"The major thing is the financial aspect, which makes it so hard."
			P9	"Financially, we don't really get financial support like that. It affects them medically and academically."
			P10	"The economy is not friendly. So, there is not enough money to take her to the hospital."
RQ4	Impact of stigma on accessing help Social perception and discrimination Perception of abnormality Social rejection	Theme 8: Stigmatization and Discrimination Associated with Down Syndrome	P1	"People believe they are not normal; they stigmatize people in her category, and they are not ready to relate. They are not ready to take care of them."
			P2	"They believe they are not normal and that they cannot cope. So, they look down totally on them. Some believe that it is a spiritual attack."
			P3	"When I put the child in the creche, some people don't want to touch her, so maybe they were thinking she is a strange person."
			P4	"So, I think it's hard because there are times when people are, why is he looking like this? Ohh this one is an imbecile. People would refer to you, Oh, that woman that has an imbecile child."
			P5	"Someone called my child a snake. So, it's difficult for someone to believe a Down syndrome child can go to school and learn."
			P6	"People believe in this, our Nigerian side, that these children, if they help them, they do not believe something will come through them."

RQs	Initial codes	Themes	Participants	Excerpts
			P7	“So, their belief is those kinds of people are different from normal people.”
			P8	“When they look down on those children, definitely then, seeking help for them may be difficult because they'll see it as a waste of time.”
			P9	“Some believe that it is contaminated, like it can be transferred if associated with them.”
			P10	“People think she can't even survive. When they think she can't survive, so some people, even though they want to help, will not help again.”
	Individual resilience Reliance on faith Relying on God	Theme 9: Experiencing Resilience through Religion /Spirituality	P1	“There is no help anyway. It is only God. God has been helping me.”
			P2	“Well, till now, there has been no help except the one I got from Grace.”
			P3	“So, it is God's gift and what God has given to you; you have to abide by it.”
			P5	“I was shocked when the doctor told me I have a Down syndrome child, this child; if he learns, it will be difficult to learn. And when he learns, literally, he will forget it quickly. I came back to my house. I look at my son. I said no matter what the doctor said, God creates you, and you will be blessed in anything you want to do.”
			P6	“I used to say that how can I cope? How can I cope with this boy? But I'll just believe that God will make a way where there is no way one day.”
			P7	“Sometimes, I'll just say God has an overall for everything. I know that God's time is the best, and I know that God will perfect everything that concerns her.”
	Responsibility to care	Theme 10: Parental Responsibility to Care	P1	“I try as much as possible to meet and provide for her. No, she’s my child. It's my responsibility to take care of her.”
			P2	“When she was supposed to sit and crawl, she was unable to do it. Which has to take us some months, extra months, so it's on you. They leave you on your own.”
			P3	“Generally, I will depend on my salary. So is the salary that we are

RQs	Initial codes	Themes	Participants	Excerpts
				spending. So, the father is a retired teacher.”
			P4	“Like me, I attend events. I go everywhere; I go practically everywhere with him.”
			P5	“Ohh, me, I love fashion design. I love very expensive things; I love looking very good; I shut down those expenses because I need the money to train my child.”
			P6	“It is not easy in Nigeria to look for help. I am struggling with anything that I can use to take care of him.”
			P7	“What I do on my own is download cartoons for her to follow up. So, from there, if they said head, she would follow up. That's what I do, but help, no help from anybody.”
			P8	“You do it on your own. Nothing, nothing comes from anywhere. It's your cross.”
			P9	“Academically, there is not much help, and the father of the children we are talking about is late.”
			P10	“I'm just doing my own as a mother. The little I can do, I just do what I can do to help her. And I make sure she eats food. And I take care of her, wash her clothes. Anything I can do for her as a mother, I'm doing it for her.”

Table 2 offers a transparent and detailed view of the data analysis process. It shows how individual mothers' pieces of the data (codes and excerpts) contribute to the formation of larger themes, which in turn address the overarching research questions. This clear linkage between data, codes, themes, and research questions emphasizes the accuracy of the qualitative analysis. It highlights the depth of the mothers' lived experiences on how they access and use support services for their children with DS in Western Nigeria.

Evidence of Trustworthiness

Ensuring trustworthiness in qualitative research is paramount for the credibility and reliability of study findings (Jeff & Corey, 2020). My goal with this research study was to explore the lived experiences of how mothers access and utilize support services for their children with DS. In order to generate genuine work, I concentrated on aspects of the evidence that bolstered reliability, such as credibility, transferability, dependability, and confirmability.

Credibility

Credibility concerns the internal validity of the study, emphasizing how accurately and authentically the research reflects the experiences of the participants (Jeff & Corey, 2020). To ensure credibility, I used several approaches, including triangulation, prolonged engagement with participants, member checks, reflexivity, and peer review (see Adler, 2022; Jeff & Corey, 2020).

Triangulation, as described by Adler (2022), entails the use of various data sources. I used multiple data sources, including virtual, face-to-face interviews with detailed questioning and observational notes, to cross-reference findings and strengthen interpretations. I fostered extensive engagement with the mothers to build trust and gain deeper insights into their experiences regarding how they access and utilize support services for their children with DS.

Member checking, as emphasized by Adler (2022), enriches the study's credibility by integrating the perspectives of mothers directly involved in the study. In this research, I engaged participants in the validation process by inviting them through email to review transcripts, thereby ensuring accuracy and resonance. All mothers responded to the email without further corrections to their interview transcripts.

Reflexivity, as described by Adler (2022), involves researchers continuously evaluating and acknowledging their assumptions, biases, beliefs, and subjectivities that might affect the research process and resulting outcomes. Throughout this study, I upheld reflexivity to reduce the influence of preconceptions, promote transparency, and bolster the credibility of the qualitative research.

Transferability

Transferability is concerned with the external validity or generalizability of the study findings. It addresses the question of whether the insights gained in one context can be applicable or transferred to other settings (Bingham, 2023; Cloutier & Ravasi, 2021). Several strategies were employed to ensure transferability in my study. Firstly, detailed descriptions of the research setting, methodology, and data collection procedures were provided to enable readers to evaluate the applicability of the findings to their own situations. Additionally, thorough documentation of participant characteristics, including demographic information and relevant contextual factors, was conducted to facilitate comparisons with other settings. Transparency regarding the limitations or constraints of the study that may affect transferability was also ensured. Moreover, readers were encouraged to consider the similarities and differences between their context and the study context when interpreting and applying the findings. Through these measures, efforts were made to enhance the transferability of the study's findings to diverse contexts and settings.

Dependability

Dependability pertains to the reliability and consistency of the research process and outcomes (Bingham, 2023; Jeff & Corey, 2020). It aims to ensure that the study's findings are dependable and can be replicated. To ensure dependability in my study, rigorous methods were employed to enhance the reliability and consistency of the research findings. Firstly, detailed documentation of the research procedures, including data collection techniques, coding processes, and analytical methods, was maintained to facilitate transparency and replication of the study. Additionally, the study maintained triangulation by consistently using multiple data sources and methods to corroborate findings and establish consistency.

Confirmability

Confirmability pertains to how much the findings of a study are objective and free from researcher bias or influence (Bingham, 2023). In my study, several measures were implemented to ensure confirmability. Firstly, reflexivity was practiced throughout the research process, where I maintained awareness of my biases, assumptions, and preconceptions, actively reflecting on how these might influence the interpretation of data. Additionally, an audit trail was established to document and track all decisions made during the research, including data collection, analysis, and interpretation, allowing for transparency and accountability. Moreover, member checking was conducted to validate the interpretations of mothers, ensuring that the mothers' perspectives were represented accurately in the findings.

Results

Upon analyzing the collected data and delineating the themes and codes as the outcomes of this study, I presented them in accordance with the four research questions. In this segment, I outlined the findings associated with the four research questions, having identified the codes, the emerging themes, and the mothers contributing to each theme. Each theme is supported by quotations from participants. A total of 10 themes resulted from the dataset: (a) challenges in accessing and utilizing support services, (b) creation and utilization of support networks, (c) absence of community and government support, (d) family support and resilience, (e) financial strain in accessing support services, (f) inadequate educational services, (g) successful access to educational resources, (h) stigmatization and discrimination associated with Down syndrome, (i) experiencing resilience through religion/spirituality, and (j) parental responsibility to care. Following Moustakas' steps, I presented the textural and structural descriptions of the participants' experiences; this hybrid form of presentation was informed by Moerer-Urdahl and Creswell (2004).

Emerging Themes

Research Question 1 (RQ1)

RQ1: What are the lived experiences of mothers accessing and utilizing supportive services while raising children with Down syndrome in Western Nigeria? This research question involved the lived experiences of how mothers access and utilize support services for their children with DS. From this research question, the dataset revealed two main themes: (a) challenges in accessing and utilizing support services and (b) creation and utilization of support networks.

Theme 1: Challenges in Accessing and Utilizing Support Services

Under this first theme, the participants expressed frustration, difficulties, and challenges in accessing and utilizing support services (Refer to Tables 3 and 4).

Table 3

Theme 1: Participant Involvement

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	Total
Theme 1: Challenges in Accessing and Utilizing Support Services	X	X	X		X	X	X	X	X	X	9

Table 4

Theme 1: Identified Codes

	Codes
Theme 1: Challenges in Accessing and Utilizing Support Services	No support services Sense of frustration Difficulties accessing special school Seeking support but not successful Difficulties locating a nearest special center Extreme measures due to lack of support

As illustrated in Table 3, nine out of the 10 participants reflected this theme. P4 did not address this theme, as her descriptions on the transcript and observational notes did not mention any challenges in accessing and utilizing support services. The identified codes emphasized that all nine participants had challenges in accessing and utilizing support services for children with DS. For instance, P1, a 54-year-old mother, expressed unhappiness and frustration about the lack of support for her daughter. She repeatedly mentioned "no help" throughout the interview.

Additionally, P1 noted that she took an extreme measure due to a lack of specialized services, educational opportunities, and therapy. She found herself in a challenging position, struggling to manage her daughter’s needs while also attending to other family responsibilities. P1 mentioned:

> There's no service here at all. I've said there is no help anyway. We've gone around; we've nearly gone around the country. Nobody is really interested in helping everybody with his or her problem. So, we are left alone to face it. It's hard to get help. From whom? Nobody to help. It has really affected her because now we can't put her in any of these private—schools with therapy to assist. There was a time when she was at home for a year. Here, we can't put her anywhere. No money, and at times, even when we go to our place of work, we lock her inside. Lock the door, and she will be alone at home. So it has not been easy at all.

P2, a 47-year-old mother, began to cry when discussing the lack of support services available for her daughter with DS. P2 responded:

> The services here are very poor. Let me even put it in the whole Western because, see, now we have been trying to get her to the school where she can fit in. Till now, we have been unable to get it.

P3 and P5 expressed their desperate need for help for their children with DS, sounding frustrated throughout the interview. Their voices conveyed a sense of urgency and exasperation, underscoring deep frustration at the lack of available support services for their children.“There’s no, you know, here, you face your own problem. So, there is no help from any other people. So, there's no special help” (P3).

> In Lagos State, to my knowledge, there are no services that are helping parents with children with Down syndrome. We do not have services that are helping us. So, I can't say whether this service is good or not. There are no services that are helping us as a parent with a child with Down syndrome. We are doing everything by ourselves. No, for me, the services here in Nigeria, Lagos especially, I can’t say it is zero, but it is too low for parents; there is none. We are not receiving any very difficult to receive help if you have a child with Down syndrome in Nigeria (P5).

P6 and P7 described their experience with the lack of access to a special school. Participants hissed twice during the interview, indicating frustration and discontent. P6 noted:

> I've been facing many problems, especially educationally because in Nigeria, they don't like taking these students in a normal school. They like complaining about them that their behavior is different from other students. So, I faced many challenges, especially on the education line. So he's just managing one place. Also, at that place, the woman sometimes used to complain that I should carry the boy to their school, so educationally, I'm facing challenges most with the boy.

P7 described: “Very poor, no help. Not like before, these days, these things are on the high side. So nobody is getting help from anybody. Everybody is just carrying his or her own cross” (P7).

P8, a 50-year-old mother with a daughter with DS, emphasized her point with a firm and assertive tone due to the lack of support services for her daughter. Her harsh voice and repetitive statements highlighted her strong feelings of dissatisfaction and hopelessness regarding the availability of support services. P8 persistently stated:

“I keep saying it, getting help down here from anybody is just zero. You can ask any other person; it's just zero. They see it as your burden in Nigeria, no support anywhere. It's a bit challenging.”

P9, a 41-year-old, and P10, a 45-year-old mother with a daughter with DS, also described the lack of access to support services, particularly noting the difficulties in accessing and locating a special school for their children with DS.

> So, academically, there is no help for him to go to a special school where he can be monitored and supervised academically, but he is in a normal school. Here, the normal school setting is different from the special school. So, I think academically, for now, he needs help academically (P9).
>
> So even now, she's going to regular school instead of a special school. I can't afford it. I can’t afford the money, so I put her in a regular school instead of a special school. You know, in Ondo state, there's no adequate care for them. Not adequate at all. It's not good at all. Because I enrolled her in a school, in a special

> school at Akure, and they rejected her. They asked me to take her to “ile-Oluji”. So, they don’t have adequate care for them in Ondo State (P10).

Theme 2: Creation and Utilization of Support Networks

The second theme revealed in the data was how the mother utilized support services that were accessible to her son with DS, enhancing the child's development, and how a support platform is aimed at helping other mothers with similar challenges. Tables 5 and 6 provide a detailed overview of the mothers who contributed, along with the corresponding themes and codes that were identified in the dataset.

Table 5

Theme 2: Participant Involvement

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	Total
Theme 2: Creation and Utilization of Support Networks				X	X						2

Table 6

Theme 2: Identified Codes

	Codes
Theme 2: Creation and Utilization of Support Networks	Creating support group for mothers Utilization of specialized services

As exemplified in Table 5, only participants 4 and 5 contributed to this theme. The identified codes emphasized P4's utilization of support services that were accessible to her son with DS, enhancing the child's development. She accessed a variety of specialized services, including therapeutic sessions and educational settings. These services were instrumental in supporting her child. P4 reported:

> I found a home, a very good place for him because they have a doctor's service. Doctors are always there. There is a clinic in the school where they get to see doctors who speak with them, who engage them; he has really improved. They see therapists who diagnose them and see what they can do with their hands or who help them with their fine motor skills.

P5 emphasized how she creates a support group for mothers with similar challenges where mothers of children with DS can connect, share resources, and offer mutual support. This platform provides emotional support, awareness, and practical advice, helping mothers navigate the complexities of raising a child with DS. P5 discussed her experience creating the support group for mothers:

> To my knowledge, there are no services that are helping parents with children with DS. For that, how difficult is it for parents to take their children and no services? No, no, I decided, on my little level, to create a little group on a platform to help parents that have a child with Down syndrome to help them understand the condition, and I will create a little help for children with Down syndrome, with less privilege. I will raise money on social media to help. Very, very difficult, like I said, to have help here in Nigeria. We do not have any structure here, and in my own knowledge, because, if possible, it exists. But it is something people don't know about it. We don't know about it.

Additionally, P5 described:

> The general school can't take the child because of the condition. It's very difficult for those children, but I try my best for my community to know I have a Down syndrome child and that a Down syndrome child can be treated like other children. I try my best to create awareness about children with Down syndrome so they can have a better future in our society, especially in the African community.

Both participants made significant strides in supporting their children with DS. P4 successfully accessed the necessary resources and support for her son, ensuring that he received the appropriate care and opportunities for development. On the other hand, P5 took a proactive approach by creating a support group for mothers, which not only aids her son but also fosters a sense of community and shared experience among other mothers facing similar challenges.

Research Question 2 (RQ2)

RQ2: How do mothers raising children with Down syndrome describe their experiences with accessing and utilizing support services within the social systems in Western Nigeria? This research question involves how mothers described their experiences of accessing and utilizing support services within the social systems. Two themes surfaced from the dataset in relation to this research question: (a) the absence of community and government support, and (b) family support and resilience.

Theme 3: Absence of Community and Government Support

The third theme identified in the dataset under RQ2 concerns mothers' experiences with the absence of community and government support. Tables 7 and 8 illustrate the mothers who contributed to this theme, along with the corresponding codes.

Table 7

Theme 3: Participant Involvement

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	Total
Theme 3: Absence of Community and Government Support	X	X	X		X	X	X	X	X	X	9

Table 8

Theme 3: Identified Codes

	Codes
Theme 3: Absence of Community and Government Support	Lack of structure related to care for DS children Lack of government and NGO support Perceived lack of interest in helping Lack of community support Lack of volunteerism Government neglect

Nine participants addressed this theme. Participant 4 did not discuss it, as she did not mention receiving support from the community or government/NGO entities. The codes identified illustrate how mothers described their experiences with a lack of support from the community and these organizations. P1 recounted:

> There's no help anywhere. Nobody is ready to help. Nobody is really interested in helping everybody with his or her problem. So, we are left alone to face it. It's hard to get help. From whom? Nobody to help. And nobody is ready to help. Nobody, nobody is ready to volunteer to help. I don't know; the government is not ready. They are not ready to help. There is no NGO.

P1 expressed visible unhappiness and frustration, often frowning and sighing heavily; she continued:

> I don't know of any to help, and there are some places that are private. They are private individuals. The government is not disposed at all. There is no plan, nothing for people in her category. There is no government. The government is not making any arrangements to help people in that category to assist or whatever. No, no help. Nothing from any angle.

P2 cried during the interview when discussing the challenges faced in accessing support services within the social systems in Western Nigeria for her daughter with DS. P2 disclosed:

> So, the schooling is very hard now to get the one they can fit in. And it is not so encouraging because what we are experiencing is just wasting the years with them. And they are not able to give us the help we need. Both from the government and the private one, the private schools.

P3 expressed dissatisfaction with the lack of support from both the community and the government. Leaving her to navigate complex systems on her own:

> No special help from anybody to her. There's no help. There's no special help from any professional to her. There's no, you know, here, you face your own problem. So, there is no help from any other people. So, there's no special help from the community. No special.

P5 and P6 described their discontentment due to the lack of support from both the community and the government. Due to the lack of structure related to care for children with DS, the mothers highlighted the significant gaps in available resources and assistance, which have made their situation more challenging. In response, they called on the government to step up and provide more comprehensive and accessible support services within the social system in Nigeria.

> We try to find information to have anything someone can do, our government can do for our children, but it was in vain. There's no structure that says, oh, you have a Down syndrome child; you can come and register here. You get this, you get that, you know, we don't have. Like I said, to have help here in Nigeria, we do not have any structure here, and to my own knowledge, the governments are not helpful because there's nothing organized to help those children with their parents (P5).

Additionally, P5 recounted:

> Now, it's very difficult here for parents because there is no organization that is helping. My own knowledge, there is no organization that is helping. I want to beg the government in Africa, I mean Nigeria, especially in Nigeria, here. They should help us to create some structure that can help us with our children with

> Down syndrome. They should give us free medication for our children; we need this from our government. We need this organization to help us out.

“There is no any professional or anybody that I can mention now that helped us with the boy. I'm just struggling from day one” (P6).

P7 and P8 described experiencing a complete absence of support services from the community, individuals, and the government within the social system. They felt entirely isolated and abandoned, with no accessible resources or assistance to help them navigate the challenges of raising their children with DS. This absence of support has significantly exacerbated their difficulties, underscoring the urgent need for a more robust and inclusive support system.

“Very poor, no help. Not like before, these days, these things are on the high side. So nobody is getting help from anybody. Everybody is just carrying his or her own cross” (P7).

> The government, there's nothing the government can do is like is your burden. It's a bit challenging. Yes, it's a bit challenging as a parent when the government is not even ready to listen or not even being there for any help. There's no help coming from anyone from any quarter. We believe if Nigeria is just like any other country. Because over there, the government set comes in, they play a very good role in helping such children. So if such is embarked here, if we have such help from the government as well, it will go a long way. You are left on your own, except you have the support of the government, which we don't have down here. We don't have it at all (P8).

Additionally, P8 noted:

> So, the government is not doing anything. So you are left alone with your burden, with your cross. Nothing is coming from any quarter from anybody. For us to have the system down here to help the children, they see them as a waste alone, except the government comes in. I just pray that one day, we will find ourselves there as well. For the government to rise up and for the government to be there for us to support these children. They can do it, and I believe they will do it. They will also get there, and they will.

P9 and P10 described their belief that the community, government, and others cannot help because they think the children are not worth the effort. This perception has led to a sense of hopelessness and neglect.

> There is no help either from the government or from the community. I worked in an orphanage home before, and one of the donors who came one day was asking me why am I working in this place. So, I told him that, like, it is nothing .... they are people like us, they are human beings like us still, she was like, don't you think if you should get pregnant? This thing that I'm saying is from a long time ago that if you get pregnant, you can have someone like one of them. And her response to me that day was that she did not know that the place was a home for people living with disability, that she would not have come (P9).

Additionally, P9 continued:

> So such people like that, that have that intention if she should go out, she might confuse people that want to come and help that they should not come. So, not

> everybody likes to associate with people with Down syndrome or who have disabilities (P9).

“It's not easier, it's harder. When they think they can't do anything, they are not ready to help them” (P10).

The experiences of all nine participants highlight a significant lack of support from anybody or both the government and the community. Many mothers described feeling abandoned, with insufficient resources and assistance to meet the needs of their children with DS. This pervasive lack of support caused frustration and hopelessness among these mothers. The situation highlights an urgent need for improved, accessible, and comprehensive support systems that can adequately address the challenges faced by these mothers.

Theme 4: Family Support and Resilience

The dataset revealed a fourth theme detailing how mothers described their experiences with family support and resilience (refer to Table 9).

Table 9

Theme 4: Participant Involvement

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	Total
Theme 3: Family Support and Resilience	X	X	X	X	X	X	X	X	X	X	10

Table 10

Theme 4: Identified Codes

	Codes
Theme 4: Family Support and Resilience	Family resilience Receiving family support

All the 10 participants addressed this theme. The codes identified illustrate how mothers described their experiences with family support and resilience. The mothers emphasized the crucial roles of family support and resilience. Their accounts illustrate how strong family ties and the ability to overcome adversity are crucial to their well-being and ability to manage life's challenges. For instance, P1 mentioned: “When people are not ready to relate, at least the immediate family, we are there for her.” P2 exhibited resilience by engaging in self-teaching strategies for her daughter with DS. The mother’s approach highlights her adaptability and determination to ensure her child receives personalized care and education despite challenges. P2 described:

> So, where she is now, they don't even have time for her. So, the little we can do at home is I have a small board for her; I just write. Sometimes, I write it on the sheet of paper, go and repeat it, and she will. Yes, she's doing the little she can.

P3 mentioned how she, her husband, and a niece to her daughter with DS helped with caregiving, enabling her to manage both work commitments and family responsibilities effectively. P3 described:

> There's no, there's no special help, so only me, my husband, and the other siblings. I'm working, so I made her niece a priority. So, because of her condition, I don't want her to feel inferior. It's me and the father who are providing for the needs. You know, because of my experience and because I used to give her moral support, financial support, and spiritual support.

P4 highlighted that her son received family support from uncles and grandparents, as well as from the family at large, emphasizing the vital role extended family plays in their support network. P4 explained:

> Like I said, maybe because I read about it, I was always curious and the family at large. The dad has been really supportive. So I think because I think for a child with Down syndrome to go far, he needs a family that is willing to support him. So, the boy got that with us, with the dad, with the uncles, with the grandparents. And he has two younger sisters, who cater to him. Who knows that this is our brother and we have to take care of him, who are proud of him. So, I feel he got love at home, so that way, it's easy for us to navigate both. In the case of my son, he got help from home; he got love. So, I may not be able to say it has affected me negatively because I don't even give room for negativity. Nobody gives room for negativity here. Like I said, support is what made it easy…. to family support and emotional support.

P5 detailed the significant sacrifices made for her son, supported by strong family involvement, illustrating the deep commitment and support within the family structure:

> When the doctor told me I have a Down syndrome child, this child, if he learns, it will be difficult to learn. And when he learns literally, he will forget it quickly. I came back to my house; I looked at my son. I said no matter what the doctor said, God created you, and you will be blessed in anything you want to do. You can study; I promise you you will study and you will not forget. Like I told you, my son is going to a normal school with normal children. The boys scored 83.73% in this term. We have sacrificed a lot to provide for the needs of the child, and what we can do to help him grow as a child with Down syndrome, we are trying our best.

P6 voiced concerns about the lack of proper educational opportunities for their son with DS, highlighting her resilience as she managed a makeshift parlor school set up to ensure continued learning for her son. P6 explained:

“I need total assistance, especially with the boy's education, because he does not have the right education at all; I'm just managing him in a parlor school because many schools in this place used to reject them.”

P7 utilizes online resources as self-initiated teaching as resilience for her daughter with DS. She recounted:

> But I only take care of her. By teaching her with the cartoons that I downloaded and also helping her on my own part, say Mama. Say, Mommy, say Daddy, apart from that. No really help from there because to get to that special school. It is money, It's a big challenge, a big challenge to me.

P8 described going the extra mile in caring for her daughter with DS, demonstrating resilience and dedication in meeting the unique needs of her daughter. P8 described:

> Like I said, it still bounced back to the same thing I keep saying: You do it on your own. Nothing, nothing comes from anywhere. It's your cross. You do it on your own. It's the way you want it. You do it. The little you have, you put it just to get at least to give a good life. So everything goes down to you. You decide on what to do. Whatever, whatever, it comes from you, not from any quarter. It's not so easy unless you go the extra mile. It costs you so much to go the extra mile.

P9 noted that taking care of their children with DS requires resilience, time, and significant expenses, emphasizing the dedication needed to manage these challenges. P9 stated:

"No, it has not been easy, ma'am like; one, it will require time and expenses in taking care of them is even much, Is even much more than people who have no disability."

P10 explained how their resilience led them to invest significantly in their daughter's well-being. P10 recounted:

> In Ondo State, especially Owo, there is no awareness for children with Down syndrome. Let me say that it has been very hard to get help because there is no one to ask for help. What people in this part of the state believe is that the child cannot be somebody, so why spend so much on her? But as a mother, I will never abandon my child. I will do whatever in my power to give her what she needs.

The participants highlight the critical role of family support and resilience in managing the challenges of raising a child with DS. Each mother's descriptions reveal a deep commitment to overcoming obstacles through personal sacrifice, time, and collaborative care, highlighting the essential nature of these support systems in enhancing the well-being and development of their children with DS.

Research Question 3 (RQ3)

RQ3: How do mothers raising children with Down syndrome describe their experiences with accessing and utilizing support service resources in Western Nigeria? This research question involves how mothers described their experiences accessing and utilizing support service resources. Three themes emerged from the dataset in relation to this research question: (a) successful access to educational resources, (b) inadequate educational services, and (c) financial strain in accessing support services.

Theme 5: Successful Access to Educational Resources

The fifth theme identified in the dataset under RQ3 concerns mothers' experience with access to educational resources. Tables 11 and 12 illustrate one participant who mentioned this theme, along with the corresponding code.

Table 11

Theme 5: Participant Involvement

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	Total
Theme 5: Successful Access to Educational Resources				X							1

Table 12

Theme 5: Identified Codes

	Codes
Theme 5: Successful Access to Educational Resources	Access to educational resources

Theme 5: Successful Access to Educational Resources

The fifth theme identified in the dataset under RQ3 concerns mothers' experience with access to educational resources. Tables 11 and 12 illustrate one participant who mentioned this theme, along with the corresponding code.

Only participant 4 addressed this theme. While the majority of the mothers reported a lack of adequate educational services, a unique account from one participant (P4) highlighted access to such resources; however, she encountered financial challenges at some point, adding a layer of complexity to the accessibility issue. P4 described:

> I found a home, a very good place for him because they have a doctor's service. Doctors are always there. There is a clinic in the school where they get to see doctors who speak with them, who engage them; he has really improved. They see therapists who diagnose them and see what they can do with their hands or who help them with their fine motor skills. There are caregivers in the home who make them feel like they belong to the society. There is no any form of ostracization. They are not ostracized. It's like a home, and this is possible because they have all the professionals they need. The occupational therapist, the

> psychologists, the doctors, and the ENT doctors are there. I remember a time that we wanted this particular instructional material, and the dad could not get it, and the owner of the home said Ohh, I have someone that makes them; we can get it for you because she believes that there is ability in disability. So, we've really gotten support.

Additional P4 explained:

> But financially, it was not really smooth because we had to pay for a lot of stuff. Then we moved to this other school where we could not really pay the fee again. We could not pay the fee, and we could not pay the boarding fee, and it was not possible for him to be a day student. We had to move to another nearby school, but because the school is not a school for Down syndrome, we had to withdraw him.

The singular experience of P4 with access to educational materials and support services for her son with DS described an exception in a setting where such resources are generally scarce or inaccessible based on other mothers' experiences of inadequate educational resources and support services.

Theme 6: Inadequate Educational Services

The sixth theme recognized in the dataset was how mothers experience inadequate educational services for their children with DS. Tables 13 and 14 show the participants who mentioned this theme with the corresponding codes.

Table 13

Theme 6: Participant Involvement

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	Total
Theme 6: Inadequate Educational Services	X	X	X		X	X	X	X	X	X	9

Table 14

Theme 6: Identified Codes

	Codes
Theme 6: Inadequate Educational Services	Inadequate educational services Lack of therapy services Supplementary support services

Nine participants addressed this particular theme. P4 did not indicate this theme, as she has access to educational resources for her son with DS. However, all nine participants agreed that there were not adequate educational resources and a lack of therapy. They used supplementary services for their children with DS. This common problem described the need for better support and more resources to help these mothers. For instance, P1 described the lack of school with therapy services for her daughter:

> It has really affected her because now we can't put her in any of these private—schools with therapy to assist. There was a time when she was at home for a year. Here, we can't put her anywhere. Then, she has not been able to acquire the skill

> she's supposed to acquire, the therapy she ought to have been given. She couldn't get it. She couldn't access it.

P2 highlighted a significant challenge, which is the complete lack of special school access for her daughter with DS. She described:

> I think that on your side, they will have a special school for special people like them. But here, we were unable to get it. And joining others in the school. There are no improvements in the academic. Till now, there has been no school for them. So, they just mixed with others. And it is not helping them at all. Let me say, let me even put it in the whole West because, see, now we have been trying to get her to the school where she can fit in. Till now, we have been unable to get it.

Additionally, P2 recounted:

> That is why I started taking her to my own school. Even though it was not allowed, but I had to beg because of her condition. Then, because of her academic performance after teaching her for some time, since she cannot cope, they leave her on her own while they face others. So that's some of the challenges.

P3 emphasized a total lack of assistance and resources for her daughter with DS: “There's none, you know, here, you face your own problem. So, there is no help from any people or school.”

P5, when faced with a lack of educational services, supplemented her son’s learning by hiring a therapist and an after-school teacher. P5 noted:

> We sacrifice all our comfort to make sure this child receives education and medication. No. Right now, my son is in a normal school, and I will get a therapist for him. After the therapist, we have an after-school teacher who is helping him, which is what we can provide for our son now. We couldn’t put him in a specialized school. Now we get help from a therapist, and well, he is going to a normal school, and the therapist is giving us four days per week to help the child to come out from some level of Down syndrome condition.

P6 described the lack of specialized schools and therapy services available for her son with DS. P6 explained:

> I’m facing many problems, especially educationally because in Nigeria, they don't like taking these students in a normal school. It's not so easy like that, and it's not easy to find things to help the boy because the boy even needs special educational help because he's not coping; education is not coping at all. I'm trying my best a little bit. So I take him to a small school. Not their own school, our own normal school so that he will not be staying alone, he will join them, because I'm also teaching in one small nursery and primary school.

Additionally, P6 continued:

> I need total assistance, especially with the boy's education, because he does not have the right education at all. I'm just managing him in a parlor school because many schools in this place used to reject them. They will tell them that they cannot cope with the children and therapists, especially speech therapy.

P7 noted the critical need for a special school for her daughter with DS, but unfortunately, she lacks access to such educational services. P7 described:

> I believe a good school will change her. A good school, a special school that is meant for them, would change her so that they can take care of her and teach her how to open your mouth. Ah, A Ah, just the way I've been using my cartoon, I mean, the cartoons on my phone for her; it's really really helping her.

P8 described a lack of educational resources, relying solely on trained assistance to support her daughter with DS for basic needs. She recounted:

"Taking her to where there are trained hands for such ease. So, that is what we tried to do for her."

P9 described the challenges over her children's academics, noting the need for additional support as their child attends a regular school instead of a specialized one for DS. P9 noted:

> Academically, there is not much help, and the father of the children we are talking about is late. So, academically, there is no help for him to go to a special school where he can be monitored and supervised academically, but he is in a normal school. Here, the normal school setting is different from the special school. So, I think, for now he needs help academically.

Finally, P10 described the concern over the absence of special education schools for her daughter in her area, highlighting a significant gap in local educational resources. P10 recounted:

> You know, in Ondo state, there's no adequate care for them. Not adequate at all. It's not good at all. Because I enrolled her in a school, in a special school at Akure, and they rejected her. They asked me to take her to “ile-Oluji”. So they don’t have adequate care for them.

All nine participants consistently highlight a profound shortfall in educational resources and support for their children with DS. Despite varying mothers' responses, the common thread is a critical need for more specialized schools, tailored educational services, and comprehensive therapeutic support.

Theme 7: Financial Strain in Accessing Support Services

The seventh theme recognized in the dataset was how mothers described financial challenges as a barrier to accessing their children's needs with DS. Tables 15 and 16 present the participants who cited this theme with the corresponding codes.

Table 15

Theme 7: Participant Involvement

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	Total
Theme 7: Financial Strain in Accessing Support Services	X	X	X	X	X	X	X	X	X	X	10

Table 16

Theme 7: Identified Codes

	Codes
Theme 7: Financial Strain in Accessing Support Services	Lack of affordability of support service center Financial Strain in Accessing Child's Needs Paying out of pocket for therapy

All the participants in the study contributed to this theme. The mothers agreed to financial constraints as a barrier to accessing support services for their children with DS. P1 described significant financial strain in accessing and utilizing support services for her daughter with DS. The services available were often far from her state/city and excessively expensive, adding to the difficulties. P1 noted:

> They are just too expensive. Too expensive. We were told there was one in Lagos, and we were told they have one in Abuja, but it is very expensive; it is a special school where she will be handled according to her peculiarity. It has not been easy. There is no help; there has not been any financial support anywhere. It has not been easy getting money. It has not been easy to get money at all. We do borrow at times to put us somewhere and begin to search for money here and there—nobody to help. No money, and at times, even when we go to our place of work, we lock her inside. Lock the door, and she will be alone at home. So it has not been easy at all.

P2 mentioned that financial constraints prevented her from accessing services for her daughter with DS, available only at a distant location. P2 described:

> We are managing because they need specialties, unlike the others. So, we keep on managing what we get to take care of her. I think if I have enough money to take care of her. We heard about a school at Port Harcourt. And when you look at our region, yes, Western, you know, if you are very conversant with us here, Ondo state to Port Harcourt is very far. And they said that is where we can still get school for her. And because of this financial constraint, we are unable to get her to that place. So that's why we are limited to what we have in our environment here.

P3 described how her limited earnings are primarily spent on caring for her daughter with DS; she emphasized the financial strain faced by the family. P3 recounted:

“There's no special help from any professional to her; I don't think because of the little I earn, I spend it on my children, so I used to attend to their needs.”

P4 recounted that due to financial constraints, she was unable to afford school fees for her son with DS, resulting in the child's withdrawal from school. She revealed:

> But financially, it was not really…It was not really smooth because we had to pay for a lot of stuff, and then we moved to this other school where we could not really pay the fees again. We could not pay the fee, and we could not pay the boarding fee. It was not possible for him to be a day student, so we had to move to another nearby school. But because the school is not a school for Down

> syndrome, it's not a school for special kids with special needs. We have to withdraw him.

P5 initially hoped to enroll her son with DS in a specialized school, but the cost of #250,000, #380,00 per term was prohibitive, preventing her from proceeding. She recounted:

> In the beginning, I wanted the child to go to a specialized school. We tried to visit some, and because of the money you pay per term, the lower price per term was #250,000 per term. For a child now, the best school that they can go to is #380,000 per term for a child. So, as a parent, if you don’t have this type of money, your child can’t go to a specialized school here in Nigeria.

P6 expressed that once she is financially stable, she plans to seek better educational and health services for her son with DS, who has faced inadequate care since he was two years old. She stated:

> If I get money or things the child needs, in that case, I will look for the perfect space for the child, especially education and health, because this time around, he is not visiting any hospital for his challenged health. I abandoned taking care of his health since he was two years old because of financial problems.

P7 reported that while a special school is available, its high costs make it inaccessible for her. She explained:

> According to a friend of mine who said there's a school, there's a special school for it, and according to her, she said the bills there are much so since we don't have something like that, we did not enroll her for that kind of school. No really

> help from there because to get to that special school. It is money, It's a big challenge, a big challenge to me.

P8 noted the high costs associated with private sector services for children with DS; she emphasized that expenses can reach thousands of naira. She revealed:

> So it's the little you have, and down here, you keep struggling, doing things. And the private sector is expensive. There are some, but they are very few very expensive. So it's only for the rich because it's just so high, so high when we talk of thousands of naira and less than three months, so when you can't get such money to put your child into such a place. So it is just challenging as parents to have those kinds of children around. It's not so easy unless you go the extra mile. It costs you so much to go the extra mile. It costs you so much to go the extra mile. Like I said, we have the private sectors that are into it, though there are few; if you have the money, you can go for it. So it costs you an extra mile. Everything boils down to its financial aspects. The major thing is the financial aspect, which makes it so hard.

Additionally, P8 continued:

> Some institutions are meant to… they have trained hands to take care of these children, they understand them even far better than we parents that have those kinds of children because they are well trained. They know the stages; they know what they need at every point in time. So, like I said, taking them to such places when you don't have the financial support, it makes it a bit hard. So all of these things boil down to the financial constraints from parents giving such children a

> beautiful life and making them have a fulfilled life as well, which is the financial aspect of it. The private sector that tried to come up with such is very expensive.

P9 described how financial limitations adversely affect her children's educational and medical needs. She highlighted the significant impact on overall care. She described:

> Financially, we don’t really get financial support like that. It affects them medically and academically. Like I said earlier, there are some places that they need to go for therapy and consultation. I mean, but since there has not been money, we are not financially stable, and they can't take them. For their educational stuff, they are still in normal school settings, and it's not helping them at all. It's not helping them because the teachers that are there are not really good at taking care of persons with disabilities. They are just trying their best there.

Finally, P10 highlighted financial constraints as a significant barrier, preventing her from taking her daughter with DS to the hospital for needed care. P2 described:

> I can't afford it. I can’t afford the money. So, the difficulty there is that anytime I take her to the hospital, I have to pay; we used to pay at FMC, so at times, there will not be money, and so I will not go. I can't lie; it's not easy, and it's the money for therapy. The economy is not friendly. So, there is not enough money to take her to the hospital. I didn't even seek any help before for her and they are not ready to help her. So the little I can do, I'm doing it. So, nobody is planning to even help.

All 10 participants described that financial strain significantly hinders their ability to access necessary educational and healthcare services for their children with DS. These economic barriers prevented all mothers from affording specialized schools and medical treatments that are often essential for their children's development and well-being. The lack of affordable options leaves all participants struggling to provide the support their children need to thrive.

Research Question 4 (RQ4)

RQ4: How do mothers raising children with Down syndrome describe their experiences with accessing and utilizing support services within the customs and cultural beliefs in Western Nigeria? This research question involves the mothers' experiences with accessing and utilizing support services with the customs and cultural beliefs.

Theme 8: Stigmatization and Discrimination Associated with Down Syndrome

Stigmatization and discrimination associated with DS emerged as the eighth significant theme, revealing the societal challenges faced by mothers of children with DS. Tables 17 and 18 present the participants who mentioned this theme with the corresponding codes.

Table 17

Theme 8: Participant Involvement

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	Total
Theme 8: Stigmatization and Discrimination Associated with Down Syndrome	X	X	X	X	X	X	X	X	X	X	9

Table 18

Theme 8: Identified Codes

	Codes
Theme 8: Stigmatization and Discrimination Associated with Down Syndrome	Impact of stigma on accessing help Social perception and discrimination Perception of abnormality Social rejection Non-adherence to people's belief

All the mothers in the study consistently described experiences of exclusion and judgment, which compounded their everyday struggles. The mothers noted that despite experiencing exclusion and judgment, they did not adhere to prevailing societal beliefs that marginalize their children. However, the social rejection hindered the mothers from accessing support services for their children with DS. This theme emphasizes the need for greater societal awareness and inclusion for individuals with DS and their families. P1 stated:

> At times, people are not ready to play. They are not ready to accept her. And at times, she's stigmatized. You know people are not ready to render any help. Always been, we and her all the time. And they believe she's not a normal person. Because she's different, the way she behaves is different from others. So, people don't want to associate with her. You know….No, people think they are not normal people. They have difficulty, and they have deficiencies. So, they are not ready to associate with them at all. It is harder because people are not ready to

> associate and help. Whatever people may think, whatever their beliefs might be. I'm not bothered about that. Do you get it now? It's my duty, the little I'm able to do, it is my duty to take care of her.

P1 continued to talk about her non-adherence to people's beliefs:

> So, whatever anybody might believe doesn't bother me. It's my duty to provide her with the little resources I have and to take care of her, which we have been doing. There is nothing they do or believe that has helped her. Because once they see them, they believe they are not normal people. They are not the type of people they should associate with. So there is nothing they can do. At all, I don't follow what people believe; my duty is to take care of her. We don't follow what people believe because people believe they are not normal; they stigmatize people in her category, and they are not ready to relate. They are not ready to take care of them. So, with the meager resources I have, I try as much as possible to meet and provide for her.

P2 described how people often look down on her daughter with DS, with some even believing it is a result of a spiritual attack. Still, she actively chooses not to adhere to the negative societal attitudes. She responded:

> You know, looking at her because their physical appearance shows who they are immediately you see them. Some look down on them; they believe they are not normal and that they cannot cope. So they look down totally on them. Some believe that it is a spiritual attack. So, I don't follow what people are saying because some believe that they cannot do anything when we talk about academic

> life, which I don't believe because I believe one day she will be able to cope. I don't believe all people say. So, I can't follow it. I don't believe it.

P3 described how her daughter with DS was labeled as an “Ebora” in the Yoruba language by society, which means spirit, leading to widespread non-acceptance.

> Well, it was when the child was very small. You know, sometimes when I put the child in the creche, some people don't want to touch her, so maybe they were thinking, she is a strange person. So sometimes, if I put her in the creche, they will not care. They will not give her food until when I come back to come and feed the baby. So, such are the things that I faced when she was very small. And you know, sometimes because of their belief that maybe she is not looking like a normal baby when she was very small, but you know, people may not want to help you to carry the baby, so you may be the one to carry the baby alone. So, people don't want to, and then you know when somebody is not welcomed by another person, it affects the social life of an individual.

P3 continued:

> You know, in the Owo area, when she was very small, they called her “Ebora," which is what they call “something strange.” Because they think that she is not normal, you know, like other mothers, they may lock the child inside. They will not want to associate with her. They will think she is not a normal human being. And so because of that, some people will lock such a child inside, so they will not want to help such a child because they believe that they cannot associate with society, so society is not welcoming such a child.

P4 described how her son with DS was derogatorily called an imbecile, evil, or monkey, "ogbanje," which means a spirit by people. P4 recounted:

> So I think it's hard because there are times when people are, why is he looking like this? Ohh this one is an imbecile. People would refer to you, Oh, that woman that has an imbecile child. But I think it is because they know that we do not refer to our own child as an imbecile or handicapped. We are able to maneuver. Yes, the societal beliefs. People think Down syndrome children are bad luck, children. People think there's a particular thing that the mother must have eaten for you to have this "ogbanje" child. I mean, this devilish or evil child.

Additionally, P4 noted:

> People who are even learned think that the syndrome is something that they attack you with. It's spiritual, and you must be God's strongest soldier. For you to have been attacked with this because this is purely an attack, this is an evil child. So they see Down syndrome as something evil, as an attack, as a curse. That is what 90% of people think. I have had someone call a Down syndrome a monkey. Like, oh, this person is a monkey. Like, it's so rash, it's so harsh. So that is what people believe about Down syndrome in Nigeria.

P5 shared that people view children with DS as abnormal, referring to them as snakes, imbeciles, vegetables, good-for-nothing, and spirits. P5 described:

> The community here, Like I said, a Down syndrome child is not a child that is easily accepted by the society, by the community where you're living. Now, the society here is not helpful. You know the African society. We have a type of

> mentality and that comes from our four ancestors is not from today; a child that is not born with normal eyes, a normal mouth where it is supposed to be, hands, legs, the child is not a normal human being. It is not today; this is from our culture. How are people looking at you in this society? Sometimes, parents just go and kill their children because of what society is thinking about them and the African culture. Some people call them imbeciles, a child just like a vegetable that can't move, can't do anything. A child like this, if someone is thinking about your child like this. What can you do for your child? Nothing. Someone who thinks your child is a snake, a spirit in African culture.

Additionally, P5 continued:

> Someone called my child a snake. Saying in their own village, a child with Down syndrome is a snake, a spirit. People think those children are not human beings. People think those children are just there to suffer their parents. This mentality is the African mentality generally. So it's difficult for someone to believe a Down syndrome child can go to school and learn. Because they think they're just like vegetables, good for nothing. No, no matter what someone is saying, it's something that will not even touch me. I do not care about who thinks what about my son. What I have to think is to focus on what I can do to make the child's future to be better.

P6 and P7 noted that people often look down on their children with DS, pushing them away at social events and that societal perceptions of abnormality prevent them from taking their children to public places.

> People believe in this, our Nigerian side, that these children, if they help them, they do not believe something will come through them. They used to look down on them. So that is the reason why they don't have time to help children like this. So they used to look down on them, that they are not behaving like normal other children. Some people will be saying that when you were pregnant, you didn't go for prayer. Where do you see this type of child? So they used to call them many names (P6).

Additional P6 recounted:

> So, for some people, the way they talk, you will not want to be communicating with them because they look down on them in many ways. So that one is affecting their education and many things in their life. So even at some party, the party that we take him to, some people will be pushing him, leave this place, leave this place. So I need to take my things and hold him, carry him along with me. It is harder in our society because of some people's way of looking down on them (P6).
>
> So, their belief is those kinds of people are different from normal people. Though I don't mingle with friends, sometimes I do shy away from bringing my daughter to them because I don't want them to be talking too much. So, not all the time I carry her to places, but I don't want too much talk. I'm this kind of person, I don't like people talking too much because it will make me cry at the end of the day. So I'm so emotional, so I don't just mingle with them to be talking too much. That is why I don't carry my baby anyway because they will talk. It changed me from

> getting help for her because of the way they are talking and their mindsets towards Down syndrome and normal kids. So that is why I don't associate with them (P7).

P8 highlighted a lack of assistance from people; she attributed it to a general lack of acceptance. P8 disclosed:

> Ohh, people sometimes seeing them, they look down on them. When they look down on those children, definitely then, seeking help for them may be difficult because they'll see it as a waste of time, so even if there's anything I can do, can anything still come out of this kind of a child? So that is the belief. So they see it as a waste. So, instead of wasting money, let me go ahead and take care of others. You understand what I'm trying to say. So I think that is it. They see it as a waste of time helping such children. Once they see any child, they see the child is being deformed and abnormal. She's my daughter, so I don't need to listen to what people are saying.

P9 explained that people avoid her children with DS due to false beliefs that it is transmittable. Despite these stigmatizing attitudes, she said she disregards these negative perceptions and remains committed to her children. P9 described:

> So, not everybody likes to associate with people with Down syndrome or who have disabilities. They believe that if they relate with them, or even if they touch them or see them at all, it can make them have somebody like them. That is one of their beliefs. Some believe that it is contaminated, like it can be transferred if

> associated with them. We follow the one that is positive. The positive comments are the ones that we give listening ears to, and the negative comments we ignore.

Finally, P10 noted that prevailing societal beliefs question the survival and worth of her daughter with DS. P10 mentioned:

> This is a local area, so they didn't believe in them. They didn't think they could survive. They think she can't do anything. So she can't talk very well. So, some people think she can't even survive. When they think she can't survive, so some people, even though they want to help, will not help again. I do not follow what people believe. I'm just doing the little I can do for her.

All the participants in this study revealed a pervasive stigma and discrimination against children with DS, evidenced by societal misconceptions of contagion and skepticism regarding the children's potential. All participants consistently encountered negative attitudes and a lack of support.

Theme 9: Experiencing Resilience through Religion/Spirituality

Experiencing resilience through religion/spirituality emerged as the ninth significant theme under RQ4, revealing how mothers experience resilience through religion/spirituality as a result of a lack of support services for children with DS (refer to Table 19).

Table 19

Theme 9: Participant Involvement

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	Total
Theme 9: Experiencing Resilience through Religion/Spirituality	X	X	X		X	X	X				6

Table 20

Theme 9: Identified Codes

	Codes
Theme 9: Experiencing Resilience through Religion/Spirituality	Individual resilience Reliance on faith Relying on God

Six out of 10 participants discussed this theme, with the exception of four participants, because they did not indicate that they experience resilience through religion or spirituality raising their children with DS. The identified codes highlighted how the mothers experience resilience through religion/spirituality as a result of a lack of support services for children with DS. For instance, P1 described:

“There is no help anyway. It is only God. God has been helping me. Yes, it is God that has been helping us; the little we were able to do, it is God that has been helping us.”

P2 noted she experienced resilience through religion/spirituality and highlighted that the only assistance she received to support her daughter was by His Grace. She explained:

> Well, till now, there has been no help except the one I got from Grace, just to keep on taking good care of her since I discovered it. There is no help except you encourage yourself. I only ask for that Grace from God to help me.

P3 described finding resilience through faith, viewing her daughter with DS as a divine gift, which has shaped her acceptance and commitment. P3 recounted:

> And you know, with the condition, you, as a mother, will not feel happy, but there's nothing we can do; I mean, you cannot help yourself with it. So, it is God's gift and what God has given to you; you have to abide by it. So, it is you that will make yourself happy, even though people are not making you happy.

P5 found resilience upon her son's DS diagnosis, empowered by her conviction that God created him purposefully. P5 described:

> I was shocked when the doctor told me I have a Down syndrome child, this child; if he learns, it will be difficult to learn. And when he learns, literally, he will forget it quickly. I come back to my house. I look at my son. I said no matter what the doctor said, God creates you, and you will be blessed in anything you want to do. This study you can study; I promise you, you will study, and you will not forget.

P6 described her resilience as rooted in a strong belief that God will aid her son with DS by sending help in the future:

> But now, I have not met any professor or anybody who stands to help this boy; it is only God. I believe that God will do it because they have a future. So we cannot lose hope in them. I believe that one day, God will make this boy bring joy to my

> heart because it's not easy to take care of him. I have suffered enough, but it is well. I will follow God's Will. And I will be trying for the boy. I know that God will send a helper that will help me because this boy, I know that God has a purpose for his life, so I will not relent on the boy till God sends a helper to help me out. If I look at the boy sometimes. I used to say that how can I cope? How can I cope with this boy? But, I'll just believe that God will make a way where there is no way one day.

Finally, P7 found resilience in a strong faith that God will take care of all aspects concerning her Daughter with DS:

> Sometimes, I'll just say God has an overall for everything. I know that God's time is the best, and I know that God will perfect everything that concerns her. I just believe in God. But there is nothing impossible that God cannot do. According to Pastor Jerry, he said, for what God cannot do does not exist.

The six participants demonstrated resilience in the face of challenges associated with raising their children with DS, strongly supported by their spirituality and religious faith. This faith instills a hopeful perspective, empowering them with the belief that divine support in the lack of access to support services will guide and improve their children's lives.

Theme 10: Parental Responsibility to Care

Parental responsibility to care emerged as the tenth and last significant theme under RQ4, revealing how taking care of their children with DS is their responsibility (refer to Table 21).

Table 21

Theme 10: Participant Involvement

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	Total
Theme 10: Parental Responsibility to Care	X	X	X	X	X	X	X	X	X	X	10

Table 22

Theme 10: Identified Codes

	Codes
Theme 10: Parental Responsibility to Care	Responsibility to care

All 10 participants discussed this theme. The identified codes highlighted how it is the mothers' responsibility to care for their children with DS. For instance, P1 described:

> I'm working. I have to work. I'm a public servant. Although our salaries are not regular, we are not paid as when due. But the little resource we have, we provide for her. So, with the meager resources I have, I try as much as possible to meet and provide for her. No, she’s my child. It's my responsibility to take care of her. The little I'm able to do. Whatever she needs. I try as much as possible to provide for her, and if I don’t have any, I leave it. Or, at times, I find an alternative.

P2 described her parental responsibility for her daughter with DS, which she often feels left to manage on her own without external support. This role encompasses educating her daughter herself due to a perceived lack of help. She noted:

> I'm a teacher, so the little I can do with her at home, I do it. Then, if you look at their development, it's not like others. When she was supposed to sit and crawl, she was unable to do it. Which has to take us some months, extra months, so it's on you. They leave you on your own.

P3 described that she primarily cares for her daughter with DS. She recounted:

> Because, you know, I'm a working mother. And so I used to get a salary. And so whatever she need, I used to provide for her. If I think it is necessary and is good for her. I used to provide. Generally, I will depend on my salary. So is the salary that we are spending. So, the father is a retired teacher.

P4 exemplifies her motherly responsibility by accompanying her son with DS practically everywhere, ensuring her son is included in all aspects of daily life and receives constant support. P4 revealed:

"Like me, I attend events. I go everywhere; I go practically everywhere with him."

P5 recounted making significant lifestyle sacrifices, curtailing all expensive activities to dedicate resources and attention to care for her son with DS. P5 described:

> Ohh, me, I love fashion design. I love very expensive things; I love looking very good; I shut down those expenses because I need the money to train my child.

P6 described her struggle as a mother in taking on the full responsibility of caring for her son with DS. P6 disclosed:

> It is not easy in Nigeria to look for help. I am struggling with anything that I can use to take care of him. I'm just managing him in a parlor school because many schools in this place used to reject them.

P7 mentioned taking responsibility by downloading educational cartoons on her phone to assist her daughter with DS in developing speech skills. She explained:

> What I do on my own is download cartoons for her to follow up. So from there, if they said head, she would follow up. That's what I do, but help, no help from anybody. I've been using my cartoon, I mean, the cartoons on my phone for her, It's really really helping her.

P8 emphasized that taking care of her daughter with DS is her responsibility. P8 described:

> You tend to do it yourself. Like I said, it still bounced back to the same thing I keep saying: You do it on your own. Nothing, nothing comes from anywhere. It's your cross. You do it on your own. The little you have, you put it just to at least give a good life. I give her the attention she needs at every point in time. I make her to be exposed to some things, to a lot of things. I go the extra mile to do that for her. They see it as your burden in Nigeria, no support anywhere. It's a bit challenging.

P9 noted receiving no additional help, as the father of her children with DS has passed away, leaving her solely responsible for their care. P9 noted:

“Academically, there is not much help, and the father of the children we are talking about is late.”

Finally, P10 explained that as a mother, she independently manages all the daily care needs of her daughter with DS. P10 described:

> I'm just doing my own as a mother. The little I can do, I just do what I can do to help her. And I make sure she eats food. And I take care of her, wash her clothes. Anything I can do for her as a mother, I'm doing it for her.

The mothers described a strong personal commitment to the caregiving responsibilities for their children with DS. They highlighted their active roles in managing daily needs and educational support as a fundamental part of their lives.

Discrepant Cases

Discrepant cases were scrutinized during coding, considering contextual factors and potential contributing elements to understand variations in the mothers' experiences. A mother's experience differed notably from the common themes identified. This case involves P4, who, despite accessing and utilizing support services for her son with DS, faced substantial financial challenges. Notably, the father of the child resides in the USA, which played a unique role in her experience. The family managed to access a range of support services, which is unusual compared to the other participants: doctor's care, specialized educational materials, and therapeutic interventions, including physical, occupational, and speech therapy, at a facility they found in Nigeria.

A distinctive part of this case is the involvement of the father, who resides in the USA. His presence abroad influenced the family's ability to secure resources and support for their son, differentiating their experience from that of other participants who lacked such connections. Most participants reported a lack of support services and financial strain. P4, while also facing financial challenges, had better access to support services for her son with DS. This discrepant case highlights the complexities and varied experiences of mothers raising children with DS in Western Nigeria.

Summary

It was not known about the lived experiences of how mothers access and utilize support services for their children with DS. Therefore, the purpose of this phenomenological qualitative study was to understand the accessibility and utilization of support services through the lived experiences of Western Nigerian mothers raising children with DS. I gathered data by conducting virtual face-to-face semi-structured interviews via Zoom and observation notes of behaviors, gestures, and mannerisms during the interviews.

Within this chapter, I presented the findings of the research investigation, which examined the lived experiences of 10 mothers who are raising children with DS in Western Nigeria. This study and its subsequent analysis were guided by four research questions. Thematic analysis was applied to identify patterns and themes within the interview transcripts, employing Moustakas's (1994) eight-step-by-step descriptive phenomenological approach.

Ten themes emerged: (a) challenges in accessing and utilizing support services, (b) creation and utilization of support networks, (c) absence of community and government support, (d) family support and resilience, (e) financial strain in accessing support services, (f) inadequate educational services, (g) successful access to educational resources, (h) stigmatization and discrimination associated with DS, (i) experiencing resilience through religion/spirituality, and (j) parental responsibility to care. Every theme illuminated both the individual and shared core of the explored experiences of mothers raising children with DS in Western Nigeria. Chapter 5 encompasses results in relation to an existing body of literature, interpretation of the findings, limitations of the study, implications for social change, and recommendations for further research.

Section 4: Application to Professional Practice and Implications for Social Change

The specific problem that I addressed in this study was that the lived experiences of how mothers access and utilize support services for their child with DS were not known. Therefore, the purpose of this qualitative phenomenological study was to understand the accessibility and utilization of support services through the lived experiences of Western Nigerian mothers raising children with DS. I collected data from 10 mothers residing in Western Nigeria who are raising children with DS. Data was gathered by virtual, face-to-face, semistructured interviews via Zoom. I created 12 open-ended questions for all participants, along with follow-up questions with observation notes of behaviors, gestures, and mannerisms during the interviews. The interview sessions lasted approximately 30-35 minutes. The problem of the study was addressed by using thematic analysis, employing Moustakas's (1994) eight-step-by-step descriptive phenomenological approach. This process was accomplished by using NVivo data analysis software and a comprehensive codebook.

My research uncovered 10 themes: (a) challenges in accessing and utilizing support services, (b) creation and utilization of support networks, (c) absence of community and government support, (d) family support and resilience, (e) financial strain in accessing support services, (f) inadequate educational services, (g) successful access to educational resources, (h) stigmatization and discrimination associated with DS, (i) experiencing resilience through religion/spirituality, and (j) parental responsibility to care.

Interpretation of the Findings

The following overarching research questions guided this study:

RQ1: What are the lived experiences of mothers accessing and utilizing supportive services while raising children with Down syndrome in Western Nigeria?

RQ2: How do mothers raising children with Down syndrome describe their experiences with accessing and utilizing support services within the social systems in Western Nigeria?

RQ3: How do mothers raising children with Down syndrome describe their experiences with accessing and utilizing support service resources in Western Nigeria?

RQ4: How do mothers raising children with Down syndrome describe their experiences with accessing and utilizing support services within the customs and cultural beliefs in Western Nigeria?

Research Question 1 (RQ1)

RQ1 involved the lived experiences of how mothers access and utilize support services for their children with DS. From this research question, the dataset revealed two main themes: (a) challenges in accessing and utilizing support services and (b) creation and utilization of support networks.

Theme 1: Challenges in Accessing and Utilizing Support Services

The majority of participants in this study reported significant challenges in accessing and utilizing support services for their children with DS. These challenges involve a range of issues, including limited availability of specialized services (specialized schools) and difficulties locating the nearest special center for their children with DS. The lack of adequate support services profoundly impacts the well-being of both the children with DS and their mothers. Nine of the 10 mothers in my study described their efforts to seek out these services as largely unsuccessful, often finding that no adequate support was available at all. This lack of support led to considerable frustration among the participants, highlighting the profound gaps in the current system and the urgent need for improved support structures to assist these mothers effectively.

These findings were consistent with the existing literature I reviewed in Section 1. Research from various studies emphasized the significant challenges faced by families raising children with DS, particularly in regions like Nigeria. Studies have shown an extensive scarcity of specialized services for children with DS in Nigeria (Daniel et al., 2021). Families often face significant challenges in accessing medical, educational, and therapeutic services that are specifically designed to meet the unique needs of their children (Mbada et al., 2021). In this current study, nine participants described they have difficulties accessing specialized schools, therapy services, and medical services for their children with DS.

Modula (2022) indentified this issue by citing that in many regions, including low- and middle-income countries, where there are limited medical, educational, and therapeutic services, families face challenges designed to meet the specific needs of their children. This lack of availability significantly impacts the well-being of both the children and their caregivers (Lee et al., 2021). Daniel et al. (2021) revealed that families often struggle to find adequate support services, which significantly impacts the overall well-being of both children and their caregivers.

Furthermore, this lack of support led to considerable frustration among the participants in my study. The frustration, sadness, and stress caused by the lack of support services are well-documented. Farkas et al. (2019) contributed to this rationale by reporting in their study that parents experienced sadness, frustration and felt unsupported due to a lack of support services for their children with DS.

The insufficient availability of specialized services for children with DS in Western Nigeria poses a significant challenge as mothers struggle to secure necessary medical, educational, and therapeutic support. This scarcity adversely affects the well-being of both the children and their mothers, leading to documented sadness, frustration, and stress. Addressing these service gaps is crucial to alleviate the substantial hardships faced by these families and improve their overall quality of life.

Theme 2: Creation and Utilization of Support Networks

The second theme revealed in the data was how the mother utilized support services that were accessible to her son with DS, enhancing the child's development, and how a support platform is aimed at helping other mothers with similar challenges. Among the 10 participants in this study, only P4, a 44-year-old mother, was able to access and use support services for her son with DS. This demonstrates a mere 5% access and utilization rate of support services among the 10 participants. This finding described the significant scarcity and accessibility issues surrounding specialized services for children with DS in Western Nigeria. It is supported by existing research indicating that families with DS children often face substantial challenges in finding adequate medical, educational, and therapeutic services tailored to their children's needs (Daniel et al., 2021; Mbada et al., 2021; Modula, 2022).

Additionally, P5, a 48-year-old mother with a DS son, took a proactive step by creating a social media platform to support other mothers in similar situations. This initiative not only highlights the critical need for community-driven support but also emphasizes the resilience and resourcefulness of the mother in seeking alternative solutions to the lack of formal services. This is consistent with previous studies, as demonstrated by Kammes et al. (2022), that mothers of children with DS use social media to share their stories and connect with other mothers of children with DS. Kammes et al. also found that social media provides mothers raising children with DS with a sense of community and support. They suggested that mothers of children with DS require additional resources and support to help them cope throughout their parenting journey (Kammes et al., 2022).

Overall, only one mother was able to access and use support services for her son with DS, highlighting a mere 5% utilization rate. This accentuates the severe scarcity of specialized services in Western Nigeria, significantly impacting the well-being of both children with DS and mothers. Also, the creation of social media platforms to support other mothers demonstrated the critical need for community-driven solutions and the resilience of the mother.

Research Question 2 (RQ2)

RQ2 was focused on how mothers described their experiences of accessing and utilizing support services within the social systems. Two themes emerged from the dataset in relation to this research question: (a) absence of community and government support and (b) family support and resilience.

Theme 3: Absence of Community and Government Support

The third theme identified in the dataset under RQ2 concerns mothers' experiences with the absence of community and government support. In this current study, nine out of 10 participants mentioned this theme. The participants described the absence of community and government support. The experiences of nine participants highlight a significant lack of support from anybody or both the government and the community. Many mothers described feeling abandoned, with insufficient resources and assistance to meet the needs of their children with DS. There is a notable deficit in community-based support systems for families. Many mothers reported feeling isolated due to the lack of structured community programs and volunteer support. The situation highlights an urgent need for improved, accessible, and comprehensive support systems that can adequately address the challenges faced by these mothers.

Though this theme was not revised in the literature review in Section 1, it came up during data collection. Several existing research studies were found that supported this finding. In their study, Sango and Deveau (2022) reported that parents of children with DS experienced negative attitudes from community members, a phenomenon that undermined their ability to access and use medical services. Additionally, 55% of the participants in the study reported having problems with healthcare systems, pointing to the lack of effective government healthcare policies to support this population (Sango & Deveau, 2022).

In yet another study, Odeh and Lach (2024) identified negative community attitudes toward raising children with DS as among the challenges that parents of these children encounter. Slana et al. (2022) emphasized the significance of community and government support for parents of children with DS by linking it to improved quality of life for the parents and the children. Based on this assertion, the absence of government and community support for Western Nigerian mothers with DS children is therefore identified as a significant barrier to the access and utilization of specialized services for these children.

Theme 4: Family Support and Resilience

The dataset revealed a fourth theme detailing how mothers described their experiences with family support and resilience. All 10 participants in this study reported that family support and resilience played a crucial role in managing the challenges associated with raising their children with DS. The participants described how the presence of a supportive family network and the ability to adapt and cope with difficulties are essential factors that contribute to their well-being and their children with DS. Family support provides emotional and practical assistance, while resilience helps to maintain a positive outlook and effectively handle challenges, especially in accessing and utilizing support services for their children.

This theme is consistent with previous research. Research consistently highlighted the importance of family support in the lives of children with Down syndrome and their caregivers. Family support can significantly alleviate the stress, frustration, and burden associated with caregiving. According to Juveriah and Gulnaz (2020), family support systems provide critical emotional and practical assistance, enhancing the overall quality of life for both children with DS and their families. Research suggested that familial support structures meaningfully influence the well-being of both mothers and their children (Juveriah & Gulnaz, 2020). Juveriah and Gulnaz concluded that mothers with supportive spouses and extended family members reported higher levels of well-being and satisfaction with their lives.

The discovery made in this study about participants receiving family support and resilience about raising their children with DS was in line with the findings of Fernández-Ávalos et al. (2020), who explored the role of the family in the lives of caregivers of children with intellectual disability. They found that family played a critical role in the well-being of parents of children with intellectual disability and their children (Fernández-Ávalos et al., 2020). In their study, Rasoulpoor et al. (2023) noted that family support was essential in reducing the caregiver burden for mothers of children with DS.

In a comprehensive review, Pastor-Cerezuela et al. (2020) suggested that the combination of strong family support and high resilience levels can significantly improve the well-being of caregivers and their children with DS. For instance, as P4, a 44-year-old mother with a son with DS, pointed out:

> Like I said, maybe because I read about it, I was always curious and the family at large. The dad has been really supportive. So I think because I think for a child with Down syndrome to go far, he needs a family that is willing to support him. So, the boy got that with us, with the dad, with the uncles, with the grandparents.

> And he has two younger sisters, who cater to him. Who knows that this is our brother and we have to take care of him, who are proud of him. So, I feel he got love at home, so that way, it's easy for us to navigate both. In the case of my son, he got help from home; he got love. So, I may not be able to say it has affected me negatively because I don't even give room for negativity. Nobody gives room for negativity here. Like I said, support is what made it easy…. to family support and emotional support (P4).

In this study, participants confirmed that family support and resilience were vital in managing the challenges of accessing and utilizing support services for their children with DS. This study highlighted that families with robust support networks and high resilience levels reported better overall well-being.

Research Question 3 (RQ3)

RQ3 involved how mothers described their experiences accessing and utilizing support service resources. Three themes emerged from the dataset in relation to RQ3: (a) successful access to educational resources, (b) inadequate educational services, and (c) financial strain in accessing support services.

Theme 5: Successful Access to Educational Resources

The fifth theme identified in the dataset under RQ3 concerns mothers who experience access to educational resources. In this study, only one among 10 participants reported having access to educational resources for their child with DS. These resources included a special school. This finding implies that access to education services was a challenge experienced by the majority of Nigerian mothers when accessing and utilizing support services for their children with DS. The general lack of access to such essential resources in Western Nigeria significantly impacts the development and well-being of children with DS, highlighting a critical area of need. Research indicates that access to educational resources for children with DS in Nigeria is limited. According to Chukwuemeka and Samaila (2020), many families in Nigeria struggle to find adequate educational and special services tailored to their children's needs. This scarcity of resources significantly affects the overall quality of life and development outcomes for these children.

This theme is consistent with the peer-reviewed literature review in Section 1 and supported by several studies showing that accessing and utilizing support services is compromised by the lack of adequate access to essential education (see Mbatha & Mokwena, 2023), the unpreparedness of educational institutions to offer specialized educational services to children with DS (see Braga et al., 2021), and the unaffordability of educational facilities for parents of children with DS (see Daniel et al., 2021). For instance, Rahimi and Khazir (2019) studied the perceived life problems experienced by parents with a DS child. They found that parents experienced inadequate available resources and a lack of educational centers for children with DS. They concluded that there is a need for the implementation of relevant educational and health programs for children with DS (Rahimi & Khazir, 2019).

In addition, Mbatha and Mokwena (2023) found that the availability of structured educational programs and specialized training is crucial for improving the learning and development of children with Down syndrome. They emphasized the need for comprehensive and accessible educational resources to support these children effectively. In my study, I found that only one participant had access to educational resources for their son with DS, which improved his life. This highlights a significant gap in the availability of essential educational resources in Western Nigeria. Research supports these findings, indicating that the scarcity of tailored education critically affects the development and well-being of children with DS.

Theme 6: Inadequate Educational Services

The sixth theme identified in the dataset under RQ3 also concerns the inadequate educational services experienced by the mothers. In this study, nine out of 10 participants reported significant challenges in accessing educational services for their children with DS. These challenges include a lack of specialized schools, inadequate training for teachers in inclusive education, and insufficient resources to support the unique learning needs of these children, as reported by the participants. The mothers reported that the scarcity of these essential educational services significantly affects the developmental and academic progress of their children with DS, leaving them without the necessary support to thrive.

These findings align with the viewpoints articulated in the peer-reviewed literature in Section 1 about the lack of educational centers for children with DS. In essence, researchers have noted that parents experienced inadequate available resources and a lack of educational centers for children with DS (Rahimi & Khazir, 2019). They concluded that it is essential to implement appropriate educational programs for children with DS (Brydges & Mkandawire, 2020; Rahimi & Khazir, 2019). For example, P2, a 47-

year-old mother, emphasized the complete lack of special school access for her daughter with DS. P2 described:

> I think that on your side, they will have a special school for special people like them. But here, we were unable to get it. And joining others in the school. There are no improvements in the academic. Till now, there has been no school for them. So, they just mixed with others. And it is not helping them at all. Let me say, let me even put it in the whole West because, see, now we have been trying to get her to the school where she can fit in. Till now, we have been unable to get it.

Furthermore, the lack of educational services not only impacts the children but also places a significant burden on their families. According to Duru et al. (2020), in Nigeria, families often have to seek alternative and sometimes costly educational resources, further worsening financial and emotional strain. This is in alignment with the study finding where one of the participants, when faced with a lack of educational services, supplemented her son's learning by hiring a therapist and an after-school teacher. P5, a 48-year-old mother noted:

> We sacrifice all our comfort to make sure this child receives an education. No. Right now, my son is in a normal school, and I will get a therapist for him. After the therapist, we have an after-school teacher who is helping him, which is what we can provide for our son now. We couldn't put him in a specialized school. Now we get help from a therapist, and well, he is going to a normal school, and

> the therapist is giving us four days per week to help the child to come out from some level of Down syndrome condition.

Moreover, the lack of adequate educational opportunities for DS children in low- and middle-income countries such as Nigeria (Mbatha & Mokwena, 2023) is considered a significant challenge that mothers of DS children experience while accessing and utilizing support services for their children. The lack of specialized schools, inadequately trained teachers, and insufficient resources not available to the mothers critically impede the academic and developmental progress of their children. This scarcity places a heavy burden on families and highlights the urgent need for the implementation of comprehensive education to support children with DS in Nigeria.

Theme 7: Financial Strain in Accessing Support Services

The seventh theme identified in the dataset under RQ3 is that all the participants in the study reported significant financial strain in accessing support services for their children with DS. The participants reported that the economic strain on them is compounded by the lack of government support, making it difficult for all mothers to afford essential services for their children with DS. These financial strains include the high costs of medical care, therapies, specialized educational resources, and specialized schools. This theme aligns with the existing literature, as demonstrated by Alabri (2023), who found that families with children with DS face financial challenges due to the high cost of medical care, therapy, and special education.

Several research studies have also identified this challenge. For instance, in their systematic review, Shetty et al. (2023) mentioned financial burden as a common phenomenon experienced by caregivers of children with DS. In their study, Daniel et al. (2021) reported financial stress as among the challenges experienced by Nigerian parents raising children with DS. Eddaoudi et al. (2023) also confirmed that financial strain is among the challenges that parents of children with DS experience when seeking support services. In their study, Eddaoudi et al. (2023) observed that 5% of parents of children with DS reported having a child with DS by stating the financial difficulties they experienced. These findings support this current research study's findings that financial challenges in accessing support services were among the issues that mothers of children with DS experienced in accessing specialized services for their children.

Additionally, previous researchers confirmed that parents or caregivers of children with DS experience significant financial and other economic challenges that negatively affect their ability to provide optimal care to the children (Desimpelaere et al., 2023). They found that financial constraints are a major barrier to accessing necessary support services (Desimpelaere et al., 2023).

In this study, the financial strains faced by mothers in accessing support services for their children with DS are substantial and pervasive. All 10 participants in this study reported significant economic burdens, including the high costs of medical care, therapies, and specialized educational resources. These financial strains are exacerbated by the lack of government support, making it difficult for mothers to afford essential services. Existing literature supports these findings, highlighting the critical need for improved financial support systems.

Research Question 4 (RQ4)

RQ4 involved the mothers' experiences with accessing and utilizing support services within the customs and cultural beliefs in Western Nigeria.

Theme 8: Stigmatization and Discrimination Associated with Down Syndrome

Stigmatization and discrimination associated with DS emerged as the eighth theme under RQ4, revealing the societal challenges faced by mothers of children with DS. All 10 participants in the study consistently described experiences of exclusion and judgment, which compounded their everyday struggles. The mothers noted that despite experiencing exclusion and judgment, they did not adhere to prevailing societal and cultural beliefs that sideline their children with DS. The mothers discussed the deep-rooted social and cultural factors that fuel stigma and discrimination against their children with DS. For instance, a mother shared that people view children with DS as abnormal, referring to them as snakes, imbeciles, vegetables, good-for-nothing, and spirits.

> Someone called my child a snake. Saying in their own village, a child with Down syndrome is a snake, a spirit. People think those children are not human beings. People think those children are just there to suffer their parents. This mentality is the African mentality generally. So it's difficult for someone to believe a Down syndrome child can go to school and learn. Because they think they're just like vegetables, good for nothing. No, no matter what someone is saying, it's something that will not even touch me (P5).

Additionally, P5 continued and noted how rejection hindered the access and utilization of support services.

> Sometimes, parents just go and kill their children because of what society is thinking about them and the African culture. Some people call them imbeciles, a child just like a vegetable that can't move, can't do anything. A child like this, if someone is thinking about your child like this. What can you do for your child?
>
> Nothing. Someone who thinks your child is a snake, a spirit in African culture.

Another mother described a lack of assistance or lack of access to and utilization of support services as a general lack of acceptance by society.

> Ohh, people sometimes seeing them, they look down on them. When they look down on those children, definitely then, seeking help for them may be difficult because they'll see it as a waste of time, so even if there's anything I can do, can anything still come out of this kind of a child? So that is the belief. So they see it as a waste. So, instead of wasting money, let me go ahead and take care of others. You understand what I'm trying to say. So I think that is it. They see it as a waste of time helping such children. Once they see any child, they see the child is being deformed and abnormal. She's my daughter, so I don't need to listen to what people are saying (P8).

This theme aligns with the literature review, and the discovery aligns with the views of some scholars. Stigmatization and discrimination of mothers of children with developmental disabilities have been reported in many research studies. In one study, Watanabe et al. (2022) report that the stigma emerged as one of the issues experienced by parents of children with DS. Also, in their phenomenological study, Deakin and Jahoda

(2020) noted that all mothers were sensitive to the stigmatized status of DS and that the mothers were at pains to protect their children from becoming aware of it.

According to Tekola et al. (2020), in addition to the challenges of raising a DS child, mothers of these children also experience stigmatization and discrimination, including negative judgment, rejection, and lack of support. These revelations confirm the responses obtained from the Nigerian mothers that they experienced stigmatization and discrimination for having a DS child. Such stigmatization and discrimination have negative implications in terms of undermining the willingness or ability of the mothers to access and utilize specialized support services for their DS children.

All Participants in this study consistently reported experiencing significant stigma and discrimination associated with raising children with DS. Societal attitudes, customs, and cultural beliefs drive this stigmatization. The pervasive discrimination contributes to social isolation, frustration, and reduced access to resources. Therefore, stigmatization and discrimination, which emerged as a major theme from the interviewed mothers, can be cited as among the significant challenges that the mothers experience while accessing and utilizing specialized services for their DS children.

Theme 9: Experiencing Resilience through Religion/Spirituality

Experiencing resilience through religion/spirituality emerged as the ninth significant theme under RQ4. The mothers described how they experience resilience through religion/spirituality as a result of a lack of support services for children with DS. The participants demonstrated resilience in the face of challenges associated with raising their children with DS, which was strongly supported by their spirituality and religious faith. This faith instills a hopeful perspective, empowering them with the belief that divine support will compensate for the lack of access to support services and enhance their children's lives.

This theme was not reviewed in the literature review in Section 1; however, it emerged as a theme. Six out of the 10 participants mentioned this particular theme. They stated that their God and spirituality kept them going. Research studies have demonstrated the key role that spirituality plays in fostering resilience in mothers raising children with DS. In one study, Oguntade et al. (2022) noted that mothers of children with developmental disabilities such as DS took their children to prayer camps and other religious places.

In another study, Karaca and Konuk (2019) reported that mothers with children with developmental disabilities such as DS used religion and spirituality as a coping strategy to help them overcome the tremendous stress as well as anxiety associated with raising a DS child. Furthermore, Duarte et al. (2022) identified religion as a crucial resource for parents of children with DS, which helped them overcome the difficulties they encountered when raising these children. Therefore, resilience derived from religion/spirituality in this current study can be cited as an enabling factor for mothers with DS children to compensate for the inadequate access and utilization of specialized support services for their children.

Theme 10: Parental Responsibility to Care

Parental responsibility to care emerged as the tenth and last significant theme under RQ4, revealing how all the mothers in this study described taking care of their children with DS as their responsibility. The mothers described a strong personal commitment to the caregiving responsibilities for their children with DS. They highlighted their active roles in managing daily needs and educational support as a fundamental part of their lives.

This theme aligns with the literature review in Section 1, as Colton and Paul (2020) confirmed this assertion that mothers are archetypally the primary caregivers for children with disabilities in Nigeria. The scholar further cited that mothers are considered responsible when they give birth to a child with a disability (Colton & Paul, 2020). As a result, they carry the weight of fulfilling the health and education requirements of their children (Celik & Kara, 2023; Colton & Paul, 2020).

Another study by Mishra et al. (2023) revealed that the majority of mothers of children with DS (77.1%) experienced a higher burden of care, with 89.6% of the mothers being always overwhelmed by their child's condition. In yet another study, Zeeshan et al. (2022) observed low to moderate emotional exhaustion in 58.7% of the mothers. These are critical findings indicating the burden associated with caring for a DS child. For instance, one of the participants, P8, a 50-year-old mother, emphasized that taking care of her daughter with DS is her responsibility and her burden in Nigeria.

> You tend to do it yourself. Like I said, it still bounced back to the same thing I keep saying: You do it on your own. Nothing, nothing comes from anywhere. It's your cross. You do it on your own. The little you have, you put it just to at least give a good life. I give her the attention she needs at every point in time. I make her to be exposed to some things, to a lot of things. I go the extra mile to do that

> for her. They see it as your burden in Nigeria, no support anywhere. It's a bit challenging (P8).

Considering that the mothers in this study reported that they provided all the needed care to their DS child, it can be rightly concluded that they experienced the burden of care associated with caring for a child with DS as a result of a lack of adequate access to support services.

Interpretation of the Findings in the Context of the Theoretical Framework

I used the Bronfenbrenner ecological model as a theoretical framework to support my study. Bronfenbrenner was the original tenet of the ecological model developed in 1977. Bronfenbrenner divided the environmental construct into five levels of influence: the microsystem, mesosystem, ecosystem, macrosystem, and chronosystem. However, my study approach includes using one of the five levels of environmental influences. The selected ecological level is the macrosystem, which consists of (a) customs and cultural beliefs, (b) resources, and (c) social systems for mothers accessing and utilizing support services for children with Down syndrome (DS) in Western Nigeria.

The 10 identified themes from the participants' responses can be categorized and interpreted on the basis of the elements of the macrosystem ecological level as follows: Customs and cultural beliefs (stigmatization and discrimination associated with DS, experiencing resilience through religion/spirituality and parental responsibility to care), resources (financial strain in accessing support services, inadequate educational services, successful access to educational resources, challenges in accessing and utilizing support services, and creation and utilization of support networks), and social systems (absence of community and government support and family support and resilience).

Customs and Cultural Beliefs

In line with Bronfenbrenner's ecological model, the themes of stigmatization and discrimination associated with DS, experiencing resilience through religion/spirituality, and parental responsibility to care can be classified under the element of customs and cultural beliefs. According to Bronfenbrenner, customs and cultural beliefs influence individuals’ responses or reactions to a particular phenomenon (see Bronfenbrenner, 1977). Most participants described experiencing significant stigma and discrimination due to societal attitudes and cultural beliefs surrounding DS. This stigma manifests in social rejection, negative cultural perceptions, discriminatory practices, and perceptions of abnormality. Within the macrosystem, cultural beliefs and societal norms play a crucial role in shaping individuals' behaviors and attitudes (see Bronfenbrenner, 1977). The negative perceptions and discrimination against children with DS and their mothers are deeply rooted in cultural norms and misconceptions. This aligns with Bronfenbrenner's theory that the macrosystem influences the broader cultural context that affects individuals' daily lives (see Bronfenbrenner, 1994; Bronfenbrenner, 1977). Most participants in this study described that God and spirituality kept them going. Religion and spirituality can provide a source of strength and resilience, helping families to manage stress and maintain a positive outlook. In the context of the macrosystem, religious and spiritual beliefs are part of the cultural fabric that influences how families cope with adversity (see Bronfenbrenner, 1977). All the mothers reported that they had the responsibility of providing all the care for their child with DS to compensate for the lack of support services. Cultural expectations and beliefs about the role of mothers deeply influence the mothers' responsibility and initiative. Within the macrosystem, these cultural norms shape how parents perceive their duties and the lengths to which they will go to provide for their children (Bronfenbrenner, 1977). Therefore, based on Bronfenbrenner’s ecological model, it is evident that customs and cultural beliefs influence how mothers raising children with DS access and use specialized services for their children.

Resources

Resources are another element of Bronfenbrenner’s macrosystem ecological level. Three themes relating to this macrosystem ecological level emerged from the participants’ responses. The themes are financial strain in accessing support services, inadequate educational services, successful access to educational resources, challenges in accessing and utilizing support services, and the creation and utilization of support networks. As noted from the responses, all the participants reported that they experienced financial challenges in accessing support services for the DS children, nine participants mentioned that they did not have access to educational services, and only one participant mentioned she had access to educational services, medical services, and therapy for their child with DS. These mothers of children with DS require resources, including financial and material resources, to access and use specialized support systems and to provide the necessary care for their children. Bronfenbrenner (1994) stated in the ecological model that resources are a component of the macrosystem ecological level that influences individuals' response to a specific phenomenon, such as caring for a child with DS, as in this case. Eddaoudi et al. (2023) and Ede et al. (2023) confirmed in their research studies that mothers of children with DS face financial demands that expose them to financial stress. Therefore, it is evident that Bronfenbrenner's ecological model, particularly the resource component of the macrosystem ecological level, significantly influences Western Nigeria mothers of children with DS to access and use specialized support services.

Social Systems

Social systems are also a component of Bronfenbrenner's macrosystem ecological level. The ecological framework holds that social systems of society significantly influence individuals' responses to a specific issue (see Bronfenbrenner, 1977; Bronfenbrenner, 1994). With respect to this particular macrosystem ecological component, two themes emerged from the participants' responses. They are the absence of community and government support, as well as family support and resilience. Social systems, including government policies and community support structures, are integral to the macrosystem (see Bronfenbrenner, 1994). Concerning this theme, the participants described the absence of support from community networks, government support, and NGOs for their children with DS. The lack of community and government support points to systemic failures in providing adequate care and resources for children with DS. This finding suggested the need for more decisive social support networks and more dynamic government policies to support these mothers. Many participants described the importance of family support and that the family was their source of support. And personal resilience in managing the challenges of raising their children with DS. Within the macrosystem, family dynamics and support networks are vital for coping with the broader societal challenges. The resilience and support provided by families emphasized the importance of strong family bonds. Therefore, the social systems of the macrosystem ecological level demonstrate how social systems significantly influence the Western Nigerian mothers of children with DS's ability to access and use specialized support services for their children.

The findings of this study, when viewed through the lens of Bronfenbrenner's (1994) macrosystem, emphasized the significant impact of customs and cultural beliefs, resources, and social systems on the experiences of mothers raising children with DS in Western Nigeria. Addressing the challenges identified in this study requires a multifaceted approach that includes cultural change, improved resource allocation, and strengthened social support systems. These efforts can lead to a more inclusive and supportive environment for children with DS and their families, which will enhance their overall well-being and quality of life.

Limitations of the Study

One of the limitations is the study sample size; the study sample size was relatively small, with only 10 participants. I initially aimed to recruit 15 mothers to ensure a comprehensive understanding of the experiences of mothers raising children with DS in Western Nigeria. Saturation was reached after interviewing 10 participants. A smaller sample size may limit the transferability of the findings. Although saturation was achieved, the smaller number of participants might not fully represent the diversity of experiences among all mothers raising children with DS in the region. The study was conducted in Western Nigeria, and the findings may not be applicable to other regions of Nigeria or other countries. A further limitation is the self-reported data; the study relied heavily on self-reported data from the mothers during interviews, where the mothers might provide responses they think are expected rather than their actual experiences. This may affect the credibility of the findings as the data may not fully represent the mothers' genuine thoughts and feelings.

Another limitation is the researchers' bias, given that I have personally raised a child with DS. However, I handled the bias by staying objective and controlling my own biases, beliefs, and preconceived notions by recording them in a journal. This practice assisted me in temporarily setting them aside, which allowed me to concentrate on the mothers and their narratives. Also, to minimize researcher bias and ensure the collection of honest responses from the mothers, an interview guide was employed throughout the interviews. By following the interview guide, I was able to maintain consistency in the questions asked while giving participants the freedom to express their thoughts and experiences fully. This approach helped to mitigate any potential bias and ensured that the data collected was authentic and reflective of the mother's true experiences.

Finally, the study focused on the macrosystem level of Bronfenbrenner's ecological model, examining customs and cultural beliefs, resources, and social systems. It did not extensively explore other levels of the model, such as the microsystem (immediate environment) or the mesosystem (interactions between different parts of a person's life) (Bronfenbrenner, 1994). Important influences at the individual or immediate environmental level might have been overlooked. A more comprehensive approach, including all levels of the ecological model, could provide a fuller understanding of the experiences of the mothers raising children with DS in Western Nigeria.

Recommendations

Based on the findings of this study, several key recommendations can be made to address the challenges faced by mothers raising children with DS in Western Nigeria. These recommendations are grounded in the strengths and limitations of this current study, as well as insights from the literature reviewed in Section 1. The local governments of Nigeria should develop and expand specialized support services for children with DS, including medical, educational, and therapeutic resources. Also, community-based programs should be developed to strengthen family support networks and provide emotional and practical support to caregivers. The study found a significant inadequate available support services, which negatively impacts the well-being of both children and their mothers.

Implementing financial assistance programs to alleviate the economic burden on families raising children with DS is crucial. Participants in this study reported considerable financial strain in accessing necessary services for their children with DS. Furthermore, a public campaign to reduce stigma and increase awareness about DS should be launched by key stakeholders, including the state and local governments, the Ministry of Health, and public health professionals. By working together, these groups can make sure the campaign reaches a wide audience and has a big impact, using their resources and knowledge to support families affected by DS.

Finally, the current study offers detailed insights into the mothers' lived experiences at a specific point in time; a single point in time may not capture how these experiences and challenges evolve. Therefore, I would recommend that future researchers conduct long-term phenomenological studies to track the evolving experiences of mothers raising children with DS over an extended period. This approach will help to understand how their challenges, coping mechanisms, and support needs change over time. Long-term studies can provide deeper insights into the sustained impact of interventions and support programs that will contribute to more effective and sustainable solutions.

Positive Social Change

The findings of this study have significant implications for social change, particularly in enhancing the support systems for mothers raising children with DS in Western Nigeria. By highlighting the critical gaps in available services, financial challenges, and the pervasive stigma and discrimination these mothers face, the study emphasizes the urgent need for comprehensive policy interventions and community-based support initiatives. These insights can inform the development of targeted programs and policies aimed at improving access to medical, educational, and therapeutic services, ultimately fostering a more inclusive and supportive environment for these mothers (see Appendix G).

Moreover, the current study emphasized how strong and resourceful mothers are in dealing with big challenges, showing that these mothers need more recognition and support. By advocating for the integration of culturally sensitive intervention embedded in the culture of Nigeria and community-driven approaches, the current research encourages a shift in societal attitudes toward greater acceptance and support for children with DS and their families. This can lead to broader societal changes, reducing stigma and fostering a culture of inclusion and empathy, which can significantly enhance the quality of life and social integration of individuals with DS in Nigeria.

Conclusion

The purpose of this descriptive phenomenological qualitative study was to understand the accessibility and utilization of support services through the lived experiences of Western Nigerian mothers raising children with DS. The current study emphasized the urgent need for comprehensive support services for mothers raising children with DS in Western Nigeria. The findings highlighted significant gaps in available resources, prevalent stigma, and the resilience of the mothers, accenting the importance of targeted policy interventions and community support initiatives. By applying Bronfenbrenner's ecological model, the study analyzed the impact of macrosystem-level concepts, such as cultural beliefs, resources, and social systems, that demonstrated both the strengths and limitations of this theoretical approach. Ethical considerations were essential in this study. I made sure to get participants' informed consent, keep their information confidential, and engage with them respectfully. This helped address the ethical challenges that come with qualitative research.

The study communicated findings effectively to diverse stakeholders, including policymakers, public health professionals, healthcare providers, local government, and the community, employing clear and open language to influence behavior and policies. The study proposed policies to enhance support services to the unique norms and customs embedded in the culture of Nigeria, reduce stigma, and improve the overall quality of life for families affected by DS, aiming to drive positive social change within the community. The fundamental essence of this study is the urgent need for enhanced support systems and targeted policies to address the challenges faced by mothers raising children with DS. By building on the resilience of mothers and getting more support from the community and government, significant improvements can be made in the lives of these families.

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Appendix A: NHREC Approval

National Health Research Ethics Committee of Nigeria (NHREC)
Promoting Highest Ethical and Scientific Standards
for Health Research in Nigeria

Federal Ministry of Health

NHREC Protocol Number NHREC/01/01/2007-11/03/2024
NHREC Approval Number NHREC/01/01/2007-01/04/2024
Date: 1st April 2024

Re: Exploring Lived Experiences of Mothers Raising Children with Down Syndrome in Western Nigeria Health Research Ethics Committee (HREC) assigned number: NHREC/01/01/2007

Name of Student Investigator: Vivian Aruwajoye
Address of Student Investigator: Walden University, USA.
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Date of receipt of valid application: 11/03/2024
Date when final determination of research was made: 01-04-2024

Notice of Expedited Committee Review and Approval

This is to inform you that the research described in the submitted protocol, consent form, advertisement and other participant information materials have been reviewed and *given expedited committee approval by the National Health Research Ethics Committee.*

This approval dates from 01/04/2024 to 31/03/2025. If there is delay in starting the research, please inform the HREC so that the dates of approval can be adjusted accordingly. Note that no participant accrual or activity related to this research may be conducted outside of these dates. *All informed consent forms used in this study must carry the HREC assigned number and duration of HREC approval of the study.* In multiyear research, endeavour to submit your annual report to the HREC early in order to obtain renewal of your approval and avoid disruption of your research.

The National Code for Health Research Ethics requires you to comply with all institutional guidelines, rules and regulations and with the tenets of the Code including ensuring that all adverse events are reported promptly to the HREC. No changes are permitted in the research without prior approval by the HREC except in circumstances outlined in the Code.

The HREC reserves the right to conduct compliance visit to your research site without previous notification.

Signed

Professor Richard A Adegbola, MSc, PhD (Dundee), FIBMS (UK), FRCPath (London) FRCP (Hons, London), FAS, FAAS, FAMedS.
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Appendix B: Interview Procedure

Demographic Questions for Mothers

Participant ID:

Email:

How old are you?

What is your ethnic/regional background?

How many children do you have?

How old is your child with Down Syndrome?

What is your marital status?

Interview Questions for mothers

Questions about accessing and utilizing supportive services

1. Can you tell me about the help you get for your child with Down syndrome?

Probing/follow-up: What problems have you faced in getting this help?

2. How do you feel about the services for kids with Down syndrome here?

Probing/follow-up: Can you give me examples of what's good or not good about these services?

3. How do these services help you and your child in your day-to-day life?

Probing/follow-up: How do these services help your child grow and stay healthy?

Questions relating to social systems

4. Can you talk about the professionals and others who help your child?

Probing/follow-up: How do these people make it easier or harder for you to get help?

5. How do you find help from people and places in your community?

Probing/follow-up: What's been hard or easy about finding help from these places?

Questions relating to support service resources

6. Can you say how easy it is to find things to help your child?

Probing/follow-up: What makes it hard to find or use these things?

7. What's it like getting money or things your child needs?

Probing/follow-up: How does not having enough money or things affect your child?

Questions about the customs and cultural beliefs

8. How do the things people believe or do affect the help you get for your child?

Probing/follow-up: Can you give examples of how what people believe affects how you get help?

9. Can you talk about what people think about Down syndrome here?

Probing/follow-up: How do these ideas make it easier or harder to get help for your child?

10. How do you follow the things people believe while getting help for your child?

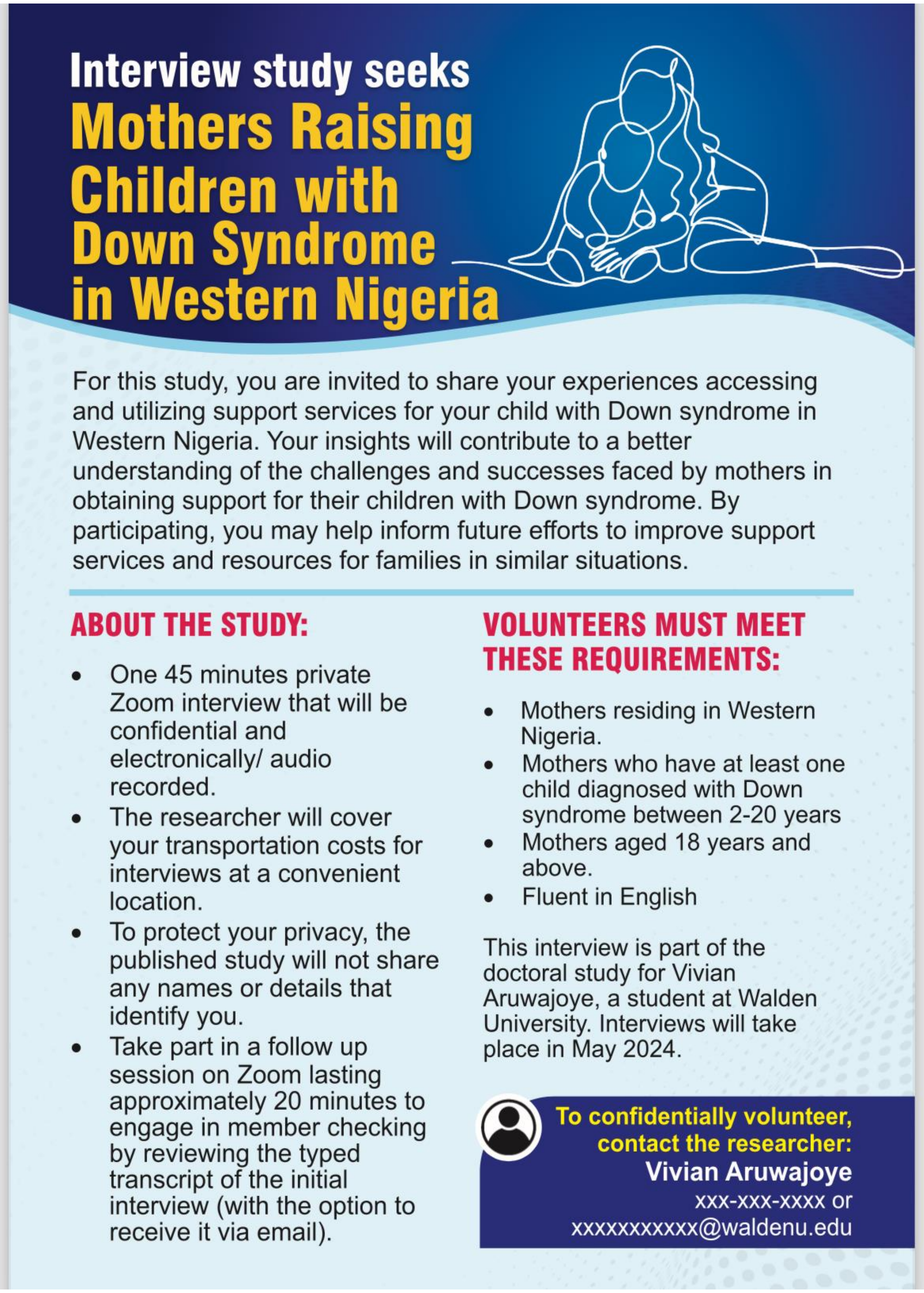
Probing/follow-up: Have you had to change what you do to follow what people believe?

11. Can you tell me about the things people do or believe that help your child?

Probing/follow-up: How do these things change how you get help for your child?

12. How do you make sure your child gets what they need while following what people believe? Probing/follow-up: What do you do to make sure your child gets what they need while also following what people believe?

Appendix C: Study Informative Flyer



Interview study seeks Mothers Raising Children with Down Syndrome in Western Nigeria

For this study, you are invited to share your experiences accessing and utilizing support services for your child with Down syndrome in Western Nigeria. Your insights will contribute to a better understanding of the challenges and successes faced by mothers in obtaining support for their children with Down syndrome. By participating, you may help inform future efforts to improve support services and resources for families in similar situations.

ABOUT THE STUDY:

- One 45 minutes private Zoom interview that will be confidential and electronically/ audio recorded.
- The researcher will cover your transportation costs for interviews at a convenient location.
- To protect your privacy, the published study will not share any names or details that identify you.
- Take part in a follow up session on Zoom lasting approximately 20 minutes to engage in member checking by reviewing the typed transcript of the initial interview (with the option to receive it via email).

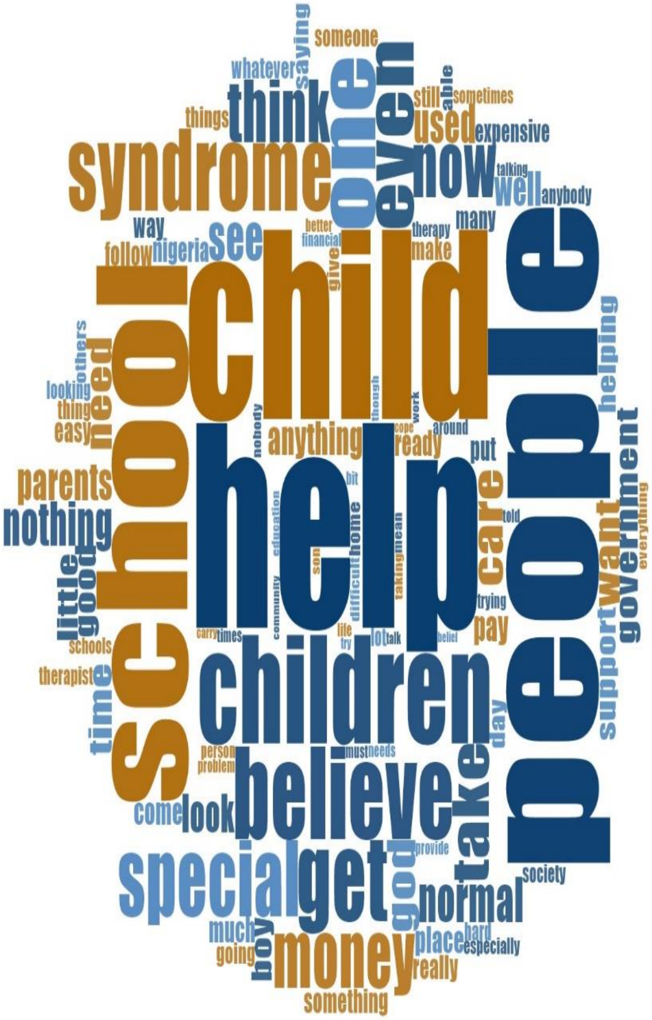
VOLUNTEERS MUST MEET THESE REQUIREMENTS:

- Mothers residing in Western Nigeria.
- Mothers who have at least one child diagnosed with Down syndrome between 2-20 years
- Mothers aged 18 years and above.
- Fluent in English

This interview is part of the doctoral study for Vivian Aruwajoye, a student at Walden University. Interviews will take place in May 2024.

To confidentially volunteer, contact the researcher:
Vivian Aruwajoye
xxx-xxx-xxxx or
xxxxxxxxxxx@waldenu.edu

Appendix D: Word Frequency Report



Appendix E: Public Health Practice and Field-Based Products

Overall Statement for Public Health Practice

The findings from this study may hold significant implications for public health practice in Western Nigeria. By understanding the lived experiences of mothers raising children with Down syndrome and their access to support services, policymakers, and practitioners can implement targeted interventions to improve the well-being of both mothers and their children. These insights can inform policy decisions, enhance awareness among healthcare providers, public health practitioners, and foster community support systems for families affected by Down Syndrome.

Field-Based Product - Policy Brief Memo

Title: Enhancing Support Services for Mothers Raising Children with Down Syndrome in Western Nigeria: A Call to Action

Background / Context and Importance of the Problem

Children with Down Syndrome face unique challenges, and their families often require specialized support services to ensure their well-being. In Western Nigeria, there is a notable lack of adequate support systems for mothers raising children with Down Syndrome. This gap is exacerbated by inadequate support services, cultural stigmas, and resource constraints. The significance of this issue cannot be overstated, as it directly impacts the quality of life for both mothers and their children. Without access to essential support services, mothers may experience increased stress, isolation, frustration, and financial strain, hindering their ability to provide optimal care for their children with Down syndrome.

Policy Recommendations

Enhance Accessibility of Support Services: Implement measures to increase the accessibility of support services for mothers raising children with Down Syndrome in Western Nigeria. This includes establishing community-based support groups, providing therapeutic services, and improving access to educational resources.

Promote Cultural Sensitivity: Develop culturally sensitive interventions that address the unique needs and challenges faced by mothers within the unique norms and customs embedded in the culture of Nigeria. Engage community leaders and traditional healers to raise awareness and reduce the stigma surrounding Down Syndrome.

Capacity Building for Healthcare Providers and Public Health Professionals: Provide training and professional development opportunities for healthcare providers to improve their understanding of Down Syndrome and enhance their ability to offer comprehensive care and support to affected families. Additionally, increase awareness among public health professionals to ensure they are equipped with the latest information and best practices in supporting families of children with Down Syndrome.

Advocate for Policy Change: Advocate for policy changes at the governmental level to prioritize the needs of families raising children with Down Syndrome. This includes allocating resources for specialized healthcare services, educational programs, and social support initiatives.

By implementing these policy recommendations, there will be a more inclusive and supportive environment for mothers raising children with Down syndrome in Western Nigeria. It is imperative that we prioritize their well-being and ensure they have access to the resources and support they need to thrive. Through collective action and advocacy, we can drive positive social change and improve outcomes for families affected by Down syndrome.

Appendix F: Executive Summary

Title: Addressing Support Services for Mothers of Children with Down Syndrome in Western Nigeria: Insights and Recommendations.

Introduction to Public Health Professionals: This executive summary presents key considerations for the development and implementation of programs aimed at supporting mothers of children with Down syndrome in Western Nigeria. Public health professionals play a vital role in addressing the needs of this population and improving their access to essential support services.

Public Health Problem or Issue: The public health problem addressed in this study is the challenges faced by mothers raising children with Down syndrome in accessing and utilizing support services. These challenges include financial constraints, inadequate educational resources, cultural stigma, and limited availability of specialized resources.

Population Impacted: The population impacted by this issue consists of mothers residing in Western Nigeria who are raising children with Down syndrome. This study found that mothers often face significant hurdles in accessing adequate support services to meet the needs of their children.

Key Findings: The study identified several key findings related to the experiences of mothers accessing support services for their children with Down syndrome. These include challenges in accessing and utilizing support services, inadequate educational resources, lack of therapeutic services, financial challenges hindering access to services, and the stigmatization and discrimination associated with Down syndrome.

Suggestions for Program Development: To address the identified challenges, program development efforts should focus on increasing awareness and acceptance of Down syndrome within the community and enhance access to specialized support services for children with Down syndrome and their families. Additionally, there is a need to establish financial assistance programs to alleviate the financial burden on families.

Suggestions for Implementation Strategies: Implementation strategies should prioritize the integration of culturally sensitive approaches to service delivery. This includes providing language-appropriate materials and engaging community leaders to promote acceptance and support for families raising children with Down syndrome.

Considerations for Community Context: Programs should be tailored to fit the specific cultural values and linguistic diversity of the community. Strategies should be developed in collaboration with community stakeholders to ensure relevance and effectiveness.

Key Takeaways: In conclusion, this executive summary highlights the importance of addressing the support service needs of mothers raising children with Down syndrome in Western Nigeria. By implementing culturally sensitive and community-driven programs, public health professionals can make significant strides in improving the well-being of these families and promoting inclusive support services.

Appendix G: Fact Sheet

Fact Sheet: Supporting Mothers of Children with Down Syndrome in Western Nigeria

This fact sheet provides key information about the proposed program and strategies aimed at supporting mothers raising children with Down syndrome in Western Nigeria. The program aims to address the unique challenges faced by these mothers and improve access to essential support services.

Program Objectives:

- Increase awareness and acceptance of Down syndrome within the community.
- Provide financial assistance to alleviate the burden on families and enhance access to support services.
- Implement culturally sensitive approaches to service delivery to ensure relevance and effectiveness.
- Engage community leaders and stakeholders to promote acceptance and support for families raising children with Down syndrome.

Role of the Nigerian Government:

Policy Development: The Nigerian government should develop and implement policies that support inclusive education and medical services for children with Down Syndrome.

Funding and Resources: The Nigerian government should allocate funds and resources to improve support services for these families.

Public Health Initiatives: The Nigerian government, through the Ministry of Health, should launch public health initiatives aimed at reducing stigma and providing comprehensive care.

Benefits of the Program:

- Increased awareness and acceptance of Down syndrome within the community.
- Improved access to essential support services for families raising children with Down syndrome.
- Enhanced well-being and quality of life for mothers and their children with Down syndrome.
- Strengthened community support networks for families affected by Down syndrome.

Key Strategies:

- Community Awareness Campaigns: Conduct community-based awareness campaigns to educate the public about Down syndrome and reduce stigma.
- Financial Assistance Programs: Establish financial assistance programs to provide support for families in need, including assistance with medical expenses, therapy sessions, and educational resources.
- Culturally Sensitive Service Delivery: Train healthcare providers and service professionals to deliver culturally sensitive care and support to families raising children with Down syndrome.
- Community Engagement: Collaborate with community leaders, religious organizations, and local NGOs to promote acceptance and support for families affected by Down syndrome.

Statistics:

Prevalence of Down Syndrome: Approximately 1 in every 865 live births in Western Nigeria is affected by Down syndrome, according to recent estimates from local health authorities.

Availability of Support Services: Currently, less than 30% of families raising children with Down syndrome in Western Nigeria have access to specialized support services, such as therapy centers and educational resources.

Economic Impact: Families raising a child with Down syndrome in Western Nigeria spend an average of 20% of their annual income on medical expenses and caregiving needs, resulting in financial strain for many households.

Call to Action:

Join us in supporting mothers raising children with Down syndrome in Western Nigeria. Together, we can make a difference in the lives of these families and promote inclusivity and acceptance within our community

Statistics References:

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