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Improving Access to Diagnostic Medical Services for Children with Autism: Caregiver Perspective

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has been found to be complete and satisfactory in all respects,
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Abstract

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MBA, Southwest Minnesota State University, 2012

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Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
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Abstract

The rising prevalence of autism among children in the United States has remained a challenge to caregivers, researchers, and healthcare providers. Medical diagnostic services struggled with inaccurate outcomes, misdiagnosis, inaccessibility, long waitlists, poor coordination, and a lack of expertise and knowledge for early intervention. There are limited studies on problems associated with diagnosing children with autism and the caregivers' perspective on improving the services. In this qualitative phenomenological study, 10 caregivers' perspectives on barriers to accessing medical diagnostic services, treatment, and management of children with autism and possible improvement of the services were explored. Resilience and health utilization models provided the conceptual framework to understand the phenomenon for this study. A semistructured interview explored the caregivers' in-depth experiences in improving medical diagnostic services. The data were analyzed using NVivo descriptive software to find emerging common themes. The findings indicate the need for more funding, expanded insurance coverage, expert practitioners, timely communication and referrals, public awareness, and healthcare providers' culturally competent training. Implications for social change through policy change include expanding insurance coverage, funding the rural Minnesota healthcare system, increasing experts such as neurologists in rural areas, and enhancing coordination and communication among private and public diagnostic services, which will benefit caregivers and children with autism.

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Dedication

This study is dedicated to my son, Ihechimere Ray Nkwocha. Ihechimere regressed to repetitive behaviors, became withdrawn, and could not communicate with simple words like Daddy and Mommy. Ihechimere was on the waiting list for over a year for medical diagnostic services. This study is also dedicated to children with autism all over the world. Improving medical diagnosis services for children with autism disorder would be of immense significance.

Acknowledgments

I thank God Almighty, who unbridled me with new vigor and courage to get to the finish line. Thank you, Ihechimere, my nine-year-old son, for inspiring me to finish what I started. Each time I looked at you, I was moved to keep digging into autism and its misdiagnosis. You provided a springboard for me to call to action toward a society free of autism and save children like you. The Almighty God will unbridle you, too.

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To my seven-year-old daughter, Munachimso Oliver Nkwocha, you are fantastic. Thank you very much for providing a haven to write my dissertation. Each time I sneaked

into my study room, you made sure your little brother, John Jr., did not come in to disturb me. You would tell him: “Daddy is busy! Daddy is writing his papers; do not enter there; he will take us to the park when he finishes; otherwise, you will not go with us.” She was very smart and always made sure nobody disturbed me. Thank you, little Oliver. You are awesome, my cheerleader, my motivator; I love you! Daddy is now Dr. Nkwocha! I thank you all, everybody, who, in one way or another, encouraged me to complete my Ph.D. program. It is done!

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Chapter 1: Introduction to the Study

Autism spectrum disorder (ASD) prevalence among children in the United States is alarming. ASD affects approximately 2% of children in the United States (McCarty & Frye, 2020). The Centers for Disease Control and Prevention (CDC) critical statistics show that one in 44 children live with ASD (Maenner et al., 2021). An estimated 449,643 adults in California live with ASD (Dietz et al., 2020). Minnesota records second nationwide after California, with 2.5% of 8-year-old children identified with autism according to the 2018 data in the 2021 CDC Community Report/Autism and Developmental Disabilities Monitoring (CDC/ADDM) Snapshot of ASD (2018). A breakdown of the statistics shows that one in 42 children has ASD in Minnesota, higher than the national average of one in 44 children. The CDC community report further projected a 10% prevalence increase of children with ASD (one in 54 children) in the United States. ASD has no barriers. It affects all races, ethnicities, and socioeconomics, except it is 4.6 times more common among boys than girls (CDC, n.d.). The spectrum nature of ASD, which underscores its severity, heterogeneity, phenotypes, and varying symptoms, may have contributed to the complexity, ethical dilemma, cultural influences, and uncoordinated diagnostic services for children with autism (Hus & Segal, 2021). It has become necessary to seek ways of alleviating the pitfalls of autism diagnostic services for the affected children and their caregivers.

A comprehensive thematic review of the pitfalls, challenges, and poor coordination of diagnostic services for children with autism shows concern about accurately identifying ASD, early diagnosis, flaws in diagnostic instruments, and an increase in delays or denied treatment (Hus & Segal, 2021). Also, the weak coordination of government-assisted autism programs, public schools, private diagnostic medical providers, pediatricians and child neurologists, child development experts, and educational or medically certified or trained diagnosticians creates consumer confusion. Hus and Segal noted that the lack of coordinated diagnosis embroiled in poor professionalism, ethical dilemmas, cultural influences, gender differences, neurobehavioral nature of the disorder, and its co-occurring conditions makes the situation more complex. The absence of a medical maker to identify the presence of ASD in a child and an entire reliance on the affected child's developmental history, observation of the child's behavior, and cognitive functions compound the situation may not be adequate and effective.

ASD is a developmental disability affecting children's social skills, communication, and behavior (Maenner et al., 2021). The American Psychiatric Association (APA, n.d.) described ASD as persistent impairments in social interaction and the presence of restricted, repetitive patterns of behaviors, interests, or activities in children or even affected adults. ASD includes several conditions which were not part of the earlier definition. The characteristics of the affected child must meet specific criteria as highlighted by the APA’s Diagnostic and Statistical Manual of Mental Disorders-DSM-5 and agreed on by experts. These conditions include autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger syndrome (CDC, n.d.; APA, n.d.).

For this study, I referred to the parents, guardians, foster parents, grandparents, family guardians, or caregivers through the school system who have the permission or consent for the cares and who take care of the affected child for treatment, management, and medical diagnosis; collectively as “Caregivers and parents.” Caregivers make extreme efforts to see the children do things like normal children. The confusing system of autism diagnostic services affects them most.

Children with ASD often communicate, interact, behave, and learn differently, which is worrisome for caregivers as the condition may extend into adulthood, (Fred & Julie, 2013). Experts in child development have recommended early intervention services, including the availability of resources and medical services to address the ASD abnormality (McCarty & Frye, 2020; Scali, 2019); & Ning et al., 2019). Studies have shown that early intervention services, especially diagnostic medical services, could create a big difference for these children and their caregivers. Specifically, the Interagency Autism Coordinating Committee (IACC,2020), report on Summary of Advances in Autism Research noted that early diagnosis of autism enhances early intervention, which is associated with improved long-term outcomes. However, most research resources are directed to finding to causes instead of what improves autistic people's lives—in a separate report of the Interagency Autism Coordinating Committee's Portfolio Analysis Report (2018), government and private entities in the United States spent over $387m on autism research. Of the expenditure, 42% went to biology, 19% to risk factors, and 13%to treatment and interventions. Only 6% of the research fund went to improving services such as diagnostics that could improve autistic people’s lives. Also, the report noted an inconsistent implementation in a real-world setting and slow referrals for at-risk children with autism in the United States.

Experts from different backgrounds on autism, including diagnosticians, child development experts, pediatricians, neurologists, and researchers, have given rise to a body of knowledge to find ways of ameliorating the management of autism. This body of knowledge also forms a base for further investigation into improving the medical diagnosis of autism. Despite researchers' and diagnosticians' efforts, a knowledge gap exists regarding diagnostic medical services (DMS) and the improvement in accessing current services for children with ASD from the caregivers' perspective. The problem is predominant among caregivers living in remote areas of Minnesota and other communities of United States. The remaining sections of the chapter are background, problem statement, purpose, research questions, and conceptual framework. The units also include the nature of the study, significance, assumptions, limitations, and delimitations of improving medical diagnostic services from the eyes of the caregivers.

Background

There is a need for early therapeutic intervention of ASD for effective diagnosis and treatment (Us department of health and human services, 2021). However, diagnosis is often delayed in some cases, partly because it is based on identifying abnormal behaviors that may not emerge until the disorder manifests. Also, the unique behavior nature of ASD makes it hard to diagnose because it does not involve urine tests, blood tests, or any form of laboratory test to identify the disorder, (CDC 2022). Usually, the medical diagnosis of ASD is a routine evaluation of a child’s developmental behavior and birth history at 18 months or under (CDC, n.d.). The CDC further explained that the full manifestation of ASD is about 2 years for a reliable diagnosis. Unfortunately, some ASD children grow up to adolescence without a regular early child development evaluation. The delay in early child health evaluation results in a high rate of ASD and early intervention

Brewer (2018) explored the experiences and challenges of mothers to steer through the health system of professional care for autism. The researcher found a complex system of improving diagnostic services and engagement of children with autism. Brewer also noted a lack of services coordination between the medical and educational systems in the United States. The present system of diagnostic service is tortious for mothers and caregivers as they struggle to find comprehensive and simplified professional care that meets the standards recommended by leading healthcare research organizations. Furthermore, Brewer noted that the experience of parents and caregivers is impacted by their low socioeconomic status and specific proximity to resources. Brewer reported that parents are often frustrated with long wait times on appointments or distance to and from seeing an autism diagnostician or specialist for their children.

Previous literature and studies regarding ASD had focused on disparity in treatment and access to resources, the need for early intervention, and factors influencing those interventions (Sapiets, Totsika, & Hastings, 2021; Zuckerman et al., 2017). Limited attention is given to the problems associated with the diagnostic system and intervention practices. Furthermore, improving access to diagnostic medical services for parents and caregivers in remote regions of the United State yet to bet been carefully addressed. Though, state governments have made considerable efforts through the school systems to provide resources to children with ASD following the reauthorized 2019 Autism Care Act, there remains a need for improving access, providing experts, and developing an integrated care system to help children with ASD (Oshima et al. 2020).

Oshima et al. (2020) examined the effectiveness of a psychoeducation program, a recently developed education program for caregivers and individuals with high functioning-ASD versus the treatment-as-usual (TAU) group. Specifically, the study assessed ASD associated with hyperactivity and impulsivity. Oshima et al. also assessed the intelligence level and other diagnostic criteria such as general anxiety, depression, panic disorder, and agoraphobia. The research showed that the type of diagnostic instrument used for ASD is critical to diagnosing the conditions of children with ASD and their parents. Oshima et al. recommended future research into the diagnosis, the type of services available to children and adolescents with ASD, and how services could be improved to allow the children the opportunity to live everyday lives.

ASD poses a problem for diagnosed children (CDC, n.d.). This problem is compounded by the failure to diagnose earlier enough and take practical measures to alleviate the menace. With 2% of children impacted by ASD (McCarty & Frye, 2020) and those that go undetected, ASD presents a significant statistic. This statistic warrants the intervention of all concerned citizens. The universal recommendation by experts to address ASD has been early therapeutic interventions and access to resources (CDC 2022). Though there are resources for early education programs, they will be more effective with early therapeutic interventions. Currently, the resources are primarily available through the school system. Also, the diagnosis of ASD is delayed for most children in remote areas of the country due to accessibility and availability of experts. Similarly, the delay may be due to the late development of abnormal behaviors that make it difficult for diagnosis to identify and establish the disorder timely (Alonim et al., 2022).

Many research ASD studies noted that early diagnosis and therapeutic intervention are primary concerns for caregivers. Sapiets et al. (2021) studied the factors influencing access to early diagnostic intervention for families of children with developmental disabilities. The authors found that while older child age facilitated recognition and identification of ASD in children without intellectual disabilities, older child age was a barrier to early intervention (EI) receipt. Furthermore, Sapiets et al. noted that the lack of early intervention is a valuable starting point to consider potential implications for policy, practice, and future research targeting investments to improve diagnosis access to EI parents of children with developmental disabilities. Sapiets et al. stated that gaps in literature also resulted in a lack of evidence and diagnosis in ASD children. In their implication for practice, the authors recommended future research investigating rates of EI access, barriers, facilitators, and moderators of access.

Also, Stahmer et al. (2019) studied caregivers' voices on improving diagnosis access to autism services. The authors found that caregivers perceive barriers to facilitating ASD diagnosis and accessing ASD-related services for underserved families. The study noted systemic challenges to accessing care for the rural populations, including black, Hispanic/Latino, and Korean communities. The results of this study called for practices and facilitators that reduce the challenges within the ASD service system. It also calls for increasing professional, family, and community education, increasing culturally responsive care, improving provider-family partnerships, and addressing practical challenges to ASD health care services and access as critical issues to the ASD community.

Therefore, the need to improve early medical diagnosis, intervention access, barriers, facilitators for children with ASD, and how caregivers deal with the situation prompted this study. Ning et al. (2019) reported that about 83.86% counties in the United States lack diagnostic resources while states with the highest diagnostic resources included West Virginia, Kentucky, Maine, Mississippi, and New Mexico. The authors noted that sparsity and uneven distribution of diagnostic resources in the United States contribute to the lengthy waitlists and travel distances. The authors recommended the need for more data through research on autism diagnosis and demand a better quantify quantified across the United States. The sparsity and uneven distribution of diagnostic resources, especially in rural Minnesota, presents a knowledge gap. This research study responds to the call for further research by Ning et al. to help bridge the gap in knowledge regarding diagnostic medical services.

Ning et al. (2019) also noted that the engagement of a combined medical and educational program for ASD in the United States lacks coordination, creating a complex situation for the families. Ning et al.'s research collaborates with the report of IACC (2020) on the need for consistent implementation and quick referrals for at-risk children with autism. The IACC report showed that over 35% of families have significant wait times before getting a diagnosis, over 41% traveled to see multiple professionals before receiving a diagnosis, and over 31% indicated a lack of available professionals. The caregivers find it difficult to get comprehensive professional care for children with autism that flows from medical to educational programs of treatment. Families face the challenges of searching for answers within the medical and educational systems. This lack of coordination has resulted in long waiting times and delays to medically diagnose the children for early intervention opportunities in rural Minnesota. The difference between the children who get earlier diagnoses and those whose parents struggle to find answers is clear. Early intervention in autism diagnosis helps access services and resources, enhances long-term lives, and educates parents about autism.

In conjunction with the CDC, the American Academy of Pediatrics (AAP) has directed a universal screening at 18 and 24 months. The AAP further recommended additional screening at 30 months to capture the late development of ASD. However, studies show low compliance by pediatricians in following this guideline (CDC, n.d.). Also, the U.S. Preventive Services Task Force (PSTF) needs to comply to a universal screening guideline (Alonim et al., 2022; CDC, n.d.). Besides the noncompliance with the screening recommendation, there exists a problem with accessing diagnostic medical services for children with ASD (Brewer, 2018). Brewer (2018) noted that the professional care system for children with ASD is fragmented, complex, and confusing. Brewer explored the mother’s experiences navigating the complex professional care system and found that engagement from the diagnosis to the treatment system is tortuous and difficult for parents. Both Ning et al. (2019) and Brewer notedthat many parents struggle to find comprehensive professional help, especially diagnostic medical care.

To alleviate the burden on caregivers, the CDC (2022) further recommends creating efficient systems for screening children who show likely symptoms of ASD. The CDC noted that developing methods to identify children at risk for developing ASD, either through consideration of medical or family history or using biomarkers, may help identify the children that require increased surveillance. The CDC also recommended improving access to diagnostic medical services and other resources and considering different treatment services and make those services available to parents in remote areas (CDC, 2022).

Caregivers face difficulties searching for answers and interventions to help their children. There are significant delays from the time caregivers report concerns to healthcare providers to subsequent referrals for evaluation and identification which result in long waiting times and delays in medically diagnosing these children for early intervention opportunities (Zablotsky et al., 2017) Also Zuckerman et al., (2015), noted that inconsistent use of screening tools and referral process delays early medical diagnosis of autism. Many caregivers were worried about the developmental trajectories of their autistic children. The reason is that the disorder's impact worsens if not diagnosed and treated in time. These children may face consistent social and daily living challenges late in life (Ozonoff et al., 2018). Some may gain essential skills over time from learned behavior, while others may show autistic characteristics more prominently at school age or older (Ozonoff et al., 2018). This study is needed to help contribute to knowledge and bridge the gap in the literature regarding autistic children and access to diagnostic medical services. It may also help advance recommendations to policymakers, caregivers, and client advocates regarding resources and access.

Problem Statement

The flaws in diagnostic instruments, poor coordination process, lack of neurological testing, and increased delays in accurately identifying ASD in children frustrate early intervention and become a social problem. Hus and Segal (2021) noted concern about accurately identifying ASD and poor coordination of diagnostic services as significant causes of late intervention and long-term autistic social problems. IACC

(2020) and Ning et al. (2019) agree that a lack of early diagnosis or delays in the diagnosis and developmental screening or monitoring is associated with lower quality of life and higher autistic traits in society, especially in Minnesota, which ranks second nationwide. The CDC statistical report (2018) predicts a 10% increase in children with ASD in the coming years, emphasizing early intervention as critical.

Therefore, I explored the caregiver challenges and barriers in accessing medical diagnostic services in a complex professional care system for children with autism. I also investigated ways to improve diagnostic services for ASD children. Unfortunately, even though the United States funds autism services, access to some of the services needs improvement (Brewer, 2018; Ning et al., 2019). Cummings et al.'s (2016) research study comparing health services use among youth with and without ASD. The researchers used logistic and count data models to examine differences in controlling demographic characteristics, comorbid physical health, and mental health conditions. Results indicated that youths with ASD had more significant need for healthcare in many categories but were less likely to receive critical early diagnosis and preventive services, including flu shots and other vaccinations. This finding is consistent with the results of other researchers such as Brewer (2018); Sapiets et al. (2021); and Stahmer et al. (2019).

A gap exists in the literature regarding access to comprehensive professional care that meets the standards recommended by leading medical research organizations for children with ASD. Specifically, access to diagnostic medical services in remote parts of Minnesota, Alaska, and other parts of the country has not been explored sufficiently.

There is a need to understand why the experience of lack of access or improvement of medical diagnostic services is more impactful for caregivers. Brewer (2018) recommended more investigations into the problem of access to essential medical services for children with ASD.

The findings from this study may contribute to the literature and help bridge the gap in knowledge by providing a balanced synthesis of diagnostic services to support children with ASD. In addition, the in-depth view of parents' feelings and experiences with access and fragmented treatment services may provide future scholars and healthcare leaders with a new insight into the discipline. Also, the findings may provide a foundation for further investigation into the study and treatment of Autism.

Purpose of the Study

In this qualitative descriptive phenomenological study, I explored the caregivers' perspective on the challenges or barriers to accessing medical diagnostic services for children with ASD in Minnesota, mainly rural Minnesota, and advancing possible improvement solutions. Many experts studying autism encourage further investigation into early intervention strategies and how to improve autism diagnosis, management, and treatment services within the care system (Brewer, 2018; McCarty & Frye, 2020; Scalli, 2018).

The CDC (CDC, n.d.) reported that many children with developmental delays or behavior concerns did not receive an early diagnosis, evaluation, or neurological testing service. Consequently, the children wait for a long time to get the help they need to do well in a social environment, school, home, and community. Unfortunately, due to significant delays that occur before diagnosis, the opportunities for intervention become low (CDC, n.d.). On the other hand, getting earlier evaluation services makes a difference in managing a child with ASD or other developmental problems (Brewer, 2018; McCarty & Frye, 2020).

This study may help reveal caregivers' experiences with children who have ASD access and use of the services, including diagnostic medical services, and their resilience in coping with uncoordinated care systems. Also, the findings may help reveal the challenges caregivers encounter and the factors that help them cope. Furthermore, the lived experiences of the caregivers may contribute to the public dialogue on the need to improve diagnostic services, and fragmented ASD treatment systems. As caregivers immerse themselves in the medical (physical and mental healthcare) and educational systems in the search for answers, they may help provide valuable information that may help bridge the gap in knowledge regarding what makes the difference for those who get an earlier diagnosis and those who do not.

Research Questions

The following research questions guided this study while follow-up questions addressed the research questions below.

RQ1: What personal and professional challenges did the parents encounter during the diagnostic process? Did they receive assistance via a health service or another entity?

RQ2: What are low-income parents' experiences with autistic children accessing medical diagnostic services?

RQ3: What health service factors do the parents consider beneficial when diagnosing their child's autism?

RQ4: What health service factors do the parents perceive as barriers in diagnosing their child's autism?

RQ5: What changes do the parents perceive necessary to improve access to and timing of an autism diagnosis?

RQ6: What factors are identified by the parents as critical in helping them cope with the diagnostic process?

Conceptual Framework

The theoretical frameworks that guided the study were Garmezy's (1991) resilience theory and the Anderson and Newman (1973) health utilization model. The resiliency theory was developed by Garmezy to describe the three main types of protective factors that form the framework of the model. The model itemizes factors that impact the individual's resilience in certain situations. The factors include (a) individual characteristics, (b) a close-knit relationship with the family, and (c) social support and structure outside their immediate family.

Garmezy (1991) noted that a person's intelligence and character form the key elements for developing resilience. According to Garmezy, resilient youths have above-average intelligence. However, children may act reasonably like average people in certain situations. Garmezy believed that social factors, including family support and external support institutions such as school, state, city, and county programs that address youth problems facilitate youth intelligent actions. Caregivers show resilience because of family and external institutional support systems that give some form of hope to them as they await services. This aspect of the theory made it a good fit for this study.

The Andersen and Newman’s (1973) framework of health service utilization was initially developed in the late 1960s by Andersen (1968. Andersen's behavioral model of health care utilization is used to explore individual and contextual characteristics that may encourage or hinder health services use. The model aims to identify the factors that may trigger the need for health assistance. The construct previses a series of predisposing, enabling, and need factors influencing people's health services usage. According to the model, predisposing factors are demographics and social structure; enabling factors include the availability of resources such as income, care availability, and access to free services, while the need factors motivate service use. Caregivers need to access health services, especially diagnostic medical services because of the need and urgency of their children’s condition.

The effective combination of the Garmezy (1991) resiliency model and the Anderson and Newman’s (1973) health utilization model provides a strong fit to explore and discuss the barriers to access care services and help advance recommendations to improve access to medical services for vulnerable ASD children. I further discuss the conceptual frameworks in Chapter 2.

Nature of the Study

The research design was a descriptive phenomenological approach involving interviews with caregivers of children with ASD. The phenomenological approach helped me explore and share an in-depth understanding of the struggles and barriers caregivers of children with autism face daily. The fundamental goal of the approach is to arrive at a description of the nature of the phenomenon's nature (Colaizzi, 1978), and I used the Colaizzi methodology to accomplish this task. Colaizzi's (1978) approach comprises of seven-step process that provides a rigorous analysis, with each step staying close to the data. The result concisely describes the phenomenon under study, and the participants validate the result. The information method depended on first-person’s experience account in face-to-face interviews, blogs, research diaries, and written narratives. The process comprises (a) familiarizing the data by reading the participant accounts several times, (b) identifying significant statements in the accounts that directly relate to the phenomenon under investigation, (c) Formulating meanings relevant to the phenomenon by carefully considering the significant statements, (d) Clustering themes to identify meanings into common themes across all accounts and avoiding presuppositions that may potentially influence existing theory, (e) Developing a detailed description of the phenomenon, including all the themes produced in Step 4, (f) Producing the fundamental structure to condense the detailed description to a statement that captures just those aspects deemed essential to the phenomenon's structure, and (g) Seeking verification of the fundamental structure from all participants, asking whether it captures their experience, and making modifications where necessary based on the feedback.

By exploring experiences, qualitative research connects themes with collected data and gives researchers an in-depth understanding of human experiences (Creswell, 2017). The qualitative method was best suited for this study because it allowed me to explore caregivers' experiences with ASD children. The quantitative research method was inappropriate for this study because it required the researcher to use standardized surveys and experiments to collect data (see Rutberg & Bouikidis, 2018). Quantitative research is not the best way to explore parents' experiences with autistic children because the researcher would have to conduct the study within the limitations of questionnaires, surveys, and experiments. Also, mixed-methods research was not appropriate for this study because it gleans from both qualitative and quantitative methodology when qualitative methods work well.

Definition of Terms

The following terms are defined to clarify the meaning and better understand the study.

Anxiety Disorder. Anxiety is a normal stress reaction and can be beneficial in some situations. For example, it can alert us to dangers and help us prepare and pay attention. However, anxiety disorders differ from normal feelings of nervousness or anxiousness and involve excessive fear or anxiety. Anxiety disorders are the most common mental disorders and affect nearly 30% of adults at some point (APA, 2020).

Applied Behavior Analysis (ABA). ABA encourages desired behaviors and discourages undesired behaviors from improving various skills. Progress is tracked and measured. (CDC, 2021)

Autism Spectrum Disorder (ASD). ASD is a developmental disability that can cause significant social, communication, and behavioral challenges (CDC, 2020). APA (2020) considers ASD a complex developmental condition involving persistent difficulties with social communication, restricted interests, and repetitive behavior. While autism is regarded as a lifelong disorder, the degree of impairment in functioning because of these challenges varies between individuals with autism (APA, 2020).

Caregiver. A person who provides direct care (for children, older adults, or the chronically ill (Merriam-Webster, n.d.).

Discrete Trial Training (DTT). DTT uses step-by-step instructions to teach a desired behavior or response. Lessons are broken down into their simplest parts, and wanted answers and behaviors are rewarded. Undesired answers and behaviors are ignored. (CDC, 2021)

Medical Diagnosis. Identifying a disease, illness, or problem by examining someone or something (Merriam-Webster, n.d.)

Screening. Medical screening is a method for detecting disease or body dysfunction before an individual typically seeks medical care. Screening tests are usually administered to individuals without current symptoms who may be at high risk for specific adverse health outcomes (U.S. Department of Labor, 2021).

Obsessive-compulsive disorder (OCD). OCD is when people have recurring, unwanted thoughts, ideas, or sensations (obsessions) that drive them to do something repetitively (compulsions). Repetitive behaviors, such as hand washing, checking on things, or cleaning, can significantly interfere with a person's daily activities and social interactions (APA, 2020).

Pivotal Response Training (PRT): PRToccurs naturally rather than in a clinical setting. PRT aims to improve a few "pivotal skills" that will help the person learn many other skills. One example of a critical skill is to initiate communication with others. (CDC, 2021)

Assumptions

In this study I assumed the following: (a) The sample size of study participants represents the general population of caregivers of children with ASD, (b) Study participants relied on the confidentiality arrangement to comfortably respond to interview questions and share their experiences freely, and (c) All participants in this study honestly answered interview questions without reservation. I did not have control over these assumptions.

Scope and Delimitations

Delimitations make a study better understood and more feasible. They also identify the constraints and weaknesses of the study that were outside the researcher's control (Creswell, 2018). The research problem is barriers to accessing medical diagnostic services for children with ASD including issues of the fragmented professional care system and possible improvement. The study is explicitly limited to the experiences of the caregivers. The result findings are also limited to the research methodology and sample population, especially that of participants in remote areas of the United States. I did not cover the caregivers who have access to diagnostic medical services and live in urban areas of Minnesota. I limited this research to the selected sample of participants and hoped that their responses answered the research questions and spoke to the experiences of parents with autistic children.

Limitations

Research projects have limitations, and it is often credible that the researcher includes the study limitations so that the audience will view the findings as credible if they know that certain aspects that impact the study were considered (Staff Writer, 2020). The study was limited to a qualitative descriptive phenomenological methodology using interviews for data collection. Time constraints and funding prevented me from conducting a longitudinal or extended study with a larger sample population in different locations within the United States.

One limitation of using interviews is that the researcher's presence could influence participant response Ross, at al., 2019). Furthermore, the researcher’s involvement in directing the discussion puts the researcher directly into the data collection process, thus impacting the process. In addition, the data collection from parents who may be biased in their responses could impact the trustworthiness of a study (Ross et al., 2019). Other research limitations concerning methodology include small sample sizes and diversity in sample sizes based on volunteer participants (Boddy, 2016). I did my best to follow ethical research practices and avoid any biases in the study to ensure integrity and report any issues that could have impacted the results.

Significance

The study is significant because it may help fill the gap in understanding autism diagnosis and treatment services problems, especially medical diagnostic services. Studies have shown that early diagnosis is critical to helping children with ASD and their caregivers gain early access to needed resources and treatment, improving development and functionality.

Generally, the study may help to explore the perspectives and understanding of parents with children who have autism, outline barriers the caregivers face in accessing diagnostic medical services, discuss the psychological impact of their experiences, and highlight the complexity of the care system. As a result, the research findings may also help advance recommendations to improve service quality and reduce wait times and misdiagnosis of ASD children. In addition, the findings may help provide information to administrators, legislators, researchers, and health policy planners and help contribute to a positive social change to address the problem of ASD.

Researchers have conducted many studies on ASD. However, most of the studies addressed early intervention in ethnic and socioeconomic disparity, (Sapiets, et al., 2021). In addition, minimal literature exits regarding improving the uncoordinated treatment services and barriers to accessing diagnostic medical services for parents in remote areas of the United States (Brewer, 2018). This completed study may support previous studies or create a new perspective that could broaden the context and knowledge of ASD. The knowledge gained from this study may help remedy the strains caregivers face. Furthermore, the study may provide in-depth insight into the thinking of parents with children with ASD and help bridge the gap in evidence based on what is gathered from this study and what is known from the findings of other related studies.

Summary

The objective of this chapter was to discuss the background, problem statement, purpose of the research, research questions, conceptual framework, nature of the study, and significance of the study. In Chapter 2 I review the current literature about ASD, the resiliency and health utilization models, associated studies, barriers to accessing diagnostic medical services and other treatments for children with ASD, and other relevant topics to give more insight into the research.

Chapter 2: Literature Review

In Chapter 2 I review the current literature and examine the peer-reviewed articles on ASD in children and caregivers' experiences. The preliminary section of this chapter includes the search strategy for related literature. In the second section I present the conceptual framework and historical context of this study. Finally, the third section provides the underpinnings of caregivers' experiences accessing diagnostic medical services and related resources for their children.

In this study I explored the caregiver challenges and barriers in accessing medical diagnostic services in a complex professional care system for children with autism. My findings may identify ways to improve diagnostic services for ASD children. The goal was to highlight caregivers' experiences, provide further insight into the diagnosis challenges of children with ASD, and advance recommendations for improving access to services. Brewer (2018) recommended more research studies into parents' experiences accessing services, how the process can improve autistic children's lives, and ease the burden on parents.

Researchers have conducted many studies into diagnosing and treating ASD in children see (Brewer, 2018; Sapiets et al., 2021; Siddiqua et al., 2020). Most of the recommendations advanced by the researchers relate to disparities in treatment, socioeconomic status (SES) impact on access to resources, and differences in the preponderance of ASD along ethnic lines. However, studies have yet to examine improving caregivers' access to diagnostic medical services in remote parts of the United

States, mainly rural Minnesota. Though ASD is well-funded in the United States, there is limited attention to improving access to medical diagnostic services.

Literature Search Strategy

The literature presents limited evidence regarding the relational elements of caregivers' burden and professional medical diagnosis support assistance. A search about ASD in children, including diagnosis, treatment services, access to services, and the disparity in diagnosis, deploys Anderson and Newman's health utilization and the Garmezy's resiliency models as a framework. Each search used the following databases: ProQuest Dissertation, Thesis Global, World Cat 5, Academic OneFile, Lexis Nexis Academic, Thoreau, Research Square, as well as the Google Scholar, ProQuest database, Sage, Walden University library, Medgar Deep Medical Search, Government databases, and the American Psychiatry Association.

I focused on caregivers' experiences with the diagnosis of ASD, treatment resources, access to services, and system improvement. I examined relevant peer-reviewed articles on ASD within 5years of publication, while seminal papers reviewed to validate the theoretical foundation and other seminal works related to the study are exceptions.

Conceptual Foundation

Garmezy's (1991) resiliency model and Anderson and Newman's (1973) health utilization model provided the conceptual frameworks for this study. The collaboration of these two models helps provide a theoretical foundation to understand the phenomenon under study.

Garmezy Resiliency Model

There is little consensus on an exact definition of the term *resiliency*. While some researchers consider it intrinsic to the individual, others consider it more holistic (van Breda & Adrian, 2018). van Breda and Adrian (2018) described resilience as people's competencies and ability to function in adversity. Kim et al. (2019) suggested that resilience is simply an individual's ability to cope with experienced stress. Garmezy (1991) considered resilience to be an individual’s intelligence level and ability to tackle an adverse situation.

The Garmezy (1991) resiliency framework allows researchers and providers to examine caregivers’ strengths of children with ASD and face challenges in accessing needed medical diagnostic services and treatment resources. Resilient individuals can show functional adequacy despite the emotional turn (Garmez, 1991). The resilience theory also suggests that someone with remarkable resilience is not necessarily courageous despite adversity. Even though some caregivers find medical diagnostic services and other autism support systems hard to access, they show resiliency. Garmezy identified three protective factors associated with resilience. These factors enable individuals to exhibit resiliency under various challenging conditions: (a) individual characteristics, (b) affinity with the family, and (c) external social support and structure. Garmezy identified that a person’s intelligence and character are basic elements in developing resiliency. For example, a resilient youth who has above-average intelligence in addressing challenging situations is aided by the second factor, family support, and the third factor, external support from institutions.

Though the autism spectrum is broad, research studies have identified significant factors contributing to resilience in children and adolescents. Some of these factors include (a) effective parenting; (b) close relationships with responsible individuals; (c) close friends and romantic partners; (d) activities involving intelligence and problem solving; (e) self-control, emotion regulation, and playfulness; (f) motivation to succeed; (g) self-efficacy; (h) faith, hope, and belief that life has meaning; (i) effective schools; and (j) influential neighborhoods and collective efficacy (Ozonoff et al., 2018). The application of these factors helps to understand resilience in autistic people. Unfortunately, there has been little or no attention to resilience in autistic children and their parents and caregivers (Howlin & Magiati, 2017). As a result, it becomes crucial to explore the feelings of caregivers' resilience in dealing with poor access to diagnostic medical services for children with autism.

Celene et al. (2017) noted that resilience is how parents cope with ASD children, especially when experiencing negativity in the family, school, and social settings. It also pertains to the parent's relentless strive to seek resources for their autistic children. Celene et al. used a descriptive, nonexperimental, cross-sectional, and correlational study to investigate the relationship between the potential resilience factors of parents of children with ASD and disability acceptance and family functioning. Celene et al.

administered a Resilience Potential Scale, a Family Functioning Scale, and a Semantic Differential Scale to 80 primary caregivers to fill to the best of their experiences. The study showed the coexistence of risk and protective factors in parenting autistic children. It also showed a strengthened emotional bond among parents when seeking help to solve problems inherent in having children with ASD (Celene et al., 2017). However, the researchers noted that when parents display distress and anguish over their autistic children, they show emotions such as slight tolerance and inconsistent rules within the family. The negative emotions indicate poor adaptability to having children with ASD and a sign of hopelessness associated with the non-acceptance of disability. On the other hand, parents' self-determination and resilience help them seek external support and maintain adequate family functioning.

Kuhlthau et al. (2020) noted that parents of children with ASD often are at risk of chronic stress dealing with the children's present and perceived future conditions and lack of access to needed diagnostic medical services. The authors conducted a study to determine the feasibility, acceptability, and preliminary efficacy of adapting virtually delivered Stress Management and Resilience Training-Relaxation, Response, Resiliency Program (SMART-3RP) for caregivers of children with ASD. The research adopted a randomized controlled trial waitlist-controlled group design. Results indicated that the virtually delivered SMART-3RP for caregivers was promising. Its use may relieve them from the challenges faced in accessing some of the services for children with ASD.

In a similar research study, Mahapatra et al. (2019) explored the effects of resilience in a survey of parents' perception of ASD and recognition of early signs of ASD. The researchers also examined parents' treatment-seeking pathways, experiences, and challenges in the overall process. The researchers found that most parents observed that their children had social difficulties but could not fathom or associate it with ASD. The research findings showed that most parents were not aware of ASD and have not heard about ASD before diagnosing their children. According to the findings, the parents consulted multiple professionals to confirm the diagnosis.

The research findings further showed that parents travel far to diagnose their children and, in most cases, consult child psychiatrists for help, (Mahapatra, et al., 2019). The researchers further noted that child psychiatrists usually referred caregivers to rehabilitation centers that do not remedy ASD. The study emphasized that parents searched hard for diagnostic services and were resilient, attempting to access services for their children (Mahapatra et al., 2019). The research authors collaboratively noted the importance of the resilient temperament of parents in facing the challenges of accessing diagnostic services and other related services for their children. The authors recommended designing awareness, presenting evidence, and providing data through further research. This attention may lead to improvement of medical diagnostic service distribution and early treatment of children with ASD. The lack of awareness, resilience, and availability of services contribute to stress, and the delay in ASD diagnosis, (Mahapatra et al., 2019).

In addition, Roberts et al. (2017), in a research study on resilience in families of children with ASD and sleep problems, showed that there is a family's progression to resilience in dealing with the strains of sleep problems of ASD children. They noted that 80% of ASD children have sleep problems capable of disrupting family sleep functionality. According to the study, 57% of the parents of ASD children with sleep problems improve resilience while the children's socialization revamps over time. Based on the study findings, Roberts et al. advocated community support for strengthening resilience as part of the intervention for parents of ASD children.

In separate studies, Renee (2017) and Ning (2017) explored the resilience of parents raising children with autism and dealing with the challenges of accessing help resources, quality health care, and specialty services. Renee focused on the resilience of low-income parents of children with autism suffering from stress, depression, decreased social interaction, and poor marital satisfaction. Renee's outcome of becoming resilient in searching for diagnostic medical services and other resources for the parents is consistent with Ning (2017). Similarly, Ning's focal point was on the sparsity of medical diagnosis resources that contribute to lengthy waitlists and distance travel. Ning's study proposed additional data to quantify the resource need that may enhance caregivers' burden and resilience.

Renee (2017) also recommended future research to determine how specialized daycares and therapeutic services could benefit low-income parents of children with autism and society. Renee further suggested additional research on providing adequate resources that would enhance resilience in dealing with ASD children and reduce stress on families of autistic children. The resiliency in accessing needed medical resources and using health services by parents of ASD children presents a perfect foundational framework for this study.

Limitations to the Resiliency Theory

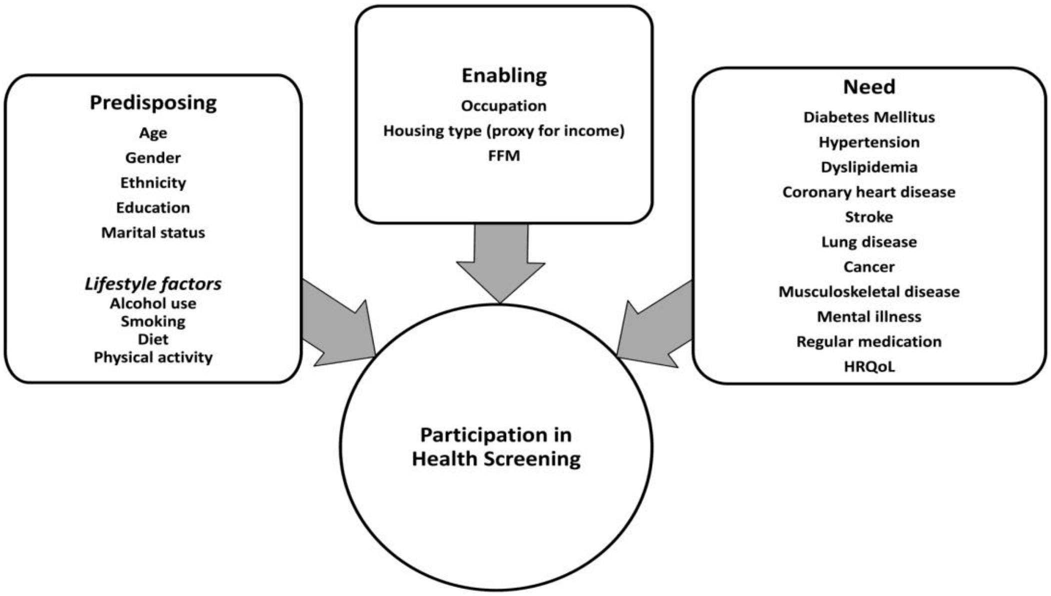
The inherent limitation of resilience-based approaches is susceptibility to adaptive traits. Resilient caregivers of ASD children can be prone to adapt to extremely harsh conditions without strategizing or implementing ways to overcome the challenges. The resilient caregivers become tolerant of the ASD children's condition without trying to challenge and improve the situation. While Chamorro-Premuzic and Lusk (2017) recognized the salience of resilience in coping with ASD children, the authors noted that over-resilience could hinder innovation and make resilient caregivers overly tolerant of the affliction. Multiple studies also suggested that even some abreast resilient caregivers are unaware of how and when to implement a transformation process that could help the ASD children transition to typical life due to adaptive resilience traits. For example, Leichenko, McDermott, & Bezborodko (2015) noted that advocating resilience is as much as bracing for a lengthy and challenging situation because, according to their study, resilience could limit effective strategies for early intervention and amelioration of the ASD children. Investigating resilience options and barriers resonates with parents and caregivers facing barriers to accessing diagnostic medical services and other resources for ASD children.

The Anderson and Newman (1973) Health Utilization Model

Andersen and Newman's (1973) Behavioral Model of Health Service Utilization, otherwise known as the Behavioral Model (MB), developed in the late 1960s by Ronald M. Andersen, is a framework that helps to understand human deportment on healthcare services use. It is a theoretical model that explores the factors influencing or hindering a person from taking advantage of health care services. The model identified three multilevel predictors: predisposing, enabling, and need factors as triggers for using health services. Anderson and Newman's model noted that the predictors arising from either personal or contextual determinants of health service use depend on the supply-induced healthcare structure of society. The predisposing factors are biological imperatives describing the demographics and social structures that enable individuals to utilize healthcare services. It includes sex, age, education, occupation, ethnicity, and value factors. The enabling factors of BM are related to financial empowerment, income, and wealth status at disposal. The model predicts that available resources, income, and access to free services enhance health services utilization. Finally, the need factors, either perceived or clinically evaluated, motivate healthcare service use. Individual levels of illness symptoms and state of functionality trigger a need for healthcare utilization. (Anderson & Newman, 1973). (See Figure 1. below).

Figure 1

The Anderson and Newman Health Utilization Model



*Note.*Source*: https://www.researchgate.net/figure/Anderson-and-Newman-Health-care-model-of-Health-care-utilization_fig1_341005468.*

Over the years, the Anderson (2011) Behavioral Model of health service utilization has had multiple layers and versions, allowing various fields of studies to adopt it as a framework. It is pliant to the ASD healthcare system; for instance, the perceived or clinically evaluated need indicator such as ASD determines the use of healthcare services. Myint Htut, Elsie Ho, and Janine Wiles (2019) noted that the complexity of the ASD landscape and the high demand for care services make it difficult to access health services due to a need factor. It also contributes to long waitlists, especially in publicly funded ASD healthcare services. Notwithstanding the complexity and challenges in the ASD landscape, Anderson's BM provides a perfect framework for this study in understanding the behaviors of ASD care caregivers’ use of health services and how caregivers go all out to meet the need factor.

In a research study exploring Anderson's health service utilization model to identify factors that leverage or hinder the use of antenatal healthcare services in the Kersa district of Eastern Ethiopia, Tesfaye, Chojenta, Smith, and Loxton (2018) they were noted that predisposition influenced the use of antenatal services. The cross-sectional study of the district comprised 1294 eligible women using a face-to-face interview approach. The findings showed that out of the 1294 respondents, 53.6% attended antenatal care at least once; 15.3% attended at least four visits. Out of the participants, 32.6% used antenatal healthcare services. Further study showed that predisposing factors such as education, previous use of antenatal care, and best friend referral were associated with the use of antenatal care. According to the study, other contextual characteristics of enabling and need factors, such as the attitudes of husbands or heads of household, perception of potential pregnancy complications, and consequences of abortion, predict the use of antenatal care services in the district. The antenatal study paralleled the ASD study in a way that caregivers in need (need factor) of helping ASD children go all out to seek help.

Similar studies also used the Anderson-Newman health utilization service model to study different phenomena. Azfederick (2016) used the Anderson-Newman health utilization model to study the use of services by adolescent girls in South-eastern Nigeria.

The author examined the predisposing characteristics of healthcare services use, such as age and enabling factors such as parental support, parental communication, and type of reproductive health facility. The study associated the need factor with the emotional condition of adolescent girls. The study showed that predictors of Anderson BM, such as age, emotional state, and type of reproductive health facility, predicted adolescents use of reproductive health services. The primary benefit of the Anderson BM is that it helps to understand the patterns of health care service utilization. For example, antenatal health service use, reproductive healthcare use, and the ASD caregivers' health utilization help direct services where they are most needed.

Weiss, Isaacs, Diepstra, Wilton, Brown, McGarry, and Lunsky (2018) studied health concerns and health service utilization, using Anderson BM as a framework. The study compared the patterns of health needs and health service use between young adults with ASD and other developmental disabilities (DD). Weiss et al. hypothesized that young adults with ASD would have higher rates of common chronic medical conditions, psychiatric diagnoses, and greater levels of specialized primary care, including emergency and hospitalizations, compared to young adults with and without other DD. Therefore, children having ASD may have more need to utilize health services. The health variables considered were common diseases and mental problems. The health services variables used in the study were family physicians, pediatricians, specialists, and Emergency Department (ED) visits. The results showed that younger adults with ASD visited the primary pediatrician, psychiatrist, physician, neurologist, gastroenterologist, and ED for psychiatric reasons more than the non-DD category. The Anderson BM as a framework will help identify the pattern of ASD healthcare utilization, where ASD healthcare services are most needed, and how the distribution of the services will meet the needs of ASD children and improve the caregivers' experiences. However, there are some criticisms of Anderson Healthcare Service Utilization.

Limitations/Criticisms of the Anderson-Newman Health Utilization Model

The most widely accepted criticism concerns the health utilization model as a factor that could be either present or absent is the need for adequate attention to culture and social interaction. Although Andersen argues that social structure is part of the predisposing characteristics component of the model (Anderson & Newman, 1973), cultural inclusion was lacking. Another criticism is dwelling so many need factors over the health beliefs system.

Autism Spectrum Disorder (ASD)

The CDC (2021) considered ASD a developmental disability that could cause significant social, communication, and behavioral challenges in children. The condition may progress into adulthood if early treatment intervention is delayed. The CDC reported that people with ASD may learn, behave, communicate, and interact differently from most other people. The spectrum of learning, thinking, ability, and solving problems of people with ASD may range from talented to severely challenged or impaired (CDC, 2021).

The Institute of Mental Health (n.d) disclosed that ASD is a developmental disorder that impairs behavior and communication. Although autism is a developmental disorder that shows up generally in the first two years of life, experts in the mental health institute believe the diagnosis could occur at any stage in life.

Diagnosis Criteria for ASD

Accurately diagnosing ASD has challenged many clinicians as the condition manifests itself differently. CDC (2020) gave an update on the diagnosis of ASD. Currently, the Center has expanded the diagnosis inclusion criteria of ASD to several previously considered conditions: autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger syndrome (CDC, 2020). A catalog of all these conditions is now called autism spectrum disorder (CDC, 2020). The American Psychiatric Association (APA) created a guide for clinicians to diagnose diseases of ASD outlined in the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-5*).

According to the APA, children with ASD have 1) Difficulty communicating and interacting with people. 2) Restricted interests and repetitive behaviors. 3) Symptoms that could impair the ability to function suitably in school, homes, workplaces, and other areas of life (APA, 2021). ASD could be a long-life disorder without intervention as early as possible. It is not explicitly related to any ethnic group or class. It occurs in all ethnic, racial, and economic groups. According to the American Psychiatric Association (APA), to meet diagnostic criteria for ASD, a child must have persistent deficits in social communication and interaction in at least two of four types of restricted, repetitive behaviors or severity. In addition, the APA reported that a child with ASD must currently or have manifested persistent deficit in social communication and interaction in the following ways: 1) Deficits in social interactions, for example, failure to hold a normal conversation, loss of interest, or emotions, or failure to show gesture. 2) Failure in nonverbal behaviors, including lack of eye contact or body language. 3) Unable to develop, maintain, or understand relationships, including difficulties in sharing play or making friends.

The APA (2021) and CDC (2021) identified that children with ASD have specific severity of social communication, impairments, and repetitive and restricted behavioral patterns. These restricted, repetitive patterns of behavior, interests, or activities manifest in two of the following: 1) Repeated movements, use of objects, or speech. 2) Lack of consistency on sameness, inflexible adherence to routines, or ritualized verbal or nonverbal behavior patterns. 3) Abnormal fixated interest or strong attachment to unusual objects. 4) Hyper or hypo-reactivity to sensory input, such as indifference to pain, adverse response to specific sounds, excessive smelling or touching of objects, and visual fascination with lights or movement (APA, 2021; CDC, 2021). The conditions outlined must be current or past in the child (CDC, 2020).

Also, APA (2021) and CDC (2020), in a separate submission, noted that children diagnosed with ASD based on social communication impairments and restricted and repetitive behavior patterns have the following symptoms: 1) Symptoms present in childhood but not fully manifested or absorbed by learned behavior. 2) Symptoms must cause significant handicaps in social skills. 3) Symptoms cannot be attributed to intellectual disability or developmental delay, although the two co-occur. Therefore, comorbid ASD and intellectual disability diagnoses often include social communication impairment (APA, 2021; CDC, 2021).

Additional Conditions for Diagnosis of ASD.

The APA (2021) further advanced that individuals with autistic disorder, Asperger's disorder, or pervasive developmental disorder (DSM-IV) should be diagnosed with ASD. In addition, there is a need to evaluate individuals with a severe deficit in social communication, even though they are not autistic, for social and pragmatic communication disorders. However, in such cases, the APA (2021) indicated that the clinician must specify the following in the diagnosis: 1) The ASD condition is with or without accompanying intellectual impairment. 2) The ASD is with or without accompanying language impairment. 3) ASD is associated with a known medical or genetic condition or environmental factor with an additional code to identify the associated medical or genetic condition. 4) The ASD is associated with another neurodevelopmental, mental, or behavioral disorder, and they must have coding notes to identify the associated behavioral disorder. 5) The ASD relates to catatonia associated with another mental disorder with coding notes; the catatonia must indicate the presence of comorbid catatonia (APA, 2021).

Screening Tools for Autism Spectrum Disorder

In the past decades, many new screening tools for ASD have emerged with the development of advanced technology and enhancements. The CDC (2021) identified the following means.

Ages and Stages Questionnaires (ASQ) - The ASQ®-3)

Scholars wondered if early educators and health care professionals use a developmental screening tool. The ASQ relies on parents as experts, and it is easy to use, family-friendly and creates the snapshot needed to catch delays and celebrate milestones. The (ASQ®-3) is a general developmental screening tool consisting of 19 age-specific questionnaires screening communication, gross motor, fine motor, problem-solving, and personal adaptive skills; results are in a pass/fail score for domains.

The ASQ-3 questionnaires are available in Arabic, Chinese, English, French, Spanish, and Vietnamese. The tool has the following characteristics: 1) It Takes just 10–15 minutes for parents to complete and 2–3 minutes for professionals to score. 2) Captures parents' in-depth knowledge. 3) Highlights a child's strengths as well as concerns. 4) Each parent about child development and their own child's skills. 5) Highlight results that fall in a monitoring zone to make it easier to keep track of children at risk. 6) Can be completed at home, in a waiting room, during a home visit, or as part of an in-person or phone interview.

Many clinicians across the United States rely on ASQ-3 as an assessment tool because of its validity, reliability, and accuracy. The ASQ-3 is cost-effective, easy to score in just minutes, and researched and tested with an unparalleled sample of diverse children. In addition, the tool provides a great way to partner with parents, makes the most of their expert knowledge, and is fun and engaging for kids. Lamsal, Dutton, and Zwicker (2018) conducted a National Longitudinal Survey of Children and Youth (NLSCY) from cycles five to eight. The researchers calculated the sensitivity, specificity, and positive and negative predictive values for the ASQ at 24, 27, 30, 33, 36, and 42 months. The researchers used fixed effects regression analyses to assess longitudinal associations between domain scores and child age.

The results showed that the specificity for the ASQ tool was high, making it practical to detect children who will not develop an NDD. The researchers noted that the sensitivity for the 1 SD cutoff at 24 months was above the recommended value of 70% for screening. Differences in ASQ domain scores between children with and without NDD increase with age. Lamsal, Dutton, and Zwicker (2018) concluded that the ASQ's high specificity and negative predictive values support its use in identifying children who are not at risk of developing an NDD.

Communication and Symbolic Behavior Scales (CSBS)

The CSBS is a standardized tool for screening communication and symbolic abilities in infants up to two years of age. Blume, Wittke, Naigles, and Master George (2021) use the CSBS to assess social communication in infants. The authors suggested that the CSBS is robust as it characterizes specific aspects of social communication. In addition, the results indicated that multiple social communication elements significantly interact with early spoken language to predict later. The researchers also highlighted a transactional relationship between early spoken vocabulary and social communication skills that bolster infant language development.

Parents' Evaluation of Developmental Status (PEDS)

is an evidence-based screening tool developed to elicit parents' concerns about their children's language. The evaluation toolkit covers a parent-interview form, a single response form used for all ages, and screens for developmental and behavioral problems that need further evaluation. It may also be helpful as a surveillance tool. To authenticate the dependability of PEDS, Sheeran, Zhao, Buchanan, and Xenos (2021) used the PEDS to investigate maternal and child health (MCH) services. The authors also noted that nurses use the PEDS to identify children at risk of developmental delays from birth to school age. The results show that nurses at MCH surveyed had more confidence in screening older children than children younger, about 12 months. However, out of the 19 nurses, 15 did not have accurate knowledge and skill in using PEDS and Brigance screens. Furthermore, in the focus group interviews, time restraints, the language used in developmental screening tools, and excessive waiting time for referral were raised as critical barriers to identifying at-risk children. Sheeran, Zhao, Buchanan, and Xenos (2021) recommended adequate training in using the instrument for better results.

Modified Checklist for Autism in Toddlers (M-CHAT) –

is a screener that helps to identify the behavior of children between the ages of 16 and 30 months. Parents complete a questionnaire of about 20 questions tailored to identify toddlers at risk for autism and determine whether further evaluation is necessary. The screening tool discovers if a child has autism or if there is a concern about autism symptoms.

Screening Tool for Autism in Toddlers and Young Children (STAT)

is an interactive screening tool for children with suspected developmental concerns and autism. The STAT is designed mainly for children between 24 and 36 months of age and consists of 12 interactive activities. The tool assesses play, communication, and imitation skills and takes 20 minutes to administer.

Diagnostic Medical Services

Early access to diagnostic medical services is crucial to the development and functioning of children with ASD. Unfortunately, according to the IACC (2020) report, many false negative screens were associated with children receiving only one diagnosis. Earlier research Blumberg, S.J et al. (2015) showed misdiagnoses of children with autism. Most children labeled with autism were later confirmed not to have autism, the report revealed. Also, Psychology Today (2015) showed that many children diagnosed with autistic had language delays. In another research, Bachman (2018) observed significant misdiagnoses where children with low IQ or learning difficulties are labeled autistic. A recent study, Camilla et al. (2021) reported that over 75% of ASD diagnosis were confirmed 8 years after first their mental evaluation. The study further noted estimated 70% to 80% of children with ASD had diagnosis of another psychiatric condition. The poor diagnosis of autism, delays in waitlists, and disparity in screening significant major challenges among the caregivers. The IACC report further noted a disparity in screening across race, sex, and socioeconomic status, which constitute delays in diagnosis.

Many caregivers in remote areas of the United States face many challenges to accessing services like diagnostic medical services **(**Carlsson, Maniscalco, kadesjo, & Laakso, 2016). Caregivers of children with autism have been resilient in seeking assistance for their children. Several enabling factors, including family and community support, socioeconomic status, educational level, and the self-will of the caregivers themselves, support this resiliency. Even though most of these services are available through the school system in the United States, some caregivers still face barriers, including the physical and mental stress of accessing these services in time. Also, the available services lack experts such as child neurologists who could carry out neurological and genetic testing to eliminate or confirm certain disorders that may cause symptoms of autism.

The complex interaction between autism healthcare and the unique educational system leaves autism caregivers confused and complicates access to services. Understanding that parents may be more knowledgeable about their children's behaviors than diagnostic service professionals, the researchers recommended that including parents in the diagnostic process would be necessary just as involving brain medical experts. Nicola Davies (2022) noted that neuroimaging laboratory tests might be carried out to determine the presence of seizures in children with ASD, adding that the ASD brain is more prone to seizures and epilepsy due to its link to genetic factors. According to the researcher, 30% of patients with ASD are diagnosed with epilepsy and seizure. Unfortunately, access to such expert ASD services is challenging for caregivers, especially in the rural areas of Minnesota.

Carlsson, Maniscalco, kadesjo, and Laakso (2016) involved 100 children with Autism from 2009 to 2011. The study aimed to increase understanding of parents' lived experiences of the neuropsychiatric process in children with ASD from the initial screening to the 2-year follow-up of the ASD diagnosis. The researchers identified three themes during the interview: seeking knowledge, trusting and challenging experts, and being empowered. Their findings revealed that caregivers expected intervention to start immediately after diagnosis but felt left alone to fight, access, and obtain resources for their children. In addition, caregivers continued to lament being left alone to manage their children's situation even though the diagnosis provided them with vital information. Carlsson, Maniscalco, kadesjo, and Laakso (2016) recommended developing a checklist outlining relevant contacts and agencies, establishing a coordinator responsible for each child, having two parts of the summary meeting in the clinic to facilitate clarity, and making more than one visit to the preschool and providing a parental training program.

In another study, Hurt et al. (2019) reported that parents faced significant adverse experiences in accessing diagnostics healthcare services for their children, and few improvement studies have focused on this area. Hurt et al. (2016) conducted a survey describing current care pathways for children with Autism. They included parameters such as enablers and barriers experienced by health professionals, education professionals, and families in South Wales, UK. The study aimed to describe the care pathways experienced by health professionals, education professionals, and families, understand the enablers and barriers when operationalizing the paths, and identify potential areas for better integration and collaboration. Data analysis showed that parents clearly distinguished between the pathway to diagnosis and post-diagnosis support paths but complained about the confusing state and difficulties obtaining assessments. Furthermore, parents expect the healthcare support system after diagnosis, but there is no pathway for post-diagnosis support (Hurt et al., 2019). Hurt et al. (2019) summarized that the parents found their journey to diagnosis stressful and confusing, with limited structure or direction and a lack of consistency.

The researchers recommended improving service delivery and an integrated system to help the children and their caregivers in all the studies.

Summary

The objective of chapter two was to present an overview of the literature regarding ASD and the theoretical framework that guides the study. The chapter also highlights the gap in the literature, precisely the challenges of caregivers' access to diagnostic medical services in remote areas of the United States, especially Minnesota. It further reiterates the benefits of diagnostic services improvement and how the Gamezy Resiliency Theory and the Anderson and Newman Health Utilization Model support the study. Chapter three analyzes the research design and methodology, including the selection of participants, data collection and analysis plan, trustworthiness, and ethical considerations.

Chapter 3: Research Method

In this qualitative phenomenological study, I explored the challenges or barriers to accessing medical diagnostic services by families with children with ASD, mostly in rural Minnesota, and possible improvement recommendations. The complexity of autism diagnosis and treatment services resulted in a fragmented professional care system creating disparities and barriers for families with ASD children (Lee, et al., 2021). The experience has been long waiting times and misdiagnosis or late diagnosis for these children. There is a need to explore caregivers' experiences in accessing diagnostic medical services and note the difference between those children who receive early diagnosis and those who do not. Furthermore, this study was an integral part of exploring the challenges these caregivers face in their quest for services and the factors that influence coping with the complex system of benefits. An analysis of the results of this finding may be beneficial to bridge the gap between what we know and what the study revealed. Scalli (2018) recommended further investigation into this problem to help provide a better insight into the phenomenon.

Chapter 3 provides an overview of this research study, design, and rationale, including the various themes under investigation. I identify the method, both explaining and justifying my choice. The research design aligned with the research questions and the study's overall objective to help advance social change through future knowledge of healthcare services and the financial implications embedded therein. Chapter 3 also includes an overview of the methodology used for this study, including the target population, the sampling procedure strategy, and how the data was selected and processed. I explained the sample size selection procedure. Furthermore, I address threats to validity, ethical considerations, and a summary of Chapter Three.

The following research questions will guide the study with some follow-up questions for clarification:

RQ1: What personal and professional challenges did the parents encounter during the diagnostic process? Did they receive assistance via a health service or another entity?

RQ2: What are low-income parents' experiences with autistic children accessing medical diagnostic services?

RQ3: What health service factors do the parents consider beneficial when diagnosing their child's autism?

RQ4: What health service factors do the parents perceive as barriers in diagnosing their child's autism?

RQ5: What changes do the parents perceive necessary to improve access to and timing of an autism diagnosis?

RQ6: What factors are identified by the parents as critical in helping them cope with the diagnostic process?

Research Design and Rationale

For this study I used a qualitative research methodology using interviews. I explored the challenges or barriers to accessing medical diagnostic services and the experiences of families with ASD children in rural Minnesota and finding possible solutions. Autism misdiagnosis and poor treatment services results in an uncoordinated professional care system creating disparities and barriers for families with ASD children (Lee, et al., 2021). The experience has been long waiting times and misdiagnosis or late diagnosis for these children, (Blumberg, S.J et al. 2015). There is a need to improve services that enhance access and provide comprehensive treatment for all families.

Qualitative methodology best fit this inquiry because it helped me identify and explore themes that emerged from in-depth interviews with parents of children with ASD. Specifically, discussions helped bring out these parents' in-depth experiences and providers' perspectives regarding access to medical diagnostic services for these vulnerable children. Quantitative methods may serve the purpose; however, they may need more in-depth insight into parents' experiences and provider perspectives on the phenomena under study (see Creswell, 2018). The central qualitative technique helped me produce rich and descriptive data to understand the participants lived experiences and realities, (Munhall, et al. 2012). It was important to hear the voices of participants, how specific words by participants help to identify themes, and how the setting and context of the research situation helped to appreciate the phenomena. Besides, qualitative research questions allowed me to get more information from participants which quantitative or any other method of research could not offer me.

Role of The Researcher

A researcher's role is vital to any research. In a qualitative study, the researcher is the primary instrument, directly interacting with participants to plan and deliver study methods (Soh et al., 2020). For this study, I was the primary instrument for collecting data from in-depth interviews, observing participant behavior, taking notes, and coding the data to identify emerging themes and patterns. In a qualitative study, the role of the researcher is emphasized as an observer-participant who investigates the experiences of a specific group in society (Williams & Morrow, 2009). Part of my role in this study as an observer-participant was facilitating a relationship of trust in which participants feel comfortable sharing their experiences.

As a researcher, I had no relationship with the participants. There was no power exertion in any form, including any personal and professional relationships with participants, or supervisory or instructor relationships, that may reflect undue influence over the participants. I ensured my actions did not influence the study by remaining as neutral as possible, deploying recommended ethical principles guiding research studies. There was no conflict of interest in the study, and no incentives were given to participants. When this research is completed, I would share research results through community libraries without any influence on the study and according to relevant ethical issues. Ethical issues involving the use of human subjects were addressed via the institutional review board (IRB) approval process to ensure no harm to participants.

Methodology

I used qualitative research methodology to identify and explore themes that may emerge from in-depth interviews of caregivers of children with ASD. I used the snowball method to recruit participants. The snowball method enables a researcher to identify and choose exceptionally knowledgeable individuals that meet the inclusion criteria about a phenomenon that sufficiently aligns with the research purpose and phenomenon under study (Naderifa, et al. 2017). Furthermore, the snowball method enabled me to recruit participants with vast experiences with ASD, thus providing information to facilitate the study because the people involved in a phenomenon know each other.

Selection of Participants

Qualitative research aims to create a deeper understanding or meaning of the phenomenon under study (Creswell, 2018). In qualitative research, there are various sampling techniques used to recruit participants. The selection of participants was through a snowball method. Snowballing is a recruitment method researcher's use to find participants that fit the target population (Naderifa, et al. 2017). The target population included caregivers with children who have ASD. My goal was to get 10 willing participants for the study but recruited 20 in case any of the participants backed out of the study. The inclusion criteria were caregivers of children with ASD living mainly in remote areas of Minnesota, participants who do not have access to DMS, and participants who have some form of access to DMS for their children. The exclusion criteria were participants with full access to DMS and living in urban Minnesota.

I recruited participants from my social network of caregivers. I did not recruit participants from a state program or medical or diagnostic service clients. I also administered the informed consent form in-person, one-and-one, to ensure participant protection after consultation. I requested participants in my social network to publish my participation invitation in their networks for any interested caregivers to contact me. I held discussions with each participant using prescribed interview and follow-up questions for clarifications and to get in-depth perspectives into their experiences of barriers and difficulties accessing DMS and related benefits where necessary. The goal was to earn enough data to answer the research questions and any relevant information to provide insight into the phenomenon.

I assured participants that their responses were confidential with no identifiers. Incentives for participation were sharing the study's findings with the participants and publishing the result findings for community libraries. I made necessary arrangements to meet each participant for an in-person interview as scheduled based on the participant's availability. The discussions were mainly at the community libraries near to the participants. Each interview was recorded using a digital recording device and noted on an observation sheet. Participants were informed about the nature of the interview recording. In addition, each participant got a copy of the completed consent form for future reference. Finally, I addressed their questions or concerns before or after each interview.

Instrumentation

I used in-depth interviews to collect relevant data to address the research questions. Creswell and Poth (2017) noted that in-depth interviews and observations are commonly used modes of data collection in qualitative research to understand phenomena thoroughly. The interview questions were unstructured and geared towards answering the research questions and providing greater insight into the phenomenon under study. For example, researchers have used in-depth interviews to understand participants' feelings and emotions (Smit & Onwuegbuzie, 2018). All relevant information was gathered and recorded.

Data Collection

Generally, data collection dramatically impacts its quality and subsequent use (Creswell, 2018; Barrett & Twycross, 2018). Many experts and researchers have collected data through interviews, a characteristic of qualitative studies. Interviews give the most direct and straightforward approach to gathering detailed and quality data regarding a phenomenon (Barrett & Twycross, 2018). Often, the researcher tailors the research questions based on the data needed, the characteristics of participants, and the preferred approach by the researcher. Most interviews are often conducted face-to-face, through telephone interviews to overcome proximity challenges. The critical variation between interview types relates to the degree of structure, whether the discussion is structured, unstructured, or semi-structured (Barrett & Twycross, 2018).

An open interview often opens opinions from just a single question. The interviewer and interviewee then shape the conversation in real time rather than following a prewritten schedule (Barrett & Twycross, 2018). Interviews can be particularly suited to methods encouraging participants to tell a story of their life or experiences, such as narrative inquiry. An example of a study using open and conversational interviews would be exploring the impact of parents' experiences with ASD children. The data collected was based on the research questions. The key terms in the study are *autism spectrum disorder, challenges, Access to Autism Care, Medical Diagnosis, Disparities, experiences of parents/caregivers of autistic children, Web-based resources, Rural communities, Autism Support Services, and Autism Treatment Services.*

- Before data analysis, the researcher must organize data, especially if the data needs translation. This study used participants with fluency in the English language. For data analysis, I employed the Collaizzi’s (1978) approach. The author suggested seven steps in organizing qualitative data, namely: 1) Reading the interview transcripts several times while listening to the audio tape. 2) Extracting essential elements and meanings from the transcript. 3) Coding the elements and meanings from the data. 4) Arranging and formulating the meanings into a cluster of themes. 5) Ensuring that descriptions were merged for every extracted theme. 6) Repeating the reading of the themes and descriptions. 7) Verifying from the participants that the data obtained was correct.

The data collection guide is available in Appendix A.

Data Analysis Plan

A researcher must have a formidable analysis plan for all data collected. Data collected in this study explored parents' experiences with children with ASD in accessing diagnostic medical services and their perspective on improving access to such services.

The study explores patients' and caregivers' resilience despite the barriers faced in their attempt to access the benefits for their children.

Even though qualitative research generates data from which researchers make inferences, Creswell (2018) noted that it is essential to quantify the data to conclude qualitative data. Some experts, especially proponents of qualitative methodology, may criticize the quantification of qualitative data because it distorts the qualities that make qualitative data distinctive. However, scientific research demands that data be presented within a scientific construct (Unite for Insight, n.d.). Therefore, there are specific steps to follow, including 1) organizing the data, 2) reading and coding it, and 3) presenting and interpreting the data (Creswell, 2018).

Data coding involves thematic analysis to identify core ideas and themes within the data (Clarke & Braun, 2016). The research questions for this study focused on exploring the challenges or barriers to accessing medical diagnostic services by families with children with ASD and the advancement of possible improvement solutions. Data themes were based on keywords and phrases, guiding the discussion, and answering the research questions. First, I familiarized myself with the data by carefully reviewing interview notes and transcribing audio and other relevant data using NVivo analysis software.

Issues of Trustworthiness

Qualitative data must be trustworthy for use in scientific research. In simpler terms, trustworthiness is the accuracy of a research study, data, and findings (Statistical

Solutions. n.d.). Researchers using qualitative methodology seek to employ credible, transferable, and confirmable data to ensure its trustworthiness. Proponents of the qualitative methods defend their research methodology. However, the opponents express concerns about the validity and rigor of qualitative studies (Johnson et al., 2019).

Qualitative researchers have used various strategies to ensure the credibility and believability of their research findings (Rose & Johnson, 2020). Rose and Johnson (2020) advanced that while continuous observation allows enough time to identify relevant aspects of the study, extensive participation permits building trust with study participants. In addition, statements in qualitative research involve the researcher's subjectivity. Rose and Johnson (2020) noted that subjectivity could contribute to the weakness in the qualitative methodology.

While there are different views on subjectivity, proponents of qualitative research argue that the subjective nature of the method is its strength because it gives a unique and in-depth understanding and insights into the research. Therefore, choosing the correct methodology for any study ensures its credibility (Stenfors, Kajamaa, & Bennett, 2020).

Credibility: Scientific research must be credible because policymakers rely on the findings to make sound policy decisions and provide grounds for evidence-based care in healthcare delivery. They have a policy and societal consequences (Sanz-Menéndez & Cruz-Castro, 2019). Ravitch and Carl (2020) noted that data credibility contributes to research validation, and as such, establishing credibility must include a solid data collection plan and accurate analysis. Credibility in qualitative research is similar to internal validity in quantitative research. Credibility ensures that the data is representative of participants and their experiences. This study intends to establish data and procedural credibility through effective listening.

Transferability: Credible scientific research must pass the transferability test. Forero, Nahidi, De Costa, Mohsin, Fitzgerald, Gibson, McCarthy, and Aboagye-Sarfo (2018) reported that the transferability of a qualitative study result is critical to qualitative validity. Transferability is how qualitative results can be applied to other phenomena (Nowell et al., 2017). It is prevalent for research designs to influence research transferability and subsequently impact the research outcomes.

The study follows research protocols to maintain the integrity of the research process by providing in-depth descriptions of the research, including participants' responses and experiences under their appropriate themes. Furthermore, proper and careful coding procedures reflected participants' responses. Following reasonable research procedures ensured the quality of the research process, and the transferability methodology might help other researchers interpret and effectively apply the context to their investigations.

Dependability: To ensure reliability, I reported every process within the study in detail to enable other researchers to repeat the study. All results were reported whether they were in line with general knowledge or not. Other forms of dependability strategy include audit trails and triangulation.

Confirmability: Confirmability is a vital criterion of qualitative validity that involves ensuring that the findings of a study are obtained from the study data. The element of confirmability requires the researcher to demonstrate neutrality and validate how interpretations and conclusions relevant to their research were derived (Nyirenda, Kumar, Theobald, Sarker, Simwinga, Kumwenda, Johnson, Hatzold, Corbett, Sibanda, & Taegtmeyer, 2020). Researchers can use methods such as providing indicators throughout their study to support their analytical and methodological choices. Providing hands regarding the analytical and methodological decisions throughout the study can help future researchers understand why specific actions were taken. This study demonstrated confirmability through reflexivity. Reflexivity refers to the scale of evaluation in which the researcher's position may influence the research (Subramani, 2019). It demonstrates reflexivity by maintaining a journal to record insights, decisions, and logistics relevant to this study.

Ethical Procedures

Ethical procedures are applied when conducting research, especially when dealing with human subjects. Duggappa et al. (2016) noted that ethical practices pertain to honoring the participant's rights regarding treatment, keeping the confidentiality of information, respecting anonymity, acquiring informed consent, and getting ethical approval from the institutional review board. The Department of Health and Human Services (HHS) (n.d.) advanced that the informed consent process involves three key features: disclosing potential research subjects' information for making an informed decision, facilitating the understanding of broadcast information, and encouraging the voluntariness of the decision about whether to participate in the research.

The qualitative study requires a deep exploration of the meanings of human experiences (Creswell, 2018), which requires researchers to investigate sensitive topics that might risk harm to participants. For example, some participants may express anxiety, the feeling of exploitation, and the risk of being identified in published articles. Therefore, the informed consent procedure must be completed more significantly to the participants' satisfaction, adhering to the outlined three conditions. A researcher may seek informed consent based on an evident appreciation and understanding of an action's facts, implications, and consequences. The individual concerned should have adequate reasoning ability and relevant facts (HHS, n.d.). According to HHS (n.d), impairments to reasoning and judgment that may prevent informed consent include basic intellectual or emotional immaturity, high levels of stress such as stress disorder, and mental disorders including intoxication.

All willing participants received an informed consent form during the in-person interviews outlining the research topic, the name of the researcher, the nature of the study, and a statement of confidentiality, as described earlier during the participant selection process.

Summary

Chapter three discusses and outlines the research methodology. The study explored the experiences and understanding of parents' perceptions of children with ASD and their barriers to accessing diagnostic medical services. It also discussed the research design, rationale, the researcher's role, methodology, and the study's trustworthiness issues. The conceptual frameworks for the study are Ronald M. Anderson's (1968) Health Care Utilization and Access Model and Norman Garmez's (1974) Resilience Theory. Data collected and analyzed from this study may provide a new understanding of caregivers' experiences in accessing diagnostic medical services, help advance recommendations to improve access, reduce those barriers they face, and finally help bridge the gap in knowledge about what we know and what is revealed from the studies.

Chapter 4: Results

In this study I explored caregiver perspectives on improving access to diagnostic medical services for children with autism, mainly in the rural areas of Minnesota. Using snowball sampling, data was collected from a small but diverse group of caregivers. The data was then analyzed, and emergent themes were identified. The results provide valuable insights into the challenges faced by caregivers in accessing diagnostic medical services for their children with autism and highlight potential solutions for improving access. In this section I present the findings of the study in detail.

Data Collection

Demographics

Participants for this study were selected using Snowball sampling, a nonprobability sampling technique (see Parker et al., 2019). Participants were identified through social networks and local interactions with families of children with autism in rural Minnesota. The inclusion criteria for participants were (a) caregivers of children with autism; (b) residing in Minnesota, especially in the rural areas; (c) do not have access to medical diagnosis services; and are 18 years and above. The exclusion criteria were (a) caregivers of children with autism who do not reside in Minnesota; (b) caregivers who have access to medical diagnosis services; and (c) caregivers who did not give informed consent for their participation in the study. Caregivers who met the inclusion criteria were asked to provide referrals to other caregivers who also met the requirements. The snowball sampling technique increased the sample size and identified participants who could not be reached through traditional recruitment methods (see Parker et al., 2019).

Recruitment

The initial participants were recruited from a social network, which consisted of caregivers of children with autism living in rural areas of Minnesota (see Lievens & Chapman, 2019). The inclusion criteria for the study were caregivers of children with ASD living mainly in remote areas of Minnesota, participants who did not have access to DMS, and participants who had some form of access to DMS for their children. The exclusion criteria were participants with full access to DMS and living in urban Minnesota. I administered the informed consent form in-person and one-on-one to ensure participant protection after consultation. Participants were requested to publish the participation invitation in their networks for anyone interested in contacting the researcher (see Hardicre, 2014). I held discussions with each potential participant using open-ended interview questions (Appendix A), with follow-up questions for clarifications and to get in-depth perspectives into their experiences with barriers and difficulties to accessing DMS and related benefits where necessary.

The goal of adopting the open-ended interview technique was to get enough data to answer the research questions and any relevant information to provide insight into the phenomenon. Participants were assured that their responses were confidential, with no identifiers. Incentives for participation were sharing the study's findings with the participants and publishing the result findings for community libraries. Necessary arrangements to meet each participant for an in-person interview or scheduled one-and-one meetings were based on the participant's availability. Each interview was recorded using a digital recording device and noted on an observation sheet. Participants were informed about the nature of the interview recording. In addition, each participant received a copy of the completed consent form. I addressed questions or concerns they had before or after each interview.

Informed Consent

The informed consent process is essential to research studies involving human participants. In this study, the purpose of the informed consent process was to obtain permission from the participants and ensure that they were fully aware of the nature and purpose of the study and their rights as participants (see Hardicre, 2014). The informed consent process began with recruiting potential participants through snowball sampling (see Parker et al., 2019). Those who expressed interest in participating were provided with a detailed explanation of the study's purpose, the procedures involved, and the risks and benefits associated with their participation. They were also informed that their participation was voluntary and that they could withdraw from the study without penalty.

Participants were informed that their responses would be kept confidential and anonymous and that their data would be stored securely. They were also told that their data would only be used for research purposes and that the study results would be disseminated through academic publications and presentations. Participants were provided with an informed consent form, which outlined the information provided to them orally. The consent form included a signature line, which participants were asked to sign if they agreed to participate in the study (see Hardicre, 2014). For those under 18, arrangements were made to obtain consent from their parents or legal guardians, but there were no participants in the study under 18 years of age. To further protect the participants' privacy, all collected data were de-identified and coded to ensure their identities could not be traced back to their responses. Any identifying information collected during the study, such as names and contact information, was kept separate from the data to maintain confidentiality.

Data Collection Measures

The data collection procedures for this study involved conducting in-person interviews with participants using structured interview questions and follow-up questions where necessary. The interviews were conducted in private locations, mainly at the nearby libraries, to ensure confidentiality and privacy for the participants. Before the interviews, I explained the study's purpose to the participants, obtained informed consent, and ensured they understood their rights to withdraw from the study at any time. Participants were assured of confidentiality, and their anonymity was protected by assigning them unique identification numbers instead of using their names.

During the interviews, I asked the participants open-ended questions about their experiences accessing diagnostic medical services for their children with autism. The questions focused on their challenges, the services they used, and the improvements they would like to see in accessing diagnostic medical services. Follow-up questions were asked where necessary to obtain further details and clarify responses. The interviews were audio-recorded with the participant's permission, and I also took detailed notes to ensure that all relevant information was captured. The audio recordings were transcribed and stored in password-protected files accessible only to me, and the participants' identities were not revealed in any of the study's findings or publications.

Quality Control Measures

During the process, I provided the participants with an overview of the study's objectives, research design, and the significance of the study for the field of autism research. They were also informed about the ethical considerations of conducting research with vulnerable populations such as children with autism and their caregivers. This included the need to obtain informed consent, ensuring confidentiality, and maintaining privacy. Also, I administered the study instruments as correctly as possible to ensure consistency and accuracy in data collection. Earlier in the process, I did self-practice, such as mock interview training and role-playing exercises, to get more comfortable with the study instruments and the interview process. The training equipped me to handle unexpected situations that could arise during data collection. This included scenarios where caregivers became emotional or distressed during the interview. The training emphasized the importance of maintaining professionalism and sensitivity to the needs of the caregivers while ensuring that the study objectives were met.

I ensured and maintained high data quality standards during the data collection phase by providing regular reviews. I also conducted frequent spot-checks to review the completed interviews, verifying that the data was accurately recorded and ensuring that all necessary information was included. In cases where errors or omissions were identified, I provided corrective feedback from the data backup notepad.

A data audit is crucial to ensure the quality of data collected in research studies and to manage information assets and risk, (Ayind & Funmilola, 2019). I conducted a data audit to ensure the data collected was complete, accurate, and consistent. This approach ensured that any errors or inconsistencies in the data were identified and corrected before analysis. The audit process began by reviewing and examining the completeness of the data. This included checking that there were all values and complete responses. All the missing information was found and retrieved from the audio recording and backup notepad. This process ensured that the data was complete and did not compromise the validity of the results. The next step in the data audit was to check for outliers. Outliers are data points that fall outside the normal range of the data and can significantly affect the study's results. I reviewed for outliers in the data and verified that they were valid data points. The data was checked for inconsistencies. Inconsistencies arise when the data is entered incorrectly into the study database. I also checked for inconsistencies in the data and verified if they were due to errors in data entry. The process allowed me to resolve any discrepancies that arose with the notepad.

Timeline

During the data collection process, I followed a self-proposed timeline, with data collection where activities began in March and concluded at the end of May. To achieve this timeline, I carefully planned the data collection process to maximize efficiency and ensure that all necessary data was collected within the allotted timeframe. The first step was to identify and recruit potential participants to participate in the study. This involved using my social caregiver’s network and collaborating with locals to identify eligible participants and inform them about the study's objectives and procedures. Once the participants were recruited, I began the data collection process with in-person interviews. These interviews were conducted at a location convenient for the participants, typically in private library rooms and community centers. The interviews were semistructured to collect information on caregivers' experiences seeking diagnostic medical services for children with ASD. After the data collection, the data was cleaned, checked for accuracy and completeness, and entered a secure database. The data was then analyzed using NVivo statistical software to identify patterns and trends. A comprehensive report summarized the study's findings and provided recommendations for improving access to diagnostic medical services for children with autism.

After the completion of data collection, the data underwent analysis. Data cleaning and entry into the database were completed, and the analysis began. The NVivo descriptive statistics data helped provide an overview of the study participants and their experiences accessing diagnostic medical services for their children with ASD. The statistical analysis included the central tendency of the participants’ lived experiences captured in a mode. The analysis further explored patterns of the data that help identify potential factors that impacted access to diagnostic medical services for children with

ASD. These patterns helped determine the themes of the research study. I began the report writing process when I completed the analysis. The report was written clearly and concisely as much as possible and summarized the study's findings. I synthesized the study's results during the report-writing stage and contextualized them with previous research.

Data Analysis

The data collected from the interviews were transcribed verbatim and reviewed for accuracy (see McMullin, 2021). The transcripts were entered into a qualitative data analysis software program to facilitate the coding and analysis process (see Williams & Moser, 2019). Two coders independently read and coded the transcripts to ensure the reliability of the findings (see McMullin, 2021). Any discrepancies in the coding were resolved during the review of the observation note, the notepad, and the audio recording. The coding process involved identifying meaningful units of text that relate to the research questions and organizing them into categories and themes. The types and themes were developed based on the content of the transcripts and were refined as the analysis progressed (see Williams & Moser, 2019). To ensure the validity and reliability of the findings, I compared notes on the emerging themes and patterns and ensured that they aligned with the research questions.

Qualitative Results

A total of 10 caregivers of children with autism residing mainly in rural Minnesota participated in this study. Most participants were female (*n*=8), and two were male. The participants ranged from 28 to 62 years, with a mean age of 42.8. Most participants (*n*=8) were parents of children with autism, while two were grandparents. The participants' education levels ranged from high school to postgraduate degrees, with a mean of 15.3 years of education. The demographic characteristics of the participants are summarized in Table 1.

Table 1

Demographics of Participants

Characteristics	Participants (n=10)
Gender	Female: 8, Male: 2
Age (years)	Mean=42.8, Range=28-62
Relationship to child	Parent: 8, Grandparent: 2
Education (years)	Mean=15.3, Range=12-20

Research Questions

Based on the data collected from participants' response to the research questions, six sets of constructs emerged which were later reduced to cluster themes in Table 2. Each set of constructs that emerged from the research questions following the responses of the participants, materialized in common themes, and represented in Table 3. Table 4 is coded to represent the significant statistics of the common themes. The *N*=10 represents all participants while 001 - 010 represents each participant

Table 2

Cluster Themes

Research Question	Theoretical Construct
RQ1: What personal and professional challenges did the parents encounter during the diagnostic process? Did they receive assistance via a health service or another entity?	Challenges and Support
RQ2: What are low-income parents' experiences with autistic children accessing medical diagnostic services?	Access and Income
RQ3: What health service factors do the parents consider beneficial when diagnosing their children with Autism?	Benefits of Health Services
RQ4: What health service factors do the parents perceive as barriers to diagnosing their child's Autism?	Barriers to Health Services
RQ5: What changes do the parents perceive necessary to improve access to and timing of an autism diagnosis?	Recommendations for Improvements
RQ6: What factors are identified by the parents as critical in helping them cope with the diagnostic process?	Coping Strategies

Table 3

Common Themes

Theme Clusters	Common Themes
Challenges and Support	• Emotional and psychological challenges • Social support from family and friends • Support from healthcare providers
Access and Income	• Access to diagnostic services • Financial burden and affordability • Transportation barriers
Benefits of Health Services	• Positive experiences with healthcare providers • Quality of care and expertise • Timely diagnosis and early intervention
Barriers to Health Services	• Limited access to child neurologists • Limited availability of services • Long wait times and delays • Lack of coordination and communication among healthcare providers
Recommendations for Improvements	• Increased availability of services in rural Minnesota • Improved communication and coordination among healthcare providers • Involving child neurologists from the early stage • Financial assistance for families with limited income
Coping Strategies	• Seeking support from peers and the community • Self-education and research • Advocating for their child's needs

Table 4

Themes

Improving Medical Diagnostic Services for Children with Autism: Caregivers Perspective	What personal and professional challenges did the parents encounter during the diagnostic process? Did they receive assistance via health services or another entity?	What are low-income parents' experiences with autistic children accessing medical diagnostic services?	What health service factors do the parents consider beneficial when diagnosing their children with autism?	What health service factors do parents perceive as barriers to diagnosing their child's autism?	What changes do the parents perceive necessary to improve access to and timing of an autism diagnosis?	What factors are identified by the parents as critical in helping them cope with the diagnostic process?
Challenges and Support	*N*=10					
Emotional and psychological	*N*=10					
Social support from family and friends	*N*=10					
Support from healthcare providers	002, 003, 004, 005, 006, 008, 009, 010					
Access and Income		*N*=10				
Access to diagnostic services		*N*=10				
Financial burden and affordability		001,002.003, 004,005,006, 007, 008,010				
Transportation barriers		001,002.003, 004,005,006, 007, 008,010				
Benefits of Health Services			*N*=10			

Improving Medical Diagnostic Services for Children with Autism: Caregivers Perspective	What personal and professional challenges did the parents encounter during the diagnostic process? Did they receive assistance via health services or another entity?	What are low-income parents' experiences with autistic children accessing medical diagnostic services?	What health service factors do the parents consider beneficial when diagnosing their children with autism?	What health service factors do parents perceive as barriers to diagnosing their child's autism?	What changes do the parents perceive necessary to improve access to and timing of an autism diagnosis?	What factors are identified by the parents as critical in helping them cope with the diagnostic process?
Positive experiences with healthcare providers			*N*=10			
Quality of care and expertise			*N*=10			
Timely diagnosis and early intervention			*N*=10			
Limited access to child neurologists			*N*=10			
Limited availability of services			*N*=10			
Barriers to Health Services				*N*=10		
Long wait time and delays				*N*=10		
Lack of coordination and communication among healthcare providers				001,003.004, 005,006,007,008, 009, 010		
Recommendation for Improvement					*N*=10	
Increase services in rural Minnesota					*N*=10	

Improving Medical Diagnostic Services for Children with Autism: Caregivers Perspective	What personal and professional challenges did the parents encounter during the diagnostic process? Did they receive assistance via health services or another entity?	What are low-income parents’ experiences with autistic children accessing medical diagnostic services?	What health service factors do the parents consider beneficial when diagnosing their children with autism?	What health service factors do parents perceive as barriers to diagnosing their child’s autism?	What changes do the parents perceive necessary to improve access to and timing of an autism diagnosis?	What factors are identified by the parents as critical in helping them cope with the diagnostic process?
Improve communication and coordination among healthcare providers					*N*=10	
Involve child neurologists from early stage					*N*=10	
Financial assistance for families with limited income					*N*=10	
Coping Strategies						*N*=10
Seeking support from peers and the community						*N*=10
Self-education and research						001,002.004, 005, 006,007, 008, 009, 010
Advocating for their child’s needs						*N*=10

Theme Cluster Results

In the study, I analyzed the experiences and perspectives of caregivers of children with autism in accessing diagnostic medical services. Based on the data collected, I identified six main themes (see Table 3) as thematic cluster: Challenges and Support, Access and Income, Benefits of Health Services, Barriers to Health Services, Recommendations for Improvements, and Coping Strategies. This analysis was summarized in Table 2 and each set was further interpreted for better understanding as well as highlighting the research questions.

Cluster 1 Challenges and Support

The participants reported several challenges during the diagnostic process. These challenges included difficulties in accessing diagnostic services, lack of expert knowledge of autism, misdiagnosis of autism, delays in receiving a diagnosis, lack of understanding and awareness about autism, and the emotional toll of the diagnostic process. Some participants also reported encountering barriers due to their rural location, including limited access to specialists and long appointment travel times. Most participants reported receiving assistance from healthcare providers or other entities, although the aid level varied. Some participants reported receiving extensive support, while others reported receiving little or no support.

Theme 1 sheds light on parents' difficulties while diagnosing their children with autism. The participants reported facing several challenges, including delays in receiving a diagnosis, a lack of understanding and awareness about autism spectrum disorder, and the emotional toll of the diagnostic process. Participant 001 said, “It took us years to diagnose our son. We visited various doctors, and each one had a different perspective. I felt like we were throwing away valuable time that could have been used to assist him, which was aggravating.” Many parents reported feeling overwhelmed and stressed as they navigated the often complicated and confusing healthcare system to get their children the needed support. Participant 001 said, “I felt so overwhelmed while getting the diagnosis. I had the impression that I lacked experience. I was concerned I was overlooking something.” The participants also reported facing several barriers to accessing diagnostic services, mainly since they lived in rural areas. Limited access to specialists and long travel times were significant barriers that created additional stress and financial burden for parents. Participant 002 stated, “We had difficulty getting the required services because we lived in this rural area. We had to travel for hours to see specialists, which was not always practical. For example, from here to Minneapolis, where we were referred, is 3 hours by road, going and coming back is 6 hours added to the wait time, the day is over already. I remember sleeping in a hotel because we could not return home the same day and come out the next day for our appointment. It was a financial strain despite everything else we had to contend with.” These challenges often made it difficult for families to receive timely and appropriate care, significantly impacting the child's outcomes. Despite these challenges, the participants reported receiving some support from healthcare providers or other entities. Participant 001 noted, “Finding a clinician who would listen to my worries and work alongside me to create a treatment plan was incredibly beneficial. It was as if a burden had been removed off my shoulders.” However, the level of support varied widely among the participants. Some parents reported receiving extensive support, including clear communication, access to knowledgeable and experienced providers, and individualized care that addressed their child's unique needs. Participants 007 also experienced fair treatment: “Although we could not get a medical diagnosis promptly, when we got one, the young man who evaluated my son was nice. He provided a list of autism Non-Profit Organizations (NGOs) for resources.” Other parents reported receiving little or no support, which exacerbated their stress and overwhelmed them.

Cluster 2: Access and Income

Most participants reported experiencing financial challenges in accessing diagnostic services, including the cost of assessments, therapies, and providing special needs for their autistic children. Some participants reported relying on public assistance programs to help cover the costs, while others reported struggling to afford the services their children needed. Several participants also reported encountering barriers to insurance coverage, including denials of coverage and limits on the number of sessions.

In theme 2, parents discussed their financial challenges while accessing diagnostic services for their children with autism. The participants reported that the cost of assessments and therapies posed a significant barrier, making it challenging to afford the services their children needed. Participant 003 with high school diploma noted, “Worrying about how we will pay for these things on top of watching our child struggle is difficult. Insurance does not cover everything our child needs. We are low-income and cannot pay for certain assessments and therapy. For us, it's simply not feasible.” This problem was particularly acute for low-income families, who found it difficult to bear the expenses of autism-related services. According to Participant 005, “Since there are no specialists close by, I had to take time off work and travel 3 hours to get my child checked. Not only does it take time and effort, but it also costs money for travel and lodging. We really can't do this regularly.” Some participants relied on public assistance programs to offset the costs, while others struggled to cover the out-of-pocket costs. Out of the 10 participants, only 009 experienced 60% satisfaction on transportation barriers: “I do not have many problems with transportation because the school system along with my county provides transportation for my son’s therapy. Although they could not do it regularly, they provided help two days in a week.”

Participants collaborated on reports of encountering barriers to insurance coverage, which compounded the financial burden of accessing diagnostic services. Several participants mentioned that their insurance providers denied specific coverage for autism-related management. In the interview, participant 004 said, “Insurance coverage for our child's therapy has been rejected on several occasions, especially getting a specialist to watch over him against self-injuries and to help him cope with basic needs. Every time, we must appeal, and it takes months to hear back. It's draining and irritating.” Others had to pay for additional expenses because of limitations on the number of sessions or therapies covered. These insurance-related challenges added to the considerable financial strain of accessing diagnostic services. The economic challenges participants faced resulted in delayed access to diagnosis and treatment, leading to adverse outcomes for their children.

Cluster 3: Benefits of Health Services

The participants identified several factors they perceived as applicable during the diagnostic process. These included clear and timely communication from healthcare providers, access to knowledgeable and experienced providers, accurate measuring/evaluation tools, and individualized care that addressed their child's unique needs. Participants also emphasized the importance of providers who listened to their concerns and worked collaboratively with them to develop a treatment and management plan.

Participants highlighted the importance of effective and empathetic healthcare providers. The interviewees identified several beneficial factors during the diagnostic process. These included clear and timely communication from healthcare providers, access to knowledgeable and experienced providers, and individualized care that addressed their child's unique needs. Participant 006 noted, “It made a huge impact when we discovered a provider who could cater their care to our child's needs. Our child felt more at ease, and we were assured that we supported him as best we could.” In addition, participant 007 said, “The medical staff members who listened to us and our worries were beneficial. Although it was a long and challenging procedure, they supported us at every turn.” Participants emphasized the need for providers to listen to their concerns and work collaboratively with them to develop a treatment plan tailored to their child's needs. They also appreciated providers who showed empathy and understanding toward their child's struggles, which helped to build trust and establish a positive working relationship. In addition, participants also emphasized the importance of healthcare systems that are designed to support families of children with autism. They expressed appreciation for healthcare providers well-versed in autism and could provide specialized care, such as developmental pediatricians and autism specialists. Participant 001 said, “Our encounter with a physician who understood autism was like finding fresh air. We felt they were on our side and aware of our child's requirements.” According to Participant 002, “It's essential for medical professionals to have compassion and empathy for families with autistic children. It can be the difference between life and death.”

Cluster 4: Barriers to Health Services

The participants identified several barriers to accessing diagnostic services, including long wait times, limited availability of providers, lack of children neurologists, and a dearth of knowledge and understanding of autism among healthcare providers. Other barriers included financial challenges, insurance coverage limitations, and healthcare system navigation.

Theme 4 identified the barriers parents faced when seeking diagnostic services for their children with Autism. Parents reported facing long wait times, limited availability of providers, and a lack of knowledge and understanding of Autism among healthcare providers. According to Participant 009, “We had to wait for such a long time for doctor appointments that it took us nearly a year to receive a formal diagnosis. We knew our child needed assistance, but we could not get it quickly enough.” These barriers made it challenging for parents to access their children's care and led to delays in diagnosis and treatment. Financial challenges were also identified as a significant barrier to accessing diagnostic services. Parents reported struggling to afford the costs of assessments and therapies, and some even had to rely on public assistance programs to help cover the costs. Insurance coverage limitations were another common obstacle, with some parents encountering denials of coverage or limits on the number of sessions allowed. Participant 004 said, “I struggled with my insurance provider to get insurance coverage for my child's therapy sessions. It was an endless battle that consumed a lot of time and energy I could have used to assist my child.” Navigating the healthcare system was another barrier highlighted by the participants in this study. The complex and confusing nature of the healthcare system made it difficult for parents to understand how to access the services their child needs. This was incredibly challenging for grandparents unfamiliar with the new order and already overwhelmed by the diagnostic process and caring for a child with Autism. Participant 008 shared an experience stating, “The healthcare system is quite complex. I felt that various individuals were continually giving me different responses, and I was unsure if I was acting appropriately. It was too much to handle.” Participants 002 experience on the complex nature of the healthcare system and long wait time also resonates with other participants but had good communication and coordination between the school and the therapy services, “The special class at school my son attends coordinated very well with the therapy services to make sure he gets extra help apart from speech lessons he gets at school."

Other participants expressed concerns about the lack of access to child neurologists, which they felt was a critical gap in diagnosing and treating children with autism. Participant 007 stated, "I was hoping to see a child neurologist who would look at the abnormal brain overgrowth that may be associated with my child's cognition and language functions. My child is nine years now, but we have never seen a specialist in this area, a neurologist who could do a range of medical diagnoses to confirm or eliminate possibilities. This is my huge concern. We do not have such services." The caregivers felt that their children would benefit greatly from the involvement of a child neurologist in the diagnostic process and ongoing treatment. However, access to child neurologists was limited, with some participants reporting that they had never been able to see one.

Cluster 5: Recommendations for Improvements

The participants identified several changes that would improve access to and timing of autism diagnoses, including increasing the availability of diagnostic services in Minnesota, especially in the rural areas, improving coordination and communication among the providers and the school system, improving insurance coverage for autism-related services, involving neurologists from the beginning to help eliminate unrelated symptoms, and increasing the number of knowledgeable and experienced providers.

Participants also emphasized the importance of early screening, intervention, increased public awareness, and education about Autism.

The participants identified various recommendations to improve access to and timing of autism diagnoses. One of the most significant recommendations they discussed was increasing the availability of diagnostic services, particularly in rural Minnesota. Participants reported difficulties in accessing specialists, which resulted in long wait times and increased travel times and costs. To address this challenge, participants suggested increasing the number of providers in rural areas or providing telehealth services. Moreover, participants requested expanding the inclusion of child neurologists in diagnosing, evaluating, treating, and managing Autism. Autism is a complex disorder that requires specialized care, and child neurologists are experts in this field. Their involvement in diagnosing and managing autism would ensure that children receive the most appropriate care and treatment, leading to better outcomes while ruling out symptoms that are often misdiagnosed as autism. Participant 007 stated, “I expect a neurologist to be involved in diagnosing, treating, and managing my child’s autism.”

Many participants reported struggling to afford the services their children needed due to the cost of assessments and therapies and the limitations on insurance coverage. The participants recommended that insurance companies cover autism-related services and treatments, including ABA therapy and speech and occupational therapy. The participants also emphasized the importance of increasing the number of knowledgeable and experienced providers. Many participants reported encountering healthcare providers with limited knowledge and understanding of autism. Participant 010 said, “It is upsetting when medical professionals lack knowledge regarding Autism and misdiagnose children suspected to have autism. Doctors and therapists have called on me to explain topics I believe they should understand.” To address this challenge, participants suggested increasing the number of providers specializing in Autism and providing training and education to healthcare providers about Autism. Participant 010 “More training and education would be beneficial.” Early screening and intervention were also identified as critical recommendations. Participants emphasized the importance of early identification of Autism and providing appropriate interventions as soon as possible. They suggested that pediatricians and primary care providers screen all children for Autism during regular checkups and provide appropriate referrals if necessary. The participants also recommended increasing public awareness and education about Autism to reduce stigma and promote acceptance. They suggested that increased public awareness would help caregivers recognize the signs of Autism earlier, leading to earlier diagnoses and interventions. Participants 003, 004, and 005 highlighted the stigma around autism. Participant 005 revealed, “A lot of stigma and misinformation still surrounds Autism. That could change with more public awareness and education. It would make our neighborhoods more tolerant and inclusive while also assisting people in identifying the early warning signs of Autism.”

Cluster 6: Coping Strategies

The participants identified several coping strategies that they found helpful during the diagnostic process. These included seeking emotional support from family and friends, educating themselves about autism, and advocating for their child’s needs.

Parents often turned to various sources of emotional support, including family members and friends, to help them cope with the challenges of diagnosis and treatment. Participant 005 showed family support helps, “My sister has been my pillar of support throughout these years. She always hears and is there when I need to vent or talk. Without her help, I do not know what I would do.” Participants also reported that educating themselves about autism and its associated challenges helped them better understand their child's condition and how to support them. Participant 001 explained her coping strategy “As soon as the diagnosis was made, I began reading books and articles regarding autism. It made it easier for me to comprehend my son's behaviors and improve my interactions with him. Knowing things helped me deal with things because knowledge is power.” In addition, caregivers said advocating for their child's needs is a crucial coping strategy. This involved communicating with healthcare providers and other service providers to ensure that their child receives appropriate care and support. Caregivers emphasized the importance of being proactive and assertive in advocating for their child, as it can lead to better outcomes and quality of life for the child. The coping strategies were highly individualized, and what worked for one family did not necessarily work for another. For instance, participants 003 did not adopt self-education and research as a coping strategy: “I find it difficult to sit in one place and read other people. I better have somebody who knows it and can talk to me about it.”

Data Management

The data collection was through in-person interviews with participants using semi structured and follow up questions where necessary. The interviews were recorded digitally using a high-quality recording device, and notes were taken as a backup to the audio recording during the interviews t. All collected data were managed, stored, and shared per ethical guidelines and data protection regulations. All identifying information was removed from the recordings and replaced with pseudonyms to ensure participant anonymity. Hard copies of the observation sheets and the notepad were kept in a locked filing cabinet in a secure location.

The data were managed using a coding scheme developed based on emergent themes identified during the data analysis. The coding system was used to label segments of the interview recordings and notes with relevant codes. The codes were used to group related data and identify patterns and trends (Williams & Moser, 2019). All codes and definitions were documented to ensure consistency across the coding process (Williams & Moser, 2019). The data were analyzed per the research questions and objectives of the study, focusing on identifying factors contributing to limited access to diagnostic medical services for children with autism, mostly in rural areas of Minnesota. There was no data sharing during the study. The data was kept confidential and would not be shared outside of the research without explicit consent from the participants. Any publications or presentations from the study included aggregated data that cannot be traced back to individual participants.

Data Quality

Several steps were taken during the data collection process to ensure the quality of the data collected. The pilot study I conducted with a small group of participants before the actual interviews helped test the interview questions and identify any issues that may have arisen. This allowed me to refine the interview questions and ensure they were clear and concise for participants to understand. I was adequately trained in the study protocol and interview techniques, including listening, and asking open-ended questions. This training helped me ensure that questions were asked consistently and unbiasedly and that they could capture detailed and accurate responses from the participants.

After the interviews, the recordings were transcribed by a professional transcription service to ensure accuracy and consistency (McMullin, 2021). I carefully reviewed the notes and transcripts to ensure the data was complete and accurate. To further ensure the accuracy of the data collected, I also conducted member-checking with participants. This involved sharing the interview transcripts with participants and allowing them to review their responses for accuracy and completeness. Any corrections or clarifications provided by participants were incorporated into the final dataset. I adopted a process of data triangulation, which involved comparing the data collected from different sources to identify patterns and verify the accuracy of the data. For instance, the researcher compared the interview data with data collected from observation sheets to ensure the consistency and accuracy of the data.

Data Archiving

The data collected during the study were archived and stored to ensure their accessibility for future use. To protect participant confidentiality, all identifiable information was removed from the data, and each participant was assigned a unique identifier code. The data was securely stored in an electronic format on password-protected computers accessible only to the researcher. The data will be kept for a minimum of 5 years after the publication of the results to ensure its availability for future research. After this period, the data will be deleted from the storage devices. Access to the data will be limited to authorized personnel, and the researcher will evaluate any access requests.

The data were archived in compliance with the regulations set by the IRB Walden University. The IRB guidelines require that all research data be stored securely and confidential to protect study participants' privacy. The IRB reviewed and approved the data archiving process to ensure compliance with the guidelines. To maximize the usability of the data, it is stored in a standardized format commonly used for qualitative research, such as Microsoft Word or Excel. This makes it easier for future researchers to access and analyze the data.

In summation, the data analysis involved identifying patterns and themes from the data and examining participant differences and similarities. I also checked for ways and themes across participants to identify everyday experiences, opinions, and attitudes related to the research questions. The data analysis findings were presented using descriptive statistics and qualitative descriptions. The descriptive statistics included frequencies and percentages of different themes, while the qualitative reports provided more in-depth insights into the experiences and perspectives of the participants. The results were organized based on the research questions and were presented clearly and concisely as much as possible. I ensured the confidentiality and anonymity of the participants throughout the data analysis process. All identifying information was removed from the transcripts, and pseudonyms were assigned to protect the identity of the participants. In the same manner, the data quality, management, and archiving were strictly followed according to IRB research guidelines. The data was securely stored and protected from unauthorized access.

Evidence of Trustworthiness

The study's ethical considerations were considered throughout the entire research process. Informed consent was obtained from all participants, ensuring that they understood the purpose of the study, their right to withdraw, and the confidentiality and anonymity of their responses (Hardicre, 2014). The consent form was presented to each participant in writing and verbally, and they were given ample time to read and ask questions before signing. Confidentiality was also a significant ethical consideration in this study. All participants' data was anonymized to protect their privacy, and no personally identifying information was collected. Additionally, all data was stored securely and password-protected on a computer only the researchers accessed. During the data analysis process, pseudonyms were used to ensure that participants could not be identified.

Participant protection was also an important ethical consideration. As mentioned previously, participants were informed of their right to withdraw from the study at any time without consequence. Additionally, I took steps to ensure that no harm was caused to participants during the study. This included not asking questions that could be potentially triggering or distressing to participants and ensuring that the interview setting was comfortable and safe. The study also considered the potential power dynamic between the researcher and the participant. To mitigate this, I tried to establish a respectful and collaborative relationship with participants, actively listening to their perspectives and experiences. The study followed the ethical guidelines of the American Psychological Association (APA). Also, the IRB of Walden University approved the research protocol, ensuring that the study was conducted ethically and in compliance with all relevant regulations and guidelines.

Limitations

The present study had several limitations that need to be acknowledged. The sample size required to be bigger, which could limit the generalizability of the findings beyond the study population. Snowball sampling may also lead to a biased sample, as participants may recruit individuals who share their views and experiences, limiting the sample's diversity (Parker et al., 2019). Another limitation is the reliance on self-reported data, which could be subject to social desirability bias. Participants may provide responses they believe are socially acceptable or desirable rather than their actual experiences or opinions. To mitigate this potential limitation, I emphasized the importance of honesty and open responses, assured participants of their answers' confidentiality and anonymity, and used probing questions to encourage participants to provide more in-depth responses.

Another potential limitation is the possibility of recall bias, where participants mainly lower educated level may not accurately remember specific details or events related to their experiences. Participant n003, for instance, had a high school diploma and she could not vividly recall if she had met a neurologist for her son’s diagnosis. She said: “we met a young lady who evaluated my son. I cannot remember what she told me, whether she said she is a trained practitioner for child brain function or a nurse, I think she said she was a nurse.” Low level of education limited this study. Some participants found it difficult to use effective vocabulary to communicate their experiences. For instance, 003 with high school diploma could not know about a neurologist but she knew a practitioner for “child brain function.” Addressing such limitations, participants were asked to focus on recent experiences and encouraged to take their time to reflect on their experiences. Lastly, the study was conducted in rural areas of Minnesota, which may not represent caregivers' experiences in urban or suburban areas. However, the rural setting provided a unique perspective on access to diagnostic medical services for children with autism, and the findings may have implications for other rural areas.

Summary

Chapter 4 provided the study result of data collected to explore the lived experiences of ten caregivers of children with autism, medical diagnostic challenges of autism, and ways of improving the services from caregivers’ perspective. The research study also aimed at addressing a literature gap of qualitative account of caregivers accessing medical diagnostic services for children with autism.

The data collected was through in-person interviews with participants using structured and follow-up questions. I adopted a data scheme based on emerging patterns of related codes. Common emerging themes include limited availability of services, delay and long waitlist, limited access to child neurologists, lack of coordination and effective communication, financial burden, inadequate insurance coverage, and emotional challenges. Recommended improvements include involving child neurologists and increasing the availability of diagnostic services, mainly in rural areas. The chapter also discussed the limitations and participants’ recall bias of their caregiving experiences and efforts made to overcome them.

Chapter 5: Discussion, Conclusions, and Recommendations

This study's objectives were to examine the barriers to pediatric medical diagnostic services for children with ASD, mainly in rural Minnesota, and to forward potential ideas for improvement from the viewpoints of the caregivers. According to the data gathered, the study noted six main theme clusters: Challenges and Support, Access and Income, Benefits of Health Services, Barriers to Health Services, Recommendations for Improvements, and Coping Strategies. Each of the set of emerging themes materialized in overreaching themes. The study also examined the encounters and viewpoints of10 caregivers of children with ASD concerning accessing diagnostic medical services. The theme cluster "Challenges and Support" was pulled from RQ1 with all the participants emphasized the challenges caregivers face when identifying their autistic children, such as delays in acquiring a diagnosis, a lack of knowledge and awareness of autism, emotional and psychological burden of the diagnostic procedures. In one of the common themes, support from healthcare providers, only two participants, 001 and 007 had a favorable experience with support from healthcare providers.

Access and Income were a direct response by participants to RQ2 that examined the costs associated with tests and treatments, problems with coverage, and the travel difficulties finding experts to diagnose their children with autism. All the participants shared similar experiences of difficulties getting professionals for their children with autism. They live in remote areas where diagnostic services were not available. The subject cluster "Benefits of Health Services" was pulled from responses to RQ3. They emphasized the significances of culture competence, and sympathetic healthcare professionals, transparent and prompt communication, availability of informed and experienced providers, and tailored care that considered their child's particular requirements. The Barriers to Health Services theme were experiences pulled from all the participants in response to RQ4. They lamented long wait times, limited availability of providers, lack of children neurologists, insurance coverage, healthcare system navigation, poor coordination and communication, and a dearth of knowledge and understanding of autism among healthcare providers. While all the participants lamented on various degrees of difficulties, Participant 002 made an exception on communication, “the school coordinated and communicated well with the therapy section for my son’s extra help.”

In the same manner, the participants overwhelmingly made recommendations for improvement in response to RQ5 such as increase diagnostic services in rural areas of Minnesota, enhance effective coordination and communication, and expand insurance coverages for children with autism. The Coping and Strategies theme was pulled from perspectives of all participant responses to RQ6 in which they identified family social support and self-education and research as critical coping strategies. However, low level of education among participants hampered self-education and research. Participant 003 said, “I find it difficult to sit in one place and read other people. I do not have such patience, but I get some resources from my peers and friends.” These finding results can assist decision makers, healthcare professionals, and other stakeholders in creating initiatives to enhance rural children with autism's access to diagnostic medical services.

Interpretation of the Findings

The study provided an excellent opportunity to investigate the caregiver perspective of medical diagnostic services available for children with autism and possibilities for improvement. The explanation of these results emphasizes the crucial elements that affect caregivers' perceptions and how they might be improved to increase access to diagnostic services for autistic children. I discovered that families have trouble obtaining diagnostic services for their autistic children due to flaws, including a lack of specialized facilities, poor coordination and communication, subpar healthcare providers, and income. There is a need to expand the number of qualified medical professionals to recognize, evaluate, and treat autism. The expansion can be achieved by investing in specialized institutions with everything needed to offer children with autism the best possible care.

I also discovered that children with autism have difficulties receiving diagnostic services because of subpar healthcare practitioners. Some medical professionals lack the expertise and training to diagnose and treat autism accurately, (Natasha, et al. 2022). It could be beneficial to invest in educational courses for healthcare professionals to have a better understanding of autism and the capacity to serve children with a high-quality treatment capable of overcoming this nascent obstacle**.**

Some significant themes from the research study include limited access to child neurologists, scanty access to competent and experienced autism diagnosticians, inaccurate diagnostic measuring tools, poor timely communication, and lack of tailored care that considers the child's specific needs. These findings were later compared with previous studies. Also, ways to improve access to diagnostic medical services for autistic children and significantly improve healthcare professionals' efficiency were discussed later. These professionals must receive training to comprehend the needs of families and children with autism. The emphasis of this training needs to be on acquiring cultural competence and the abilities required for efficient and sympathetic communication with these families. This training entails actively listening, demonstrating understanding, and assisting caregivers. Caregivers' associated stress and worries can dramatically reduce when healthcare providers establish trust with the families during the diagnostic procedure. The following is an overview of the findings and how the findings relate to previous studies.

RQ1: Challenges and Support

The study's findings indicate that parents have difficulties getting accurate diagnostic services for children with autism. These difficulties include misdiagnosis, psychological pressure, monetary limitations, and restricted access to specialized treatments. Yvette and Osnat (2021) noted that ASD is often mixed up with other neurodevelopmental disorders, which may lead to inaccurate diagnosis and delayed outcomes in treatment. Their study findings also revealed flaws in diagnostic instruments challenging accurate diagnostic services for children with autism.

Manmeet and Harmeet (2021) showed that caregivers of children with autism face various challenges, including psychological well-being and financial difficulties. According to the study, financial impact due to specialized treatment and management, which leads to loss of hours at a job and consequently loss of pay, became a challenge for caregivers of children with autism. These separate studies relate to this study and strengthen the need for action.

RQ2: Access and Income /Insurance Coverage

The accessibility of resources is a crucial element that affects caregivers' perceptions. Many caregivers financially struggle when getting diagnostic services, which might restrict their options and cause delayed diagnosis. The high cost of evaluations, management, therapies, and insurance may hamper caregiver access. The finding showed that financial limitations were another significant hurdle noted in the study. Many families might be unable to afford the cost of autism examinations; as a result, it is essential to find a solution to these financial issues and ensure everyone can afford and get diagnostic services and therapy. For instance, enhancing funding and expanding insurance coverage of autism-related healthcare services would help overcome this obstacle. A critical step in enhancing access to healthcare for children with autism is to improve insurance coverage. Kilmer and Boykin (2022) confirmed that an essential element affecting the cost burden on families pursuing a medical diagnosis for their autistic children is insurance coverage. The study showed that many families need more resources to navigate challenging insurance frameworks to get diagnostic services. To guarantee that children with autism receive prompt and adequate diagnostic care, removing the barriers and widening the coverage is critical.

Numerous insurance plans in the United States do not pay for diagnostic tests, therapies, or other services associated with autism (Wallis et al., 2020). The insurance providers that cover autism demand higher copayments than common healthcare issues. Families looking for a diagnosis for their children are under heavy financial strain due to the absence of broader coverage. For instance, the cost of an autism diagnostic evaluation, which may run into thousands of dollars, is out of reach for many families. Adopting laws requiring insurance providers to pay for autism diagnostic services can be crucial to enhancing children with autism's access to healthcare. Additionally, by adding diagnostic services to the essential health benefits under the Affordable Care Act, insurance companies can be encouraged to offer coverage for these services (Wallis et al., 2020).

Also, insurance companies and healthcare providers should work together to develop explicit and open insurance coverage guidelines for diagnostic services. Healthcare professionals can support families receiving diagnostic services and help them navigate the insurance system (Wallis et al., 2020). How insurers communicate with healthcare professionals and families about insurance benefits and coverage can be improved.

RQ3: Collaboration with Healthcare Providers

Building trust, effective communication, and maintaining healthy connections with caregivers and children with autism play a significant role in reducing the suffering of caregivers. This study shows that compassionate and efficient autism healthcare professionals bring about good relationships between caregivers and healthcare providers, which benefits the caregivers. Rilveria (2022) confirmed that more precise communication on the diagnosis, ensuring that the children and their caregivers understand the diverse nature of autism and support them, is beneficial to the healthcare professionals and the caregivers. Healthcare professionals should exercise patience and offer caregivers and kids with autism plenty of time to express their worries. To assist caregivers in making wise decisions, they must also be able to communicate facts clearly and intelligibly (Hyman et al., 2020). Access to diagnostic services depends on prompt communication as well. Healthcare professionals must effectively communicate with caregivers about the various available assessments, the diagnosis process, and the anticipated results (Barbaro et al., 2022).

Additionally, they healthcare professionals must give precise directions for referrals and follow-up care. Likewise, prompt communication is required to guarantee that the diagnosis procedure finishes on time, which can assist the caregivers and kids in feeling less stressed and anxious (Nik, et al., 2019). Individualized care that considers the requirement of the kid is crucial. Autism affects children differently, and they have different healthcare demands. The ability to give tailored treatment and management that considers each child's unique needs, abilities, and problems must be taught to healthcare professionals (Barbaro et al., 2022). Individualized management involves creating treatment strategies distinctive to the child's requirements and resources, emphasizing raising the child's quality of life.

It is crucial to enhance access to DMS for children with autism, ensure efficient and supportive healthcare providers, maintain transparent and prompt communication, provide knowledgeable and experienced diagnosticians, and pay individual attention to the child's needs. Families should receive precise information about the diagnostic procedure, including what to anticipate during evaluations, the findings of the examinations, and any treatment choices the healthcare providers offer. This information should be communicated promptly, emphasizing the need to minimize wait time for diagnosis and treatment (Hyman et al., 2020). Additionally, healthcare professionals must ensure that information reaches the families promptly and effectively, considering linguistic or cultural disparities.

RQ4: Diagnostic Services Barriers

From the results of this study, I discovered that caregivers experienced several obstacles when getting children with autism access to diagnostic services. Long wait periods were one of the biggest obstacles, which may be aggravating and draining emotionally for parents looking for information regarding the state of their kids. Families that reside in remote locations, where there may be a shortage of medical professionals qualified to diagnose and treat autism, may find this particularly challenging.

Professional diagnosticians of autism challenge caregivers in a variety of ways, such as a lack of prompt diagnostic services and accurate information tailored to individual autistic children. The delay in receiving appropriate treatment and support results in poor intervention and outcome. Since early detection and treatment have enhanced outcomes for children with autism (Jennifer, et al. 2017), the delay in diagnosis and misdiagnoses are crucial problems in the context of autism. A delayed diagnosis and misdiagnosis may impact the development and well-being of the kid because it may prevent the child from receiving early intervention and treatment.

Although the causes of diagnostic delays are many, the study's findings coincide with Dimian et al. (2021), indicating delays in the autism diagnostic process and propositioning the need to raise public awareness and comprehension of autism for consumers and health practitioners as a meaningful way to solve the problem. Delays in diagnosis can be minimized by improving healthcare personnel's knowledge of the early indicators of autism, screening techniques, and diagnostic standards.

Additionally, early diagnosis and accurate medical testing of autistic children can assist medical professionals in the early identification and referral of kids to timely diagnostic services and minimize evaluation and diagnosis wait times (Stronach et al., 2019). A greater understanding of autism and its early symptoms among the public may inspire parents to look out for early intervention programs and support for their children (Dimian et al., 2021). The awareness can enhance the child's health outcomes and lessen the need for future, more expensive, and extensive therapies. Improving access to diagnostic services is another method for reducing diagnosis holdups.

According to this study, acquiring diagnostic services took much work for caregivers, especially in rural locations. Enhancing access to diagnostic services can assist in shortening wait times and guarantee that autistic children receive timely diagnosis and intervention. A timely intervention would be accomplished by creating specialized diagnostic services and expanding the pool of qualified experts in the diagnosis of autism, as suggested by Stronach et al. (2019). In the same manner, increased funding for rural healthcare systems and more specialized healthcare professionals who can diagnose and treat autism may be beneficial in removing diagnostic barriers. These measures will ensure that families receive access to the care they require.

Also, telehealth and telemedicine technology can increase access to diagnostic services, especially in rural and isolated places. Telehealth services can help save travel time and increase access to care by enabling medical professionals to evaluate and diagnose autistic children from a distance (Manahil, et al. 2020). Another theme from RQ4 is the lack of child neurologists in diagnosing children with autism.

RQ4: Limited Access to Child Neurologists

I separated this theme from general diagnostic flaws because participants emphasized that the absence of child neurologists in the evaluation, diagnosis, treatment, and management of children with autism materially impacts the children's life outcomes.

Access to specialized medical professionals, such as child neurologists, remained a significant challenge for many families seeking to diagnose and manage their children with autism. Many caregivers expressed frustration at the lack of specialists available to diagnose and treat their children's condition. As identified earlier, some of the caregivers have had their children misdiagnosed.

Kalkbrenner et al. (2011) research study relates closely to this finding that misdiagnosis could result in poor outcomes. The study showed that without access to autism specialists, children with autism might miss out on crucial medical tests and treatments that could improve their quality-of-life outcomes. For instance, medical laboratory tests can help confirm or eliminate specific symptoms of autism, such as seizures, that may be present in some children with the condition. These tests can only be performed by medical specialists, like child neurologists, trained to identify and treat these specific symptoms (Kalkbrenner et al., 2011). Unfortunately, there is a shortage of child neurologists available to provide these services, which makes it difficult for parents to access the care their children need.

The lack of access to specialized care not only impacts the child with autism but also places an emotional and financial burden on families. It is not uncommon for families to travel long distances to see a specialist, which can be costly and time-consuming. Additionally, the frustration and anxiety associated with navigating the healthcare system and waiting for appointments can take a toll on the mental health of parents and caregivers.

RQ5: Improve Professionalism

Another crucial element in enhancing access to diagnostic medical care for autistic children is having access to trained and experienced professionals. The sparse knowledge and expertise in autism among healthcare practitioners affects how caregivers view their profession. The study emphasizes the significance of competent and compassionate healthcare professionals who can interact effectively with caregivers and deliver specialized treatment tailored to each child's requirements. This study shows that accessing skilled and experienced physicians can be difficult for caregivers, especially in remote locations.

It is crucial to equip healthcare professionals with the training and support to identify and treat autism effectively. The report also emphasizes timely and effective communication among caregivers, diagnosticians, therapists, the school system, medical professionals, and all the stakeholders. The delay in diagnosis and a lack of prompt communication between the healthcare providers and caregivers can increase the emotional stress the caregivers go through. Caregivers can comprehend their child's needs and find suitable support options by communicating clearly and promptly. The report also highlights the need for greater public understanding and awareness of autism. The caregivers frequently struggle with a lack of knowledge and comprehension of autism, prolonged time getting a diagnosis and starting treatment, and overall outcome. Therefore, public education and awareness campaigns need funding to encourage early diagnosis and prompt therapy access.

Ingersoll et al. (2020) research study supports this finding that healthcare providers must be available even in rural areas and offer children more specialized evaluations and therapies, which may improve their prognosis. Such evaluation should be individualized care considering the child's particular needs. Each autistic child is unique and needs tailored treatment that considers their needs and abilities (Grzadzinski et al., 2020). The researchers' suggestions relate to this study, indicating the need for more effective treatment by creating a care plan for each child that addresses their unique needs and considers their strengths and weaknesses. The study further collaborates the results of this finding that enhancing access to diagnostic services can be accomplished by raising knowledge and understanding of autism. It is also critical to have access to knowledgeable and experienced professionals. Healthcare professionals with experience and training in diagnosing and treating autistic children must be available to families (Ingersoll et al., 2020). It is necessary to ensure that sufficient experts are on hand. Policymakers and healthcare providers must take appropriate action to guarantee that families can access the required resources.

RQ5: Improve Public Knowledge and Comprehension of Autism

Increasing public awareness and comprehension of autism is one of the essential suggestions from caregivers' perception to enhance access to diagnostic medical services for kids with autism. This study shows that accessing diagnostic services is partly hampered by a lack of more comprehensive public knowledge and understanding of autism which collaborates with Stahmer et al. (2019) research study on a limited awareness of autism among the public and healthcare professionals. As a result of a limited understanding of autism, caregivers are frequently misinformed, relating autism to myths, thereby experiencing delays in receiving accurate and prompt diagnoses. The myths and misinformation raise the bars of frustration and distress, impairing the child's general development outcome. There is a need for more public education and autism awareness to address this problem (Stronach et al., 2019). Public awareness campaigns, neighborhood engagement initiatives, and healthcare professional training can help achieve a better diagnosis.

Also, public education initiatives can promote early detection and intervention, remove myths and misconceptions, and raise awareness and understanding of autism (Stronach et al., 2019). Community outreach initiatives can better the availability of diagnostic services and offer families impacted by autism information and assistance. Training medical professionals in autism can advance their expertise in identifying and treating autism, resulting in prompt and precise diagnosis. Adequate training of healthcare professionals may help increase understanding and remove the cumbersome that influences caregivers' impressions.

RQ6: Coping Mechanisms

According to this study, it is difficult for parents to get their autistic children into diagnostic medical services for early intervention. Besieged by long wait times, tight budgets, a need for specialist facilities, and subpar medical staff, the study shows that caregivers develop coping mechanisms to overcome stress and challenges associated with caring for children with autism. In their study, Ismael et al. (2018) collaborated on this finding that caregivers resort to help from religious faiths, family, friends, and support groups to deal with the situation. This aid can help caregivers deal with the stress and difficulties of caring for an autistic kid by offering practical and emotional support (Marsack-Topolewski, 2020). According to this study, support groups can help caregivers better navigate the healthcare system and get access to essential diagnostic services by providing helpful information on resources and services that are out there.

Supporting the interest of children with autism is another coping method caregivers use. To do this, one must actively look for information and resources, interact with healthcare professionals, and remove obstacles to getting diagnostic services (Connell et al., 2020). To make sure their children with autism receive the proper care and support, caregivers might have to be persistent and demanding. Advocacy can be especially effective when caregivers partner with healthcare professionals to address the child's needs. In addition, caregivers may use self-care techniques to cope with the difficulties and stress associated with caring for an autistic kid (Connell et al., 2020). The techniques could entail taking pauses, getting professional counseling, taking up relaxing hobbies or pastimes, getting enough sleep, and eating a healthy diet (Connell et al., 2020). These techniques are essential for the caregiver's health and can improve their capacity to give their child high-quality care.

Limitations of the Study

The study's limited sample size of only ten individuals is a drawback. The sample may not indicate all parents of autistic children in rural Minnesota, even if I could locate participants by snowball sampling, a non-probability sampling technique. This is because the sample may not fairly represent the variety and breadth of experiences among caregivers of autistic children in the communities under study. The study's conclusions are also less broadly applicable due to the limited sample size. It is challenging to draw general conclusions regarding the experiences of caregivers of autistic children in rural Minnesota with only 10 participants. Furthermore, the research’s statistical ability may be constrained by its small sample size, making it challenging to identify critical distinctions or patterns in the data. The tiny sample size impeded the study's validity. A limited sample size increases the possibility of bias since many people's experiences and viewpoints may disproportionately impact the outcomes. Due to the small sample size, I suggest further studies for more thorough research and investigating the subtleties of the caregivers' experiences.

This study's concentration on a particular region, notably rural Minnesota, is one of its limitations. As a result, the findings might not be relevant to metropolitan settings, where various factors might impact the experiences and viewpoints of those who care for autistic children. Other regions could have different assets, difficulties, and cultural aspects that could affect the caregivers' experiences and perspectives. Urban carers, for instance, can have access to more specialized medical treatments, but they might also encounter unique difficulties with transportation and navigating a convoluted healthcare system. This limitation is crucial since it emphasizes the need for more research in other areas to comprehend the viewpoints and experiences of carers of autistic children. Future research may also examine caregivers' experiences in metropolitan settings and explore limited insurance coverage for autism. Studies examining how cultural influences affect caregivers' attitudes and experiences may also shed light on how to care for this population more efficiently and culturally sensitively.

The fact that the study only used self-reported information from the participating caregivers is a disadvantage. This implies that biases and oversights in the data gathered may exist. The objectivity of the findings may have been hampered by caregivers' reactions, which may have been impacted by their beliefs, principles, and experiences. Given their perspectives and experiences, some caregivers may have exaggerated or misrepresented their challenges in getting their children access to diagnostic medical treatments. Furthermore, some caregivers could have been reluctant to provide specific details or experiences out of concern for criticism or stigma. Likewise, the study should have taken steps to confirm the integrity of the information supplied by the carers, like consulting medical records or speaking with healthcare professionals. The data may then have inaccuracies or inconsistencies as a result. As a result, care must be taken when interpreting the study's findings, and additional research utilizing different data collection techniques may be required to support them.

This study's lack of an investigation of the viewpoints and views of healthcare professionals who offer diagnostic medical services to autistic children in rural Minnesota is one of its limitations. As a result, the perspectives presented in this study are limited to those of the carers who obtain the services rather than those of the healthcare professionals who render them. This is significant because healthcare professionals may have knowledge and experiences that could add to the knowledge about the difficulties that rural children with Autism have in receiving diagnostic treatments. They might also have ideas for enhancing the accessibility of these treatments through changes to the healthcare system. Their viewpoint might have enabled the creation of more focused interventions and a more thorough knowledge of the problem. Additionally, it is essential to comprehend the views of healthcare professionals because they are vital in providing diagnostic medical treatments to autistic children. Rural locations may present difficulties and obstacles for them to overcome, such as scarce resources and specialized expertise. To understand the specific needs of healthcare professionals in rural areas and to assist in developing interventions to meet those needs, their insights may be valuable.

Recommendations

In this study, I attempted to explore caregivers' perceptions of improving access to medical diagnostic services for children with autism in rural Minnesota. Only ten participants (n=10) participated in the study; n-8 were women, while n=2 were men. However, future research studies on improving diagnostic services in the rural areas of

Minnesota can take a more significant number of participants representing different rural areas for greater generalization and impact. Also, future research could focus on the feasibility of introducing telehealth care systems and mobile diagnostic programs for children with autism. The study may contribute to the knowledge and gain insight into improving diagnostic services in rural Minnesota. Scholars can focus research on the impacts of limited insurance coverage for children with autism. Such a study may contribute to more generalized knowledge of insurance limitations and help policymakers take positive action for the children. Another area of study focus, from caregivers' perspective, is the impact of the lack of child neurologists in diagnosing, treating, and managing children with autism. Further studies can also focus on public awareness and how improving the knowledge of autism can help reduce poor intervention outcomes.

To guarantee that children with ASD receive the proper diagnostic medical care, increasing awareness of and education about autism spectrum disorder (ASD) is essential. Healthcare professionals frequently lack the requisite understanding and knowledge regarding autism, according to caregivers of children with ASD. This results in a delayed or inaccurate diagnosis. Creating and implementing focused educational initiatives and training courses for healthcare professionals to address this problem are necessary (Ayasrah & Khasawneh, 2023). Healthcare providers and stakeholders need to focus on raising awareness of ASD, its diagnosis, and the value of early intervention. Parents and the broader public should be involved in creating awareness campaigns and education (Ayasrah & Khasawneh, 2023). Resources such as public service announcements, social media campaigns, and neighborhood gatherings may accomplish this goal. Parents and caregivers will be better able to spot the disorder in their children and find the proper diagnostic assistance if they have a greater understanding of ASD (Ayasrah & Khasawneh, 2023). Additionally, it is crucial to give healthcare professionals, patients, and families access to culturally relevant instructional resources. Cultural competence may reduce inequalities in access to diagnostic services for kids from different cultural and linguistic origins.

The inclusion of child neurologists in the whole process of diagnosing autistic children is vital. Access to diagnostic services is reportedly quite tricky, especially in low-income and rural locations where there may not be many accessible healthcare resources. ASD diagnostic services must be widely available in these communities to solve this problem. This solution could involve partnerships with community organizations to offer diagnostic services in unconventional settings, telehealth services, or mobile diagnostic machines that travel to areas where services are scarce (Gardner et al., 2022). Partnerships with community organizations and the availability of child neurologists could help autistic children receive a prompt and accurate diagnosis. Child neurologists can confirm or eliminate specific symptoms of autism and other related conditions, such as seizures. They also provide more clarity and understanding of the child's condition, enabling caregivers to make informed decisions about their child's care. Child neurologists can also provide valuable insights into the child's cognitive and language functions, which are critical for developing effective treatment plans.

Furthermore, child neurologists can collaborate with other healthcare professionals, such as speech and behavioral therapists, to provide holistic care to children with autism. This multidisciplinary approach would ensure that children receive comprehensive care that addresses all aspects of their condition, leading to better outcomes. Regardless of their financial situation or insurance coverage, ensuring that all families can afford and utilize these diagnostic services is crucial. Government can fund insurance coverage eligibility by giving families who cannot afford diagnostic evaluations monetary support for those services (Gardner et al., 2022). In addition, healthcare professionals should assist families in utilizing the healthcare system and locating the required resources. The caregivers had described the referral procedure for medical diagnostic services for autism spectrum disorder (ASD) as a source of uncertainty and aggravation. The procedure is frequently time-consuming and complicated. It also delays diagnostic services for children who require it promptly (Gardner et al., 2022). For families who may already be dealing with stress from raising a kid with ASD, this can be very difficult.

The referral process for diagnostic services needs streamlining to overcome this problem. Even if it entails developing a centralized referral system that is simple to use and open to all healthcare professionals (Stahmer et al., 2019), clear directions and instructions on how to recommend children for diagnostic services, in addition to details on the available resources and support services, should be given to healthcare professionals. Families must also be included in the referral process, and it is crucial to ensure they are informed and always supported. The coordination and clear explanations of the referral process, including what to anticipate and what actions are required, should be given to families (Stahmer et al., 2019). Additionally, there should be assistance and directions on how to use the healthcare system and access resources. Healthcare providers can contribute to ensuring that children with suspected ASD are referred for diagnostic services promptly and effectively by expediting the referral procedure (Stahmer et al., 2019). Ultimately, this can improve outcomes for kids with ASD and their families by reducing delays in receiving and ensuring accurate diagnostic development.

Families may continue to experience stress due to logistical, financial, and emotional difficulties. In addition to the economic challenges connected with getting diagnostic treatments, like the price of screenings and assessments, caregivers may experience emotional strain from caring for a child with ASD. Support for families is required to tackle these issues (Stahmer et al., 2019). One way to do this is to offer financial aid for diagnostic services, like subsidies or reimbursement plans to help reduce the cost of examinations and assessments. Families may also get access to counseling services to offer them emotional support and aid them in overcoming the difficulties of raising a child with ASD (Stahmer et al., 2019).

Furthermore, it is crucial to understand that families could experience logistical challenges in accessing diagnostic services, like transportation and scheduling concerns (Stahmer et al., 2019). Support could be given to families to assist them in navigating the healthcare system, gaining access to transportation services, setting up appointments, and managing other logistical issues to remove these obstacles (Stahmer et al., 2019). Facilities can lessen the difficulty of obtaining diagnostic services for ASD and enhance outcomes for children with ASD and their families by offering support to families. This support can reduce financial and emotional strain while giving families the tools and help to navigate the healthcare system and get their children the required diagnostic services. Improving collaboration between healthcare providers and caregivers has been cited as one of the significant issues faced by parents and carers of children with autism spectrum disorder (ASD). Children with ASD may encounter setbacks and inconsistencies in their diagnosis and treatment if healthcare experts do not collaborate. Caregivers frequently trying to get through a complicated healthcare system and receive the resources their children need may need clarification and clarity. Improved coordination between healthcare professionals and caregivers would help reduce problems associated with healthcare system navigation. (Stahmer et al., 2019). This coordination may involve creating provider communication and cooperation standards, like common electronic health records, frequent team conferences, and standardized evaluation and treatment methods (Stahmer et al., 2019). Training healthcare professional programs could help them comprehend the unique requirements of children with ASD and the need for cooperation and coordination in delivering quality treatment (Stahmer et al., 2019). The stress on caregivers getting around a complex healthcare system can be lessened by improving coordination among healthcare professionals and ensuring that children with

ASD obtain timely and consistent care (Stahmer et al., 2019). By cooperating, healthcare professionals can give children with ASD more efficient respect and contribute to better outcomes for these kids and their families.

Implications

The results of this study have significant ramifications for those who research rural healthcare access and autism. The study highlights the challenges families encounter while attempting to obtain diagnostic medical treatments for their autistic children, such as obstacles linked to location, lack of expertise, knowledge, financial capability, and insurance coverage, and suggests possible improvements. These difficulties may lead to delays in diagnosis and restrict access to necessary interventions and therapies, which may harm the long-term outcomes for autistic children. Researchers can create treatments that specifically target these barriers and assist families in gaining access to the required expertise and diagnostic services by studying the unique difficulties experienced by families in rural locations. This approach may involve initiatives to make diagnostic services more accessible in remote areas, like telehealth or mobile diagnostic units. Additionally, it can entail lobbying for increased financing for public assistance programs that aid low-income families in paying for diagnostic procedures and interventions, as well as improved insurance coverage for services connected to autism.

The research results significantly impact medical professionals treating autistic children and their families. The significance of prompt and clear communication with parents during the diagnosis process should be one of the primary lessons learned by healthcare professionals. Caregivers who had favorable interactions with healthcare professionals frequently emphasized the value of practitioners who paid attention to their worries, thoroughly clarified the diagnostic procedure and assessment results, and offered support and direction throughout the process. The report also emphasizes the need to have access to knowledgeable, experienced doctors. They were accessing experts in autism diagnosis, and management guarantees the practical tools and knowledge required to offer high-quality diagnostic services to children with autism. Also, healthcare providers can overcome long wait times, referral delays, misdiagnosis, and precise coordination and communication. The study also highlights the significance of giving each child specialized care tailored to their requirements. When healthcare professionals took the time to comprehend the strengths and challenges of children with autism and created a treatment plan specific to those requirements, parents reported favorable experiences. It is essential to thoroughly understand each child's needs and develop tailored treatment plans to meet those needs. Tailored treatment would enhance healthcare providers with improved autism quality of care delivery.

The research findings have significant policy implications, especially considering low-income families' financial hardships and insurance coverage restrictions when obtaining diagnostic services for their autistic children. Because of their rural locations, study participants reported challenges obtaining diagnostic services, delays in acquiring a diagnosis, and limited access to experts. They also emphasized that there is a substantial financial barrier to getting diagnostic services, assessments, and therapies for their children with autism. This finding may help policymakers push for more funds for public assistance programs that aid low-income families with paying for diagnostic services. For families traveling a great distance to seek specialist treatment, these programs might offer financial support for evaluations and therapies and travel and lodging costs.

Policymakers could also seek to enhance insurance coverage for services associated with autism by resolving coverage rejections and session limitation issues. Expanding Medicaid coverage may improve access to diagnostic services for low-income families and encompass more extensive autism-related care. The study emphasizes the significance of expanding diagnostic service accessibility in rural locations. Policymakers should encourage recruiting and retaining medical professionals in rural areas, especially those trained in diagnosing and treating autism. Healthcare providers should include incentive packages for healthcare professionals working in rural areas and financing for telehealth initiatives that let families in rural areas get specialized treatment from healthcare professionals in metropolitan areas.

Conclusion

Increasing the availability of diagnostic medical care for kids with autism is complicated and necessitates a diversified strategy. Several significant recommendations have been proposed in this study following caregivers' viewpoints. These recommendations can help improve access to diagnostic services and guarantee that kids with autism receive prompt and efficient care. This study's key conclusions include raising autism awareness and educating the public, enhancing diagnostic services' accessibility, streamlining the referral procedure, aiding families, and enhancing healthcare providers' coordination. Implementing these recommendations may help reduce the hurdles that hinder children with autism from receiving the required treatment in healthcare systems. This study discovered that to ensure children with autism receive the proper care and support, improving access to diagnostic medical services is imperative. The suggestions made could help healthcare systems, policymakers, and other stakeholders increase access to diagnostic services for children with autism, which will eventually allow these kids and their families to achieve better results.

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Appendix A: Interview Questions and Follow-up

Main Research Questions:

RQ1: What personal and professional challenges did the parents encounter during the diagnostic process?

Interview Questions:

1. Please explain the personal challenges you face when accessing diagnosis services for your child with autism.
2. What diagnosis services did health services providers offer your child?
3. How helpful are health service professionals during the diagnosis process?

Main Research Question:

RQ2: What are low-income parents’ experiences accessing medical diagnostic services for children with autism?

1. What assistance do you get from the health services or other entities, if any, when accessing diagnosis services?
2. What is your perspective about the services received, if any, among low-income, middle-income, and affluent caregivers accessing medical diagnoses for children with autism?
3. What are the barriers low-income caregivers face accessing diagnosis services?

How is the availability of diagnosis resources within reach for low-income parents and caregivers alike?

Main Research Question:

RQ3: What health service factors do the parents consider beneficial when diagnosing their child's autism?

1. What are the most benefits you receive while accessing a diagnosis for your child with autism?
2. Do you perceive it helpful to have access to diagnosis within reach for children with autism?

Main Research Question:

RQ4: What health service factors do the parents perceive as barriers in diagnosing their child's autism?

1. What are the barriers to accessing medical diagnosis for children with autism?
2. Do you think the measuring tools for diagnosing children with autism are accurate?
3. Do you perceive weaknesses in the health services for diagnosing children with autism?

Main Research Question and Interview Questions:

RQ5: What changes do the parents perceive necessary to improve access to and timing of an autism diagnosis?

1. How do you improve access to medical diagnosis?
2. What do you expect from healthcare services to help cope with the diagnosis process?
3. What is your perspective on diagnostic timing for children with autism?

Main Research Questions:

RQ6: What factors are identified by the parents as critical in helping them cope with the diagnostic process?

1. What can the health service administrators, government, or non-governmental entities do to help cope with the challenges of accessing diagnostic services for children with autism?
2. What area of autism medical diagnosis services do your health service professionals focus more on?