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PARENTING PERSPECTIVES ON AUTISM: A COMPARATIVE STUDY OF EXPERIENCES IN NIGERIA AND THE UNITED STATES

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Abstract

Study Description: This study investigates the experiences of parents with children diagnosed with autism spectrum disorder (ASD) in Nigeria and the United States, concentrating on societal acceptance, systemic influences, and specialized caregiving approaches. Families with Children with autism encounter distinct challenges, such as accessing resources and dealing with societal perceptions. While there is a wealth of research in high-income nations like US, the experiences of parents in low- and middle-income countries, such as Nigeria, have received scant attention. **Study Rationale:** The study seeks to fill a gap in understanding how parents in varying sociocultural and economic environments handle the responsibilities of caring for children with ASD. In the US, parents typically have access to formal support networks and legal protections, yet they still experience emotional and financial pressures. In contrast, Nigerian parents face cultural misunderstandings, social stigma, and limited resource availability, which significantly impact their caregiving. **Theoretical Framework:** The research utilizes an ecological systems framework, which highlights the interplay of individual, family, and societal factors in shaping caregiving experiences. Additionally, resilience theory supports the analysis, focusing on how families navigate challenges through coping strategies and support systems. **Methodology:** A snowball sampling technique was employed, and structured interviews were carried out with parents with children living with autism in Nigeria and the US. Data collection centered on parental understanding of autism, cultural viewpoints, access to diagnosis and interventions, and societal stigma. Given the sensitive nature of the subject, structured questionnaires were designed to fit the busy schedules of participants. **Findings:** Parents in the US gain from structured support networks but encounter emotional and financial challenges. Nigerian parents deal with cultural misunderstandings, social stigma, and scarce resources, which add to the difficulties of caregiving. The study underscores the necessity for tailored interventions, stressing the importance of autism awareness initiatives in Nigeria, fair access to support services, and international cooperation to enhance care for children with autism and their families.

Keywords: Autism Lived Experiences, Parents, Nigeria and USA.

1. Introduction

Raising a child with autism spectrum disorder (ASD) is a complex and often intimidating experience, influenced by cultural beliefs, institutionally available supports, and societal perceptions. ASD is a neurodevelopmental disorder with features such as communication challenges, repetitive behavior, and sensitivity to sensory input, which affect not only the individual with ASD but also the family as a whole (American Psychiatric Association, 2022). Parents have a crucial role in ensuring that their children receive relevant supports, but their experience is subject to awareness, availability of services, and socio-economic circumstances within their societies (Lai et al., 2020). With increasing ASD cases worldwide, inequalities still exist concerning how parents experience care across different contexts (Zuckerman et al., 2021). While parents residing in high-income economies, for instance, the United States, have access to organized intervention services, they still face bureaucratic barriers, financial burdens, and social misconceptions (McCoy et al., 2021). Parents residing in low- and middle-income countries (LMIC), e.g., Nigeria, do not have formal diagnostic and intervention services, and as a consequence, they have to rely on informal coping strategies (Igwe et al., 2020).

Global estimates suggest that 1 out of 100 children have ASD, though detection is variable across countries (World Health Organization [WHO], 2021). Early intervention has been shown effective for improving developmental outcomes (Dawson et al., 2020), but access is not equal. In the United States, legislation including the Individuals with Disabilities Education Act (IDEA) and the Autism CARES Act supports funding for intervention programs, special education, and research (Zablotsky et al., 2019). However, there are racial and economic disparities, with Black and Hispanic communities having a greater chance of having late detection and restricted access to therapy services (Magana et al., 2019). Minority parents in the U.S. experience a challenge navigating complicated healthcare and educational systems, leading to variable care (Jack et al., 2021). Families also have to fight for their children's access to necessary services, further adding emotional and psychological distress (Hoffman et al., 2020).
By comparison, there are not organized autism policy and state-funded intervention programs for Nigeria, and parents have to fend for themselves (Bakare & Munir, 2021). Without diagnostic services at a young age, most children do not get a diagnosis until they have severe behavioral issues, at which point intervention is not as effective (Ajuwon et al., 2019). Furthermore, cultural misconceptions about autism cause stigmatization, with most Nigerian communities perceiving the condition as spiritual, and therefore pursue religious or traditional healing, not a medical one (Igwe et al., 2020). Such beliefs lead to social exclusion, as children

with ASD are excluded from school and community involvement due to lack of understanding and accommodation (Ohan et al., 2021). The few trained personnel and exorbitant private therapy fees also limit parents' access to necessary interventions (Arias et al., 2020).

Parents' difficulties in Nigeria and the U.S. extend beyond institutionally erected barriers into the psychological domain. It has been consistently documented through research that parents of children with ASD report higher levels of anxiety, depression, and stress than parents of neurotypical children (Irvin et al., 2020; Hayes & Watson, 2013). Financial stresses add to these, as ASD treatments like applied behavior analysis (ABA), occupational therapy, and speech therapy can be very costly and entail out-of-pocket expenses (Pickard & Ingersoll, 2019). Without insurance coverage for autism services, as in the case of Nigeria, families must either pay for expensive private services or resort to home-based care (Bakare & Munir, 2021). Families in the U.S., with better access to medical care, nonetheless incur significant economic costs, particularly when insurance will not cover all aspects of ASD treatment (Liptak et al., 2020). Resilience theory is a useful framework for understanding how parents navigate these challenges. Resilience is a process of adjusting to adversity, using coping strategies and external networks for well-being (Ungar, 2021). Parents, whether in Nigeria or the United States, have a variety of strategies for coping with caregiver stress. Social networks for support, including extended family, internet-based networks for parents, and religious communities, have been identified as essential for reducing caregiver stress (Gibson et al., 2021; Kirby et al., 2022). Religious organizations provide emotional and, on occasion, financial supports for families in Nigeria, but parents also join advocacy groups for policy reforms and increased funding for services for autism in the United States (Magana et al., 2019). Parental burnout remains a challenge, however, where there are few resources and where there is variable support (Jack et al., 2021).

Ecological systems theory also explains how parents' experience is shaped through interactions between individual, family, institution, and societal factors (Bronfenbrenner, 2005). Parents in the U.S. must negotiate multiple levels of bureaucracy, including school administrations, insurance providers, and state agencies for disabilities, all of which impact the level of care that their child receives (Zuckerman et al., 2021). Families in Nigeria, because of the absence of state intervention, must rely on interpersonal networks, which commonly translate into disparate access to services based on socio-economic status (Ajuwon et al., 2019). These system factors influence how parents perceive ASD, what they expect for their child's future, and whether they are able to access intervention services (Ohan et al., 2021).

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Understanding these dynamics is vital for policy interventions and public campaigns, healthcare worker training, and state-funded financial aid for families must be given priority in Nigeria. Research has shown that community-based early intervention services may have a huge impact on low-resource communities (Bakare & Munir, 2021). Back in the US, policymakers will have to focus on closing racial disparities in autism diagnosis and care, giving minority families equal access to early intervention services (Magana et al., 2019). Expanding insurance coverage for therapies for autism will also alleviate financial burdens on families (Liptak et al., 2020).

This research contributes to growing evidence on parenting with ASD, highlighting cultural beliefs, system barriers, and adaptive coping strategies at their intersection. Drawing a comparison of parents' lived experience across Nigeria and the United States, this research illuminates how sociocultural contexts impact caregiving experience. Ultimately, closing these gaps will require a multi-faceted strategy, with governments, healthcare, educators, and autism advocacy organizations collaborating to give all children, regardless of geography and socio-economic standing, what they require for success.

2. Method

Study Design and Sampling

Parents of autistic children in Nigeria and the US were recruited for this study using a snowball sampling technique. Given the comparatively low frequency of autism and the possible challenges in recruiting consenting participants especially in communities where stigma against autism is still pervasive snowball sampling was judged adequate. Online parental forums, special education centers, and autistic advocacy groups were used to find the first participants. The sample was then increased by these parents' referrals of more qualified individuals.

Data Collection Procedure

Parents' knowledge of autism, cultural beliefs, access to diagnosis and therapies, and experiences with social stigma were all investigated through structured interviews. The purpose of the interviews was to obtain detailed answers while maintaining uniformity and clarity between the

two study sites. Interviews were done in-person, over the phone, or virtually using Zoom and WhatsApp sessions to accommodate participants' various schedules and comfort levels. In order to minimize participant weariness and provide a thorough examination of parental experiences, each interview lasted between thirty and forty-five minutes.

Standardized data collection across both countries was made possible by the development of a structured open ended questionnaire to supplement the interviews. The questionnaire covered topics such as parental knowledge of autism symptoms, interactions with medical professionals, accessibility to autism-related interventions, and social perceptions of autistic children. It contained both closed-ended and open-ended items. The open-ended questionnaire allowed participants to expound on their own experiences and contextual factors impacting their perceptions and choices, the structured nature of the questionnaire ensured that responses could be studied methodically.

Data Analysis

Finding patterns in the attitudes and experiences of parents was made possible by the transcription and thematic analysis of data from structured interviews. Through the use of descriptive and inferential statistics, quantitative data from structured questionnaires was examined, and responses from participants in the United States and Nigeria were compared. This mixed-methods strategy gave researchers a thorough grasp of how healthcare, cultural, and economic issues influence autism experiences in both areas. In addition to providing insightful information on potential obstacles to diagnosis and intervention in various sociocultural contexts, this methodology guaranteed a thorough, moral, and culturally aware approach to researching parents' perceptions of autism.

Ethical Consideration

All participants gave their informed consent, and responses were anonymized and pseudonyms were used when needed to ensure confidentiality given the delicate nature of conversations pertaining to autism. Additionally, participants were made aware of their freedom to leave the research at any time without facing any repercussions.

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3. Results

The study looked at parents' experiences in the US and Nigeria who were raising autistic children. The results show disparities in cultural attitudes, caregiving difficulties, and availability to support resources, but they also indicate shared difficulties like financial and emotional strains.

Table 1: Comparison of Parental Experiences in the U.S. and Nigeria

Theme	U.S. Parents	Nigerian Parents
Access to Diagnosis and Early Intervention	Readily available autism screening and diagnostic services.	Limited access to professional diagnosis; reliance on traditional explanations.
Availability of Support Services	Well-structured support networks, including therapy and special education programs.	Scarcity of trained professionals, specialized schools, and therapy centers.
Financial Burden	High costs of autism therapy, despite insurance and state-funded programs.	Therapy and interventions are largely out-of-pocket, making access difficult for low-income families.
Emotional and Psychological Impact	Emotional stress from navigating complex healthcare systems and advocacy for services.	Anxiety and stress due to societal stigma, isolation, and lack of support.
Social Stigma and Cultural Perceptions	Growing societal acceptance of autism, though misconceptions still exist.	Widespread cultural misconceptions, leading to exclusion and discrimination.
Educational Opportunities	Federal laws mandate inclusive education and accommodations in schools.	Limited special education programs and lack of legal framework for inclusive schooling.
Parental Advocacy	Many support groups, advocacy	Weak parental advocacy due to

and Community Support	organizations, and initiatives.	parent-led stigma and lack of awareness.
Governmental and Policy Support	Policies supporting autism research, funding, and disability rights.	Minimal government involvement, with most autism support driven by NGOs and private institutions.

The study shows that although formal support services are helpful to American parents, they still have to deal with emotional and financial challenges including paying for therapy, navigating bureaucratic red tape, and making sure their kids have the right kind of school modifications. Nigerian parents, on the other hand, face several obstacles, such as cultural stigma, a lack of knowledge, and restricted access to expert assistance. Many people mistakenly believe that spiritual issues, rather than neurological ones, are the cause of autism. These difficulties are made worse by financial limitations, since specialist solutions are either completely unavailable or prohibitively expensive.

4. Discussion

This study indicates stark disparities in parents' lived experience with children with autism spectrum disorder (ASD) in Nigeria and the United States. While there are shared challenges for parents on both sides, including financial burden, emotional distress, and advocacy, their scope and character differ extensively due to differences in societal attitudes, institutional services, and policy. The study highlights cultural perceptions, access to healthcare, and educational services as determinants of parents' lived experience, and therefore calls for context-specific interventions for managing these disparities. Parents in the US have greater access to diagnostic services, early interventions, and organized networks of supports than do their Nigerian counterparts. The existence of laws such as the Individuals with Disabilities Education Act (IDEA) ensures that ASD-affected children have a right to special educational services and therapy services (Zuckerman et al., 2021). Despite these legal protections, disparities exist in care for autism, particularly among low-income and minority communities (Magana et al., 2019). Parents from African American and Hispanic communities, for instance, face diagnostic delay, restricted access to quality therapy, and greater financial burdens when seeking access to intervention services (Jack et al., 2021). Even where services exist, parents must overcome bureaucratic obstacles, insurance limitations, and outrageous fees for private therapies, which place a heavy financial and emotional burden on families (Liptak et al., 2020). Findings from this research are

congruent with previous finding that, despite formal supports for autism existing within the U.S., their availability is subject to socioeconomic factors, race, and geographic location (McCoy et al., 2021).

In comparison, what is clear from the experience of parents in Nigeria is a very different set of challenges and the lack of state-provided services for autism, few diagnostic centers, and severe shortages of trained staff present serious barriers for early intervention and long-term care (Bakare & Munir, 2021). Parents have a difficult time obtaining a formal diagnosis for their children, with attendant delay in specialist care or educational provision. The absence of policy for inclusive education means a high number of children with ASD cannot access mainstream schools, and parents have few, often costly, private school options (Ajuwon et al., 2019). Additionally, cultural misconceptions about autism drive increased stigma and social exclusion. Autistic individuals are often explained through a spiritual or supernatural lens, with parents being advised to seek religious or traditional healing, not medical or therapy (Igwe et al., 2020). Such societal stigma not only affects children's well-being with autism but also places a serious psychological burden on parents, feeling stigmatized and isolated within their communities (Ohan et al., 2021).

Despite these differences, the studies highlight that parents from Nigeria and the U.S. have shared coping strategies for dealing with challenges associated with raising a child with ASD. Parental resilience is a common thread, with parents seeking self-education, advocacy, and social networking for their children's interests (Ungar, 2021). American parents engage with advocacy organizations, collaborate with autism organizations, and campaign for policy reforms for effective service delivery (Gibson et al., 2021). For their part, Nigerian parents, with weak formal networks, rely on religious communities, extended family networks, and peer networks for information and emotional support (Arias et al., 2020). The evidence from research supports ecological systems theory, which argues that experience as a parent is affected by interactions among individual, family, institution, and societal factors (Bronfenbrenner, 2005). Parents on either side turn for help within their social and cultural milieus, but with varying degrees of effectiveness depending on institutional supports available. Financial constraints are a common issue for parents in both settings, with varying degrees of financial burden depending on welfare and healthcare systems. With privatized and expensive autism services in Nigeria, low-income families cannot afford therapies such as applied behavior analysis (ABA) or speech therapy, limiting development for their children (Bakare & Munir, 2021). Despite insurance and state-

funded programs, many American parents also experience financial burdens, as special educational services and therapy sessions are not necessarily covered by insurance agencies and are expensive (Liptak et al., 2020). These financial constraints place additional burdens on parents, and consistency with measures for interventions, which is vital for developmental outcomes for children with ASD, becomes a challenge (Pickard & Ingersoll, 2019).

Another crucial discovery is the psychological burden for parents with children with ASD. Studies have all pointed out that parents with children with autism experience higher levels of anxiety, depression, and stress compared with parents with neurotypical children (Hayes & Watson, 2013). The current research supports that this emotional burden is prevalent among parents in Nigeria and the U.S., but with varying factors. While parents with children with ASD in Nigeria feel guilty, ashamed, and helpless due to a lack of social understanding and limited access to professional counseling services (Igwe et al., 2020), American parents experience stress due to coordinating with multiple services, insurance agencies, and ensuring school accommodations for their children (Jack et al., 2021). In either setting, inadequate mental health services for parents increase their level of stress, and there is a clear necessity for additional targeted psychological interventions. This study emphasizes the need for significant reforms in autism care systems, not just in Nigeria but also in the United States. Public awareness campaigns need to be launched in Nigeria to dispel myths and stigmatization of autism. Autism training needs to be incorporated into medical and educational curricula for early detection and intervention at an early age. Subsidized autism care services also need to be invested in, with an aim to provide children from low-income families with access to basic therapies. Autism advocacy agencies also need to be empowered, and parents' involvement needs to be encouraged at policy-making levels for improved services and attitude change at societal levels.

In this country, closing socioeconomic and racial disparities in care for autism is a priority. Early intervention services have to be equitably distributed for all families, not based on background. Expanding insurance coverage for autism therapies and streamlining access for individualized education programs (IEPs) would eliminate financial and logistical burdens on parents. More school-based autism programming and training for teachers would also help children with ASD placed in mainstream schools. This research contributes to growing evidence on autism parenting experience, showing how cultural, economic, and institution forces affect care-giving challenges and coping responses. Comparing Nigeria and the US, it highlights system weakness as well as strengths among parents, with valuable lessons for policymakers, educators, and advocacy organizations. Ultimately, having a welcoming and supportive space for children with autism requires a multi-tiered approach, with involvement from governments, healthcare, educators, and

community organizations. Longitudinal studies on how parents' experience changes over time, as well as assessment of interventions for improving autism care worldwide, are areas for future research.

5. Conclusion

This study highlights differences in autism care among Nigeria and the United States, emphasizing cultural beliefs, institutionally provided supports, and economic factors as shaping parents' experience. While U.S. parents have well-organized policies, racial and socioeconomic inequalities compromise access to early intervention. Stigma, lack of trained personnel, and high therapy fees are barriers to autism care in Nigeria, forcing families into informal networks. Despite all these challenges, advocacy and parent resilience are essential for caring for ASD children.

6. Recommendations

To solve these issues, there is a requirement for culturally modified interventions, improved policy, and increased awareness for ensuring equal support for all families.

1. Governments and stakeholders have a mandate to put high priority on autism awareness, detection at an early age, and intervention services.
2. Misconceptions should be dispelled through information campaigns, and screening for ASD should be part of routine healthcare.
3. Special educational programs must be increased, with trained educators capable of accommodating neurodiverse students.
4. Financial aid, including subsidies and additional insurance coverage, will also help ease economic burdens on families. Parent advocacy groups and mental health services for caregivers must also be increased for the well-being of caregivers.
5. Autism centers must be established at community levels, particularly for low-access areas, with affordable and sustainable services for all children, regardless of socioeconomic or geographic location.

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