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Multi-Level Challenges in Autism Caregiving: A Socio-Ecological Qualitative Study of Caregivers in Nigeria

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Abstract

This study explores the lived experiences and unmet needs of caregivers of children diagnosed with autism spectrum disorder (ASD) in Nigeria. ASD is increasingly prevalent in the country and places a substantial economic and psychosocial burden on affected families and society at large. Caregivers often face restricted social engagement, social exclusion, and stigma associated with the condition. Despite these challenges, limited research has focused on the psychosocial impact of ASD on caregivers in Nigeria. This study addresses this gap by generating empirical evidence and drawing attention to the caregiving realities and unmet support needs within this context. A qualitative research design was employed, involving twenty-three caregivers purposively selected for participation. Interview and discussion guides were developed by adapting questions from the PREPARE and Zarit Burden Interview instruments. Data were collected from caregivers of children attending selected special needs schools in Cross River State, Nigeria. Both inductive and deductive analytical approaches were applied, with data management and analysis conducted using NVivo 20 Pro software. The socio-ecological model guided the organization of themes and interpretation of participants' narratives.

Analysis of the data revealed four overarching themes and eleven sub-themes corresponding to the four levels of the socio-ecological model. Findings indicated that caregivers commonly experienced intense emotional distress, shock, fear, and disbelief following their child's diagnosis. In addition, many families and social networks struggled to understand or accept the diagnosis, often leading to strained relationships, conflict, and miscommunication. Broader socio-cultural factors, including stigma, discrimination, and social isolation, were also prevalent and significantly shaped caregivers' experiences. Given the substantial psychological burden and pervasive stigma faced by caregivers and children living with ASD, there is an urgent need for context-specific interventions in Nigeria. Such interventions should adopt a multi-level approach that integrates individual, interpersonal, institutional, and policy-level strategies. Strengthening caregiver-led advocacy and increasing public awareness across all levels of society are essential to reducing stigma and improving support systems for families affected by ASD in Nigeria.

Keywords: Autism caregiving, Caregivers, ASD, Nigeria

Introduction

Autism Spectrum Disorder (ASD) is a complex group of neurodevelopmental conditions that primarily emerge in early childhood and are marked by long-term functional impairments [1, 2]. These impairments typically manifest as challenges in social engagement and communication, restricted or repetitive patterns of behavior, and atypical cognitive development, often co-occurring with intellectual disability [3, 4]. In recent years, ASD has gained increasing attention as a major public health concern due to its rapidly rising prevalence worldwide. Available estimates suggest that the global burden of ASD has increased by nearly 40% over recent decades [5–7]. Data from the Centers for Disease Control and Prevention (CDC) indicate that more than 28 million individuals are currently living with ASD globally, with

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approximately one in every 36 children affected [7]. Similarly, the World Health Organization (WHO) estimates that ASD affects about one in 100 people worldwide, further highlighting the scale of the condition [1]. Among high-income countries, the United Kingdom reports one of the highest prevalence rates, estimated at 700 cases per 100,000 population [8, 9]. However, in many regions—particularly in Africa and other low- and middle-income countries—the true prevalence of ASD remains poorly documented due to underdiagnosis and limited reporting systems [10].

Research conducted across African countries demonstrates that ASD is present throughout the continent, although reported prevalence varies widely. A comparative study conducted in Tunisia and Egypt documented prevalence rates of 11.5% and 33.6%, respectively [11]. In contrast, a longitudinal investigation in Uganda reported a substantially lower prevalence of 0.68% [12]. In 2019, the estimated number of individuals living with ASD in North Africa and the Middle East reached approximately 1,879,528, representing 6.6% of the global ASD burden [13]. Similarly, estimates from Kenya suggest that up to 800,000 children may be living with ASD [14]. Within Nigeria, reported prevalence rates differ considerably across regions. Studies from the southwestern region have estimated prevalence at about 2.3% [15], while research in the southeastern region reported a lower prevalence of 0.8% [16]. Conversely, a study conducted in Lagos State among children reported markedly higher rates, reaching 34.5% [17]. These inconsistencies likely reflect variations in study design, diagnostic practices, and screening tools, as well as persistent challenges related to misclassification and underreporting, necessitating cautious interpretation of available data.

As lifelong conditions, ASD and intellectual disability (ID) exert far-reaching effects not only on individuals living with these conditions—particularly children—but also on their caregivers [18, 19]. While the experiences of caregivers have been extensively explored in high-income countries, comparable evidence from low-resource and developing settings remains limited [20, 21]. In addition to the core developmental challenges—such as difficulties in attention, memory, speech and language, sensory processing, and social functioning—ASD is often accompanied by significant psychosocial consequences, including heightened stress, anxiety, stigma, and social withdrawal among affected individuals and their families [18, 22, 23]. In many parts of sub-Saharan Africa, autism and other mental health conditions are frequently interpreted through spiritual or supernatural lenses, commonly attributed to ancestral wrongdoing, witchcraft, demonic influence, or divine punishment [24]. Such beliefs often result in ASD being perceived as a curse or punishment from God [18, 19, 25], thereby reinforcing stigma and social exclusion directed at affected children and their families [19, 26].

The responsibility of caring for a child with ASD presents considerable emotional, social, and practical challenges, particularly in contexts where specialized services and formal support systems are scarce or inaccessible [1]. Evidence indicates that caregivers of children with ASD experience disproportionately higher levels of psychological stress, emotional exhaustion, and burnout compared with caregivers of children without developmental disorders [19, 27, 28]. In addition to emotional strain, ASD is associated with substantial financial costs at both household and societal levels [29]. Children with ASD often require long-term medical care, specialized education, and continuous supervision, all of which demand significant financial investment [26]. Many caregivers report experiencing both direct and indirect economic hardship, including job loss, reduced work hours, and missed educational or career opportunities as a result of the intensive time commitments required for caregiving [26, 30].

Despite growing recognition of the burden associated with ASD, there remains a significant gap in empirical research examining the lived experiences of caregivers in Nigeria. This study seeks to address this gap by exploring the challenges faced by caregivers of children with ASD, with a particular focus on socio-cultural influences, perceived community and social support, and caregivers' unmet needs. By generating context-specific evidence, this research aims to inform the development of culturally appropriate and sustainable support interventions for caregivers in Nigeria and other low-resource settings. Ultimately, the findings contribute to efforts toward achieving the United Nations Sustainable Development Goal 3, which emphasizes good health and well-being while ensuring that vulnerable populations are not left behind.

Materials and Methods

Study design

This study was informed by a constructivist epistemological perspective, which acknowledges the absence of a single, objective reality and recognizes knowledge as socially constructed through individual experiences [31]. A cross-sectional qualitative research design was adopted and guided by the socio-ecological model to frame data interpretation and presentation. The socio-ecological model offers a comprehensive framework for examining the multiple, interacting levels that influence health outcomes, including individual, interpersonal, social, physical, and policy-related environments [32].

Study population

The target population comprised caregivers of children under the age of 18 years who had been diagnosed with autism spectrum disorder and were enrolled in special needs schools located in Calabar, Nigeria. Confirmation of ASD diagnosis was based on documented psychiatric assessments provided at the point of school enrollment.

Sample size and sampling procedure

The sample size for this study was determined in line with existing qualitative research recommendations, which suggest that participation of between 6 and 30 individuals is generally sufficient to address study objectives [33, 34]. Participant recruitment continued until data saturation was achieved—that is, when no new insights or themes emerged and additional data collection yielded repetitive information [35]. A purposive sampling approach was employed to identify caregivers who could provide rich and relevant insights into the phenomenon under study. Data collection involved two focus group discussions (FGDs), each comprising eight caregivers, as well as seven in-depth interviews (IDIs) conducted with caregivers and parents.

Data collection instruments

The interview and focus group discussion guides were developed using selected questions adapted from the Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences (PRAPARE) [36] and the Zarit Burden Interview (ZBI) [37]. These instruments have been widely utilized across diverse settings in Africa, North America, and Europe to assess a broad range of social determinants and caregiving-related needs, including housing, employment, education, safety, transportation, and social connectedness [38, 39]. Prior to the main study, the tools were pretested among a separate population in Cross River State. Feedback from the pretesting informed revisions to enhance clarity, refine question sequencing, address ambiguities, and estimate the duration of data collection.

Data collection procedures

Before the commencement of data collection, three research assistants were engaged and received comprehensive training on qualitative research methods and the overall objectives of the study. The training sessions covered detailed orientation on the data collection instruments, mock interviews, field simulations, and standard procedures for post-interview debriefing. Data collection was conducted over a seven-week period between March and April 2024 across three special needs secondary schools in Cross River State, Nigeria. Approval was obtained from school administrators, who facilitated access to caregivers and scheduled appropriate times for engagement with the research team. Data were gathered using both focus group discussion (FGD) and in-depth interview (IDI) guides. Participants provided informed consent for audio recording of all interviews and discussions, which were subsequently transcribed verbatim and translated for analytical purposes [40]. Field notes recorded during the interviews were also incorporated into the dataset to enhance analytical depth.

Data analysis

All interview transcripts were carefully reviewed for accuracy and completeness prior to being uploaded into NVivo software (version 20) for analysis. A combined inductive–deductive thematic analysis approach was employed. Initially, a deductive coding framework was developed based on existing literature and relevant theoretical models. As analysis progressed, new codes and thematic patterns that emerged from the data were continuously identified and integrated into the coding scheme. This iterative process ensured that the analysis remained responsive to participants' narratives and consistent with the inductive principles of thematic analysis, wherein themes are derived from the data rather than being rigidly predetermined [25].

Ethical considerations

Ethical approval for the study was obtained from the Cross River State Ministry of Health. Both written and verbal informed consent were secured from all participants after providing a clear explanation of the study's objectives, relevance, and procedures. Participants were assured that their participation was voluntary and that all information shared would be treated with strict confidentiality. The study involved no foreseeable risks to participants. All data collected were securely stored by the principal investigator and were permanently destroyed upon completion of the study.

Operational definition

For the purpose of this study, a primary caregiver was defined as the individual who assumes the principal responsibility for a child's care and development, and who is most actively involved in caregiving activities, including hospital visits, specialist consultations, and other clinical or therapeutic interventions [41].

Positionality statement

We acknowledge and explicitly state our positional positioning in relation to the subject under investigation. The principal investigator has prior professional experience working with vulnerable populations in Nigeria, particularly within the areas of child health and neurodevelopmental conditions. This background may have influenced the formulation of the research questions, the data collection process, and the interpretation of study findings. To mitigate potential bias arising from this positioning, a reflexive approach was deliberately adopted throughout the research process, incorporating perspectives and analytical inputs from multiple researchers. Additionally, we recognize that our professional identities as health practitioners, together with the cultural and social contexts in which we operate, may have shaped our understanding of autism and caregiving practices in Nigeria. Throughout the study, we remained committed to accurately representing caregivers' lived experiences and perspectives, while also acknowledging the broader socio-cultural complexities that characterize the research setting.

Results and Discussion

Socio-demographic characteristics of participants

A total of seven caregivers participated in the in-depth interviews (IDIs), comprising two males and five females, while the focus group discussions (FGDs) included sixteen participants, of whom four were male and twelve were female. The mean age of IDI participants was 35.5 years (±7.56), compared with a mean age of 33.0 years (±8.29) among FGD participants. Most respondents in both groups were married, with four married participants in the IDI group and nine in the FGDs. Regarding educational attainment, the majority of IDI participants had completed tertiary education (n = 4), whereas most FGD participants reported having primary-level education (n = 5). Civil service employment was the most commonly reported occupation, accounting for four IDI participants and seven FGD participants. A detailed summary of participants' socio-demographic characteristics is presented in **Table 1.**

Table 1. Socio-demographic characteristics of participants (FGD N = 16; IDI N = 7)

Participant Characteristics	Focus Groups Frequency (%)	In-depth Interviews Frequency (%)
Sex		
Female	12 (75.0)	5 (71.4)
Male	4 (25.0)	2 (28.6)
Marital Status		
Widowed	2 (12.5)	1 (14.3)
Single	5 (31.3)	2 (28.6)
Married	9 (56.3)	4 (57.1)
Age (years)		
21–30	8 (50.0)	2 (28.6)
31–40	4 (25.0)	3 (42.9)
41–50	4 (25.0)	2 (28.6)
Current Employment Status		
Civil servant	7 (43.8)	4 (42.9)
Unemployed	4 (25.0)	–
Business/tradesperson	5 (31.2)	3 (57.1)
Education Level		
Primary	5 (31.2)	1 (14.3)
Secondary	3 (18.8)	2 (28.6)
Tertiary	4 (25.0)	4 (57.1)
No formal education	4 (25.0)	–

Individual-level factors

As presented in **Table 2**, caregivers of children with autism commonly reported significant emotional challenges at the individual level. Their experiences often began with shock and denial following the initial diagnosis, followed by a gradual process of understanding and acceptance. Throughout this journey, caregivers described experiencing intense and often conflicting emotions, including fear, uncertainty, and anxiety. Despite these difficulties, many caregivers also reported developing coping mechanisms, acquiring knowledge about the condition, and drawing personal strength as they adjusted to their caregiving roles over time.

Table 2. Summary of themes and sub-themes

Socioecological Level	Sub-Themes	Themes
Public Policy Level	10. Government support and policies for autism 11. Advocacy efforts for improved services and rights	Influencing autism support and rights
Societal and Institutional Levels	6. Awareness of support centres and services 7. Educational challenges and school support 8. Navigating healthcare systems 9. Public perceptions of autism	Obstacles and available resources in autism care
Interpersonal Level	4. Friendships and support 5. Societal stigma and misconceptions	Support networks and societal obstacles
Individual Level	1. Initial reaction to the diagnosis 2. Journey of understanding and acceptance 3. Managing responsibilities	Navigating the experience of caregiving for autism

Navigating the caregiving journey for autism

This section captures the experiences of caregivers as they progress from the initial shock of receiving an autism diagnosis to gradually achieving understanding, acceptance, and effective management of the multifaceted responsibilities involved in supporting an individual with autism. Participants highlighted both the emotional struggles and practical difficulties they encountered, along with their growing adaptation to the caregiving role.

Initial response to the diagnosis

Upon receiving the autism diagnosis, caregivers frequently described a blend of intense emotions and uncertainty. Over time, many found comfort in adjusting to the new reality and its impact on their own lives and those of their family members.

"When the diagnosis came for my son, I knew very little about autism. I felt panicked—I was worried about how he would feel and what his future might look like. But as time went on, I've accepted that this is simply who he is, and I worry much less about what others might think." (Participant 1—IDI).

Path toward understanding and acceptance

Caregivers recounted their personal evolution following the diagnosis, starting with initial shock and moving toward full embrace of their loved one's condition. This process involved actively learning about autism and coming to terms with it as a permanent aspect of their family life.

"Autism has been a path of exploration and growth for our family. It has prompted us to rethink our priorities and focus on what truly strengthens our son." (Participant 3—FGD 2).

"While autism brings its own challenges, the deep bond and insight it fosters remain. My son might not engage with things in the usual way, but he is incredibly unique and has remarkable talents that I treasure deeply." (Participant 6—IDI).

"Autism has taught me a great deal and has become a journey of personal growth. It has shifted my perspective in a positive way, helping me focus on life's true priorities and my son's specific needs." (Participant 4—FGD 1).

Balancing responsibilities (work and home)

Participants discussed the difficulties of juggling professional commitments, household duties, and the demands of caregiving for a loved one with autism. This often involved feelings of guilt, overload, and the challenge of dividing attention across multiple roles.

"It's difficult to be fully present at work when you're constantly concerned about your loved one's well-being. Even at home, guilt creeps in for not giving enough attention to other duties." (Participant 2—FGD 1).

"It sometimes feels like I'm rushing to keep up with my autistic child's needs while also meeting the demands of work and home life. These responsibilities often overlap, making it tough to manage everything effectively." (Participant 3—IDI).

Interpersonal-level factors

As summarized in **Table 2**, caregivers' experiences at the interpersonal level were shaped by their interactions with family members, friends, colleagues, and the wider community. Caregivers frequently encountered misunderstanding and stigma within their social environments while simultaneously relying on social networks for emotional, practical, and advocacy-related support. These interpersonal relationships significantly influenced how caregivers perceived and navigated the complexities associated with autism, affecting both their coping strategies and caregiving experiences.

Social support and interpersonal challenges

This theme highlights the contrasting interpersonal experiences reported by caregivers, reflecting both the value of supportive relationships and the challenges posed by stigma and limited understanding within their social circles. While friendships and community support often provided encouragement and resilience, caregivers also described the persistent need to address misconceptions and negative societal attitudes toward autism. Their experiences illustrate ongoing efforts to balance supportive interpersonal connections with the realities of stigma and social exclusion.

Role of friendships and social support networks

Caregivers emphasized the importance of supportive friendships, peer relationships, and connections with individuals who demonstrated understanding and acceptance of autism. These relationships played a critical role in providing emotional reassurance, empathy, and encouragement, helping caregivers cope with the demands of caregiving.

One caregiver described friends as a central source of strength, noting that their willingness to listen, offer empathy, and remain present during difficult moments made a significant difference in her caregiving journey (Participant 4—FGD 1).

Another participant expressed gratitude for having friends and family members who offered support without judgment, explaining that such understanding helped ease the emotional burden associated with caring for a child with autism (Participant 7—IDI).

However, caregivers also reported that extended family members often struggled to fully understand or accept an autism diagnosis, which sometimes resulted in strained relationships and emotional distress. These experiences highlighted the need for greater awareness, education, and advocacy within families to promote acceptance and shared support.

One participant noted that while immediate family members were largely supportive, misunderstandings and resistance from extended relatives created additional emotional challenges (Participant 3—FGD 1).

Another caregiver shared that a lack of support from family led her to seek understanding and encouragement from colleagues in the workplace instead (Participant 4—IDI).

Societal stigma and misconceptions about autism

Caregivers frequently reflected on the stigma and widespread misconceptions surrounding autism within society, which often manifested as social exclusion, judgment, and discriminatory attitudes. These experiences contributed to feelings of isolation and reinforced the need for public education and awareness.

One caregiver recalled that following her daughter's diagnosis, she encountered societal attitudes that framed autism as a defect requiring correction rather than a difference to be accepted, which intensified feelings of marginalization (Participant 5—IDI).

Another participant emphasized the importance of challenging stigma and discrimination, advocating for greater societal acceptance of neurodiversity and a more inclusive environment for individuals with autism and their families (Participant 7—FGD 2).

Societal and institutional-level factors

As indicated in **Table 2**, caregivers described multiple challenges arising from broader social and institutional systems. Their accounts highlighted varying degrees of institutional support, particularly from educational settings, alongside persistent barriers in accessing healthcare services and prevailing societal attitudes toward children with autism. These structural and social factors played a significant role in shaping caregivers' experiences and their ability to support their children effectively.

Structural barriers and available resources in autism care

This theme captures caregivers' experiences in engaging with institutional systems and public services designed to support individuals with autism. Participants discussed their awareness and use of support centers, difficulties in obtaining appropriate educational services, challenges encountered within healthcare systems, and societal perceptions of autism. Across these domains, caregivers emphasized their active role in advocating for improved services, increased accessibility, and greater public understanding, while navigating multiple systemic constraints.

Awareness and access to support centers and services

Caregivers spoke about their knowledge of facilities that offer psychological support, counseling, and guidance for families caring for individuals with autism. While these centers were viewed as valuable sources of reassurance and community, participants noted that limited availability and lack of information often restricted access and utilization.

"Knowing that support systems exist to help parents manage the challenges of raising a child with autism is reassuring. These centers create a sense of community that can positively impact families living with autism" (Participant 8—FGD 2).

"I am only recently becoming aware of such support centers. If these services are available, it is important that parents are informed and able to reach them easily" (Participant 6—IDI).

Educational barriers and school-based support

Participants reflected on the difficulties involved in identifying suitable educational environments and securing adequate support services for their children with autism. They emphasized the importance of inclusive and supportive school settings that foster both academic growth and social development, while also highlighting the need for stronger collaboration between families and educational institutions.

"Finding the right school for our son has been challenging because we want him to receive appropriate support while interacting with other children. We are thankful for schools that provide care, learning opportunities, and understanding for his needs" (Participant 1—FGD 2).

"We have also struggled to find a suitable educational setting for my daughter. It is crucial to balance learning with emotional and social development, especially because every child with autism has unique needs" (Participant 2—FGD 1).

Experiences within the healthcare system

Caregivers described significant obstacles in navigating healthcare services and accessing specialized interventions tailored to their children's needs. They highlighted gaps in availability, affordability, and specialization, emphasizing the need for more accessible and coordinated healthcare support for individuals with autism.

"Trying to obtain therapies and interventions for our child has been extremely difficult. Issues such as lack of insurance coverage and distance to services have made the process overwhelming and increased our stress as caregivers" (Participant 5—IDI).

"We have faced challenges when dealing with the healthcare system, particularly in locating specialists who understand and can meet my child's specific needs" (Participant 3—FGD 2).

"Accessing specialized healthcare and therapy services has been an ongoing struggle, with long waiting times and limited professionals available. Navigating the system often leaves us feeling exhausted and discouraged" (Participant 6—IDI).

Public awareness and societal perceptions of autism

Caregivers also discussed broader societal attitudes toward autism, noting widespread misunderstandings and limited awareness. Participants emphasized the importance of promoting accurate information, empathy, and acceptance to reduce stigma and foster inclusion for individuals with autism and their families.

"Many people still do not understand what autism truly is, which leads to misconceptions and harmful beliefs within society" (Participant 3—FGD 1).

"Societal attitudes toward autism often lack compassion, reinforcing stigma and making life more difficult for people with autism and their families" (Participant 5—IDI).

"Creating a more inclusive society requires awareness and collective effort. By understanding and respecting diversity, we can better support individuals living with autism" (Participant 8—FGD 2).

Policy-level influences

At the policy level, as reflected in **Table 2**, caregivers described their interactions with the broader political and governance environment as they sought improved support mechanisms for individuals with autism. Participants emphasized the absence of adequate policy frameworks and called for stronger governmental involvement in addressing autism-related needs. They stressed that inclusive policies are essential to improve access to healthcare, education, and social welfare services for individuals on the autism spectrum and their families.

Advancing autism support systems and rights

Caregivers highlighted the importance of governmental policies, institutional support, and advocacy initiatives in shaping services and opportunities for individuals with autism. They noted that public-sector interventions play a critical role in determining the availability and quality of support resources. In addition, participants discussed the collective efforts of caregivers, advocacy groups, and other stakeholders in pushing for improved services, legal protections, and recognition of rights. These narratives underscored ongoing collaborations aimed at influencing policy reform and ensuring that individuals with autism have equitable access to essential services and opportunities.

Government involvement and autism-focused policies

Within this subtheme, caregivers discussed how government programs and policy actions affect the well-being of individuals with autism and their families. They emphasized the need for a coordinated and inclusive support system that guarantees access to healthcare services, appropriate educational opportunities, and financial assistance. Participants also highlighted the role of advocacy in influencing policy formulation and ensuring that governmental commitments translate into tangible benefits for autism communities.

"Government involvement is crucial in responding to the different needs of autistic individuals and their families. When education, healthcare, and public assistance are accessible, it significantly improves their overall quality of life." (Participant 4—FGD 1).

"Public initiatives and government action are necessary to support people with autism, but continuous advocacy is needed to ensure these supports are actually delivered and meet real needs." (Participant 2—IDI).

"Policies and government-led programs can support the development of autistic individuals by increasing awareness and organizing activities that promote understanding and acceptance of their differences." (Participant 6—FGD 2).

Advocacy for enhanced services and recognition of rights

Caregivers described their engagement in advocacy efforts aimed at improving service delivery and protecting the rights of individuals with autism. They acknowledged that equal access to available resources is often limited and requires sustained advocacy. Participants reported involvement in awareness campaigns, policy dialogues, and community initiatives designed to influence decision-makers and improve conditions for autism communities. Through these efforts, caregivers sought to address structural barriers and ensure that individuals with autism receive appropriate support, accommodations, and opportunities to achieve their full potential.

"Advocacy helps ensure that autistic individuals can access their rights and the support systems meant to help them grow and succeed. We will continue to raise our voices and push for better services for our loved ones." (Participant 4—IDI).

"Taking part in advocacy activities has empowered me to defend the rights of autistic individuals and has contributed to improvements in services available to our families." (Participant 5—FGD 1).

"Advocacy requires persistence and accountability. Speaking out is necessary to demand fair access to services and rights for autistic individuals so that existing resources can be fully and effectively used." (Participant 4—IDI).

This study set out to examine the lived experiences and challenges encountered by caregivers of children diagnosed with autism spectrum disorder (ASD). The findings illustrate that caregiving is characterized by a profound emotional trajectory, beginning with distress and uncertainty at the point of diagnosis and extending to fears surrounding acceptance, alongside ongoing exposure to societal stigma and misinformation. Throughout this process, caregivers often depend heavily on close family members and trusted social networks for emotional and practical support. The results further underscore the critical role of sustained advocacy and community-level education in encouraging acceptance of autism and in mitigating stigma and discriminatory attitudes.

It is important to acknowledge that the study sample exhibited a degree of homogeneity, as all participants were recruited from special needs educational institutions. Consequently, the findings may not fully represent the experiences of caregivers whose children are enrolled in inclusive educational settings or those whose children are not engaged in formal schooling. These underrepresented groups may encounter different challenges and follow alternative emotional and caregiving pathways. Future studies should therefore explore these populations to provide a more inclusive and comprehensive understanding of caregiving experiences across varied educational and social environments.

Caregivers described a wide spectrum of emotional reactions upon learning of their child's diagnosis, ranging from fear and uncertainty to gradual hope and personal growth. Initial responses were frequently marked by shock, grief, and emotional overwhelm, a pattern that has been consistently reported across diverse cultural and geographical contexts [42, 43]. However, evidence from Nigeria indicates that caregivers face additional burdens related to socio-cultural beliefs and limited access to resources [44]. The process of adapting to and accepting an ASD diagnosis is strongly shaped by cultural norms, belief systems, and societal expectations [45, 46]. While some caregivers benefit from robust support systems and access to therapeutic services, others must navigate caregiving responsibilities with minimal resources and limited social support [47– 49]. Despite prevailing socio-economic constraints, Oduyemi *et al*. reported notable resilience and commitment among Nigerian caregivers striving to meet their children's needs [50]. Furthermore, coping mechanisms differ across Nigerian cultural contexts [50, 51]. Whereas some caregivers seek professional counseling or peer support groups, many rely on religious faith and traditional healing practices for emotional comfort [17, 44, 50]. These cultural dimensions play a significant role in shaping caregivers' perceptions, coping strategies, and overall well-being throughout the caregiving journey.

At the interpersonal level, caregivers described a complex negotiation between seeking support from family, friends, and the broader community and confronting prejudice, misunderstanding, and social exclusion. Research from various settings has consistently highlighted the importance of social relationships in providing emotional reassurance, practical assistance, and encouragement to caregivers [42, 43]. Within the Nigerian context, however, these dynamics are often complicated by cultural expectations and structural limitations that hinder widespread awareness and acceptance of autism [15, 52]. As a result, caregivers frequently depend on close social networks while simultaneously struggling to challenge entrenched misconceptions and stigma, factors that significantly influence their coping strategies and perceptions of autism [17, 24, 50]. These findings emphasize the necessity of culturally responsive interventions that address context-specific barriers, strengthen social support systems, and empower caregivers within their communities.

At the societal and institutional levels, the findings reveal persistent challenges related to awareness, accessibility, and utilization of formal support services. Previous research has highlighted the importance of educational and healthcare institutions in enhancing outcomes for caregivers and individuals with autism [53, 54]. In Nigeria, however, caregivers often report limited knowledge of available services, inadequate access to institutional support, and pervasive societal biases regarding autism [52]. Oshodi *et al*. documented similar challenges, noting caregivers' difficulties in accessing appropriate healthcare and navigating educational systems that are ill-equipped to accommodate the needs of autistic individuals [17]. These systemic shortcomings not only impede service utilization but also reinforce social narratives that marginalize caregivers and individuals with autism [55]. Many Nigerian communities continue to experience institutional weaknesses that undermine equitable access to services and perpetuate negative societal perceptions of autism [50, 51]. Addressing these barriers requires culturally grounded strategies that emphasize community engagement, public education, and policy reform to foster inclusive attitudes and environments [56].

Finally, caregivers in this study strongly emphasized the need for improved support frameworks and policy interventions that address the multifaceted needs of individuals with autism. Existing literature underscores the importance of government leadership and advocacy in the development of inclusive policies that enhance access to healthcare, education, and social protection for individuals with autism [42, 43]. Nonetheless, significant disparities persist, particularly within the Nigerian context, where systemic challenges continue to limit policy effectiveness [50, 57]. Structural obstacles—including insufficient funding, shortages of trained professionals, and bureaucratic inefficiencies—remain major impediments to the implementation of comprehensive and inclusive autism policies [57]. Similar concerns have been reported in earlier studies identifying weak institutional structures and inadequate support systems as major barriers to effective caregiving for children with ASD [58, 59]. Strengthening collaboration among policymakers, advocacy groups, and caregivers is therefore essential to advance policy reforms that promote equity, accessibility, and social inclusion for individuals with autism and their families.

Strengths and limitations

A major strength of this study lies in its multilevel analytical approach, which examined caregiving experiences across the micro (individual and interpersonal), meso (societal and institutional), and macro (policy) domains. By integrating findings across these interconnected levels, the study provides a holistic understanding of the complex and layered challenges associated with caring for individuals with autism. Another notable strength is the central emphasis on caregivers' perspectives, allowing participants' lived experiences, emotional burdens, and coping strategies to be directly represented. This caregiver-centered approach yields contextually grounded insights that are valuable for informing the development of targeted and responsive support interventions. Overall, the study contributes meaningfully to the existing literature on autism by amplifying caregiver voices and offering evidence to guide the design of effective support mechanisms and intervention strategies for individuals with autism and their families.

Despite these strengths, several limitations must be acknowledged. First, the possibility of sampling bias exists, as participants were self-selected and recruited exclusively from special needs educational settings. Consequently, caregivers whose children reside in community settings, attend inclusive schools, or are not enrolled in formal education may have experiences that differ from those captured in this study and were therefore not represented. Second, reliance on self-reported data introduces the potential for response bias, as participants' accounts may be influenced by recall or social desirability. Additionally, the cross-sectional nature of the study restricts the generalizability of the findings, as it does not allow for longitudinal assessment of how caregiving experiences evolve over time. Addressing these limitations in future research—particularly through longitudinal designs and more diverse sampling strategies—would enhance the robustness, applicability, and depth of understanding regarding the experiences of caregivers of individuals with autism.

Conclusion

Caregiving for individuals with autism in Nigeria unfolds within a complex context shaped by emotional responses, societal attitudes, and structural constraints. While caregivers across different settings commonly experience initial shock and emotional strain following diagnosis, Nigerian caregivers often contend with additional challenges stemming from limited resources and deeply rooted sociocultural beliefs. Cultural norms play a significant role in shaping how caregivers interpret and respond to their child's condition. At the same time, many caregivers in Nigeria share experiences similar to those of caregivers globally, particularly in recognizing the value of social support and connectedness as they seek to understand and adapt to life with ASD. Persistent inequalities at societal and institutional levels highlight the urgent need for systemic reforms that are both contextually appropriate and culturally sensitive. Tailored interventions that address these disparities are essential to improving long-term outcomes for children with autism and supporting the well-being of their caregivers in Nigeria.

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