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Research

Experiences and unmet needs among caregivers of children living with autism spectrum disorder in Nigeria: a qualitative study using the socio-ecological model

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Abstract

Introduction This study examines the experiences and unmet needs of caregivers of children with autism spectrum disorder in Nigeria. With a high prevalence in Nigeria, autism spectrum disorder poses a heavy economic burden on society and the patients' families, with limited social interactions and stigma. Despite this, the unmet needs and psychosocial burdens of autism spectrum disorder on caregivers have been understudied in Nigeria. The study contributes evidence and raises interest in this area of research.

Methods This qualitative study was conducted among twenty-three purposively selected caregivers. Questions from the PREPARE and Zarit Burden Interview tools were adapted for the interview and discussion guides. Data were collected among caregivers of pupils in selected special needs schools in Cross River State, Nigeria. Inductive and deductive approaches were used for the analysis using NVivo 20 pro. The socio-ecological model was used to generate the themes and quotes.

Results The study generated four themes and eleven sub-themes across four levels of the socio-ecological model. Findings from our study showed that caregivers of children undergo significant emotional distress, disbelief, and fear at the early stage of diagnosis. Furthermore, families and friends had difficulty comprehending or accepting their children's diagnosis, which further created tension and misunderstanding. Socio-cultural contexts such as stigma and isolation were not uncommon in the society.

Conclusion Given the burden of the psychological demand and stigma attached to caregivers and children with autism, there is an urgent need for a tailor-made intervention with the key interplay of individual, interpersonal, societal/institutional, and policy in Nigeria. Advocacy efforts and awareness chaired by caregivers should be strengthened across all levels of the society in Nigeria.

Keywords Autism spectrum disorder · Caregivers · Children · Nigeria · Stigma · Cross River State

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1 Introduction

Autism Spectrum Disorder (ASD) represents a range of neurodevelopmental disorders characterized by persistent deficits commoner among children [1, 2]. These deficits may include social interaction and communication, repetitive and stereotyped behavioral patterns, and uneven intellectual development often with intellectual disability [3, 4]. ASD has become a major public health concern, at a significantly increasing rate over the past decade. Over the last decades, cases of ASD has been on rise by almost 40% [5–7]. The Center for Disease Control (CDC) indicates that over 28 million ASD cases were reported around the world, with approximately 1 in 36 children been identified with the disorder [7]. WHO also reported that 1 in 100 individuals globally have been identified with ASD, further underscoring the increasing burden of the disorder [1]. Recent data reports that the United Kingdom has the highest reported prevalence, with 700 cases per 100,000 individuals [8, 9]. Despite these figures, the prevalence of ASD remains underreported in some regions, particularly in parts of Africa and other low- and middle-income countries [10].

Several studies on ASD Africa indicate its considerable prevalence across the continent. A cross-country study in Tunisia and Egypt showed a prevalence of 11.5% and 33.6%, respectively [11]. Similarly, a longitudinal study in Uganda reported a prevalence of 0.68% [12]. In terms of absolute population, the prevalence cases of ASD in North Africa and Middle East was estimated to be 1,879,528, which forms about 6.6% of the world burden in 2019 [13]. In the same vein, a study in Kenya estimated that up to 800,000 children are identified with ASD [14], In Nigeria, the prevalence of ASD varies across different regions. In the Southwest, studies report a prevalence of approximately 2.3% [15], while in the Southeast, another study reported a prevalence 0.8% [16]. Another study among children with the highest rates reported 34.5% in Lagos State, Nigeria [17]. These variations in prevalence may reflect differences in study designs, diagnostic criteria, and challenges related to underreporting or misdiagnoses, emphasizing the need for caution when interpreting these figures.

Being lifelong developmental disorders, ASD and intellectual disability (ID) negatively affect both autistic individuals, especially children and caregivers in multiple ways [18, 19]. Developed countries have been able to record these challenging experiences of caregivers, but in developing and underdeveloped countries, there is almost no information about them [20, 21]. Beyond the core symptoms—such as dysfunctions in attention, memory, language (speech), perception, and social interaction- ASD is associated with significant levels of stigma, anxiety, stress, and isolation, affecting both autistic individuals and their families [18, 22, 23]. In some part of Sub Saharan Africa, mental disorders and autism are widely believed to be mystical in sub-Saharan Africa, mostly attributed to lineage curses, enemies, the devil, or punishment from God [24]. As a result, ASD is also regarded as curse or punishment from God [18, 19, 25], leading to societal stigmatization for autistic individuals' families [19, 26]. Caregiving for autistic individuals presents significant challenges, particularly in contexts where access to essential services and support systems is insufficient [1]. Studies have reported that caregivers with autistic individuals experience higher stress and burnout compared to their counterparts without autistic individuals [19, 27, 28]. Furthermore, ASD imposes a heavy economic burden on society and autistic individuals' families [29], as these patients require considerable care, demanding significant financial resources [26]. Caregivers have reported direct and indirect financial difficulties owing to loss of job due to caregiving, or, losing out on opportunities due to time commitments to care for their children with ASD [26, 30].

While previous studies have provided important insights, there is dearth of data regarding the experience of caregivers with autistic individuals in Nigeria. This study aimed to contribute to existing literature by exploring the experiences and challenges of caregivers with autistic individuals, particularly in terms of socio-cultural context, perceived community support to families, and the unmet needs of caregivers. Findings from this research are essential for informing the design and implementation of tailored support programs for caregivers of autistic individuals in Nigeria and other low-resource settings, while contributing toward achieving the United Nations SDG 3—Good health and well-being and leaving no one behind.

2 Methods

2.1 Study design

The research drew from the tenets of constructivist epistemology. Recognizing that there is no single objective definition of the "truth" [31]. Our study utilized cross-sectional qualitative design, framed by the socio-ecological model, to report the findings. This model provides a framework for incorporating various of levels of life that affect health ranging from individual, interpersonal, social environment, physical environment, and public policies [32].

2.2 Study population

The population of interest was caregivers to children (below 18 years) with ASD attending special needs schools in Calabar, Nigeria. Diagnosis relied on the child's psychiatrist reports for enrolment into the school.

2.3 Sample size/procedure

In this study, we followed the recommendations highlighted in previous studies of having 6 to 30 participants, as it seemed viable to meet the study aims [33, 34]. The guiding principle in sampling in qualitative research was the attainment of data saturation or at the point when there was no new information in the data collected and redundancy of information is reached [35]. A purposive sampling was used to select respondents for the study. Hence, we had 2 Focus Group Discussions (FGDs) with caregivers (8 respondents in each) and 7 In-Depth Interviews (IDIs) with caregivers and parents.

2.4 Data collection tool

Questions for the IDI and FGDs on unmet needs were extracted from the Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences (PRAPARE) [36], and the Zarit Burden Interview (ZBI) [37]. These tools have been applied internationally and across various contexts in Africa, North America, and Europe to get information on a host of social needs including housing, employment, education, security, transportation, and social integration [38, 39]. The tools were pretested among a different population in the Cross-River State, and appropriate changes and refinement were done to remove ambiguities, improve question sequence, and estimate data collection time.

2.5 Procedure for data collection

Prior to data collection, three field researchers were recruited and trained on aspects of qualitative data collection and the objectives of the research. The training also included familiarity with the data collection tool, data collection dry run, and best practices for debriefing. Data were collected over 7 weeks, between March and April 2024 from three special needs secondary schools in Cross River State, Nigeria. The school authorities were notified, and appropriate time slots were allotted to the research team, to meet the caregivers of the children. Data was collected using the FGD and IDI guides, informed consents were obtained to audio-record the interviews and discussions using a voice recorder and these were transcribed and translated for analysis [40]. Additionally, the notes taken during the interview were also included in the data analysis.

2.6 Data analysis

The qualitative data, represented as transcripts, were thoroughly checked for errors before being imported into NVivo (version 20) for analysis. A hybrid approach combining inductive and deductive thematic analysis was employed. The deductive analysis utilized a pre-specified codebook, which was designed based on relevant literature and theoretical frameworks. As new themes and patterns emerged during the analysis, they were iteratively developed and incorporated into the coding structure, ensuring the analysis remained flexible and adaptive to the data. This approach aligns with the inductive nature of thematic analysis, where themes 'emerge' from the data rather than being strictly imposed, allowing for a deeper exploration of participants' experiences [25].

2.7 Ethical consideration

Appropriate ethical approval was obtained from the Cross River State Ministries of Health. Additionally, verbal and written informed consent was obtained from the respondents upon duly informing them of the study's relevance and purpose.

They were assured of the confidentiality of their volunteered information. The study posed no known risks to participants. The collected data were securely stored by the Principal Researcher and were destroyed upon the completion of the study.

2.8 Operationalized definition

The primary caregiver is the one primarily responsible for the development of the child and is most involved in taking care of him or her, whether during hospitalization, specialist consultation, or any clinical intervention [41].

2.9 Positionality statement

In this light, we declare our positionality regarding the subject matter at discussion. The lead investigator has work experience with vulnerable populations in Nigeria, particularly in child health and neurodevelopmental disorders. This may have consequently encouraged the framing of research questions, collection of data, and consequently the interpretation of findings. To reduce these possibilities, we adopted a reflexive stance in the conduct of this study by incorporating the views and approaches of several researchers. We also acknowledge that our background as health professionals, along with the cultural and social contexts in which we practice, would have influenced how we viewed autism and its caregiving challenges in Nigeria. We remained committed to the faithfulness of voice and experience for the caregivers, while at the same time accounting for the socio-cultural complexity of the setting in which the research was conducted.

3 Results

3.1 Socio-demographic characteristics of participants

There were 2 male and 5 female for the IDI and 4 male and 12 female participants in the FGDs. The mean age was 35.5 ± 7.56 for IDI and 33.0 ± 8.29 for focus group discussants. Most respondents were married in the IDI group 4 and FGD, 9. The majority of respondents in the IDI had tertiary education level 4, and 5 discussants had primary level education. Most of the respondents were civil servants; 4 and 7 in the IDI and FGD, respectively (Table 1).

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

Characteristics	In-depth interviewees Frequency (%)	Focus group Frequency (%)
Age (years)		
21–30	2 (28.6)	8 (50.0)
31–40	3 (42.9)	4 (25.0)
51–50	2 (30.5)	4 (25.0)
Sex		
Male	2 (28.6)	4 (25.0)
Female	5 (71.4)	12 (75.0)
Marital status		
Single	2 (28.6)	5 (31.3)
Married	4 (57.1)	9(56.3)
Widowed	1 (14.3)	2(12.5)
Education		
No formal education	–	4 (25.0)
Primary	1 (14.3)	5 (31.2)
Secondary	2 (28.6)	3 (18.8)
Tertiary	4 (57.1)	4 (25.0)
Current employment status		
Unemployed	–	4 (25.0)
Business/tradesperson	3 (57.1)	5 (31.2)
Civil service	4 (42.9)	7(43.8)

4 Individual level

As shown in Table 2, caregivers of autistic individuals experience emotional distress. Ranging from the disbelief of the diagnosis to understanding and embracing the diagnosis. They dealt with mixed feelings of fear and anxiety, at the same time learning and finding strength on the way.

4.1 Navigating the path of autism caregiving

This reflects the journey caregivers undertake from the initial shock of diagnosis through the stages of understanding, acceptance, and ultimately, managing the complex responsibilities associated with caring for someone with autism. The emotional and practical challenges caregivers face, and their evolving understanding and adaptation to their role were reported.

4.1.1 Initial reaction to the diagnosis

After getting the news of autism, caregivers often mixed with emotions and uncertainty find solace as they try to handle the situation and the new turn it takes in their lives and the lives of their loved ones.

> "When I got the news of my son's diagnosis, I didn't know much about what autism was. I panicked because I was bothered about my son's feelings and what the future holds for him, but as each day passes by I've come to the understanding that this who my son is and I'm less concerned with what the world will say." (Participant 1—IDI).

4.1.2 Journey of understanding and acceptance

Caregiver narrated their development from when they got the news of their loved one's autism, the shock, and how they are embracing it. This journey engaged in learning about autism and adopting the fact that this is the life of their loved ones.

> "Autism has been a journey of discovery and development for us. It has made us review our priorities, going for those things that strengthen our son." (Participant 3—FGD 2).
> "Autism comes with its difficulties, but the connection and understanding lingers. My son may find things not worth engaging, but his so unique in his own way and possesses talents that I cherish so much." (Participant 6—IDI).
> "Autism has taught me so much and has been a journey of development for us. It has framed my mind positively, and I have been drawn to prioritize the most important things in life and my son's needs." (Participant 4—FGD1).

Table 2 Summary of themes and sub-themes

Socioecological level	THEMES	Sub-Themes
Individual level	Navigating autism caregiving	1. Initial reaction to the diagnosis 2. Journey of understanding and acceptance 3. Managing responsibilities
Interpersonal level	Support and societal challenges	4. Friendships and support 5. Societal stigma and misconceptions
Societal and institutional levels	Challenges and resources in autism care	6. Awareness of support centres and services 7. Educational challenges and school support 8. Navigating healthcare systems 9. Public perceptions of autism
Public policy level	Shaping autism support and rights	10. Government support and policies for autism 11. Advocacy efforts for improved services and rights

4.1.3 Managing responsibilities (work, home)

Participants shared the experience of balancing their relevance in their workplace, at home and taking care of their loved ones with autism. This encompasses the management of their employment, household, and caregiving coupled with the feeling of guilt and overwhelming.

> "It's often hard to give in full attention at work while being bothered about the well-being of your loved ones. Even when you're home, feeling remorseful of negation of other responsibilities sets in." (Participant 2—FGD 1).
> "It feels like I'm in a race trying to catch up with my autistic child's need and what work and home demands. At times it's overlapping and I find it hard to fix it." (Participant 3—IDI).

5 Interpersonal level

From Table 2, at the interpersonal level, caregivers of individuals with autism dealt with mistaken understanding, and societal stigma while relating with family members, friends, and communities. They rely on their social networks, practical assistance, and advocacy, yet dealt with the difficulties of nurturing understanding, and embracing the condition of their loved ones. Interaction with relatives, friends, and colleagues tends to their caregiving experiences, impacting their perspective in dealing with the complexities of autism.

5.1 Support and societal challenges

The dual challenges faced by caregivers of individuals with autism were explored. The importance of friendships and support networks in their journey contrasts with the societal stigma and misconceptions they encounter were reported. These emphasize the caregivers' navigation through both supportive community interactions and the broader societal attitudes towards autism, documenting their efforts to foster understanding and acceptance while overcoming societal barriers.

5.1.1 Friendships and social support

Participants dwelt on the importance of supportive relationships, peers, and friends with the same understanding of a positive perspective of autism during caregiving experiences. These relationships aided emotionally, being a vehicle that contributed to the strength of overcoming the difficulties in taking care of our loved ones with autism.

> "My friends have been my backbone, supporting me when I needed them the most. They gave me their time and listening ear, and their empathy has given me strength in my caregiving experience." (Participant 4—FGD 1).
> "It's such a blessing to have friends and family who are willing to go through this situation with you without judgment. Their kindness and support makes all the difference in caregiving experience." (Participant 7—IDI).

Caregivers described instances where extended family members struggled to comprehend or accept their loved one's autism diagnosis, leading to tensions and misunderstandings within familial relationships. These challenges underscored the importance of education and advocacy within extended family circles to foster greater understanding and support for individuals with autism and their caregivers.

> "While our immediate family has been incredibly supportive, we've encountered challenges with extended family members who don't fully understand or accept our child's autism." (Participant 3—FGD1).
> "It's tough when you don't feel supported by your own family members. In my case, I've found support and understanding from my colleagues at work." (Participant 4—IDI).

5.1.2 Societal stigma and misconceptions

Participants reflected on facing societal stigma and misconceptions involved in autism, which often shaped into isolation and discrimination. They highlighted the importance of tackling misinformation that perpetuates stigma rather than promoting diversity.

> "When we first learned about our daughter's autism, I was faced with the misconception and stigma that tagged along. It felt like the society sees it as something broken and needs to be fixed rather than embraced." (Participant 5—IDI).
> "It's essential for society to move past the stigma and discrimination associated with autism and embrace diversity and acceptance. We all can help in creating a comfortable and understanding world for individuals with autism and their families." (Participant 7—FGD 2).

6 Societal/institutional level

Table 2 shows that at the societal/institutional level, caregivers shared their challenges in dealing with social and institutional structures. They recounted accessible support from institutions including schools, difficulties in reaching healthcare systems, and the way society sees autistic children.

6.1 Challenges and resources in autism care

Caregivers recounted experiences in navigating various systems and services to support individuals with autism. It encompasses their awareness and utilization of support centers, challenges of securing adequate educational support, navigating healthcare systems, and addressing public perceptions of autism. Reports underscore the caregivers' role in advocating for improved services and understanding, emphasizing their efforts to access resources while promoting awareness and acceptance in the broader community.

6.1.1 Awareness of support centers and services

Caregivers discussed their acquaintance with systems providing psychological support, counseling, and reassurance in dealing with the difficulties in caring for individuals with autism. They highlighted the role of these centers in providing sustainable guidance and community while expressing the availability hindering their utilization of such resources.

> "It's encouraging to know that there are systems available to aid parents cope with the difficulties of raising an autistic child. These systems create a world or community that can make a difference in the lives of families affected by autism." (Participant 8—FGD 2).
> "I am just getting to know about these centers. However, if these centers exist, it's important to ensure that parents know about them and can access the help they need." (Participant 6—IDI).

6.1.2 Educational challenges and school support

Caregivers reflected on the challenges experienced when securing proper educational systems and support services for their autistic children. They emphasized the importance of creating conducive environments in promoting their child's progress academically and socially while highlighting the importance of greater collaboration between families and the educational system.

> "We want our son to receive the support he needs while acquainting with his peers therefore finding education settings for our son has been difficult. We are grateful that there is an educational system that offers all the opportunities, care, and support he needs." (Participant 1—FGD 2).

> "We have also had difficulties in finding a system for my daughter. It is of utmost importance to balance the academic progress, and social and emotional development of these children as they are unique." (Participant 2—FGD 1).

6.1.3 Navigating healthcare systems

In the subplot, caregivers shared the challenges they experienced in navigating healthcare systems and accessing counseling personalized to the needs of their loved ones with autism. They highlighted the need for improved accessibility and comprehensive support to ensure the timely needs of autistic individuals are being met to support their development.

> "We've encountered numerous barriers when trying to access therapies and interventions for our child with autism. Whether it's a lack of insurance coverage or geographical restriction limiting our options, the process has been intimidating and has added to the stress of caring for our loved one." (Participant 5—IDI).
> "We've experienced challenges in dealing with healthcare system and finding specialists that suits my autism child needs." (Participant 3—FGD 2).
> "Accessing healthcare services and specialized therapies for our child with autism has been a constant struggle. From long wait times to limited availability of qualified professionals, navigating the system has been incredibly challenging and often leaves us feeling frustrated and overwhelmed." (Participant 6—IDI).

6.1.4 Public perception and awareness of autism

Caregivers shared societal attitudes and levels of understanding towards autism, highlighting common misunderstandings and the importance of increased awareness. They emphasized the need to promote accurate information and nurturing acceptance to limit stigma and create a more inclusive environment for autistic individuals and their families.

> "The fact is that, not everyone is aware of the realities of autism, resulting to misconceptions and hurtful beliefs." (Participant 3—FGD 1).
> "The way the society view autism often lack empathy and kindness, fostering stigma and making it difficult for individuals with autism." (Participant 5—IDI).
> "Making the environment more inclusive requires collaboration and awareness, by understanding and creating diversity we can help individuals with autism." (Participant 8—FGD 2).

6.2 Policy level

At the policy level, Table 2 shows that caregivers engage with the broader socio-political scenery to advocate for advanced support systems and policies tackling the needs of individuals with autism. They highlighted the need for government initiatives and advocacy efforts to create policies that promote inclusivity in accessing healthcare, education, and social services for the autism community.

6.3 Shaping autism support and rights

The critical roles of government support, policies, and advocacy efforts in shaping the landscape for individuals with autism and their caregivers were reported. Participants highlighted the influence of governmental initiatives in providing essential support systems and resources. Additionally, they emphasized the proactive advocacy efforts undertaken by caregivers and stakeholders to improve services, promote rights, and foster a supportive environment for individuals with autism. They further explored the collaborative efforts aimed at creating meaningful policy changes and ensuring equitable access to services and opportunities for the autism community.

6.3.1 Government support and policies for autism

In the subplot government support and policies for autism, caregivers shared the function of governmental efforts and policies in providing support and resources for individuals with autism and their families. They emphasized the significance of a thorough support system, including the ability to reach healthcare, educational services, and financial assistance, to address the diverse importance of the autism community. In addition, caregivers highlighted the importance of advocacy role to impact policy development and ensure that government support reaches the needs of autism communities.

> "Government role play is important for tackling the diverse needs of autistic and their families. Accessibility of education system, healthcare, and governmental assistance will aid the quality of livelihood of autistic individuals and their families." (Participant 4—FGD 1).
> "Government and initiative are of importance in supporting individuals with autism and an advocacy for this supports to be met are of great need in other to meet the needs of individuals with autism." (Participant 2—IDI).
> "Government policies and initiatives can help in the development of autistic individuals by creating awareness and hosting programs that enlighten the uniqueness of autistic individuals." (Participant 6—FGD 2).

6.3.2 Advocacy efforts for improved services and rights

Caregivers are involved in advocating for improved services and rights for individuals with autism, acknowledging the need for equitable access to support systems. They actively engage in advocacy campaigns, lobbying efforts, and community initiatives to impact policy changes and progress the rights and well-being of autism communities. Through their advocacy efforts, caregivers aim to tackle systematic obstacles and guarantee that individuals with autism receive adequate resources and accommodation to thrive.

> "Advocacy is important to ensure that autistic individuals access the right and support systems provided to aid them meet their needs and thrive. We won't stop speaking and demanding for e better services to our loved ones." (Participant 4—IDI).
> "Engaging in advocacy campaigns has helped me harness the rights of autistic individuals and has influenced improved services for our loved ones." (Participant 5—FGD 1).
> "Advocacy work is a continuous process of making an impact and holding policymakers accountable. We must speak for equitable access to services and rights for individuals with autism aiming at better utilization of services." (Participant 4—IDI).

7 Discussion

Our study aimed to explore the experiences and challenges of caregivers of children with ASD. Consequently, findings from our study revealed a significant emotional journey for the participants, ranging from emotional distress as a result of the initial diagnosis, to the fear of acceptance, and dealing with the societal stigma and misconceptions while relying on support from close family and friends. Our study revealed the significance of advocacy and education for families and communities aimed at fostering acceptance, and ultimately reducing stigma and discrimination.

It is important to note, however, that the participants in this study were somewhat homogeneous, as they were all recruited from special needs educational settings. This might not fully capture the diverse experiences of caregivers whose children are in inclusive education settings or those whose children are not attending school at all. It is possible that these caregivers, while perhaps in the minority, may face distinct challenges and follow different emotional and caregiving trajectories. Further research is necessary to explore the experiences of these less-represented groups to ensure a comprehensive understanding of caregiving experiences across diverse educational and social contexts.

Caregivers of individuals with autism expressed an array of emotions on receiving the diagnosis of their ward; from fear and doubts to hope and personal development. When a close one is diagnosed with autism, the caregivers are usually overwhelmed by a feeling of shock and grief. Such initial reactions have been observed across different cultural and geographical contexts [42, 43]. However, research from Nigeria suggests that caregivers face additional challenges rooted in socio-cultural factors and resource limitations [44]. Caregivers' experiences while embracing the journey and acceptance of children's ASD diagnosis vary depending on the culture and norms of the society [45, 46]. While some caregivers may receive all the support they require and benefit from countless therapeutic options, others face the caregiving process with scarce resources and social contacts [47–49]. Oduyemi et al. stressed that despite the various socio-economic challenges in Nigeria, parents/carers in their study showed a lot of strength in trying to support their children [50]. Moreover, evidence on how caregivers manage the emotional stress related to caregiving differs from one Nigerian culture to another [50, 51]. Whereas some caregivers seek counseling and support groups, most of the caregivers in Nigeria get consolation through religious faith and other traditional healers [17, 44, 50]. These cultural nuances shape the perceptions and coping strategies of caregivers, influencing their overall well-being in the caregiving journey.

Interpersonally, findings from the study revealed that caregivers negotiate between turning to friends, families, and other members of society for support and acceptance while facing prejudice and misconceptions. The studies across various settings thus establish the importance of the families, friends, and community in offering encouragement, help, and support to the caregivers [42, 43]. However, in the Nigerian experience, differences come to the foreground, as caregivers have to deal with cultural expectations and systemic realities that prevent the improvement of awareness and acceptance of autism in one's community [15, 52]. Hence, caregivers in these settings rely on their social networks for support, and they face difficulties in eradicating misconceptions and avoiding stigma, which affects the perception of and coping mechanisms for the caregivers in dealing with the issues surrounding autism [17, 24, 50]. These challenges underscore the need for culturally sensitive interventions that address the unique challenges faced by caregivers in diverse settings, facilitating greater understanding and acceptance within their social networks while fostering resilience and empowerment in the caregiving journey.

At the societal and institutional levels, our findings reveal that caregivers encounter issues related to knowledge and utilization of support services across societal institutions. Previous studies have revealed the importance of institutional support services such as education and health care to enhance support for caregivers of people with Autism [53, 54]. However, in Nigeria, disparities have been observed since caregivers have poor knowledge and access to the necessary support services, and there are social prejudices regarding autism [52]. Thus, Oshodi et al. enlighten the public about the problems of caregivers in Nigeria, as well as their inability to obtain proper health care and deal with the educational system that does not meet the needs of people with autism [17]. These systemic barriers not only negatively affect the seeking and delivery of necessary support but also reinforce social assumptions that contribute to the marginalization of parenting or caregiving to an autistic individual [55]. Several communities in Nigeria deal with system-related issues that continue to undermine equal opportunities for autistic individuals in terms of support services as well as how society views autism [50, 51]. Culturally sensitive approaches that prioritize community engagement, awareness-raising initiatives, and policy reforms are imperative to dismantle barriers and foster inclusive societal attitudes towards individuals with autism and their caregivers [56].

Findings from our study indicate that caregivers of persons with autism emphasize the need for better support systems and policies to respond to the complex needs of persons with autism. Research has highlighted the role of governmental leadership and advocacy in developing inclusive policies focused on enhancing access to health, education, and social support for people with autism [42, 43]. However, disparities still exist across regions, particularly for caregivers in Nigeria. They face pervasive systemic constraints and are confronted with several challenges restricting the effectiveness of policies [50, 57]. Structural constraints such as inadequate funding, lack of trained health workforce, and bureaucracy impede the development of inclusive policies that adequately respond to the needs of citizens with autism [57]. Notably, similar findings have been documented in previous studies where institutional and poor support systems were reported as constraints to receiving support for caregivers of children with ASD [58, 59]. Cultivating partnerships between policymakers, advocacy organizations, and caregivers is essential to drive systemic reforms that promote equity, accessibility, and social inclusion for individuals with autism.

7.1 Strengths and limitations

The study analyzes caregivers' experiences at the micro level (individuals and relationships), meso level (societal/institutional), and macro level (policy). In synthesizing the findings at these different levels, the study offers a more composite picture of the multifaceted issues that are associated with caregiving for autistic individuals. Related to the first strength is the focus on the caregiver perspective, which allowed for the inclusion of the participants' subjective experiences, stressors, and coping mechanisms. Thus, focusing on the caregiver's perspective, the present study provides meaningful findings that can help design better support interventions from which the caregivers can greatly benefit. In conclusion, our work can be seen to support the body of knowledge on the matters concerning the experiences of patients with autism as well as their carers, in the effort to design effective intercessions and mechanisms for the management of autism.

However, there are some weaknesses in the present research that need to be considered, for the following reasons. First of all, one can speak about the problem of sampling bias because the participants were free to join the study, and they are all members of the community of special needs people. Hence, carers whose children live in communities or are not school children who may have different experiences from our study sample may not have been represented. Secondly, the use of self-reported experiences brings in a certain level of response bias in the results obtained. Furthermore, the cross-sectional design limits the generalizability of the study's findings due to its inability to follow participants for consecutive years to consider the temporal changes in the experiences of caregivers. As a result, the advancement of these limitations in future research could increase the validity and relevance of findings concerning the experiences of caregivers to people who live with autism.

8 Conclusion

The journey of caregivers of individuals with autism in Nigeria is characterized by a dynamic interplay of emotions, societal perceptions, and systemic issues. Although caregivers from various backgrounds universally experience shock and emotional distress at the time of diagnosis, those in Nigeria face additional challenges based on resource limitations and sociocultural factors. Culturally embedded norms influence how caregivers respond to their child's condition. At the same time, many Nigerian caregivers echo the perspectives of their international counterparts on the importance of having access to social connectedness as they strive to make meaning out of their experiences with ASD. Societal and institutional disparities exist at different levels, which calls for urgent systemic changes tailored to the local context in addition to cultural congruity ineffective intervention efforts that will facilitate lifespan outcomes for children with autism in Nigeria.

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Author contributions AOA conceptualized the study in his proposal for the Royal Society of Tropical Medicine and Hygiene Early 2023 Career Grants Programme, led the data collection process, coded transcripts, PCA supported the data analysis, applied themes to generate results, and contributed to writing the manuscript. ELO, MOE, TA, JA, CKO, PNT, ERU, and GSA contributed to the study implementation, data processing, analysis of findings, and revision of the manuscript critically for intellectual content. All authors read and approved the final manuscript.

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Data availability No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate This study was conducted in line with the principles of health research – written informed consent was obtained, with the confidentiality of volunteered information assured and ensured. Ethical approval was obtained from the Cross River State Ministry of Health's Research and Ethics Committee with the approval number CRSMOH/HRP/REC/2024/504.

Competing interests The authors declare no competing interests.

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