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Caregiving for autistic children in Nigeria: experiences and challenges

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Abstract

Background Raising autistic children poses a daunting task for their caregivers. Providing care may take a toll on caregivers' physical, psychological, social, and financial wellbeing. This study explored the experience of the responsibility of care among caregivers of autistic children in Nigeria and informed targeted psychosocial support interventions.

Methods This phenomenology qualitative study was conducted among 103 caregivers in Cross River, Nigeria. The PREPARE tool was used for the data collection. Data were analyzed using the inductive and deductive approaches qualitatively, using NVivo software.

Results Stigma and misunderstanding of autism, emotional impact and acceptance, transportation and accessibility, lack of support networks, and balancing responsibilities and care responsibilities with personal commitments were the major challenges reported by our participants. These factors contributed to emotional strain, underscoring the complexities associated with caregiving experiences.

Conclusion Given the significant responsibilities of caregivers, targeted intervention must be taken to properly enlighten Nigerian societies on autistic people, and the need for acceptance. Key stakeholders must provide suitable healthcare facilities and resources for autistic people. Also, social support groups would help establish a sense of belonging and support.

Keywords Autistic People · Caregivers · Children · Emotional distress · Nigeria · Stigma · Cross River State

1 Background

Autism is a neurodevelopmental phenomenon characterized by differences in reciprocal communication [1]. Being classified as a spectrum, it manifests diversely among individuals [2]. Variations in verbal and non-verbal communication styles, repetitive behaviors, highly focused interests, sensory sensitivities, and a preference for structured routines are some of the common traits [3]. Including Autism, Asperger Syndrome, and other related profiles, individuals often exhibit unique communication systems [4]. Hence, fostering understanding and adaptation in communication methods

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between autistic and non-autistic individuals is essential for effective interaction [5]. Typically emerging within the first two years of life, early recognition of autism allows for the introduction of communication approaches that align with the needs of autistic individuals, helping them navigate the world while preserving their authenticity [6].

With a global prevalence estimated between 1 and 5% [6], the World Health Organization has projected that by 2030, it will represent a significant health consideration, partly due to increasing recognition and diagnosis rates [6]. In Africa, approximately 1 in 145 children are identified as autistic [7]. However, Aderinto and colleagues suggest that this figure may not fully reflect reality, given the challenges associated with identifying and supporting autistic people in resource-limited contexts [8]. Reports of autism spectrum prevalence vary significantly across Africa, with estimates ranging from 0.33% in Libya [9], 0.68% in Uganda [10], and 2.3% in Nigeria [11]. In Nigeria, prevalence rates differ regionally, with 0.8% reported in Southeastern Nigeria [7] and 2.3% in Southwestern Nigeria [11].

Raising autistic children involves navigating educational, medical, and psychological dimensions, particularly in environments where specialized resources are limited [12]. These experiences may be perceived as challenging by caregivers, who often balance responsibilities that require substantial emotional and practical investment [13, 14]. Caregivers' experiences can also affect their physical, psychological, social, and financial well-being [15]. Factors influencing these experiences include caregiver demographics (e.g., gender, relationship to the child), cultural context, and personal resilience [16, 17]. The role of family caregivers is especially vital, as many provide consistent support throughout an autistic individual's life [18].

A national study in the US linked caregiving with adverse health outcomes, including sleep disruption, depression, anxiety, and substance use [19]. Additionally, the co-occurrence of autism and attention deficit hyperactivity disorder (ADHD) or epilepsy, and intellectual disability, may contribute further complexity to caregiving [20, 21]. These intersecting factors underscore the importance of providing resources and support tailored to caregivers' needs [22, 23]. For instance, research from China has highlighted the impact of societal stigma, which may lead caregivers to experience affiliate stigma—shame or guilt arising from public attitudes toward autism [24]. This phenomenon can result in social isolation and an increased risk of depression among caregivers, affecting their ability to provide optimal care [25–27].

Despite insights from global studies on caregiving for autistic children [28, 29], the lived experiences of caregivers in Nigeria remain underexplored. This study aims to fill that gap by documenting caregivers' experiences, identifying challenges, and recommending strategies to enhance well-being for both caregivers and the autistic individuals they support.

2 Methods

2.1 Study design

This cross-sectional study adopted a qualitative research approach. This approach allows for the expression of ideas and experiences that may otherwise be unaccounted for in structured interviews [30, 31]. Data collection for iterative purposes allows for in-depth exploration from the perspective of participants, hence, giving an edge over other method [32]. We used the phenomenological approach for this study which allows participants to share their personal stories and lived experiences from their lenses and perspectives [30]. This methodology enabled us to gather the nuances of participants' experiences in the way they see fit [33, 34].

2.2 Study population

Caregivers (adults above 18 years) of autistic children (less than 18 years old) enrolled in special needs schools in Calabar, Nigeria, were the population of interest. The diagnosis was based on the child's psychiatrist's reports for school enrollment.

2.3 Sample size/procedure

We leveraged the principle of saturation or redundancy of information as recommended by Polit and colleagues for the data collection [35]. Consequently, we conducted interviews and discussions until saturation was reached—meaning the study's objectives were met or when participants began to provide repetitive information. We used purposive sampling 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. We conducted the FGDs in a bid to explore the shared experiences of caregivers, while the IDIs sought to examine individual variations in these experiences, identifying unique perspectives that may differ from person to person.

2.4 Data collection tools

The IDI and FGDs guides were extracted and adapted from the Protocol for Responding to and Assessing Autistic individuals' Assets, Risks, and Experiences (PREPARE) [36]. These tools have been used in different contexts to collect data on social needs [37–39]. The guides were drafted on the experiences and unmet needs of caregiving. The respondents were asked pivotal questions such as: "How do you describe your experiences with societal attitudes towards you and your child?", "Can you share some of the challenges, if any, that have influenced your caregiving?", and "What impact has caregiving for an autistic child had on your life?". The pretesting of the data collection tool was conducted in Cross-River State among different populations, and essential refinement was done to clarify the questions and remove ambiguities [40].

2.5 Procedure for data collection

Prior to data collection, we recruited and trained three data collectors on the multi-methods data collection process and the research objectives. Data were collected over 7 weeks, between March and April 2024 in special needs schools in Cross River State, Nigeria. Data were collected using a validated structured questionnaire and thematically developed FGD and IDI guides; for the purpose of acquiring different kinds of data. We obtained informed consent to audio-record the interviews and discussions using a voice recorder and these were transcribed verbatim and translated for analysis [41]. Additionally, the notes taken during the interview were also included in the data analysis.

2.6 Data analysis

The qualitative data, in the form of transcripts, were checked for errors and imported into the NVivo (version 20) software for appropriate analysis. Inductive and deductive (hybrid) thematic analysis approaches were used for the analysis with a pre-designed codebook generated from similar previous studies. First, we became familiar with the data by immersion and reading through the transcript, following by independent data generation by two researchers from our team. After generating an initial set of codes, the two researchers compared their findings to identify similarities and eliminate conflict. This collaborative approach ensured the reliability of the coding process. As new themes emerged during the analysis, we iteratively incorporated them into the codebook and applied them systematically to the entire dataset, refining the thematic framework to capture the data's contents [42].

2.7 Ethical consideration

The study was conducted in line with the 2013 Declaration of Helsinki on research involving human subjects. We obtained ethical approval to conduct the study from the Cross River State Ministry of Health Research and Ethics Committee (CRSMOH/HRP/REC/2024/504). Before data collection, verbal and written informed consent was obtained from study participants, with the confidentiality of volunteered information assured and ensured. 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 [43].

3 Results

The demographic information of participants who completed FGDs or IDIs is summarized in Table 1 above. The participants were between the age ranges of 21–30 years, 31–40 years and 51–50 years. The percentage of individuals involved in IDI were almost evenly distributed across the age ranges, majority of the focus group discussants were from the 21–30 age range. For both IDIs and FGDs, the females and married people had the highest percentages of participants. Results also showed that majority of the IDI participants were business people (57.1%), while majority of the FGD participants were civil service workers (43.8%).

Qualitative analysis of the FGD and IDI responses revealed 5 main themes contributing to caregiver burden, namely, stigma and misunderstanding of autism, emotional impact and acceptance, transportation and accessibility challenges, support networks in autism, and balancing responsibilities and care. Each of these themes is discussed below with illustrative quotations.

3.1 Stigma and misunderstanding of autism

Stigma and misunderstanding of autism emerged as significant challenge reported by most participants in our study. The qualitative responses gathered reflect the emotional challenges faced by caregivers of autistic individuals within their communities. A caregiver recounted an incident where her child suffered burns after coming into contact with ash from a neighbor's burning waste and her neighbor's reaction when approached, causing her significant emotional distress. *"One of my neighbors burned her waste outside the compound, I was inside and my son ran outside and deep his hands into the ashes, and his hands burnt. I tried talking to my neighbor about trying to avoid some acts that pose risks to the autistic child, and she asked me if she was the one responsible for my the state of my child. I felt pained."*—(Key Informant, Female caregiver).

Participants emphasized how both autistic individuals and their families often face judgment and unfair treatment from others, which exacerbates their sense of isolation. *'Sometimes, it can be embarrassing and shameful. Now, it is not about the autism itself, or the experiences associated with it. It is like how people treat autistic children and even some of us the family members*—(FGD Participant).

A male caregiver shared a poignant experience of overhearing parents describe his daughter as "not normal" when discussing communication strategies with their own children. This insensitive remark deeply affected him, reflecting the hurtful impact of societal stigma on caregivers and their families. "*I've overheard some parents telling their child that my daughter is not normal when their children try talking to them about how they can have healthy communication with my daughter. Each time, and this sends chills to my heart"* (Key Informant, Male Caregiver).

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		
Unemployment	–	4 (25.0)
Business/tradesperson (31.2)	3 (57.1)	5 (31.2)
Civil service	4 (42.9)	7 (43.8)

3.2 Emotional impact and acceptance

A few participants in our study highlighted the significant emotional impact and the evolving process of acceptance they experienced in both social and professional environments. Caregivers highlighted the emotional impact and evolving acceptance they experienced within social and professional environments. A discussant from the focus group expressed feelings of insecurity and discomfort when colleagues discussed their children and family experiences. She shared her struggle with comparing her own experiences, which often revolve around the challenges of raising an autistic child, to those of her peers. "*Honestly, I have these insecurities that I have an autistic child whenever my colleagues start discussing their children and family experiences at work or in our social gathering*" (Focus Group Discussant, Female).

However, another key informant described a journey towards acceptance and understanding of her child's autism. Initially experiencing sadness and difficulty accepting the differences, she eventually reached a point of acceptance. She noted that while unwelcoming reactions from colleagues, school, friends, and even church were once distressing, they now bother her less as she has come to terms with her child's unique needs and abilities. *"I have understood that my child is not like others. Yes, this used to be sad and hard for me to acknowledge and accept. But now, I have come to terms with it—so, I feel less bothered when I get some unwelcoming reactions from my colleagues, school, friends and even in the church"*—(Key Informant, Female).

3.3 Transportation and accessibility challenges

Transportation challenges emerged as a significant theme, mentioned in the groups and individual interviews, which reveals how public and private infrastructure can impact the burden of care. One discussant from the focus group shared the reliance on a close friend with a car to transport her child to healthcare appointments and other destinations. However, she expressed the limitations of this arrangement due to her friend's busy schedule, which often leaves her struggling to manage transportation needs independently. *"My close friend who happens to have a car helps me often to take my child to the health care center and sometimes drops us off at our destination, but you know we can't often rely on people because sometimes he gets so busy and those times I find it difficult moving about with him."* (Focus Group Discussant, Female).

Another caregiver described the emotional strain of using public transport with her autistic child, noting how negative reactions from others make it embarrassing. Despite the proximity of essential services like hospitals, schools, and churches to her home, she expressed concerns about the sustainability of managing transportation challenges over time. *"Oftentimes we have to walk to this center because I find it embarrassing when people give ill reactions over my child's behavior while using public transport. But the good thing is that the hospital, school, and church are not very far from home. But for how long would I continue."*- (Key Informant, Female).

A different discussant explained her decision not to let her child use the school bus, opting instead for a school where a relative teaches and can provide additional support. This choice stemmed from concerns about her child's well-being and her own emotional health, highlighting the careful considerations and sacrifices made due to the challenges posed by autism. *"My child doesn't use the school bus. I enrolled my child in a certain school previously because one of my relatives teaches there so she takes care of him, but because of this disorder I don't allow my son to use the school bus for his own well-being and my emotional health."*- (Focus Group Discussant, Female).

3.4 Support networks in autism

Qualitative responses revealed the varied social experiences and support systems of caregivers of autistic children, highlighting both challenges and sources of resilience within their social circles. One key informant described feeling isolated and socially excluded following her child's autism diagnosis. She expressed a sense of abandonment by friends who ceased associating with her after learning about her child. *"I feel like people are unwilling to interact with me because maybe they have assumed that I have adapted to the behavior of my child. Most of my friends before I had this child stopped associating with me after they found out my child has autism. It may not be deliberate, however, I have noticed that people do not associate well with me and my child"*—(Key Informant, Female).

Conversely, another discussant shared a more positive perspective, acknowledging that while some people may avoid interactions due to a lack of understanding about autism, her experience has been largely positive due to strong support from family and friends. She emphasized the importance of this support network in helping her navigate the challenges of caregiving, indicating that she has not felt neglected despite occasional social misunderstandings. *"Sometimes, you know, people who do not understand autism may avoid you. Yeah, I have experienced that. But never been worried because my family and friends have been so supportive and have always helped me care for my child, so, I would not say I have been neglected"*—(Focus Group Discussant, Female).

3.5 Balancing responsibilities and care

Balancing caregiving responsibilities with other aspects of life emerged as a key theme in the study. Some caregivers described the challenges they face in caring for autistic children in balancing caregiving responsibilities with other aspects of life, as well as the profound emotional connections and sacrifices involved. A key informant expressed the stress of managing work commitments alongside caring for her autistic child, particularly when her husband, who assists with caregiving, is unavailable. *"It is often stressful for me to maintain balance with work and taking care of my child whenever my husband who helps out goes on a trip or is not available"* (Key Informant, Female).

A male discussant from the focus group acknowledged the inherent challenges of balancing work demands with the intensive caregiving required for a child with autism. Despite these difficulties, he emphasized his unwavering love for his child as a driving force that helps him navigate and overcome challenges, reflecting the deep emotional commitment and resilience of caregivers. *"To be honest, caring for a child with autism is challenging to meet up with work demands and giving much attention to my child, but, I cannot complain because perfect love casts away all fears and I love my child so much."* (Focus Group Discussant, Male).

Another discussant shared her struggle with balancing attention and love among her children, feeling conflicted about the perceived differences in affection towards her autistic child compared to her other children. "*It is difficult for me to balance my attention and love at home because I feel so attached to my child now and her siblings feel like I show more love and give higher attention to her.*"—(Focus Group Discussant, Female).

4 Discussion

Our study explored the caregiving experience for autistic children through a qualitative method approach. Based on our qualitative data, this heightened burden appears to stem from prevalent social stigma, widespread misinformation, adverse societal perceptions, and limited supportive social structures. Upon interviewing the study respondents, results showed that stigma was an issue faced by caregivers. This stigma may have contributed to some of the challenges observed in the analysis. The social and emotional impacts associated with this stigma likely compounded the challenges that caregivers faced [44]. Participants reported that stigma from society was so dire that their neighbors forbade their offspring from associating with their autistic children. This level of stigma made the participants feel significant emotional distress. Other studies in China, Ethiopia, Kenya also shown that stigma towards autistic children and their families result in significant emotional distress, tampering with their mental health [24, 26, 44, 45]. The use of public transportation was described as contributing to challenges faced in societal attitudes. Participants shared feelings of discomfort and distress due to the way their autistic children were treated in public spaces, which influenced their decision to limit their children's use of public transportation. Generally, it can be deduced that stigma extending from autistic individuals to their caregivers has a poor psychological impact on the caregivers, as some studies opine that affiliate stigma is one of the leading causes of depression, anxiety, and mental health disorders noticed among caregivers of autistic children [46]. This was in congruence with findings by Papadopoulos and colleagues, who identified affiliate stigma in caregivers as a cause of depressive symptoms among them [25]. Research suggests that affiliate stigma is one of the leading causes of depression, anxiety, and mental health disorders noticed among caregivers of autistic children [46]. Similar studies Taiwan and Greece have also shown that poor mental health of caregivers culminates in poor physical health as well and this would invariably affect the quality of health care being offered to the child, endangering their health [47, 48]. It is therefore pertinent that proper enlightenment be provided for societies, as stigma towards autistic children is majorly due to misunderstanding and misconceptions. This assertion was revealed in a study in Kenya by Cloete and Obaigwa in 2019, who reported that respondents believed spiritual factors were behind the incidence of autism [45].

Lack of support systems and acceptance was another challenge identified from the qualitative analyses, as participants reported that the social neglect, they faced was a huge difficulty. A consequent adaptation to this was social exclusion by the respondents, as they indicated that people believed they had picked up autistic behaviors from their children. This misconception resulted in a significant level of neglect, not just from society but also from family. Neglect from society prompts caregivers of autistic children to resort to self-isolation, and even exclusion from healthcare services [49, 50]. Participants also reported that lack of acceptance from society resulted in their harboring of different forms of insecurities. These included not revealing details about their children to colleagues at work, for fear of maligning. Together with stigma, lack of acceptance from society and family is one of the major emotional challenges as recounted by some of the caregivers of autistic children [27]. To this end, the government ought to commit to abolishing stigma towards autistic children, while driving for inclusivity and acceptance.

Caregivers reported that balancing personal responsibilities with caregiving often felt overwhelming. Many expressed the constant struggle of working to provide for their children while also meeting the demanding needs of raising an autistic child. The time, patience, and energy required can be exhausting, leaving little room for personal or social activities. Studies have shown that this constant juggling act can take a heavy toll on caregivers' mental and physical well-being [44]. In India, similar research found that some parents and caregivers of autistic children experienced not only emotional strain but also significant physical health issues due to caregiving stress [51]. Personal achievements and social lives take the lowest priority when one spends most of the time caregiving. For sure, disrupted routines and unrealized personal ambitions do keep these people unfulfilled, according to how the caregivers expressed their sentiments. To augment financial means, many work extra, thus adding to physical stress.

Participants in this study also spoke to emotional burden stemming from social judgment. The negative attitude of people around them deepened their sense of isolation, making it hard to seek support or build social networks. This is consistent with the findings of Gabra and Hashem [52], who reported that caregivers for children and ADHD confronted significant social difficulties due to the high demands on their time and the lack of understanding in the community [52]. Lack of supportive social networks increased feelings of loneliness and hopelessness [53]. For some, withdrawing from society seemed to be the only way forward, which ironically led to greater isolation at such a cost [26]. Isolation from one's environment is associated with poorer mental health outcomes [54], which can, in turn, affect the well-being and coping abilities of caregivers. This may lead to increased challenges in managing caregiving responsibilities, potentially influencing their mental health and overall quality of life [44]. As highlighted in this study, respondents shared that managing care for their autistic children alongside other responsibilities often presented significant challenges. Many caregivers discussed the complexities of balancing these demands. These caregiving experiences are shaped by factors such as stigma, limited support, and lack of acceptance, which can result in social exclusion and isolation.

5 Strengths and limitations

The study explored the caregiving and phenomenological analysis of caregivers' experiences with autistic children/wards using a qualitative approach. In synthesizing the findings using a qualitative approach, the study offers a more composite picture of the multifaceted issues that are associated with caregiving for autistic persons among the participants in Nigeria. Additionally, the study focuses on the experiences and challenges of caregivers, providing meaningful findings that are veritable in designing psychosocial support for them and contributing to the body of literature and evidence on the multifaceted experiences of caregivers supporting autistic individuals. However, as with many other cross-sectional studies, our study has weaknesses including possible bias with the qualitative nature of the study as purposive sampling was employed and our findings cannot be generalized. This is because it captures the lived experiences of a particular community of caregivers and does not include longitudinal follow-ups with participants to consider the temporal changes in the experiences of caregivers. Therefore, we encourage further longitudinal research to explore the evolving dynamics of caregiving over time.

6 Conclusion

Inferences from the results gathered from the lived experiences of the respondents indicate that the challenges faced by caregivers were primarily influenced by community-related factors. These challenges encompassed a range of socio-cultural and environmental influences that shaped the caregiving experience. Studies in sub-Saharan Africa have shown that the majority of societies in Africa stigmatize autistic individuals due to misconceptions and false perceptions [8, 55]. This has led to consequent social exclusion of the caregivers and their children. A lot of these false perceptions arise from cultural and religious beliefs and traditions. To this end, the right steps must be taken to properly enlighten Nigerian societies on the nature of autism, and the need for acceptance. Given the apparent low levels of information about autism among Nigerian public, it is therefore ideal for the government to carry out enlightenment programs. This

Table 2 Recommendations for improving experiences and support caregiving for autistic individuals

Findings	Recommendations
Stigma and misunderstanding of autism	Proper education programs should be facilitated by the government. Health agencies and personnel should serve as resource persons in educating the public on the need for inclusivity. This may help towards improving attitudes towards people with autism
Support networks in autism	Setting up support societies for caregivers with autistic children may foster inclusion and provide a sense of societal support. These networks could offer opportunities for connection, sharing experiences, and accessing resources, while promoting positive outcomes for both caregivers and autistic children
Balancing responsibilities and care	Allocating stipends to caregivers with autistic children could help reduce the number of hours they need to work, potentially easing their responsibilities and improving their overall well-being
Enhance accessibility of public transport	Government agencies could partner with advocacy groups and transport operators increase understanding and acceptance of autistic individuals in public settings. Additionally, flexible seating or priority spaces for families with autistic children could be implemented

would make for better understanding, inclusivity, and acceptance, which would allow their caregivers feel comfortable enough to seek medical help and assistance where necessary. Additionally, the establishment of social support groups for caregivers may help establish a sense of belonging and support.

7 Recommendations

Based on the findings of this study, a series of actionable recommendations have been identified to address the challenges faced by caregivers of autistic individuals in Table 2. These recommendations aim to foster inclusivity, reduce stigma, and enhance the quality of life for both caregivers and individuals with autism.

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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, and led the data collection process. PCA supported the qualitative data analysis, applied themes to generate results, and contributed to writing the manuscript. AOA, MOE, TA, UFI, MN, CKO, PNT, ERU, and GSA contributed to the study implementation, data processing, quantitative 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 Data is provided within the manuscript.

Declarations

Ethics approval and consent to participate The proposal for this research work was reviewed by the Cross River State Ministry of Health Research and Ethics Committee, which approved it under the number CRSMOH/HRP/REC/2024/504. The study was conducted in adherence to the Helsinki Declaration on research involving humans. Written informed consent was obtained from the study participants before data collection, under conditions of assurance and ensuring the confidentiality of volunteered information.

Consent for publication The authors consent to publish the declaration.

Competing interests The authors declare no competing interests.

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