Journal of Disability Studies 2026, 12(2), 27-44

JOURNAL OF DISABILITY STUDIES

Exploring the Lived Experiences of Caregivers of Children with Autism in Accra

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ABSTRACT

Background: Caring for children with autism (CWA) can place substantial emotional, social, financial, and psychological demands on caregivers, particularly in low-resource settings with limited specialised services and institutional support. Despite growing research on autism caregiving in Ghana, limited attention has been given to caregivers' lived experiences.

Objective: To explore the lived experiences of caregivers of CWA in Accra, focusing on their caregiving roles, needs, challenges, and coping mechanisms.

Methods: A qualitative interpretive phenomenological approach was used. Purposive sampling recruited 20 caregivers of CWA with support from three institutions providing autism-related services in Accra. Data were collected through individual in-depth interviews and analysed thematically using Braun and Clarke's approach.

Results: Three interconnected educational and therapeutic roles emerged alongside traditional parental responsibilities, increasing caregivers' burden of care. Mothers assumed greater caregiving responsibility, whereas fathers reported greater psychological stress. Caregivers' needs centred on acceptance, which was challenged by negative societal attitudes and associated with physical, social, and psychological difficulties. Financial reframing, social support, and religious activities were important coping mechanisms.

Conclusion: Caregivers of CWA undertake complex educational and therapeutic roles in addition to routine caregiving, contributing to substantial burden. *Recommendations:* Social protection programmes should better address the needs of CWA and their caregivers, alongside caregiver-skills training, family-inclusive strategies, and community-based autism awareness through partnerships among government, NGOs, traditional authorities, faith-based organisations, and social workers.

Keywords: Autism, caregiver, identity theory, caregivers, inclusivity

Received on: June 22, 2026 Accepted on: July 13, 2026 Published Online: Sep 16, 2026

INTRODUCTION

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterised by persistent deficits in social communication and interaction, alongside restricted and repetitive behaviours, interests, or activities (American Psychological Association, 2023). Autism has a complex and multifactorial aetiology involving a combination of genetic, developmental, and environmental influences. Rather than being attributed to a single cause, autism has been associated with a range of genetic and non-genetic factors. These include inherited genetic variants, de novo mutations, copy number variations, single-nucleotide variants, and epigenetic mechanisms, as well as certain prenatal

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Cite as: Issahaku, M. M., Naami, A., & Boateng, A. (2022). Exploring the lived experiences of caregivers of children with autism in Accra. *Journal of Disability Studies, 12*(2), 27–44. https://doi.org/10.29120/jds.v12i2.859

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and perinatal factors. However, these factors should be understood as genetic contributions, associations, or potential risk factors rather than established direct causes of autism (Tye et al., 2019; Rylaarsdam & Guemez-Gamboa, 2019; Alvares, 2019). Early signs include delayed speech and social development, repetitive behaviours, restricted interests, and difficulty adapting to routine changes (Rylaarsdam & Guemez-Gamboa, 2019).

In Ghana, neurodevelopmental service infrastructure is heavily constrained, concentrating private, costly diagnostic and therapeutic services in urban centers like Accra and Kumasi, while local cultural beliefs often attribute autism to spiritual causes, curses, or ancestral wrongdoing, leading to severe social stigma and isolation. Although previous Ghanaian studies have documented caregiver stress, stigma, coping and support needs, fewer studies have examined how caregivers understand the transformation of their caregiving role through the specific theoretical lens of Caregiver Identity Theory.

In accordance with the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision* (DSM-5-TR; American Psychiatric Association, 2022), autism spectrum disorder is classified across three distinct levels of severity based on the degree of support required for social communication deficits and restricted, repetitive behaviours. These are categorised as Level 1 ("requiring support"), Level 2 ("requiring substantial support"), and Level 3 ("requiring very substantial support"), replacing older, less precise descriptors such as "mild, moderate, or severe." Globally, ASD prevalence is estimated at 0.76%, while prevalence in the United States ranges from 1.68% to 2.5% and more than doubled between 2000 and 2012 (World Health Organisation, 2013; Autism and Developmental Disabilities Monitoring Network, ADDM, 2012; World Health Organisation, 2013). African prevalence estimates remain inconsistent, and Ghanaian data are limited (Khabala, 2018; Akpeke et al., 2024). Differences in prevalence may reflect variations in diagnostic criteria, research methods, awareness, and access to screening rather than actual occurrence (Baxter et al., 2015; Elsabbagh et al., 2012; Fombonne, 2009; Lord et al., 2020)

Caregiving involves providing physical, emotional, and financial support to individuals requiring continuous care (Davy et al., 2022; Charalambous, 2023; Pop et al., 2022). Autism caregiving requires structured routines, sensory adaptations, communication support, and collaboration with professionals (Louis-Delsoin et al., 2022; Naidoo & Govender, 2022). In Ghana, caregivers face financial burdens, stigma, inadequate services, emotional stress, and limited institutional support despite programmes such as the Livelihood Empowerment Against Poverty (LEAP) programme (MoGCSP, 2008; Nutifa & Amponsah, 2020; Apaah et al., 2023). Existing studies provide a limited theoretical understanding of the lived experiences of caregivers of CWA in Accra. Therefore, this study explores the roles, needs, challenges, and coping mechanisms of caregivers of CWA in Accra through the lens of Montgomery, Rowe, and Kosloski's (2007) Caregiver Identity Theory to inform policy and strengthen support systems in Ghana.

Roles of Caregivers of Children with Autism

Caregivers of CWA perform diverse responsibilities aimed at ensuring their children's well-being. These roles include assisting with personal hygiene, managing medication, providing mobility support, advocating within healthcare and educational systems, offering emotional support, fostering independence, and coordinating medical appointments and therapies (Leigh et al., 2020). In Ghana, caregivers prioritise providing food, clothing, affection, and educational resources while regularly monitoring their children's welfare in special schools (Acheampong et al., 2017). Mothers often assume primary caregiving responsibilities. They monitor educational, health, and recreational activities, negotiate for their children's welfare, participate in home-based teaching, and support professionals involved in their children's care (Stoner & Stoner, 2016). Fathers are more likely to serve as breadwinners, bearing the financial burden of diagnosis, treatment, medication, and other care-related expenses (Burrell et al., 2017).

Needs of Caregivers of Children with Autism

Caregivers require access to specialised education, therapy, support services, respite care, counselling, financial assistance, and culturally sensitive interventions (Shivers et al., 2019). Caregivers also value

effective intervention programmes but are often constrained by the high costs of consultation and therapy (Al Awaji et al., 2024). In Africa, caregiver needs are shaped by limited resources, stigma, and low awareness, making advocacy and access to specialised services essential (Ruparelia et al., 2016). In Ghana, caregivers face limited access to diagnosis, therapies, educational support, and counselling services.

Early intervention programmes such as the Early Start Denver Model (ESDM), Treatment and Education of Autistic and Communication Handicapped Children (TEACCH), and Applied Behavioural Analysis (ABA) have demonstrated effectiveness in improving cognitive, language, and social outcomes Vismara & Rogers (2010). In Ghana, these services remain concentrated in Accra and Kumasi and are largely dependent on private institutions, limiting accessibility for many families (Franz et al., 2017). Caregivers, therefore, play a crucial role in supporting interventions at home (Anthony, 2010).

Inclusive education policies globally emphasize flexible curricula, collaboration among schools, health services and families, autism-specific teacher training, and Individualised Educational Programmes (IEPs) (Van Kessel et al., 2020; Autism Europe, 2003; Teodoro, 2020), which face some structural challenges in Ghana. Caregivers, therefore, advocate for tailored IEPs, special schools, and private tutoring to support their children's development (Gomda et al., 2022). Additionally, the WHO Caregiver Skills Training (CST) programme provides parent-mediated training through group sessions and home visits, although implementation challenges persist in low- and middle-income countries (Salomone et al., 2019).

Challenges Faced by Caregivers of Children with Autism

Caregivers face emotional, social, and economic challenges. Caregivers in Asia experience elevated risks of unemployment, divorce, poor mental health, and stigma (Shorey et al., 2020). Similar stressors have been reported in Eastern Europe, where behavioural difficulties contribute to parental strain (Colic et al., 2022). In Ghana, caregivers experience stress, shame, depression, limited knowledge about autism, and cultural beliefs linking autism to curses or ancestral wrongdoing (Appiah & Osei, 2023; Ensink & Normandin, 2023).

Family challenges include strained relationships, limited social support, and stigma (Dabrowska & Pisula, 2010; Mbamba & Ndemole, 2021). In Accra, caregiving occurs largely within nuclear families, reducing support from extended relatives despite relatively better access to diagnostic and therapeutic services (Tagnan et al., 2022; Oti-Boadi et al., 2022).

Financial burdens are substantial, with many caregivers reducing their working hours or leaving employment altogether because of caregiving demands (Lee & Meadan, 2021). Costs for therapy, education, transport, and medical care further exacerbate financial strain (Van der Linde et al., 2019; Apaah et al., 2023; Opoku et al., 2021). Socio-cultural challenges include discrimination, exclusion from mainstream education, inadequate healthcare infrastructure, and limited autism-specific policies and services (Shorey et al., 2020; Anthony, 2010).

Coping Mechanisms

Caregivers rely heavily on support from family, friends, and professionals for emotional, practical, financial, and informational assistance (Skitsko, 2023; Samadi & Samadi, 2020; Zarzycki et al., 2023). In Ghana, where formal support is limited, such networks remain essential (Allotey, 2019). Spirituality is also a major coping mechanism, with caregivers seeking support through prayer and religious leaders while simultaneously pursuing medical interventions (Gona et al., 2017; Allotey, 2019). Spirituality contributes to resilience and life satisfaction among caregivers (Dey et al., 2019). Furthermore, self-education enables caregivers to better understand autism through information obtained from teachers, social workers, social media, and personal learning initiatives (Gona et al., 2017; Allotey, 2019; Appiah & Osei, 2023).

OBJECTIVES

The general objective is to understand the lived experiences of primary caregivers of children with Autism. Specific objectives are:

1. To explore the roles of caregivers of children with autism in Accra.
2. To find out the needs of caregivers of children with autism in Accra.
3. To identify the challenges that the caregivers of children with autism in Accra face.
4. To investigate the mechanisms that caregivers of children with autism in Accra use to manage the challenges they face.

MATERIALS AND METHODS

The study is grounded in the Caregiver Identity Theory (CIT) developed by Montgomery, Rowe, and Kosloski (2007). CIT explains how caregiving evolves from an existing familial role into a caregiver identity as care demands increase. The theory proposes five phases: role assumption, identity transformation, psychological impact, coping mechanisms, and social support (Montgomery, Rowe, & Kosloski, 2007).

In Phase I (Role Assumption), caregivers gradually take on responsibilities beyond traditional family duties. In the context of autism care in Accra, this theory could help explain caregivers' transitions from routine parenting tasks to specialised caregiving responsibilities such as therapy support and school coordination. Cultural beliefs and stigma may delay this recognition, as unusual behaviours are sometimes attributed to curses rather than a medical condition (Allotey, 2019).

Phase II (Identity Transformation) occurs when caregiving becomes central to self-identity. Caregivers increasingly prioritise securing specialised services and adapting to the realities of autism. This transition may be difficult because of societal expectations and misconceptions surrounding disability. O'Connor (2007) argues that caregivers develop meaning and understanding of their role through continuous interaction with others.

Phase III focuses on Psychological Impact. Identity discrepancy between parental expectations and intensive caregiving responsibilities can lead to stress, anxiety, depression, guilt, and burnout (Montgomery, Rowe, & Kosloski, 2007). Similar emotional burdens among caregivers of CWA have been reported by D'Arcy et al. (2023).

In Phase IV, caregivers develop coping strategies such as seeking support, positive reinforcement, self-care, and religious faith to reduce stress and strengthen resilience (Montgomery, Rowe, & Kosloski, 2007; Dey et al., 2019).

Phase V emphasises social support. Recognition and assistance from family, friends, religious organisations, and professionals help caregivers manage identity strain (Montgomery, Rowe, & Kosloski, 2007). This phase helps explain what support systems exist in Accra that caregivers rely on for caregiving (Opoku et al., 2021; Samadi & Samadi, 2020; Acheampong, 2017).

CIT is relevant because it helps to explain identity transformation, emotional and other challenges, coping processes, and support needs among caregivers of CWA in Accra, and could inform targeted interventions and policy support.

The study employed an interpretive phenomenological design, with thematic analysis used to identify and interpret patterns in participants' accounts. The study targeted primary caregivers of CWA who were actively involved in the day-to-day activities of the child in Accra, Ghana. Purposive sampling was used to recruit 20 caregivers of CWA in Accra until data saturation was achieved, with the support of three institutions that were directly providing care for children with Autism: AACT, ACA, and TMCT. The choice of participants was informed by their caregiving role, availability, and willingness to provide in-depth information on their lived experiences. Eligible caregivers were unpaid primary caregivers (biological parents, extended family guardians, grandparents, or foster caregivers) living in the Greater Accra Metropolitan Area who provided direct daily care, healthcare, and educational management for a child aged 5 to 16 with a formal ASD diagnosis. Excluded were paid or professional non-family care providers, caregivers of children without a formal clinical ASD diagnosis and secondary extended family members without primary care responsibilities. The sample was equally split by gender; ages ranged between 30 and 50 years old. Thirteen of the participants were married, and 7 were single.

Data were collected through individual in-depth interviews using a semi-structured interview guide, allowing participants to freely describe and interpret their experiences. Interviews were conducted in English and Twi; a trained translator assisted with the Twi interviews. Interviews were transcribed into English using TurboScribe, a cloud-based automated transcription service, in accordance with the ethical approval granted by the University of Ghana's Ethics Committee for the Humanities (ECH 053/24-25). Audio files were de-identified before upload, transmitted using encrypted protocols, and deleted from the cloud server after local download. De-identified transcripts were stored on password-protected, encrypted local storage accessible only to the research team. Each interview lasted approximately 60 minutes and was audio-recorded with participants' consent. Participants selected the interview location; most chose the school premises, while others opted for their homes or workplaces.

Before the main data collection, the interview guide was pilot-tested with three caregivers of CWA who were not part of the final study sample. This pre-testing helped to assess the clarity, relevance, and sequencing of the questions. Based on the feedback received, minor revisions were made to simplify ambiguous questions and improve the flow of the interview. This process enhanced the credibility and trustworthiness of the instrument for capturing caregivers' lived experiences. Ethical approval was sought and granted by the Ethics Committee for the Humanities at the University of Ghana (ECH 053/24-25). Prior to interviews, caregivers received detailed study information and provided written or audio-recorded verbal informed consent, including explicit separate consent for interview participation, audio recording, and publication of anonymized quotes. Caregivers were also informed of their right to skip questions or withdraw at any time without penalty. To protect confidentiality in a small localized sample, the researchers removed all personal identifiers and unique details were removed or generalized, pseudonyms were assigned, and institutional affiliations were anonymized in quote reporting. Audio recordings and de-identified transcripts are securely stored in password-protected cloud storage accessible only to the research team and will be destroyed per institutional retention protocols.

Data were analysed using a thematic analysis articulated by Braun and Clarke (2012). Transcripts were repeatedly read for familiarization, followed by systematic coding of caregivers' lived experiences. Codes were collated, reviewed, refined, and organized into themes that captured patterns across the dataset. Themes were then defined, named, and synthesised into an analytical narrative supported by participant quotations. The resulting themes were subsequently interpreted through Caregiver Identity Theory (CIT), particularly role assumption and transformation, identity negotiation, therapeutic responsibility, social recognition, psychological impact, and coping. This integration enabled the analysis to examine how caregiving experiences shaped, challenged, and transformed caregivers' identities. Each researcher independently conducted the analysis manually. The researchers subsequently compared and contrasted their coding and interpretations, discussed areas of convergence and divergence, and reached consensus on the final themes and findings. The researchers maintained anonymity by using pseudonyms in place of participants' real names, ensuring that their identities remained confidential throughout the study.

The study recruited caregivers primarily through institutions providing services to children with autism, as accessing caregivers outside formal service settings was practically challenging. This recruitment strategy may have limited the diversity of perspectives represented in the study. For example, caregivers who rely exclusively on traditional or religious systems, those living in rural dwellings or those whose children remain undiagnosed. Consequently, the findings reflect the experiences of caregivers who access formal institutional services and should not be interpreted as representing all caregivers of children with autism in Accra. Nevertheless, the findings provide valuable insights into the lived experiences, challenges, adaptations, and support needs of caregivers within this service context.

Also, reflexivity was maintained throughout the study in recognition of the researchers' positionalities and potential influence on the research process. One researcher worked at the institution from which some participants were recruited, creating the potential for pre-existing relationships and institutional familiarity to influence data collection and interpretation. Another researcher had personal experience of disability, although not autism, and extensive scholarly engagement with disability-related issues. These experiences were acknowledged and critically reflected upon throughout the research process. The researchers engaged in reflexive bracketing by consciously identifying and setting aside their

preconceptions, experiences, and expectations during data collection and analysis, while remaining attentive to how their positionalities might shape interpretation. This process was intended to minimise undue influence on participants' accounts and enhance the credibility and trustworthiness of the findings.

RESULTS

Socio-demographic characteristics of caregivers

The study included 20 caregivers, and their socio-demographic characteristics are presented in Table 1. The caregivers ranged in age from 29 to 47 years. The largest proportion of participants were 35 years old (35.0%), followed by those aged 30 years (20.0%). Participants aged 29 and 42 years each constituted 15.0% of the sample, while 10.0% were 47 years old. One participant (5.0%) preferred not to disclose their age.

The gender distribution of the caregivers was evenly divided, with 10 males (50.0%) and 10 females (50.0%). In terms of their relationship with the child, mothers constituted half of the participants (50.0%), while fathers accounted for 40.0%. The remaining 10.0% were guardians. Regarding marital status, 13 caregivers (65.0%) were single, whereas 7 (35.0%) were married.

Table 1. Socio-demographic characteristics of caregivers (N = 20)

Characteristics	Category	n	%
Age (years)	29	3	15.0
	30	4	20.0
	35	7	35.0
	42	3	15.0
	47	2	10.0
	Prefer not to say	1	5.0
Gender	Male	10	50.0
	Female	10	50.0
Relationship to child	Mother	10	50.0
	Father	8	40.0
	Guardian	2	10.0
Marital status	Married	7	35.0
	Single	13	65.0
Educational level	Undergraduate	2	10.0
	Senior High School	10	50.0
	No education	8	40.0
Occupation	Employed	5	25.0
	Self-employed	10	50.0
	Unemployed	5	25.0
Religious affiliation	Christianity	11	55.0
	Islam	9	45.0

With respect to educational attainment, half of the caregivers (50.0%) had completed Senior High School (S.H.S.). Eight participants (40.0%) reported having no formal education, while 2 (10.0%) had undergraduate-level university education. The occupational profile showed that half of the caregivers (50.0%) were self-employed. Five participants (25.0%) were employed, while another five (25.0%) were unemployed.

Religious affiliation indicated that Christianity was the predominant religious affiliation, reported by 11 caregivers (55.0%), while 9 caregivers (45.0%) identified with Islam. Overall, the participants represented a diverse group in terms of age, educational background, occupation, and religious affiliation, while the sample was equally distributed by gender. Mothers and fathers constituted the

majority of caregivers, with a smaller proportion represented by guardians. These characteristics provide an overview of the socio-demographic profile of the caregivers included in the study.

Roles of Caregivers of Children with Autism in Accra

The first objective sought to explore the roles of caregivers, and three major roles emerged under the theme expanding the caregiver role beyond parenting: home-based therapeutic work, coaching and skills development, and preparing and regulating the child. Participants viewed their daily routines as a form of home therapeutic work because they were stabilising and soothing their children while simultaneously teaching essential life skills. This was reported by participants across the three institutions and mostly by those with longer years of caregiving experience. An example is given below:

*For us, the structured routine was our home therapy. On weekdays, every minute from packing her lunch to managing transitions created a predictable rhythm that reduced anxiety and promoted calm. I have been doing this since she was born, and she is now 12 years of age***.** **(**Caregiver 1, Mother, 47 years, ACA**)**

Another role reported is coaching and skills development. Participants recounted instances where they had to actively engage the child in both regular activities of daily living and specialised ones, such as cooking and washing dishes, which doubled as a way of coaching their children to be independent. Noteworthy is that male participants also reported this experience, as stated below by Father 11:

Because of the severity of my child's condition, normally I had to engage him with activities that factored into his sensory needs and then into his daily activities. Normally, we say ILS, independent living skills, maybe brushing his teeth and learning how to shave, but mostly the sensory was my concern because without the sensory, he mostly got hyperactive due to the severity of his condition. He liked to work in the kitchen. I saw him in the kitchen more often with knives, trying to do kitchen stuff, so I mostly engaged him in peeling cassava or cutting tomatoes. **(**Caregiver 11, Father, 35 years, AACT).

In addition, preparing and regulating the child was mentioned as a major role played by the participants in this study and it involved preparing the children psychologically for the day and helping them anticipate and adjust to daily activities. This practice was particularly described by participants whose children with autism had moderate to substantial support needs, illustrating how caregivers adapted their practices to their children's individual needs and, in the process, developed role-specific strategies that became part of their caregiver identity, typically between early childhood and pre-adolescence. By combining gentle movement, sensory games, and picture symbols, caregivers across the three centres described how they created a fun therapy session that strengthened their children's bodies and improved their communication skills. An example was given by Caregiver Mother 2.

Every morning, I used simple physical exercises with visual aids to teach him before we stepped out into any environment. This routine helped him regulate his emotions and prepared him for the day ahead, which helped ease his worries about new challenges. **(**Caregiver 2, Mother, 29 years, AACT**)**

Needs of Caregivers of Children with Autism in Accra

Regarding the needs of caregivers of CWA in this study, the theme search for recognition and acceptance emerged. Stigma and cultural explanations, social withdrawal, marital consequences, lack of recognition of caregiver roles and family-inclusive strategies were identified as their needs. Stigma and culture explained the lack of acceptance in their communities, which they claim worsens their burden of care, as the extra roles they take on to support their children are usually not recognised.

As Africans and Ghanaians, our culture often dismissed the heavy burden carried by us, thinking that we just performed our role as parents and that was it. No! The focus shouldn't just be on the child; we need to address the challenges that affected us, the parents, too, right to the very root. (Caregiver 12, Father, 34 years, ACA)

Cultural beliefs and practices, such as labelling CWA as "cursed", "bewitched", possessed", as well as name-calling, were cited to have conditioned Ghanaians' mindset regarding CWA and their caregivers to the extent that people who should understand the situation stigmatise them and ignore their burden of care.

The cultural mindset was part of the problem. People knew autism existed, but they rarely tried to understand the hidden burdens we bore as caregivers. They judged without recognising that our efforts were the foundation for our children's support. (Caregiver 7, 32 years, Guardian, AACT)

Participants reported experiencing social withdrawals because of stigma, including honouring invitations for life events and going to religious gatherings "*I overheard church members say I was a 'lazy father' because he did not look healthy like other children. It changed how I felt about being there.* (Caregiver 15, Father, 42 years, ACA)" and community meetings; "*I have stopped going to community meetings. I cannot handle the looks.* (Caregiver 4, Mother, 39 years, AACT).

Participants also described marital consequences associated with experiences of stigma, including strain within relationships, separation, and, in some cases, eventual divorce. In this study, the mothers reported that their husbands left them because they gave birth to a child with a disability, as reported by Mother 5:

He accused me of being cursed and said that our son's condition was proof. I felt so alone and unsupported. He wouldn't focus on solutions or therapy, only on blaming me. We couldn't continue like that. (Caregiver 5, Mother, 34 years, ACA)

Acceptance in this study was reported as necessary for both the caregivers of CWA and their children because acceptance could reduce stigma and discrimination and promote support for caregivers of children with autism.

There was this cultural belief that children like mine were cursed or bewitched, which not only stigmatised the child but also made my parenting tough. That misconception needs to change first, and then afterwards, we as caregivers can be accepted, and we will be okay. (Caregiver 6, Mother, 35 years, TMCH)

Another need was family-inclusive strategies. Caregivers stated that schools, community initiatives, and social service provision focus mostly on children with autism, thus overlooking the caregivers and their families' needs, such as respite services and emotional support arising from exhaustion from effectively engaging systems that do not adequately provide for CWA and their caregivers.

I had to fight tirelessly to secure a place in schools that claimed to offer education for all, and along the way, I was left feeling exhausted, and nobody seemed to have a solution for families like mine. I gave up and later enrolled my child with Autism Compassion Africa, where they helped me a lot. (Caregiver 8, Mother, 30 years, TMCH)

Challenges Faced by the Caregivers of Children with Autism in Accra

Major challenges reported in this study were educational and therapeutic costs, anxiety and uncertainty, communication and marital. Educational and therapeutic costs arose due to the high special education expenses, as government schools were barely in place for CWA, and the few existing ones did not make adequate provision for them. Some caregivers who are parents struggled to pay for the fees, as recounted by Father 13.

I work as a mechanic, and on good weeks, I make enough to feed the family. But when it came to enrolling my son in a school that could cater to his condition, I realised that 'enough' was no longer enough. The fees were far beyond what I had budgeted for any of my children. I had to sell my old motorbike to pay for the first term. It's painful, but I knew that giving up on his education wasn't an option. (Caregiver 13, Father, 47 years, ACA)

Another contributor to educational and therapeutic costs is the medical, dietary and therapeutic costs, such as speech training, sensory integration, behavioural therapy and occupational therapy.

An additional layer of financial vulnerability is that services were rarely covered by insurance, and there were no government support systems for caregivers of CWA.

Financial support was the biggest gap. If we had had the financial means, we could have gotten better education and care for our children, but the schools needed more funding to help children with autism. The government should have provided resources like school materials, which would have allowed caregivers to use their limited income on other important needs. (Caregiver 9, 35 years, Mother, AACT)

Beyond structured costs, many of the participants, both mothers and fathers, described additional unanticipated expenses arising from incidental and unintentional damage to household items that must be replaced, caused by their children.

One evening, he threw the remote at the television because we changed the channel. The screen shattered instantly. It wasn't the first time either. We'd just paid for a new blender he had smashed the previous month during a meltdown over food. These things were never planned for in our budget. As a taxi driver, I barely make enough for our basic needs, let alone replace electronics. (Caregiver 14, Father, 29 years, AACT)

Anxiety and uncertainty were a central aspect of caregiving challenges that were expressed by participants from diverse backgrounds. They expressed feelings of anxiety, guilt, emotional exhaustion, and isolation, highlighting the immense burden of care they carry. Anxiety in this study was linked to the fear of the future of their CWA, given the lack of support from the home, community and government and the huge financial cost accompanying care of children with Autism. A caregiver of a 10-year-old child with autism with moderate to substantial support needs and Down syndrome had similar worries about her child. She said:

Every day, I worried about what would happen to my child when I wasn't there, looking at his autism, which is not normal and this Down syndrome thing. I constantly worried about whether he would be safe and able to take care of himself. Even if someone were to take care of him, how many people would accept staying with this child? (Caregiver 8, Mother, 30 years, TMCH)

Guilt arises from resting, which is also restless because they keep thinking about work and cannot relax. This compounds emotional and psychological stress.

I felt guilty when I was exhausted, like I should have been doing more, but it was hard when there was no one to lean on. It was isolating, like the world was moving on without me. (Caregiver 19, Father, 37 years, AACT)

Anxiety and uncertainty were so overwhelming that some of the caregivers reported nearly losing their jobs, and this is peculiar to the fathers, who all reported being employed.

It affected me mentally, as I often thought about how I would cope with these children. I have had a hard time adjusting, especially with the two of them each having different problems. My head felt like it wanted to explode sometimes. It also affected my focus at work in so many ways, as I almost got fired one time. The mental stress was very heavy (Caregiver 15, Father, 42 years, ACA).

Communication difficulties compounded the emotional and psychological stresses of the caregivers who participated in this study. For many caregivers, the inability to interpret their child's needs translated into ongoing anxiety and emotional exhaustion and complicated daily caregiving routines.

She pressed her forehead against the window, repeating the same soft 'mmm.' I offered snacks, toys, and everything I could think of. When none worked, she screamed and kicked the seat. I sat in the dark, my hands shaking on the wheel, wondering if I'd ever learn what she was saying. (Caregiver 16, Father, 42 years, AACT)

Anxiety and uncertainty were mostly reported by the fathers giving care to their CWA. This could be attributed to the fact that all of them reported working in addition to providing care for their children.

Marital strain was also reported in this study. Emotional intimacy between partners was described as a vital tool for the survival of some marriages. However, due to rigorous caregiving duties by some partners, it became almost impossible to maintain that bond between them. This issue was reported by married mothers and fathers.

Every day was busy. By the time we came home, we barely had the energy to look at each other. We were focused on his routine and forgot how to spend time as a couple. It felt like our love was on pause. (Caregiver 10, Mother, 39 years, ACA)

From 6 a.m. until the second I fell into bed, the stress was constant. We were always helping him calm down after a meltdown, coordinating with therapists, and receiving endless phone calls from school.

And by the time we were finally alone, we were too exhausted to connect. It felt like we were growing apart (Caregiver 17, Father, 40 years, ACA)

Another marital strain relates to parenting conflicts arising from the two caregivers thinking and acting differently regarding what is best for their child, especially their teenage children.

He was growing. We ended up arguing over the smallest details, like who should set curfew, how strict we should be. It was frustrating, because we both wanted what's best for him, but we couldn't agree on what 'best' looked like anymore. (Caregiver 1, Mother, 47 years, ACA)

Mechanisms Used to Manage the Challenges Faced by the Caregivers of Children with Autism

To manage the challenges of caregiving, the participants adopted the following strategies: motivation, financial reframing, support systems, religious activities, empathy and intuition.

Caregivers used motivational strategies such as structured play and physical exercises to manage their children's behaviour. These strategies were most common among caregivers with relatively higher levels of education and longer years of caregiving.

He was interested in music and cars, so we got him toy cars. Playing with them calmed him. Sometimes I played music, and he enjoyed it until he got tired and left. (Caregiver 18, Father, 49 years, AACT)

Another strategy used was financial reframing. Caregivers framed their financial sacrifices as investments in their children's development and future. Rather than focusing solely on the money they spend, they emphasised that the benefits of therapy and developmental gains for their children give them more satisfaction. This finding was reported mostly by fathers of CWA. An example is given below:

As a self-employed electrician, where I don't get access to money all the time, but with the little money I got, I used it wisely because I realised that checking the real value of every progress in my son's life brought me joy. I remember when my son made progress in his speech after we had a speech therapist assist us. We could communicate a little with him then. (Caregiver 12, Father, 34 years, ACA)

Support to manage their numerous challenges was another strategy employed by the caregivers who participated in this study. Support came from schools, friends, relatives and peers. Schools offered practical training, and teachers offered tips to try at home, as reported by father 12:

Through the team at the school, I got so much guidance on how to keep her motivated and engaged. At home, I started letting her help me fold laundry or set the table—just small chores—but it's amazing how these little tasks turn into teaching moments for her to learn new words and build confidence (Caregiver 12, Father, 34 years, ACA)

Participants also reported having received diverse forms of support from friends; notable among these is rotating cycles to help with routines, which gave the caregivers some respite.

My best friends had arranged a rotating cycle where they pass by my house to assist with his upkeep weekly and organised a play routine in our living room, and each visit had given me a few precious hours to myself. (Caregiver 5, Mother, 34 years, ACA)

Another form of support reported is from family members. One participant said:

My cousin from my mother's side had driven from Kwahu every two weeks to bring fidget toys, groceries, clothes, among other items and had coached me on simple sign language gestures that he learnt online. (Caregiver 13, Father, 47 years, ACA)

Other forms of support were from peers: "*I had a group of caregivers who also had children on the spectrum. Talking to them refreshed my mind and motivated me to keep going.* (Caregiver 10, Mother, 39 years, ACA), and the community support group;

"*Someone in the community support group shared their experience; I realised that my struggles were not greater than anyone else's. It gave me different perspectives and made me understand that every child's situation is unique"*. (Caregiver 8, Mother, 30 years, TMCH)

Furthermore, faith-based coping was central to many participants. The participants reported relying on prayer, church fellowship, gospel music, and guidance from religious leaders, including Islamic faith, to find strength and peace.

Our church family had been a lifeline, especially during prayer sessions. Their counselling after service reminded me we were not alone. (Caregiver 4, Mother, 39 years, AACT).

A respected Muslim elder often prayed with us and offered guidance. His words grounded me when I felt lost. (Caregiver 20, Father, 41 years, AACT)

It is noteworthy that while some stop participating in religious activities due to stigma, others use religion as a way of coping with the challenges of caring for a child with Autism.

The final strategy employed in this study by the participants, especially mothers, was relying on empathy and intuition to anticipate their children's needs and calm them during episodes.

When I saw him staring at the floor with his shoulders dropped and breathing shallow, I knew he felt overwhelmed. I sat down beside him, took his hand, and gave it a gentle squeeze so he could feel I was there and he wasn't alone. (Caregiver 8, Mother, 30 years, TMCH)

When she was in the middle of a meltdown, I softly hummed her favourite song just a few familiar notes and watched her shoulders relax. Before long, a small smile spread across her face. It really showed me that it's the little things that make her feel safe. (Caregiver 4, Mother, 39 years, AACT).

When it came to intuition, many caregivers, particularly mothers, recounted experiences where their intuition was very helpful in anticipating the needs of their children. An example was given by Mother 3.

When he began pacing back and forth, I realised it was his warning sign of a meltdown. I quickly guided him to his favourite puzzle, which was a mix of some colourful pieces which always caught his attention, and within minutes, he was focused and relaxed again. (Caregiver 3, Mother, 38 years, AACT)

DISCUSSION

This study set out to explore the lived experiences of caregivers of CWA in Accra, focusing on their roles, challenges, unmet needs and coping strategies. Using a phenomenological approach and guided by the Caregiver Identity Theory (CIT), the study provides nuanced insights into how caregiving roles are negotiated within the Ghanaian socio-cultural and economic context. Rather than merely documenting parental strain or public stigma, which have been established in previous Ghanaian literature (Apaah et al., 2023; Oti-Boadi et al., 2022), these findings extend local research by demonstrating how sustained caregiving in a resource-limited setting continuously restructures self-concept, parental identity, and family dynamics over time

A key insight emerging from this work is that caregivers' roles extend far beyond traditional parenting boundaries into formal instructional and clinical domains. The narrative accounts revealed three interconnected caregiving roles: home-based therapeutic support, coaching, and preparing and regulating the child. These roles are not only interconnected, educational and therapeutic in nature, but also extend beyond traditional parental roles. Home-based therapeutic support reflects caregivers' assumption of therapeutic responsibility, as they extend their caregiving role to include the delivery or reinforcement of therapeutic activities in the home environment. The caregivers' engagement in coaching reflects role assumption and role transformation, as they adopt instructional and facilitative responsibilities that extend beyond conventional parenting. Through this process, the caregiver increasingly assumes the role of a coach or teacher in supporting the child's development. Preparing and regulating the child reflects identity transformation because caregivers develop new ways of thinking, coping, and understanding themselves in response to the demands of caregiving. The experience, therefore, does not merely change what caregivers do; it also changes how they perceive themselves and their roles. This finding is consistent with existing studies indicating that caregivers caring for a child on the spectrum frequently assume multiple roles that extend beyond traditional parenting (Leigh et al., 2020; Naidoo & Govender, 2022).

The primary care providers of CWA in Accra who participated in this study used routine daily activities as structured interventions to support emotional regulation, manage sensory sensitivities, and promote skill development, which reflects a broader pattern observed in low-resource settings, where limited access to specialised services compels caregivers to adapt and internalise therapeutic roles (Aderinto et al., 2023; Oti-Boadi et al., 2022). Thus, caregivers of CWA in this study seem to do a lot more than caregivers of children without Autism. Still, the burden of care seems to fall more heavily on mothers than fathers, confirming Acheampong et al.'s (2024) observations of gendered caregiving among caregivers who participated in this study. This could be because fathers are more likely to serve as breadwinners, bearing the financial burden of diagnosis, treatment, medication, and other care-related expenses (Burrell et al., 2017).

These findings about the roles of primary care providers of CWA in this study align with those of Montgomery, Rowe, & Kosloski (2007) CIT's notion of role assimilation, where individuals progressively adjust and internalise the caregiving role as a central part of their identity. Further, this study illustrates how caregivers experienced their expanded roles as burdensome. This conceptualisation highlights how caregivers of CWA in this study adapt these roles within a context characterised by limited institutional support systems and resources (Allotey, 2019), cultural beliefs such as disability being "cursed", "bewitched", possessed", and practices that discriminate and stigmatise persons with disabilities and their caregivers (Appiah & Osei, 2023; Dada et al., 2021; Ensink & Normandin, 2023; Naami, 2014). Stigma challenges the social recognition of caregiver identity by subjecting caregivers to negative judgments, misunderstanding, and social devaluation, thereby limiting the extent to which their caregiving role is acknowledged and validated by others. This study also reveals that misconceptions about disability resulted in separation and/or divorce for some caregivers, specifically mothers. Some men usually leave the marriage, blaming their wives for giving birth to a child with a disability.

Findings regarding the needs of caregivers of CWA in this study centred largely on acceptance, which was challenged by negative societal attitudes and, consequently, contributed to physical, social, and psychological difficulties. (Apaah et al., 2023; Anthony, 2010; Ruparelia et al., 2016). Acceptance is a necessary condition to meet the unique needs of caregivers of CWA, as emphasised by Ruparelia et al. (2016). Lack of acceptance limits the recognition and validation of caregivers' roles, potentially making them feel misunderstood, unsupported, and undervalued in their caregiving identity. Negative societal attitudes in Ghana are deeply rooted in Ghanaians' socio-cultural beliefs and practices, which mostly discriminate against and marginalise persons with disabilities and their caregivers (Appiah & Osei, 2023; Dada et al., 2021; Ensink & Normandin, 2023; Naami, 2014), thereby impacting acceptance and onward adequate support for caregivers of CWA. The finding relating to acceptance aligns with CIT; caregiving is not just a set of tasks; it is a social role that becomes part of the "who I am" concept of the caregiver, and societal recognition of that role serves several vital functions in strengthening a caregiver's identity.

The findings also echo the necessity of systems that engage the entire family rather than focusing solely on the CWA. Caregivers in this study observed that the few existing schools and community programmes often excluded caregivers' needs for inclusive strategies that would equip families with clear guidance, emotional counselling, and practical assistance, ensuring that every member, from mother to father and sibling to guardian, is prepared and supported. These findings partially agree with Genovesi et al. (2023) on inclusive strategies for children with developmental disabilities in Sub-Saharan African mainstream classrooms. The agreement lies in the emphasis on family and support systems in promoting inclusion. Genovesi et al. (2023) focus mainly on educational inclusion, whereas this study highlights broader inclusion that incorporates emotional guidance and practical support for caregivers and families. This further suggests that the unmet needs identified in this study are not only practical gaps in support but also factors that influence how caregivers construct and sustain their identities, particularly in contexts where formal recognition and structured support systems are limited. The cultural norm of collectivism plays a major role in caregiving.

The study further reveals that financial, communication, psychological and emotional exhaustion, and marital challenges are the most pressing challenges of caregivers of CWA in this study. These challenges are consistent with Apaah et al. (2023), who also documented financial hardship and

emotional stress among Ghanaian caregivers. This study further demonstrates that unanticipated expenses, such as property damage during meltdowns, compound financial vulnerability.

Financial demands and emotional pressures associated with caregiving can generate stress, anxiety, exhaustion, worry, and feelings of being overwhelmed, demonstrating the psychological consequences of the caregiver role. Emotional and psychological challenges were expressed by participants from diverse backgrounds through feelings of anxiety, guilt, emotional exhaustion, and isolation. As caregiving demands intensified, caregivers described feeling trapped or overwhelmed by the role. Some sought to redefine their caregiving responsibilities to protect their well-being, while others resisted fully embracing the role in an effort to preserve other aspects of their identity, reflecting what CIT conceptualises as identity negotiation. Notably, these experiences appeared to differ by gender: although both mothers and fathers experienced the demands of caregiving, fathers more prominently described emotional and psychological stress, whereas mothers more often described the practical and day-to-day responsibilities of caregiving. This suggests that the demands of caregiving were experienced and negotiated differently by mothers and fathers, highlighting a gendered dimension of caregiver identity negotiation.

All eight fathers reported being employed alongside their caregiving responsibilities. Burrell et al. (2017) argued that fathers are more likely to serve as breadwinners, bearing the financial burden of diagnosis, treatment, medication, and other care-related expenses.

Communication barriers in this study reinforced feelings of helplessness. These accounts mirror findings by Oti-Boadi, Osei-Tutu and Mate-Kole (2022), who identified communication difficulties as a major stressor for Ghanaian caregivers managing neurodevelopmental conditions of CWA, often linked with guilt and isolation. Gona et al.'s (2016) study reported similar emotional strain due to limited understanding of children's needs. Woodgate, Ateah, and Secco (2008) also argued that caregivers of CWA often described caregiving as living in a world of their own, were miscommunication deepened stress and social isolation.

The final challenge, which was disagreements between caregivers, made it harder to coordinate care, increased stress, and led to inconsistent ways of managing the child. Similarly, co-parenting conflicts are reported in Ghana (Oti-Boadi et al., 2022) and in some African and European countries (Karst & Van Hecke, 2012) as families adapt to changing developmental needs. According to CIT, these external challenges often led to shifts in caregivers' identities as they struggled to balance caregiving responsibilities with societal expectations and personal well-being. CIT explained that caregiving was not a fixed role but rather a dynamic identity that evolved through several phases, from the gradual assumption of caregiving tasks to the point where the caregiving role became central to one's self-concept.

From the findings in this study, as these external challenges persisted, many caregivers struggled to maintain a balance between their caregiving responsibilities and other personal or societal roles. CIT suggests that these struggles frequently led to feelings of identity overload, role captivity, or role engulfment.

To manage their burden of care, the study reveals motivation, financial reframing, social support, religious activities, and empathy/intuition to manage challenges. These strategies mirror coping models in other studies conducted in Africa (Franz et al., 2017; Ruparelia et al., 2016). Social and religious networks provide emotional, practical, spiritual, and relational resources that help caregivers cope with caregiving demands, stress, and challenges, yet the findings in this study underscore a unique intersection of religiosity and cultural attribution. Spirituality was described as both a source of resilience and as a lens through which autism was interpreted, a duality also found in Allotey's 2019 study.

The findings also confirm the significance of culturally embedded coping strategies such as extended family and community support, aligning with CIT's assertion that caregiving identity is negotiated not only individually but also communally. Social support systems such as the extended family and community networks, which could provide a buffer against caregiver stress, were sporadic and unreliable (Oti-Boadi et al., 2022). This study strengthens those claims by documenting how caregivers

reframed expenses as investments to preserve hope, an adaptive psychological strategy less visible in prior Ghanaian and other studies.

The caregiver identity theory highlights how caregivers adapt to their roles by developing coping mechanisms that help them navigate the emotional and practical challenges of caregiving. CIT's emphasis on role adaptation was reflected in these mechanisms. Caregivers of CWA in this study developed a deep intuitive understanding of their children's behaviours, learning to anticipate needs before they were verbalised. This proactive approach illustrated the resilience of caregivers and their ability to adapt to ever-changing demands.

Caregiver Identity Theory provides a useful framework for understanding how caregivers adapt to the demands of their caregiving roles through the development of coping mechanisms and role-related competencies. In this study, CIT's emphasis on role adaptation was evident in the way caregivers of children with autism (CWA) developed an intuitive understanding of their children's behaviours and learned to anticipate their needs before they were verbally expressed. This suggests that caregiving was not merely a set of responsibilities imposed on caregivers but an evolving process through which they acquired knowledge, skills, and behavioural competencies that became integrated into their caregiver identity. Their ability to interpret subtle behavioural cues and proactively respond to emerging needs indicates an adaptation of the caregiver role in response to the unique and changing demands of caring for a child with autism. From a CIT perspective, this adaptation reflects the development of role-based coping resources, through which caregivers become increasingly confident and responsive in enacting their caregiving identity. Thus, the caregivers' proactive responses can be understood not only as evidence of resilience but also as an indication of how sustained caregiving experiences reshape and strengthen their capacity to perform and internalise the caregiver role.

CONCLUSION

The findings demonstrate that caregiving for CWA in Accra transcends traditional parenting, requiring caregivers to assume therapeutic and educational responsibilities in addition to routine domestic roles. Financial, psychological, and communication challenges, as well as the lack of government support, spontaneous familial support, and the lack of acceptance, increase the vulnerability of caregivers of CWA.

The findings have significant implications for policy, practice, and academic research. From a policy perspective, caregivers' experiences highlight the need to integrate autism-related issues into Ghana's social welfare and healthcare frameworks. Their accounts reveal gaps in financial support, therapy services, and specialised education, underscoring the importance of autism-sensitive policies that promote inclusivity and affordability. Addressing these gaps would reduce family burdens and support the holistic development of children with autism.

RECOMMENDATIONS

To address the profound economic burdens faced by families, the Ministry of Gender, Children and Social Protection (MoGCSP) and the Ministry of Health should consider adapting existing social protection frameworks. Specifically, the National Health Insurance Scheme (NHIS) could be expanded to cover essential developmental therapies, such as speech, occupational, and behavioural therapies. Additionally, eligibility criteria for the Livelihood Empowerment against Poverty (LEAP) cash transfer program could be adjusted to explicitly include primary caregivers of children with neurodevelopmental conditions like autism, providing critical financial relief.

In practice, social workers and non-governmental organizations (NGOs) should collaborate to design community-centered autism awareness and empowerment initiatives across Greater Accra. These programs should integrate public education campaigns, stigma-sensitive workshops for educators and healthcare personnel, and accessible caregiver support platforms (helpline or messaging support groups).

Furthermore, given the influential role of culture and faith in Ghana, social workers should partner with traditional authorities and faith-based organizations to co-create culturally sensitive community forums and town hall discussions aimed at dispelling myths regarding autism and promoting social inclusion.

We further recommend training by social workers in collaboration with the government for frontline professionals to ensure appropriate interventions for CWA. For example, teachers require enhanced skills to integrate CWA into mainstream classrooms. Social workers could also provide psychosocial support services to alleviate the emotional and psychological pressures on caregivers and to promote resilience.

To address caregivers' expressed needs for skill development and mutual support, social work practitioners and relevant NGOs could establish structured caregiver skill-training and family-inclusive programs. These initiatives should offer flexible modules covering behavioural management, communication strategies, and caregiver self-care. Incorporating peer-mentorship models where experienced caregivers are paired with newly diagnosed families for ongoing mutual encouragement and knowledge sharing could further strengthen caregiver resilience and informal support networks.

SOURCE OF FUNDING

This study was self-financed

CONFLICT OF INTEREST

We do not have any conflict of interest.

ETHICAL CLEARANCE

We sought and received ethical clearance from the Ethics Committee for Humanities (ECH) at their university with the ethical approval/reference number ECH 053/24-25.

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