A qualitative enquiry into the challenging roles of caregivers caring for children with Autism Spectrum Disorders in Ghana

Jennifer Appah, Vivian Efua Senoo-Dogbey, Deborah Armah, Delali Adwoa Wuaku, Lilian Akorfa Ohene

Background: Autism Spectrum Disorder (ASD) is a condition commonly characterized by challenges with social interaction, repetitive atypical behaviour, and restricted interest. It is estimated that about 1 in 160 children has ASD. Caring for children with ASD is challenging for many parents or caregivers.

Objectives: The study aims at exploring the challenges experienced by caregivers of children with ASD.

Methods: A qualitative phenomenological study was employed using an exploratory descriptive research design. A total of 10 participants were recruited in this study using a purposive sampling technique. Data were analysed using content analysis procedures.

Result: Caregivers of children with ASD face social, financial, and emotional challenges, challenges in accessing health care, education and training of their children in mainstream school settings.

Conclusion: The numerous challenges have implications for the quality of life of the caregivers and their children. The financial challenges and inaccessibility of specialist health services have serious implications for the continuous medical care and monitoring of children with ASD. The challenges in education and training of children with ASD has negative consequences for enrolment and retention of children with ASD in mainstream school settings.

Keywords: Access to healthcare, Autism spectrum disorder, Caregivers, Challenges, Social and emotional

Introduction

Autism Spectrum Disorder (ASD) is a complex developmental condition involving persistent challenges with social communication, restricted interests, and repetitive behaviour (American Psychiatric Association, 2013). Caregivers of children with ASD suffer an array of challenges, as they support children with varied levels of communication and intellectual disabilities (Tathgur & Kang, 2021).

The problem of independence coupled with other social and communication deficits makes caring for ASD-affected children very tough and demanding (Tathgur & Kang, 2021). The nature of the condition is such that caregivers take up additional responsibilities associated with diagnosis, health, behaviour, and assisting their children in everyday life activities. According to Eapen and Guan (2016), problems with the child’s behaviour, lack of sufficient professional assistance, and social perceptions of ASD are other factors that contribute to the stresses associated with caring for children with ASD.

Ayeni-Bepo (2023) recently observed that the challenges faced by caregivers with children with ASD range from mild to profound, and this also correlates with the position of the affected child on the ASD spectrum. This observation is what gives credence to the opinion that the challenges of caregivers of children with ASD are never-ending. Seemingly, meeting the high care demands of affected children requires much time, effort, and patience (Hoefman et al., 2014). Unfortunately, these challenges have been proven to have a significant effect on both the physical and psychological health and well-being of caregivers (Agyekum, 2018; Tathgur & Kang, 2021).

In Ghana, estimates available indicate that the proportion of children below age 14 suffering from ASD is increasing (Ruparelia et al., 2016).
Another study in 2009 specifically reported a prevalence of 0.08% with a marginal increase to 11.4% in 2012 among children with Intellectual Disabilities (Bakare et al., 2009, 2012). These estimates provide evidence that ASD cases are gradually rising in Ghana, and correspondingly, many caregivers are being faced with challenges as they care for their affected children. It has been documented that caregivers of children with ASD in Ghana are stigmatized and hence rely on some documented strategies as coping measures (Oti-Boadi et al., 2020). The situation of the Ghanaian caregiver is compounded by a lack of awareness of the disorder even among HCWs (Sampson & Ashiagbor, 2018). Diagnosis and healthcare for children with ASD in Ghana is also an issue of concern, as there are limited numbers of specialists and facilities in the country to offer care and support to affected children and their families (Salifu & Mate-Kol, 2014; Sampson & Ashiagbor, 2018).

Most of the studies done in Ghana among caregivers of children with ASD focused mainly on the social challenges with little or no emphasis on the psychological, educational and healthcare challenges. These estimates provide evidence that ASD cases are gradually rising in Ghana, and correspondingly, many caregivers are being faced with challenges as they care for their affected children. It has been documented that caregivers of children with ASD in Ghana are stigmatized and hence rely on some documented strategies as coping measures (Oti-Boadi et al., 2020). The situation of the Ghanaian caregiver is compounded by a lack of awareness of the disorder even among HCWs (Sampson & Ashiagbor, 2018). Diagnosis and healthcare for children with ASD in Ghana is also an issue of concern, as there are limited numbers of specialists and facilities in the country to offer care and support to affected children and their families (Salifu & Mate-Kol, 2014; Sampson & Ashiagbor, 2018).

The researchers employed a qualitative explorative research design using a phenomenological approach (Greene, 2004). This approach is used by health and social science researchers to understand the context of the ‘lived experiences’ of people and the meaning of their experiences (Alase, 2017). Hence, this qualitative research design was adopted to examine the real-life experiences of caregivers caring for children with ASD. We utilized this research approach to gain insight into the challenges they face as caregivers of children diagnosed with ASD. The descriptive phenomenological approach is an effective way of identifying subjective experiences that may contribute to the development of new theories, changes in policies, or changes in responses. This approach was chosen for this study due to its flexibility and ‘participant-oriented’ nature that helps to get to the real ‘lived experiences’ of the research participants (Alase, 2017). In addition, since the area of ASD and associated challenges has not been widely explored in Ghana, we chose this approach to allow the participants of the study to contribute to the development of new knowledge in that area of ASD care and support (Hunter et al., 2019).

The study was performed in Ghana, which is an anglophone country in West Africa with a population of close to 30 million people. The country has a social health insurance scheme and offers free basic and secondary-level education to children. The study setting is a regional hospital located in the capital city of Ghana. This facility is the only regional hospital in the region and serves as a referral point for many other primary care facilities. The facility runs specialized clinics for children under 18 years. These clinics include an asthma clinic, a sickle cell clinic, and most importantly, a neurological clinic for children with cognitive impairment, such as cerebral palsy, Attention Deficit Hyperactivity Disorder (ADHD), and ASD who are younger than 18 years. The facility sees about 50–80 cases of ASD and other childhood neurological disorders in a month. The facility also has neurologists, speech and language therapists, occupational therapists and psychologists who support the care and treatment of children with ASD.
Content analysis, which is a subjective interpretation of the content of text data through the systematic classification, coding and identification of themes or patterns, was the analysis procedure utilized in this study. The steps described by Braun and Clarke (2006) guided the analysis of data generated from the in-depth interviews. First, the researchers familiarized themselves with the data to be analysed by listening at least twice to the recorded interview and reading the transcripts to ensure that they corresponded to the audio recording. This was to obtain a clear idea of the data and to possibly have some initial analytical interests or thoughts. The familiarization process also involved reading through the text and taking initial notes. Initial codes were generated and highlighted. This was done by identifying and giving succinct labels in responses based on the research questions. Relevant and interesting data connected to the research question were coded as well. During the coding process, we paid full and equal attention to all retrieved data, whereas vital information that formed the basis of the themes was labelled accordingly. Similar codes were categorized into potential themes with associated quotes grouped. We then reviewed the themes and mapped them out. The identified themes were compared with the research questions, objectives and information available in the literature concerning the challenges of caregivers. To achieve reflexivity in data collection and analysis we employed the phenomenon of bracketing which is a process through which researchers attempt to set aside any aspects of themselves (e.g. knowledge of pre-existing theories, personal views, etc.) that might influence their study (Neubauer et al., 2019).

Ethical issues

Permission was duly obtained from the director of the Greater Accra Regional Hospital as well as the head of the neurology clinic of the institution. The study received ethical approval from the Ethics Review Committee of the Ghana Health Service with approval number - [GHS-ERC 043/06/22]. All participants signed the informed consent form before their inclusion in the study. Privacy and confidentiality are major ethical issues in research that were considered in data collection, data processing, data storage and reporting of findings of this study.

Findings

Sociodemographic characteristics of the participants

All 10 participants were females, direct biological parents of the affected children. The participants were married and within the age range of 31 to 45 years. Out of the 10 participants, nine had a tertiary-level education, and only 1 had a basic school-level education. Nine out of the ten participants were government workers. Out of the 10 children who were diagnosed with autism ASD, two were females, whereas the remaining eight were males. The participants had cared for children with ASD for five years or less. Information on the sociodemographic characteristics of the participants is summarized in Table 1.

Themes and subthemes

The challenges of caregivers living with children with ASD were grouped under two themes: psycho-social and healthcare and education. These two themes produced five subthemes, which also included social challenges, financial challenges, emotional challenges, challenges in accessing health care, and educational and training challenges. The findings are discussed and illustrated with direct quotations in italics. Participants’ identities were replaced with a symbol to ensure anonymity, as indicated in brackets, for example, (R1) for respondent number one. The themes and subthemes identified in this study are summarized in Table 2.

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Sociodemographic characteristics of the participants.</th>
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<tbody>
<tr>
<td><strong>Respondent</strong> <strong>Age</strong></td>
<td><strong>Educational background</strong></td>
</tr>
<tr>
<td>R.1 35</td>
<td>Tertiary</td>
</tr>
<tr>
<td>R.2 37</td>
<td>Tertiary</td>
</tr>
<tr>
<td>R.3 34</td>
<td>Tertiary</td>
</tr>
<tr>
<td>R.4 37</td>
<td>Tertiary</td>
</tr>
<tr>
<td>R.5 34</td>
<td>Tertiary</td>
</tr>
<tr>
<td>R.6 36</td>
<td>Tertiary</td>
</tr>
<tr>
<td>R.7 31</td>
<td>Tertiary</td>
</tr>
<tr>
<td>R.8 39</td>
<td>Tertiary</td>
</tr>
<tr>
<td>R.9 40</td>
<td>Tertiary</td>
</tr>
<tr>
<td>R.10 45</td>
<td>Basic school</td>
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***Age completed in years ** All respondents were married.

<table>
<thead>
<tr>
<th>Table 2</th>
<th>Themes and subthemes derived from the study.</th>
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<tr>
<td><strong>Main Themes</strong></td>
<td><strong>Sub-Themes</strong></td>
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<td>a. Psychosocial issues</td>
<td>1. Social Challenges</td>
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<tr>
<td>b. Healthcare and Education needs</td>
<td>2. Accessibility to inclusive education in mainstream school settings</td>
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....hmm.... in my society, my home is tagged as “home of bad luck". How I wish I could relocate...... but unfortunately, it is our own house so we have nowhere to go. (R5)

Sub-Theme 2: Financial challenge

Participants mentioned the stress on the families’ resources as another challenge. The purchase of prescribed medications, having access to specialists for review and treatment, and the overall care of the child with ASD require extra income, which is not always available. The need for financial support was emphasized by most participants. Even though few participants had good-paying jobs and some even insured their children, they were still very concerned about the high cost of medications, the high cost of specialist care for their children, and transportation costs to and from the hospital, as some may have to travel a very long distance to see the specialist. Participants described the financial hardship as follows:

“Yeah, financially I am stressed. I travel to Accra only for my child to be reviewed by a specialist. Even the cost of the consultation is quite expensive. (R4)

……Madam…. for me is not just about the consultation fee, even the transportation to the hospital and back home is another big problem. (R6).

Even though I have the insurance company giving me a refund sometimes, it is still not enough. (R7)

“Yeah, financially it is true because when I go to Korle Bu consultation and therapies cost me a lot, and transportation to and from the hospital poses great financial challenges. I come from Battor to Accra; it is stressful and stretches me financially, even though my insurance refunds some of the money to me, but it is still not enough” (R.9 F 40 years)

Apart from the therapies I have to go to, schooling alone is a challenge, but we cannot afford speech therapy; for instance, speech therapy is ghc250 for just a session, and we need two or three sessions in a week, making ghc750 in a week. It is a lot of money, so we go as and when there is money available” (R.3 M 34 years).

Subtheme 2: Emotional challenges

The fact that children with ASD present with behaviour patterns that are inconsistent with what is known and considered to be normal by society presents an enormous emotional challenge for parents and caregivers. Caregivers frequently become very different from how other children behave has an enormous emotional challenge. Participants frequently become very sad and emotionally broken. This was described by two participants as follows:

Sometimes, I become emotionally broken when I look at my child, as I expect him to behave like a normal child or act like other children do. (R3)

I become so sad when I go out and see my colleague’s children behaving normally. (R6)

….hmm…. the fact that the father of my son is not involved in the care of the child is another problem altogether that gives me stress and sleepless nights. This act alone makes me feel so emotional. (R5)

Theme 2: Healthcare and Educational Challenges

Subtheme 1: Accessibility to healthcare services

Another major challenge identified in this study was the problem of inaccessibility of healthcare. Participants revealed that the inequitable distribution of specialists and therapy centres in the country poses a great challenge and difficulty to the care of their children. The inequitable distribution of specialists and therapy centres has resulted in caregivers and their children travelling a very long distance to the capital city of Ghana, where there is a concentration of specialist clinic services and therapists. Below is what some caregivers shared about the unavailability of specialist clinics and therapists within their reach.

Sometimes we have to go to Ridge, Legon Hospital or Korle Bu for therapy. It would have been fine if one could have all the sessions at a single hospital that is close and accessible. (R8)

There aren’t lots of facilities that are readily accessible, we wish there were more, the government must get involved in it. (R9)

Yes, yes, I’m in Sunyani, and we do not have a speech therapist, nor do we have an occupational therapist in any of the hospitals around. (R1)

I have to move all the way from Techiman to Accra for those therapies, and that’s where I feel the stress so much. (R10)

Subtheme 2: Accessibility to inclusive Education in mainstream school settings

Special education and training are needed for children with ASD to enable them to reach their potential. The caregivers described how the schools are faced with the difficult decision of choosing the best strategies to use to optimize teaching and learning. The caregivers believe that provision for children with ASD in the general or mainstream educational systems is inadequate.

The high cost of putting children with ASD in special schools is another challenge. Some caregivers are unable to educate their children due to the severity of the disability. The caregivers expressed their sentiments as follows:

“My child needs special training and education, but he is still in the same school with his other siblings who have no problem. That was his first school, and I have not taken him out of that school. There is no special arrangement for him in the classroom. He is just there…. (R2)

I just could not afford the fees meant to be paid at the special school. I had no option but to let him join the mainstream. (R5)

As for me, my girl is still home and not able to start school because she is unable to speak. (R10)

Discussion

The present study, which was performed in the Greater Accra Region of Ghana and aimed at exploring the challenges of caring for children with ASD among caregivers, revealed that most of the participants experienced varied challenges ranging from social, emotional, and financial challenges. Other challenges identified in this study include challenges associated with accessing health care and education and training. Studies performed in India, Kenya, and Malaysia also reported that caregivers with autistic children face numerous challenges (Masaba et al., 2021; Tathgur & Kang, 2021; Zainal et al., 2021).

Caregivers in this study admitted suffering negative reactions and negative attitudes from society, and they felt socially excluded because their children had atypical behaviour patterns (Wesselmann et al.,
Social exclusion is a situation experienced by individuals primarily due to marginalization from society through economic deprivation, social isolation, and fragmentation of social relations (Zhang et al., 2021). Individuals depend upon social relationships to fortify their physical and psychological well-being. The social exclusion reported in this study is worrying since it has been identified and well-documented as a risk factor for poor health and negative effects on the physical and mental health of individuals with health or social challenges (Hämmit, 2019; Ingram et al., 2020). In Ghana, studies have reported the exclusion and marginalization of individuals and families with neurological and mental health challenges (Karr et al., 2020; Mfoafo-M’Carthy & Grischow, 2022), all born from widespread lack of awareness of the causes of these problems and personal beliefs and cultural positions of individuals and society.

This study also found that caregivers suffer emotional challenges in the form of sadness and emotional breakdowns because of unusual or atypical behaviour patterns and a lack of adequate support from significant others. This finding is consistent with the findings reported in a study by Ponte et al. (2012), who reported that caregivers of autistic children experience emotional pain due to the loss of their ideal child (ren) and the disruption of their expectations, as well as shock and/or helplessness after diagnosis. In Ghana, Oti-Boadi (2017) also observed that mothers with children with ASD experience sadness and worry about their children’s future and the enormous stress associated with childcare. The emotional breakdown among Ghanaian caregivers could be compounded by the stigmatization and poor attitudes of the general Ghanaian public towards children with ASD and their caregivers. Studies have indicated that these emotional challenges can have a significant effect on the health-related quality of life and overall well-being of caregivers (Rahman et al., 2021). Caregivers of children with ASD need family support and other forms of social support to be able to build confidence and cope with the stresses of childcare.

Caring for children with ASD poses serious financial challenges to caregivers and the entire family. In this study, the cost of transportation for accessing health services and to pay for specialist care and treatment was the main source of financial stress on the caregivers and the immediate family. Tathgur and Kang (2021), also observed that caring for children with ASD causes a financial imbalance in the immediate family of the affected child.

Another important challenge that was identified in this study is the inaccessibility of health facilities and specialists who have the skills and knowledge to care for children with ASD. The participants revealed that the health facilities that have specialists are found in the nation’s two largest cities, making accessibility to the specialist facilities with their services very challenging, as they (caregivers) had to travel long distances and hours to the nation’s capital to access specialist care for their ASD-affected children. This observation is not surprising because, in Ghana, no specialty area has the needed number of specialists per population (Adanu, 2023), and the majority of the few specialists are found working in the large teaching hospitals in two regions of the country (Snow et al., 2014), resulting in poor access to specialist services, including services for children with ASD. This challenge has consequences for regular follow-up visits and the overall monitoring of children with ASD. The inaccessibility of specialists and therapists may also lead to poor support and care, which can ultimately have negative consequences on the overall development of the child on the ASD spectrum. The inadequate healthcare affects the physical well-being and the overall quality of life of children with ASD (Sutton-clark, 2022). There is the need to equitably distribute the few specialists to all the regions to provide equitable access to healthcare for all who would need specialist services. The study is calling for equitable distribution of specialists, therapists, and treatment centres in the country to ensure geographical access to treatment and care for children with ASD.

In many settings, children including those with ASD are enrolled in school early in their pre-school years. For those with ASD, studies have reported that parents and caregivers face a lot of challenges whilst trying to support their teaching and learning (Güleç-Aslan, 2020; Nah, 2020). This present study also found that caregivers of children with ASD worry about their children not being adequately supported in specialized educational settings for children with ASD in their preschool years. This finding agrees with observations made by Mathur and Koradia (2018) and Sammani et al. (2023) that caregivers felt very worried as they faced numerous challenges in getting their children to be fully supported in specialized education settings and even included in mainstream educational systems. Globally, child protection laws and regulations require children with ASD to be educated in the least restrictive environment and be instructed by teachers who are qualified and sufficiently resourced to support their teaching and learning to help them become the best they can be (Al Jaffal, 2022). A policy on the inclusive education of children with special needs was formulated in Ghana in 2015 and included guidelines for educating children with disabilities (including ASD) (Ministry of Education, 2015). However, unavailability of resources, poor awareness and low level of teacher orientation to ASD as well as lack of supervision and support for teachers have been documented as barriers to the successful inclusion of children with ASD (Karr et al., 2020; Mprah et al., 2015; Nyaaba et al., 2021). These barriers create worry and anxiety for caregivers since they have no assurance that their children will receive the needed support for learning in the mainstream classroom to achieve their learning goals. The lack of assurance and confidence in the child inclusion strategy coupled with social exclusion and stigmatization of the affected children may deter caregivers from enrolling and retaining their children in school (Aruldas et al., 2023; Mulenga, 2019).

**Conclusion**

Caregivers face numerous challenges as they devote themselves to the care of their children with ASD. These challenges include social challenges, financial challenges, emotional challenges, challenges in accessing health care, and educational and training challenges. The numerous challenges have implications for the quality of life of caregivers and their children. For example, social challenges have implications for their level of social interaction and integration. The financial challenges and inaccessibility of health services have serious implications for the continuous medical care and monitoring of the affected child. The financial challenges may also have consequences for the overall economic state of the entire family. Challenges with education and training may affect child enrolment and retention in the general school system. The findings from this study provide the basis to recommend that caregivers be given emotional and social support by family members and members of society. Government and Non-Governmental Organizations, civic society and nonprofit organizations should be more attentive to the needs and challenges faced by caregivers, especially the challenge of inaccessibility of ASD-related specialist services, and the challenges associated with the successful inclusion of children with ASD in mainstream school settings.

**Study limitations**

As this study was qualitative, we were unable to assess the mediating roles of child characteristics and severity of symptoms on the
challenges that caregivers face. Second, the sample distribution was skewed to the female gender. The experiences shared and the challenges reported in this study may be different for male caregivers. This study was not able to assess and establish the inherent differences in experiences and challenges faced by caregivers who had formal education and those who did not. This is because, all the participants in the study were educated.

**Implications for research**

Quantitative research methodologies are needed with the utilization of standard validated tools/instruments to objectively measure the impact of ASD severity and caregiver sociodemographic factors on the degree of challenges faced by caregivers.

**Implications for practice and policy**

Caregivers of children with ASD should have geographical access to specialist health facilities irrespective of where they reside in the country. Health facilities should be structured to integrate specialist care for children with ASD into routine health services for children. Equitable distribution of specialist centres and specialists in health facilities can help relieve some of the stresses associated with caring for children with ASD.

**Research involving human participants, their data or biological material**

The study received ethical approval from the Ethics Review Committee of the Ghana Health Service with approval number - [GHS-ERC 043/2018/10/22].

**Informed consent**

Informed consent was obtained from all individual participants included in the study.

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**CRediT authorship contribution statement**

Jennifer Appah: Writing – original draft, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. Viviana Efua Senoo-Dogbey: Writing – review & editing, Writing – original draft, Validation, Project administration, Methodology. Deborah Armah: Writing – review & editing, Writing – original draft, Supervision. Delali Adwoa Waaku: Writing – review & editing. Writing – original draft. Lilian Akorfa Ohene: Writing – review & editing, Writing – original draft.

**Data availability**

The data used in this is available upon reasonable request.

**Declaration of competing interest**

All authors certify that they have no affiliations with or involvement in any organization or entity with any financial interest or nonfinancial interest in the subject matter or materials discussed in this manuscript.

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