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Research Article

Exploring the Unmet Needs of Primary Caregivers of Autistic Children and Its Implications for Social Work Practice in Ghana

Kofi Awuviry-Newton ¹, **Seyram Ama Kukah**,² and **Kwamina Abekah-Carter** ³

¹College of Sport, Health and Engineering, Victoria University, Melbourne, Australia

²Department of Social Work, University of Ghana, Accra, Ghana

³School of Social Work, Memorial University of Newfoundland, St. John's, Canada

Correspondence should be addressed to Kofi Awuviry-Newton; kofi.awuviry-newton@vu.edu.au

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Caring for an autistic child is fraught with various difficulties and may present unmet needs that could affect the overall well-being of caregivers and children themselves. Consequently, gaining insight into the unmet needs of these caregivers is imperative for the development of targeted and effective interventions to enhance their quality of life and improve their ability to care for their children. Using a descriptive qualitative research design, this study engaged 10 primary caregivers of autistic children in Ghana to understand their unmet needs. Data were collected through in-depth interviews and thematically analyzed. The analysis revealed the urgent need for financial support for primary caregivers, the availability of more special schools, and the services of trained professionals in the field of autism. Caregivers also called for the intensification of public education to help reorient the perspectives of the general population on the autism condition. Based on the findings, some recommendations for policy and practice were made. The implications of the findings for social work are also discussed.

1. Introduction

Globally, the prevalence of autism is increasing, attributed to increased public health awareness, evolving diagnostic criteria, and advances in service delivery [1]. The available evidence estimates that about 1 in 100 children are autistic [2]. This estimate serves as an average, recognizing variations in observed incidence across studies, with well-controlled research consistently indicating higher figures [3]. Data on this issue in the sub-Saharan context, including Ghana, are largely unknown due to issues such as the scarcity of validated tools to diagnose cases [4]. However, some reports suggest that in Ghana, about 38.7% of children under 14 years old are autistic [5]. Autism is a heritable neurodevelopmental lifelong disability [6]. The challenges encountered by primary caregivers of autistic children cannot be overlooked when the focus is on improving the health and social needs of these children.

Primary caregivers, typically family members, play a crucial role in providing daily living support, navigating therapeutic interventions, and addressing the unique needs of autistic children [7, 8]. However, the journey to care for these children could be challenging and can impact the general well-being of caregivers [9]. For example, the complex nature of autism poses a unique set of issues, including communication deficits and impairments of social skills [10, 11]. As primary caregivers navigate these challenges, they often encounter barriers that hinder their ability to provide the best possible care for their children [12].

Globally and specifically in Ghana, disability stigma contributes to the stigmatization of primary caregivers of autistic children [13, 14]. Due to this, some families caring for disabled children may lose their sense of belonging, isolate themselves from society, and may even be forced to blame themselves for the condition of their children [15]. The challenges associated with the care of autistic children are likely to hamper caregivers' functioning, ultimately

affecting the growth and development of the children [16]. Therefore, understanding the unmet needs of primary caregivers while caring for autistic children is crucial for the development of targeted and effective interventions in Ghana to enhance their quality of life and improve their capacity to care for their children.

Existing interventions and laws related to disability in Ghana have primarily targeted persons with disabilities, with little or no focus on the caregivers of these vulnerable individuals [17]. For example, Ghana's Disability Act (Act 715) requires free education, as well as special schools for people with disabilities [18]. Despite this, only a few of these institutions exist in Ghana, and reports further indicate that they are even more expensive to patronize [17, 19]. Therefore, this high cost associated with fulfilling the educational needs of autistic children can present a financial burden to primary caregivers. This lack of commitment by the state or nongovernmental organisations could contribute to insufficient evidence on depth and breadth of the impact of caregiving for autistic children present for primary caregivers.

It is important to recognize that few Ghanaian studies have explored the experiences of caregivers of autistic children, shedding light on the challenges that can hinder optimal caregiving and family stability [19, 20]. Furthermore, some Ghanaian studies report that primary caregivers who are unable to interpret autistic children's communication signals are likely to experience emotional stress [21] and enormous financial pressure in caring for autistic children [15, 19, 22]. The existing evidence is different from our current study because (1) some of these studies broadly researched the impact of caring for children with developmental disabilities without specifically studying autistic children [15, 23] and (2) none of the studies clearly explored the implications of the findings for the profession of social work. Consequently, more studies focusing on understanding the unmet needs of this demographic are needed to increase the depth of knowledge in this research area.

The current study aimed to understand the unmet needs of caregivers of autistic children in Ghana. It is quite unique from previous studies, as it emphasizes the role social workers could play in assisting these caregivers to address their needs and improve their wellbeing in this context. A multidisciplinary field like social work plays an integral role in addressing the varied needs of families with autistic children and in promoting inclusive and supportive environments [24]. Therefore, exploring the unmet needs associated with the care of autistic children is crucial for social workers, as well as policy makers and researchers who pursue the development of targeted interventions and support systems that address the specific demands of caregiving in the context of autism. Additionally, it would contribute to the establishment pragmatic measures to support these caregivers in obtaining these services.

1.1. Theoretical Perspective. Bronfenbrenner's ecological systems theory was adopted to derive an understanding of the unmet needs of primary caregivers of autistic children. This theoretical perspective underscores the essence of understanding people within the context of their environments, as well as how these environments affect them [25]. The ecological systems theory categorizes environmental systems into five, namely, the microsystem, mesosystem, exosystem, macrosystem, and chronosystem [26, 27]. In this study, we focused on the micro, meso, exo, and macro systems, as they were more applicable to the context and findings of the study.

The microsystem comprises the pattern of social roles, activities, and interpersonal relationships, which the individual experiences in a direct setting [25]. For primary caregivers of autistic children, the system may include the family, school, neighbourhood, and other close relationships. Therefore, the relations and dynamics within these microsystems play a vital role in shaping caregiver experiences and their ability to meet the needs of their care recipient. The mesosystem also encompasses social connections, links, interrelationships, and processes between microsystems and how they affect or influence behaviour [28]. Regarding the context of primary caregivers, this can include the relationship between the child and the school or interactions between the caregiver and support services. Any gap within the mesosystem could be a contributing factor to the unmet needs among primary caregivers.

The exosystem focuses on external factors (e.g., community resources, policies, social services) that may indirectly affect an individual [25]. For primary caregivers, the availability and accessibility of interventions, such as financial assistance programs or support services, could influence their ability to meet their needs and address the unique needs of autistic children. The macrosystem entails the broader cultural context, including prevailing social norms, cultural, and religious beliefs, as well as the broader legal and economic systems [25]. These factors could influence the experiences of primary caregivers. For instance, negative stereotypes, as well as unmet service, special school, and financial needs, may be addressed or worsened by the existing macrosystem.

These tenets of ecological systems theory were applicable to the study as they helped to understand and explain the unmet needs of primary caregivers of older people within multiple environmental contexts. They also helped the researchers emphasize the importance of focusing on other factors that shape the caregiver experience other than the autistic child.

2. Methods

2.1. Research Design. This study used the descriptive qualitative research design given its usefulness in providing an in-depth understanding of the meanings people ascribe to

phenomena [29]. Although quantitative or mixed methods designs may be adequately useful for a study like this, we opted for the descriptive qualitative research design because our aim was to seek reality from the narratives of primary caregivers of their experiences and feelings and to produce in-depth descriptions of their experiences [30]. According to Lambert and Lambert [31], the descriptive qualitative approach is appropriate for the current study to provide a comprehensive summary of unmet needs as experienced by caregivers of autistic children. According to Sandelowski [32], the descriptive qualitative approach is eclectic in that it makes use of workable methods from other established approaches such as ethnography, phenomenology, and grounded theory to achieve its aim of ensuring a categorical description of an event as opposed to an interpretive description. Therefore, adopting this design for this study allowed the researcher to understand the unmet needs of primary caregivers of autistic children.

2.2. Study Site and Population. This study is part of a larger research conducted to explore the experiences of primary caregivers of autistic children in Ghana. The study was carried out in the Greater Accra Region of Ghana, which has a population of 4,943,075, which represents approximately 23.3% of the country's population [33]. This study area was selected because it hosts most of the private institutions available that care for autistic children in the country. The specific site where the participants were recruited was the AwaWaa2 Early Intervention Centre. Established in 2006, it is a community-based educational centre that primarily serves the needs of children with communication difficulties. Over the years, the services provided by this agency have expanded and now serve children with other forms of development disabilities, such as autism and cerebral palsy. Given the agency's regular contacts with caregivers of autistic children, we found this setting convenient for easily identifying and recruiting potential participants. Furthermore, upon contacting other agencies, they were the only one willing to assist the researchers to get in contact with some primary caregivers for the interviews.

A nonprobability sampling technique, particularly purposive and snowball sampling, was used to recruit the study participants. The proposed sampling technique was adopted based on the claim that it allows researchers to select participants who are considered competent and knowledgeable about the phenomenon under study [34]. To be included in this study, a potential participant (a) had to be a parent or have a close relationship with the child, (b) have a caregiving experience of at least six months, and (c) must have cared for a child aged 2 years or older (to 17 years) who had been diagnosed with autism for more than six months. Setting the caregiving experience at six months was to ensure that participants had adequate experience and knowledge to contribute to the study. Furthermore, by targeting caregivers of autistic children who were 2 years or older, our study captures the perspectives of caregivers during a crucial period of early development when interventions and support strategies are critical. Additionally, paid caregivers,

caregivers who had no close relationship with their care recipients, as well as primary caregivers whose care recipient was 18 years old (adults) and over, were excluded from the study.

To reach the participants, the first author sent a letter to the head of the AwaWaa2 institution to explain the purpose of the research. She was then given the chance to sit in several meetings organized by the institution where the welfare of the children was discussed with the parents. Sitting in the meeting helped the first author to establish a rapport with the parents, through this means, she also introduced the study to them, and sought their consent to participate. Six participants indicated their willingness, and an appropriate date and time was scheduled with them to conduct the interviews. Four other participants who met the inclusion criteria were also recruited through the snowballing technique. Participants who participated in the study linked researchers to these caregivers and this helped to reach data saturation. Therefore, data saturation was achieved after interviewing the tenth primary caregiver.

2.3. Data Collection Procedure. Data were gathered through in-depth interviews, and this enhanced the richness and depths of our inquiry [35]. An interview guide developed by the researchers was used to collect research data. The questions asked during the interviews revolved mainly around the perceived needs of the participants (e.g., *What are the things you will need to help you care for your child better?*). The interviews lasted between 30 and 60 minutes and were conducted in English, Twi, or Fante, depending on the language the participants could speak and understand easily. All interviews were recorded with permission of the participants.

2.4. Data Handling and Analysis. All recorded interviews and transcripts were saved on a personal computer and uploaded to an e-mail account to ensure that unauthorized persons do not access them. Following the six steps of Braun and Clarke [36], the data accrued from this study were thematically analyzed. The use of these analysis steps provided a systematic framework to analyze and interpret the patterns of meaning within the data gathered. The steps included listening and transcribing the audios to gain insight into the emerging patterns. All interviews were transcribed verbatim and the transcripts in Twi and Fante were translated into the English language. The authors are conversant with these languages; therefore, the translation phase did not pose any major difficulty. The translations were done by the second author and the translations were checked by the other authors for accuracy. The second author then systematically went through the entire data set to generate codes and collated them to develop themes. After this, all the authors met and relooked at these themes and refined into more exact ones to ensure they followed a coherent pattern. Following this, the essence of each thematic area, as well as the aspect of the data they captured, was identified. Lastly, a report of the findings was prepared and presented.

2.5. Ethical Considerations. Researchers obtained the informed verbal and written consent of each participant prior to engaging in the interview. The primary caregivers were also informed that their participation in this study was voluntary, so they could opt out at any time without consequences. Participants were also protected confidentially, and pseudonyms were used to replace their actual names in the research report. To ensure the credibility and trustworthiness of the data, he employed member checking [37]. Thus, the interview transcripts, as well as the summary of the findings, were sent to the participants to confirm if what they said had been captured appropriately. Through this, all participants confirmed that their submissions had been accurately presented. The study also used peer debriefing to consult scholars who were not part of the study to assess its validity and investigate the thinking around the research process. In the next section of the article, the study findings are presented and discussed.

2.6. Positioning the Researcher. In qualitative methods, the researcher is considered an instrument of data collection and analysis, and as a result, the researcher may influence the study findings. To reduce the potential influence in this study, the researcher responsible for data collection (SAK) analyzed all factors that could influence the researcher-participant relationship, and which can affect the researcher's interpretation of the data.

SAK upholds social work values such as nonjudgemental attitude, respect, confidentiality, and genuine interest, and conducted the study under the guidance of these values. These principles helped the SAK understand the issues from the perspective of the study participants. In addition to this, researchers have been trained in qualitative research methods, including qualitative descriptive design, which made researchers competent to analyze the data of participants. The researchers have conducted interviews as well as interpreted and analyzed qualitative data taken from participants of both genders and different ages.

3. Findings

3.1. Characteristics of the Participants. Table 1 summarizes the demographic characteristics of the participants. A total of ten primary caregivers (men, $N=4$ and women, $N=6$) participated in this research. Most of the participants were biological parents ($N=9$) and one was a cousin of an autistic child. The ages of the participants ranged between 32 and 45 years, while the ages of the children under their care ranged between three (3) and eight (8) years. Furthermore, seven (7) caregivers had attained tertiary education, one (1) had attained junior secondary education, and the remaining two (2) had acquired secondary education at senior high school. Furthermore, six (6) of the participants were married, three (3) were divorced, and one (1) was a widower. Also, the majority (8) of them were employed, while the remaining (2) were unemployed.

TABLE 1: Demographic characteristics of participants (study participants $N=10$).

Characteristics of caregivers	<i>N</i>	%
<i>Gender</i>		
Female	6	60
Male	4	40
<i>Age</i>		
32–39	8	80
40–45	2	20
<i>Ethnicity</i>		
Akan	9	90
Ga	1	10
<i>Marital status</i>		
Married	6	60
Divorced	3	30
Widowed	1	10
<i>Occupation</i>		
Employed	8	80
Unemployed	2	20
<i>Age of diagnosis of child</i>		
3–5	9	90
6–8	1	10
<i>Educational level</i>		
Tertiary	7	70
SHS	2	20
JSS	1	10
<i>Religion</i>		
Christianity	10	100
<i>Relation with child</i>		
Parent	9	90
Cousin	1	10
<i>Income level</i>		
100–1,000	3	30
1,500–2,500	4	40
3,000–5,000	3	30
<i>Age of child</i>		
4–6	8	80
7–9	2	20
<i>Gender of child</i>		
Female	4	40
Male	6	60

3.2. Analytical Themes. The findings derived from the analysis were classified under four main themes and together elucidated our understanding of the unmet needs of primary caregivers of autistic children. These include: (a) the need for financial support to pay for health services, (b) the creation of public awareness of autism, (c) the need to establish more special schools, and (d) the need to train more professionals in the autism condition.

3.3. The Need for Financial Support to Afford Health Services. Some participants (8) mentioned that the care of autistic children brought a financial burden in accessing healthcare for their care recipients. They expressed the need for state assistance in the form of monthly stipend, reducing the cost

of medicine, and including some of the medications on the National Health Insurance Scheme (NHIS) to reduce the financial burden. The National Health Insurance Scheme is a Ghanaian healthcare initiative that aims to provide equal access and financial coverage for basic health services to Ghanaian citizens.

A female participant voiced her need for monetary assistance to help cater for her child's needs:

If the government can support us by giving us money, maybe monthly, we will be very happy, as other countries are being given stipends. It will not be bad at all, because parents like us go through a lot financially (Mother, Primary Caregiver 10).

Another participant revealed that if the government could reduce the cost of the medicines their children take, it could help reduce the financial burden on primary caregivers. She said:

Even if the state does not give us money, it can reduce the cost of the medications we buy, so we can also be relieved of some of the financial difficulties we go through. Their medicines are so expensive, and you cannot say that you will not buy them either (Father, Primary Caregiver 8).

A participant also expressed the need for the government to include some of the medicines in the NHIS:

Our health insurance policy in Ghana does not cover the medicines these children take. I even heard that if you go to the hospital and are asked for paracetamol, it is difficult. How much more are these medicines? If they could group the medications covered by the health insurance, it could help (Mother, Primary Caregiver 7).

3.4. Creating Public Awareness of Autism. The study found that all primary caregivers believed that most people did not know about autism and its impact, which led the general population to stigmatize caregivers of autistic children. Therefore, they indicated the need for public awareness of autism and its impacts. A father and a primary caregiver revealed this:

If there is more awareness through education, I believe it will help educate everyone about autism and help reduce the stigma and discrimination we face daily (Father, Primary Caregiver 3).

Another participant explained the need for sensitization among the public to create awareness.

What I would suggest and call for is some awareness creation, sensitization, and public education so that the public does not shy away from these children and think of them as spiritual children. A little more education on the medicines and medical factors surrounding all these. That is what I will call for (Father, Primary Caregiver 8).

3.5. The Need to Establish More Special Schools. Some of the primary caregivers (7) had difficulties in providing the educational needs of their children. They mentioned that special schools were limited and expensive, making access to them difficult.

A male participant mentioned the need to build more special schools:

One thing I realized when we first came from Australia was the limited number of special schools. If the government could invest in building more, it would go a long way toward helping parents (Father, Primary Caregiver 1).

A participant expressed the need for a discounted or free special school system.

I wish there were less expensive special schools so that we could take our children there without having to deal with any difficulties. Or, better still, if the government could make it free like the public schools, we parents would be very happy (Mother, Primary Caregiver 6).

3.6. The Need for Training of More Professionals. Most primary caregivers (8) mentioned trained personnel in the field of autism such as speech therapists and occupational and physical therapists as the main need to help ease the burden on primary caregivers. A participant revealed this:

There is a need for more trained people to help because we realized that most of the people who take care of these children in mainstream schools do not have the necessary training to take care of these children. It causes children to go through a lot of stress. And even teachers themselves may have to face stress to be able to care for them as expected (Father, Primary Caregiver 1).

A mother also revealed the need for more therapists to ease the burden:

I wish there were more therapists to help these children easily. Through Facebook, I met a friend who lives in the US and was telling me how these therapists are all over. So, it's like it even helps children to talk faster. It helps them with the psyche. And she was telling me within 2 years that her son started talking. But here in Ghana, these things are for the rich, you see, and it has already drained our finances. So where would we even get the extra money to continue with this therapy? So, I wish there were more therapists. With that, I think we can afford it because their fees would be reduced due to their availability (Mother, Primary Caregiver 6).

A female participant revealed the need for training more people in the field:

So, with mainstream schools, if the government could give them the required training for teachers, like special schools, that would not be bad. (Mother, Primary Caregiver 7).

4. Discussion

This study provided some information on the needs of primary caregivers of autistic children. It also presents some suggestions, as shared by the participants, to address these needs. In this section of the article, the research findings are thematically discussed and coalesced with extant literature as well as the adopted theoretical perspective.

4.1. The Need for Financial Support. The study found that the need for financial support was crucial for the participants. The expression of caregivers for state assistance reflects the economic burden associated with caring for autistic children, aligning with the findings of other studies [38, 39]. The findings are also in tandem with the theory of ecological systems, emphasizing the need for key stakeholders to address these financial concerns by adopting a comprehensive approach that considers the interconnectedness of the environmental levels of caregivers. For example, access to affordable medication is vital for the well-being of autistic children [40], which indirectly impacts the microsystem through broader environmental influences. Therefore, the formulation, implementation, and promotion of state policies that consider the needs of primary caregivers of autistic children should be prioritized.

Furthermore, the call for monthly stipends from primary caregivers is crucial. If adequate financial support is available, it could positively impact the family's microsystem by facilitating the acquisition of adequate resources for the care of autistic children. It is recommended that the government expands the coverage of the existing social cash transfer program, known as the Livelihood Empowerment Against Poverty (LEAP Programme Ghana [41]) to target and provide financial assistance to more needy primary caregivers of people with disabilities, including autistic children. Such financial support could go a long way in enabling caregivers to provide some descent support to their care recipients.

4.2. Creating Public Awareness of Autism. Our study found that primary caregivers perceived a lack of public awareness of autism. This lack of understanding, they believe, contributes to the stigma and discrimination faced by autistic children. This finding corroborates that of Broady et al. [42], which indicated that low knowledge of autism contributed to stigmatizing experiences. This finding applies to three levels of ecological systems theory. In the microsystem, a lack of understanding about autism can lead to prejudice and labelling of autistic children. This stigma, experienced by caregivers and children, can make it difficult to form social connections [43, 44], affecting the mesosystem. At the exosystem level, social beliefs and public opinions can influence policies and support systems. The call for public sensitization by primary caregivers is one in the right direction. This is because sensitization campaigns could go a long way in clarifying the misconceptions surrounding autistic children and their primary caregivers, thus creating more inclusive and supportive environments.

4.3. Establishing More Special Schools. The primary caregivers involved in this research also highlighted challenges in accessing special schools for their children due to their limited number and high fees. This finding corroborates evidence from Ghana that has indicated a similar issue among caregivers [19]. The finding also suggests the existence of a gap in the availability of educational resources tailored to the needs of autistic individuals. Limited access to special school could strain the relationship between the child, the primary caregiver, and the educational setting (mesosystem). Therefore, addressing this issue may require systemic changes in the educational setting (exosystem). Special schools are educational settings that are known to be effective in understanding the needs of autistic children and assisting with their development [45]. It is therefore important that the state, guided by the provision of the Disability Act (Act 715), which calls for the establishment of special schools for disabled persons, take appropriate steps to improve the availability and affordability of these facilities.

4.4. Training of More Professionals. The study also revealed that there were inadequate trained personnel, such as special education teachers and therapists. Subsequently, this caused stress for autistic children, the primary caregiver, and available professionals. The prevalence of this situation is likely to adversely affect the quality of care and education that autistic children receive (microsystem), as well as the relationship between caregivers, autistic children, and educational institutions (mesosystem). This assertion is also corroborated by findings from some existing studies [46, 47] (e.g., this issue requires urgent attention, and the government, through appropriate policies and initiatives, should make efforts to address this issue). A practical recommendation would be to establish a training program to equip individuals with skills relevant to addressing the educational and therapeutic needs of autistic children. The presence of trained professionals would help to improve the positive development of autistic children [45]. It could further ease some of the care burden on primary caregivers.

5. Implications for Social Work

The findings have some implications for social work. Social workers could play a vital lobbying role in advocating for the establishment of state financial support services geared toward increasing the financial strain associated with the care of autistic children. Furthermore, social workers could advocate for the implementation of a policy that will subsidize or even make healthcare for autistic children free. Such initiatives can go a long way toward reducing the financial stress of primary caregivers of autistic children. Social workers could offer appropriate counselling services that are geared toward helping caregivers adopt relevant coping mechanisms to manage their emotions and stress. In addition, social workers could play a crucial role in educating the public about autism and the adverse effects that stigma has on families of autistic children. This could help reduce

the stigmatization of families with autistic children. Most importantly, social workers must collaborate with primary caregivers to carry out this activity. Since the current Disability Act advocates for the provision of free education and the establishment of special schools for people with disabilities, social workers could, from a social justice standpoint [17], advocate for an intensified implementation of this provision to facilitate the availability of special schools and other support services for autistic children. Lastly, social workers could research to explore the experiences of caregivers of autistic children in various Ghanaian contexts to provide more information on their circumstances and gather findings that could inform the formulation and implementation of policies and programs aimed at addressing the unmet needs of these caregivers.

5.1. Study Limitations. The primary caregivers involved in this research were recruited from one service agency and their opinions may not necessarily reflect those of other caregivers who utilize services from other agencies. Furthermore, the recruitment of participants from a service agency indicates the exemption of primary caregivers who are not in contact with a service agency from this research. The needs of caregivers in contact with service agencies may be different from those of their counterparts who are not in contact with such institutions. Therefore, it is recommended that future studies also engage primary caregivers who are not in contact with a service agency to help gather a more nuanced perspective on the topic. Future studies can explore the impact of caregiver unmet needs on their quality of life and those of their care recipients. It should also explore how caregivers navigate the provision of care amid their unmet needs. It is also important to note that the reluctance of some caregivers to participate in the study accounted for the low number of participants. Some of them stated that they did not get any positive results from previous research studies in which they had participated. This indicates that a sensitization campaign that focuses on the importance of research, as well as expressing perspectives and experiences through research activities, should be prioritized in Ghana.

6. Conclusions

This study has shed light on the current unmet needs of primary caregivers of autistic children. It was found that the availability of financial support to pay the medical expenses of autistic children was important for the primary caregivers. Additionally, caregivers called for the establishment of special schools, the creation of public awareness of autism, and the training of professionals to provide adequate services to autistic children. The findings of this research highlight the need for comprehensive support systems that address not only the needs of autistic children but also those of their primary caregivers.

For example, the state could intensify public awareness efforts to educate people about autism and the need to support families with autistic children. Furthermore, the establishment of specialized schools for autistic children

would facilitate the fulfillment of the educational needs of these children. When more professionals are trained to offer various services to autistic children, it could facilitate their development and relieve some burden on primary caregivers. Furthermore, caregivers themselves need to be supported to improve their ability to provide adequate care and support to autistic children.

Data Availability

The data used to support the findings of this study are available upon reasonable request.

Additional Points

What Is Known about This Topic? (i) Caring for children with developmental disabilities presents challenges for parents and healthcare workers. (ii) The unmet needs of primary caregivers of autistic children are often overlooked by state, policymakers, and other potential stakeholders in Ghana. (iii) The experiences and perspectives of primary caregivers of autistic children can influence the policy and social support services that affect them and their care recipients. *What This Paper Adds?* (i) This study explores the unmet needs of primary caregivers of autistic children. (ii) This study highlights the implications of the unmet needs of primary caregivers of autistic children for the social work profession. (iii) The study makes some theoretical contribution by discussing the findings through the lens of the ecological systems theory.

Conflicts of Interest

The authors declare that they have no conflicts of interest.

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References

- [1] C. Mitchell and N. Holdt, "The search for a timely diagnosis: parents' experiences of their child being diagnosed with an autistic spectrum disorder," *Journal of Child and Adolescent Mental Health*, vol. 26, no. 1, pp. 49–62, 2014.
- [2] World Health Organization, *Autism*, World Health Organization, Geneva, Switzerland, 2023, <https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders>.
- [3] J. Bravo-Benítez, M. N. Pérez-Marfil, B. Román-Alegre, and F. Cruz-Quintana, "Grief experiences in family caregivers of children with autism spectrum disorder (ASD)," *International Journal of Environmental Research and Public Health*, vol. 16, no. 23, pp. 4821–4918, 2019.
- [4] A. Abubakar, D. Ssewanyana, P. J. de Vries, and C. R. Newton, "Autism spectrum disorders in sub-Saharan Africa," *The Lancet Psychiatry*, vol. 3, no. 9, pp. 800–802, 2016.
- [5] Trt Afrika, *The voice to Ghana's autistic children*. TRT Africa, 2023, <https://www.trtafrika.com/lifestyle/the-voice-to-ghanas-autistic-children-12252188>.
- [6] American Psychiatric Association, *What Is Autism Spectrum Disorder?*, American Psychiatric Association, Virginia, USA,

- 2018, <https://www.psychiatry.org/patients-families/autism/what-is-autism-spectrum-disorder>.
- [7] A. Brewer, "We were on our own: mothers' experiences navigating the fragmented system of professional care for autism," *Social Science & Medicine*, vol. 215, pp. 61–68, 2018.
 - [8] S. Srinivasan, A. Ekbladh, B. Freedman, and A. Bhat, "Needs assessment in unmet healthcare and family support services: a survey of caregivers of children and youth with autism spectrum disorder in Delaware," *Autism Research*, vol. 14, no. 8, pp. 1736–1758, 2021.
 - [9] M. K. Tathgur and H. K. Kang, "Challenges of the caregivers in managing a child with autism spectrum disorder: a qualitative analysis," *Indian Journal of Psychological Medicine*, vol. 43, no. 5, pp. 416–421, 2021.
 - [10] D. L. Fewster, P. Govender, and C. J. Uys, "Quality of life interventions for primary caregivers of children with autism spectrum disorder: a scoping review," *Journal of Child and Adolescent Mental Health*, vol. 31, no. 2, pp. 139–159, 2019.
 - [11] D. Laister, G. Vivanti, P. B. Marschik, J. Fellingner, and D. Holzinger, "Enhancement of social communication behaviors in young children with autism affects maternal stress," *Frontiers in Psychiatry*, vol. 12, pp. 797148–797210, 2021.
 - [12] S. K. Kapp, "Social support, well-being, and quality of life among individuals on the autism spectrum," *Pediatrics*, vol. 141, pp. 362–368, 2018.
 - [13] J. S. Agbenyega and S. Klibthong, "Assessing Thai early childhood teachers' knowledge of inclusive education," *International Journal of Inclusive Education*, vol. 18, no. 12, pp. 1247–1261, 2014.
 - [14] H. M. Aldersey, S. Kavira, J. Kiasimbua, W. Lokako, P. Miaka, and L. Monte, "Stigma experienced by families with members with intellectual disabilities in Kinshasa, Democratic Republic of the Congo," *Intervention*, vol. 16, no. 2, pp. 119–128, 2018.
 - [15] M. Oti-Boadi, A. Osei-Tutu, and C. C. Mate-Kole, "Challenges and support needs of parents of children with developmental disabilities (DD) in Accra, Ghana," *Research in Developmental Disabilities*, vol. 128, pp. 104274–104315, 2022.
 - [16] C. Y. Huang, H. C. Yen, M. H. Tseng, L. C. Tung, Y. D. Chen, and K. L. Chen, "Impacts of autistic behaviors, emotional and behavioral problems on parenting stress in caregivers of children with autism," *Journal of Autism and Developmental Disorders*, vol. 44, no. 6, pp. 1383–1390, 2014.
 - [17] D. Doh, K. Awuviry-Newton, and S. Dakey, "Disability and dementia care in Ghana: a political economy review," in *The Routledge International Handbook of Disability and Global Health*, L. Ned, M. R. Velarde, S. Singh, L. Swartz, and K. Soldatić, Eds., pp. 672–685, Routledge, London, UK, 2024.
 - [18] Government of Ghana, *Persons with Disability Act, 2006 Act 715*, Government of Ghana, Accra, Ghana, 2006, <https://sapghana.com/data/documents/DISABILITY-ACT-715.pdf>.
 - [19] C. R. Mbamba and I. K. Ndemole, "I paused my life: experiences of single mothers caring for their autistic children in Ghana," *Journal of Social Service Research*, vol. 47, no. 5, pp. 659–669, 2021.
 - [20] J. Apaah, S. D. Vivian Efua, D. Armah, and L. A. Ohene, "We have challenges': the cry of caregivers with children living with autism spectrum disorders in Ghana," *Social Sciences Research Network (SSRN)*, 2023.
 - [21] H. A. Agyekum, "Challenges of parents with autistic children in Ghana," *Brain Disorders & Therapy*, vol. 07, no. 04, pp. 1–4, 2018.
 - [22] Y. Agyemang, "Assessing the challenges faced in raising children with autism spectrum disorder among parents and healthcare workers in Ghana", M.S. thesis, Lithuanian University of Health Sciences, Kaunas, Lithuania, 2022.
 - [23] J. Asare Bediako, "Raising disabled children: The perspectives of caregivers in-Bosomtwe, Ghana", M.S. thesis, University of Manitoba, Winnipeg, Canada, 2023.
 - [24] C. Mogro-Wilson, K. Davidson, and M. B. Bruder, "An empowerment approach in teaching a class about autism for social work students," *Social Work Education*, vol. 33, no. 1, pp. 61–76, 2014.
 - [25] U. Bronfenbrenner, *The Ecology of Human Development: Experiments by Design and Nature*, Harvard University Press, Cambridge, MA, USA, 1979.
 - [26] U. Bronfenbrenner, "Developmental ecology through space and time: a future perspective," in *Examining Lives in Context: Perspectives on the Ecology of Human Development*, P. Moen, G. H. Elder Jr., and K. Lüscher, Eds., pp. 619–647, American Psychological Association, Washington, DC, USA, 1st edition, 1995.
 - [27] N. A. Khairul Amali, M. U. Mohd Ridzuan, N. H. Rahmat, H. Z. Seng, and N. C. Mustafa, "Exploring learning environment through bronfenbrenner's ecological systems theory," *International Journal of Academic Research in Progressive Education and Development*, vol. 12, no. 2, pp. 144–162, 2023.
 - [28] U. Bronfenbrenner, "Towards an experimental ecology of human development," *American Psychologist*, vol. 33, pp. 513–531, 1977.
 - [29] J. W. Creswell and J. D. Creswell, *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*, Sage Publications, New York, NY, USA, 5th edition, 2017.
 - [30] J. W. Creswell, *Research Design: Qualitative, Quantitative and Mixed Methods Approaches*, Sage, New York, NY, USA, 2014.
 - [31] V. A. Lambert and C. E. Lambert, "Qualitative descriptive research: an acceptable design," *Pacific Rim International Journal of Nursing Research*, vol. 16, no. 4, pp. 255–256, 2012.
 - [32] M. Sandelowski, "What's in a name? Qualitative description revisited," *Research in Nursing & Health*, vol. 33, no. 1, pp. 77–84, 2010.
 - [33] Ghana Statistical Service, *Population and Housing Census, 2010*, Ghana Statistical Service, Accra, Ghana, 2010, https://www.statsghana.gov.gh/gssmain/storage/img/marqueeupdater/Census2010_Summary_report_of_final_results.pdf.
 - [34] J. W. Creswell, A. C. Klassen, V. L. Plano Clark, and K. C. Smith, *Best Practices for Mixed Methods Research in the Health Sciences*, National Institutes of Health, New York, USA, 2011, <https://obssr.od.nih.gov/research-resources/mixed-methods-research>.
 - [35] S. D. Lambert and C. G. Loiselle, "Combining individual interviews and focus groups to enhance data richness," *Journal of Advanced Nursing*, vol. 62, no. 2, pp. 228–237, 2008.
 - [36] V. Braun and V. Clarke, "Using thematic analysis in psychology," *Qualitative Research in Psychology*, vol. 3, no. 2, pp. 77–101, 2006.
 - [37] N. Golafshani, "Understanding reliability and validity in qualitative research," *Qualitative Report*, vol. 8, no. 4, pp. 597–606, 2003.
 - [38] C. N. Marsack-Topolewski and H. L. Church, "Impact of caregiver burden on quality of life for parents of adult children with autism spectrum disorder," *American Journal on Intellectual and Developmental Disabilities*, vol. 124, no. 2, pp. 145–156, 2019.
 - [39] N. Mazibuko, H. Shilubane, and S. Manganye, "Caring for children diagnosed with autism spectrum disorder: caregivers'

- experiences,” *Africa Journal of Nursing and Midwifery*, vol. 22, no. 2, pp. 1–14, 2020.
- [40] A. G. Feroe, N. Uppal, A. Gutiérrez-Sacristán et al., “Medication use in the management of comorbidities among individuals with autism spectrum disorder from a large nationwide insurance database,” *JAMA Pediatrics*, vol. 175, no. 9, pp. 957–965, 2021.
- [41] Leap Programme Ghana, *46TH Payment Cycle of Leap Social Cash grant to All Beneficiary Households across the Country*, LEAP Programme Ghana, Accra, Ghana, 2017, <http://leap.gov.gh/46th-payment-cycle-of-leap-social-cash-grant-to-all-beneficiary-households-across-the-country/>.
- [42] T. R. Broady, G. J. Stoyles, and C. Morse, “Understanding carers’ lived experience of stigma: the voice of families with a child on the autism spectrum,” *Health and Social Care in the Community*, vol. 25, no. 1, pp. 224–233, 2017.
- [43] K. K. S. Chan and C. B. Lam, “Self-stigma among parents of children with autism spectrum disorder,” *Research in Autism Spectrum Disorders*, vol. 48, pp. 44–52, 2018.
- [44] S. Dababnah, W. E. Shaia, K. Campion, and H. M. Nichols, “We had to keep pushing: caregivers’ perspectives on autism screening and referral practices of black children in primary care,” *Intellectual and Developmental Disabilities*, vol. 56, no. 5, pp. 321–336, 2018.
- [45] D. Tilahun, C. Hanlon, A. Fekadu, B. Tekola, Y. Baheretibeb, and R. A. Hoekstra, “Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country: a cross-sectional facility-based survey,” *BMC Health Services Research*, vol. 16, no. 1, p. 152, 2016.
- [46] Y. Ding, L. Y. Yang, K. Salyers et al., “Assessing needs and challenges reported by caregivers and teachers of children with autism spectrum disorders in China,” *Journal of the International Association of Special Education*, vol. 11, no. 1, pp. 4–14, 2010.
- [47] R. Sulek, D. Trembath, J. Paynter, D. Keen, and K. Simpson, “Inconsistent staffing and its impact on service delivery in ASD early-intervention,” *Research in Developmental Disabilities*, vol. 63, pp. 18–27, 2017.