

Examining Sibling Dynamics in Ghanaian Families Affected by Autism: A Qualitative Investigation in Accra, Ghana

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ABSTRACT

The study was a phenomenological study which explored the relationship between siblings without autism and their siblings with autism in Ghana. The family systems theory served as the theory that guided the study. The population of the study entailed siblings and parents of children with autism in Accra. Five siblings and five parents were conveniently sampled from Accra, Ghana, for the study. In-depth interviews were used to collect data. The data were coded and analysed using the thematic approach. The results of the study showed that siblings without autism generally had positive attitudes towards their siblings with autism. This was observed in their willingness to support their siblings when there was a need for such support. It was further revealed that siblings without autism were found to mostly play the role of caregivers to their siblings with autism. Again, the study found that the presence of children with autism in families had some challenging impacts on siblings without autism. These challenging impacts include stigmatisation from members of society, psychological stress and fear of acquiring a disability. From the outcome of the study, it was recommended that professional guidance and counselling sessions should be organized for siblings without autism in families with children with autism. This was to make them well-equipped to deal with the challenges of taking care of their siblings with autism. The study also suggested that future research could focus on exploring the coping strategies used by siblings without autism and their families as they cater to their children and siblings with autism. This study concluded that siblings of individuals with autism in Ghana play very crucial caregiver roles in the lives of their siblings with autism with autism, however they go through psychological stress and social stigma because of their siblings with autism, and therefore require professional counselling on coping strategies.

Keywords: Autism in Ghana, Caregiving Roles in Families, Psychological Impact on Siblings, Sibling Dynamics in Autism, Support and Coping Strategies

I. INTRODUCTION

Autism is a developmental condition characterized by pervasive impairments in social communication, interaction, repetitive, stereotyped behavior, and interests (American Psychiatric Association, 2022). Autism has been found to often combine with intellectual disability, language disorders, sleep disorders, gastrointestinal disorders, sensory integration disorders, attention deficit hyperactivity disorder, anxiety disorders, and epilepsy. However, with each autism diagnosis, there appear to be diverse differences and variations in intelligence, interaction and communication, adaptive behaviours and sensory needs (Kovshoff et al., 2017). Due to the multifaceted complexity of autism, management of the condition requires multifaceted intervention in education, communication, and medical support. Ensuring people with autism live in an environment that meets their complex needs requires excellent commitment from the family (Green, 2013).

Supporting people with autism, therefore, tends to pose challenges to parents, siblings, and the entire family. Green (2013) and Koyshoff et al. (2017) reported that families who raise children with autism mostly experience stress which arises out of social stigmatisation, unavailable support services and resources, financial challenges, and poverty. However, van der Merwe et.al. (2017) noted that siblings of children with disabilities are resourceful and instrumental in serving as role models and helping their autistic siblings learn various skills.



Research by Green (2013) revealed that growing up with a sibling with autism has been found to have positive effects on children without autism. These positive effects include self-perceived competence, increased maturity, and positive psychosocial and emotional development. On the other hand, other researchers Moss et al. (2019); Corsano et al. (2017) have indicated that some children without autism who grow up with siblings who have autism may experience some adverse effects, including behavioural adjustment problems, disturbances with their sibling with autism's behaviour, and distressing emotions such as guilt. These adverse effects perhaps arise from the situation where children who have a sibling with autism in the family are sometimes saddled with responsibilities they are not prepared for, such as keeping an eye on their siblings with autism, dressing them up, feeding and protecting their siblings from bullying due to the sibling's limited social abilities, including difficulty in understanding social norms. These challenges present huge responsibilities for children who have siblings with autism and are expected to be extra vigilant and protective.

In a study conducted with 30 adolescents who had siblings with autism in South Africa, van der Merwe et al. (2017) revealed that adolescents had positive attitudes toward their siblings with autism but had challenges interacting daily with their siblings with autism. The study, therefore, recommended that siblings without disabilities need to be part of support groups where they will be taught how to interact with their siblings with autism.

1.1 Statement of the Problem

In Ghana, there appears to be a gradual identification of persons with autism (Dixon et al., 2015). Nonetheless, there is very little about documented prevalence rates of autism in Ghana, which appears to suggest a paucity of research on the relationship between children without autism and their siblings with autism. Research conducted in Ghana by Appiah and Osei (2023) found that parents of children with autism spectrum disorders experience greater levels of stress, anxiety, and depression.

Another research by Dogbe et al. (2019) focused on the impact caring for children with cerebral palsy had on parents and siblings of the child with cerebral palsy (CP). This study revealed that there was a cordial relationship between typically developing siblings and children with cerebral palsy. However, typically developing siblings showed signs of sadness or depression because of the impact of the sibling with CP on their family life. Having a child with cerebral palsy in the family also brought about a lot of family tension and conflicts between parents of children with cerebral palsy. The impact of having a child with autism spectrum disorders on parents as well as the impact of having a child with cerebral palsy on the siblings and parents as found by Dogbe et al. (2019) and Appiah and Osei (2023) can only be indirectly inferred to understand the impact of having a sibling with autism. The purpose of this study, therefore, was to find out the relationship between siblings without autism and their siblings with autism in Ghana and its effects on the family unit, specifically typically developing siblings.

1.2 Research Objectives

The study sought to:

- i. Find out the attitude of children without autism towards their siblings with autism in Ghana
- Explore the perceived impact of having a sibling with autism in Ghana. ii.

II. LITERATURE REVIEW

2.1 Theoretical Framework

The study on families of children with autism in Ghana was based on many theoretical frameworks that helped to explain the phenomenon under investigation. The study concentrated on the relationship between siblings with autism and their siblings without autism. Among these frameworks were the theories of family systems, and ecological systems. In the context of autism, each of these ideas provided distinctive viewpoints and insights into the intricacies of sibling relationships, familial dynamics, and individual adaptation. The study sought to thoroughly analyse these families' relationships, difficulties, coping strategies, and resilience by integrating various theoretical lenses. This analysis was intended to inform interventions and support services specifically catered to the needs of autistic people with their families in Ghana.

2.1.1 Murray Bowen's Family Systems Theory

Murray Bowen's Family Systems Theory, which proposed that families operate as complex, interconnected systems rather than separate entities, completely changed our understanding of familial dynamics (Bowen, 1978). According to this concept, the acts of others influence and are influenced by the behaviour and feelings of each family member. This hypothesis becomes particularly insightful when it is applied to families where there is a sibling with autism. It clarifies how autism in one sibling can affect relationships, communication styles, and emotional dynamics within the family system by analysing how family members interact. For example, it might show how parents' reactions to the child with autism's needs might affect their neurotypical children's experiences inadvertently,

affecting their sense of self, responsibilities in the family, and mental health. Comprehending these intricacies is crucial to devising interventions and support frameworks that effectively cater to the requirements of every family member.

2.1.2 The Ecological Systems Theory

The Ecological Systems Theory developed by Urie Bronfenbrenner (1979) provides a thorough framework for comprehending the complex factors influencing the personal growth of individuals in families impacted by autism. This approach considers the influence of multiple environmental systems, such as the family, community, and broader societal background. It sheds light on how societal perceptions, cultural values, and the availability of resources influence the experiences of neurotypical and autistic siblings in the instance of Ghanaian households with autistic children. Cultural norms about disability, for instance, can impact the degree of social support that families receive, and the accessibility of community resources like schools and treatment services can differ. Researchers can create culturally appropriate interventions that cater to the demands and difficulties faced by Ghanaian families of autistic children by looking into these environmental factors.

2.1.3 How do these Theories Align with the Current Study?

These theoretical frameworks offer functional perspectives through which to view different facets of the interactions and experiences of children without autism and their autistic siblings within the framework of the current study on families with autistic children in Ghana.

Family Systems Theory integration provides essential insights into the complex dynamics amongst family members, illuminating the complex interplay of behaviours and emotions inside the familial unit (Bowen, 1978). This theoretical lens offers a framework for comprehending how family members are interrelated and how each person's behaviours and emotions influence and are influenced by other family members. The Ecological Systems Theory also extends the range by considering the impact of diverse environmental systems on personal growth and development of an individual (Bronfenbrenner, 1979). The ecological systems theory offers understanding on the influence and impact a sibling with autism has on the life of their typically developing siblings. This offers valuable perspectives on how cultural convictions, societal perspectives, and resource availability influence the lives of siblings without autism and their autistic siblings in Ghanaian households.

2.2 Empirical Review

Numerous studies have focused on the attitudes and behaviours that ordinarily developing siblings exhibit towards their autistic brothers and sisters. According to Johnson et al. (2020), typically developing siblings frequently show their siblings with autism support and positivity. The readiness of youngsters in Ghana who are not autistic to help and support their siblings who are on the spectrum is proof that this phenomenon crosses cultural boundaries (Johnson et al., 2020). Fostering a healthy household atmosphere where siblings feel valued and included is facilitated by such supporting behaviour. Simultaneously, studies conducted in the United States by Smith and Perry (2005) and Jones et al. (2019) demonstrated comparable supportive behaviours and favourable views among siblings of children with autism, underscoring the universality of sibling support dynamics.

Fundamental components of sibling relationships include kindness and empathy, especially when those families are parenting children with autism. According to Shivers (2019), siblings who are usually developing often show compassion and understanding to their siblings who have autism, which fosters a positive family dynamic. Similarly, there were clear examples of non-autistic youngsters in Ghanaian homes showing empathy and providing care for their autistic siblings. These attributes strengthen the ties between siblings and improve the family's cohesiveness by encouraging empathy and understanding (Shivers, 2019; Mokoena & Kern, 2022).

Assuming caring tasks and obligations is a common aspect of sibling relationships, particularly in households with autistic children. Siblings of children with autism take on essential caregiving responsibilities, such as helping with everyday chores and offering emotional support, as Hall and Rossetti (2018) described. A recent study in Ghana revealed that participants took carer roles for their siblings with autism, highlighting a shared responsibility for their wellbeing (Hall & Rossetti, 2018; Appah et al., 2024). This demonstrates the vital role that siblings play in supporting and caring for one another and ensuring the smooth operation of the family. Further highlighting the complex nature of sibling roles in families affected by autism, studies by Smith and Perry (2005) and Jones et al. (2019) discovered that siblings of children with autism frequently acquire excellent leadership and organisational abilities as they negotiate their caregiving obligations.

Sibling relationships are inherently fraught with difficulties and disappointments, especially when one sibling has autism. In a study of siblings without autism living in homes impacted by autism, Martinez et al. (2022) reported sentiments of irritation and worry about their siblings' impairments. In the same way, participants in the Ghanaian study voiced concerns and disappointments about their siblings' skills, especially considering their incapacity to participate in specific activities with them (Martinez et al., 2022). These emotional intricacies highlight the necessity



for family members to understand and support one another as siblings deal with the difficulties brought on by their siblings' autism. Furthermore, compared to their counterparts, siblings of children with autism frequently feel higher levels of tension and anxiety, according to a study by Kuhlthau et al. (2023), underscoring the need for sibling resiliency relaxation training for their mental wellbeing.

Siblings of children with autism also confront stigmatisation and social difficulties because of societal perceptions about people with autism. According to Viswanathan et al. (2022), siblings who are associated with their siblings with autism may face social obstacles and stigmatisation. Likewise, stigmatisation was experienced by typically developing siblings in Ghana, highlighting the wider societal influence of autism views on family members (Viswanathan et al., 2022; Mokoena & Kern, 2022). These results highlight the significance of promoting inclusivity and increasing awareness to safeguard the welfare and social integration of all family members impacted by autism. Moreover, a study conducted by Mokoena and Kern (2022) revealed that siblings of children with autism frequently encounter obstacles when attempting to establish friendships and social bonds outside of their immediate family, underscoring the social difficulties that siblings in autistic households confront.

III. METHODOLOGY

The study employed the qualitative research approach and used phenomenology as the research design. The qualitative approach was used to enable the researchers to explore the inner experiences of children without autism who have siblings with autism in Ghana. This was in line with the viewpoint of Sutton and Austin (2015), who noted that the qualitative research method enables researchers to explore the inner experiences of participants, particularly in areas that still need to be thoroughly researched.

3.1 Research Design

Phenomenology was used as the research design of the study. A phenomenology was used in this study because it enables researchers to describe the lived experiences of research participants in a specific phenomenon. This description consists of what they experienced and how they experienced it (Qutoshi, 2018; Creswell, 2012). The study was focused on finding out the relationship between children without autism and their siblings with autism in Ghana and the effects on the family unit. It was, therefore, imperative to determine the experiences of these siblings through a phenomenological study.

3.2 Population and Sampling

The population of interest for the study was siblings and parents of children with autism in mainstream schools in Accra, Ghana. A total of five siblings and five parents participated in the study. Homogeneous convenience sampling was used to select the study participants. The ages of siblings without autism ranged from nine years to eighteen years. All the participants were selected based on their availability and accessibility during the study and because they shared similar characteristics of being close relatives or caregivers of children with autism. Homogenous convenience sampling is limited to a homogeneous sample concerning one or more sociocultural factors (Jager et al., 2017; Cohen et al., 2007).

3.3 Data Collection and Analysis

In-depth interviews were used for data collection, with an interview guide. This instrument was used in adherence to the recommendation by Fraenkel and Wallen (2009), who noted that interviews are one of the main techniques used to collect data in qualitative research. In the interviews, the researchers included probes and prompts to aid further exploration. The probes and prompts helped explore and develop the participants' views and prevented participants from going off the main line of questioning (Roberts, 2020). The themes in the research questions raised guided the interview questions. In this regard, in-depth interview items were developed to cover the key themes raised in the research questions, and the interviews were conducted in the natural setting of the participants, their homes, or schools. This was done to reflect the reality of life experiences more accurately (Mcmillan & Schumacher, 2001).

The interviews were conducted at the participant's choice of time and location after permission had been sought from the families who identified as having children with autism to elicit their cooperation and assistance. Creswell (2012) maintains that it is essential to respect the site where research takes place. This respect is shown by gaining permission before entering the site. The researchers made a phone call conversation, and a pre-interview visit to the families to explain the purpose of the study to participants and to book appointments with them. Participants were assured of the confidentiality of information to be gathered.

During the interview sessions, the participants were allowed to express their feelings and experiences without undue pressure. The interviews were tape-recorded with the permission of participants and transcribed for analysis. The interviews lasted an average of thirty minutes and consisted of some introductory questions aimed at establishing rapport. The participants were then asked to describe their siblings and were asked what it is like to grow up with



someone with autism. The participants were then asked if they ever worried about their siblings and, if appropriate, what they worried about and what coping mechanisms they employed when they worried about those concerns. Finally, the participants were asked how they envisioned their future and how they envisioned the future of their siblings with autism as well.

Credibility, dependability, transferability, and confirmability were used to ensure the study's trustworthiness, as guided by Lincoln and Guba's (1985) four-factor model to assess trustworthiness. Data triangulation and member checking were used to ensure credibility (Varpio et al., 2017). Using data triangulation, both siblings of children with autism and their parents were participants in the study. This range of respondents was used to gain a holistic picture of siblings' experiences of children with autism. After this, member checking was done by reporting the findings to the participants to ensure accuracy. A detailed audit was conducted by taking records and describing the various steps taken to conduct the research to ensure dependability and transferability as guided by Kyngäs, Kääriäinen & Elo, et al (2020). The study's findings were also compared to other studies to ensure confirmability. Confirmability is the confidence that the results of the study would be corroborated by other researchers (Forero et al., 2018; Kyngäs et al., 2020).

Before the data analysis, the researchers scheduled another meeting with the participants, where the transcripts of the interviews were read to the participants to confirm that the transcripts represented the views they experienced. The data was analyzed using thematic analysis. The transcripts of the interview data were assigned codes to identify responses from the different participants. Fraenkel and Wallen (2009) noted that the first step in coding data was to assign identity numbers to every participant from whom data has been collected. Colors were also used to code the interview data for the categorization of the themes that emerged from each research question (Bogdan & Biklen, 2007; Creswell, 2012; Dogbe, 2015). According to Bogdan and Biklen, coding allows for the categories and patterns emerging from data to be decided in advance. It facilitates the interpretation of smaller units since the analysis begins with the researcher reading all the data to understand the whole. The participants 'verbatim expressions were quoted when reporting the data where necessary.

3.4 Ethical Considerations

This study took ethical factors into account. The researchers obtained the participants' consent to participate in the study to protect their health, safety, respect, and fidelity. The researchers informed participants that collecting data did not require their names or any other personal information. This was done to protect the participants' privacy. Once more, the researchers took great care to protect the participants' rights and ensured they were aware of the study's goal before the interviews. While focusing on listening and providing prompts, the researchers also asked for participants' consent to record comprehensive information on tape during the interview. To obtain ethical clearance for this research, the University of Ghana Ethics Committee for Humanities examined the proposal, assessed the study's ethical implications, and ensured the work adhered to established guidelines. ECH 039/19-20 was the number provided for ethical clearance. It was guaranteed that the participants would have access to the study's results and could contact the researchers with any questions or concerns.

IV. FINDINGS & DISCUSSIONS

4.1 Response Rate

The results and discussion of findings are presented based on the research questions posed for the study.

4.1.1 What attitudes do children without autism have towards their siblings with autism in Ghana?

During the interviews, the researchers sought to understand the participants' attitudes toward their siblings with autism. One theme from the data was used to analyse this research question.

Willingness to help siblings with autism

Concerning the attitudes of children without autism towards their siblings with autism in Ghana, the interview revealed that typically developing children had positive attitudes towards their siblings with autism. The participants also indicated that typically developing siblings were willing to offer assistance to their siblings with autism when needed or demanded.

A sibling remarked:

"Sometimes when my sister tries to call somebody for help, but it is difficult for her, I go and call my mummy for her."

Another sibling also commented that:

"I always try to help my sister when I see that she needs something. For example, when I realize that she wants to remove her dress and it is difficult for her, I go and help her to remove it".

A parent also stated that:



"I always thank God that all my other children are helpful to him. They always try to assist him in doing some petty activities at home. I have also been told that they help him in school during the break time, they check in him."

The participants' comments could deduce that siblings without autism possess some positive attitudes towards their siblings with autism. They are also willing to offer some assistance and support to their siblings.

4.1.2 What is the perceived impact of having Siblings with Autism?

Research question two explored the perceived impact of having a sibling with autism. Some themes were identified from the interviews regarding the impact of having a sibling with autism. They included showing kindness and empathy, stigmatisation, taking up caregiver roles, and fear of siblings imitating inappropriate behaviours.

Showing kindness and empathy

It emerged from the responses of the participants that typically developing children exhibit some level of empathy towards their siblings with autism. This was noted from the response made by one of the siblings, who indicated that:

> "Taking care of my sister has taught me to be kind and patient towards people in need. Because my sister can just spoil something because they are playing or behave in a way that is not so nice, like biting herself or hitting herself, that if I do not have patience, like I will react harshly, but I have to be very patient and tell her to stop what she is doing".

A parent revealed that:

"I see that sometimes her brothers try to show her some empathy. Especially if they are all doing something, and she is the only one who cannot do it. They try to include her like in cooking or doing some house chores and periodically when the go out, they take her along."

Stigmatisation

Another theme that emerged from the comments of the participants was stigmatisation. The participants revealed that typically developing children sometimes encountered some stigmatisation because of their association and relationship with their siblings with autism. A parent commented:

> "My older daughter told me that whenever she goes out with her sister, and they use the 'trotro bus, people stare at them because of how her sister behaves and sometimes warn her not to let her sister sit close to them. This makes her feel embarrassed, so she sometimes ends up picking an argument on the 'trotro' bus or sometimes refuses to go out with her."

A sibling also remarked that:

"My brother does not talk well; he just repeats words and sentences, so the children in the school have been laughing at him and try copying how he talks, so I mostly try to defend him and tell them to stop. I do not like how the children in the school treat my brother, it does not make me happy."

A sibling also revealed that:

"The last time I heard one of the mothers of one of my friends came to the school and saw my friend with me and I sister, later I heard her telling my friend not to be coming close to me or my sister, so that my friend does not get my sisters problem. It pained me a lot because I like my friend very much".

Another sibling stated that:

"Sometimes I am unhappy because my brother cannot do some things. Because of that, I feel bad. Moreover, some of my friends stopped playing with me when my brother comes near to play with us. Some of my school and area friends use my brother's problem to insult me when they are annoyed at me."

Taking up caregiver roles

Again, it was revealed that participants take up the role of caregivers to their siblings with autism. This was observed in the responses made by some of the participants. For instance, one parents indicated that:

> "My daughter mostly bathes her younger sister and goes to school with her; because they are in the same school, she always goes to check on her younger sister and sometimes feeds her during break time at school."

A sibling also stated that:

"I wash my brother's clothes, and I always iron his clothes. If we leave him to iron his clothes, he may end up burning the whole house. He cannot wear his shoes properly, so I always must check on him and help him do his homework."

Another parent revealed that:



"In fact, my older girl does so well that she can take good care of her sister. She will be completing secondary school this year. When she is on vacation, I can leave my child with the problem with her and travel for a few days. I am even planning on letting the two of them go on a trip to visit our hometown. Her sister can take care of her very well, so I will not worry when they go for the trip."

The participants' responses indicate that typically developing children do their best to provide some services to their siblings with autism. They offer such services by assuming the role of caregivers.

Fear of siblings imitating inappropriate behaviours

In terms of the impact of the presence of a child with autism in the family, it was observed from the interview that some siblings without autism were restricted from playing with their siblings with autism due to fear of the typically developing siblings imitating some inappropriate behaviours from their siblings with autism. Some of the participants affirmed this through the following comments: A parent said:

> "My husband had fears that my younger son will begin to imitate his older brother, so my husband tried to restrict their contact with each other, but I refused."

A sibling also indicated that:

"At first when I was small, I was afraid I might also fall sick and behave like my brother. So, sometimes I did not want to play with my brother for a long time. However, now I am no longer afraid of something happening to me. Nothing has happened to me; I love my brother a lot.

From the responses made by the participants, it is evident that some family members and typically developing children in families with children with autism harbour some fears about the possibility of copying some inappropriate behaviours from the siblings with autism.

4.2 Discussion

The study examined the relationships between children without autism and their siblings with autism in Ghana. Specifically, the researchers sought to find out the attitudes of the children toward their siblings with autism and the perceived impact of having a sibling with autism. The results revealed that siblings without autism generally had positive attitudes towards their siblings with autism. It was also revealed that children without autism appeared to show a willingness to support their siblings with autism. These findings are consistent with the outcome of a study conducted by van der Merwe et al. (2017) in South Africa, which revealed that children without autism mostly helped their siblings with autism. The current study also found that having a sibling with autism in the family had some positive impact on siblings without autism. Thus, siblings without autism developed positive social values, such as being more empathetic and kinder towards people. Also, siblings without autism were found to mostly play the role of caregivers to their siblings with autism. These findings reiterated Melli et al.'s (2016) findings, which indicated that children without autism develop self-perceived competence, increased maturity, and positive psychosocial and emotional development because of taking care of their siblings with autism.

On the other hand, having a sibling with autism in the family was also revealed to have some negative impact on siblings without autism. The outcome of this study revealed that siblings without autism sometimes experienced stigmatisation from classmates and members of society, including their friends and peers. It also emerged from the outcome of the research that siblings without autism also went through psychological stress and fears of acquiring the disabilities that their siblings had. This outcome reaffirmed earlier findings reported by Kovshoff et al. (2017), Mazumder & Thompson-Hodgetts (2019), and Mokoena & Kern (2022), who indicated that children without autism sometimes experience stigmatisation, behaviour adjustment problems, worry about siblings' behaviour, guilt and embarrassment, because they were mostly not prepared for the responsibilities of taking care of their siblings. This situation corroborates the viewpoint that having a child with autism poses several challenges to the family system (Kovshoff et al., 2017). This finding is consistent with van der Merwe et al. (2017), who revealed that siblings without autism had challenges interacting daily with their siblings with autism. This outcome reiterated the need for training and counselling to be given to siblings without autism and the entire family of the child with autism to make them well-equipped to deal with the challenges of taking care of children with autism. It is important for individual and group counselling to be organized for siblings of children with autism to empower them with coping skills as they support their siblings with autism.

V. CONCLUSION & RECOMMENDATIONS

5.1 Conclusion

In conclusion, the study observed that siblings without autism who had siblings with autism in Ghana play very crucial roles in the lives of their siblings with autism. Arising from these roles is the situation where siblings without autism experience several effects, both positive and negative. Therefore, it is suggested that future research could be conducted that focuses on exploring the coping strategies used by children without autism and their families



as they cater to children or siblings with autism. Also, families of children with autism in Ghana should be equipped with the relevant competencies required to provide adequate care for their children with autism.

5.2 Recommendations

Based on the study's findings, it is recommended that there must be a counselling center or clinic where periodic professional guidance and counselling sessions be organized for siblings to equip them with coping strategies in supporting their siblings with autism. This would help in alleviating psychological stress and phobias of acquiring the disability and guilty feelings siblings without autism and their families may experience as they support children with autism. Secondly, it is suggested that training programmes be organized for families with children with autism, especially for their children without autism, on effective home-based or educational strategies that they could use in supporting their siblings with autism. Apart from training in educational interventions, siblings without autism must also be trained in nutrition, giving appropriate emergency aid, and knowing how to administer (depending on their age) the medications their siblings with autism need, as most siblings without autism have been found to take up the roles of caregivers. Support groups should be created for siblings without autism, these support groups should hold frequent meetings where members can share their experiences, learn and share success stories, and interact with knowledgeable resource persons who could share their expert advice. Lastly to reduce stigmatisation of siblings with autism, it is important that disability groups organize intensive community and school advocacy and education, at parent teacher association (PTA meetings, community meeting places such as churches and mosques to sensitise classmates and the public about autism to demystify negative societal attitudes, to reduce stigmatisation towards siblings with autism.

Disclosure statement

No potential conflict of interest was reported by the authors.

REFERENCES

- American Psychiatric Association (2022). Diagnostic and statistical manual of mental disorders (5th ed., text rev.). Washington, DC: American Psychiatric Association.
- Appah, J., Senoo-Dogbey, V. E., Armah, D., Wuaku, D. A., & Ohene, L. A. (2024). A qualitative enquiry into the challenging roles of caregivers caring for children with autism spectrum disorders in Ghana. Journal of Pediatric Nursing, 76, 23-29
- Appiah, S. & Osei, E. A (2023). "People keep staring at you in public for no reason": Experiences and coping strategies of parents with autistic children in Accra, Ghana. International Journal of Africa Nursing Sciences, 18(2023) 100536 https://doi.org/10.1016/j.ijans.2023.100536.
- Bogdan, R. C., & Biklen, S. K. (2007). Qualitative research in education: An introduction to theory and methods (5th Ed.). Boston: Pearson Education, Inc.
- Bowen, M. (1978). Family therapy in clinical practice. New York: Aronson.
- Bronfenbrenner, U. (1979). The ecology of human development: Experiments by nature and design. Cambridge: Harvard University Press.
- Cohen, L., Manion, L., & Morrison, K. (2007). Research methods in education (6th Ed). New York: Routledge.
- Corsano, P., Musetti, A., Guidotti, L., & Capelli, F. (2017). Typically, developing adolescents experience growing up with a brother with an autism spectrum disorder. Journal of Intellectual & Developmental Disability, 42(2), 151-161.
- Creswell, J. W. (2012). Educational research: Planning, conducting, and evaluating quantitative and qualitative research (4th Ed.). Thousand Oaks, CA: Sage.
- Dixon, P., Badoe, E. V. & Owusu, V. N. A. (2015). Family perspectives of autism spectrum disorder in Urban Ghana. *Journal of the International Child Neurology Association, 1*(1), 1-7. doi:
- Dogbe, D. S. Q. (2015). Preparing students with disabilities to transition from secondary school to postschool settings in Ghana: Perceptions of teachers and administrators. Doctoral Dissertation, Ball State University, USA.
- Dogbe, J.A., Kyeremateng, J.D. A, Opoku, M.P., Nketsia, W. & Hammond, C. (2019). 'There is family tension, but they understand...': familial and sibling relationships following the diagnosis of cerebral palsy in children in Ghana. Int J Dev Disabil. 10;68(1):35-46. doi: 10.1080/20473869.2019.1573572. PMID: 35173962; PMCID:
- Forero, R., Nahidi, S., De Costa, J., Mohsin, M., Fitzgerald, G., Gibson, N., McCarthy, S. & Aboagye-Sarfo, P. (2018). Application of four-dimension criteria to assess rigour of qualitative research in emergency medicine. BMC health services research, 18, 1–11.
- Fraenkel, J. R., & Wallen, N. E. (2009). How to design and evaluate research in education (7th Ed). New York: McGraw-Hill.



- Green, L. (2013). The wellbeing of siblings of individuals with autism. International Scholarly Research Notices -Neurology. 2013(1), 1–7. Article ID 417194. http://dx.doi.org/10.1155/2013/417194
- Hall, S. A., & Rossetti, Z. (2018). The roles of adult siblings in the lives of people with severe intellectual and developmental disabilities. Journal of Applied Research in Intellectual Disabilities, 31(3), 423-434.
- Jager, J., Putnick, D. L., & Bornstein, M. H. (2017). II. More than just convenient: The scientific merits of homogeneous convenience samples. Monographs of the Society for Research in Child Development, 82(2),
- Johnson, M. T., Williamson, R. L., Casey, L. B., Stockton, M., & Elswick, S. (2020). Sibling relationships when one sibling has ASD: A preliminary investigation to inform the field and strengthen the bond. Children and Youth Services Review, p. 116, 105190.
- Jones, E. A., Fiani, T., Stewart, J. L., Sheikh, R., Neil, N. & Fienup, D. M. (2019). When one sibling has autism: Adjustment and sibling relationship. Journal of Child and Family Studies, 28:1272-1282.
- Kovshoff, H., Cebula, K., Tsai, H.W.J. & Hastings, R.P. (2017). Siblings of children with autism: The Siblings embedded systems framework. Current Developmental Disorders Reports, 4(2), 37-45. doi:10.1007/s40474-017-0110-5
- Kuhlthau, K. A, Traeger, L., Luberto, C.M., Perez, G. K., Goshe, B. M., Fell, L., Iannuzzi, D. & Park, E.R. (2023). Resiliency intervention for siblings of children with autism spectrum disorder: A randomized pilot trial, Academic Pediatrics, 23 (6)1187-1195
- Kyngäs, H., Kääriäinen, M., & Elo, S. (2020). The trustworthiness of content analysis. In: Kyngäs, H., Mikkonen, K., Kääriäinen, M. (Eds), The Application of Content Analysis in Nursing Science Research, (pp. 41-48). Cham: Springer. https://doi.org/10.1007/978-3-030-30199-6 5
- Kyngäs, H., Kääriäinen, M., Elo, S. (2020). The Trustworthiness of Content Analysis. In: Kyngäs, H., Mikkonen, K., Kääriäinen, M. (eds) The Application of Content Analysis in Nursing Science Research.
- Lincoln Y., Guba E. (1985). Naturalistic inquiry. Beverly Hills, CA: Sage.
- Martinez, B., Pechlivanoglou, P., Meng, D., Traubici, B., Mahood, Q., Korczak, D., Colasanto M., Mahant S., Orkin J. & Cohen, E. (2022). Clinical health outcomes of siblings of children with chronic conditions: a systematic review and meta-analysis. The Journal of Pediatrics, 250, 83-92.
- Mazumder, R., & Thompson-Hodgetts, S. (2019). Stigmatisation of children and adolescents with autism spectrum disorders and their families: A scoping study. Review Journal of Autism and Developmental Disorders, 6(2),
- McMillan, J. H., & Schumacher, S. (2001). Education research: A conceptual introduction (5th ed.). New York:
- Melli S., Grossi E., & Zarbo C. (2016). Mental stress in parents and siblings of autistic children: review of the literature and an original study of the related psychological dimensions. United States: Nova Science Publishers, Inc.; 2016.
- Mokoena, N., & Kern, A. (2022). Experiences of siblings to children with autism spectrum disorder. Frontiers in Psychiatry, 13(959117), 1-10.
- Moss, P., Eirinaki, V., Savage, S., & Howlin, P. (2019). Growing older with autism-The experiences of adult siblings of individuals with autism. Research in Autism Spectrum Disorders, pp. 63(1), 42–51.
- Qutoshi, S. B. (2018). Phenomenology: A philosophy and method of inquiry. Journal of Education and Educational Development, 5(1), 215-222.
- Roberts, R. E. (2020). Qualitative interview questions: Guidance for novice researchers. Qualitative Report, 25(9). 3185–3203.
- Shivers, C. M. (2019). Empathy and perceptions of their brother or sister among adolescent siblings of individuals with and without autism spectrum disorder. Research In Developmental Disabilities, 92(103451), 1-9.
- Smith, T., & Perry, A. (2005). A sibling support group for brothers and sisters of children with autism. Journal on Developmental Disabilities, 11(1), 77–88.
- Sutton, J., & Austin, Z. (2015). Qualitative research: Data collection, analysis, and management, The Canadian Journal of Hospital Pharmacy, 68(3), 226–231.
- van der Merwe, C., Bornman, J., Donohue, D., & Harty, M. (2017). The attitude of typically developing adolescents towards their siblings with autism spectrum disorder. South African Journal of Communication Disorders, 64(1), 1-7. a184. https://doi.org/10.4102/sajcd.v64i1.184
- Varpio, L., Ajjawi, R., Monrouxe, L. V., O'Brien, B. C., & Rees, C. E. (2017). Shedding the cobra effect: problematising thematic emergence, triangulation, saturation and member checking. Medical education, 51(1), 40-50.
- Viswanathan, P., Kishore, M. T., & Seshadri, S. P. (2022). Lived experiences of siblings of individuals with autism spectrum disorder in India: An interpretative phenomenological analysis. Indian Journal of Psychological Medicine, 44(1), 45-52.