

Challenges of Parents with Autistic Children in Ghana

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Abstract

This study looks into the challenges that parents with autistic children face in Ghana. The study looks specifically at challenges that being a parent in Ghana entails. Semi structured interviews were used as a form of data collection. Prominent themes the study highlights are the challenges of parents, which was associated with the inability of the parents to have meaningful conversations with their children, the financial burden of taking care of them, and stigmatization of their autistic children as well as themselves. The study was measured against already done work on the topic. From the study, parents major challenge had to do with finances, they explained the various sources in which these expenses were incurred to include transportation, medical bills and school fees. The study brought out transportation as a financial expense because of the where the study was conducted. Parents went on to address how people stigmatize them and their children whenever they are in public. The study also highlighted the challenge of not being able to communicate with their children with disability.

Keywords: Financial; Behavior; Ghana; Social; Children

Introduction

Over the years, autism has seen a widespread throughout the world. Bolte [1] defined autism as “a neurodevelopmental disorder persisting deficits in social interaction across multiple contexts, alongside restricted, repetitive patterns, interests, or activities as manifested by at least two prototypically inflexible behaviors”. Marcus [2] asserted that parents have a hard time with the day to day management of their children. The time that could have been used by the parents for productive activities like working, would have to be used up in taking care of their child, since they cannot do anything by themselves. Although the symptoms of autism tend to last for a long period of time, it is stated that, it is more difficult for the parents to take care of the child when he is younger [3] or when the child is a toddler [4].

Autism is a developmental disorder characterized by difficulties with social interaction, social communication and an unusually restricted range of behaviors and interests [5]. Autism symptoms can be seen by parents or daycare givers, upon the realization that the child is growing differently from his peers [6]. It is a highly delved into topic, hence the numerous changes in the understanding of the disorder [7]. Wolff hinted that, since its discovery, there have been a lot of journals and publications on it, which were mostly funded by parents’ associations. This goes to prove that, parents are always eager to know more about their children with autism and what they can do to help them.

Parents with autistic children daily go through challenges in the upbringing of their children. This point has been implicated by many researches [8], and this study serves as a confirmation of what has been documented. The challenges faced by these parents though may be different still have an underlying problem that is common to them, to which the study has outlined. Parents from this study explained challenges with respect to their financial life, stress in performing their childcare duties, and having to face stigma. The aim of this study is to explore the challenges that parents are facing in their daily activities of taking care of their children. Even though, parents with autistic children go through many challenges, much work has not been done in Ghana to ascertain the particular problem that these parents here are facing. With this, there is the need for a research work that will look at the challenges that parents with autistic children in Greater Accra, the capital city of Ghana goes through in their daily lives.

Methodology

The current study is designed to have a qualitative background. The study developed a semi-structured instrument as a guide in the data collection process. Each interview spanned between fifteen to forty minutes. The study was conducted in the Greater Accra region of Ghana. Majority of the research work was done at PACID, an institution for parents who have children with disabilities and certain parts of Accra.

A total number of thirty-three parents were interviewed for the purpose of this research. Seven of the parents were single parents, and thirteen of them were couples. The ages of the participants ranged from twenty-five years to sixty-four years, while the ages of the children ranged from 5 months to twenty-four years. There were variations in occupation, which included both the formal and informal sectors of the Ghanaian economy. The formal sector is employment in sectors that have regulated economic enterprise or activity and the informal falling under unregulated economic activities. Most of the parents had a high level of education while others had very low level of education. All parents shared their views on the questions that were asked. Most of the participants had one out of their children being autistic, there was however a parent that had male twins being children with autism. The parents were classified as older and younger parents based on the ages of their children. Parents were described as older parents if their children were above 18 years.

Results and Discussions

Theme 1: Financial problems

Taking care of autistic children is expensive since they require extra services and care than children without autism. Parents in the study

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brought out various ways in which taking care of a child with autism was more expensive than taking care of a child without disability. The expenses of parents with autistic children ranges from the normal expenses that parents without autistic children face, with theirs being overly expensive when compared. Järbrink, Fombonne and Knapp [9] asserts that, the financial cost of raising a child with a disability is estimated to be approximately three times greater than the cost incurred by raising a typically developing child. Childcare especially for toddlers is expensive [10]. Parents in this study listed out the extra expenses they had to make because of their autistic children which they did not have to make with their other children without autism. From the study it was realized that the ever-increasing financial burden on the parents was as a result of the medical expenses incurred in the treatment of the child with autism, the transportation cost and the cost involved in educating their children.

Medical expenses: Expensive medical bills are general themes that run throughout what all the parents complained off. They explained that, the routine checkup that their autistic children had to do as part of the intervention plan is very expensive. Sharpe and Baker [11] stated in their article that the probability of financial problems is associated with the use of medical interventions, having unreimbursed medical or therapy expenses, and having relatively lower income. This point has been accentuated in this study. Receiving quality medical attention in Ghana is very expensive. Even though there is the National Health Insurance Scheme, the treatment for autistic children is not included. Parents have to pay for all screening, checkup, and treatment for their children. Autistic children need special treatments for speech, movement and others. A parent remarked that anytime they go to the hospital they do not spend less than three hundred Ghana Cedis on checkup and scans, exclusive of the drugs that would be prescribed. Literature brings out the financial burden on parents with autistic children to be the medical bills of these children, which is a result of their medical treatments from professionals coupled with low income of parents causing financial burden [12]. However, parents in this study both financially endowed and less financially endowed complained about the medical expenses. From observation, this is the leading cost for parents as every participant brought up this point. The issue of medical bills is what is leading most parents with autistic children to seek spiritual intervention instead of the medical intervention; this will stop if something is done about it. The government can help reduce this financial burden by implementing the provision on health in the Disability Act of Ghana (2006). The Act calls for free medical screening and treatment for persons with disabilities. Social workers should therefore advocate for this policy to be fully implemented in the country.

Traveling expenses: Another item that expanded the financial burden of the parents was transportation of the autistic child. Parents shared that they have to always take “dropping” to prevent them from having to face people who were not ready to accept their children or make any contacts with them. For example, a father described an experience he had on a public transport, which led to him resorting to dropping: when going somewhere with him, you always have to take dropping. There was one situation where I boarded the “trotro” with my child to Korle Bu for his routine checkup. Immediately we entered the “trotro”, other passengers started insinuating that even though our rewards or punishments are in heaven or hell, others have started theirs on earth. They were murmuring amongst themselves why God will give someone a child like this? Though they thought they were murmuring I heard it all. After that day, my daughter, [parent referring to researcher] I have decided to pick dropping, to avoid avid statements like these. The

participants explained that the avid behavior people show around their children when they choose public transport left them with no other option than to resorted to picking “dropping”, which is not so with children without autism, where the public would love to play with when they come into contact with them. “Dropping” is a term used in Ghana for picking taxis to and from your destination. Parents commented that taking care of their children with autism is very difficult as they have to always pick private transportation instead of the public one they usually use with their other children. Parents in this study consented to this point, saying that due to stigmatization there is no way they could take public transportation, which is a relatively cheaper means of transporting. In Ghana disability is usually linked to the spiritual and people have various ideas about the causation of the disorder, which usually does not end favorably. Parents would therefore have to pick vehicle even for distances they could easily walk with their children without disabilities. This study brought up this point which is usually not in other studied because of where the study was done: Ghana.

School fees: Parents shared that the school fees of their autistic children is rather expensive. A participant whose children with autism were not in school explained that the school fees required enrolling her children in a special school is very expensive, hence the reason the children are home.

Literature brings out the financial burden on parents with autistic children to be the medical bills of these children, which is a result of their medical treatments from professionals coupled with low income of parents causing financial burden [12]. This is however not totally the case in this study. This is because in Ghana, it can be seen that the number of people who use public transportation are more with few using taxi, but parents with autistic children would have to use taxis because of the discrimination against their children when they get on the public transport, causing them extra financial cost.

The issue of school fees is raised in Ghana because most of the special schools in the country are private, with the only special school specifically for autistic children (Autism Awareness and Training Centre) being private. Even in the mainstream schools, private education is more expensive than the public ones, being a special school will mean more cost, since these schools run a different curriculum and need different studying materials for their students. This show a different cost factor parents with autistic children in Ghana face.

The finding on the extra transportation cost incurred by these parents implies that the attitude the society shows towards a child with autism could increase the financial burden on his or her parents, which is a bad attitude. Societies should therefore be made aware of the impact of their behavior on the family of the child with autism by social workers and encouraged to help these parents by being tolerant. The issue of school fees implies that only the rich can send their autistic children to school. The government must therefore seek to increase the number of public special schools in the country and provide the private schools with materials for their studies to reduce the amount parents have to pay for fees. Social workers can form a fund which will consist of government contribution and private donations that parents with autistic children can rely on. Autism Speaks has a fund where donations are made into to provide financial assistance to parents with autistic children in the US. Ghanaian social workers can adopt this strategy in order to provide assistance to these parents. The issue of medical bills is what is leading most parents with autistic children seeking spiritual intervention instead of the medical intervention; this will stop if something is done about it. The government can help reduce this financial burden by implementing the provision on health

in the Disability Act of Ghana (2006). The Act calls for free medical screening and treatment for persons with disabilities. Social workers should therefore advocate for this policy to be fully implemented in the country.

Theme 2: Discrimination

There is a lot of stigma attached to disability in Ghana [13], and autism is not a left out. Stigma arises from the perception people have about a particular thing. In Ghana, perceptions about disability are not a good one which has led to disability in all aspect of the society. Disability is a term for discrimination against someone because of his or her disability. The stigma that the society showed towards autistic children put a strain on their parents. Parents in this study mainly faced stigma when they sent their children to public gatherings. The study realized that the family of the parents of children who had autism did not stigmatize the autistic children but treated them as members of the family. Their major concern was however raised from the attitudes the society expressed when around their autistic children.

Parents received discouraging and insulting comments when they went out with their autistic children, which caused younger parents especially the mothers in this study to keep their children from the public. A mother shared during the interview that she had to keep her baby in the room because people kept asking her if her baby will ever walk (Participant 6). Another issue of stigma this study realized is the attitude teachers showed to autistic children in mainstream schools. The society as we know always stigmatizes autistic children, but parents in this study brought out that, teachers who are expected to accept all children were also stigmatizing and isolating children with autism. This weighed down parents and made them consider sending their children with mild autism to special schools instead of keeping them in mainstream schools. Isolation of autistic children does not weigh only the parents down but also the children themselves. A mother who her autistic son in a mainstream school had stated that the teacher complained about the child was always found under a table during classes (Participant 9). One may wonder the kind of situation could have caused a child to hide during class hours.

Gray [14] is of the view that parents with autistic children are stigmatized because of their children and this comes in the form of insults from the public. Bayat [15] in his work also stated that parents show pride in their autistic children in public during disability. This study could not hold on the assumptions of Bayat [15] in the sense that, perceptions about autism in Ghana does not allow parents to stand tall defending their children when they are being stigmatized. This implies that for attitudes to change towards stigmatization against children with autism, the basis perceptions Ghanaians have on the disorder will have to change, which can be done as said earlier by social workers holding public education to enlighten the society about the disorder and the need to accept autistic children as a diversity of human beings. Stigmatizing of autistic children by teachers in the mainstream schools is also evident in Ghana because the curriculum for training teachers does not include how to teach children with special needs. They therefore come out not knowing there will be coming in contact with student with special needs, teachers therefore expect all their students to behave the same way. Social workers should therefore advocate for teachers under training to be taught how to handle children with autism and disability in general. This is because, when teachers are made to understand that there is a possibility of them having children with special needs in their classes, they will get accustomed to the idea, and the training will help them to bring the best out of the children with disabilities.

Theme 3: Communication

Communication is the only way people can pass on their ideas to other people. To be able to take a better care of a child, the parent would have to know exactly what is wrong with the child. This is why many parents communicate with their babies though the baby cannot make sense of what the parent is saying. These parents have the hope that after a while their children will be able to talk to them, this is however not the case of parents with autistic children. Autistic children have a problem communicating with others which ranges from mild to severe and this does not go down well with their parents. The study highlights parents' frustration on the inability of their autistic children to communicate with them. Parents are of the opinion that they are not able to provide them with the needed services at the appropriate time because the children cannot communicate to them what they need. Some parents also worried that they could not hold proper conversations with their child as they would have if the child was not autistic. Frith (2003) (4) has talked about the inability of autistic children to communicate, but much has not been done with regards to the effect this symptom of autism has on the parents with autistic children. The parents in this study came up with this challenge because they are of the view that their challenges with taking care of their autistic children would be minimized if the children could communicate what they wanted at a particular point in time. They also fretted on the fact that their children wanted to hold conversations with them sometimes, but they could not understand what they wanted to say to them. Communication cannot be perfected in autistic children, however with constant practice with them the children can pick up signs and symbols that signifies daily routine activities they perform. On this note, social workers should encourage parents to hold frequent communicate with their children, and with time, they could pick up a few words and gestures to help them in communication. Parents must also be advised to get cards with drawings of daily activities on it so that their children can point out the activity they want to perform to aid in communication.

Conclusion

The study looked at the challenge's parents with autistic children in Ghana face. One major challenge parent in this study have with their autistic children, is the struggle to have meaningful conversations with their children. Parents shared that they had a hard time trying to figure out what their children wanted at a particular point in time. Parents also live with the pain of experiencing financial challenges in their daily activities with their autistic children. These financial challenges usually emanate from the cost involved in paying for medical bills of their children, the cost of educating their children as well as the cost of transporting with them. Parents additionally face stigmatization from the public especially when the children are sent to public gathering. Much concern on stigma was raised by parents whose children had mild autism, as such, were enrolled in mainstream school. Issues on the demandingness of autistic children posing stress on their children was also raised as part of the challenges parents in this study are facing.

Limitation of the Study

The main limitations of the study were finding people for the study, it took a lot of time for the researcher to get in touch with parents since a clear cut between developmental disability is not done in Ghana. Also, parents did not want to be part of the research because of the stigma attached to disability in Ghana.

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