

The views and knowledge of parents of children with autism spectrum disorder

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ABSTRACT

Studies so far look at the causes and cure for autism, however, little work has been done on the challenges parents of these children face in their upbringing. This study brought out the challenges that parents with autistic children face as well as the coping mechanisms these parents adopt in their quest to cater for their children. Semi-structured interviews were used as a form of data collection. Prominent themes the study highlights

is 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, stigmatization of their autistic children as well as themselves, and the demandingness of the autistic children. With these problems, parents in the study adapted to their situation by accepting the situation of their wards, depending on God for strength, receiving support and encouragement from some family members and friends, joining support groups, as well as taking leave from work to help their children seek proper medical care.

Key Words: Autism; Neurocognitive impairment; Intellectual disability

Autism symptoms can be seen by parents or daycare givers, upon the realization that the child is growing differently from his peers [1]. Autism Spectrum Disorder is a very common developmental disability which occurs in 1 out of 110 children over the world (Speaks, 2011). [2] The term has been defined by Bolte (2014 pp. 58) [3] 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.” It is a highly delved into topic, hence the numerous changes in the understanding of the disorder [4]. Wolff hints that, since its discovery, there have been a lot of journals and publications on it, which were mostly funded by Parent’s Associations. This illustrates that parents are always eager to know more about their children with autism and what they can do to help them. The numerous works done by researchers over the years have brought about frequent changes in the concept and definition of the term, which recently ended with it being called autism spectrum disorder [4,5]. The major symptoms that autistic children show are atypical social behavior; disrupted verbal and non-verbal communication; and unusual patterns of highly restricted interests and repetitive behaviors [6]. The cause of autism has mainly been linked to either biomedical perspectives or spiritual forces or both [7]. Shen, Dies & Weissman, (2010) as well as Folstein and Rosen-Sheidley [8-10] have emphasized that; there is a strong genetic contribution to Autism Spectrum Disorder. Simmons, Robertson, McKay, Toal, McAleer, and Pollick, (2009) is of the view that autism is environmentally caused. It is however likely that both environmental and genetic factor could be the influential cause of autism [11]. The cause of autism can also be linked to either biomedical perspectives or spiritual forces or both.

Knowing what is wrong with your child will also help with seeking prompt solution for him or her. It is against this backbone that the study looked at the knowledge parents with autistic children had about the disorder and what their perception of the disorder was.

METHODS

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 Parents Association of Children with Intellectual Disability (PACID), an institution for parents who have children with disabilities and certain parts of Accra.

A total number of ten parents were interviewed for the purpose of this research. Four of the parents were single parents, making the participants a total of sixteen parents. There were variations in occupation, which included both the formal and informal sectors of the Ghanaian economy. Both 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. Five of the parents in this study constitute older parents while the other five were categorized as younger parents. Parents were described as older parents if their children were above 18 years. Five of the parents in this study constitute older parents while the other five were categorized as younger parents.

RESULTS

Theme 1: Influential factors

From the interview conducted, it came to light that, all parents shared the fact that autism was a result of a brain malfunction. Though parents could not tell exactly what could have caused the disorder, they were convinced that a brain damage that could have occurred during pregnancy or child birth resulted in the child’s disorder. Participant 6 shared her thoughts as this:

I got to know about it at Korle Bu. From what I know, it is a brain problem that normally happens when the baby is in the womb. It affects the baby’s movement and behavior, which I realized as my baby was growing. (Participant 6)

Though there are different influencing causes of the disorder, most parents were abreast with the fact there is a brain disorder that causes a distinction between the child with autism and other children without autism. The parents were of the view that, due to the damage done to the brain, the children would develop at a slower pace as compared to other children their age.

Brain damage being the major influential factor established, some participant went on to say that the disorder could be acquired from severe jaundice that a child suffers from when he or she is a baby. About four out of ten participants held the view that the disorder was caused by jaundice immediately after birth. A parent articulated this in her own words saying:

I could not breastfeed my baby for three day because I was not producing breast milk. I realized the baby’s eyes were yellow on the third and sent him to Ridge Hospital, where I was told he has jaundice and it had affected his brain so he will not be normal again. (Participant 2)

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Aside jaundice, infections during pregnancy was another influential cause that parents brought up for autism. The parents shared that autism could occur when the mother of the autistic child had an infection while she was pregnant. About three of the participants collectively attested to this, for instance, Participant 8 stated during the interview that;

When I took my daughter to psychological assessment at 37 Hospital I was told her mother picked up infections when she was pregnant. But my wife did not seek treatment so our little girl had to suffer for it. (Participant 8)

Participant 3 was of the view that the disorder can be caused when a mother gives birth at an old age, to which other participants agreed, however, Participant 1, an older parent, said she had realized younger parents are now giving birth to children with autism, as such she doubts that the age matters. The parent for the former explained that, when mothers are above forty years and give birth they are likely to have babies with disabilities in general.

Some other participants think the disorder stems from a spiritual realm. One mother more explicitly shared how her husband had come to believe their children's (Participant 10 has twin boys who are both autistic) problems were caused by her [Participant] mother:

What I know is that it is spiritual. My husband and I kept sending them to the hospital, but they could not cure it, so we started consulting herbalists. (Participant 10)

Theme 2: Parental knowledge on the major characteristics of the disorder

From the data collection, the characteristics of autism spectrum disorder are what made the parents realize that their children had the disorder. Majority of the parents did not have any prior knowledge about the disorder. A parent, who is currently on pension, describes how she was alarmed by the symptoms of the disorder, making her seek for medical attention for her daughter:

I did not know anything about the disorder. My daughter was actually in a normal school, I was told by the teacher that she always tears her book when given work to do, so I had to seek help for her. A woman then advised me to bring my child to New Horizon School. It was at New Horizon that the psychologist told me [mentions child's name] has autism. (Participant 1)

Children with autism from the views of the parents have a slow rate of development unlike children without autism. The intensity is seen in their communication, age at which they start to walk, and how long they take to develop social skills. Parents shared experiences proving that such children usually threw a tantrum when they did not like an activity they have been asked to engage in. This usually occurs when their routine changes. An older mother in the study spoke of the characteristic of the disorder that her child was showing and how far better she had gotten after intervention had been given. She described her experience as

I know their growth takes time, the therapist told me that if it is time for [mentions child's name] to walk and she is not I should not worry it will come with time, and I have come to realize that fact. My daughter for instance walked at three. She is all better now, her tantrums have gone down, because she could be a bit hyper but now thankfully it has gone down. (Participant 3)

The major source of information for parents in this study was their doctors, with a few looking the disorder up on the internet for more information as to how best they can help their children. For instance, one mother explained that, there was a lot of information on the disorder now, so she usually researches on the disorder (Participant 3).

DISCUSSION AND CONCLUSION

The study findings revealed that many parents had no prior knowledge of the disorder. Parents gained interest in information about the disorder after their children were diagnosed with the disorder. From the study, all participants in order to gain information on the disorder usually relied on their doctors and other medical practitioners as their main source of information. However, three out of the ten participants conducted research on the disorder to add on to the information their doctors provided them. These three participants shared that, researching about the disorder helped them know more about the disorder and how to handle situations that arise when dealing with their autistic children. Most parents in this study joined parental associations to help them deal with their situation. From literature, it was found out that parents with autistic children when they find out about their children's condition rely on doctors as their main source of information [12], with Wolff also asserting that parents of autistic children all over the world gather to form associations that provide them with information about the disorder and how they can deal with it. The findings of this study agrees with Barake, et al. on their assertion that parents relied on doctors as their

source of information on their children's disorder, however, parents in this study also relied on other medical professional who attended to their autistic children, as well as look through the internet for other sources of information that may help them with their situation. Most participants were part of PACID, an association for parents with children with disabilities which is in line with what [4] suggest, they however joined these associations not only to get information on the disorder, but used it as an avenue where they could freely open up and share their problems without judgment from their audience. This study has proven the fact that, with emerging technology and more information being provided on the internet, parents can freely peruse new information that their doctors are not able to provide to them. They can also make enquires on their own anytime they need clarifications on issues instead of going to the hospital. Also, parents in the study did not have any prior knowledge about the disorder, which implies that seeking for intervention plans for their children would be delayed, where as if they knew of the disorder they would have started intervention right after birth.

This study also moved towards what Anthony [7] has said about the potential causation of autism, which implies that, Ghanaians in general see disorders being caused either from a medical perspective or a spiritual perspective, not paying much attention to their environment or genetics. The study goes on to imply that Ghanaians can have a medical perspective on the cause of an illness, just as Anthony has pointed out, but will rather seek for a spiritual intervention plan, because they believe more in the spiritual than in the medical. This is evident in the increase in number of prayer camps in Ghana that focus on healing as opposed to their main objective of praying.

It therefore behooves social workers to educate the public on the disorder and what they should look out for in their children during their early stages for symptoms of the disorder. The government in helping with early diagnosis of the disorder should implement the Disability Act particularly sections 34 and 35 that targets periodic screening of children in order to detect, prevent and manage disability as well as the establishment and operation of health assessment and resource centers at each district as a means of providing early diagnostic medical attention to mothers and infants.

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