PSYCHOLOGICAL IMPACT OF PARENTING CHILDREN WITH AUTISM IN TENDER BRAIN REMEDIAL CENTRE, OREDO LOCAL GOVERNMENT AREA

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ABSTRACT

The study examined the psychological impact of parenting children with autism in tender brain remedial center, Benin City, Edo State, Nigeria. Literatures relevant to the study were reviewed to through more light on the topic. The study adopted the explorative design that understudied the strategies of coping with autistic school children. A total of 12 respondents were interviewed due to the Population of the study. First hand data was gotten and analyzed. The result revealed that more mothers participated in the study, which was due to the fact that they are closer to the children and also the home makers. The study recommends that there is an urgent need for social support which must be re-emphasized in order to reduce the anxiety parents might feel about their child's welfare and extra measures need to be put in place to ensure that the financial. Furthermore, there should be heightened societal awareness, especially through the mass media on autism and its symptoms in children. This awareness should be aimed at making the society more responsive to the needs of autistic children and their caregivers in order to suppress any form of embarrassment as a result of the child's disability.

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ARTICLE HISTORY

Received: 19/06/2023 Accepted: 05/09/2023 Published online: 25/10/2023

KEYWORDS

Autism, children, impact, parenting, Psychological



Introduction

Children are a source of joy to the family and healthy children bring joy to the society. However, parenting a child with autism can be very stressful and tasking. The family is a primary social group that plays a role in the formation and development of the individual and in the affective, cognitive, and psychological domains. Nevertheless, there is a change in the entire family cycle when a child is born with a disability because, there will be a need to rearrange and add new expectations for new realities to emerge (Estes, Olson, Sullivan, Greenson, Winter, Dawso,n and Munson, 2012).

Autism diagnosis not only changes the life of the child diagnosed, but also that of family members. Parents of autistic children have to bear a lot of stress owing to complicated therapy schedules, home treatments, and juggling job responsibilities and family commitments. There is also financial stress coming from the expensive therapies and treatments. Parents experience worry and concern that their children may be potentially harmed because often, they cannot communicate verbally and are highly vulnerable. Such stress may affect family life in various adverse ways. Parents of autistic children need to meet the needs of their children, as well as address the needs of their families. Coping with the stresses involved in being parents to an autistic child can strengthen families and marriages, but this requires a great support system and a lot of hard work.

Literature Review

Mothers and fathers reported more stress when having a child diagnosed with autism as opposed to parents who have children with Down syndrome and parents of typically developing children (Meadan, Halle, & Ebata, 2010). With the causes of autism still unknown, parents experience blame for their child's autism. Some fathers may blame the autism on their wives (Neely-Barnes, Hall, Roberts, and Graff, 2011). This was once defined as a refrigerator mother. The term "refrigerator mother" was invented by Leo Kanner. It was used to describe a parent who was seen as cold and uncaring and as

a result, traumatized their child causing them to retreat into autism. Each family handles the vision of their child differently. Just as the spectrum varies, so does each family's experience. Upon hearing their child's diagnosis, one study found that in parents, "52% felt relieved, 43% felt grief and loss, 29% felt shock or surprise, and 10% felt self-blame" (Neece, Green, and Baker, 2016). Parents often experience stressful situations upon the initial diagnosis that relate to their child's behavior, adapting to this new lifestyle, and the complexity of finding access to the appropriate services useful to the family (Neece, et al., 2016). Below are several ways families with children of ASD or autism are affected.

Emotional Impact: Autism brings with it a lot of emotional ups and downs for the family members, which start prior to the diagnosis and continue indefinitely. A study in the journal Pediatrics states that mothers of children with ASD often rated their status of mental health as fair or poor. Compared with the general population, their stress level was much higher. Besides having higher stress levels, children may experience the following:

Embarrassment over their child's behavior in public, Feeling socially isolated, Frustration at the difference between the <u>parenting</u> experience they are having and the one they had envisioned, Guilt from thinking that they may be responsible for their child's challenges, Despair because of the disorder's incurable nature, Resentment of their child and guilt due to the resentment, Anger at themselves, doctors and spouse, Relief because there's a name for their child's challenges and Feeling of overwhelm.

Marital Impact: A study indicated siblings ages 7-20 who have a brother/sister diagnosed with ASD mentioned feelings of embarrassment. Another study confirmed these results with siblings reporting the negative aspect of having a brother/sister with autism is feelings of embarrassment (Orsmond, Kuo and Seltzer, Seltzer, 2009). A child with autism also influences his or her neuro-typical siblings. The siblings undergo many of the stresses faced by the other family members. Moreover, parents may not be able to provide them with full support, as they are overwhelmed meeting the needs and demands of their autistic child. In families having children with ASD as well as typically developing siblings, a more intense form of sibling rivalry can be seen. The

autistic child's need for more attention and time may cause siblings to feel left out and resentful. However, most families can surmount these challenges if they have control over the other factors leading to stress.

Financial Impact: Families with autistic children often face a huge financial burden. Expenses for autism treatment and therapies are not covered by most private health insurance, and they are quite expensive. The bills parents incur for medications and office visits often lead to massive financial debt. According to a study featured in Pediatrics, families with an autistic child underwent an average loss of 14 percent in their entire family income. Working full-time becomes very tough for both parents. So, the family has to bear the increased expenses, in spite of having a lowered household income. Full-time employment is important for many parents for providing health insurance, and so, losing a full-time job may dramatically affect the family's financial condition.

Perhaps the first step to sorting out the difficulties arising in families due to autism understand the way it affects family members and relationships. Family counseling can help parents deal with communication and marital problems, whereas psychotherapy can help deal with autism's emotional impact. Family members and parents can also consider joining support groups where they can meet other parents with autistic children. Parents must take care of themselves too, besides caring for their children with ASD, as to become better caregivers; they must care for themselves (Edwards, Brebner, & McCormack, 2016).

2.4. Some Early Signs of Autistic Learning Disabilities (ALD)

According to Preece (2014), children with Autistic learning disorder may manifest an array of symptoms which includes difficulties in math, reading, writing, spelling, comprehension, and memory and reasoning skills. Hyperactivity, inattention and perceptual coordination may also be associated with learning disabilities but are not learning disabilities themselves, hence disabilities include; Reversals in writing or reading, Difficulty discriminating size, shape, colour, Poor performance on group tests, Difficulty with temporal (time) concepts, Poor visual – motor coordination, Difficulty

copying accurately from model, Difficulty with tasks requiring sequencing, Overly distractible, difficulty concentrating, Slowness in completing work, Poor organizational skills, Easily confused by instructions, Often obsesses on one topic or idea, Poor short-term or long-term memory, Impulsive behavior, lack of reflective thought prior to action, Low tolerance for frustration, Poor peer relations, Poor social judgment, Lags in developmental milestones (e.g. motor, language), Behavior often inappropriate for situation, Overly excited during play, Failure to see consequences for action, Lack of hand preference or mixed dominance, Disorganized thinking and Overly gullible; easily led by peers.

2.5. Professional Help for Parents Coping with Autistic Children

The extent to which formal professional support is available, valued – and indeed, how much it helps – appears to be highly variable (Edwards et al., 2016; Preece, 2014), with parents reporting considerable difficulties accessing such support (Altiere and Von Kluge, 2009; Meirsschaut, Roeyers, & Warreyn, 2010; Preece, 2014; Woodgate, Ateah, & Secco, 2008).

Interventions/Treatments

There are several services and approaches to utilize when working with a child diagnosed with autism. One study found that parents of children diagnosed with ASD were in need of consistent therapy with their children as well as assistance from knowledgeable professionals. Another study indicated speech therapy being the most common service for children diagnosed with autism as 87.3% of families utilized this source followed by occupational therapy with 67.5% of families utilizing this source. This study also indicated that 45.6% utilized behavioral management programs while 42.7% utilized learning strategies and study skills assistance (MacFarlane and Kanaya, 2009).

Further studies indicated that in school, 83% of families used speech and language therapy, 64% of families used occupational therapy, 28% used social skills training, and 11% used physical therapy. Findings in this study indicated that outside of school, 57% of families used care from family or friends, 12% used special summer camp, 11% used respite care and only 1% used residential placement. Twenty-eight percent of these families used a case manager and only 8% used a behavioral specialist. Forty percent of these families used medication, 10% used supplements only and 8% used a combination of the two. Picture exchange communication was used by 23% of families outside of the home and 21% used sensory integration therapy outside the home. Thirty percent of families used parent support groups and only 4% used family counseling. Only 1% of siblings used support groups (Thomas, Morrissey, and McLaurin, 2007).

Some primary places in which parents can receive support include support groups, other parents of children with autism, social workers, occupational therapists, special education teachers, and other mental health professionals. One study indicated that social support from friends, family, and spouses reduced depression and increased the well-being of parents of children with autism.

Spousal support was indicated as the most beneficial source of support as they provide respite, divide household responsibilities, and share disciplinary roles for one another. Another study indicated respite care to be a significant support in coping with autism. According to Chan and Sigafoos (2001); Harper, Dyches, & Harper, (2013), respite support refers to short breaks in the United Kingdom. Preece and Jordan (2007) is also valued by parents but have been suggested to be insufficient to meet the growing needs of autistic children and their families (Carlin and Cramer, 2007).

Also, effective intervention is video modeling. Video modeling is used to target various behaviors in different aspects of functioning such as language, social behavior, play, academics, and adaptive skills in a child diagnosed with autism. The purpose of this intervention is to facilitate observational learning. The absence of external support can have significant implications for parents' well-being. The lack of support to help manage stress can negatively impact parents 'self-efficacy (Kuhn and Carter, 2006), decreasing parents 'perceived ability to cope, increasing the impact of stressors, and

potentially leading to an increased sense of isolation and a further reduction in their experience of social support (Donenberg and Baker, 1993; Schaaf, et al., 2011).

Respite Support (R.S) is a service in which another adult assumes the role of the parent for a child diagnosed with autism, giving the natural parents a break. This has been found to reduce stress levels in both parents (Meadan, et al., 2010). One study indicated social stories to be an effective tool when working with children diagnosed with autism. This showed improvement in classroom behavior for students following social stories (Chan, et al., 2011). Social stories are short narratives used to promote positive behavior. The language used in social stories is simple and emphasizes what to do in certain situations after being provided with descriptions of the environment. Social stories allow children diagnosed with ASD to learn social skills, deplete bad behavior while improving communication skills and learn self-help skills.

In some countries, these concerns have resulted in efforts to enact laws mandating early diagnosis and intervention; the provision of free, appropriate services and education for children with autism; acceptance and inclusion of such children in mainstream or regular schools; and training of special education and regular teachers on best practices in meeting the goals of each child's individualized education plan. Self-stimulating behaviors such as bouncing, rocking and covering the ears are all common in children diagnosed with autism. Although these methods can be self-stimulating for them, they can also interfere with the child's ability to attend, communicate, learn, and interact. It is important for sensory interventions to be implemented in order for the child to focus and learn new skills. Sensory interventions also allow the child to register and regulate sensory stimuli responses which will prevent over-reactive or under-reactive behavioral responses from occurring (Case-Smith, Weaver, & Fristad, 2015).

In January 2007, a group of parents and professionals formed Autism Associates, whose primary goal was to campaign for early detection, appropriate diagnoses and intervention for ASD. Autism Associates is also assisting with the formation of CADD (Centre for Autism and Developmental Disabilities) which will focus on advocacy, research, and training. There is a need for specialized services such as speech and

occupational therapies, and there is also a great need to train the medical community and educate them on early detection and diagnosis of autism.

Fathers report high stress usually because of their children's daily management, the need to search for and deal with available services and educational programs, and the potential financial strains. Furthermore, fathers' lack of knowledge about their children's disability and the lack of active planning for fathers' engagement in all areas of service delivery (Premberg, Hellstrom, and Berg, 2008) can lead to high patenting stress. The prolonged nature of parenting stress highlights the significant short and long-term risks to fathers' mental and physical health. Another intervention used by occupational therapists is the weighted vest. The purpose of the weighted vest is to provide deep pressure stimulation to the child in order to calm the central nervous system. It is a sensory tool provided by the sensory integrative framework. In one study, 82% of occupational therapists in schools reported using this intervention (Morrison, 2007). These occupational therapists witnessed positive benefits of calming, increased attention and decreased self-stimulating behaviors. One study found moderate improvements in focus and decreased distractions by the students while wearing the weighted vest (Morrison, 2007).

Play therapy is an intervention often used by occupational therapists when working with a child diagnosed with ASD. Children are more apt to express themselves through play as it is a way professionals can enter the children's world. Play allows these children to problem solve by using toys as well as express any fears, anxieties, fantasies and guilt through objects. One researcher indicated that play has resulted in emotional, social and intellectual growth (Parker and O'Brien, 2011). Sand play is a technique often used in play therapy with children on the autism spectrum as it provides high sensory stimulation.

Unpublished work provides scant information on how children with autism are perceived (Cohen, 2012). Lack of evidence-based information on challenges and possible coping strategies of parents of children with autism could negatively influence the initiation of community-based rehabilitation. Community-based rehabilitation is a strategy initiated by the World Health Organization for rehabilitation, equalization of

opportunities, poverty reduction, and social integration of persons with disabilities and their families (WHO, ILO, UNESCO, 2004)

Theoretical Framework

The theoretical framework for this study is the Resiliency Model of Family Stress, Adjustment, and Adaptation developed by McCubbin (McCubbin and Thompson, 2001). The resiliency model is a strength-based model expanded from the family stress theory. The main emphasis of the resiliency model is on family resiliency or their ability to maintain the equilibrium of health in spite of adversity. The resiliency model has been used in many studies of families' stresses, strengths, and outcomes in family life changes, such as gains and losses, strains and transitions, and acute and chronic illnesses.

Family resiliency theory has been used extensively to study families at risk. Having a child with autism can cause extreme stress in a family, which may already have other risk factors such as single parenting or divorce, child-care needs, care of ill or elderly extended family members, or lack of financial resources; all of these can create a psychological effect. Families that adapt successfully tend to have traits of resiliency, good coping skills, and informal and formal social support from the community.

Methodology

The study adopted the explorative design that understudied the strategies of coping with autistic schoolchildren in the Tender Brain Remedial Centre in Oredo Local Government Area, Benin City. The population of the study was a total number of Twenty-Five (25) parents of autistic schoolchildren and they happen to be the primary caregivers of these children in Tender Brain Remedial Center, G.R.A, Oredo Local Government Area. The study was purely qualitative because of the population. A total of 12 respondents were randomly selected to form the sample size. The in-depth interview was used as the main instrument for data collection.

This study made use of a qualitative analytical tool called the QDA Miner for data analysis. This enabled the systematic description of written, spoken or visual communication and information given by the respondent and also analyzing the respondent's views and opinions.

Data Analysis and Findings

Research Question: What are the psychological effects of parenting a child with autism in the Tender Brain Remedial Centre?

Questions were asked based on the research question above and the responses are stated thus:

Response 1:

"I experience a lot of stress dealing with my child".

Response 2:

"I cannot just be angry. But sincerely times I experience stress and this makes me angry".

Response 3:

"I get frustrated at times because of the stressful situation I get to contend with, especially with the societal perception of my child. I can be depressed too and anxious unnecessarily".

Response 4:

"It is not easy. The situation can get so ugly times and I get so tired".

Response 5:

"There are some actions she exhibits that get on my nerves, I get so embarrassed too. But I just find a way out somehow. I can be anxious too especially when taking her out".

Response 6:

"The process of catering for the welfare of my child can be frustrating. Like I just feel like running away".

Response 7:

"It is a rigorous and stressful way of living".

Response 8:

"I get frustrated and tired and this makes me angry"

Response 9:

"It is very stressful, like you tend to adjust and readjust constantly to fit her into the family plan".

Response 10

"I get anxious, frustrated, angry and depressed too".

Response 11:

"It is stressful and frustrating".

Response 12:

"The way the society attributes sentiment to my child makes me angry".

Table 1. A tabular distribution of the Psychological effects of dealing with an autistic schoolchild

Psychological Effect	Anger	4	5.1%	1	33.3%
Psychological Effect	Anxious/anxiety	5	6.4%	1	33.3%
Psychological Effect	Constant Readjustment	3	3.8%	1	33.3%
Psychological Effect	Depression	5	6.4%	1	33.3%
Psychological Effect	Embarrassment	2	2.6%	1	33.3%
Psychological Effect	Frustration	7	9.0%	1	33.3%
Psychological Effect	Rigorous	2	2.6%	1	33.3%
Psychological Effect	Societal Sentiment	2	2.6%	1	33.3%
Psychological Effect	Stress	10	12.8%	1	33.3%

Distribution of codes (Frequency)

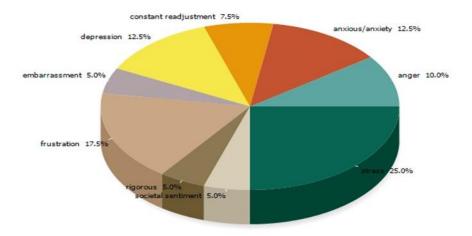


Figure.1.

Distribution of codes (No of Cases)

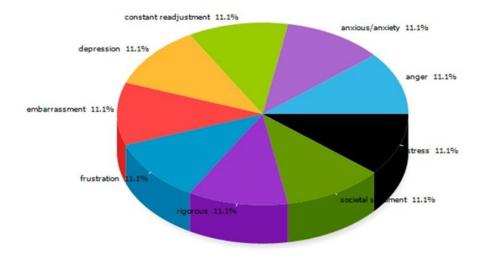


Figure.2.

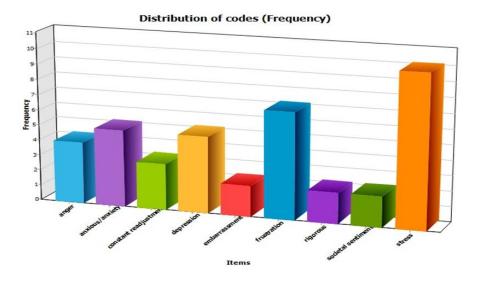


Figure 3.

Table 1 and Figure 1-3, illustrate the analysis of the psychological effect of coping with an autistic child, which was demonstrated in a tabular, pie chart, and bar chart respectively. A summary of the analysis shows that stress was at the top of the chart with 12.8%, followed by frustration at 9.0%, depression and anxiety were tagged at 6.4%, anger was 5.1%, constant readjustment 3.8%, embarrassment, rigorous, and societal sentiment was at the bottom of the chart at 2.6%. According to this analysis, stress is considered to have the most psychological effect on parents coping with autistic schoolchildren.

Conclusion and Recommendation

Parenting a child with autism is very challenging due to the nature of the aliment. The study identified stress as the major psychological effect of parenting a child with autism. Also, frustration is another major psychological effect felt by parents caring for autistic children. However, only a minimal percentage of the respondents opined that they feel embarrassed, experience negative societal sentiments, or even feel caring for

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an autistic child is rigorous. Therefore, there is a need for social and psychological

support for parents to reduce the stress and anxiety they face while caring for autistic

children.

As a result of the discussion above it is recommended that members of the family

should give their support to make the tasks become easier and to lessen the stress on the

parents. Also, special schools for autistic children should be established. The

government should make autistic and special schools free for autistic children and

should provide facilities and equipment that will make the learning process easy for

them. Also, more teachers should be trained to teach children with special needs using

curricula that can adequately reach out to children in this category. This will reduce the

amount of pressure and stress parents feel in the process of teaching their children on a

daily basis.

Disclosure statement

No potential conflict of interest was reported by the authors.

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Cite this article as Kimori .D., Sanderson .A.S.(2023). Psychological impact of parenting children with autism in Tender Brain Remedial Centre, Oredo local government area . International Journal of Humanities and Social Development Research. Volume 7 (2). pp. 62-77. DOI: 10.30546/2523-4331.2023.7.2.62