Sapientia Global Journal of Arts, Humanities and Development Studies (SGOJAHDS), Vol.4 No.1 March,, 2021; p.g. 23 – 31; ISSN: 2695-2319 (Print); ISSN: 2695-2327 (Online)

ADOPTABLE COPING STRATEGIES OF PARENTS WITH AUTISTIC SCHOOL CHILDREN IN TENDER BRAIN REMEDIAL CENTRE, OREDO LOCAL GOVERNMENT AREA, BENIN CITY, EDO STATE

OLAKITAN ISAAC, OPELUSI
Department of Sociology and Anthropology
Faculty of Social Sciences
University of Benin, Benin City
isaac.opelusi@uniben.edu
+2348169077663

&

OSAGIE LUCKY, OMORUYI
Department of Sociology and Anthropology
Faculty of Social Sciences
University of Benin, Benin City
osagie.omoruyi@uniben.edu
+2348064442219

Abstract

Autism is an emerging topical issue and a subject of concern in recent times among parents and guardians. The study examined coping strategies of parents with autistic school children in Tender Brain Remedial Centre, Benin City, Edo State, Nigeria. From the study population, a sample of 12 respondents was drawn for in-depth interview using purposive and snowballing sampling techniques. The data collected were analysed using manual content analysis because the study was purely qualitative in nature. The major finding of the study was thatcaring for autistic child/children can lead to stress, that is, the difficulties experienced and the coping strategies adopted by parents as a result of behavioural and emotional stress associated with autism. The study recommends among others the interaction between affected child/children and their parents/caregivers by focusing on the urgent need for social support in order to reduce the anxiety parents' feels about their child/children's welfare and the need to be put in place a financial support mechanism to assist parents who cannot afford therapy in caring for autistic child/children.

Keywords: Autism, Coping Strategies, Parents, Autistic Child/Children.

Introduction

Healthy children are a joy to parents and human society at large. To every parent, their desire is to bring forth a healthy and proper child void of any medical or hereditary health conditions. This is because healthy children are the delight of parents as well the society. Though this is not always the case, some children are born with certain health challenges which parents often find difficult to cope with. Children with special needs are a concern for most parents thus, various coping strategies adopted to curb the challenges of having such a

child is demanding, socially unbearable and stressful (Hastings, et al. 2005).Studies demonstrate that parents often seek support in order to cater for children with uncommon disability (Zablotsky, Bradshaw and Stuart 2013).The coping ability of parents with Autistic children possesses substantial implementation cost and presents sustainability and feasibility changes in low resources settings (Dwan et al, 2015; Peters-Scheffer, Didden and Korzilius2012).

Crane, Chester and Godda (2016) maintained that certain health condition such as autism poses serious concern to parents than others. They suggest that autism is associated with birth defects and has to do with pervasive developmental disorder often characterize by chronic impairment in social interaction and reciprocal communication that tend to be a stereo-typed patterns of behaviour, interest or activity. This condition tends to bring psychological trauma to persons living with autistic children. Hastings, et al. (2005) argues that very little is known about the underlying structure of coping strategies used by parentsautistic children. In addition, very few studies of families of children with disabilities have examined how different coping methods are associated with parent distress and well-being, and, in particular, whether the effects of different coping strategies on parent outcomes are moderated by child characteristics such as the severity of child autism symptomatology or maladaptive behaviour.

According to the World Health Organization (2017), Autism begins in childhood and tends to persist into adolescence and adulthood. In most cases the conditions are apparent during the first five years of life and this can be attributed to environmental and genetic factors. Children with Autism are known as special children; therefore it is required of the society and the parents to help them through this challenge to become useful people in life and discourage any form of limitation of their capacity to conduct daily activities. Some researches clearly indicate that the demand of raising a child with autism can result in marked psychological distress for many parents (Hastings, 2008).To this effect, special schools and homes have been created to assist and support parents with their autistic children and empower them with the right tools and strategies to cope with their challenge and one of these schools is Tender Brain Remedial Centre.

Statement of the Problem

Previous research has suggested that mothers of children with autism experience higher rates of depression than fathers; however, fathers of children with autism report more depressive symptoms than the general population (Hastings et al., 2005; Jones, Totsika, Hastings, and Petalas, 2013; Olsson and Hwang, 2001). But, this actually failed to recognize other forms of stressors pertaining to coping with autistic school children. However, these experiences are not universal with some families coping well and wide variability for individual parents and families in terms of their outcomes. Two important variables that have been linked to individual differences in outcomes, that may be amenable to change, are coping strategies and social support (McStay, Trembath, and Dissanayake, 2014;Paynter, Riley, Beamish, Davies and Milford, 2013).

Another stressor is the effect on the family's finances. Dobson and Middleton (as cited in Jarbrink, Fombonne and Knapp, 2003) estimated that the cost of raising a child with a disability is approximately three times greater than the cost of raising a child with no

disability. Jarbrink and colleagues developed a scale to measure the cost of raising a child who is autistic. The negative impact of this to the family can include difficulties maintaining employment, lost leisure time opportunities, less time available for other children in the family, and difficulty finding or paying for adequate child care or therapy. Research studies have shown that being a parent of a child with autism can be more stressful than parenting a child with a chronic illness or developmental disability (Tunali and Power, 2002; Sounders, DePaul, Freeman and Levy, 2002).

It is noteworthy that as primary caregivers, mothers are more likely to experience parenting related difficulties. One study that examined child related stressors, availability of resources, and coping strategies among parents of children with autism found that mothers experienced higher levels of stress than fathers (McStay, et al. 2014). Parents of children with autism use various coping styles, such as acceptance, humour, and gaining hope from child's improvement (Marshall and Long 2009).Some coping styles used may be counterproductive or maladaptive (Hall and Graff 2011; Sivberg, 2002). A recent longitudinal study, which was conducted over a 7-year period, on maternal coping styles and adjustment among mothers of children with autism found that increased use of maladaptive coping styles was related to increased stress proliferation and distress, and decreased parental efficacy (Benson, 2014). It is therefore important to examine the parental coping styles, in particular those of mothers in the management of autistic school children in tender brain remedial centre, Oredo local government area, Benin City, Edo State.

Objective of the Study

1. The objective of this study was to identify the coping measures adopted by parents of autistic children in Tender Brain Remedial Centre, Oredo Local Government Area.

Research Question

1. What are the coping measures adopted by parents of autistic children in Tender Brain Remedial Centre, Oredo Local Government Area?

Literature Review

Concept of Autism

Autism is a neuro-developmental disorder, present from early childhood, characterized by great difficulty in communicating and forming relationships with other people and in using language and abstract concepts. The term Autism also known as Autism Spectrum Disorder (ASD) is a developmental syndrome with growing global health concern. This syndrome is characterized by deficit in social and communication skills, restricted and repetitive behavior; and these actually impairs quality of life to those affected as well as their families (Lord, Cook, Leventhal and Amaral, 2000).Autism spectrum disorder has been shown to account for over 7.6 million disability adjusted life years and approximately 0.3% of the global burden diseases (World Health Organization, 2013).

Beginning in the United States in the early 1940s and in South Africa in the mid-1960s, serious efforts have been made in many parts of the world to recognize autism as a disability in its own class and to address its many challenges. In South Africa, this effort began when Dr. Vera Buhrmam became aware of the extent of the problem of autism in Cape Town. In 1970, the first school for autistic learners opened in the city, and there are now about five such schools

in South Africa. However, the situation in Nigeria seems to hark back to pre-1943 America, when children with autism were thought to be schizophrenic or mentally retarded, and when maternal deprivation and spiritual causation held sway as explanations for its cause. In many parts of Nigeria today, particularly in rural areas, people with autism are thought to be possessed or evil.

The level of awareness about autism in Nigeria is pathetically low. There is some awareness amongst those in the medical community, but the extent of their knowledge is often limited. Most only know the symptoms and manifestations of "infantile autism". The majority do not know that there are other forms of autism spectrum disorders (such as regressive autism); though autism has no cure yet but nearly 70 percent have no clue as to where to refer cases and/or what to do even when sure about a diagnosis.). Many children in Nigeria with autism are either not diagnosed early or misdiagnosed (Okey-Martins, 2010).Some end up being hidden at home and some categorized with the deaf, dumb or mentally ill children. In rural areas, where there are no psychiatric hospitals, many are isolated, abandoned or labeled 'insane'.

Nigeria's first experience with individualized, one-on-one treatment for autism dates back to 2001, when Dr. Helen Nwanze began working with an American expatriate boy. At the same time, the boy's parents brought in Ms. Stephanie, a behavioural therapist who they met in South Africa, to work with him. Soon after, they invited Linda Herbert, a Cape Town-based behavioural consultant who was also a teacher at the prestigious Vera School for autistic learners in Cape Town. Herbert and a colleague of hers offered a diverse intervention technique called Special Needs Adapted Programme (SNAP), which later became the Autistic Spectrum Adapted Programme(Autism Society, 2011).

Parents Coping Strategies in the Management of Children with Autistic Disorder

Coping strategies have been posited as one mechanism by which individuals respond to threats of stress, including stressors associated with parenting a child with autism. Based on the stress and coping model of Lazarus and Folkman (1984), researchers have often grouped coping methods into two general types, problem-based coping (strategies aimed at solving the problem or doing something to change the source of stress) and emotion-based coping (strategies aimed at reducing or managing feelings of distress associated with the stressor). Parents are able to adapt adequately when they receive support from others through networking. Information from health care providers and agencies is also helpful (Meadan et al., 2010). Further suggestions parents can utilize in order to cope with the stress of raising a child with autism include prayer, exercise, deep breathing/relaxation exercise, writing in a journal, keeping a daily schedule of things to accomplish, advocacy, and individual, marital or family counseling. Coping with a loss is significant and will make it easier to find acceptance in that loss (Autism Society, 2011).

Another way parents can cope with the stress of autism is by networking with other families who have been affected by the disorder. This provides parents with comfort in finding others who are experiencing similar situations as well as receive advice that will be useful in the parenting process (Autism Society, 2011).In studies of family caregivers, including parents of individuals with autism and intellectual disability, use of emotion-focused coping strategies (e.g. denial, venting) have generally been found to be associated with higher levels of

psychological distress, while use of problem-focused coping methods (e.g., planning, taking action to address the problem) have often, but not always, been associated with improved mental health outcomes (Abbeduto, et al., 2004).

In addition, many coping methods serve both instrumental and affective functions. For example, while taking direct action against a source of stress clearly involves problem-solving, it may also reduce negative emotions associated with the stressor, such as anxiety (Skinner Edge, Altman, and Sherwood 2003; Folkman and Moskowitz, 2004).Parents also harness a range of strategies to cope with these challenges, among others, three strategies used by parents of children with autism: accommodation of the biological basis of autism, in which the parents accept that the disorder is a result of natural causes; resistance to the biological basis of autism, where parents tend to view autism as a consequence of external influences or forces; and the use of spiritual beliefs to understand their situation, which is based on beliefs in God and the conviction that everything is possible through faith. Other coping strategies include accessing information, withdrawal from social interactions, shifting expectations, and working towards inclusion and greater acceptance of the child (Gray, 2006; Loung, Yoder and Canham, 2009).

Hastings, et al. (2005) used exploratory factor analysis to classify the coping methods used by135 parents of children with autism in the United Kingdom. Based on their analysis of parent responses on the Brief COPE, four reliable coping dimensions were extracted, which they termed active avoidance coping, problem-focused coping, positive coping, and religious/denial coping. While the first two of these dimensions corresponded closely to the emotion- and problem-focused coping categories commonly used in stress research (Folkman and Lazarus, 1985), the latter two were viewed as being more specific to the unique circumstances associated with parenting a child with autism or other disability. In bivariate analyses, Hastings, et al. (2005) found passive avoidant and religious/denial coping to be significantly related to increased parent stress, anxiety, and depression, while problem-focused coping was unrelated to any of these distress measures (positive coping was negatively correlated with depression only.

Research Method

This study adopted the exploratory research design that seeks to understudy the strategies of coping with autistic school children in Tender Brain Remedial Centre in Oredo Local Government Area. Exploratory design is chosen to gain background information and to define the research problem. The population of study was30 parents of the autistic school children in Tender Brain remedial Center, G.R.A, Oredo Local Government Area. Due to the qualitative nature of the study and a limited population size, the sample size was 15parents of the autistic school children who were randomly selected.

The purposive and snowballing sampling techniques were used for this study strictly because this study is qualitative in nature. Purposive in the sense that, irrespective of gender and age, selected respondents was based on homogeneity and the confidential nature of the research area, the study was confidently in other to make sound judgment from information given. Snowballing technique also known as referral/chain sampling technique is a non-probability sampling technique which helped in reaching out to others who also are experiencing same challenges the research intends solving. The in-depth interview guide was adopted as the

main and primary instrument in the collection of data for this study. The qualitative data collected was analyses through content manual analysis.

Analysis of Thematic Issues in Relation to the Study Question and Discussion of Findings
Research Question 1

What are the coping measures adopted by parents of autistic children in tender Brain Remedial Centre?
In answering the question above, some of the interviewed respondents who were parents responded as follows:

> *I put some flexible patterns in laid down rules to guide our experiences, modify his behaviour and also follow up (**IDI, respondent female, parent, 2020)**.*
>
> *I try to reduce the length of instructions given per time. I alsoteach him to self-regulate when anxious, which includes asking for a break, bouncing on the therapy balls or using a trampoline **(IDI, respondent, female, parent, 2020)**.*
>
> *I use constant prompting and instructions methods. I also use visual aids like television and wildlife/zoo; I put some rules, I train her to follow and also have a time table that assists me**(IDI, respondent, male, parent, 2020)**.*
>
> *I involve my girl in a lot of communicative therapy and speech aid tools. I also use a play way method and recitation mechanism. I sometimes clap my hands to gain her attention and focus**(IDI, respondent, female, parent, 2020)**.*
>
> *I do a constant redirection to follow through on anything i want her to do. I also put specific rules in place to modify her behaviour and follow through. I also have a child schedule for daily activities and this guides me **(IDI, respondent, female, parent, 2020)**.*
>
> *Personally, I adopt patience because dealing with her requires a lot of time. Aside this, I take her for a drive and also fun areas like the park, beach and cinema**(IDI, respondent, female, parent, 2020)**.*
>
> *It can be so difficult at times, that I have to act as a clown or puppet, thereby imitating a particular thing in order to send the right signal of the message I am trying to pass across (**IDI, respondent, female, parent, 2020)**.*
>
> *I involve my child in a lot of fun games, also known as play therapy, vocational skill training, listening therapy and other seasoned approach**(IDI, respondent, male, parent, 2020)**.*
>
> *I was advised by her school to use a Montessori Method, which works sometimes. These are the applied behavioural analysis, speech and occupational therapy. This helps to balance her relationship with people around her (**IDI, respondent, female, parent, 2020)**.*

> *Her school has actually trained us to use the sensory activities and heavy work exercise mechanism whether in picture form, video or life scenarios like the animals in the zoo. I adopt play therapy and therapeutic listening too (**IDI, respondent, female, parent, 2020)**.*

> *I engage him in a lot of physical activities. So I patiently interact through these physical activities. I teach him how to express anger without being too aggressive, ignoring irritating, attention-getting behaviour, in the process also shows love and interest **(IDI, respondent, female, parent, 2020)**.*

Discussion of findings

From the above information, it can be deduced that some parent interviewed asserted that they use flexible rules and regulations to guide the behaviour of their autistic child as a part of their coping method in managing their child's behaviour. Similarly, some parents opined that they usually reduced the number of instructions to the child due to cognitive deficiency of the child. Some parents also use visual aids such as watching of cartoon, wildlife/zoo videos etc to modify the behavioural pattern of their child. The use of communication therapy and speech aid tool was also put forward by another parent as one the coping methods adopted to correct their defective speech.

According one of the parents interviewed, to successfully cope with autistic child, parent need to adopt patience. The parents further asserted that she normally takes her child to recreational centres such as cinema, park, beach etc. A parent opined that it is usually difficult for her to manage her child with autism. However, part of her coping strategy is mimicking a particular behaviour in order to send a particular message. Further responses revealed that some parents engage their autistic child in a lot of fun games (play therapy) and listening therapy. These methods help to balance the relationship of autistic child with other him or her. As part of coping method, some parents responded that they use sensory activities like pictures, videos and life scenarios to manage their autistic child.

Conclusion

The family, as the major agent of socialization is very vital in determining the developmental outcome of the child. However, in the case of children with special needs, such as autism, the task of child rearing might be quite challenging than parenting children with usual development and therefore, some parents tend to employ various coping strategies in tending to the needs of the child. In the case of autistic children therefore, The urgent need for social support 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 as well as other paramount needs of the parents are provided to guarantee the welfare of autistic children.

Recommendations

Based on the discussion above, the following recommendations were made to enhance the wellbeing of parents with autistic children. Firstly, parents should jointly care for their autistic children to reduce the effect of stress on any single individual. Secondly, siblings (if any) should also be encouraged to participate in the nurturing of autistic children. The contribution of every member of the family unit is therefore important as it makes the tasks easier. Thirdly,

there should be creation of support groups where parents of autistic children can come together on a regular basis to share experiences and discuss ways to make the caring process fun, not only for the children but for themselves also.

References

Abbeduto, L., Seltzer, M.M. & Shattuck, P. (2004). Psychological well-being and coping in mothers of youths with autism, Down syndrome, or fragile X syndrome. *American Journal of Mental Retardation* 109(3): 237–254.

Benson, P. (2014). Coping and psychological adjustment among mothers of children with ASD: An accelerated longitudinal study. *Journal of Autism and Developmental Disorders, 44*, 1793–1807. Doi: 10.1007/s10803-014-2079-9.

Crane, L., Chester, J. & Godda, L. (2016). Experiences of autism diagnosis: a survey of over 1000 parents in the United Kingdom. *Autism* 20: 153–162.

Folkman, S., &Moskowitz, J.T. (2004).Coping: Pitfalls and Promise. Annual Review of Psychology, 55, 745–774

Gray, D. (2006). Coping over time: The parents of children with autism. *Journal of Intellectual Disability Research, 50, 970–97*

Hall, H.R. & Graff, J.C. (2011).The relationships among adaptive behaviors of children with autism, family support, parenting stress, and coping. *Issues in Comprehensive Pediatric Nursing* 34: 4–25.

Hastings, R. P. & Johnson, E. (2001). Stress in UK families conducting intensive home-based behavioral intervention for their young child with autism. *Journal of Autism and Developmental Disorders,31(3), 327–336. Doi: 10.1023/A: 1010799320795.*

Hastings, R.P. (2008). Stress in parents of children with autism. In E. McGregor, M. Nunez, D. Cebula, & J. C. Gomez (Eds.), Autism: An integrated view from neuroscience, clinical, and intervention research (pp. 303–324). London: Blackwell.

Järbrink, K., Fombonne, E.& Knapp, M. (2003). Measuring the parental, service and cost impacts of children with autistic spectrum disorder: A pilot study. *Journal of Autism and Developmental Disorders*, *33*(4), 395–402. doi:10.1023/a:1025058711465.

Jones, L., Totsika, V., Hastings, R.P.&Petalas, M. A. (2013). Gender differences when parenting children with autism spectrum disorders: A multilevel modeling approach. *Journal of Autism and Developmental Disorders, 43, 2090–2098. doi:10. 1007/s10803-012-1756-9*

Lazarus, R.S., & Folkman, S. (1984). Stress, Appraisal and Coping. New York, NY: Springer.

Lord, C., Cook, E.H.,Leventhal, B.L. & Amaral, D.G. (2000) "Autism spectrum disorders," *Neuron*, vol. 28, no. 2, pp. 355–363,

Loung, J., Yoder, M. K.& Canham, J. (2009). Southeast Asian parents raising a child with autism: a qualitative investigation of coping styles. *Journal of School Nursing, 25:222–229.*

Marshall, V.& Long, B.C. (2009). Coping processes as revealed in the stories of mothers of children with autism. *Qualitative Health Research* 20: 105–116.

McStay, R.L.,Dissanayake, C.&Scheeren, A. (2014).Parenting stress and autism: the role of age, autism severity, quality of life and problem behaviour of children and adolescents with autism. *Autism* 18: 502–510.

Meadan, H., Halle, J. W.& Ebata, A. T. (2010). Families with children who have autism spectrum disorders: Stress and support. Exceptional Children, 77(1), 7-36. Retrieved from the ERIC database.

Okey-Martins, N.(2010). Retrieved from_ http://www.autismaroundtheglobe.org/countries/nigeria.asp.Autism around the World 2014

Olsson, M. B. & Hwang, C. P. (2001).Depression in mothers and fathers of children with intellectual disability.*Journal of Intellectual Disability Research, 45, 535–543.*

Paynter, J., Riley, E., Beamish, W., Davies, M.& Milford, T. (2013). The double ABCX model of family adaptation in families of a child with an autism spectrum disorder attending an Australian early intervention service. Research in Autism Spectrum Disorders, 7, 1183–1195. doi:10.1016/j.rasd.2013.07.006 1–13.

Peters-Scheffer, N.,Didden, R.&Korzilius (2012). Cost comparison of early intensive behavioral intervention and treatment as usual for children with autism spectrum disorder in the Netherlands. *Research in Developmental Disabilities* 33(6): 1763–1772.

Sivberg, B. (2002). Family system and coping behaviors. *Autism: The International Journal of Research and Practice, 6*(4), 397–409.

Skinner, E. A., Edge, K., Altman, J.& Sherwood, H. (2003).Searching for the structure of coping: A review and critique of category systems for classifying ways of coping. Psychological Bulletin, 2, 216–269.

Sounders, M. C, DePaul, D., Freeman, K. G.& Levy, S. E. (2002).Caring for children and adolescents with autism who require challenging procedures. *Pediatric Nursing, 28,* 555-564.

Tunali, B.& Power, T. G. (2002).Coping by redefinition: Cognitive appraisals in mothers of children with autism and children without autism. *Journal of Autism and Developmental Disorders, 32,* 25-34.

World Health Organization (2013).*Meeting Report: Autism Spectrum Disorders and Other Developmental Disorders: From Raising Awareness to Building Capacity*. Geneva: Switzerland.

Zablotsky, B., Bradshaw, C.P.& Stuart, E.A. (2013). The association between mental health, stress, and coping supports in mothers of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders* 43(6): 1380–1393.