

## **Coping Strategies for Parents of Autistic Children in Benue State**

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### **Abstract**

The study determined the different coping strategies used by parents of autistic children. Three research questions guided the study. The survey research design was used. Population was made up of 118 parents of autistic children under the custody and care of three institutional homes in Benue State. Questionnaire was used for data collection. Data were analyzed using mean and standard deviation. Findings include, among others, that parents of autistic children face a lot of challenges prominent of which are discrimination, vulnerability to physical stress, poor standard of living, and psychological depression. Effective coping strategies identified include: seeking professional support, self control and accepting responsibility. Recommendation include, among others, that parents of the autistic children should be encouraged through counseling (workshops, seminars and conferences) on how to handle, care and raise autistic children in a manner that will reduce stress and other challenges.

**Key Words:** Autism, Spectrum Disorders, Children, challenges, Coping, Strategies.

### **Introduction**

The stress parents of autistic children undergo can be challenging. Autistic children need special attention that may be difficult for parents to cope with on their own. Autism also known as Autism Spectrum Disorders (ASD) once considered rare is now increasingly recognized throughout the world (Fombonne, 2009). According to Pushpalatha and Shivakumara (2016) autism is a neurodevelopment disorder characterized by impaired social interaction, verbal and non-verbal communication, and restricted and repetitive behavior.

Autism is characterized by moderate to severe impairments in social interactions, language and cognitive development including repetitive behaviours, restricted interests and emotional distress from environmental changes. Where some autistic children are severely affected, they lack interest in others, have no language skills and show a very restricted repertoire of interests Those that show only slight impairment may show concern for others but have no social skills, have formal communication skills but not at a pragmatic level, have good cognitive

function but may have specific skills in an area that becomes a stereotyped interest (Pozo, Sarria, & Brioso, 2011).

Autism affects essential human behaviors such as social interaction, ability to communicate ideas and feelings, imagination, and establishment of relationships with others (Obiozor, Onu, & Ugwoegbu, 2010). According to Tager-flusberg and Caronna (2007) communication problems include delayed onset babbling, unusual gestures, diminished responsiveness, and resynchronization of vocal patterns with the care giver. Many professionals in the medical, educational, and vocational fields are still discovering how autism affects children and how to work effectively with individuals with autism (Adelusi, Nnadi, Amesi & Amaewhule, 2012).

Nwokolo (2011), Bakare and Munir (2012) stated that the level of awareness about autism in Nigeria is pathetically low. Audu and Egbochukwu (2010) also asserted that there is a low level of awareness among parents and institutional care givers about autism. Available report also shows growing increase within the West African Sub-region which records about 2-20 cases in 1000 children at birth to three years.

In Benue State the prevalence rate of autism is high. The level of low awareness is pathetic and this is due to what Nwokolo (2011) termed parental misconception and cultural misinterpretation of autistic children as child witching. Some parents of the autistic children resort to hiding them while some troop to Christian worship

centers or traditional institutions to seek for solutions.

There are several organizations and government institutions in Nigeria such as the National Society for Autism Nigeria, Autism Associates, Healthcare Assessments, Aids and Training, Lagos and GTB Orange Ribbon Initiative working towards ensuring intervention and providing coping strategies for parents with autistic children. The interventions provide a method of functional communication and ample health and educational opportunities for parents and autistic children. Much is however, still needed to be done in enlightening the parents on best practices in caring-for and managing an autistic child (Nwokolo, 2011).

Prior research has characterized the experience of parenting a child with an ASD as stressful and psychologically distressing. For instance Mancil, Boyd, and Bedesem (2009) investigated into parental stress and found that autism is significant to parental stress among other factors.

Hing, Olivier and Everts (2013) investigated into coping with Autistic Spectrum Disorder, parental challenges and the role of School-Based Family Counseling. The research presents a South African perspective on the ASD-related challenges of parents. Three issues were addressed; difficulties experienced by parents of autistic children; their comprehension of autism and what is needed in order to cope effectively; and how professional intervention pertinent to School-Based Family Counselling (SBFC) can be of help. The first two issues were

addressed through a qualitative research investigation, with data collected by means of personal interviews with parents. The results indicate that parents often do not initially understand the lifelong nature of autism; they do not know how to adjust their family lives to meet the needs of the autistic child and other children in the family; and they are often overwhelmed by how to manage their ASD child. Therefore they are in need of professional intervention. In addressing such need for professional help, SBFC is considered.

Alli and Mupawose (2015) investigated into parent's journey into the world of autism. A qualitative descriptive research design was selected to explore the objectives of the study. Ten participants who were parents of a child with ASD attending Learners with Special Educational Needs School in Gauteng, South Africa were used for the study. Data were collected through a semi structured face-to-face interview survey comprising open and closed-ended questions, and were analysed using thematic content analysis. The results revealed five main themes, namely communicative challenges, family experiences, communicative coping strategies, speech and language therapy services and strategies provided by the speech language pathologist (SLP). This study concluded that parents and children with ASD experience challenges in communication and interaction.

Gona, Newton, Rimba, Mapenzi, Kihara, Vijver, and Abubakar (2016) investigated into challenges and coping

strategies of parents of children with autism on the Kenyan coast. They held thirty-seven interviews and eight focus group discussions with parents of children with autism and professionals in regular contact with these parents from rural and urban counties of the Kenyan coast. A purposive-convenience sampling procedure was used in selecting the study participants. The results indicate that parents of children with autism on the Kenyan coast experience common challenges including stigma, lack of appropriate treatment, financial and caring burdens regardless of their religious and cultural backgrounds. Coping strategies applied by parents comprised problem-focused aspects that involve diet management and respite care, and emotion focused aspects that consist of beliefs in supernatural powers, prayers and spiritual healing.

Arora and Pandey (2016) determined the level of stress and different coping mechanisms used by parents of children with Autism Spectrum Disorder on pre-training and post-training tests. A researcher-developed training module was used to impart training to enhance the coping mechanisms used by parents to reduce their level of stress. A sample of 100 parents of one child with Autism Spectrum Disorder was taken. They were sourced from early intervention centres, specialist schools, Autism associations and support groups in New Delhi. The study utilized a quantitative approach, using Means, Standard Deviation and t-test in analysing data. Results reveal that parents of autistic

children differed significantly on coping strategies and level of stress after the training.

The above related empirical studies all ascertained coping strategies adopted by parents with very few suggested effective coping strategies an indication that much is still needed to be done since the challenges of parents of autistic children and those related to the children still remain a serious concern. Most a times the coping strategies of parents are affected by a number of factors including religious beliefs, level of education, financial status, cultural norms and living in rural areas. It is to this effect that this study was carried out to enumerate coping strategies that will be more effective and less expensive for parents of autistic children in Benue State.

### **Objectives of the Study**

The main purpose of the research was to study the coping strategies that could help parents of autistic children in Benue State. Specifically, the study:

- 1.identified the challenges faced by families with autistic children in Benue State.
- 2.identified coping strategies presently being used by families in handling children with autism in Benue State.
- 3.determined coping strategies parents still need to be adopted in the management and care of autistic children in Benue State.

### **Research Questions**

The following questions guided the study:

- 1.What are the challenges faced by parents of autistic children in Benue State?
- 2.What are the coping strategies presently being used by parents to reduce stress with autistic children in Benue State?
- 3.What coping strategies do parents still need to adopt to reduce stress with autistic children in Benue State?

### **Methodology**

**Area of the study:** Area of the study was Benue State. The study was conducted in three special institutions in Benue state. They are; St. Francis School Vandikya, Elim School Ibilla Oju and Nan-Tor Special School, Makurdi.

**Research Design:** The survey research design was adopted for the study.

**Population for the study:** Population of the study consists of 118 parents of autistic children in three special institutions in Benue State. This is made up of 5 parents in St. Francis School Vandikya, 67 parents in Elim School Ibilla Oju and 46 in Nan-Tor Special School Makurdi. Their records were accessed from Benue State Ministry of Women Affairs and Social Development in August, 2016.

**Sample and Sampling Technique:** The researcher adopts a purposive sampling technique. Therefore 118 respondents formed the entire sample and there was no sampling because the sample size is small, with peculiar characteristics and the results are not generalized.

**Instrument for data collection:** The instrument used in data collection was Coping Strategies for Parents of Autistic Children Questionnaire (CSPACQ). The

questionnaire was divided into sections A - C and covered all the objectives of the study. The study adopted a 5 point likert scale with Strongly Agree SA - 5points; Agree A - 3points; Strongly Disagree SA -2points and Disagree D - 2point, undecided - 1point. The instrument for data collection was validated by three experts in Child/Developmental Psychology and Statistics at Federal University of Agriculture, Makurdi. The reliability of the instrument was established using cronbach Alpha and .60 was taken as significant for the instrument.

**Data Collection Techniques:** A total of 118 copies of the questionnaire were

distributed by hand. On-the-spot administration and collection of the instrument was adopted. All the copies of questionnaire administered were duly returned. This gives 100 percent return.

**Data Analysis Techniques:** Descriptive method of data analysis was used in analyzing the research questions. Specifically, the research questions were analyzed using mean and standard deviation.

### Results

The results of data analysis are presented below in Tables 1 - 3 below.

**Table 1:** Mean responses on challenges faced by parents of autistic children in Benue State

Challenges faced by Parents of autistic children	Mean	Std. Deviation	Remarks
1. Vulnerability to physical stress	4.66	.589	Accepted
2. Financial stress	4.54	.675	Accepted
3. Poor standard of living	4.66	.596	Accepted
4. Psychological depression	4.55	.675	Accepted
5. Divorce	4.22	.978	Accepted
6. Discrimination	4.67	.593	Accepted
7. Loss of employment	4.28	.789	Accepted
8. Reduction in Leisure activities	4.26	.972	Accepted
9. Treats to established relationship within the family	4.43	.721	Accepted
10. Disorganization and despair	3.60	1.137	Accepted
12. Lack of verbal speech by the child	4.66	.589	Accepted
13. Difficulty expressing needs and wants by the child	4.66	.589	Accepted
14. Discrimination from siblings	4.66	.596	Accepted
15. Poor response to verbal instruction by the child	4.28	.789	Accepted
16. Difficulty in relating with others by the child	4.43	.721	Accepted
<b>TOTAL</b>	<b>4.43</b>	<b>.824</b>	<b>Accepted</b>

Table 1 shows the challenges faced by parents including those related to the children. The major challenge faced by families of Autistic Children in Benue State is discrimination with a mean score of 4.67, vulnerability to physical

stress, poor standard of living and challenges related to the children such as lack of verbal speech, difficulty expressing needs and wants and discrimination from siblings with a mean score of 4.66 each. This is closely

followed by psychological depression with a mean of 4.55, financial stress with a mean of 4.54. The child's difficulty in relating with others has a mean of 4.43, poor response to verbal instruction by the child has a mean of

4.28, while the least challenge is disorganization and despair with a mean of 3.60. The overall mean score for the challenges faced by parents of autistic children in Benue State is 4.43.

**Table 2:** Mean responses on coping strategies presently being adopted by parents to reduce stress with autistic children in Benue State

Coping strategies adopted by parents	Mean	Std.Dev.	Remark
1. Seeking for medical attention	4.02	0.984	Accepted
2. Seeking for more knowledge about Autism	3.52	1.340	Accepted
3. Adapting to the health challenge	3.95	1.327	Accepted
4. Adapting to the behavioural tantrums	3.95	1.327	Accepted
5. Getting support from family and friends	4.22	0.986	Accepted
6. Joining Association and groups concerned with autism	4.02	0.984	Accepted
7. Hiding the child	3.60	1.137	Accepted
8. Seeing the child as cursed	3.52	1.340	Accepted
9. Seeking for traditional and spiritual help	3.95	1.327	Accepted
<b>TOTAL</b>	<b>3.98</b>	<b>1.037</b>	<b>Accepted</b>

Table 2 shows that the major coping strategies presently being adopted by parents of autistic children in Benue State are seeking social support system from family and friends with a mean of 4.22, seeking for medical attention and joining association and groups concerned with autism with a mean score of 4.02 each, adopting to the health challenge, adapting to the

behavioural tantrums and seeking for traditional and spiritual help with a mean score of 3.95 each; hiding the child with a mean score of 3.60 while seeking for more knowledge about autism and seeing the child as cured have a mean score of 3.52. The overall mean score for the coping strategies adopted by parents with autistic children in Benue State is 3.98.

**Table 3:** Mean responses on coping strategies that parents still need to adopt.

Coping Strategies to be adopted by Parents	Mean	Std.	Remark
Behavioural Therapy	4.02	0.984	Accepted
Seeking support from professionals	4.22	0.986	Accepted
Set up reinforcement coping	4.02	0.984	Accepted
Emotional regulation coping	4.02	0.984	Accepted
Positive reframing	3.93	1.107	Accepted
Escape/avoidance coping	3.93	1.107	Accepted
Planful problem-solving	3.93	1.107	Accepted
Self-control by parents	4.22	0.984	Accepted
Parents accepting responsibility	4.22	0.986	Accepted
Confrontative coping	3.93	1.107	Accepted
<b>TOTAL</b>	<b>3.96</b>	<b>1.096</b>	<b>Accepted</b>

Table 3 shows that the major coping strategies that parents of autistic children in Benue State still need to adopt are seeking support from professionals (medical practitioners and care givers), self control by parents and parents accepting and taking up the responsibility with a mean score of 4.22 each, behavioural therapy (a systematic way of managing a disruptive behavior of autistic children), set up reinforcement coping, and emotional coping or control with a mean score of 4.02 each; positive reframing (changing one's view of a stressful situation in order to see it in a positive or more tolerable light), escape/avoidance coping, planful problem solving (coping with stress in organized manner), and confrontative coping (tackling the situation with aggression) with a mean score of 3.93 each. The overall mean score for the coping strategies that parents of autistic children in Benue State still need to adopt is 3.96.

### Discussion

From the analysis, the results of the study revealed that families of autistic children in Benue State face a lot of challenges prominent of which is discrimination, vulnerability to physical stress, poor standard of living, psychological depression, financial stress, treats to established relationship within the family, loss of employment, reduction in leisure activities, divorce, and disorganization and despair. Brown and Remington (2005) stated that parents of autistic children face a lot of challenges and the care of such children

cannot be borne by parents alone; the inability of the parents to successfully play this role may frustrate them thus, deprive the children from developing adaptive coping strategies. Also Montes and Halterman (2007) assert that mothers of a child with autism are highly stressed and more likely to report poor or fair mental health. These findings also support the findings of Gona *et al* (2015) who reported that raising a child with autism puts a tremendous strain on parents due to the stigma associated with the disorder and that the need for constant monitoring of the child with autism has negative economic impact on the parents.

The difficult task of bringing up the autistic children and managing with these challenges may also result in psychological and mental stress for the parents. Bhagat, Simbak and Haque (2015) states that parents of autistic children are found with disturbances in their psychological parameters such as social, sexual, economic, and emotional. This shatters them from their interpersonal relationship and family life. Ghanizadehm, Alishahi, and Ashkani (2009) emphasize that the burden of parents of autistic children is not just limited to psychological aspects but on the quality of life, economic aspects, and parent-child relationship. Knapp, Remeo and Beecham (2007) assert that the consequences of autism can be seen in many domains, including family and other social relationships, employment, leisure activities, standards of living, social and personal functioning, and of course an individual

and family quality of life. Bashir, Bashir, Lone and Ahmad (2014) found out that the presence of an autistic child in a family adversely affects marriage and relationship among siblings. These consequences may not be too far from financial and other severe implications. According to Arora & Pandey (2016) frequent and intense tantrums to extreme rigidity and refusal to sleep are some few behaviour problems that autistic children often have thereby straining relationship in the entire family, siblings and marriage.

Coping strategies currently being adopted by parents of autistic children are identified as getting support from family and friends, seeking for medical attention, seeking for traditional and spiritual help among others. This agrees with Dunn, Burbin, Bower, and Tantleff-Dunn (2001) who reported that social support were effective coping mechanism for dealing with the daily stress of parents with autistic children. Also Predescu and Şipoş (2013) found out that coping strategies of mothers of children with autism spectrum disorders such as positive refocusing, positive re-evaluation and catastrophizing significantly correlates family quality life. On the other hand Gona *et al* (2016) found out that coping strategies applied by parents comprised emotion focused aspects that consist of beliefs in supernatural powers, prayers and spiritual healing. Qodariah and Puspitasari (2016) however found out that the effective aspect of coping strategy more effectively applied by mothers is problem focused coping.

The major coping strategies identified that need to be adopted are seeking social support from professionals, self control and accepting responsibility. This means that when parents are supported by health practitioners, professional care givers and non-governmental organizations and government it will assists in reducing their stress since the task of caring for autistic children is so involving. This agrees with Hing, Olivier, and Everts (2013) who found out that parents also look for support from professional resource personnel, who will hopefully, act in a constructive and multidisciplinary manner. Also self control by parents and accepting responsibility play a significant role in psychological and physical wellbeing of parents of autistic children as it changes ones view of a stressful situation in order to see it in a positive or more tolerable light. Furthermore, reinforcement, emotional coping, positive reframing, escape/avoidance coping, planful problem solving and confrontative coping are all significant in curbing the psychological feelings of parents with autistic children. Vidyasagar and Koshy (2010) have found that those who handle autistic children frequently use coping strategies like social support, escaping/avoiding or by positively reappraising the situation more. This also agrees with Pottie and Ingram (2008) who found that higher levels of daily positive mood were predicted by problem focused, social support, positive reframing, emotional regulation and compromise coping.



Parents who adopt coping strategies of active avoidance (denial distraction and guilt) report more stress than those who adopt positive and problem focused strategies. That is, parents should positively confront the challenges instead of avoiding the problem.

Developing communication and social skills is an important part of teaching and learning process in autistic children as it helps them to know what is expected of them in specific situations and to assist them in anticipating what comes next and to learn and generalise a variety of skills (Lovannone, Dunlap, Huber & Kincaid, 2003). To Dawson (2008) a communication system that uses alternative and augmentative forms of expression may be necessary and parents needs to have full knowledge of it. Similarly, Litras, Moore and Andreson (2010) assert that social stories greatly aid in teaching children with autism on how to manage their behaviour during social situations. Therefore, Autism should be treated as a state of mind and people dealing with autistic children must have positive social skills of appropriate communication.

### **Conclusion**

Autism is a mental condition characterized by difficulty in communication and social interaction. This study established that parents of autistic children face a lot of challenges prominent of which is discrimination, vulnerability to physical stress, poor standard of living, psychological depression, financial stress, treats to established relationship within the

family, loss of employment, reduction in leisure activities, divorce, and disorganization and despair. It is imperative for practitioners to provide appropriate professional support and other social support systems to families with autistic children. Parents counselling, creating awareness on care services and developing appropriate trainings are some of the measures suggested to enhance effective coping strategies.

### **Recommendations**

Based on the results, the following recommendations are made.

1. Parents of the autistic children should be encouraged through counseling (workshops, seminars and conferences) on how to handle, care and raise autistic children in a manner that will reduce stress and other challenges.
2. Governmental and NGOs, Community and Faith Based organizations should all be involved in creating awareness about autism. The focus should include creating awareness on care services, eliminating the negative perception of parents, family members and siblings about autism. This will go a long way in assisting parents adopt appropriate coping strategies devoid of negativism leading to reduction in their stress and other challenges.
3. Donor agencies and other humanitarian organizations should look into the direction of autistic children in Benue State with a view to assisting in their educational development, training people in the

area of behavioral therapy, reduction in prevalence rate and enhancing their social status which will also go a long way in reducing the social challenges of the parents.

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