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Parenting Stress in Families of Children With Autism Spectrum Disorder: The Roles of the Extended Family

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Abstract

Objective: This study focused on the role of extended family in mitigating the stress experienced by parents of children with autism and the possible challenges of involving them, especially in modern Nigerian society. The study identified the sources of stress for parents of children with autism, and considered location and family size factors in stress experienced by parents, the role of the extended family in mitigating the stress and the challenges that may inhibit the involvement of the extended family.

Method: The study adopted a descriptive survey research design and was carried out in South East, Nigeria. All parents and guardians of children with autism in the three special needs schools that cater for children with autism in the two selected states were used for the study. Data was collected using a self-report questionnaire with 36 items to elicit information on the sources of stress for parents and the role of the extended family in mitigating the stress. A semi-structured 26 items interview schedule adapted from Smithfield's (2011) parents of children with autism questions covering the child's behaviour, parent's feelings, and role of the extended family was also used to generate firsthand information on the issues raised and to complement data collected through the self-report questionnaire. There was a researcher observation guide for monitoring progress in the study. Mean and standard deviation was used to answer the research questions while regression analysis, t-test and Analysis of variance were used to test the null hypotheses at 0.05 level of significance.

Results: The findings revealed that parents of children with autism experience stress that is hinged basically on the behaviour of the children. Family size does not influence parents' stress experience but location does. Some parents receive child care and/or financial help sometimes from extended family members.

Conclusion: Parents of children with autism face a lot of stress that is hinged basically on the behaviour of the children. Some of the rural parents, however, have the opportunity of getting help sometimes from extended family members since special need schools are not located in their area or even nearby. The extended family relations sometimes offer financial help but from all indications, the modern urbanization has really eroded their help. Family size does not influence parents' stress experience and role of extended family but location does.

Keywords: autism, parenting stress, family size, location, extended family

1. Introduction

Parenting is the act of taking care of or nurturing children both biological and adopted. It is a stressful task and parenting children with autism is more stressful. Autism spectrum disorder has been defined as a group of disorders that include autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger's Disorder (The American Psychiatric Association, 2000). Mayo Clinic (2013) defined autism as a neurodevelopment disorder characterized by early onset (before 3 years of age) of significant impairment in social interaction and communication and unusual, stereotyped behaviours. The term "spectrum" implies that these disorders affect each child differently and involve delays in the development of basic skills like the ability to socialize or form relationships with others and to communicate effectively (The Autism society, 2013).

Autism spectrum disorder goes with concomitant disabilities such as developmental and intellectual disabilities

and behavioural challenges (Newschaffer et al., 2007). Other symptoms vary in severity and include the inability to participate in a conversation in spite of the fact that the child is able to speak, difficulty with non-verbal communication like gestures and facial expressions, social interaction, repetitive body movements or patterns of behaviour such as hand flapping, spinning and head banging (Heward, 2013). These may constitute a stress to parents. A study by Hodapp and Dykens, (1997) revealed that parents of children with developmental disabilities experience higher levels of stress than parents of typically developing children. Webster and colleagues (2008) reported that over 40% of parents of children with developmental delay had scores above the 85th percentile in the Parenting Stress Index indicating significant parenting stress.

Studies on parents of children with ASDs found that children's behaviour and conduct problems were strongly related to parental stress (Lecavalier, Leone, & Wiltz, 2006; Hastings, Kovshoff, Ward, Espinosa, Brown, & Remington, 2005). Bulldogrocks (2010) reported a mother's view that screaming fits that may lead to pulling the hair, scratching and banging the head among others are difficult to handle, heartbreaking and sometimes discouraging especially when it is obvious that one cannot help. Bowman (2012) opined that trying to sort out what the child's true needs are and how to meet them is stressful for parents. The difficulty in getting interventions and the level of professionals' knowledge about autism spectrum disorders equally frustrate parents, according to Osborne and Reed (2008). Plant and Sanders (2007) however, attributed the stress to the challenges of going through a number of educational, medical, and behavioural services. This condition is known to be financially and emotionally challenging and may be too difficult for parents without adequate mental preparation and readiness to cope.

Stress would vary based location and family size. For instance, Gona et al. (2015) reported that most parents and the professionals from rural and urban settings interviewed reported that parents of children with autism are being stigmatized and sometimes blamed for their child's condition and behaviour. These parents are disregarded and even banned from church services especially in urban areas when their children are seen moving about and disturbing people.

For working mothers and families with other children to care for, their frequent moves to get a medical and spiritual diagnosis and interventions are sources of cumulative stress. This Ayers (2012) opined, predispose families to the adverse effects of caregiver burnout.

Several studies have reported increased depression, anxiety, decreased family cohesion, increase in somatic complaints and burnout among parents of children with autism spectrum disorders (ASDs) (Higgins, Bailey, & Pearce, 2005; Sivberg, 2006). According to Patterson,(2005); Turnbull, Turnbull, Erwin, and Soodak (2006), the stress encountered in parenting a child with autism has been shown to be capable of causing emotional distress leading to a variety of physiological changes that affect health such as increased heart rate, elevated blood pressure, and a dramatic rise in hormone levels.

In the traditional Nigerian society where child care use to be a collective duty of both immediate and extended families, such situations outlined above are alleviated by extended family in terms of encouragement, financial support and sometimes, caregiving to enable the parents to face other issues of the home. Extended family according to Adinlofu (2009) structurally comprises a number of joint, large compound, elementary and nuclear families occupying separate but nearby homesteads and is one institution in Nigeria and Africa that has stood the test of time especially in rural communities. Adinlofu (2009) observed that traditionally, the extended family provides emotional succour to all members, acts as a basic economic unit, ensures early care and training of children among others. Thoits (2011) reported that grandparents are likely to be the main source of support for many parents, providing emotional as well as financial and instrumental assistance.

Report from studies on the role of the extended family on parental stress varies. In a survey of 2,600 grandparents of children with autism, the Interactive Autism Network (IAN, 2009) investigated how having a grandchild with autism changed their lives and their role in meeting the emotional and economic needs of their adult children and grandchildren. The result showed that about 30% of grandparents were the first to notice their grandchild's developmental challenge; nearly 90% felt closer to their adult child and grandchild due to their experience, while 72% of grandparents involve themselves in making treatment decisions for their grandchild, more than 7% had actually come to live with their grandchild's family to help them cope with the stress of raising a child with autism. Fourteen per cent had moved closer (but not into the same home) for the same reason. The result also showed that over 34% take care of their grandchild at least once a week; about one in five grandparents provide regular transportation for the child, about 6% of grandparents had taken the role of the parent since the family situation had become so untenable.

Financially, a quarter of grandparents reported spending up to $99 a month on their grandchild's autism-related

needs, some contributed more than $500 or $1,000 monthly. Overall, the major concern for grandparents is the well-being of their adult children since a child's autism diagnosis can lead to emotional, financial, and marital stress. Levinson in Ime and Ukpong (2013) stated that parents and grandparents are expected to guide during tough times due to their wealth of experience in enduring and surviving economic challenges and marital troubles. Extended family members not only serve as mentors and role models, they aspire and inspire their later generation to work, but often as emergency caregivers.

A study of families of children with a developmental disability according to Trute, (2003), found that the effects of grandparent support on maternal stress varied based on the type of support received, and which grandparent was responsible. While Hastings and Johnson, (2001), Bishop et al. (2007), and Ekas, Lickenbrock and Whitman (2010) showed that parents reported lower parenting stress with increased informal (extended family) support, which Bromley, Hare, Davison & Emerson, 2004attributed to the fact that parents receive more informal support, Wellard, (2011); IpsosMORI and Department for Education (2013) reported that almost two thirds of grandparents provide some form of childcare, with grandmothers playing a larger role than grandfathers.

The main purpose of this study, therefore, was to investigate the role of the extended family in mitigating the stress of parents of children with autism. Specifically, the study identified the sources of stress for parents of children with autism, explored the location and family size factors in stress they experienced, investigated the role the extended family can play in mitigating the stress and the challenges that may inhibit the involvement of the extended family.

The following research questions guided the study

1) What are the sources of stress for parents of children with autism?
2) What is the mean difference in sources of stress for parents of children with autism based on location?
3) What is the mean difference in sources of stress for parents of children with autism based on family size?
4) What roles does the extended family play to mitigate parental stress?
5) What are the challenges that inhibit the involvement of the extended family?

The following hypotheses were tested at 0.05 level of significance

1) Location will not significantly influence the stress experienced by parents.
2) Family size will not significantly influence the stress experienced by parents.

2. Method

The study adopted a descriptive survey research design in exploring the roles of the extended family in mitigating the stress parents of children with autism experience. The study was carried out in South East, Nigeria. Enugu and Abia states were randomly chosen because of the availability of special needs schools. The population consisted of all parents of children with autism in the special needs schools these states. Data was collected using a 36 items self-report questionnaire for parents of children with autism to elicit information on the sources of stress for parents and the role of the extended family in mitigating the stress. A semi-structured,26 items interview schedule adapted from Smithfield's (2011) parents of children with autism questions covering the child's behaviour, parent's feelings, challenges and role of the extended family in mitigating the stress was equally used to elicit information on the issues raised and compliment the self-report questionnaire data. Mean and standard deviation was used to answer the research questions while regression analysis and Analysis of variance were used to test the null hypotheses at 0.05 level of significance. The qualitative data collected were first transcribed, then, coded before interpretation and discussion of results. The discussion was based on identified themes.

3. Results

3.1 Research Question One: What Are the Sources of Stress for Parents of Children With Autism?

Table 1. Descriptive Statistics of Mean and Standard deviation showing the sources of stress for parents of autistic children

Items		N	Mean	SD
1.	The aggressiveness of the child	39	3.26	.59
2.	A child always banging the head and have self-inflicted injuries	39	3.44	.75
3.	The inability of the child to make friends with other children of the same age.	39	3.31	.77
4.	Constant cries and refusal to be comforted.	39	3.10	.82
5.	Community isolation of the parents	39	3.31	.86
6.	Destructive tendency of the child	39	3.10	.97
7.	Inability of the child to babble or coo by 12 months of age.	39	3.44	.75
8.	Inability of the child to wave or point at a thing by 1 year of age.	39	3.56	.72
9.	Inability of the child to say single words by 16 months of age.	39	3.13	.55
10.	Inability to establish eye contact or make facial expressions.	39	3.38	.59
11.	Inability to respond to others' facial expressions.	39	3.33	.81
12.	Inability to participate in a conversation in spite of the fact that the child is able to speak.	39	3.56	.68
Overall		39	3.33	.35

The result in Table 1 shows the inability of the child to wave or point at a thing by 1 year of age and participates in a conversation in spite of the fact that the child is able to speak as the highest source of parental stress. Other sources of parental stress include child banging the head and have self-inflicted injuries and inability of the child to babble or coo by 12 months of age, aggressiveness of the child, inability of the child to make friends with other children of the same age, constant cries and refusal to be comforted, community isolation of the parents, destructive tendency of the child, inability of the child to say single words by 16 months of age, inability to establish eye contact or make facial expressions and inability to respond to others' facial expressions.

3.2 Research Question 2: What is the Mean Difference in Sources of Stress for Parents of Children With Autism Based on Location?

Table 2. Descriptive statistics for sources of stress by location

Place of Residence		Sources of Stress
Urban	Mean	3.34
	N	27
	Std. Deviation	.36
Rural	Mean	3.29
	N	12
	Std. Deviation	.35
Total	Mean	3.33
	N	39
	Std. Deviation	.35

Result in Table 2 shows that urban respondents had a mean score of 3.34 for sources of stress, compared to rural

respondents' means scores of 3.29 on sources of stress.

3.3 Research Question 3: What Is the Mean Difference in Sources of Stress for Parents of Children With Autism Based on Family Size?

Table 3. Descriptive statistics for sources of stress by family size

Family size		**Sources ofStress**
1-3 (Small)	Mean	3.36
	SD	.356
	N	17
4-6(Moderate)	Mean	3.23
	SD	.356
	N	13
7-9(Large)	Mean	3.39
	SD	.35
	N	9

Table 3 shows that small family has mean scores of 3.36, 3.43 and 3.55 in sources of stress. Moderate family size has mean of 3.23 in sources of stress, while large family size has mean of 3.39 in sources of stress.

3.3 Research Question Four: What Roles Does the Extended Family Play to Mitigate Parental Stress?

Table 4. Mean responses on the role of the extended family in mitigating the stress for parents

Items: The role of the extended family in relieving the stress.	**N**	**Mean**	**SD**	**Dec.**
1. They provide social support by being available to spend time with the children both indoors and outdoors.	39	3.05	.69	A
2. They provide emotional support by being available to listen and encourage the parents.	39	3.26	.79	A
3. Act as advocates in the community or be a source of information about their grandchild with ASD.	39	3.59	.72	SA
4. Help with household tasks	39	3.72	.51	SA
5. Help manage behaviour problems.	39	3.44	.72	A
6. Help financially sometimes.	39	3.44	.59	A
7. Provide care for their grandchild with ASD.	39	3.28	.69	A
8. Go to therapy sessions to learn more about how the child learns and responds to other people.	39	3.23	.67	A
Overall	39	3.37	.28	A

Table 4 indicates that they help most with household tasks, being advocates in the community or a source of information about their grandchild with ASD, manage problem behaviours and give financial help sometimes beside all other assistance listed as shown by the results of data analysis.

3.4 Research Question 4: What Are the Challenges that Inhibit the Involvement of the Extended Family?

Table 5. Mean responses on the challenges that inhibit the involvement of the extended family

	The challenges that inhibit the involvement of the extended family in mitigating the stress.	N	Mean	SD	Decision
1.	The impact or demands of being a caregiver, which can be a big commitment.	39	3.72	.51	SA
2.	Fear of the future and new crises that might develop	39	3.21	.73	A
3.	Not knowing whether they should wait to be asked for help or just 'jump in'	39	3.62	.54	SA
4.	Lack of understanding of children with ASD	39	3.41	.49	A
5.	Poor relationship with their extended family members.	39	3.39	.63	A
	Overall	39	3.33	.81	A

Table 5 shows that the respondents agreed to all the items while items 1 and 3 appear to be the major challenges that inhibit the involvement of the extended family.

3.5 Hypothesis One

There is no significant difference in the mean ratings of urban and rural parents of children with autism on the stress they experience.

Table 6. t-test on the influence of location on stress experienced by parents of children with autism

Location	N	Mean	SD	df	t	P
Urban	25	3.06	.39	37	.727	.069
Rural	14	2.97	.28			

Result in Table 6 shows that t-value of .727 with an associated probability value of .069 was obtained. Since the probability value of .069 was greater than the level of significance set at .05, the null hypothesis was accepted implying that location has no significant influence on the stress parents of children with autism experience.

3.6 Hypothesis Two

There is no significant difference in the mean ratings of stress experienced by parents of children with autism based on family size.

Table 7. One-way Analysis of variance of influence of family size on the stress experienced by parents of children with autism

Sources	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	.592	2	.296	3.732	.534
Within Groups	2.857	36	.479		
Total	3.450	38			

The result in Table 7 shows that an F-ratio of 3.732 with an associated probability value of .534 was obtained which is greater than the level of significance set at .05. Thus, the null hypothesis was accepted implying that family size does not significantly influence the stress experienced by parents of children with autism.

4. Discussion

The study investigated the role of the extended family in mitigating the parental stress of families of children with autism. To achieve this aim, sources of stress for parents of children with autism, the role the extended family play in mitigating the stress and the challenges that inhibit the involvement of the extended family were identified.

Location and family size were intervening variables in the stress of the parents. The result shows that behaviours such as aggressiveness, banging the head and having self-inflicted injuries, the inability of the child to make friends with other children of the same age, constant cries and refusal to be comforted among others, stressed parents of children with autism. Community isolation of the parents equally constituted a source of stress. The findings corroborate Lecavalier, Leone and Wiltz (2006) and Hastings and Bulldogrocks (2010) who reported that the behaviour and conduct problems of children with ASD were strongly related to parents' stress. Previous research by Plant and Sanders (2007) attributed the stress to the financial and emotional challenges of going through a number of educational, medical, and behavioural services which may be too difficult for parents without adequate mental preparation and readiness to cope. The resultant effects according to Weiss (2002), Higgins, Bailey and Pearce (2005), and Yirmiya and Shaked (2005), Sivberg (2006) includes increased depression, anxiety, decreased family cohesion, increase in somatic complaints and burnout among parents of children with autism spectrum disorders.

An interview with parents of children with autism revealed that their most challenging experiences include taking them to the hospital regularly and the high cost of medication. According to them, each test conducted on the children cost up to N40, 000 which is quite tasking in view of the economic downturn. A parent reported that urinating on the bed at 17 years of age and carelessness which nearly resulted in the burning of the house but for the intervention of family members was quite traumatic. The stress of medical attention is felt more by the rural parents who have to travel to the towns with better hospitals and staff to care for their child. This is aggravated by the fact that they do not have anybody to stay within the town when the visit ends late. The extended family (which is a source of informal support) to some extent mitigate parental stress. While Pottie et al. (2009) reported that both formal and informal sources of social support have been found to increase positive mood in this population of parents, Boyd (2002), Bishop et al. (2007), and Ekas, Lickenbrock and Whitman (2010) found that parents reported lower parenting stress with increased informal but not necessarily formal social support. Bromley, Hare, Davison and Emerson (2004) stated that this can be attributed to the fact that parents receive more informal than formal support.

In an interview with urban and rural parents of children with autism, only a few urban parents reported that they take their children to their parents' house or extended family members who live near to help take care of the children when they are away. Although rural parents have more access to extended family members since they live close by and sometimes visit the family, only a few parents reported receiving some help from them.

Another intervening variable on the stress experienced by parents with autistic children was the location. Result shows that urban respondents had a mean score of 3.34 on sources of stress, 3.44 on role of the extended family and 3.42 on challenges mitigating the involvement of the extended family members compared to rural respondents' means scores of 3.29, 3.24 and 3.50 for sources of stress, role of the extended family and challenges mitigating the involvement of extended family members respectively. Hypothesis testing result revealed a t-value of .727 with an associated probability value of .069 which is greater than the level of significance set at 0.05. Consequently, the null hypothesis was accepted implying that location has no significant influence on the stress parents of children with autism experience. Studies (Tomanik et al., 2004; Gona et al., 2016) reported that behavioural deficits, sociability and health, physical or behaviour of a child with ASD are great sources of parental stress. Considering the fact that behavioural deficits are hallmarks of autism, the finding of no significant difference in stress experienced is not surprising. Besides, a stigma which is manifested by social isolation is common with both urban and rural parents. Parents in Kenya reported non-acceptance of the child with autism by peers, family members, relatives, and the wider community resulting in the social exclusion of the child. The parents are disregarded, blamed and even banned from church services especially in urban areas when their children are seen moving about and disturbing people.

On the role of extended family in mitigating the stress, Result indicates that they help most with household tasks, manage problem behaviours and give financial help sometimes beside all other assistance such as providing social support (being available to spend time with the children and providing emotional support among others). The findings lend credence to the report of the Interactive Autism Network (IAN, 2009) survey of 2,600 grandparents of children with autism which investigated their role in meeting the emotional and economic needs of their adult children and grandchildren. The result showed that about 30% of grandparents were the first to notice that there was a problem with their grandchild's development; nearly 90% felt closer to their adult child and grandchild due to their experience, while 72% of grandparents said they get involved in making treatment decisions for their grandchild, more than 7% said they had actually come to live with their grandchild's family so they could help them cope with all that is involved in raising a child with autism. Fourteen per cent had moved closer (but not into the same home) for the same reason. The result also showed that over 34% said they take care of their grandchild at

least once a week; about one in five grandparents provide regular transportation for the child, about 6% of grandparents said that they had taken the role of the parent since the family situation had become so untenable. The finding also corroborates Thoits, (2011) report that grandparents are likely to be the main source of support for many parents, providing emotional as well as financial and instrumental assistance. Wellard, (2011); Ipsos MORI and Department for Education, (2013) also found that almost two-thirds of grandparents provide some form of childcare, with grandmothers playing a larger role than grandfathers. Overall, the major concern for grandparents is the well-being of their adult children who are parenting a child with autism their reason being that a child's autism diagnosis can lead to emotional, financial, and marital stress. Contrary to the findings of this study, some parents who were interviewed said that the extended family pretends to care for the child when a family member is around but cannot accept to care for the child alone. Some agreed to receive occasional financial help and occasional help in house chores from the extended family. A male parent declared "they are hypocrites, I am the pillar and provider for my family".

When the family size is taken into consideration on the source of stress, roles of the extended family and challenges militating against the involvement of extended family, the respondents had mean scores above 2.50 on all items.The result of hypothesis testing shows that an F-ratio of 0.18 with an associated exact probability value of 0.67 was obtained and found not to be significant. The null hypothesis was therefore not accepted indicating that, family size does not significantly influence the stress experienced by parents of children with autism. Family size does not significantly influence the role of the extended family in mitigating the stress of parents since the mean scores of the small, moderate and large family sizes were above the benchmark of 2.50. They are all in the same range although moderate family had the highest mean score. The finding on the role of the extended family is not expected. One would have expected that small family would be helped significantly since, in the African and Nigerian setting, the extended family helps in taking care of children especially when they are tender but the care decreases as more children are born and they help in taking care of their younger ones. The current trend whereby the extended family relationship is being eroded may have created the situation of no significant family size influence on parental stress, and the role of extended family.

The challenges that may inhibit the involvement of the extended family in mitigating the stress for parents include fear of the future and new crises that might develop, their understanding of ASD, relationship with their children who are involved with their grandchild and the impact or demands of being a caregiver among others. This is in line with the findings of Parkes, Sweeting and Wight (2015). Interview responses show that some of the parents have not involved their extended family because of what they called "their attitudes generally", some parents reported that they are living in the town with no relations around so they are not involved, while just one parent said that she sends her son to her extended family members who live in the same town with her when she has to go shopping or any other chore that will take her away most of the day. She even confessed that it was her elder sister who first noticed that her son was different barely three weeks after birth.

5. Conclusion

Parents of children with autism face a lot of stress that is hinged basically on the behaviour of the children. Some of the rural parents, however, have the opportunity of getting help sometimes from extended family members since special need schools are not located in their area or even nearby. The extended family relations sometimes offer financial help but from all indications, the modern urbanization has really eroded their help. Family size does not influence parents' stress experience and role of extended family but location does. One implication of the findings is that parental stress will continue to be a problem especially for rural dwellers if special needs schools and hospitals are not established by the government to alleviate the stress. The schools used are all private and organization owned. Therefore, the government should establish special needs schools and hospitals in both the rural and urban areas to cater for the special needs children to alleviate their parents' stress. The cost of treatment in these hospitals should also be subsidized to accommodate the low-income parents of these children with autism.

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Competing Interests Statement

The authors declare that there are no competing or potential conflicts of interest.

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