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Psychosocial Burden of Mothers' Care of Children with Autism Attending Federal Neuro-Psychiatric Hospital Yaba Nigeria

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Abstract

Autism spectrum disorder (ASD), or simply autism, occupies an extreme position among childhood pathologies due to its severity, duration, and impact on the family. This descriptive study assessed the psychosocial burden of care on 60 mothers of children with childhood autism. The instrument consisted of socio-demographic characteristics, 12-item General Health Questionnaire (GHQ-12), and the Zarit Caregiver Burden Interview (ZCGI). Data were analyzed using SPSS version 23. Results indicated a significantly high level of psychological distress (51.8%) among mother of children with autism, and (30%) thirty percent of mothers of children with autism had a low burden. Bivariate analysis revealed factors that were associated with psychological distress in mother of these children were the presence of social type of impairments and a high number of impairment in the child having to cut down or give up work and a high burden score on these women believed to be a spillover from the care burden. Results also showed the number of impairments at various periods: 12 months (51.79%), 6-12 months (30.36%), and less than 6 months are (17.86%). Mothers' employment rate was cut down to 51.9%, while 25.9% gave up their job completely. These were significantly and independently associated with psychological distress. Conclusively, the study revealed that mothers of children with autism experience significant higher levels of burden. Hence, an urgent need for the implementation of intervention programmes to reduce the burden of care among this group of mothers in Nigeria with social support and governmental assistance and approaches.

Keywords: *Autism, Caregiver burden, Mothers, Psychosocial burden, Public health.*

Introduction

Autism is a childhood developmental disorder that is characterized by a combination of qualitative impairments in social interaction, communication, restricted, repetitive and stereotyped patterns of behaviour, interests, and activities [1]. It occupies an extreme position among childhood pathologies in terms of its severity, chronicity and impact on the family. Most children with this disorder are not recognized by appearance as having autism, rather the disorder manifests in a range of puzzling and distributing behaviours that profoundly different from the behaviours of typical children. In the past, Autism Spectrum disorder (ASD) was considered to be a rare childhood condition however recent studies have shown a consistent increase in its prevalence [2].

The stress of caring for a child with autism is

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suggested to be higher than some other childhood disabilities. Mother of children with developmental disabilities faces a lot of challenges placing them at risk for a high level of stress and other negative psychological outcomes mothering a child with autism may pose additional stressors related to the child's challenges in communicating difficult behaviour, social isolation, difficulties in self-care and lack of community understanding [3].

Earlier studies had reported increased psychological distress, including depression, anxiety, and other components of stress, such as decreased family cohesion and increased complaints and burnout among mothers of typically autism and related autism spectrum disorder compared to parents of typically normal developing children [4-6]. According to Omigbodun [7], autism is found in every country, ethnic ground and socio-economic class and affects males about 3 to 4 times more than females. Interestingly, there is no recorded report with the prevalence of infants with Autism in Nigeria and no noticeable work or research done on the aspect of prevalence/incidence majority of earlier reports are concerned with psychological effects on the children as well as educational implications among such children.

Autism is a developmental disability with considerable impairment in not only a child's life but also in the family. This could significantly impact on the mental and physical health of the caregiver. Mother has to come to term with having a child with an incapacitating, lifelong development disability. In addition, they are faced with various concerns such as the chronicity of care and disappointing prognosis, the effects on the family system, increased financial problems, lack of independence, the attitudes of the public towards them and the very low- levels of social support received by mother [8, 9].

Gray [10] emphasizes the importance of the child's developmental stage in determining the specific challenges that face the mother of autistic children. During the pre-diagnostic phase, mothers are often confused, anxious and highly stressed as their children's problems grow more pronounced and they struggle to obtain an accurate diagnosis and treatment for their children. Once a diagnosis has been made, the mother with an autistic child faces yet other challenges, namely learning, adjusting to and coping with the needs ends and multiple demands of such child. This stage of the child's life, however stressful, since mothers have to negotiate and interact with professionals to obtain appropriate educational and treatment if their children initially, shock may result from the news of the autism diagnosis, and the mother may further enter into denial about the accuracy of diagnosis stage or experience debilitating quit and shame that may have done something wrong during the pregnancy and developmental year of the child's life that somehow child's condition, mother struggle with the expression of anger at themselves, their spouses or perhaps at God. Anger typically gives way to bargaining, during which mothers convince themselves consciously and /or unconsciously that the child will be "cured" if they follow certain dietary or behavioural programmes and devote themselves entirely to the task of caring for the child with autism and that the symptoms of autism can diminish with persistent intervention and they can direct their energy to the realistic goal of teaching the autistic child ways to function in the real world [11].

In under developing countries like Nigeria, where there are few or inadequate respite facilities for autistic children, most caregiving in the community is carried out by the unpaid mother of autistic children, who often are without adequate information. The burden of caring for a child diagnosed with autistic disorder in a family falls mainly on the primary caregiver, who often is the mother.

Some studies have shown that primary caregivers of children with disabilities receive little or inadequate assistance from relatives

who are outsides their immediate family, leaving their mother to bear the major weight of caregiving responsibilities mothers with autistic children have been reported to experience poor physiological and emotional health consequent to the strain of care giving [12, 13]. While efforts have been made in area of care with the provision of few facilities for the care of autistic children, the burden of care, and psychological as well as social problem of the autistic child are enormous, and mothers go through a lot of stress managing the autistic children. Hence, this study was conceived to examine the psychosocial burden of mothers' care of children with autism, at Federal Neuropsychiatric Hospital, Yaba, Nigeria, with the specific objectives of the study:

1. To identify socio-demographic indices in the mothers caring for autistic children.
2. To describe the level of burden of care experience by mother caring for children with autism spectrum disorder.
3. To determine the prevalence and psychological morbidity of the mother of children with childhood autism.

Methodology

The research design adopted in this study is a descriptive research design. This study was carried out at the Child and Adolescent of Federal Neuro-psychiatric Hospital, Yaba, Nigeria, with 70 consecutively selected mothers of children with autism attending the hospital. However, sixty (60) mothers of children with childhood autism attending the Child and Adolescent Clinic met the criteria for the study.

The instrument of study was questionnaire made up of the Socio-demographic profile, General Health and Burden Interview Questionnaire and Feelings taking care of another individual. General Health and Burden Interview Questionnaire is ideal for use in the community, primary care and medical outpatient. It was used to assess for psychological distress in the mothers of children with autism. The scoring of the GHQ12 used in this study was the 0-0-1-1, and the cutoff point for psychological distress used in this study was at a score of 3 as suggested by Gureje and Obikoya [14].

The third section of the instrument was an 18-item questionnaire which assessed how a person feels when taking care of another person. There are five item responses which range from 0 to 4 and are scored as "0"= "never", 2="sometimes", "3"=quite frequently, "4"= nearly always". The rating of the sum of points gives the severity of the burden experience by the caregiver. A point of between 0-20 means little or no burden 21-40 points mild to moderate burden to severe burden, and 61-88 severe burden. A score of 40 points and below was classified as low burden, while a score above 40 points was designated high burden. This instrument has been used and found to be adequate for Nigerian subjects [15].

The data collected were statistical analyzed using SPSS version 23 for the demographic and inferential statistics. Ethical clearance was sought and obtained from the ethical and research committees of the Hospital as well as the respondents were assured of absolute confidentiality of information provided.

Results

Socio-demographic Characteristics of the Mothers of Children with Autistic Spectrum Disorder

As shown in Table 1, the mothers are predominantly urban dwellers (94.6%), Christians (83.9%), married (96.4%) and relatively young and educated (78.6% had secondary school education or above). Over 60% of them are also employed with low income (90.6% earn N100, 000.00 or less that about US$200 per month) (Table 2). This is in Lagos, Nigeria, a metropolitan city where the cost of living is quite high.

Table 1. Socio-demography of the mothers of children with Autistic Spectrum Disorder

Variable	Frequency	Percentage
Age		
>30years	17.0	30.36
31-40years	25.0	44.64
41years and above	14.0	25.00
Total	56.0	100.0
Residential Area		
Urban	53	94.6
Rural	3	5.4
Total	56	100.0
Religion		
Christianity	47	83.9
Islam	9	16.1
Total	56	100.0
Marital Status		
Married	54	96.4
Separated	2	3.6
Total	56	100.0
Years of Marriage		
<10years	17	30.4
10-20years	17	30.4
21-30years	16	28.6
>30years	6	10.7
Total	56	100.0
Educational level		
No formal Education	18	32.1
Nursery School Completed	28	50.0
Primary School Uncompleted	8	14.3
Primary School Completed	1	1.8
Total	56.0	100.0
Residential Area		
Urban	53	94.6
Rural	3	5.4
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Marital Status		
Married	54	96.4
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Years of Marriage		
<10years	17	30.4
10-20years	17	30.4
21-30years	16	28.6
>30years	6	10.7

Total	56	100.0
Employment Status		
Unemployed	21	37.5
Employed	35	62.5
Total	56	100.0

Economic Status of the Mothers of Children with Autism

As shown in Table 2, the economic status of the mothers revealed that a larger percent of 62.5% are gainfully employed, with only about 37.5% are unemployed. Out of those employed, a larger percent of about 50% fall under the monthly income of ₦50,000 and less, while another 40.6% fall under the monthly income range of ₦50,000-100,000; only a fewer percentage of 6.3% and 3.1% fall under a monthly income of ₦101,000-150,000 and ₦151,000-200,000 respectively. These show that a larger percentage of the mothers of children with Autistic Spectrum Disorder are low-income earners.

Table 2. Socio Economic Status on Mother with Autistic Children

	Frequency	**Valid Percent**
₦50,000	16	50.0
₦50,000-100,000	13	40.6
₦101,000-150,000	2	6.3
₦151,000-200,000	1	3.1
Total	**32**	**100.0**

Mental Health Status of Mothers of Children with Autism

The mental health status of mothers of children with autism was determined by GHQ median Score. Table 3 shows that 39 of the mothers had a negative health state due to the care burden, representing a 69.6% of the total respondents (mothers), while only30.4 % of the mother scored a positive health state.

Relationships between GHQ and Age of Children with Autism

The health status of the children with autism and their ages was related, as shown in Table 4.

Table 3. Mental Health Status of Mothers of Children with Autism as Determined by GHQ Median Score

Mental health status	**Frequency**	**Percentage**
Positive	17	30.4
Negative	39	69.6
Total	56	100.0

Table 4. General Health Questionnaire and Age of Children with Autism

Age	**GHQ Positive**	**GHQ Negative**	**Total**
<5years	11 (55.0%)	9 (45.0%)	20 (100.0%)
5-10years	5 (17.2%)	24 (82.8%)	29 (100.0%)
11-15years	1 (16.7%)	5 (83.3%)	6 (100.0%)
>15years	0 (0%)	1 (100%)	1 (100%)
Total	17 (30.4%)	39 (69.6%)	56 (100.0%)

Pearson Chi Square= 9.072; df=3; p-value=0.28

From Table 4, children less five years showed more positive health status than other age categories, while those aged between 11 and 15 years had more negative health status. The only child aged 15 years or more reported negative status. However, there is no statistically significant association between GHQ and age of the children with autism.

Relationships between Mothers' Level of Burden and General Health Questionnaire

In Table 5 showing the cross tabulation reveals that 82.8% of mothers of children with autistic spectrum disorder who had higher care burden also had negative health status. Also, about 62.5% of a mother with moderate care burden had a negative health status, and 45.5% of those with low care burden had a negative health status. One the other side, 54.5%t of mothers with low care burden had positive general health status. 37.5% of mothers with moderate care burden had positive health status, while only 17.2% of those with high burden had positive general health status. These reveal that as the mother care burden moves from low to high, their general health status approach negative.

Table 5. Mothers' Level of Burden and General Health Questionnaire

Burden Level	GHQ Positive	GHQ Negative	Total
Low	6 (54.5%)	5 (45.5%)	11 (100.0%)
Moderate	6 (37.5%)	10 (62.5%)	16 (100.0%)
High	5 (17.2%)	24 82.8%)	29 (100.0%)
Total	**17(30.4%)**	**39(69.6%)**	**56(100.0%)**

Pearson Chi square=5.790; df =2; p-value=0.55.

There is no statically association difference between GHQ and Burden interview.

Similarly, Table 6 reveals that overall, 80.4% of the mother's experience moderate to high burden. The care burden on the mother increases as the age of the child with Autistic disorder increases. About 45% of the mothers experience high care burden when the child was less than 5 years old, 51.7% of the mothers were freed with high care burden for children of age group 5 to 10 years, for children of 11 to 15 years of age, about 66.7% of the mother claim to experience high care burden, Also 100 percent of the mothers had high care burden for children of 15 years older with Autistic disorder. The hypothesis testing, using the chi-square with 6 degree of freedom and 5% level of significance, revealed that there is no statistically association difference between age and care burden. There is no statistically association difference between age and burden interview.

Table 6. Tabulation of Age of Child and Burden Interview

Age	Low	Moderate	High	Total
<5 years	4(20.0%)	7(35.0%)	9(45.0%)	20(100.0%)
5-10	5(17.2%)	9(31.0%)	15(51.7%)	29(100.0%)
11-15	2(33.3%)	0(0%)	4(66.7%)	6(100.0%)
>15 years	0(0%)	0.0%)	1(100.0%)	1 (100.0%)
Total	**11(19.6%)**	**16(28.6%)**	**29(51.8%)**	**56(100.0%)**

Pearson Chi square =4.090 df=6; p-value=.665

Discussion Of Findings

The Prevalence and Psychological Morbidity of Mothers' of Children with Autism

Socio-demographic Indices in the Mothers Caring for Autistic Children

A larger percent of their mothers lies between 31 to 40 years of age, mostly Christians who resides in urban areas and had a higher level of education. A larger percentage gave birth to these children when they were around 26 to 30 years of age. Majority of these mothers are gainfully employed but fall within the lower-income groups. The study confirms that the care burden has a cut down effect on the work of these women as about 52 percent indicated that the general health question also shows a more than average negativity of about 70 percent, which is believed to be spill over from the care burden for the women. Majority of them were males and in nursery schools. The order of birth shows that a higher percentage of the male first child, as reported by the American Center for Disease Control And Prevention Hopkins report [15] that "Autism occurs four times more often in boys (usually first born) than in girls. This abnormality was noticed in most of them between 6months of age and beyond. Mothers visit to a child psychiatric clinic for the first diagnosis was late, at about 1 year to 3 years of age, because about 91.1 percent of mothers have not heard of Autistic disorder at all before diagnosis.

The Level of Burden of Care Experiences by Mothers Caring for Children with Autism spectrum disorder

The study also indicated that mothers experience severe care burden, in terms of its effect on work performance, even to the extent of giving up of work for care of their children. Findings also show that mothers with higher care burden also had negative health status. These reveal that as the mother care burden move from low to high, their general health status approach negative, while their health status falls as their care burden increases from low to high. In like manner, the cross-tabulation of age of the children with Autistic spectrum disorder and burden interview of their mothers shows that care of burden on the mother increases as the age of the child with Autistic disorder increases; although these associations were not statistically significant.

In line with the previous report by Hasting and Brown [3], mothers of these children experience severe care burden, which showed that mother of children with developmental disabilities like Autistic disorder is faced with a lot of challenges which places them at risk of the high level of stress and other negative psychological outcomes. The findings by [16] linking the autistic spectrum disorder with family at the biochemical level could even contribute to the psychological burden experienced by parents, especially mothers.

Other findings appear to report similar results. For example, the study by [17] revealed that parents of children with ASD had a high caregiver burden; and they recommended many clinical implications, such as the need for nurses to take a to improve the families' capacity to mitigate such burdens of care by parents. According to them, social support networks need to be strengthened. Another study by [18] also recommended the provision of specific psychological and family supports for families with autistic children, including educational support for clinical behaviours of ASD for early detection.

Parental and family caregiver burdens are not unique to parents or caregivers of children with autism. Many other evidences show such situations. For example, the problem of psychological and economic burden in other neurological disorders has been reported in family caregivers elsewhere in Nigeria [19]. Due to the traditional set-up of the Nigerian community, such burdens are usually enormous in children with neurological deficits, especially at the psychosocial, economic and domestic

fronts [20; 21]. Like in our present study, multi-Centre studies like the study by [22] have also indicated that parents of children with ASD experience enormous caregiving burden, in addition to other factors associated with such burden, for example, psychological distress, lower social support and the differential share of such burden, with others reporting greater subjective burden than fathers. Designs of effective interventions aimed at reducing the burden among the parents of children with ASD are also highly recommended [22].

Implications for Nurse Practitioners

Community health education about the early symptoms of autistic disorder, prevention and diagnosis to discourage late contact with child psychiatric clinic and it care burden implications. Adequate professional assistance should not be given to the children alone but also the mothers of these children in order to reduce the effect of this burden on their work and health condition. Since the study discovered an increased care burden can lead to increase negative health conditions of mothers, the family members should be encouraged to assist these women, and nurses pay sufficient attention to both the children and their mothers in order to facilitate their recovery and prevent relapse. More research are also needed to further exploration for intervention models.

Conclusion and Recommendations

The result of this research shows that autism spectrum disorder remains a health problem among children in the urban areas of the country, sapping away energy from the care-givers, especially the mothers of such children. Hence, adequate support from both other families of the sick person, organizations, the government at all levels, and healthcare providers like nurses are needed. The support and care received by these sick persons have lot of effect on their improvement. Psycho-social, financial, and domestic supports will improve the health conditions of both the children and their mothers (and parents).

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Conflict of Interest

The author declares that there is no Conflict of interest.

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