



The relationship between the pattern of impairments in autism spectrum disorder and maternal psychosocial burden of care

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Abstract

Introduction

Compared with several other chronic childhood disorders, autism spectrum disorder (ASD) is a serious and disabling group of neurodevelopmental disorders. Relatively little attention has been given to its early identification and the pattern and impact of impairments' on the primary caregiver of children with autism in sub-Saharan Africa. This study determines the relationship between the type and pattern of autistic impairments found in children with autism and the psychosocial burden on their mothers.

Methods

Children ($n = 60$) with ASD and their mothers ($n = 60$) attending a child neurodevelopmental clinic in Lagos were recruited for the study over a 6-month period. Diagnosis of autism was made using the DSM-IV criteria. A symptom checklist was used to determine the pattern of impairments found in each child with a diagnosis of autism. The 12-item General Health Questionnaire and the Zarit Burden Interview were used to assess psychological distress and social burden, respectively, in the mothers of affected children.

Results

Children with ASD had impairments in social, communication

and behavioural areas. On bivariate analysis, the presence of social type of impairments and a large number of impairments were significantly associated with psychological distress and burden in mothers. Following multiple linear regression, only a large number of impairments ($\beta = 0.484$, 95% CI = 0.090 – 0.877, $P = 0.017$) remained significantly and independently associated with psychological distress in the mothers.

Conclusion

The number and type of impairments found in children with autism affect the psychological health and social burden of their mothers. Clinicians assessing children can use this information to determine the degree of support to be given to carers. Implementation of early intervention programmes is critical for early detection of autism as well as for the reduction of burden on mothers of such children in the West African region.

Introduction

Autism spectrum disorder (ASD) is a complex, disabling, lifelong neurodevelopmental group of disorders^{1,2}, which afflict a child usually before the age of 36 months. Impairments in ASD affect virtually all aspects of the child's functioning. However, three key areas are majorly affected^{2,3}. One of these areas is the area of social skills, from which the term 'autism' was derived. The other two core areas of deficits are with communication and behavioural skills^{2,4}. ASD is found in every country, ethnic group and socioeconomic class; it afflicts males about three to four times more than females². A child with autism may experience sensory

and intellectual impairments^{5,6}, with possible deficits in educational attainment and self-care skills. Problems associated with impairments in autism (social, communication and behaviour) may have profound effect on the level of care provided by the mother and may be a major factor in the caregiver burden.

Caring for a child with autism has been associated with family stress, and increase in physical and emotional problems, especially in mothers⁷⁻⁹. Compared with other types of disabilities, mothers of children with autism have to manage and cope with the various forms of severe impairments present in the child and bear the psychological, social, financial and social brunt of their child's condition. They have been observed to be prone to social isolation, 'burn out syndrome' and at a higher risk of developing psychological disorders such as depression and anxiety⁹⁻¹². Despite the seriousness of this impact, facilities and measures that could strengthen this unpaid carer with a potential of reducing the burden of care are either lacking or deficient in developing countries. In Nigeria, for example, there are scarce facilities for the care of children with autism^{5,13,14}; hence family caregivers bear virtually all the burden of care¹⁵.

A search of the literature revealed a scarcity of data on the relationship between impairments in autism and the burden of care experienced by mothers of children with autism in sub-Saharan Africa. In addition to dearth of studies, many of the few studies on this issue are limited in their lack of an objective confirmation of diagnosis

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of autism as well as associated burden. This study aims to determine the association between autistic impairments and the psychosocial burden of care on mothers of children with ASD in Nigeria. The emergent findings will expand knowledge on the caregiver burden for autism and will help to provide a basis for instituting appropriate interventions for early detection of autism and reduction of burden on mothers of the affected children, especially in low-resource countries.

Materials and methods

This work conforms to the values laid down in the Declaration of Helsinki (1964). The protocol of this study has been approved by the relevant ethical committee related to our institution in which it was performed. All subjects gave full informed consent to participate in this study.

Participants and sampling

Sixty mothers and their children ($n = 60$) who had autism, recruited from the Neurodevelopmental Child Clinic of Federal Neuro-Psychiatric Hospital Lagos, participated in the study. This clinic is one of the few child psychiatric clinics in Nigeria and the biggest in terms of structure, services and manpower in Nigeria. The clinic caters for children and adolescents below the age of 18 years with mental health problems and also receives referral from other parts of the country. The children with autism recruited for this study were those that resided with their biological mothers. Those mothers were in charge of the child's care and had been taking care of them since birth.

Materials and procedure

A sociodemographic questionnaire, General Health Questionnaire-12 (GHQ-12), Zarit Burden Interview (ZBI) and a symptom checklist for autism were used for data collection.

The sociodemographic questionnaire covered questions such as the

child's age, sex, birth order and level of education. Details on the mother's age, marital status, level of education, employment status and the type of occupation were also required.

GHQ-12 is a self-administered tool used in this study to assess psychological distress in the mothers of children with autism. It is ideal for use in the community, primary care and medical outpatients¹⁶. GHQ-12 has been validated for use in Nigeria¹⁷. The GHQ validity coefficients, reported locally, at the 0/1 cut-off are specificity 74%, sensitivity 67%, positive predictive value 59%, negative predictive value 80% and overall misclassification rate 29%. This version of the GHQ contains only 12 questions. It was preferred to the other versions because it is quick to administer, easy to score, reliable, valid and as sensitive as the other longer versions of the GHQ. Like other versions of the GHQ-12, its answer options are 'Better than usual', 'Same as usual', 'Worse than usual' and 'Much worse than usual'. The scoring of the GHQ-12 used in this study was the 0-0-1-1, and the cut-off point for psychological distress used in this study was at a score of 3 points as suggested by previous studies in Nigeria¹⁷. Mothers with a GHQ-12 score of 2 or below were classified as having no psychological distress, while those with a score of 3 and above were deemed to have psychological distress. Both the English and the Yoruba versions were used in this study.

ZBI¹⁸ is a self-administered, 22-item questionnaire, which assesses how a person feels when taking care of one's relative. A slight modification made on this instrument was that the word 'relative' was modified to 'child'. There are five-item responses that range from 0 to 4 and are scored as '0 = never', '1 = rarely', '2 = sometimes', '3 = quite frequently' and '4 = nearly always'. The rating of the sum of points gives the severity of the burden experienced by the caregiver. A point of between 0 and 20 represents

little or no burden, 21 and 40 points mild-to-moderate burden, 41 and 60 points moderate-to-severe burden and 61 and 88 points severe burden. In this study, the level of burden was dichotomized into low burden and high burden. A score of 40 points and below was classified as low burden, while a score of above 40 points was classified as high burden.

The authors developed a symptom checklist for autism by using the DSM-IV criteria. It consists of 20 symptoms of autism. On this checklist, there are seven symptoms on the social impairment subdivision, five on the communication subdivision and eight symptoms on the behavioural subdivision. Responses on the checklist were rated as either Yes (1 point) or No (0 point). The checklist was pilot tested on 10 children with autism and found to have good face validity and test-retest reliability of 0.91 kappa. The checklist was administered to mothers of children with autism. The checklist assesses for the presence or absence of autism in the three core areas of impairments (social, communication and behavioural). In addition, it was used to determine the pattern of autistic impairments present in the affected child.

The study instruments, except GHQ-12, which has a Yoruba version, were translated into Yoruba by a Yoruba-speaking psychiatrist and a linguist. A different psychiatrist and linguist independently performed the back translation. Before use, the back translation was compared with the original translation by an independent panel and confirmed to be satisfactory.

Procedure

DSM-IV criteria were used to make a diagnosis of autism in all the children whose mothers were recruited for this study. The process of making diagnosis of autism was carried out in two stages. First, clinicians carried out a detailed psychiatric assessment on all the children with previous

diagnoses of autism and any suspected new patients. A diagnosis of autism was then made using the DSM-IV criteria. Second, the symptom checklist designed based on the DSM-IV criteria was then used to determine the pattern of impairments present in each child with DSM-IV diagnosis of autism.

All the mothers of children with autism who met the inclusion criteria were interviewed individually, in the consulting rooms, on their various clinic days. The instruments of the study were administered to mothers. They were interviewed in either English or Yoruba. Those participants who could not communicate in English were interviewed in Yoruba. The literate mothers ticked the appropriate answers by themselves, while the authors read out the questions and responses to those that were illiterate as well as helped them tick the responses chosen by them.

Data analysis

SPSS version 16 software was used to analyse the data. Frequencies, proportions, means and standard deviations were calculated. Comparison of categorical data was by chi-square. Analysis of variance (ANOVA) was used to find association between psychosocial burden and types and pattern of impairments in autism. All the significant variables were entered into a multiple linear regression to show any independent significant relationships. The entire tests were two-tailed, and the level of significance was set at $P < 0.05$. β and 95% CI were calculated for the significant variables.

Results

Sixty children with diagnosis of autism and their corresponding mothers ($n = 60$) were recruited for the study. Seventy per cent of the children were males; their ages ranged from 2 to 17 years with a mean age of 9.45 ± 4.33 . The sociodemographic characteristics of the children are summarized in Table 1.

Table 1 Sociodemographic characteristics of children with ASD ($n = 60$)	
Variables	n (%)
Age range	
Mean	9.45
SD	4.33
Range	2–17 years
Sex	
Males	42 (70.0)
Females	18 (30.0)
Educational level	
None	25 (41.7)
Nursery uncompleted	24 (40.0)
Primary uncompleted	10 (16.7)
Primary completed	1 (1.7)
Birth order	
First child	23 (38.3)
Middle child	19 (31.7)
Last child	18 (30.0)

Table 2 summarizes the sociodemographic characteristics of the mothers. Their age range was 25–54 years with a mean age of 38.93 ± 6.99 . Majority of the mothers were Christians (78.3%), resided in urban area (66.7%), were aged 40 years and below (65%), were married (90%) and had a minimum of secondary school education (63.3%).

All the children in this study met the DSM-IV diagnostic criteria for autistic disorder. On the symptom checklist, the score on the social impairment domain ranged from 4 to 7 with a mean score of 4.65 ± 0.86 ; communication impairment domain was 2–5 with a mean of 3.85 ± 0.79 , while the behavioural impairment domain ranged from 1 to 8 with a mean of 5.08 ± 1.63 . The sum impairments (total number of impairments) score ranged from 9 to 17 with a mean score of 13.58 ± 1.97 . Using the mean score as a cut-off point, scores on these subdivisions were dichotomized into low (below

Table 2 Sociodemographic characteristics of mothers of children with autism ($n = 60$)	
Variables	n (%)
Age	
Mean	38.93
SD	6.99
Range	25–54 years
Marital status	
Currently married	54 (90.0)
Separated/divorced/widowed	6.0 (10.0)
Religion	
Christianity	47 (78.3)
Islam	13 (21.7)
Family setting	
Monogamous	57 (95.0)
Polygamous	3.0 (5.0)
Educational level	
Primary or less	22 (36.7)
Secondary	14 (23.3)
Tertiary	24 (40.0)
Residence	
Urban	40 (66.7)
Suburban	17 (28.3)
Rural	3.0 (5.0)
Number of living children	
One to two children	18 (30.0)
Three to five children	34 (56.7)
Six to seven children	8 (13.3)
Level of husband support	
Poor/fair	11 (18.3)
Good	49 (81.7)
Occupation	
ISCO class 1–3	9 (15.0)
ISCO class 4–6	31 (51.7)
ISCO class 7–9	4 (6.7)
Unemployed	16 (26.7)
Income/month (USD)	
Nil	16 (26.7)
<60 USD	30 (50.0)
60–300 USD	14 (23.3)

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mean score) and high (above mean score) impairment scores.

The GHQ-12 scores obtained by mothers of children with autism ranged from 0 to 11 with a mean of 4.30 ± 3.46 . Sixty-five per cent of mothers scored 3 points and above (classified as having psychological distress). The ZBI score for the mothers ranged from 1 to 81 with a mean of 47.63 ± 13.66 . A little or no burden (0–20 scores) was experienced by 1.7% of the mothers, 28.3% had mild-to-moderate burden (21–40), 58.3% had moderate-to-severe burden (41–60), while 11.7% of them had severe burden (above 60 scores). Using 40 as a cut-off point, the level of burden was then dichotomized into low burden (score ≤ 40 points) and high burden (>40 points). Thirty percent of the mothers were then classified as having low burden, while 70% as were classified as having high burden.

The relationship between GHQ-12 score of the mothers and their child's autistic symptom score is summarized in Table 3. The majority of mothers with children with a high number of impairments in all the domains/subdivision of impairments had a GHQ-12 score of ≥ 3 ; this was found especially for high scores in the social impairment subdivision. Table 4 summarizes the relationship between ZBI scores of the mothers and the number of impairments present in the child. The findings observed in this table are similar to that seen with the mothers' GHQ-12 scores (Table 3).

ANOVA was used to test for the associations between both GHQ-12 and ZBI scores and the mean scores of each type of impairment as well as the sum impairments present in a child with autism. It was observed that, although there were no statistically significant associations between the communication ($F = 0.474$, $P = 0.520$) and the behavioural forms of impairment ($F = 3.691$, $P = 0.060$) and the mothers' GHQ-12 score, there

Impairments	GHQ-12 < 3	GHQ-12 ≥ 3	Total (%)	Differences
	$n = 21$ Frequency (%)	$n = 39$ Frequency (%)		
Social domain				
1–4 points	18 (52.9)	16 (47.1)	34 (100)	$\chi^2 = 11.101$ df = 1 $P = 0.001^*$
5–7 points	3 (11.5)	23 (88.5)	26 (100)	
Communication domain				
1–3 points	9 (40.9)	13 (59.1)	22 (100)	$\chi^2 = 0.533$ df = 1 $P = 0.465$
4–5 points	12 (31.6)	26 (68.4)	38 (100)	
Behavioural domain				
1–5 points	14 (46.7)	16 (53.3)	30 (100)	$\chi^2 = 3.590$ df = 1 $P = 0.058$
6–8 points	7 (23.3)	23 (76.7)	30 (100)	
Sum impairments				
1–13 points	16 (53.3)	14 (46.7)	30 (100)	$\chi^2 = 8.864$ df = 1 $P = 0.003^*$
14–20 points	5 (16.7)	25 (83.3)	30 (100)	

*Significant.

were significant differences in the social type of impairment ($F = 13.169$, $P = 0.001$) as well as the sum impairments present in the child ($F = 10.054$, $P = 0.002$) and the mothers' GHQ-12 scores. Also, although there was no significant association between ZBI score and communication ($F = 0.053$, $P = 0.819$) as well as behavioural impairments ($F = 2.900$, $P = 0.094$), the findings revealed a statistically significant relationship between the burden experienced by the mothers of children with autism and the social type of impairment ($F = 8.218$, $P = 0.006$) as well as the sum impairments present in the child ($F = 5.324$, $P = 0.024$).

To test for independent association between the variables and psychosocial burden, the significant variables associated with psychosocial burden were entered into a multiple linear regression. Total number of

impairments was the only variable found to be significantly and independently associated with maternal psychological distress ($\beta = 0.484$, 95% CI = 0.090–0.877, $P = 0.017$).

Discussion

ASD is characterized by the presence of deficits in three major areas of impairments – socialization, communication and behaviour. Disabilities affecting these three areas of functioning can be devastating. Although a few documented studies have examined the relationship between autistic impairments and the stress on mothers/caregivers, there is virtually no information on this subject in sub-Saharan Africa. This study assessed the relationship between the pattern of impairments in autism and psychosocial burden on mothers of affected children in African culture.

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Table 4 Relationship between burden experienced by mothers and autistic impairments ($n = 60$)

Impairments	Burden level		Total (%)	Differences
	Low burden (≤ 40) Frequency (%)	High burden (> 40) Frequency (%)		
Social domain				
1–4 points	15 (44.1)	19 (55.9)	34 (100)	$\chi^2 = 7.447$ df = 1 $P = 0.006^*$
5–7 points	3 (11.5)	23 (88.5)	26 (100)	
Communication domain				
1–3 points	7 (31.8)	15 (68.2)	22 (100)	$\chi^2 = 0.055$ df = 1 $P = 0.815$
4–5 points	11 (28.9)	27 (71.1)	38 (100)	
Behavioural domain				
1–5 points	12 (40.0)	18 (60.0)	30 (100)	$\chi^2 = 2.857$ df = 1 $P = 0.091$
6–8 points	6 (20.0)	24 (80.0)	30 (100)	
Sum impairments				
1–13 points	13 (43.3)	17 (56.7)	30 (100)	$\chi^2 = 5.079$ df = 1 $P = 0.024^*$
14–20 points	5 (16.7)	25 (83.3)	30 (100)	

*Significant.

The results of our study showed that the higher the number of impairments present in a child with ASD, the higher the psychosocial burden experienced by the mother. This observation is in keeping with the results of previous studies that found an association between the stress experienced by mothers of children with autism and the number or type of autistic impairments^{19–22}. Though earlier studies observed that multiplicities of the child's impairments are significantly associated with stress in the mothers, however many of those studies examined individual symptom without relating their findings to the core group of impairments in autism^{20,21}. For instance, Milgram and Atzil²¹ administered a parenting satisfaction questionnaire on 23 mothers of autistic children between the

ages of 7 and 14 years in Israel and observed that the higher the number of autistic symptoms present in the child, the higher the stress of the mothers/caregivers. The instrument used in their study to assess levels of stress comprised of a list of tasks that mothers had to attend to in caring for an autistic child, while core areas of impairments in autism were not specifically assessed.

Although we found that maternal psychological distress increases with higher number of autistic impairment, this relationship was particularly significant for the number of impairments in the social deficit subdivision. Our finding is in accordance with that reported by previous studies. A study by Allik et al.²⁰, in Sweden, showed an association between psychological well-being of mothers

of children with autism and impairments. Using a 12-item Short-Form Health Survey (SF-12), the authors observed that the mental health component of the SF-12 (MCS-12) showed that the higher the difficulty in the child's social relationships, the greater the psychological stress of the caregiver.

Another important finding in this study was an association between the type of impairments and psychological distress. Just as was illustrated with the number of impairments, the social type of impairment was significantly associated with high levels of maternal psychological distress, similar to a report of the work by Allik et al.²⁰ Their study used the Strength and Difficulty Questionnaire to measure the extent of social difficulty and other psychopathologies in autism and found that psychological distress was significantly associated with impairment in a child's social relationships.

The findings from our study are not surprising, as social impairment is considered a hallmark feature of autism²³. Human beings are social animals; hence, disabilities that affect the social interactive capability can be devastating, not only for the affected child but also for the mother. The relationship between maternal stress and social type of impairment could also be related to the social stigma attached to this disabling condition. Social deficits are difficult to cope with, especially in a situation of a high social stigma. Social stigma is a universal phenomenon which has been described as high in West African countries^{14,24,25}. In a study carried out in Nigeria, Odejide et al.²⁴ demonstrated that the society considers individuals with disabilities as a mark of shame on their families. Information about specific areas of impairment associated with burden of care in autism could be of help in designing and implementing appropriate interventions to help mothers understand and cope with the behaviour of a child with autism.

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Our study had some limitations. The study population comprised individuals in a hospital setting; a caution is required in inferring the findings to what obtains in the community. The strengths of the study lie in the use of a well-defined study sample, comprising 60 children with DSM-IV diagnosis of autistic disorder and their corresponding mothers. The study also made an objective assessment of the relationship between autistic impairments and maternal psychosocial burden of care.

Conclusion

This study revealed that caring for children with autism constitute a significant source of burden on mothers of affected children. Impairment in childhood autism has a direct relationship with maternal psychosocial burden of care. While both high social impairment score and number of autistic impairment were indices significantly associated with psychosocial burden in mothers caring for children with autism, only a high number of autistic impairment was predictive of maternal psychosocial burden.

The implications of these findings are enormous. First, it suggests that there is a high psychosocial burden of care on mothers of children with autism. The impact of this could affect even the health of the child being cared for. Targeting mothers at risk will go a long way in reducing the burden of care on the mothers and reciprocally improve the health of affected children and the society at large. The direct relationship between autistic impairments and burden experienced by the mothers also support the need to incorporate the screening of affected mothers for psychological distress into the psychiatric assessment of their child. In addition, the findings of our study could also give baseline information to the attending clinicians on the level of support required by mothers caring for such children. Longitudinal

studies addressing this issue in sub-Saharan Africa are highly desirable.

Abbreviations list

ANOVA, analysis of variance; ASD, autism spectrum disorder; GHQ, General Health Questionnaire; ZBI, Zarit Burden Interview

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