

The Impact of Autism Spectrum Disorder in Comparison with Other Neuro-Developmental Disorders in Children on the Family: Single Centre Experience

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ABSTRACT

Background: Neurodevelopmental disorders (NDD), especially autism spectrum disorder (ASD), have a substantial impact on the family, with a consequent decrease in the quality of life. The current study was undertaken to understand if having ASD contributed to a higher impact on families compared to other NDD and to understand additional factors impacting families of children with either disorder in a low-middle income country (LMIC) setting. **Methods:** Impact of ASD and other NDD along with sociodemographic factors was examined, by a retrospective analysis, among 540 children in a tertiary care center in South India. **Results:** Both ASD and NDD had high, but comparable, impact on the family. Being a girl child, having seizures, and having sleep problems predicted a higher impact. **Conclusions:** In children with NDD, managing co-morbidities such as achieving better seizure control and addressing sleep-related problems may improve the impact of NDD on the family. Gender disparity in disability needs to be studied within the local cultural context.

Key words: Autism spectrum disorders, children, impact on family, neurodevelopmental disorders

Key messages:


- Autism spectrum disorder and neurodevelopmental disorders had high, but comparable, impact on the family.
- Being a girl child or having comorbid epilepsy or sleep problems had a higher impact on the family.
- Early identification and appropriate interventions of the comorbid problems are necessary in children with neurodevelopmental disorders.

Neurodevelopmental disorders (NDD), including autism spectrum disorder (ASD), have a multi-faceted impact on the family, including restriction of parental

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time and occupation, family and societal relationships. They also affect the physical as well as psychological well-being of the family members and cause a significant financial burden.^[1] Raising a child with NDD contributes to an increase in parental mental health problems and parental stress with a decrease in well-being and quality of life.^[2] ASD is reported to have a higher impact than other NDD, probably due to the pervasive nature of ASD along with limited services and support systems for these families in comparison to other NDD such as cerebral palsy.^[3-6] Compared to high-income countries, care and support systems for all NDD are still only evolving in the low-middle income countries (LMIC), compounding their overall impact on the families. NDD, including ASD, have a high impact on families in the LMIC, resonating similar trends across the world.^[7-14] The current study was undertaken to understand if having ASD contributed to a higher impact on families compared to other neurodevelopmental disorders and to understand additional factors impacting families of children with either condition in a LMIC setting.

METHODS

The present retrospective study was conducted using the inpatient database of all children admitted to a residential facility attached to the Developmental Paediatrics Unit in a tertiary care center in South India from 1st January 2015 to 31st December 2016, i.e., over 2 years. Each child was diagnosed and interventions planned by a multidisciplinary team of developmental pediatricians, psychologists, and therapists. The ASD diagnosis was confirmed by Diagnostic and Statistical Manual of Mental Disorders-fifth edition (DSM-5) diagnostic criteria and Childhood Autism Rating Scale-Second edition (CARS-2). The current study was approved by the institutional review board. All families, on admission, had given the written consent for anonymized data to be used for annual statistics and research. Information about all children admitted is kept in an anonymized departmental database for annual statistical analysis and is password protected.

Measures

All children admitted to the inpatient facility underwent a detailed history taking and neuro-developmental examination. Separate single item questions were asked to the parents about the presence of seizures and sleep and feeding problems as part of the standard co-morbidity questionnaire (developed in the Developmental Paediatrics Unit) administered to all children who visit the Unit. Information about socioeconomic factors, such as maternal and paternal education and employment, were also collected. The developmental assessment was done for all children

by trained clinical psychologists, using Griffith Mental Developmental Scale (GMDS), and adaptive skills were assessed using Vineland Adaptive Behavior Scales or Vineland Social Maturity Scale (VSMS).

Vineland Adaptive Behavior Scales-Second Edition was used to assess adaptive behavior in four domains: communication, daily living skills, socialization, and motor skills. It provides standard scores in each of the domains and an overall adaptive behavior composite. Lower scores indicate greater impairment in adaptive functioning.^[15]

VSMS estimates the social age (SA) and social quotient (SQ) and the score shows a high correlation (0.80) with intelligence. It is designed to measure social maturation in eight social areas: self-help general (SHG), self-help eating (SHE), self-help dressing (SHD), self-direction (SD), occupation (OCC), communication (COM), locomotion (LOM), and socialization (SOC). The scale consists of 89 test items grouped into year levels. It can be used for the age group of 0–15 years.^[16]

GMDS is used to assess the development of a child from 0 to 8 years across six separate subscales: locomotor, personal-social, language, eye-hand co-ordination, performance, and practical reasoning.^[17]

Childhood Autism Rating Scale-Second Version (CARS-2) was scored for all children with ASD. This behavioral rating measure is used to identify children with autism and rates the severity of their behavior using 15 items, with the final score ranging between 15 and 60.^[18]

Other informal assessments developed by the Unit were also used to monitor play, behavior, and social interaction. Global developmental delay was considered if there were deficits in more than two domains of development, including fine motor skills, language, social skills, and cognition.

The revised Impact on Family Scale (IOF) was used to assess parents' perceptions about the impact on the family and has 15 items and one factor. Parents can rate each item on a four-point Likert scale as 1–“strongly agree”; 2–“agree”; 3–“disagree”; or 4–“strongly disagree” with the items reverse scored as necessary. The scale has acceptable reliability and validity.^[19,20] It is routinely administered to all families in the inpatient setting to assess the impact of NDD and to provide appropriate support. Parents who could understand English completed the questionnaire by self, while others used the help of one of the investigators. An item score of >1 and a total score >15 are considered

to indicate an impact on the family.^[19,20] For analysis, missing values were excluded from the final analysis. The IOF score was taken as a categorical variable, with values above the 66th centile considered as high impact and the ones below, low impact. Bivariate analysis was done between the IOF score and the diagnosis to evaluate the odds ratio with a 95% confidence interval. Further, a multivariate logistic regression was done, adjusting for other variables such as sex, age, presence of developmental delay, paternal and maternal education, and co-morbidities such as seizures, sleep problems, and feeding problems.

RESULTS

The study group had 540 children, with a male preponderance [Table 1]. The group consisted mainly of higher educated mothers and fathers with either a graduate or postgraduate degree. 45.2% of children had a diagnosis of ASD, while the diagnosis of other NDD, including cerebral palsy (CP), dysmorphic states, and specific language disorders accounted for the rest. Two children had a co-existing diagnosis of CP and ASD. The majority of children had developmental delays, and approximately a fourth had seizures. Sleep and feeding problems were present in 25.1% and 12.2%, respectively. Incomplete IOF forms were found in 51 children and were excluded from the final analysis.

All families reported a high impact with a mean (\pm SD) of 38.14 (\pm 11.0). All items of the impact questionnaire had a comparable impact on both ASD and other NDD. Both sets of parents reported “being tired” as the highest impact item.

There was no significant difference between the impact of ASD and other NDD [OR (odds ratio): 1.08, Table 2]. Being a girl child (OR: 1.69) and associated problems such as seizures (OR: 2.60) and sleep problems (OR: 1.70) predicted a higher impact on family, which remained significant in multivariate logistic regression.

DISCUSSION

The impact of NDD, including ASD, in different cultural contexts needs to be evaluated not only to understand the spectra of influences of these conditions but also to devise culture-specific measures to modulate their impact. The main objective of this study was to understand the factors that impact Indian families of children with either ASD or NDD and to explore whether this impact differed for each of these conditions. Current reviews on the impact on families of children with NDD have predominantly covered research from high-income countries and reported higher stress for

Table 1: Demographic characteristics of the study group (n=540)

Variable	Category	n (%)
Gender	Boys	398 (73.7%)
	Girls	142 (26.3%)
Diagnosis #	ASD:	244 (45.2%)
	Others:	294 (54.4%)
Age	≤5 years	408 (75.6%)
	>5 years	132 (24.4%)
Development (%)	Global delay	510 (94.4%)
	No global delay	30 (5.6%)
Seizures (%)	Absent	396 (73.3%)
	Present	144 (26.7%)
Sleep problems (%)*	Absent	404 (74.8%)
	Present	135 (25.0%)
Feeding problems	Absent	474 (87.8%)
	Present	66 (12.2%)
Maternal education**	≥Graduate	337 (62.4%)
	Lower	193 (35.7%)
Paternal education**	≥Graduate	342 (63.3%)
	Lower	188 (34.8%)

#2 children had cerebral palsy and ASD. *1 missing value. **10 missing values. ASD–Autism spectrum disorder

parents of children with ASD than those with other NDD.^[6,21] Subsequent studies after the reviews have also confirmed that parental stress is higher in ASD compared to children with developmental delay or typically developing children.^[22,23]

Literature from India has reported that families of children with NDD show higher financial problems and parental health concerns; decreased social relationships, social support, and quality of life; and increased worry for the future of the affected child.^[10,11] Though limited facilities available for children with NDD remain a concern across the studies, a few have highlighted the cultural burden for parents of a child with NDD in the LMIC: These include, but are not limited to, parental guilt, generalized perception of parental “bad karma” or the punishment of God responsible for the disability, blame on the mother, and societal exclusion.^[8,9]

Studies have shown multi-dimensional impact of ASD, including occupation discontinuation and personal time constraints on parents. Several unmet needs, with sub-optimal service provisions, were compounded by a low awareness of the society, a negative outlook toward disability, and stigma and discrimination.^[24-26] The parental and family adaptation and coping to disability are aided by positive supportive family and social environs, including sociocultural factors.^[26] Religion and spirituality can aid in this coping process in multi-cultural societies such as that of India.^[13]

Our current study, though observational, is the first quantitative study from India analyzing the impact

Table 2: Risk factors for high impact on family of children with neurodevelopmental disorders

Risk factor	Impact of family		Unadjusted OR (95% CI)	Adjusted OR (95% CI)
	High impact No. (%) (n=159)	Low impact No. (%) (n=328)		
Females	53 (33.3%)	75 (22.9%)	1.69 (1.11-2.56)*	1.67 (1.09-2.59)#
ASD	64 (40.3%)	158 (48.1%)	0.72 (0.49-1.07)	1.08 (0.68-1.70)
Older age	41 (25.8%)	76 (23.2)	1.15 (0.74-1.78)	0.99 (0.60-1.63)
Developmental delay	152 (95.6%)	311 (94.8%)	1.19 (0.48-2.92)	0.95 (0.33-2.69)
Seizures	63 (39.6%)	66 (20.1%)	2.60 (1.71-3.95)*	2.49 (1.55-3.98)#
Sleep problems	52 (32.7%)	73 (22.3%)	1.70 (1.11-2.59)*	1.63 (1.02-2.60)#
Feeding problems	21 (13.2%)	37 (11.3%)	1.19 (0.68-2.12)	0.85 (0.45-1.61)
Higher maternal education	92 (57.9%)	198 (60.4%)	0.85 (0.57-1.29)	0.85 (0.51-1.42)
Higher paternal education	104 (65.4%)	206 (62.8%)	1.09 (0.71-1.65)	1.34 (0.80-2.26)

OR - Odds ratio, ASD–Autism spectrum disorder. * $P < 0.05$, Bivariate analysis, # $P < 0.05$

of ASD along with that of other NDD. The finding of comparable high impact of both ASD and NDD in our study, unlike the findings from high-income countries, might be related to sub-optimal service provisions for both the conditions in the LMIC setting. Resources, awareness, facilities for early diagnosis, and interventions for other NDD are available and accessible in most high-income countries. The evolving status of definition, diagnosis, and interventions for ASD, along with the requirements of highly intensive therapy, might add additional stressors for families of children with ASD in such settings.^[27,28] Service provisions for all NDD are in a preliminary state in India, leading to the finding of a uniformly high impact on the families.

Parents of girls from either group reported a higher impact than parents of boys. The gender disparity of favoring a boy child has been prevalent in many sociocultural contexts in India, starts even before birth, and is mirrored in the current analysis of the impact on the family.^[29] The discrimination against girls is reflected in both the smaller number of girls seeking medical attention and intervention compared to boys in our study as well as being a girl considered a significant factor for impact on families.

Comorbid medical and psychological problems can worsen the impact of NDD.^[3] In the current study, the presence of seizures predicted a higher impact on the family, as is documented in other studies.^[30,31] Caring for a person with seizures/epilepsy can be challenging in terms of acute care during an episode as well as daily prophylactic medications. Moreover, the presence of seizures can indicate a higher severity of the condition, such as in the case of cerebral palsy, which also contributes to a higher impact.^[30] Sleep problems in children with NDD can impact the child's behaviors and academic achievement as well as parental sleep patterns, thus affecting the overall quality of life of the family. The high impact of sleep problems as reported in the current study is in line with the existing literature.^[32,33] In our study,

the presence of developmental delay did not predict a higher impact on the family, which is contradictory to available reports.^[28,34] This might probably be due to a high percentage of children with global developmental delay in the inpatient population in this analysis.

There are limitations to this study, including it being an observational retrospective analysis done in a tertiary care center. There can be questions raised about the generalizability of study findings. However, this study highlights the high and comparable impact of both ASD and NDD in the LMIC setting and brings to the fore sociocultural factors such as gender disparity. Future neuro-developmental studies in India need to incorporate local cultural factors for better understanding. This study also highlights that clinicians taking care of children with NDD should evaluate and manage co-morbidities because additional co-existing conditions can impact families. Optimal management of co-morbidities, such as seizure control and ensuring better sleep quality, using either non-pharmacological or pharmacological measures, can improve the overall quality of life of the family.

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Conflicts of interest

There are no conflicts of interest.

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