July 2024 | Volume 2 | Issue 3 | RNI No.: MPENG/2022/83989 | Quarterly

ISSN : 2583-9454 (PRINT)
ISSN: 3048-4871 (ONLINE)

IJDBP

Indian Journal of Developmental & Behavioral Pediatrics

Official Journal of IAP Chapter of Neurodevelopmental Pediatrics

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CONTENTS

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Dr. Zafar Mahmood Meenai
Director, Ummeid Child Developement Centre,
Z-30, Meena Tower, Polytechnic Main Road, Civil Lines, Bhopal-462002
Mobile : +91-8989039786 **Email :** editor.ijdbp@gmail.com
Journal Website : https://ijdbp.in **Chapter Website** : https://iapndp.org

PUBLISHED BY

IAP Chapter of Neurodevelopmental Pediatrics
7th Floor, IMA House, Jawaharlal Nehru International Stadium Road, Palarivattom, Cochin, Keral-682025
Email : cdgiap@gmail.com, **Website** : www.iapndp.org

PRINTED BY

Aadarsh Pvt. Ltd.
Shikhar Varta, 4, Press Complex, Zone-I, M.P. Nagar, Bhopal-462 011 (M.P.) INDIA
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Aims and Scope of Indian Journal of Developmental and Behavioural Pediatrics (IJDBP)

IJDBP is a specialty journal in Developmental and Behavioural pediatrics published by Indian Academy of Pediatrics Chapter of Neurodevelopmental Paediatrics

The Journal welcomes Original papers, Review articles, Case reports and other articles relevant to child development & Behaviour including :

- Neuro developmental disorders,
- Developmental delays,
- Behavioural issues,
- Autism,
- Attention deficit hyperactivity disorder,
- Learning difficulties,
- Intellectual disabilities,
- Evidence based role of early intervention,
- Family centred multidisciplinary intervention,
- Neurogenetic disorders affecting child development,
- Neuroimaging & Neurological issues affecting child development,
- Corrective and assistive surgeries
- Home environmental and environmental issues affecting child development,
- Medical conditions
- Low birth weight and High-risk neonate requiring neonatal intensive care & its outcome,
- Preventive aspects in adolescents and pregnancy.
- Management of conditions covered in Rights of Persons with Disability Act,2016 of GOI.

It aim to promote advances in research in the field of child development and Behavioural issues so that latest evidenced based information is shared to enhance the quality of care and improve lives of children with special needs and their families.

The journal will be National Double Blind Peer review Open access journal published Quarterly. We will accept for publication manuscripts that were not published earlier in any form. The journal is devoted to publishing quality papers based on original innovative and most advance research in the field of developmental behavioural pediatrics.

The Journal aims to have the highest possible ethical and publication standards by scrutinizing the papers, through peer review assisted by eminent experts from prestigious teaching institutes from the country. For all Manuscripts submitted the journal will employ a plagiarism detection system for detecting plagiarism against previously published work.

INVITED GUEST EDITOR

Paediatrics is a multidimensional field with growth, development and behaviour as integral and important aspects. Owing to the epidemic of Autism and ADHD in the last few years, the focus of Paediatrics is shifting from infectious disorders to the field of development paediatrics.

Rapid urban shifts of families, competitive spirit, and economic challenges of modern society have made both parents work and adopt the one-child policy. These issues have a significant impact on child emotional, cultural, nutritional and social environment thus affecting their development.

We are already witnessing parents' growing concerns about their child's psychosocial development and academic performance. Rearing a child into a mature, independent, responsible, and sensitive individual adult requires the contribution of parents, teachers, caretakers, professionals, and society in general. Though we know the clinical signs, early makers, and diagnostic criteria of these disorders which is getting revised by international agencies but clearcut aetiology is still uncertain and considered to be multifactorial. This is a crucial time to understand this challenge and needs the contribution of all stakeholders and policymakers and involve them in research of this important field of child & development.

Addressing this burning issue, the Neurodevelopmental paediatrics chapter of IAP is doing phenomenal work for last few years and delivering its best by creating awareness among the masses through its public awareness programs and creating a brigade of young child developmental paediatricians across the country. Journals are the mirrors of facts and truths we all need to know. They provide us with scientific credibility of the data available to us through evidence-based medicine based on which medical practitioners can plan their treatment, management, and interventions. But collecting authentic research needs effort, attitude, patience, knowledge, and good teamwork. With the sustained efforts of this competent editorial team, this tremendous work is getting done and available to you through the articles in this journal. With the persistence of this academic agenda, together we can definitely make an impeccable impact in improving the children of our country with psychosocial issues and developmental deficits. Kudos & congratulations to editor in chief Dr. Zafar Meenai & the editorial team of the IJDBP for this academic venture and special compliments for inspiring the clinicians to do research in this crucial field of Child Growth, Development, and Behavioural issues.

With Regards & Best Wishes,

Dr Uday Bodhankar
Executive Director COMHAD
Ex National President of IAP
Advisor IJDBP.

EDITORIAL

Emerging trends in childhood disability & intervention are influenced by various factors, including advances in medical research, societal changes, and policy developments. These trends reflect a holistic approach to childhood disability, recognizing the importance of early and ongoing support, inclusive environments, and the integration of technological and medical advances. Advances in genetic testing and neuroimaging are helping in earlier diagnosis of many NDDs and early intervention and inclusive policies are helping in improving the outcomes of these cases. Personalised treatment plans and family centric care has brought the focus to providing a nurturing framework to the child in such a way that the child can achieve the full potential. Another area which is evolving rapidly and holds lot of potential benefits for these children is the area of artificial intelligence(AI). AI is helping individuals with disabilities in various ways. Voice recognition and language processing powered by AI enable hands-free device interaction for people with limited mobility. AI algorithms provide real-time captioning and sign language translation, making digital content more accessible to individuals with hearing impairments. AI is advancing assistive technologies like prosthetics and exoskeletons, improving mobility and functionality. Computer vision systems aid individuals with visual impairments in navigation and reading through text-to-speech conversion. AI communication tools support those with speech impairments, enhancing communication efficiency. Personalised AI assistants offer tailored assistance and information, empowering individuals to overcome daily challenges. AI-driven automation creates new job opportunities and facilitates flexible work arrangements for people with disabilities. AI also supports skills development, equipping individuals with the tools to succeed in the workforce. Harnessing the power of AI to support accessibility for persons with disabilities also requires willingness and commitment from regulators, educators, designers, and content developers. The internet provides new possibilities for social inclusion and for safeguarding the rights of persons with disabilities. In order to maximise the technological possibilities for people with disabilities, there is a need for a robust internet governance and policy framework. The main international instrument in this field is the Convention on the Rights of Persons with Disabilities, adopted by the UN in 2006 and signed by 181 countries. It establishes rights that are now in the process of or are included in national legislation by the signatories, therefore making these rights enforceable. The Internet Rights and Principles Coalition (IRPC) and the Dynamic Coalition on Accessibility and Disability (DCAD) are both focused on the rights of persons with disabilities. In line with the Convention, the IRPC's Charter of Human Rights and Principles for the Internet (Section 13) specifies that persons with disabilities have a right to access, on an equal basis with others, to the Internet and that steps must be taken to ensure the availability and effective use of the Internet by people with disabilities. We are entering into a very interesting era which holds lot of opportunities but only if we keep ourselves abreast the new developments.

Best Regards

Dr. Zafar Mahmood Meenai
FRCPCH(UK), MSc paediatric Neurodisability (UK)
Editor-in-Chief, IJDBP

Date Received : 12 APRIL 2024 I Accepted: 20 JUNE 2024
Indian Journal of Developmental & Behavioral Pediatrics
(Official Journal of IAP Chapter of Neurodevelopmental Pediatrics)
RESEARCH ARTICLE

Sensory processing disorders in Indian children with Autism spectrum disorder

Dr. Suman Bhattacharyya, Developmental Paediatrics, Christian Medical College Vellore.
E-mail - suman.nbmc@gmail.com
Mrs. Lincy Biju, Developmental Paediatrics, Christian Medical College Vellore.
E-mail – lincybsamuel@yahoo.co.in
Mrs. Anu Jacinth Abraham, Developmental Paediatrics, Christian Medical College Vellore.
E-mail - anu.abraham.ahs20@cmcvellore.ac.in
Mrs. Margaret Manoharan, Developmental Paediatrics, Christian Medical College Vellore.
E-mail - margaretmanoharan@cmcvellore.ac.in
Dr. Beena Koshy, Professor, Developmental Paediatrics, Christian Medical College Vellore
E-mail – beenakurien@cmcvellore.ac.in

Corresponding author: Dr. Beena Koshy
Professor, Developmental Paediatrics unit,Christian Medical College and Hospital, Vellore, India
ORCID - 0000-0002-9058-1392 E-mail: beenakurien@cmcvellore.ac.in Ph: 0091-416-2283260

Access this article online :
Quick Response Code:
Website :
https://ijdbp.in
DOI :
https://doi.org/10.5281/zenodo.13133382

Abstract:

Sensory processing disorder (SPD) is common in children with autism spectrum disorder (ASD). The current cross-sectional study evaluated the prevalence of SPD in Indian children with ASD and its association with autism severity and sleep disturbances. Children who visited an inpatient residential facility attached to the Developmental Pediatrics Unit in a tertiary care center in south India from January 2016 to December 2016 with a diagnosis of ASD were included. The sample of 83 children comprised predominantly boys (83.1%). At least one sensory abnormality was found in 75 children (90%). Among sensory sections, auditory processing (62.7%) and oral sensory processing difficulties (45.8%) were reported maximum, while low registration (73.5%) and sensory avoidance (68.6%) were commonly reported among sensory quadrants. Children with severe autism had a higher proportion of auditory processing difficulty when compared to children with mild-moderate autism (80.8% vs 54.4% respectively; p=0.028). Children with sleep problems had also a higher proportion of auditory processing difficulty when compared with children having no sleep concerns (92.9% vs 7.1% respectively; p=0.013). The high prevalence of SPD and its association with autism severity and sleep disturbances in Indian children with ASD necessitate early screening for SPD for children with autism in low- and middle-income settings.

Keywords: autism spectrum disorder, sensory impairments

Introduction:

Children with Autism Spectrum Disorder (ASD), apart from having deficits in social communication and restricted repetitive behavior, show a wide range of abnormalities in their

sensory perception(Lord et al., 2020). As per the Diagnosis and Statistical Manual, 5th edition (DSM - V), diagnostic criteria of ASD include sensory processing disorder (SPD), defined as "Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment" (American Psychiatric Association, 2013).

Incidence of SPD in children with ASD varies widely with some studies showing as high as 100%(Jorquera-Cabrera et al., 2017; Suarez, 2012).These abnormalities may involve auditory processing, vestibular processing, and processing of visual stimuli, tactile information, and olfactory sensory information. In addition, there can be inappropriate responses to multiple sensory stimuli processing, integration, and modulation as suggested in the quadrant model (Dunn, 1997).

Site-specific population-based prevalence of ASD in India ranged from 0.5 to 1.7% in 2-6 year-olds and 0.2-1.9% in 6-9 year-olds (Arora et al., 2018), and a systematic review showed a pooled prevalence of around 0.1%, while highlighting inadequate quality evidence (Chauhan et al., 2019). There is a dearth of SPD data in Indian children with ASD. A hospital-based prevalence study done in north India showed that all children with severe autism had SPD with the maximum number having auditory processing disorders(Kadwa et al., 2019). In this background, the current analysis was conducted to assess the incidence of various SPD in children with ASD in a tertiary care center in south India and their associations with autism severity and co-morbidities.

Materials and Methods:

All children welcomed to an inpatient residential facility attached to the Developmental Paediatrics Unit in a tertiary care center in south India from January 2016 to December 2016 with a diagnosis of ASD were included in this cross-sectional analysis. Children were diagnosed by a multidisciplinary team of developmental pediatricians, psychologists, and therapists using DSM-V criteria (American Psychiatric Association, 2013). The current study was approved by the Institutional Review Board. All admitted families had given written consent for anonymized data to be used for audit and research activities.

Measures:

Demographic information was collected from parents/caregivers. Co-morbidity information collected included the presence of seizures and sleep concerns.

The Childhood Autism Rating Scale™, Second Edition (CARS™-2)

The Childhood Autism Rating Scale™ – second edition (CARS™-2)(Schopler, 2010) was used to analyze autism symptom severity in children and was scored by the psychologist with inputs from parent/s. This 15-item rating scale can be used from two years of age onwards and has good validity and reliability with raw scores ranging from 15-60 (Chlebowski et al., 2010).

The Sensory Profile

The Sensory Profile assesses the sensory difficulties of children using parent reports and has 125 items. The Likert scale responses areconverted into a score with lower scores indicating greater symptoms and can be categorized under typical performance, probable difference, and definite difference. Items can be grouped under four quadrants as per Dunn's model (*viz* low registration, sensory seeking, sensory sensitivity and sensory avoidance) and five sections (*viz* auditory processing, visual processing, vestibular processing, tactile

processing and oral sensory processing) (Dunn & Brown, 1997; Dunn & Westman, 1997).

Data entry and analysis:

Data entry and analysis were done using the SPSS package 16.0. Continuous and categorical variables were summarized using mean (SD) and count (proportion) respectively. Sensory performances under each domain and section were described using proportions. Probable and definite differences reported were considered together as atypical sensory performance or SPD(Dunn & Brown, 1997). Associations were evaluated between sensory abnormalities and demographic variables such as age, sex, and parent education; autism severity and presence of co-morbidities such as sleep disturbances, and seizures using chi-square tests. Severe autism was considered if CARS™-2 score was (≥37) (Dunn & Westman, 1997).

Results:

The sample of 83 children had a median age of 47.92 months and comprised 69 boys (83.1%) (Table 1). The median CARSTM-2 score was 34.3 with 32.5% showing severe autism symptoms. Above 70% of parents were at least graduates.

At least one sensory abnormality was found in 75 children (90%). "Definite difference" in sensory processing was found in 65 out of 83 children (78.3%) while "probable difference" was present in the remaining 10 children. Auditory processing (62.7%) and oral sensory processing difficulties (45.8%) were reported maximum. Difficulties in visual processing, tactile processing, and vestibular processing were respectively 38.5%, 44.6%, and 30.1%. Quadrant analysis revealed that low registration (73.5%) and sensory avoidance (68.6%) were commonly reported. Sensory-seeking behavior and sensory sensitivity were found in 22.9% and 51.8% respectively.

Children with severe autism had a higher proportion of auditory processing difficulty when compared to children with mild-moderate autism (80.8% vs 54.4% respectively; p=0.028) (Table 2). There was no significant difference in SPD in other sensory quadrants and sections between children with severe autism and those with mild-moderate autism. Children with sleep problems had a higher proportion of auditory processing difficulty when compared with children having no sleep concerns (92.9% vs 7.1% respectively; p=0.013).There was no statistically significant relationship between demographic factors such as sex and age of the child, and prevalence of seizures and other sensory abnormalities.

Discussion:

The current analysis from a hospital-based sample has shown a high prevalence of 90% of at least one sensory abnormality in children with ASD. Auditory processing disorder was the most reported with its higher prevalence associated with severe autism symptomatology and sleep problems.

A close relationship has been reported between ASD and SPD in the literature including significant associations between SPD and core features of ASD, medical co-morbidities such as sleep and feeding concerns, and secondary behaviors including anxiety and problem behaviors(Ben-Sasson et al., 2009; Glod et al., 2015). It has been hypothesized that sensory behaviors as demonstrated in the SPD might affect the 'priori' brain constructs resulting in autistic behavior(Pellicano, 2013). It is also possible that this close association might be differing manifestations of aberrant brain connectivity with complex interlinkage(Posar & Visconti, 2018). However, there is a consensus that SPD cause a significant impact on the quality of life of

individuals with ASD (Ben-Sasson et al., 2009; Posar & Visconti, 2018; Suarez, 2012).

Early identification of SPD in children with ASD can help not only in specific sensory interventions and environmental modifications but also in planning and integrating the overall autism interventions with sensory needs (Ayres, 1979). A high prevalence of SPD in ASD as seen in the current study has been reported in the literature (Ben-Sasson et al., 2009; Glod et al., 2015; Jorquera-Cabrera et al., 2017; Suarez, 2012). A hospital-based study in north India reported that all children with severe autism had SPD while only 40% with mild-moderate ASD had SPD concerns (Kadwa et al., 2019), similar to our findings.

Sensory quadrant analysis in our study showed a high prevalence of low registration and sensory avoidance. Low registration is considered sensory hypo-responsiveness while sensory sensitivity is considered hyperresponsiveness (American Psychiatric Association, 2013). Sensory hyperresponsiveness and sensory seeking behaviors increase till the age of 6-9 years of age with a decrease in later years, but there is limited exploration of sensory hypo responsiveness including avoidance and low registration in individuals with ASD (Ben-Sasson et al., 2009; Glod et al., 2015; Posar & Visconti, 2018). Another quadrant dimension of 'enhanced sensory perception' has been added recently to address sensory experiences in individuals with ASD (Ausderau et al., 2014; Posar & Visconti, 2018).

The current analysis found a high prevalence of auditory processing disorder in children with severe autism similar to reports in systematic reviews(Ben-Sasson et al., 2009; Posar & Visconti, 2018). Auditory processing difficulties can manifest as 'apparent deafness' where the child does not respond to name calls, increased sensitivity to high-pitched sounds, and repetitive verbal stereotypy, all among the core symptoms of ASD. In addition to uni-sensory auditory perception, integration of auditory to visual and other sensations can also be impaired, which can manifest as poor integrated social communication (Ben-Sasson et al., 2009; Posar & Visconti, 2018).

Children with sleep concerns had a high prevalence of auditory processing disorders in the present study consistent with other analyses (Ben-Sasson et al., 2009; Posar & Visconti, 2018). Hyperarousal associated with auditory sensitivity can impair sleep initiation and sleep depth(Posar & Visconti, 2018).

The current study had many limitations including hospital-based small sample size and parent report measures. Subjective parent reporting can be affected by the phase of parental understanding, engagement, and acceptance as well as culture-specific experiences (Desai et al., 2012). Nevertheless, the present analysis highlighted the high prevalence of SPD and its association with autism severity and sleep disturbances in Indian children with ASD necessitating early screening for SPD for children with autism in low-and-middle-income settings. Along with specific autism interventions, an intervention plan for SPD also should be included for such children. An integrated plan can help in improving adaptive behavior and quality of life in children with ASD.

Financial Support and sponsorship : Nil

Conflicts of interest : There are no conflicts of interest

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Table 1: Demographic profile (n=83).

Factors	Range
Age in months- range (median)	24- 101 (47.92)
Sex	Female-14 (16.9%) Male- 69 (83.1%)
CARS™-2 score – range (median)	28-48 (34.3)
Father's educational status	<12th standard- 23 (27.7%) Graduate and above- 60 (72.3%)
Mother's educational status	<12th standard- 24 (28.9%) Graduate and above- 59 (71.1%)
Seizures	Present- 6 (7.2%) Absent- 77 (92.8%)
Sleep dysfunction	Present- 14 (16.9%) Absent- 69 (83.1%)

CARS™-2 - Childhood Autism Rating Scale™ – second edition

Table 2: Association between prevalence of sensory processing disorders and severity of autism.

	Mild-moderate autism n=57	Severe autism n= 26	Statistical significance
Sensory sections			
Auditory processing	31 (54.4%)	21 (80.8%)	**.028**
Visual processing	22 (38.6%)	10 (38.5%)	1.000
Tactile processing	25 (43.9%)	12 (46.2%)	1.000
Vestibular processing	17 (29.8%)	8 (30.8%)	1.000
Oral sensory processing	23 (40.4%)	15 (57.7%)	.161
Sensory quadrants			
Low registration	41 (71.9 %)	20 (76.9 %)	.790
Sensory seeking	15 (26.3%)	4 (15.4%)	.399
Sensory avoidance	39 (68.4%)	18 (69.2%)	1.000
Sensory sensitivity	31 (54.4%)	12 (46.2%)	.636

Date Received : 4 MARCH 2024 | Accepted: 25 MAY 2024
Indian Journal of Developmental & Behavioral Pediatrics
(Official Journal of IAP Chapter of Neurodevelopmental Pediatrics)
RESEARCH ARTICLE

Knowledge, attitude and practice (KAP) among pediatricians about gastrostomy tube feeding in cerebral palsy children

Authors
Dr. Preeti Solanki MD, Dr. Surendra Kumar Tripathi PG 3rd Year, Dr. Deepak Dwivedi MD, PGDDN, Professor
Contributions
Dr. Preeti Solanki, Dr. Surendra Kumar Tripathi : Concept, design, Data collection
Dr. Deepak Dwivedi: Concept, Analysis, Corresponding author
Institution:
Department of Pediatrics, Shyam Shah Medical College, Rewa, Madhya Pradesh 486001
Disclaimers: none
Corresponding author:
Dr. Deepak Dwivedi, D-2/8, Doctors Colony, Rewa (M.P.) Pin 486001
Phone:7869918636, Email: deepakdwi72@gmail.com

Abstract:

The report a longitudinal, prospective, multicentre cohort study designed to measure the outcomes of gastrostomy tube feeding in children with cerebral palsy (CP). Knowledge, attitude and practice method of tube feeding is based on the likely timespan that is needed for tube supplementation, the availability of an experienced surgeon, recommendations by the treating doctor, and specific symptoms of the child.

Keywords : cerebral, gastrostomy, réhabilitation, nutritional

Access this article online :
Quick Response Code:

Website :
https://ijdbp.in
DOI :
https://doi.org/10.5281/zenodo.13133768

Introduction :

Feeding problems are very common in children with cerebral palsy. About 30 – 80% of disabled children feed with difficulty because they are at risk of oral, pharyngeal, or oesophageal dysplasia due to oral motor dysplasia [1-3]. So nutritional rehabilitation is of prime importance in these children, as failure to do so may result in poor nutritional status, growth failure, chronic aspiration, esophagitis, and respiratory infections [1,2]. Multiple approaches such as sensorimotor stimulation, positioning, food thickness, and caloric supplementation have been used in children with growth failure [4]. For children with moderate to severe aspiration, malnutrition-related oral pharyngeal dysplasia, and GER, surgical interventions with a gastrostomy tube or jejunostomy tube may be necessary to improve nutritional status and reduce the risk of chronic aspiration [5,6]. The method of tube feeding is based on the likely timespan that is needed for tube supplementation, the availability of an experienced surgeon, recommendations by the treating doctor, and specific symptoms of the child.

Gastrostomy tube feeding has been used increasingly to overcome oromotor dysfunction in children with severe neurological disabilities

by providing nutrients, medications, and fluids directly into the stomach. It has been a standard of care for children with neurological diseases, especially cerebral palsy, for nutritional rehabilitation in Western countries with incidence ranging from 6%-22% [7]. However, this modality is underutilized in India for nutritional rehabilitation of children suffering from cerebral palsy. So this study was conducted to assess knowledge, attitudes, and practices among pediatricians/ Pediatric neurologists for gastrostomy tube feeding of CP patients and to understand the hindrances in this practice.

Materials & methods:

A cross-sectional, descriptive study was undertaken. 500 pediatricians, through Indian Academy of Paediatrics mailing lists, were approached for the study through emails, calls, and messages. KAP toward G tube feeding in CP patients was assessed using a pre-validated questionnaire. A self-administered 21-item questionnaire was used for data collection. In addition to the 7 questions on demographic data,6 questions explored the knowledge towards G tube, 4 questions focused on attitude, and 4 questions addressed practice towards G tube feeding in CP patients. The questionnaire was pre-validated through 50 participants. Responders were asked to answer in multiple choice questions format in Google Forms. The choices for answering questions about knowledge, attitude, and practices were according to the Likert scale as given below:

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree

Statistical Analysis:

Descriptive statistics were used to illustrate demographic characteristics. Categorical variables were measured as percentages and was analyzed using the chi-square test/fisher exact test while continuous variables were expanded as mean and analyzed using student t-test. SSPS v.16.0 was used for data analysis.

Results:

A total of 70 pediatricians out of 500 participated in our study. Out of this, 51(72.9%) were females and 49(27.1%) were males with the majority (70%) belonging to the age group of 26 to 40 years. 34(48.6%) of the participating pediatricians had an experience of less than 5 years while 11(15.7%) had an experience of above 20 years and of these, the majority had no fellowship in neurology (81.5%). **(Table 1)**

Table 1: Demographic characteristics of participating paediatricians.

Gender	**Frequency (%)**
Males	29 (41.4)
Females	41 (58.6)
Age range	**Frequency (%)**
26-40 years	49 (70)
40-55 years	13 (18.57)
>55 years	8 (11.43)
Mean age (years)	**39.04±11.27**
Speciality	**Frequency (%)**
Pediatric neurology	13 (18.5%)
None or others	57 (81.5%)

Setting of practice	**Frequency (%)**
Urban	67 (95.7)
Rural	1 (1.4)
Others	2 (2.9)

In this study, it was found that the majority

(58%) of these pediatricians attended less than 10 children with cerebral palsy while 9% attended more than 50 such children in a month.

Table 2: Data of pediatricians practicing as CP physicians.	
Distribution of practicing years as an attending physician specifically for CP children	
Years of practice	Frequency (%)
<5 years	40 (57.14)
5-10 years	12(17.14)
10-20 years	7(10)
>20 years	11(15.72)
Distribution of CP children attended in a month	
CP children in a month	Number of pediatricians (%)
<10	41(58.57)
10-20	16(22.86)
20-50	4(5.7)
>50	9(12.87)

The frequency at which pediatricians attended a CP patient	
	Number of pediatricians (%)
As needed	32(45.71)
Once per year	3(4.29)
Twice per year	12(17.14)
>twice per year	23(32.86)
Age at which CP children are referred:	
Age range	Number of paediatricians (%)
<2 years	36(51.43)
2-5 years	33(47.14)
6-10 years	01(1.43)
>10 years	00

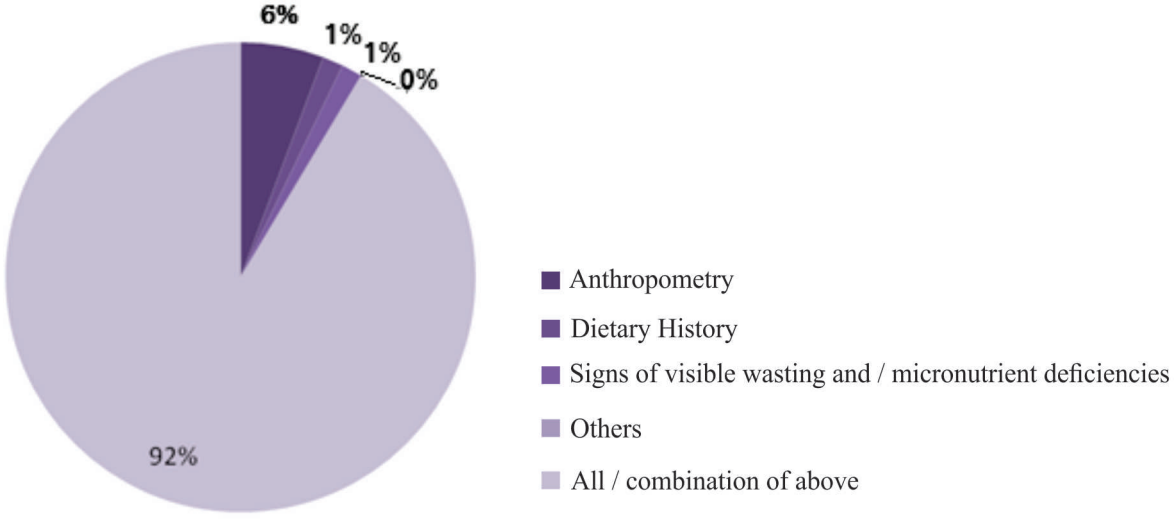

Figure 1: Methods of identifying Malnutrition

Table 3: Knowledge Question.

QUESTIONS	**Likert rating**				
	5.(Strongly agree**)**	**4(**Agree)	**3**(Neither disagree nor agree)	**2**.(Disagree**)**	**1(**Strongly disagreed)
	Number of paediatricians (%)				
1. Malnutrition and growth failure further increase the chances of neurodevelopmental disability and mortality in CP children	50(71%)	20(29%)	0(0%)	0(0%)	0(0%)
2. Is Feeding difficulty a common problem in children with Cerebral Palsy?	47(67%)	23(33%)	0(0%)	0(0%)	0(0%)
3. Cause of feeding difficulty in children with Cerebral Palsy					
Sucking and swallowing problems	46(66%)	23(33%)	1(1%)	0(0%)	0(0%)
Oral motor dysfunction	24(34%)	39(56%)	6(9%)	1(1%)	0(0%)
Unable to self-feed due to motor impairment	15(21%)	28(40%)	17(2%)	0(0%)	0(0%)
Others: vomiting, regurgitation, tongue difficulties	39(56%)	15(21%)	12(1%)	4(6%)	0(0%)
4. Do you think the anthropometric assessment is important in CP patients for identifying malnutrition and thus indirectly, feeding difficulty?	30(43%)	27(39%)	12(1%)	1(1%)	0(0%)
5. Do you think gastrostomy tube feeding is important in cerebral palsy children?	23(33%)	26(37%)	15(2%)	4(6%)	2(3%)
1. Out of the following feeding methods rate which do you consider is the most effective mode for feeding in severely disabled child?					
A. Gastrostomy tube feeding	26(37%)	26(37%)	11(1%)	5(7%)	2(3%)
B. Orogastric/nasogastric tube feeding	10(14%)	29(41%)	18(2%)	8(11%)	2(3%)
C. Oral appliances /feeding devices	10(14%)	16(23%)	26(3%)	17(2%)	1(1%)
D. Others oral sensori-motor, neuromuscular electric stimulation, positioning	15(21%)	20(29%)	24(3%)	10(1%)	1(1%)

Table 4: Attitude Questions.

QUESTIONS	**Likert rating**				
	5	4	3	2	1
	Number of pediatricians (%)				
1. Which CP patients would you consider for G tube feeding?					
A. All patients	8(11%)	7(10%)	18(2%)	24(4%)	13(19%)
B. Moderate to severe motor impairment (spastic quadriplegia)	24(34%)	30(43%)	6(9%)	8(11%)	2(3%)
C. Chronic aspiration	28(40%)	29(41%)	4(6%)	4(6%)	5(7%)
D. Malnutrition and/or growth failure	14(20%)	39(56%)	11(15%)	15(21%)	1(1%)
2. Gastrostomy tube feeding can be the better alternative for nutritional rehabilitation in severely disabled CP children with malnutrition	31(44%)	27(39%)	7(10%)	4(6%)	1(1%)
3. What are the hindrances according to you in practicing G tube feeding in CP children?					
A. Parent's denial	26(37%)	33(47%)	7(10%)	2(3%)	2(3%)
B. Nonavailability of pediatric surgeon	10(14%)	18(26%)	14(20%)	23(33%)	5(7%)
C. Nonavailability of G tube	2(3%)	14(20%)	20(29%)	19(27%)	15(21%)
D. Due to the risk of its complications	6(9%)	23(33%)	21(30%)	12(17%)	8(11%)
4. Do you consider gastrostomy feeding in CP children a safe mode of treatment?	15(21%)	38(54%)	14(20%)	3(4%)	0(0%)

Table 5: Practice Questions.

QUESTIONS	Likert rating				
	Number of Paediatricians (%)				
	5	4	3	2	1
1. According to you, the most preferred way of Gastrostomy tube placement in CP patients?					
A. Percutaneous endoscopic G tube (PEG)	17(24%)	10(14%)	4(6%)	4(6%)	0(0%)
B. Laparascopic techniques for G tube placement	6(9%)	15(21%)	9(13%)	3(4%)	0(0%)
C. Open surgical techniques	9(13%)	9(13%)	7(10%)	10(14%)	0(0%)
2. Comment on the complications you think is most important because of gastrostomy tube feeding					
A. Wound infection/ bleeding/peristomal leakage	8(11%)	22(31%)	4(6%)	2(3%)	0(0%)
B. Tube Dysfunction	4(6%)	13(19%)	11(16%)	5(7%)	0(0%)
C. Gastroesophagealreflux leading to aspiration/respiratory complications	3(4%)	7(10%)	7(10%)	15(21%)	3(4%)
D. Others	2(3%)	4(6%)	15(21%)	15(21%)	5(7%)
3.Do you think the outcome of this feeding modality (G tube feeding) is satisfactory in most CP patients	11(16%)	20(29%)	2(3%)	2(3%)	0(0%)

Discussion:

A total of 70 pediatricians participated in our study among whom a combination of anthropometry, dietary history, and signs of visible wasting and/or micronutrient deficiencies was used by 91% of participating pediatricians while others used a single parameter out of these (Figure 1). **M Thommessen et al** used weight for height, triceps skinfold thickness, and energy intake to assess malnutrition and found that 15% of the CP children had feeding problems. [2] In our study, 67% of pediatricians agreed very strongly that feeding difficulty is a very common problem in children with CP. Also, 71% of pediatricians very strongly believed that malnutrition and growth failure further increase the chances of neurodevelopmental disability and mortality in CP children (Table 3). A study conducted by M Thommessen et al also found that 50% of children with cerebral palsy had feeding problems while 48% of them had growth retardation. [2] Sucking and swallowing problems were suggested as the main difficulty in feeding by 65% of our participants **(**Table 3).

About 37%of our participants strongly agreed that gastrostomy is important for feeding children with cerebral palsy while just 3% felt it least important. This might be due to the increasing awareness among pediatricians about these surgical modalities and better accessibility to such pediatric surgeries. In our study, 40% of pediatricians strongly suggested G tube insertion as the most effective feeding method in severely disabled CP children while orogastric/ nasogastric

tube feeding, oral appliances /feeding devices, oral sensorimotor, neuromuscular electric stimulation and positioning were very strongly supported by 14%, 14%, and 21% participants respectively (Table 3). According to a study by Brian Rogers et al, oral sensorimotor therapy may be effective in promoting oral motor function but has not been found to be effective in promoting oral feeding efficiency, pharyngeal phase function, caloric intake, and weight gain. [9] In our study, most of the participating pediatricians (40%) recommended gastrostomy tubes for CP children with chronic aspiration while other indications were spastic quadriplegia and malnutrition where the G-tube was very strongly recommended by 34% and 20% of the participants respectively. 20% of the participating pediatricians also think the outcome of G tube feeding is satisfactory in most CP patients (Table 4). A study by Peter B Sullivan et al also observed that among the 46 children with cerebral palsy included in their study, 91% had significant weight gain by 12 months. [9]

A major hindrance in practicing G tube feeding in CP children according to our participating pediatricians (37%) was denial by the parents. However, a study by **Brian Rogers** et al indicated that parents are usually highly satisfied after the procedure (80% to 90%). [10] Other common obstacles included non-availability of pediatric surgeons (14%), risk of complications (8%), and nonavailability of G tube (3%). Most of our participants (76%) consider gastrostomy feeding in CP children a safe mode of treatment (Table 4). Only 17% of my participants have advised/ managed CP children with Gastrostomy tube feeding despite knowing the prevalence and complications of malnutrition in children with cerebral palsy. This might be due to the prejudiced notion against gastrostomy feeding, the lack of clear guidelines, and parents' anxieties related to surgical intervention (Table 5). Though many studies relating to gastrostomy tube insertion are not available, it is found that the prevalence of gastrostomy in Swedish children with Cerebral palsy is as high as 22% which is the highest in Europe. [10,11] The most important complication because of gastrostomy tube feeding according to my participants was wound infection/ bleeding/peristomal leakage (43%). Other complications included tube dysfunction (24%) and gastroesophageal reflux leading to aspiration/ respiratory complications (14%) (Table 5). A study by Peter B Sullivan et al found that the major complications were minor site infection (59%) granulation tissue (42%), leakage (30%), tube blockages (19%), tube migration (7%), tube pulled out by the child (4%)and peritonitis (2%)[9]

Conclusion:

Feeding difficulties, malnutrition, and its associated complications are very common in children living with cerebral palsy. Nutritional rehabilitation is of prime importance in these children, as failure to do so may result in poor nutritional status, growth failure, chronic aspiration, esophagitis, and respiratory infections. Hence from our study, it can be concluded that the KAP of our pediatricians regarding gastrostomy tubes for feeding children with CP is just satisfactory, and better awareness and well-defined guidelines should be formulated to improve the feeding and hence quality of life in children with cerebral palsy.

Financial Support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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Date Received : 12 APRIL 2024 | Accepted: 5 JUNE 2024
Indian Journal of Developmental & Behavioral Pediatrics
(Official Journal of IAP Chapter of Neurodevelopmental Pediatrics)
RESEARCH ARTICLE

Clinical profile of children with Autism spectrum disorder in a quaternary care hospital in south India

Authors
Dr. Jeeson C Unni[1], Dr. Sitara Kannan[2], Dr. Susan Mary Zachariah[3], Dr. Maria Grace Treasa[4]
1 Senior consultant, Department of Pediatrics, Aster Medcity, Kochi
2 Pediatrician, Department of Pediatrics, Aster Medcity, Kochi
3 Developmental pediatrician, Aster Kind, Aster Medcity, Kochi
4 Speech and language specialist, Aster Kind, Aster Medcity, Kochi
Corresponding author
Dr. Jeeson C Unni
Senior consultant, Department of Pediatrics, Aster Medcity, Kuttisahib Road,
Cheranelloor, Chittoor, Kochi, Kerala, Pin 682037
Mob no. 9847245207, Email – jeeson1955@gmail.com

Abstract:

Background: A multitude of presentations, co-morbid conditions, risk factors, and severity are associated with Autism Spectrum Disorders (ASD)

Aim: To describe the clinical profile of children affected with Autism spectrum disorder in a

quaternary care hospital in South India.

Methods: A cross-sectional descriptive study using a questionnaire method among children

aged 1.5-6 years was conducted. Demographics, risk factors, and developmental domains were assessed.

Results: The mean age of presentation was 34 months, male to female ratio was 7:1, 65% of patients were delivered by LSCS, most were firstborn, 88% had appropriate weight for gestational age, and 30% were preterm. The age of conception in 95% of mothers was < 30 yrs and 82% of fathers < 35 years. 80% were mild and the rest were moderate autism. 32 % of mothers had gestational diabetes mellitus and 30% had hypothyroidism. Respiratory distress and sepsis were the most common postnatal events noted. 70% of affected children had E-media exposure of more than 2 hours. Multiple regression analysis to determine the influence of various risk factors showed that all risk factors studied contributed 19% to the severity of autism. Multiple sensory domains were affected in 85%; mainly auditory, visual, and touch. Prevalence of developmental regression was 27%. Allergy and sleep disorders were the commonest comorbidities and were present in 67% of the study population.

Conclusion: Autism spectrum disorder has a variety of presentations and an onset within thefirst 2 to 3 years of life, making it imperative to facilitate early diagnosis and intervention. Appropriate awareness and use of severity scales and assessment systems can help inlocalizing the

Access this article online :
Quick Response Code:
Website :
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DOI :
https://doi.org/10.5281/zenodo.13133837

main area of deficits in individual children and targeting treatment accordingly.

Keywords: Autism spectrum disorder, Indian Scale for Assessment of Autism, Developmental Profile 3, children, risk factors.

Introduction:

The prevalence of ASD in India seems to be steadily increasing, probably due to greater awareness and case identification. However, the scarcity of high-quality population-based epidemiological studies on ASD in India prevents accurate estimation of its prevalence [1].Despite the various symptoms of autism spectrum disorder appearing in early childhood, due to various reasons, there is a significant delay in diagnosis in India. [2] Early diagnosis and intervention have proven to cause significant improvements in cognitive, language, and social-emotional functioning in children with ASD. [3] The studies on the socio-demographic profiles of ASD are sparse inIndia. As the facilities for evidence-based intervention of children with ASD are becoming increasingly available in India, we must be better aware of the possible presentations, co-morbidities, risk factors, and the socio-demographic profile of these children. We attempt to study these aspects in children treated at our quaternary care referral center for children with ASD.

Materials & methods:

A hospital-basedcross-sectional observational descriptive study was conducted on all children between 1 and a half and 6 years of age who fulfilled the DSM 5 criteria for autism spectrum disorder and underwent detailed assessment and evaluation at our Integrated NeuroDevelopmentalCenter, from June 2020 to July 2021 after getting consent from the parents/caregivers.Institutional ethical and scientific committee clearances were obtained before commencing the study. The parents of all children studied were provided with the patient information sheet. Written informed consent from the parent/guardian was taken in a simple and easily understandable unambiguous language.

A detailed history (personal history, family history, socioeconomic history, birth history, risk factors, comorbidities, exposure to E-media and scholastic history), clinical examination (as described in proforma), Sensory profile (SSP 2), Autism severity (ISSA scale), development assessment (DP-3 scoring) were done. Developmental profile 3 (DP3) scoring was applied under 5 domains; physical, adaptive, social-emotional, cognitive, and communication; and a total standard score and composite General Development Standard (GDS) score was attained.

The revised Kuppuswamy socioeconomic status scale was used to assess the socioeconomic status (SES) of the family. [4]

The target sample size calculated by the formula $N = Z^2 (1-\alpha/2)p (1-p)/d^2$, where prevalence (p) was taken as 2.5/10000, was 37.

The data was collected and entered into a Microsoft Excel sheet. Statistical analysis was performed by IBM SPSS Statistical software trial version 21. Categorical variables were described as frequency and percentage and continuous variables were described as Mean±S.D Yates corrected Chi-square/ Fisher Exact test was used to find the significance of study parameters on a categorical scale between two or more groups, non-parametric setting for qualitative data analysis. Fisher exact test was used when cell samples were very small. Multiple regression analysis was carried out to determine the influence of individual risk factors on the severity of autism (between mild and moderate autism groups).

Results:

The mean age of the 40 children recruited into

the study was 34 months; 35 (85%) were males. In 95% of cases,the maternal age at conception was less than or equal to 30 years and the paternal age was less than or equal to 35 years in 85.2%. Education qualification was graduation or more in 77.5% of fathers and 87.5% of mothers and 92.5% of the families were from upper and upper middle class.

Possible antenatal risk factors were noted in 65% of children [Table 1] and 30% and 12.5% of children had 2 and 3 or more risk factors, respectively. Gestational diabetes mellitus and hypothyroidism were the most common antenatally.The perinatal risk factors reported by caregiversare listed in Table 2. Sixty-five percent were delivered by LSCS and the rest were delivered vaginally. Eighty percent of the cohort were firstborn babies and the remainder were 2nd born; 88% had appropriate weight for gestational age, 1 baby had very low birth weight; and 30% were born preterm.

Table 1: Probable antenatal risk factors.

ANTENATAL RISK FACTORS	Number	Percentage
GESTATIONAL DIABETES MELLITUS	13	32.5%
HYPOTHYROIDISM	12	30.0%
URINARY TRACT INFECTION	6	15.0%
ANEMIA	5	12.5%
PREGNANCY-INDUCED HYPERTENSION	5	12.5%
ANTEPARTUM HEMORRHAGE	3	7.50%
HYPEREMESIS	2	5.00%
FEVER	2	5.00%

Table 2: Probable perinatal risk factors.

PERINATAL EVENTS	Number	Percentage
PREMATURITY	12	30%
RESPIRATORY DISTRESS	6	15%
SMALL FOR GESTATIONAL AGE	5	12.5%
SEPSIS	4	10%
HYPOGLYCEMIA	3	7.5%
PERINATAL ASPHYXIA	2	5%
CNS INFECTIONS	1	2.5%

Thirty children (75%) had a significant family history; out of which the most common was allergy (Table 3). Two of the cases had a family history of autoimmune arthritis.

Table 3: Significant Family History.

MEDICAL FAMILY HISTORY	Frequency	Percentage
ALLERGY	27	69.1%
SPEECH DELAY	5	12.5%
SEIZURE	4	10.3%
PSYCHIATRIC ILLNESS	3	7.5%
INTELLECTUAL DISABILITY	2	5.0%
AUTOIMMUNE ARTHRITIS	2	5.0%
SYNDROMIC	1	2.5%

A history of developmental regression was obtained in 11 (27.5%) of children. 70% of children were exposed to more than 2 hours (on an average 3-4 hours) daily to e-media.

Dysmorphic features were noted in 15%; neurocutaneous markers and macrocephaly in 10%, each (Table 4).

Table 4: Relevant examination findings in the cohort.

EXAMINATION FINDINGS	Frequency	Percentage
DYSMORPHIC FEATURES	6	15%
MACROCEPHALY	4	10%
NEUROCUTANEOUS MARKERS	4	10%
TONE ABNORMALITY	1	2.5%
NORMAL	25	63%

Autism severity assessed using ISAA scoring categorized 80 % as mild autism group, and the rest as moderately severe autism. The sensory domains affected in the cohort are given in Table 5 – most affected was auditory sensation (70%), followed by visual and touch. 87 % of moderate autism children had 3 or more sensory domains affected, while only 56 % of mild autism had 3 or more domain affection; 85 % of children had multi-domain affection.

Table 5: Profile of sensory domains affected.

SENSORY DOMAINS AFFECTED	Frequency	Percentage
AUDITORY	28	70.0%
VISUAL	19	47.5%
UNDER RESPONSIVENESS / SEEKING	18	45.0%
TOUCH	17	42.5%
ORAL SENSORY	15	37.5%
BODY POSITION PROPRIOCEPTION	15	37.5%
MOVEMENT	11	27.5%

Evaluation of developmental domains using DP3 showed that in our cohort the social, emotional, and cognitive domains were slightly more affected than the communicative domain (Table 6), The mean global developmental score was 49.2, indicating delay.

Table 6: DP3 scores of different domains.

DEVELOPMENT PROFILE DP3	MEAN	SD
PHYSICAL	79.7	12.4
ADAPTIVE	66.5	11.2
SOCIAL-EMOTIONAL	55.3	10.1
COGNITIVE	54.9	10.6
COMMUNICATIVE	57.4	11.4
GENERAL D SCORE	49.2	11.1

Multiple regression analysis was done on various risk factors (Table 7); none of them showed any significant influence on the severity of autism. The main 10 risk factors studied together accounted for around 19% of the variation in the explained variable (severity of autism).

Table 7: Multiple regression analysis of risk factors influencing the severity of Autism.

PREDICTORS	R-value	P value	Partial regression coefficient
GDM/DM (antenatal)	0.2	0.2	-0.01
Anemia (antenatal)	-0.2	0.2	-0.23
UTI (antenatal)	-0.03	0.8	-0.06
Mode of delivery	-0.02	0.8	-0.19
Respiratory distress (neonatal)	0.1	0.4	0.03
Sepsis(neonatal)	0.04	0.8	-0.16
Allergy(neonatal)	0.2	0.2	0.28
Speech delay (family history)	-0.2	0.24	-0.21
Seizure (family history)	0.06	0.7	0.14
Time spent on electronic media	-0.1	0.6	-0.13
Total R of all predictors	0.43		
Total R^2 of all predictors	0.19		

Total R-value between 0 to 0.3 shows negligible correlation and between 0.3 to 0.5 low positive correlation

The total R^2 value is 0.19 implies that the 10 main factors studied together account for 19% of the variation in the explained variable (severity of autism)

Discussion:

The mean age of presentation in our study was 34 months, with reported mean ages in literature ranging from 38-120 months. [5] This may be due to the relatively early suspicion, and consultation by the educated parents, from the upper to upper-middle socioeconomic status in our study cohort. The male predominance [87.5% males] in our study correlated with existing data in Indian and Western literature. [6,7]The known risk factors for autism spectrum disorders include advanced parental and maternal age, a sibling with ASD, prematurity, a history of ART, maternal diabetes, and maternal obesity, as well as the use of antiepileptic or antidepressant drugs. [8] No significant correlation with parent's age at conception was noted in our study with only 17 % of parents having an age above 35 years at conception. The firstborn child was affected in 80 % of our cases, as in theexisting meta-analysis. [9] One possible reason for this pattern could be that parents may be worried about having a second child with ASD - a phenomenon described as the "stoppage rule". [10]

One-fourth of our children had some form of family medical history, the most prevalent being allergies, speech delay, and seizures. A positive family history of mental and neurological disorders including ASD has been associated with higher odds of ASD in index persons. [11]

Our study had hypothyroidism in 30% of mothers - a known association reported not due to direct effects of thyroid hormones. It is postulated that pathways that influence maternal thyroid function may have etiologic roles in ASD. [12] Maternal diabetes isassociated with ASD in a meta-analysis. [13] Children with ASD in our study had 32.5% mothers with GDM. The pathway through which hyperglycemia may impact neurodevelopment may be mediated by oxidative stress. Further, GDM is associated with a greater risk of adverse obstetric outcomes. Anemia was documented in 12% of mothers in our study and when diagnosed during the first 30 weeks of pregnancy, but not later, was associated with an increased risk of diagnosis of ASD and lower IQ. [14,15] Iron deficiency affects fetal myelination, dendrite arborization, and synthesis of monoamine neurotransmitters, which are implicated in the etiology of ASD and ADHD. Maternal hyperemesis [16], and to some extent, pregnancy-induced hypertension,[17]cesarean delivery,[18]and preterm delivery [19,20] are risk factors for ASD in the offspring as noted in this study.

Despite some small studies suggesting the association of some perinatal insults as risk factors for ASD, it is not clear whether they are risk factors for ASD by themselves or play a secondary role in children with a genetic predisposition. It is possible many events that are known to produce neonatal morbidity could together increase the risk.[21,22] We have noted some perinatal insults in our children of which respiratory distress and sepsis were prominent. Seventy percent of patients had a screen time of more than 2 hours in our study, though there was no statistically significant correlation noted. Higher screen exposure in young children interferes with cognitive development (23) and is associated with altered brain processing.[24] In siblings of children with ASD who go on to develop ASD, overgrowth of the visually related brain areas at 6 to 12 months of age is one of the earliest findings. [25] However, children predisposed to ASD may have a preference for screens, or parents of children already displaying ASD symptoms may be more reliant on screens to soothe a child with self-regulation issues. Children with ASD process sensory information in a different manner such that they may tend to seek out media content that is more visually intense or calming.

Multiple regression analysis was done on various risk factors included in this study. The 10 risk factors for autism studied together accounted for around 19% of the variation in the explained variable and after controlling the variables, none of the risk factors by themselves showed a significant influence on the severity of autism. This could be because a synergistic influence of many risk factors may lead to the development of autism; no single risk factor can be implicated. [26]

The spectrum of autism in the community varies from 26% mild, 41.6% moderate, and 33.3% severe in a group of 2–5-year-old children in Bihar [27] to 46% mild, 47% moderate and 7% severe in a Spanish school cohort. [28] Autism severity assessed in our study using ISAA scoring recorded 80 % to mild autism group, and the rest to moderate severity. No case of severe autism was noted in our study group. The data suggests that the bulk of the increase in autism prevalence the world over may be attributed to the increasing number of children on the mild

end of the spectrum being diagnosed. This also implies that many children in the spectrum may be able to live a life on their own if appropriate interventions, at the right time, are instituted.

In 70 % of our patients, the auditory domain was affected followed by visual and touch. Three or more sensory domains were affected in 56% and 87% of mild and moderate autism, respectively and multi-domain affection was noted in 85% of children in our study. An increasing number of domains affected and the presence of multiple co-morbidities are the feature of higher severity of autism. [29]Developmental regression was noted to be 27 % in our study, which is comparable to other studies[30] and the age when regression was reported was around 2 years as in our study. The reasons for regression and the presence of developmental deviances before the time when regression was noted, were not studied.The domains affected according to DP3 scales and co-morbidity profile were different in our study in comparison to textbook cases. The social, emotional, and cognitive domains were mostly affected, though classically communication and social interaction are more detailed in the literature. Allergy and sleep disorders constitute about 67% of co-morbid conditions in our cohort, as compared to the higher prevalence of ADHD and anxiety disorders.

Limitations of the study:

The small sample size and the predominantly upper and upper-middle-income group in our cohort cannot be extrapolated to the ground statistics in Kerala. Only children up to 6 years old were studied without follow-up; hence the effect of age of diagnosis on outcome could not be assessed.

Conclusion:

Autism spectrum disorders are one of the commonest, yet most delayed-diagnosed cognitive impairment disorders of childhood. The earlier mean age at diagnosis in our study can be attributed to greater awareness and education status of the caregivers, and more cases will likely be diagnosed earlier owing to the increased availability of specialist services. The risk factors previously described in literature such as male gender, maternal co-morbidities, and screen time were present but no correlation with the severity of the disorder could be established. Increasing awareness could be the reason for the large number of mild cases being detected; suggesting the contribution of these cases to the increasing incidence of autism reported in recent times. No risk factor singly could be identified as the cause of ASD suggesting a synergistic influence of multiple factors. With the increasing availability of specialists and advanced interventions in the country, coupled with the proven benefits of early management, it is imperative to spread awareness about the clinical profile of autism to facilitate early diagnosis and early intervention.

Financial Support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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Date Received : 28 APRIL 2024 | Accepted: 27 JUNE 2024
Indian Journal of Developmental & Behavioral Pediatrics
(Official Journal of IAP Chapter of Neurodevelopmental Pediatrics)
RESEARCH ARTICLE

Diagnostic accuracy of AIIMS Modified INCLEN Diagnostic Tool (AIIMS Modified INDT–ASD) for diagnosis of Autism Spectrum Disorder

Authors

Dr. Abhinayaa Janakiraman[1], Dr. Fatima Shirly Anitha George[2], Dr. Udayakumar Narasimhan[1], Dr. Meenakshi Tanwar[2]

1 Department of Paediatrics, Karthikeyan Child Development Unit-Sri Ramachandra Institute of Higher Education and Research, Chennai, India

2 Developmental Paediatric Service, Surrey and Borders Partnership NHS Foundation Trust, Leatherhead, Surrey, UK

Corresponding author:

Dr. Fatima Shirly Anitha George, Developmental Paediatric Service, Surrey and Borders Partnership NHS Foundation Trust, Leatherhead, Surrey, UK. Email-drfatimashirly@gmail.com

Access this article online :
Quick Response Code:
Website :
https://ijdbp.in
DOI :
https://doi.org/10.5281/zenodo.13133967

Abstract:

Introduction: Autism spectrum disorder (ASD) is a neurodevelopmental condition with increasing prevalence over the years. The assessment tools validated for the diagnosis of ASD are based on the population in the West. We assessed the diagnostic accuracy of the AIIMS Modified INCLEN Diagnostic tool INDT-ASD against the Childhood Autism Rating Scale CARS-2 (ST) using DSM-V as the reference standard.

Methods: Children aged 2 to 9 years of age with suspected ASD, as identified by one or more of the red flags described by the American Academy of Neurology, were enrolled in the study. Those with cerebral palsy, global developmental delay, hearing impairment, and neurodegenerative disorders were excluded. CARS-2 (ST) and AIIMS modified INDT-ASD were done by two different professionals and the results were kept blinded. The DSM-V criteria were applied by a third professional to confirm the diagnosis.

Results: The study included 108 children. There was male predominance and the mean age of presentation was 36.9 months. AIIMS MODIFIED INDT-ASD was found to have a Sensitivity of 91.4%, a Specificity of 78.5%, a Positive predictive value of 89.2%, and a negative predictive value of 82.5%.

Conclusion: AIIMS Modified INCLEN INDT-ASD is a simple indigenous tool helpful in the diagnosis of ASD in the Indian population.

Keywords: Autism spectrum disorder, Childhood Autism Rating Scale, DSM-V criteria, INCLEN, neurodevelopmental

Introduction: Autism spectrum disorder (ASD) is a neurodevelopmental disorder with Core deficits in two domains namely social communication/ interaction and restrictive, repetitive patterns of behaviour, as defined by the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) [1] The prevalence is estimated as 1 in 36 children by the Center for Disease Control and Prevention.[2]There is a scarcity of population prevalence studies in India for an estimate of children affected with Autism Spectrum. A study by Chauhan et al. found that the prevalence of Autism among Indian children aged 1 to 18 years was 0.09% in urban areas and 0.11% in rural areas. [3]There must be meticulous developmental surveillance to identify and diagnose autism at the earliest. As always known, early diagnosis opens the window of opportunity for early interventions and support for the child. There are some challenges to the diagnosis of ASD in limited-resource countries. Many of the tools that are validated for the assessment of ASD are based on the population in the West. Some of them include the Childhood Autism Rating Scale CARS-2 (ST), Autism Diagnostic Observation Scale (ADOS), and Autism Diagnostic Interview (ADI-R). They need certified training and are expensive to use in developing countries with limited resources. They may also not be culturally acceptable and are patented tools that are available only in English.

AIIMS Modified INCLEN INDT-ASD has been developed in India and used in wider parts of the country as a valuable aid for the assessment of Autism Spectrum Disorder.[4] It is closely mapped to DSM-V which is now being used for the diagnosis of ASD. The tool requires both history from the child's caregiver and direct observation of the child for some of the criteria. This has been standardized and validated against CARS-2 (ST).

Materials & Methods:

The study was conducted in a Child Development Unit in a tertiary care hospital in South India from October 2019 to June 2020. This was a prospective study to assess the diagnostic accuracy of AIIMS Modified INDT-ASD against CARS-2 (ST) using DSM-V as the reference standard. We also evaluated the sensitivity and specificity of AIIMS Modified INDT-ASD against theChildhood Autism Rating Scale CARS-2 (ST). The tool was originally validated for children in the age group of 1 to 14 years. Children with suspected ASD referred to our centre from 2 to 9 years of age alone were enrolled in the studydepending upon convenience sampling after informed consent. This included childrenwho had one or more of the red flags described by the American Academy of Neurology. These were no babbling or not using gestures like pointing by 1 year of age, not speaking meaningful words by 16 months, and two-word phrases by 2 years. Loss of language or social skills at any age in a child is another symptom to suspect ASD.[4] Children with comorbidities like Attention deficit hyperactivity disorder and cerebral palsy, global developmental delay, hearing impairment, and neurodegenerative disorders were excluded.

AIIMS Modified INDT-ASD has two sections, A and B. Section A has a total of 28 questions, including questions in both social interaction and communication (A1) and Repetitive and Restricted behaviours (A2). A1 is further divided into A1a, A1b, and A1c and contains questions for social-emotional reciprocity, non-verbal communication, and building relationships. A2 is divided into A2a, A2b, A2c, and A2d and has questions on repetitive behaviour, insistence on routines, restricted interests, and sensory symptoms., respectively. These are all derived from DSM-V criteria for ASD. Each question

has three responses- yes, no, and unsure. These questions have to be answered based on both the history of the primary caregiver and the observation of the child. In case of a discrepancy between the history and observation, an asterisk present on either one will indicate which should be considered to answer the question. The number of abnormal responses for the age should be calculated. Abnormal responses can be 'yes' or 'no' based on the question, and this will be indicated in the questionnaire. Section B is the scoring section which contains 9 questions to help make the diagnosis. Abnormal responses in all 3 subsections of A1 and at least 2 subsections of A2 are mandatory for a diagnosis of ASD. Along with this, symptoms onset in the early developmental period and symptoms impairing functioning are required to make a diagnosis. Healthcare professionals with appropriate training can administer this tool.

The Childhood Autism Rating Scale CARS-2 (ST) is a tool that helps to assess ASD. It can be used in children aged 2 years and above. It has 15 items which are scored based on observation and parental reports. The scoring is done on a 7-point scale from 1 to 4. The peculiarity, intensity, frequency, and duration of the child's behaviour must be kept in mind before scoring. Raw scores are added up and calculated. The scores are given in three categories based on the raw score. The child is said to have minimal to no symptoms of ASD if the score is 29.5 or below. If the score ranges from 30 to 36.5, the child has mild to moderate symptoms of ASD. If the score is above 36.5, the child has severe symptoms of ASD. [5]

CARS-2 (ST) was done by the psychologist, and AIIMS-modified INDT-ASD was done by the Developmental Paediatrician. The results were kept blind in a sealed envelope after scoring. DSM-V criteria were taken as the gold standard to confirm the diagnosis. The criteria were applied, and the diagnosis was confirmed by another Developmental Paediatrician. We enrolled 108 children with suspected ASD in our study. Considering the prevalence of ASD to be 1% in India, we calculated a sample size of 95 with a precision of 2% and a confidence interval of 95%. [6]

Results:

In our study, out of 108 children enrolled, the age range was from 25 months to 84 months of age. The mean age of presentation in our study was 36.9 months. There was male predominance in our study with a male-female ratio of 5.3:1. The commonest presenting complaint (referral concern) in our study was speech delay. Developmental / Intellectual Quotient –DQ / IQ were completed by the Bayley scale of Infant Development 3rd edition and Wechsler scales, respectively. We found (14.8%) as Average, (16.6% as below average, (37%) Mild delay, (12.9%) Moderate delay and around (18.5%) could not be tested.

CARS-2 (ST) was suggestive of ASD in 75 of the 108 children. AIIMS MODIFIED INDT-ASD administered was suggestive of ASD in 77 of the 108 children. Seven children diagnosed as ASD by CARS-2 (ST) were diagnosed as Not ASD by AIIMS MODIFIED INDT-ASD (false negatives). Similarly, 9 children diagnosed as ASD by AIIMS MODIFIED INDT-ASD were diagnosed as Not ASD by CARS-2 (ST) (false positives). Out of the 108 children, 24 were diagnosed as Not ASD by both CARS-2 (ST) and AIIMS MODIFIED INDT-ASD. DSM-V was suggestive of ASD only in the 75 children diagnosed with ASD by CARS-2 (ST).

ASD (n)		CARS-2 (ST) (comparable to DSM-V gold standard based on expert diagnosis)		TOTAL (n)
		No ASD (n)		
AIIMS MODIFIED INDT-ASD	ASD	68	9	77
	No ASD	7	24	31
TOTAL		75	33	108

AIIMS MODIFIED INDT-ASD was found to have a Sensitivity of 91.4%, a Specificity of 78.5%, a Positive predictive value of 89.2%, and a Negative predictive value of 82.5%.

Discussion:

In our study, 108 children with suspected Autism Spectrum Disorder from 2 to 9 years of age were enrolled. The mean age in our study was 36.9 months. There was a male predominance in our study (84%), similar to a study done by Juneja et al. with 71.4% boys [7]. Speech delay was the most common presenting complaint (87.9%) in our study, similar to a study done by Perera et al. [8]. From the results of our study, 77 children were diagnosed with ASD by the AIIMS Modified tool, but only 75 children were diagnosed as ASD by CARS-2 (ST). DSM-V was taken as the gold standard to make a definitive diagnosis. Only the 75 children diagnosed by CARS-2 (ST) were diagnosed with ASD by DSM-V.

Seven children were given a false negative diagnosis by AIIMS Modified INDT-ASD and nine children were given a false positive diagnosis of ASD when compared with CARS-2 (ST). 24 children were diagnosed as Not ASD by both CARS-2 (ST) and AIIMS Modified INDT-ASD. The seven children who were given a false negative diagnosis got a score of 30.5 and 30 by CARS-2 (ST) showing mild symptoms of ASD, which could possibly be the reason for their misdiagnosis by AIIMS Modified Tool. The nine children with false positive diagnoses of ASD were reanalyzed, and there was found to be a discrepancy between the history and observation. Five of the nine children were diagnosed with Social communication disorder, and the other four had Intellectual Impairment. They were given a false positive diagnosis of ASD, possibly because they had poor verbal and nonverbal communication.

The Sensitivity and specificity of AIIMS Modified INDT-ASD against CARS-2 (ST) were 91.4% and 78.5%, respectively. The Positive Predictive Value and Negative Predictive Value of the tool were 89.2% and 82.5% in our study. The development and validation of AIIMS-modified INDT-ASD was done by Gulati et al. in which the sensitivity and specificity of the tool were found to be 98.4% and 91.7%, respectively [4].

Indian Scale for Assessment of Autism (ISAA) is the tool that is mandated for certifying Autism as a disability according to the Government of

India guidelines. This is a detailed assessment tool consisting of 40 items, and it's based on observation, informant interviews as well as testing.[9] ISAA could, however, be used for certification of Disability due to ASD only in children aged 6 years and above, according to the guidelines by the National Trust (India) in 2016. A study by Mukherjee et al found that the specificity of ISAA is low when used for diagnosis of Autism in children aged 2-5 years. The specificity of ISAA in their study was found to be 28.9% in the 2 to 3 years age group, and 33.3% in the 3 to 5 years group. This, therefore, runs a risk of children being inaccurately labelled as ASD when ISAA is used for the younger age group[10]. In our study, we found the AIIMS Modified INDT-ASD tool to have higher specificity (78.5%) in the younger age group compared to the analysis with ISAA being administered in the same age group.

Some of the limitations of the AIIMS Modified INDT-ASD tool are that it is not externally validated for the Western population, and it could be challenging for children with ASD and good verbal skills. The relevant use of the tool in the Western population is that it could be used in referral triage by health visitors and schools. It can form part of the assessment pathway for Autism spectrum and, more importantly, can be used by doctors within the time constraints of Clinics.

Conclusion:

AIIMS Modified INDT-ASD is a simple, effective, user-friendly tool based on DSM V. This requires minimal training and is quick to administer. It can be a useful contribution to the ASD diagnostic pathway alongside other assessments. It is an indigenous tool developed to be culturally acceptable similar to the ISAA. Although validated for the Indian population, the tool can also be used in Western countries in primary care for triage, and in Asian minority populations as the questions are simple to comprehend.

Financial Support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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Date Received : 29 APRIL 2024 I Accepted: 22 JUNE 2024
Indian Journal of Developmental & Behavioral Pediatrics
(Official Journal of IAP Chapter of Neurodevelopmental Pediatrics)
CASE REPORT

Concomitant Duodenal atresia and Hirschsprung's disease in Down's Syndrome – A rare variant

Authors

1.Dr. Anshika Taiwade - Junior Resident, Department of Paediatrics, LN Medical College and JK Hospital, Bhopal, MP

2. Dr. Nitin Vyas – Paediatric and Neonatal surgeon, Department of Paediatrics Surgery, LN Medical College and JK Hospital Bhopal ; Dr. Shweta Anand - Professor, Department of Paediatrics, LN Medical College and JK, Bhopal, MP

3. Dr. Rashmi Vishwakarma - Associate Professor, Department of Paediatrics, LN Medical College and JK Hospital, Bhopal, MP ; Dr. Priyanka Shrivastava - Assitant Professor, Department of Paediatrics, LN Medical College and JK Hospital ,Bhopal, MP

CORRESPONDING AUTHOR

Name- Dr.Anshika Taiwade - Junior Resident,
Department of Pediatrics, LN Medical College and JK Hospital, BHOPAL-462042, Madhya Pradesh
Mobile Number : 7697551280, E-mail : anshika22.taiwade@gmail.com

Access this article online :
Quick Response Code:
Website :
https://ijdbp.in
DOI :
https://doi.org/10.5281/zenodo.13133891

Abstract:

Background: This case report describe the association of Duodenal Atresia results from failed recanalization of the intestinal lumen during gestation with Hirschsprung's Disease also known as congenital aganglionic megacolon, results when the migration of neural crest cells from cecum to rectum is arrested prematurely, in patient with Down's syndrome. Duodenal Atresia and Hirschsprung's Disease are rare congenital anomalies, their co-existence with Down's syndrome is a Diagnostic and Management challenge.

Clinical Description:

A two days-old Preterm (32+-2week),very low birth weight (1.4kg) male baby with features suggestive of Down's Syndrome was referred to our hospital, already diagnosed antenatally Duodenal Atresia for surgery. Physical examination shows epigastric fullness and features suggestive of Down's Syndrome. An abdominal radiography showed the double-bubble sign, characteristic for duodenal atresia, Gastrojejunostomy was done with prediagnosis of Duodenal Atresia. However, during the course of hospitalization Hirschsprung's Disease was suspected and the diagnosis was confirmed by biopsy. In this study, we described the case of duodenal atresia together with Hirschsprung's disease in a patient with Down Syndrome.

Result and conclusion :

Association of Duodenal Atresia and Hirschsprung's Disease in a patient with Down's syndrome is possible,and should be considered for correct diagnosis and treatment.

Key words: Duodenal Atresia; Hirschsprung's Disease; Down 's syndrome

Introduction:

Trisomy 21 is the most common genetic etiology of moderate intellectual disability. The incidence of Down's syndrome in live births is approximately 1 in 733 (1). In addition to cognitive impairment, Down's syndrome is associated with congenital anomalies and characteristic dysmorphic features. Although there is variability in the clinical features, the constellation of phenotypic features is fairly consistent and permits clinical recognition of trisomy 21. Affected individuals are more prone to congenital heart defects (50%), Pulmonary complication, Central nervous system involvement, Gastrointestinal tract anomalies, Craniofacial, Cutaneous and Musculoskeletal involvement.(1) Gastrointestinal tract anomalies present in 12% of patient of Down Syndrome (2) which include Duodenal atresia, Annular pancreas, Tracheoesophageal fistula, Hirschsprung's disease, Imperforated anus, Neonatal cholestasis(1,2). Hirschsprung's disease occurs in approximately 1 in 5000 live births,10% of all cases occur in children with Down's syndrome. Hirschsprung's disease, also known as congenital aganglionic megacolon, results when the migration of neural crest cells from cecum to rectum is arrested prematurely or when the ganglion cells undergo premature death(3). The association between Down's syndrome and Hirschsprung's disease may be linked to the Down's syndrome cell adhesion molecule gene on chromosome 21, overexpression of which leads to neural defects (4) The Duodenal atresia associated with Hirschsprung Disease in a patient with down syndrome is rare presentation (5,6). This case report describes the Duodenal atresia associated with Hirschprung's Disease in a patient with Down's syndrome.

Case Description:

A two days old, preterm (32+-2 week), VLBW(1.4kg) male neonate was referred to our hospital with complaint of respiratory distress, bilious vomiting, inability to accept feed since birth. Physical examination showed epigastric fullness and features suggestive of Down's Syndrome. There was significant past history of death of previous sibling, also a known case of Down's syndrome at 18 months of age due to complex cyanotic congenital heart disease. Antenatal scan of current pregnancy confirmed features of Down's syndrome and impression of Duodenal Atresia. Patient was admitted in NICU, treatment started and necessary investigations sent. An abdominal radiography detected the Double-Bubble sign, classical for duodenal atresia (Figure 1), which was also confirmed by ultrasonography. An echocardiography revealed presence of small ASD. Baby was operated in view of Duodenal atresia, Exploratory Laparotomy with Gastrojejunostomy was performed. Intraoperatively, sigmoid colon was found to be dilated and filled with meconium which could not be squeezed out of rectum. Gradually feed started after confirming the patency in gastrografin meal (Figure 2) but Patient did not pass stools spontaneously and only defecates after syringing. With suspicion of Hirschsprung's disease, loop colostomy was done and biopsy taken from collapsed distal sigmoid colon (Figure 3). Post operatively stoma was functional and baby started passing stool. Biopsy revealed no ganglionic cell and was confirmatory for Hirschsprung's disease(figure 4). Inspite of all the symptomatic and supportive care in NICU, baby could not be saved and succumbed after 51 days of life because of severe septicemia and DIC

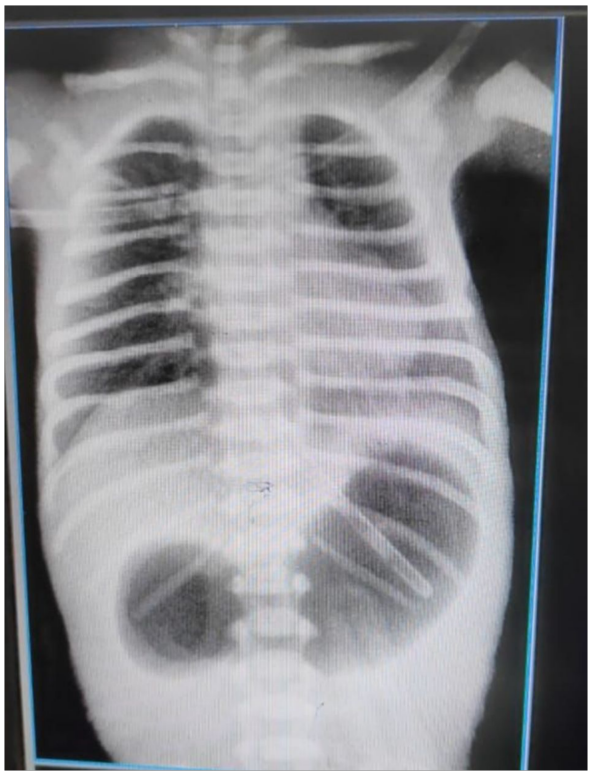

Figure 1

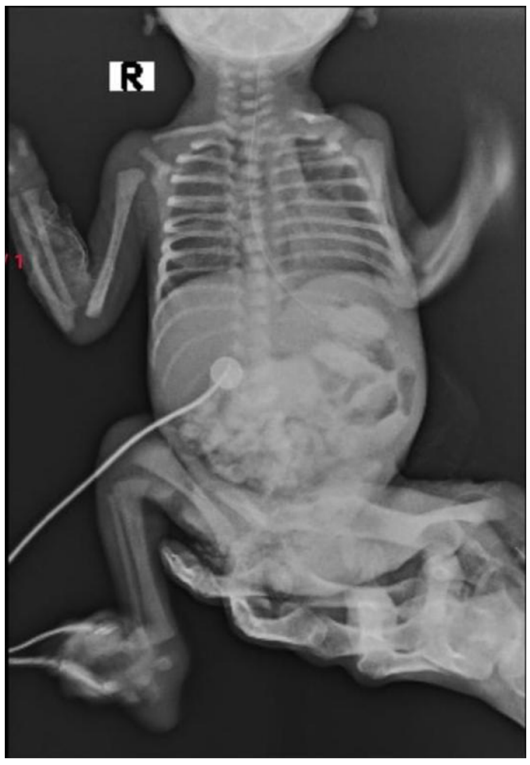

Figure 2

Figure 3

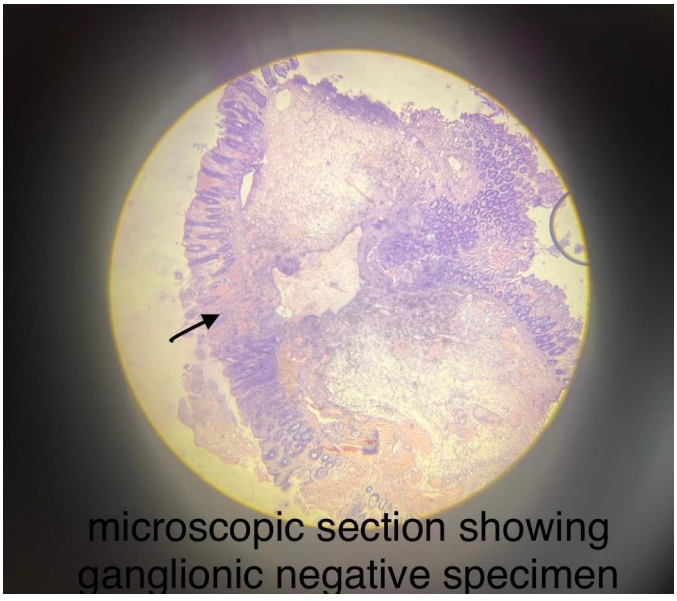

Figure 4

Discussion:

Duodenal atresia results from failed recanalization of the intestinal lumen during gestation. Throughout the 4th and 5th week of normal fetal development, the duodenal mucosa exhibits rapid proliferation of epithelial cells. Persistence of these cells, which should degenerate after the 7th week of gestation, leads to occlusion of the lumen (atresia)(4). Approximately 30% to 40% of children with duodenal atresia have Down's syndrome. There is a 3% prevalence of congenital duodenal atresia among patients with trisomy 21/ Down's syndrome (7).

10% of all cases of Hirschsprung's disease occur in children with Down's syndrome. Hirschsprung's disease, also known as congenital aganglionic megacolon, results when the migration of neural crest cells from caecum to rectum is arrested prematurely or when the ganglion cells undergo premature death. This produces a distal intestinal segment that lacks both the Meissner's submucosal plexus and the Auerbach's myenteric plexus, termed aganglionosis. The association between Down's syndrome and Hirschsprung's disease may be linked to the Down's syndrome cell adhesion molecule gene on chromosome 21, overexpression of which leads to neural defects in experimental models (4). Full thickness rectal biopsy is the "gold standard" for diagnosing Hirschsprung's disease. A contrast enema is most likely to aid in the diagnosis, classical findings are based on the presence of an abrupt narrow transition zone between the normal dilated proximal colon and a smaller-caliber obstructed distal aganglionic segment. Association of Duodenal atresia and Hirschsprung's disease in a patient of Down's syndrome has been reported in literature but exact incidence is unknown.In Down's Syndrome babies operated for duodenal atresia who is not defecating spontaneously, coexistence of Hirschsprung's disease should be kept in mind and should be managed aggressively.

Conclusion and Lesson Learnt:

There is association of Duodenal atresia and Hirschsprung's disease in a newborn with Down's syndrome. So pediatrician and pediatric surgeon should regard this issue for correct diagnosis and treatment.

Financial Support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest

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Editor Dr. Zafar Mahmood Meenai.