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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.

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INVITED GUEST EDITOR

Medicine –at cross roads

Who is a Medical Doctor?

Every time this Q springs up, different people have variable pictures conjuring in their mind, and over the years the profile has been changing. The medical profession is undergoing a painful review of ends and means, resulting in revolutionary changes with sociological importance.

Recent years has seen a rise in consumer activism and litigation, and the way we deliver health care –the so called corporate culture, and financing of medical care have generated a growing amount of apprehension both within organized medicine and among its individual practitioners about medicine's continued ability to maintain its professional status as an autonomous provider of health care services.

New scientific knowledge is accumulating so rapidly as to far outstrip the knowledge of its application and is often at odds with the current outlook. Even if one is able to maintain a regular habit of literature survey they are likely to be behind by years as time goes on.

Medical education is at an important crossroads, given all these technologies. Medical training as directed by present-day academics, is usually narrow, for the want of larger cultural and social interests. The students are led to believe that the ethos of medicine is sickness-orientated, as is seen in the hospitals, and are given little chance to study other aspects, such as the prevention of diseases. Forgotten is the philosophy of medicine –are we meant to care or only cure? Are we training them to have the qualities of the doctor-of integrity, empathy and love for his fellowmen? That's the Q which puts the teachers at cross roads!!

Medical teachers should adopt the newer technologies and train themselves to teach, and their sole objective should be to teach the student and not to teach the subject. Current changes in the curriculum by NMC is an effort in this direction but how well it turns out is yet to be seen. Students are more focused on achieving scores on assessments but is this good enough.

As Dr S. Mukerjee, in his book on The laws of Medicine stated “Good medicine lives in a balance between that fervor and the intellectual honesty—what works and doesn't work, what harms and doesn't harm patients. Develop the flexibility in practice develop the intuition and ability to deviate from protocols but within the bounds of safety.” “That is what I would call developing the Gut Feeling’.

New research is unravelling the mysteries of pathologies and the newer technologies are becoming more and more complex, the therapies still more complex and expensive, makes us wonder how to teach the new generation of doctors.

Technology has brought in host of ways to acquire knowledge but medicine is not acquired from books, as I usually tell my students “your patients are representative of a single topic in the book” study them! Read them to understand how the human body behaves differently in each situation. This is all the more relevant to a pediatrician where he has to get used to understanding the dynamicity of child development.

The rush to go in for Post-graduation and specialist courses is creating a larger cadre of specialists so where is the generalist of future- Is he lost in the passage of time? While at crossroads of clinical

practice the road towards becoming general physician is larger, but are there any takers.

Even policy makers are a crossroads!!

There are times when even learned doctors conceal their medical qualification for fear they may be unable to solve a simple medical problem, which is not in their area of expertise, should they refer? it is a catch 22 situation!!

So if we have to serve the society in truest sense we should train ourselves to handle any medical problem in a logical manner so that we are able to rise to the call in the public

“Is their doctor in the house?”

Choose the correct path at the crossroads.

Warm regards,

Dr. S. Sitaraman

Vice Chancellor,
Indian College of Paediatric

EDITORIAL

This year Autism awareness theme “Moving from Surviving to Thriving” emphasized on holistic approach & inclusion. In a significant positive development On 12th March, 2024 in THE GAZETTE OF INDIA, In exercise of the power conferred by Section 56 of the Rights of Persons with Disabilities Act, 2016 (49 of 2016) and in supersession of notification issued vide No. 16-21/2013-DD-III dated 25th April, 2016 and No. 16-9/2014-DD-III [S.O. 76 (E) Dated 4th January, 2018] of the Ministry of Social Justice and Empowerment, Department of Empowerment of Persons with Disabilities (Divyangjan), the Central Government notified the guidelines for the purpose of assessing the extent of following specified disabilities in a person namely:-

- i. Locomotor disability ;
- ii. Visual Impairment ;
- iii. Hearing Impairment and Speech & Language Disability ;
- iv. Specific Learning Disability, Intellectual Disability & Autism Spectrum Disorder ;
- v. Mental illness ;
- vi. Blood Disorder ;
- vii. Multiple Disorder ; and
- viii. Chronic Neurological Disorder.

It was very heartening to note the use of the term Developmental Pediatrician for the first time in Government notification in context of services for person with special need. Moreover with the Government notification we hope to have uniformity in assessment, certification & planning of these conditions.

Best Regards

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Psychosocial burden on caregivers of children with cerebral palsy

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ABSTRACT

BACKGROUND : Caregiving for a child with Cerebral Palsy is time consuming and stressful, often leading to psychosocial burden and lowering the quality of life of the caregiver.

AIMS:

1. To assess caregiver burden and Quality of life of primary caregivers of children with Cerebral Palsy (CP)

2. To make a comparison of the Quality of life and burden among caregivers of children with different functional levels.

SETTINGS AND DESIGN: A cross sectional study was done on primary caregivers of children with Cerebral Palsy (n=60) on regular follow up in Government Medical College, Thrissur to assess their psychosocial burden and quality of life and its association with child's level of functioning.

METHODS AND MATERIAL: Functional levels were assessed by the GMFCS and MACS scores. The psychosocial burden was assessed using the Zarit Burden Interview and quality of life(QOL) was measured using the WHOQOL-BREF.

STATISTICAL ANALYSIS: Data analysis was done using Chi-square test and student t-test.

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RESULTS:

All caregivers were mothers. Two third had moderate to severe psychosocial burden and QOL scores in all domains were low (<50). Mothers of children with poorer GMFCS and MACS scores had more chance of having moderate to severe psychosocial burden (p value-0.001) and had poorer quality of life (QOL) (p value-0.009). Mothers with moderate to severe psychosocial burden had poorer QOL (p value-0.01).

CONCLUSIONS:

Mothers of CP children have significant burden, and interventions to reduce burden and improve quality of life are imperative to reduce stress; which would affect both the child and the caregiver.

Key-words : *Cerebral Palsy; GMFCS; MACS; Psychosocial burden; Quality of life.*

INTRODUCTION

Raising a child with intellectual or physical disability is a challenging task for any parent. This is especially so, when the child is suffering from a condition like Cerebral Palsy where physical as well as cognitive abilities of the child are affected to varying levels [1]. This creates extensive social and economic burden on the caregivers. [2,3]The mother is still expected to fulfill all her usual roles at home, and the stress leads to psychological as well as physical health issues. Studies have identified factors influencing the psychosocial burden to be the disability level of the CP patient as well as the age, marital status and education of the caregiver.[4-6]

Most of the research on the psychological status of the primary care giver in Cerebral Palsy have come from the West whose functioning is totally different from that of our country. The level of awareness as well as the economic support from the State helps to reduce the burden in a developed country. In a country like ours, where there is a significant proportion of the population below the poverty line, the resources available for parents of children with disabilities are few. Estimating the nature of caregiver's problems will lead to better focus on caregiver interventions in the long-term care of disabled children.

Kerala has among the highest literacy rates as well as a well-established public health system[7].No studies have been conducted so far in this set up to assess the burden among mothers of children with CP. This study measured the psychosocial burden of these caregivers; as well as their quality of life. It also looked at the influencing factors with special emphasis on the functional level of the child.

MATERIALS AND METHODS:

This cross-sectional descriptive study was conducted between January 2014 to May 2015 in the Department of Pediatrics, in Government Medical College, Thrissur, a tertiary care institution in Kerala. The study was approved by the Institutional Ethics Committee. Primary caregivers of children with Cerebral Palsy attending the Pediatric Neurology Clinic were recruited after obtaining informed consent. Caregivers of children less than two years of age and caregivers with chronic illnesses were excluded. From a previous study done using WHOQOL BREF and Zarit Burden Interview among caregivers of children with CP in India, the mean and standard deviation in the psychological domain of quality of life was taken for calculation of sample size[8].

Mean = 36.6, SD = 7.35

Sample size = $\frac{Z\alpha^2 \times SD^2}{d^2}$

$z\alpha^2 = 3.84$, SD = 7.35, d is variability, taken as 2.

$$n = \frac{3.84 \times 7.35 \times 7.35}{2 \times 2} = 51$$

Taking a non-responder rate of 10%, sample size is taken as 60.

A total of 60 caregivers were included in the study. The details of affected children including age, gender, SES status, type of CP and disability pension status was collected. The health care needs of the children were assessed in terms of number of hospital visits, need for hospital admissions and chronic medication in the three months prior to interview. The functional status of the children was evaluated using the GMFCS and MACS classification.[9-12]

Caregiver details including age, gender,

education, occupation as well as family support was collected. The caregiver burden of subjects in this study was assessed using the Zarit Burden Interview [13] developed by Zarit, Reever and Bach (1980). This interview schedule contains 22 items, and for each item, caregivers were asked to respond about the impact of the patient’s illness on their life, by indicating how often they felt in a particular way, (“never”, “rarely”, “sometimes”, “quite frequently”, “nearly always”).

The caregiver quality of life was assessed by the WHOQOL-BREF – World Health Organization Quality of Life BREF – Assessment Instrument: short version which contains 26 questions divided into four domains:

- A. *Physical health.*
- B. *Mental health/Psychological*
- C. *Social relationships.*
- D. *Environment*

Each question was assigned an appropriate number of points from 1 to 5 with 1 point denoting very dissatisfied and 5 very satisfied. The mean scores of the questions pertaining to each domain was computed, which gave the raw domain score. The transformed domain score was used for analysis.[14,15]

The socioeconomic status of the caregiver was assessed using the modified Kuppuswamy scale, meant for use in urban Indian population.[16]

Data analysis :Data was analysed using SPSS version 18. Student t test was used for analysis of continuous variables and Chi square test was used for categorical variables.

RESULTS:

A total of 60 caregivers were enrolled. Of the sixty affected children, there was an almost equal male-female distribution. The study included

children with ages from two to eighteen, and 50% belonged to the five to ten years age group. Majority belonged to the upper lower socio economic class (60 percent) followed by upper middle class (37 percent) . Among the different types of Cerebral Palsy, Spastic quadriplegia (32 percent) and spastic hemiplegia (28 percent) followed by spastic diplegia (20 percent) were the most common while choreoathetoid CP was the least common (3 percent). Under the GMFCS, 27 out of the sixty children belonged to Level 5, and 25 of these children had a level five MACS as well (Table 1). Because these children have poor functioning ability, they were bedridden and required caregiver support for all activities of daily living. Only 50% of the children were receiving state provided disability pension.

Table 1: GMFCS and MACS levels of CP children

Levels	GMFCS		MACS
	Frequency	Percentage	Frequency
1	10	16.67	13
2	15	25	12
3	2	3.33	5
4	6	10	5
5	27	45	25
Total	60	100	60

17 percent of the children required frequent medical attention; atleast one visit per month. Around 40 percent of children required hospital admissions in the last 3 months with an average duration of stay of 5.6 days. The average expenditure of hospital stay was Rs. 2900. 75 percent of children were on regular medication; most of the time, the children were on anti epileptic drugs. Average cost of medicines for a month was around Rs. 300.

All the sixty primary caregivers in this study were mothers; and 60% of them were above 30 years of age. 77 percent caregivers had completed secondary education. Ten of these mothers had done graduation level studies and one had completed her post graduation. There were no illiterate mothers. Only around 17 percent of the mothers were employed; and more than half of them had only part time jobs. Seven of the mothers had given up their jobs and six of them had to cut down on working hours in order to look after the disabled child. The average income was Rs. 2000 per month. The state government aided caregiver pension was being procured by only 18 mothers. Although almost all of them were aware of this provision, they reported that the application process was tedious and they were kept waiting for more than a year before the amount got sanctioned. The payment was also reported to be irregular.

In majority of households, the spouse of the caregiver was the head of the household. Most of the caregivers were living in their own homes (90 percent) and there was overcrowding in more than half of the households. In our study, 70 percent of mothers had support from other family members in caring for their child, commonly the husband or mother-in-law. However, the help was available only for an average of two hours per day and the bulk of the caregiving was still

being handled by the mother alone. None of the caregivers had paid help- night or day.

1. Caregiver Burden

The caregiver burden assessed using the Zarit Burden Interview divides the caregivers as those with no burden, mild, moderate or severe burden. In the study group, 58 percent of mothers had moderate caregiver burden and 6 percent had severe burden ie almost two third of mothers had moderate to severe burden (Table 2).

Table 2: Caregiver Burden

Severity of burden	Frequency	Percentage
No burden	2	3.3
Mild burden	19	31.7
Moderate burden	35	58.3
Severe burden	4	6.7
Total	60	100

A positive association was seen between higher level of GMFCS and severity of caregiver burden. The difference between the two groups were highly significant with a p value of 0.001. (Table 3). Mothers of children with poorer MACS(3,4,5) had more probability of having moderate or severe burden. (p value of 0.001). In our study, no significant association was found between the primary caregiver's educational or occupational status and caregiver burden.

Table 3 : Caregiver Burden vs GMFCS and MACS

	Caregiver Burden			
GMFCS	No burden	Mild burden	Moderate burden	Severe burden
Level 1& 2	2	15 (79%)	9 (20%)	1 (25%)
Level 3,4,5	0	4 (21%)	26(80%)	3(75%)
Total	2	19	35	4
Chi Square - 17.198		p value: 0.001		
MACS	No burden	Mild burden	Moderate burden	Severe burden
Level 1& 2	2 (100%)	14 (74%)	8 (22%)	1 (25%)
Level 3,4,5	0	5 (26%)	27 (78%)	3 (75%)
Total	2	19	35	4
Chi square-16.365		p value : 0.001		

2. Quality of Life

The transformed mean score in all domains were less than 50 indicating a less than satisfactory quality of life. The worst affected was the psychological domain indicating a psychological stress related to the child’s condition (Table 4).It was found that mothers with moderate to severe burden had lower domain scores indicating

poorer quality of life. The Quality of life of the caregiver was better in all four domains when the child had good gross motor functioning (GMFCS 1&2); highly significant in the physical and psychological domains. Better fine motor functioning of the child caregivers had a better quality of life in all domains (Table 5). Caregiver Quality of life had no correlation with caregiver’s education or occupational status.

Table 4: Mean domain scores and Standard deviation

Domains	Mean ± SD	Max - Min scores
Physical health	48.03 ± 10.9	78.5 - 25
Psychological	39.79 ± 11.02	70.8 - 16.6
Social Relationships	42.77 ± 12.9	66.6 - 16.6
Environmental	41.9 ± 11.6	59.4 - 21.8

Table 5: Quality of life and functional classification

Domains	GMFCS 1&2 mean score (n = 25)	GMFCS 3,4,5 mean score (n = 35)	df	t test value	p value	
Physical	52.43	44.89	47	2.01	0.009	
Psychological	45.83	35.47	48	2.01	0.0002	
Social	46.67	40	43	2.02	0.06	
Environmental	44.63	41.69	45	2.03	0.39	
Domains	MACS 1&2 Mean(n=25)	MACS 3,4,5 mean(n=35)	df	t test value	p value	
Physical	53.43	44.18	47	2.01	0.001	
Psychological	46.33	35.12	47	2.01	0.00007	
Social	47.67	39.28	43	2.02	0.01	
Environmental	46.5	40.36	33	2.03	0.06	

Discussion:

The study found an almost equal male-female ratio among subjects. The most common types of CP were spastic quadriplegia and spastic hemiplegia. In a study done in 2002, Singhi PD had reported that spastic quadriplegia was the most common, suggesting no major changes over the past 15 years. [17]

The process of application for disability pension is tedious, as a result of which many of the children do not receive eligible support. There is a need for swift action from the policymakers in order to help improve the lives of children affected with chronic illnesses.

All the sixty caregivers enrolled in the study were mothers of the affected children. Though the spouse was the head of household in the majority, mothers had the lion’s share of responsibility in looking after children as well as managing household chores. This can be taken as a reflection of the patriarchal type of society prevalent in our

country. The youngest mother was 22 and the eldest 42 with a mean age of 32.5 years.

In contrary to the rest of the country, Kerala is acknowledged for its high literacy rate and abundance of educational institutions. 77 percent of the caregivers in this study had completed secondary level education and almost 20 percent had done higher education.

The task of caregiving for a child with disability is in itself a full time responsibility and when there is no other caregiver, an additional job is almost impossible. This could explain the low rate of employment among our study group. None of the mothers who had children with GMFCS level 5 could work; indicating the increased time demands in caring for such a child.

Mbugua[18] had identified unemployment as a risk factor for maternal depression. In this study, most of the mothers with moderate or severe burden were unemployed but the difference was not found to be significant.

The state government provides a monthly pension to caregivers of the chronically ill[19], but only 30 percent of mothers were receiving this pension. The process of application and its approval is a long drawn process and very often the mother is unable to follow it up due to the other demands on her time, leading to delay in availability of pension. Making this process an easier and transparent one could go a long way in helping these mothers.

Management of Cerebral Palsy is multidisciplinary with rehabilitation through physiotherapy, occupational therapy and drugs for management of complications. We found that this leads to a heavy burden on the caregiver, both physical and economic with hospital admissions are an additional burden. Khanna [20] and Vadivelan [2] have described similar findings.

Majority of the study group had significant psychosocial burden and this indicates the need for effective interventions to reduce the burden, as this has been proven to have a negative impact on both the caregiver as well as the child [3,5]. This could be done by forming peer groups where problems could be discussed and issues addressed.

There was a significant positive association between the caregiver's burden and level of the child's disability as measured by MACS and GMFCS. Previous investigators have found conflicting results in this regard. Glenn[21], Marx[22] and Wallander[23] had reported no significant difference in caregiver stress based on the child's GMFCS levels while Basaran [24] found a significant difference in caregiver depression with poorer functioning abilities of the child. Chavez also described a worsening of burden with severe disability [3]. Most of the studies which could find no significant difference are from Western literature where there is an

efficient state run support system for children with disabilities, as well as their caregivers. The major issue in those settings would be understanding the child's prognosis rather than the day to day exertion which mothers in our setting have to face.

Relationship of other factors like caregiver education, caregiver occupation, informal help and availability of pension with the caregiver burden was assessed. Gambhir [25] had found that higher levels of education led to a favorable attitude to Cerebral Palsy. Chavez [2] described an increased burden in caregivers with less than secondary level schooling, but our study found no significant difference based on level of education in terms of caregiver burden.

The caregivers in our study had a poor quality of life. Adenuga[26] had reported poorer QOL in CP caregivers and had found physical health, social relationships and environmental health to be more affected. Similar findings have been reported by Basaran[24], Ones [27] and Pandit [28]. Pruthi [8] had published similar results in a comparison study of caregivers of children with Cerebral Palsy, Thalassemia and no major illnesses. However, a few studies reported a good Health Related QOL in caregivers of CP children [29].

Psychological domain was the worst affected. Mothers with moderate or severe caregiver burden had poorer quality of life in all domains, with significant difference between the two groups. This proves that there is a negative association between quality of life and caregiver burden, which emphasizes the need for interventions to reduce the caregiver burden and thereby improve their quality of life.

The caregivers of children with better GMFCS and MACS scores had a better quality of life in all

domains. With respect to GMFCS, the difference was significant in the physical and psychological domains which appear to be more affected due to the caregiving role. Similar findings were reported by Sonune et al [30]. Physical, psychological and social domains were significantly affected when the child had poor MACS scores. Previous investigators had looked into this relationship with respect to GMFCS. Adenuga [26] had found that physical health, social relationships and environmental health were more affected.

To summarize, caregivers of children with CP

have significant psychosocial burden and poor Quality of life. The medical community has to recognize the need to take care of not only the child, but also the mother.

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Motor dysfunctions in preschool children with Autism and its functional implications in life

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Abstract:

Background: Neurodevelopmental disorders (NDD) comprises of highly heterogeneous group of diseases characterized by impairments in cognition, communication, behaviour, and motor functioning as a result of atypical brain development. Standardization and development of guidelines for motor phenotyping of the motor abnormalities in ASD, has not got enough attention when compared with their behavioural and developmental counterparts. Hence, the need for this study by which we can determine the common motor abnormalities so that they are corrected at the earliest.

Methods: A Cross-sectional study was conducted for a period of 10 months after enrolling a total of 60 children in between age group 3-5 years of age who met the inclusion criteria by convenient sampling method. After entering their demographic details in the proforma, diagnosis was made using DSM-5 criteria and standard diagnostic tools and all ASD's were selected. All the children were subjected to Peabody Developmental Motor Scale (PDMS -2) assessment to assess their gross motor and fine motor functions, and then WeeFIM was



administered to assess the extent of functional impairment in their daily activities. 1-sample Binomial test was used to analyse WeeFIM and PDMS-2 scores in each subset in the total sample. Correlation between each subset in PDMS -2 and WeeFIM in the total sample and then only ASD children was done by using t-Test, Levene's equity of mean, Chi-square test. **Results:** In the present study 41 out of the total 60 (68.3%) ASD children were found to have motor impairments as seen by the Total Motor Quotient which was in the range of below average, poor and very poor in PDMS -2. Among the gross motor the commonest subset affected was object manipulation (34/60) 58.3% followed by locomotion (48.3%) and stationary (46%) whereas, in fine motor domain

the most affected subset was visual -motor integration (35/60) 58.3% followed by grasping (35%). Among all NDD children the functional significance was assessed by WeeFIM which revealed self-care and cognition domains as the most affected and even though the gross motor functions were the most affected still it did not affect functional mobility of the child. ASD and all of these children had motor impairments as seen on PDMS -2 and in the day to day activities the most affected subdomain was eating followed by grooming and bathing in the self-care domain. **Conclusion:** Hence in NDD's like ASD where motor dysfunctions are not overtly present, if any functional impairment is present, we need to assess both the fine motor and gross motor dysfunctions in detail with the help of a standardized tool; find the domains interfering with functional abilities and take the necessary corrective measures, so that we can improve the day -to-day functioning of the child.

Keywords: Autism, PDMS, Functional assessment, Motor dysfunctions, Developmental delay, Speech delay

Introduction:

Neurodevelopmental disorders (NDD) encompass a highly heterogeneous group of diseases characterized by impairments in cognition, communication, behaviour, and motor functioning as a result of atypical brain development. Motor dysfunctions of predominantly non-motor neurodevelopmental disorders (NDD) such as autism spectrum disorder (ASD), Attention deficit hyperactive disorder (ADHD) etc. have been traditionally a neglected topic in both clinical practice and research. Even though, motor delays and impairments are not a core diagnostic feature in children with autism spectrum disorders (ASD), they are still present in

majority of individuals with ASD.^[1] Most of the available standardized measures assess the motor milestones and skill acquisition but they often fail to capture more qualitative or subtle differences in overall motor function. Like all other neurodevelopmental domains (such as cognition or social skills), a better assessment of the full spectrum of differences and impairments in motor skills would serve to shed light on specific neural mechanisms of atypical development as well as provide more specific targets for motor -based interventions which, could result in improvement in other core features of ASD.^[2] For example, rather than quantifying whether a child is able to walk between 2 points, better information can be obtained if evaluated to see if the gait is wide based, rigid, or asymmetric implicating the different underlying mechanisms. Since, motor function is a common intervention target, accurate measurement to individualize therapy improves the overall outcome. Standardization and development of guidelines for motor phenotyping of the motor abnormalities in ASD, despite its pervasive, variable nature and importance, has not got enough attention when compared with their behavioural and developmental counterparts.

Hence, this study was conducted to determine not only the motor dysfunctions which were commonly associated with the ASD but also the extent of functional disability that these motor dysfunctions will cause in the day-to-day living of these children between 3-5 years of age.

The objectives of this study were to:

1. To identify the various motor dysfunctions which are associated with ASD in children between 3-5 years of age.
2. To determine the extent of functional disability that these motor dysfunctions will cause in the day -to-day living of these children.

Materials and methods:

Study design:

A Cross-sectional study was conducted in Saveetha Child Development centre (SCDC) and 3 branches of Vistara Child Development Centres (VCDC), Chennai and Hyderabad for a period of 11 months. Study was started after getting the ethical committee approval (No.-SMC/IEC/2019/1/003). A total of 60 children in between age group 3-5 years of age who met the inclusion criteria were enrolled, convenient sampling method was used to select the sample size. Children suspected to have developmental disorders, delays or high risk are referred from Pediatric OPD to SCDC and those with speech and behavioural problems referred to VCDC were enrolled. Children were assessed by a multidisciplinary team consisting of Developmental Paediatrician, Developmental therapist, speech therapist, Occupational therapist and Clinical psychologist.

Children aged between 3- 5 years of age referred to CDC and those with Primary ASD with a normal routine CNS examination were included into the study. Sample size was estimated at 60 considering the lack of exact prevalence of motor disturbances in ASD in India. Children below 3 years and above 5 years of age and children with motor NDD such as Cerebral Palsy, Pediatric stroke, Children with metabolic or known genetic and syndromic causes were excluded as prognosis in these disorders vary significantly from Autism Spectrum disorder. Their demographic details were entered in the proforma, diagnosis was made clinically using DSM-5 criteria and CARS-2. Participant's information sheets in English and local language was provided to the parents and the need of the study was explained to them along with reassurance regarding safety and confidentiality of their data as the principal investigator signed an agreement ensuring the same with one copy

retained by them. All the children who were part of the study underwent Peabody Developmental Motor Scale (PDMS -2) assessment. This test was used to assess the gross motor and fine motor functions, and then Wee-FIM was administered to assess the extent of functional impairment in their daily activities. Presence of any major or subtle motor dysfunctions was identified and quantified by a qualified Pediatric occupational therapist and Principal investigator together using PDMS-2^[3] Test for each subscale, was administered from the starting point defined by the chronological age of the child (entry point), as per the instructions given in the manual. Some items required a verbal request, whereas others required verbal request with the demonstration of the action. Physically helping the child to perform the required test was not allowed, but PI was allowed to reformulate the verbal instructions or demonstrate the required action making it more understandable (for example through the use of objects). The PDMS-2 final raw scores were converted to standard scores for subsets and the quotients for gross motor (GMQ), fine motor (FMQ), total motor (TMQ) and then these scores were classified performance wise into 7 categories: very superior, superior, above average, average, below average, poor and very poor. This was followed by assessment with Wee-FIM scale and the extent of functional impairment that these motor dysfunctions are causing in the daily living of the child was measured in the domains of Self - help, mobility and cognition.^[4] The scores were given between 1-7 based on the flow-charts provided and later these scores were compared to the age norms as per the chronological age of the child.

Statistical analysis: The collected data were numerically coded and entered in Microsoft Excel 2010, and then analyzed using SPSS-

Version 23.0., (SPSS Inc, Chicago, USA). Proportions, means, medians, standard deviations and confidence intervals were calculated as appropriate for demographic characteristics, main parental concerns and test results. Using SPSS-23 software, 1-sample Binomial test was used to analyse scores in each subset in the total sample. Correlation between each subset in PDMS -2 and WeeFIM in the total sample was done by using t-Test, Levene’s equity of mean, C hi -square test.

Results:

This study had 60 children with ASD of which 38 among them were males (58.3%). 48.7% reported that the main parental concern was decreased response to name call and decreased eye contact and 40% reported speech delay. The mean age of children was found to be 45.97 months +/- 7.97 SD in the present study population. The

mean maternal age was found to be 26.1 years +/- 2.796SD.

In the present study, 41 out of the total 60 (68.3%) ASD children were found to have motor impairments as seen by the Total Motor Quotient which was in the range of below average, poor and very poor in PDMS -2. Among the gross motor domain, the commonest subset affected was object manipulation (34/60; 58.3%) followed by locomotion (48.3%) and stationary (46%) whereas, in fine motor domain the most affected subset was visual -motor integration (35/60; 58.3%) followed by grasping (35%). When comparing the motor quotients of PDMS -2 it was found that Gross motor functions were affected in 71.7%, Fine motor in 65.1% and Total motor functions were affected in 68.3% of children with ASD. (Table:1)

Table:1 Performance of ASD children in PDMS-2 in Subsets& Motor Quotients

Std score	Above average		Average		Below Average		Poor	
Parameter	n	%	n	%	n	%	n	%
Locomotion	1	1.7	30	50	29	48.3	-	-
Stationary	1	1.7	32	53.3	26	43.3	1	1.7
Object Manipulation	1	1.7	24	40	32	55	2	3.3
Grasping	1	1.7	38	63.3	18	30	3	5
Visual- motor integration	1	1.7	24	40	30	50	5	8.3

Quotients parameter	Above average		Average		Below average		Poor		Very poor	
	n	%	n	%	n	%	n	%	n	%
GMQ	1	1.7	16	26.7	36	60	7	11.7	-	-
FMQ	1	1.7	20	33	31	51.7	7	11.7	1	1.7
TMQ	1	1.7	18	30.36	29	48.3	10	16.7	2	3.3

When ASD was compared with motor scores subsets, all had significant issues with stationary, object manipulation and visuo-motor integration (Table:2). When PDMS2 quotients were analysed, present study finds all 3 quotients were significantly affected(p<0.05).

Table:2PDMS subset scores and quotientsin ASD

Subset Variable	Yes	no	Total(N)	Test Statistic	P-value	Quotients	Total(N)	Test Statistic	P-value
Stationary	46	14	60	46	0.007	GMQ	60	17	0.001
Locomotion	40	20	60	40	0.124	FMQ	60	21	0.028
Object Manipulation	51	9	60	51	0.001	TMQ	60	19	0.007
Grasping	35	25	60	35	0.441				
Visual-motor integration	51	9	60	51	0.001				

When the functional significance of all the identified motor issues were analysed using Wee-fim it showed thatall ASD children were affected in a statistically significant way (P value<0.05) in self-care (eating, grooming, bathing, bowel & bladder management and total self-care); and cognition, but not in mobility.

Table:3 Wee-Fim functional scores in ASD.

SELF CARE					
Variable	Yes	No	Test Statistic	P-value	
Eating	57	3	57	<0.001	
Grooming	48	12	48	<0.001	
Bathing	39	21	39	0.028	
Dressing(upper)	33	27	33	0.519	
Dressing(Lower)	27	33	33	0.519	
Toileting	35	25	25	0.245	
Bowel management	21	39	39	0.028	
Bladder management	16	44	44	<0.001	
Self-care total	58	2	58	<0.001	

COGNITION					
Variable	Yes	No	Test Statistic	P-value	
Comprehension	60	0	-	-	
Expressive	59	1	59	<0.001	
Social interaction	43	17	17	0.001	
Problem solving	56	4	56	<0.001	
Memory	52	8	52	<0.001	
Cognition total	60	0	-	-	

MOBILITY					
Variable	Yes	No	Test Statistic	P-value	
Transfers - chair	1	59	59	<0.001	
Transfers –toilet	31	29	29	0.897	
Locomotion-walking	11	49	49	<0.001	
Locomotion -stairs	9	51	51	<0.001	

Among the scores in Wee-fim, Mobility was not significantly NOT affected in any of the children. Everyone was significantly affected in other two areas with p value of ≤ 0.001 .

Table:-4- GMQ vs WEEFIM

WeeFim- Variables	GMQ	N	Mean	SD	F	df	p-Value
Eating score	No	17	4.82	0.636	5.012	58	<0.001
	Yes	43	3.63	0.874			
Grooming score	No	17	3.88	0.781	0.878	58	<0.001
	Yes	43	2.74	0.79			
Bathing score	No	17	3.94	0.659	2.442	58	<0.001
	Yes	43	2.79	0.833			
Dressing (Upper) score	No	17	4.53	0.717	1.73	58	<0.001
	Yes	43	3.53	0.909			
Dressing (Lower) score	No	17	4.35	0.606	3.618	58	0.001
	Yes	43	3.56	0.881			
Toileting score	No	17	4.88	0.781	2.276	58	<0.001
	Yes	43	3.79	0.989			
Bladder management score	No	17	5.35	0.493	3.832	58	0.016
	Yes	43	4.7	1.036			
Bowel management score	No	17	6.12	0.485	7.663	58	0.02
	Yes	43	5.47	1.077			
Self-care total score	No	17	37.88	3.967	3.124	58	<0.001
	Yes	43	30.16	6.264			
Transfers-Wheel chair score	No	17	7	0	1.642	58	0.534
	Yes	43	6.98	0.152			
Transfers-Toilet score	No	17	6	0.612	9.895	58	0.057
	Yes	43	5.56	0.854			
Transfers-Shower score	No	17	5.71	0.47	4.128	58	0.046
	Yes	43	5.42	0.499			
Locomotion-Walk score	No	17	6.41	0.507	4.819	58	0.002
	Yes	43	5.95	0.486			
Locomotion-Stairs score	No	17	6.06	0.429	20.552	58	0.001
	Yes	43	5.51	0.551			
Mobility total score	No	17	31.18	1.551	1.072	58	0.001
	Yes	43	29.42	1.88			
Comprehension score	No	17	3.82	0.636	2.763	58	0.143
	Yes	43	3.51	0.768			
Expression score	No	17	3.41	0.939	2.599	58	0.632
	Yes	43	3.23	1.411			
Social interaction score	No	17	3.47	0.8	0.318	58	<0.001
	Yes	43	2.53	0.855			

Problem solving score	No	17	4.41	1.004	0.032	58	0.007
	Yes	43	3.63	0.976			
Memory score	No	17	4.35	0.786	0.094	58	0.064
	Yes	43	3.91	0.84			
Communication total score	No	17	19.47	2.764	2.901	58	0.016

To understand how the issues in GMQ affected the functional ability of child, GMQ was compared with variables of Wee Fim, it was found nearly all the variables in functional ability were affected except expression, comprehension and memory.

Table:5:- FMQ vs WEEFIM scores

Variable	FMQ	N	Mean	SD	F	df	p-Value
Eating score	No	21	4.76	0.7	2.404	58	<0.001
	Yes	39	3.54	0.822			
Grooming score	No	21	3.86	0.854	0.004	58	<0.001
	Yes	39	2.64	0.668			
Bathing score	No	21	4	0.707	1.235	58	<0.001
Dressing (Upper) score	No	21	4.52	0.75	0.734	58	<0.001
	Yes	39	3.44	0.852			
Dressing (Lower) score	No	21	4.38	0.669	1.361	58	<0.001
	Yes	39	3.46	0.822			
Toileting score	No	21	4.95	0.74	4.308	58	<0.001
	Yes	39	3.64	0.903			
Bladder management score	No	21	5.48	0.512	3.75	58	<0.001
	Yes	39	4.56	0.995			
Bowel management score	No	21	6.24	0.539	4.544	58	<0.001
	Yes	39	5.33	1.034			
Self-care total score	No	21	38.19	4.106	1.631	58	<0.001
	Yes	39	29.21	5.587			
Transfers-Wheel chair score	No	21	7	0	2.254	58	0.468
	Yes	39	6.97	0.16			
Transfers-Toilet score	No	21	6.19	0.68	0.683	58	<0.001
	Yes	39	5.41	0.751			
Transfers-Shower score	No	21	5.76	0.436	4.27	58	0.002
	Yes	39	5.36	0.486			
Locomotion-Walk score	No	21	6.43	0.507	7.656	58	<0.001
	Yes	39	5.9	0.447			

Locomotion-Stairs score	No	21	6.05	0.384	28.983	58	<0.001
	Yes	39	5.46	0.555			
Mobility total score	No	21	31.43	1.502	0.033	58	<0.001
	Yes	39	29.1	1.667			
Comprehension score	No	21	3.95	0.669	1.94	58	0.006
	Yes	39	3.41	0.715			
Expression score	No	21	4.76	1.071	0.259	58	0.14
	Yes	39	3.54	1.373			
Social interaction score	No	21	3.86	0.75	0	58	<0.001
	Yes	39	2.64	0.785			
Problem solving score	No	21	4	0.978	0.123	58	<0.001
	Yes	39	2.64	0.854			
Memory score	No	21	4.52	0.746	0.03	58	0.007
	Yes	39	3.44	0.823			
Communication total score	No	21	4.38	2.971	0.645	58	<0.001

When FMQ was analysed with WeeFim , the present study finds only transfer wheel chair and expression were not affected significantly.

Table:-6 TMQ vs WEEFIM total score

Variable	TMQ	N	Mean	SD	F	df	p-Value
Eating score	No	19	4.74	0.733	2.043	58	<0.001
	Yes	41	3.61	0.862			
Grooming score	No	19	3.79	0.855	0.016	58	<0.001
	Yes	41	2.73	0.775			
Bathing score	No	19	3.95	0.705	1.373	58	<0.001
	Yes	41	2.73	0.775			
Dressing (Upper) score	No	19	4.47	0.772	0.832	58	<0.001
	Yes	41	3.51	0.898			
Dressing (Lower) score	No	19	4.32	0.671	2.167	58	0.001
	Yes	41	3.54	0.869			
Toileting score	No	19	4.95	0.78	2.961	58	<0.001
	Yes	41	3.71	0.929			
Bladder management score	No	19	5.42	0.507	3.642	58	0.002
Bowel management score	No	19	6.21	0.535	4.906	58	0.002
	Yes	41	5.39	1.046			

Self-care total score	No	19	37.84	4.167	2.33	58	<0.001
	Yes	41	29.8	6.071			
Transfers-Wheel chair score	No	19	7	0	1.932	58	0.501
	Yes	41	6.98	0.156			
Transfers-Toilet score	No	19	6.11	0.658	3.637	58	0.005
	Yes	41	5.49	0.81			
Transfers-Shower score	No	19	5.74	0.452	4.507	58	0.012
	Yes	41	5.39	0.494			
Locomotion-Walk score	No	19	6.42	0.507	5.991	58	<0.001
	Yes	41	5.93	0.469			
Locomotion-Stairs score	No	19	6.05	0.405	25.302	58	<0.001
	Yes	41	5.49	0.553			
Mobility total score	No	19	31.32	1.529	0.408	58	<0.001
	Yes	41	29.27	1.789			
Comprehension score	No	19	3.89	0.658	2.402	58	0.035
	Yes	41	3.46	0.745			
Expression score	No	19	3.53	0.964	1.324	58	0.325
	Yes	41	3.17	1.412			
Social interaction score	No	19	3.47	0.772	0.24	58	<0.001
	Yes	41	2.49	0.84			
Problem solving score	No	19	4.47	0.964	0.033	58	0.001
	Yes	41	3.56	0.95			
Memory score	No	19	4.37	0.761	0.019	58	0.035
	Yes	41	3.88	0.842			
Communication total score	No	19	19.74	2.746	2.268	58	0.002

Table:7 :- TMQ vs WEEFIM scores

Comparison of TMQ with Wee Fim score variables also give almost all parameters except expression was significantly affected.

Variable	TMQ	N	Mean	SD	F	df	p-Value
WEEFIM score	no	19	88.89	7.355	2.169	58	<0.001
	yes	41	75.68	10.859			

Total Wee-Fim score analysed with TMQ also gives a significant P value(<0.001).

Discussion:

This study was done to gain an understanding of the various possible motor abnormalities, if any, that manifest and functionally interferes in children with ASD. The two assessment tools that were selected- PDMS-2 and Wee-Fim(3-8 years) are designed to pick up even the minute aspects of age appropriate development of the motor domain and its functional implications.

There are direct standardized assessments of motor function which provides quantification of motor ability in children, and it makes it simpler to compare and contrast to typically developing children. However, there remains a significant gap in our ability to evaluate motor function in NDD children particularly with ASD, due to the heterogeneity encountered, and these gaps are Ingrid in the individual and global limitations of these assessments.^[5] PDMS-2 was selected to evaluate the finer aspects of motor development which may miss the eyes of even the astute clinician, especially in NDD's like ASD. Further refinement in assessing this important aspect of development is possible only by identification of these gaps.

In the present study the male preponderance (n=35;58.3%) was slightly more than that of female (n=25; 41.7%). This is in congruence with the INCLLEN study and census 2011 which states that prevalence among boys was 12.4% (95CI10.2-15%) and 10.2% in girls. The mean age of NDD children was 45.97 months+/- 7.97SD in the present study.^[6]

58.3% of all ASD's(n=35) had comorbidities; among the comorbidities Seizures were more common comorbidity in ASDs (n=13; 21. 7%). The most frequent primary parental concern was decreased response to name call and decreased eye contact (46.7%) closely followed by speech

delay (40%). This shows that among the non-motor problems, main concerns parents identify earlier and are distressed about are mainly centered on speech and social interaction. Only 8.3% of parents of children with ASD reported sensory issues as a pressing issue affecting their kids.

This also raises a valid question- whether the parents need to be made aware of the additional sensory issues that most of these children have, which may be identified by the treating personnel as symptoms/signs of an ASD, increasing their stress levels or should the sensory issues be curtailed to the treating personnel (therapist/doctor) at their discretion. A larger study on the identifying the need of creating awareness for parents on sensory issues and benefits of the same may give better idea about this issue.

To assess the presence of motor impairments, PDMS-2 was administered. PDMS-2 assessed the children in 2 motor domains- Gross and Fine motor. In the gross motor domains the commonest affected was object manipulation (n=34; 58.3%) followed by locomotion (n=29; 48.3%) and stationary (n=26; 46%).(Table:1) Even though we selected children with ASD, this analysis brings out the gross motor dysfunctions that were missed out in clinical examination. Though the clinical examinations couldn't pick the subtle changes, it was found to be interfering in the test parameters in a significant way making children underperform. In fine-motor sets, visual motor integration (n=35; 58.3%) was most affected followed by grasping (n=21; 35%). (Table:1).

A One sample chi-square analysis showed the following-in stationary, locomotion object manipulation, grasping domains most were either above the hypothesised number for "above or below average"; however, in object manipulation and visuo-motor integration, the observed values

were significantly more than the hypothesised values in “below average” category when compared with average category.

Fulceri francesca et al in their study had slight difference from the present study. They found that locomotion and grasping were the most affected in pre-school children with ASD whereas in ours object manipulation and visuo-motor integration were more affected. [7] This may be due to exclusion of all ASD children with any overt motor impairments, genetic causes or syndromes such as Rett syndrome, Lennox-Gestau syndrome, Tuberous sclerosis etc in the present study. The purpose of our study was not to find if motor impairments are present or not in ASD, but was to find out the subtle motor dysfunctions which are missed during routine general examination and may affect the functionality of the child in day- to- day life. In this study both Gross Motor (Object manipulation and locomotion) and Fine Motor (mainly visuomotor integration) skills are impaired, suggesting the possibility of motor difficulties due to some specific mechanism involving motor control (i.e., motor planning). We found that skills such as object manipulation and VMI are more impaired than Stationary and grasping skills (Table:2), this is in agreement with previous reports [8,9,10]. Object manipulation represents the most noticeable gross-motor vulnerability area in pre-schoolers with ASD and it is in concordance with a lack of coordination or a defect of motor planning [11]. A kinematic analysis of gait (ELITE system) indicates that, rather than gait parameters or balance control, the main components affected in autistic children during locomotion are the goal of the action, the orientation towards this goal and the definition of the trajectory due probably to an impairment of movement planning.

Analysis of motor quotients in PDMS-2 in

ASD showed 100% of ASD had gross motor dysfunction. Gross motor domain was most affected with 71.7%, followed by fine motor quotient 65.1% and total motor quotient 68.3%. In FMQ, Fine motor dysfunctions were seen in 63% of children with ASD with 51.7% being in below average, 11.7% in poor and 1.7% falling in very poor category. When total motor quotients also had similar results and were significant also. (Table:1, 2)

To check the presence of functional disability in ASD children and to assess the affected domains in day to day living, we administered Wee-Fim test. Analysis of data showed that all children had issues in “Self-care” domain especially in eating (95%), grooming (80%), bathing (65%), toileting (58.3%), dressing upper body (55%), dressing lower body (45%) (Table:03). The difference in percentages in upper body and lower body dressing could be due to the higher amount of fine motor skills and concentration involved in putting dress for upper body.

In the mobility domain, none had any problems in transfer from wheel chair and transfer from shower. 51.6% had issues in transfers- toilet. In cognition, comprehension all had issues (Table:3). All ASD had dysfunctions in toileting pointing to a probable combination of skill deficit due to motor component along with sensory issues in this disorder.

A study using developmental delayed children of same age group as the present study found that significant correlation between Functional Independence Measure for Children scores (Wee-Fim) with both verbal comprehension age and verbal expression age. [12] This points to the possibility of interference of language in assessing using Wee-Fim tool, which we acknowledge might have caused interference.

One sample binomial test done for each subsets of

Wee-Fim. It was found that statistical significance was there for eating, grooming and bathing and total self-care (Table:4). In mobility p-value was not statistically affected. In Cognition all 5 subsets were significantly affected.

Binomial analysis done for all subsets in PDMS in ASD children; None of them came to be significant. When Binomial analysis was done in motor quotients, all 3(GMQ, FMQ, TMQ) were found to be significant (Table: 2) This maybe because certain items in each subset would have been given more weightage. Hence, when you take them individually it may not appear to be affected but however, when you take them in toto, it becomes significantly affected scores.

When two-tailed test and Levene analysis was done on GMQ vs Wee-Fim parameters to assess how much the dysfunction on gross motor affects functional ability in ASD children, all subsets of self-care was affected (P value<0.001). Eating, followed by bathing and toileting were more affected among them. (>Fvalue). (Table:4) In mobility GMQ was significantly affecting the following subsets- locomotion- stairs, locomotion-walk, transfer-toilet was significantly affected (p-value<0.05). In Cognition, GMQ was influencing problem solving and social interaction more. This could be due to motor dysfunctions making it difficult to face the community.

When FMQ was assessed for significance with functional abilities, it was found that all self-care skills were significantly affected (p-value<0.001). Levene's analysis shows more F-value for bowel management, toileting, bladder management and eating in that decreasing order showing these were more affected by fine motor issues. For locomotion domain also, climbing stairs, toilet-transfer and walk was affected significantly in decreasing order (P value-<0.001). Climbing stairs was very significantly affected among

the three according to Levene's analysis. In the cognition domain, Social interaction and problem solving were more affected, which is expected of ASD children. (Table-05). TMQ vs Wee-Fim score analysis were statistically correlating (<0.001). (Table:06). There are studies which used similar diagnostic tools bringing out the possibility of using them together. ^[11]

When functional abilities in ASD was assessed using Binomial test for Wee-Fim, we found eating, grooming and bathing to be significantly affected (p<0.001). In mobility subset, only transfer- toilet was affected(P <0.05).(Table:03)

When ASD diagnosis was correlated with motor quotients, object manipulation and visuo-motor integration were significant (P-value=0.001) (Table2). The motor impairment characterized by a relative preservation of static abilities along with a major impairment in VMI and object manipulation skills appear to be relative stable at preschool age as correlation analysis between chronological age and PDMS-2 measures did not reveal any significant results. This is in agreement with some studies. ^[12]Present study supported the existence of a stable pattern of motor impairment in pre-schoolers with ASD. However, further longitudinal studies are needed to establish motor dysfunctioning and its effect over time.

The motor impairments which were present in the so called non-motor ASD ^[13] were not significant enough to cause statistically significant functional impairments in day to day living, which was found by Levene's test and 2-tailed test.

Hence, we reject the hypothesis that these motor issues are statistically significant to cause functional impairment in ASD. Even though, motor dysfunctions are significantly present in NDD/ASD on its own^[14] they are not significantly affecting the functional ability of the child, but may be along with other issues such as visual,

hearing, sensory, familial, environmental, genetic factors etc. may be the contributing factors for functional difficulties that the NDD children are facing.

Conclusion:

Gross motor functions were found to be slightly more affected than fine motor in preschool children with ASD. Among the gross motor domain the commonest subset affected was object manipulation followed by locomotion and stationary. In the functional day to day activities the most affected skill was eating followed by grooming and bathing. All the children with ASD had motor impairments on PDMS-2. Among all the ASD children the functionality in day-day living as assessed by Wee-FIM showed self-care and cognition domains as the most affected. Even

though, gross motor functions were the most affected still it did not affect functional mobility of the child.

ASD appears as a typical prototype for NDD and has almost the same dysfunctions when assessed separately. Hence in NDD's where motor dysfunctions are not overtly present, if any functional impairment is present, we need to assess them for both fine motor and gross motor dysfunctions interfering with functional abilities and take necessary corrective measures including assessing for other parameters which may be confounding the functional assessments.

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Symptoms Suggestive of Mental Health Problems and their correlates among Female Nursing students in Thiruvananthapuram, Kerala

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Abstract

Introduction: Nursing students have a higher prevalence of mental health issues compared to students from other healthcare branches. This study aims to assess the prevalence of perceived mental health problems and their socio-demographic associations, as well as introduce a classroom based intervention model for the same.

Methodology: Data for perceived symptoms of mental health problems was collected using Section C of Young Adult Screening Questionnaire. The students were thereafter introduced to the intervention module. **Results:** 6.8% students had mental health issues. A statistically significant association was observed between lower age, second academic year and perceived symptoms suggestive of mental health problems. **Conclusion:** The present study highlights the need for early identification and management of mental health problems among young students, without labelling the person, and includes a simple classroom-based package for the same.



Keywords: mental health, nursing students, intervention package

Introduction

The Global Burden of Disease 2019 reported mental health problems among the top ten causes of DALYs in the world, with depressive disorders accounting for the largest proportion.¹ A cross-sectional study conducted in South India including 201 school going adolescents found that 40.8% of students showed depression (from mild mood disturbance to severe and extreme depression) while 54.7% participants had anxiety. Prevalence

of depression was higher in females². According to Erikson's stages of psychosocial development, young adulthood is 'Intimacy vs isolation' stage, with the major conflict being centred on forming intimate, loving relationships with peers. Success at this stage leads to fulfilling relationships while failure to do so can result in feelings of loneliness and isolation, paving the way for mental health problems³.

Globally, studies have shown that nursing students have lower general and mental health status than other health related disciplines and non-medical students^{4,5}. Stigmatisation of mental illnesses is common even among nurses^{6,7} that can deter early diagnosis of symptoms of mental health conditions and care-seeking practices. Previous research, however, have shown that group-based interventions in young adults may improve the future outlook and perceived symptomatology of mental health problems^{8,9}. A previous study among young adults have shown that 11.2% of school dropouts had severe and extreme grades of depression as against 3% among school going and nil among college going adolescents¹⁰. This study has also shown feasibility of a class based approach in early detection and group intervention for mental health problems without labelling effect.

The present study was done to identify early symptoms, which may indicate possible mental health problems among undergraduate nursing students, without having a labelling effect, as well as develop a group based intervention model.

Objectives

1. To estimate the prevalence of perceived symptoms indicative of possible mental health problems among female nursing students using Teen Screen Questionnaire (Mental).
2. To find out the correlates of mental health problems among female nursing students.

3. To develop a structured teaching programme for improving mental health.

Methodology

This was a descriptive cross-sectional study to understand prevalence of symptoms suggestive of mental health disturbances, conducted on the female B.Sc. Nursing students from first to fourth academic years of NIMS College of Nursing, Neyyattinkara, Thiruvananthapuram. Census method was adopted for recruiting samples using the college admission register. The tools included a personal data sheet comprising of the socio-demographic details of the individual students and Section-C of the Young Adult Screening Questionnaire, appropriately modified from Teen Screen Questionnaire- Mental, with 30 questions to be marked on a 3-point Likert scale¹¹.

After getting clearance from Institutional Ethical Committee and college authority (ECR/218/Inst/Ker/2013/RR-16 Approval No NIMS/IEC/2021/04/07), informed consent was obtained from individual students. Google form of the questionnaire was sent electronically via WhatsApp of each class group. The responses were automatically recorded and saved in Google Drive. Thereafter, a structured care counselling program was conducted via a didactic one-hour session on Google Meet platform for each academic year. Data analysis was done by descriptive statistics using SPSS version 25. The data was found to be non-normally distributed by the Shapiro-wilk test of Normality, hence median was taken as the cut-off in TSQ-M to denote poor mental health status. Association with socio-demographic variables was assessed using Chi Square Test.

Results

221 nursing students of NIMS College of Nursing were included in the study. The socio-demographic characteristics of the study

population were as follows;

- Age: ≤20 years: 102 (46.2%), >20 years: 119 (53.8%);
- Religion: Hindu: 109(49.3%), Christian: 92(41.6%), Muslim: 20(9%);
- Type of family: Nuclear: 181(81.9%), Extended: 25(11.3%), Joint: 15(6.8%)
- Residence of family: Urban: 160(72.4%), Rural: 61(27.6%)
- Current residence of students: Home: 98(44.3%), Hostel: 123(55.7%)
- Socio-economic status: APL: 124(56.1%), BPL: 97(43.9%)
- Academic year: 1st year: 56(25.3%), 2nd year: 56(25.3%), 3rd year: 59(26.7%), 4th year: 50(22.6%)

Table 1: Prevalence of perceived symptoms suggestive of mental health problems among female nursing students based on TSQ (M)

Items	Frequency N(%)		
	Never	Sometimes	Always
Item suggestive of ADHD/CD/ODD			
1.Difficulty in focussing on one task	89(40.3)	127(57.5)	5(2.3)
2.Problems in sitting still	74(33.5)	122(55.2)	25(11.3)
3.Been involved in setting fires, stealing, lying or fist fight	180(81.4)	30(13.6)	11(5.0)
4.Been suspended from school /involved in police case	213(96.4)	8(3.6)	-
Items suggestive of Anxiety state			
5.Nervous during public speaking	77(34.8)	118(53.4)	26(11.8)
6.Fears that are perceived by others as unreasonable	118(53.4)	96(43.4)	7(3.2)
7.Worry about mishaps	93(42.1)	116(52.5)	12(5.4)
8.Feeling stressed at times	54(24.4)	163(73.8)	4(1.8)
9.Can manage stress well	39(17.6)	141(63.8)	41(18.6)
10. Feel that it is normal for students to be stressed	36(16.3)	143(64.7)	42(19.0)
11. Bed-wetting	208(94.1)	11(5.0%)	2(0.9%)
Item suggestive of Depressive state			
12.Feeling more sad than peers	121(54.8)	95(43.0)	5(2.3)
13.Change in sleep	74(33.5)	133(60.2)	14(6.3)
14.Change in appetite	94(42.5)	120(54.3)	7(3.2)
15.Change in bowel habits	114(51.6)	106(48.0)	1(0.5)
16.Thoughts of hurting oneself	133(60.2)	82(37.1)	6(2.7)
17.Feeling of Guilt	131(59.3)	84(38.0)	6(2.7)
18.Feeling of Worthlessness	149(67.4)	65(29.4)	7(3.2)
19.Feeling of Hopelessness	162(73.3)	49(22.2)	10(4.5)
20.Feeling of Helplessness	165(74.7)	53(24.0)	3(1.4)

21.Life is not worth living	155(70.1)	58(26.2)	8(3.6)
22.Thoughts of suicide	186(84.2)	32(14.5)	3(1.4)
23.Lost interest in activities previously enjoyed	128(57.9)	90(40.7)	3(1.4)
Item suggestive of OCD			
24.Troubled by recurrent uncontrollable thoughts	130(58.8)	85(38.5)	6(2.7)
25.Repeating certain acts beyond control	119(53.8)	93(42.1)	9(4.1)
Item suggestive of Psychosis state			
26.Hearing voices/seeing people when alone	185(83.7)	35(15.8)	1(0.5)
27.Feeling of being talked about/ being harmed by others	174(78.7)	42(19.0)	5(2.3)
Items suggestive of Substance Use			
28.Tobacco use	217(98.2)	3(1.4)	1(0.5)
29.Smoking	218(98.6)	3(1.4)	-
30.Alcohol consumption	212(95.9)	9(4.1)	-
Perceived mental health status <i>(Taking the median of TSQ-M as cut-off)</i>	Symptoms suggestive of mental health problems: 15 (6.8%)		

Table.2 :Association of Mental Health Status with key sociodemographic factors

Domain	Mental Health Status		Chi.sq.	df	p-Value
	Normal	Abnormal			
Age of students					
≤20 years (n=102)	91(89.2%)	11(10.8%)	4.783	1	0.029
>20 years (n=119)	115(96.6%)	4(3.4%)			
Present Educational Status					
1st year (n=56)	53(94.6%)	3(5.4%)	8.799	3	0.030
2nd year (n=56)	48(85.7%)	8(14.3%)			
3rd year (n=59)	55(93.2%)	4(6.8%)			
4th year (n=50)	50(100.0%)	0			
Religion					
Hindu (n=109)	107(98.2%)	2(1.8%)	15.241	2	0.001
Christian (n=92)	84(91.3%)	8(8.7%)			
Muslim (n=20)	15(75.0%)	5(25.0%)			

A statistically significant relationship was found between higher perceived mental health problems and lower age (<20 years: p=0.029), being in the second academic year (p=0.03) and belonging

to Muslim religion ($p=0.001$) (Table 2). No significant relationship was found with other socio-demographic variables in this study.

Discussion

The principal aim of the present study was to identify perceived symptoms which could be early predictors of mental health problems, without labelling the student and intervene early. In this study, taking the median of TSQ-M as cut-off, 6.8% ($n=15$) of the students had symptoms suggestive of mental health problems (Table.1). The maximum prevalence was observed in the items of nervousness during public-speaking(11.8%) followed by problems in sitting still(11.3%). The results are similar to previous studies which suggest that high levels of social anxiety is present among university students¹². On the other hand 42 (19%) students felt that stress was a normal part of student life, and 41(18.6%) were confident of coping with stress well.

A statistically significant association was observed between abnormal mental health status and younger age and second year of academics. These findings are consistent with a previous study by Kim et al, where anxiety levels have been seen to be lower in case of nurses who are older and who have more years of academic/nursing experience¹³. Due to the small sample size, it would not be prudent to draw conclusions on religion from the present study because prior studies in Islamic countries have demonstrated that religious education and internalised religious orientation, are negatively correlated with perceived mental health problems^{14, 15}.

According to WHO (2019) report, suicide is the fourth leading cause of death among young adults aged 15-29 years old¹⁶. In the present study, 2.7% of the students reported thoughts of self-harm while 1.4% reported suicidal ideation. Previous studies report a similar prevalence of

suicidal ideation among young adult population¹⁷. Nursing students, being at a transitional stage of their careers, moving away from home to a residential college, academic stress, lack of peer and family support and cognitive distortions related to depression could contribute to thoughts of self-harm and suicide¹⁸. It is important that these symptoms be detected as early as possible, as immediate intervention can potentially prevent loss of life.

The bio-psycho-social model highlights the importance of pharmacotherapy, cognitive behaviour therapy and social counselling as effective management of mental health disorders. However, chances of being isolated are possible among students at-risk, because of the high prevalence of social stigma around psychiatric disorders, especially for young women¹⁹. Group counselling sessions could be an effective model of intervention among the young adult population, because it reduces the risk of ostracization of the student. Hence, we have developed such a model for intervention, based on previous experience doing school based group counselling²⁰.

Conclusion

Mental health is the foundation of an individual's well-being and social functioning. Early identification of perceived symptoms of mental health issues faced by young adults by college authorities can help the students receive early and appropriate intervention. This study not only underlines the need for early screening of mental health problems, but also can help formulate a teaching module for the same in different institutions, modified according to the requirements of the students.

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Appendix-1

CLASSROOM BASED INTERVENTION MODEL

Group intervention: Type of activities	Reason/ Comments
Session 1: Ice-breaking	
a. Simple games like describing a classroom partner's name, age, residence, likes and dislikes b. 9 dots game	Ice-breaking activities help the student overcome their inhibitions and relax. It increases their interest and involvement in the forthcoming sessions.
Session 2: Understanding social involvement	
a. Group exercises: Where am I b. Small group sharing c. Doubt clearing/ Q and A session	a. Help the participant realise the degree of their involvement in a social setting and the possible emotions they felt. b. To foster peer bonding in small groups, describing their own findings in the prior game. c. Identifying the barriers in our brain which prevent social involvement
Session 3: Understanding moods	
a. Simplified learning material on cognitive distortions b. Learning material on the reasons for harbouring negative attitudes (including desire for approval, love, achievement, perfectionism, entitlement, omnipotence etc)	The learning materials are presented and explained in a lucid way, in a language the students are comfortable in, giving ample time for intervening doubt-clearing sessions. The counsellor can take assistance of audio-visual modes of teaching.
Session 4: Building self-esteem	
a. Group exercise: Listing good and bad qualities in self b. Sharing the finding in small groups c. Help the students share their insight from the exercise	Cognitive distortions often cloud self-perception of good qualities. This exercise demonstrates that every person has positive characteristics, which we often choose to ignore in ourselves.

Session 5: Risk taking and fear	
<p>a. Ask for volunteers from the class without explaining the exercise</p> <p>b. After few students have volunteered, one member from each group should describe the emotion he/she felt when asked to volunteer</p> <p>c. The student is asked to describe previous similar situations in life, how they reacted and identify the causes of their said behaviour</p>	<p>Hesitation to participate in social activities often stems from a conceived notion of self-perfection. This exercise demonstrates to the participant, the absurdity of perfectionism and encourages them to come out of their comfort zones.</p>
Session 6: Ways to resolve conflicts	
<p>a. Describing three ways of conflict resolution</p> <p>b. Group exercises involving reflection on how a student can resolve a possible conflict in their lives</p>	<p>This exercise helps students understand alternative ways of conflict resolution by critical self-analysis and steps of implementing it.</p>
Session 7: Locus of control	
<p>a. Exercises to reflect on how much power we give to ourselves and others over our emotions</p> <p>b. Group sharing</p> <p>c. Discussion on the reasons of said behaviour</p>	<p>This exercise portrays the idea of internal and external locus of control, and how switching to an internal locus can empower us to modify our behaviour for betterment.</p>

Source: John R, George S, Nair MKC. Classroom intervention for symptoms of Depression. Adolescent Pediatrics. 2nd ed. New Delhi: Noble Medical Publishers; 2023.p-130-147.

Prevalence of Autism Spectrum disorder in 18 to 24 months of age by MCHAT screening

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Abstract

Background

Autism spectrum disorder (ASD) is a neurodevelopmental condition marked by challenges in social communication and the presence of restricted interests and repetitive behaviors. With the DSM-5, ASD is now conceptualized as a spectrum diagnosis, consolidating the separate pervasive developmental disorder (PDD) diagnoses from the DSM-IV, including autistic disorder, Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (PDD-NOS), into one. Notably, Rett syndrome is no longer classified under ASD in DSM-5, being recognized as a distinct neurological disorder. ASD profoundly impacts an individual's social interaction abilities and communication skills. Those with autism commonly experience difficulties in social interactions and exhibit repetitive and restricted patterns of behavior, interests, and activities, which can vary in severity along the spectrum.

Methods

The present study was a cross-sectional retrospective study of children who were between 18 months to 24 months of age attending Pediatric



OPD at GMC Amritsar and were assessed for autism spectrum disorder using the M-CHAT-R scale (by recall memory of parents). The data was tabulated in Microsoft Excel and analyzed with SPSS V.24 software.

Results

In the present study, the majority of the cases were having age of 18 months which included 226 (32.3%) followed by 24 months having 175 (25%) and 20 months that had 144 (20.6%) cases. 105 (15%) cases had age of 20 months. The least no of cases 06 (0.85%) had the age of 21 months. The mean age of the cases is 20.66 months. 379 (54.14%) were males while 321 (45.86%) were females. The male-to-female ratio was 1.2:1.

Conclusion

Certainly, it is imperative to conduct national

epidemiological studies utilizing alternative approaches to discern the trends in Autism Spectrum Disorder (ASD) prevalence. Continuing research endeavors to thoroughly grasp the mechanisms underlying these structural abnormalities and how they evolve over time. This survey has the potential to facilitate the creation of an effective collaborative program between the government and non-governmental organizations (NGOs). Early identification of ASD in children could pave the way for timely interventions, enabling these individuals to make significant contributions to society and the nation through proper training and education. It is acknowledged that a larger sample size may be necessary for the study to more confidently determine the prevalence of autism in very young children.

Keywords

Autism, Neurodevelopment disorder, M-CHAT-R scale

INTRODUCTION

Autism spectrum disorder (ASD) is a neurodevelopmental condition distinguished by challenges in social communication and the display of restricted interests and repetitive behaviors [1]. The DSM-5 introduced the idea of a spectrum diagnosis for ASD, consolidating the individual pervasive developmental disorder (PDD) diagnoses from DSM-IV, including autistic disorder, Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (PDD-NOS), into a unified classification. Rett syndrome is no longer included under ASD in DSM-5 as it is considered a discrete neurological disorder. A separate social (pragmatic) communication disorder (SPCD) was established for those with disabilities in social communication, but lacking repetitive, restricted behaviours.

Furthermore, severity level descriptors were introduced to assist in classifying the level of assistance required by individuals with ASD. This updated definition aims for greater precision and strives to facilitate earlier diagnosis of ASD. [2]. Nevertheless, research projecting the potential consequences of transitioning from the DSM-IV to the DSM-5 has suggested a decrease in the prevalence of ASD [3,4]. Furthermore, there has been apprehension regarding whether children previously diagnosed with PDD-NOS would meet the criteria for an ASD diagnosis under the new classification. [4-6].

Autism spectrum disorder (ASD), a neurological developmental disorder that has severe effects on an individual's ability to interact with others and communicate appropriately. Individuals having autism faces difficulties in social interactions and how repetitive and restricted patterns of behaviour, interest, and activities which may vary in severity across the continuum. They have trouble in linking words with their meanings, do not like changes in an already established routine, and will act in unexpected, abnormal ways. They exhibit verbal and nonverbal communication delays and problems. They have poor eye contact, do not respond to name-calling, and speak slowly. A correct diagnosis of autism can be made as early as 18-24 months of age because it is during this time that characteristics pertaining to the age start showing, distinguishing typical development from atypical development or delayed development. [7] Different reports provide diverse estimates regarding the magnitude and consequences of this transition. A particular study indicated that using only parental reports of ASD symptoms, the DSM-5 criteria successfully identified 91% of children previously diagnosed with clinical DSM-IV PDD.[8]

According to the World Health Organization (WHO), the global prevalence of ASD is estimated at 0.76%, yet this figure represents only around 16% of the total global child population. [9]. The Centers for Disease Control and Prevention (CDC) approximates that approximately 1.68% of children in the United States aged 8 years (equivalent to 1 in 59 children) receive a diagnosis of ASD.[5,10] Within the United States, ASD diagnoses reported by parents averaged slightly higher in 2016, reaching around 2.5%. The prevalence of ASD in the US more than doubled between 2000–2002 and 2010–2012 according to Autism and Developmental Disabilities Monitoring Network (ADDM) estimates [5]. Although it may be too early to comment on trends, in the US, the prevalence of ASD has appeared to stabilize with no statistically significant increase from 2014 to 2016 [11]. Changing diagnostic criteria may impact prevalence and the full impact of the DSM-5 diagnostic criteria has yet to be seen [10].

Over the last twenty years, there has been a significant rise in ASD prevalence estimates among 8-year-old children according to data from the ADDM Network, increasing from 6.7 per 1,000 (one in 150) in 2000 to 23.0 per 1,000 (one in 44) in 2018 [12,13]. Additionally, earlier data indicate that ASD prevalence among White children was 50% higher compared to Black or African American (Black) or Hispanic children. Similarly, robust associations between autism prevalence and higher socioeconomic status were observed in ADDM Network sites during 2002–2010 [14]; however, this association was much more variable in 2018 [13]. These trends have mostly been understood as advancements towards more fair recognition of ASD, especially for children in demographics with limited access to or encountering greater obstacles in receiving

services, such as diagnostic assessments. Nonetheless, persistent inequalities regarding co-occurring intellectual disability persist, with Black children representing the highest proportion among all children with ASD identified with this condition. [5, 15].

Screening tools for ASD in this population include the Modified Checklist for Autism in Toddlers, Revised, with Follow-up (M-CHAT-R/F) and Survey of Wellbeing of Young Children (SWYC) [16,17]. Signs of concern in preschool-aged children could involve restricted pretend play, unusual or intensely concentrated interests, and inflexibility. Meanwhile, in school-age children, observable behaviors may include a tendency towards literal or concrete thinking, difficulty grasping emotions, and potentially displaying an interest in peers while lacking conversational abilities or appropriate social interaction skills. If there is suspicion of ASD in these groups, screening tools available include the Social Communication Questionnaire (SCQ), Social Responsiveness Scale (SRS), and Autism Spectrum Screening Questionnaire (ASSQ) [18-20].

The DSM-5 diagnostic criteria for Autism Spectrum Disorder (ASD) include two primary components:

(A) Enduring deficits in social communication and social interaction. (B) Patterns of restricted and repetitive behavior, interests, or activities.

A child can exhibit all A criteria as young as 2 years old if they fail to respond to their name, display limited or no joint attention, and demonstrate a lack of reciprocal interaction. An illustration of the B criteria in a toddler might involve an intense fascination with a play telephone, during which they do not interact with their mother, respond to their name, or share enjoyment with

their mother regarding the phone. Adherence to rigid routines can result in challenges during transitions and may lead to disruptive behaviors, such as tantrums. [21].

MATERIALS AND METHODS

The present study was a cross sectional retrospective study children who were between 18 months to 24 months of age attending Pediatric OPD at GMC Amritsar were assessed for Autism Spectrum disorder using M-CHAT-R scale (by recall memory of parents). Study period one year. A total of 700 toddlers were screen after recall of things from the parents

STUDY DESIGN: Cross Sectional Study

STUDY SITE: Department Of Pediatrics, Government Medical College, Amritsar

STUDY SUBJECTS-Toddler of age group 18 to 24 months of age

INCLUSION CRITERIA

1. Children age between 18 months to 24 months who are attending outpatient department in Government Medical College Amritsar
2. Those Children for whom informed consent is obtained from parents.

EXCLUSION CRITERIA

1. Children with visual or hearing impairment.
2. Children diagnosed with neurodegenerative disorder / presence of any neurological deficits.
3. Children for whom consent couldn't be obtained from parents

STATISTICAL ANALYSIS

The information was organized in Microsoft Excel and processed using SPSS Version 24 software. Continuous variables were described using measures of central tendency such as

mean and standard deviation, while categorical variables were summarized using frequency and percentage.

RESULTS

The present cross sectional retrospective study was conducted on toddlers of age between 18 to 24 months in the Department Of Paediatrics, Government Medical College, Amritsar. The data was compiled through a set of questionnaires and following observations were noted.

Table 1: Distribution of cases on the basis of age group

Age (in months)	Number	%age
18	226	32.3
19	34	4.85
20	144	20.6
21	06	0.85
22	105	15
23	10	1.4
24	175	25
Total	700	100

In the present study, majority of the cases were having age of 18 months which included 226 (32.3%) followed by 24 months having 175 (25%) and 20 months that had 144 (20.6%) cases. 105 (15%) cases had age of 20 months. The least no of cases 06 (0.85%) had the age of 21 months. The mean age of the cases is 20.66 months.

Table no 2: Distribution of cases on the basis of gender of the case

Gender	Number	%age
Male	379	54.14
Female	321	45.86
Total	700	100

In the present study, 379 (54.14%) were males while 321 (45.86%) were females. The ratio of male to female was 1.2:1.

Table no 3: Distribution of cases on the basis of Mode of delivery

Mode of Delivery	Number	%age
LSCS	546	78
Normal Vaginal Delivery	154	22
Total	700	100

In the present study, majority of cases underwent LSCS in 546 (78%) cases while

154 (22%) had the birth through normal vaginal delivery.

Table no 4: Distribution of cases on the basis of place of delivery

Place of Delivery	Number	%age
Government Hospital	598	84.4
Private Hospital	102	14.6
Total	700	100

In the present study, 598 (84.4%) births included in the study took place in the Government Hospital while 102 (14.6%) took place in private hospital.

Table no 5: Distribution of cases on the basis of Breast Feeding

Breast Feeding	Number	%age
Exclusive Breast Feeding	636	90.9
Sub Optimal Breastfeeding	64	9.1
Total	700	100

In the present study, exclusive breast feeding was present in 636 (90.9%) cases while in 64 (9.1%) Sub optimal Breastfeeding was present.

Table no 6 : Distribution of cases on the basis of Immunization status

Immunization status	Number	%age
Fully Immunized	675	96.4
Partially Immunized	25	3.6
Total	700	100

In the present study, Fully immunized children were present in 675 (96.4%) cases while in 25 (3.6%) Partially Immunized were present.

Table no 7: Distribution of cases on the basis of Parents Education

Parents education	Number	%age
Both parents \geq 12 standard	215	30.7
One parents \geq 12 standard	289	41.3
Both parents \leq 12 standard	196	28
Total	700	100

In the present study, in 289 (41.3%) cases, the parents of children had only one parent that had education \geq 12 standard, while in 215 (30.7%) cases both parents had education of \geq 12 standard while in 196 (28%) both parents had education of \leq 12 standard.

Table no 8: Distribution of cases on the basis of M chat score

M chat SCORE	Number	%age
0	621	88.7
1	67	9.6
2	6	0.85
3	0	0.0
4	0	0.0
5	1	0.14
6	1	0.14
7	3	0.43
8	1	0.14
9	0	0.0
10	0	0.0
11	0	0.0
12	0	0.0
13	0	0.0
14	0	0.0
15	0	0.0
16	0	0.0
17	0	0.0

18	0	0.0
19	0	0.0
20	0	0.0
TOTAL	700	100

In the present study, majority of the cases 621 (88.7%) had zero score followed by one score in 67 (9.7%) cases, two score in 6 (0.85%), seven in 3 (0.43) and 01(0.43%) cases present in five, six and eight score each.

Table no 9: Distribution of cases on basis of severity of autism spectrum disorder

Screening positive	Number	%age
No (0 -1)	688	98.3
Mild (2-8)	11	1.56
Severe (8-20)	01	0.14
Total	700	100

In the present study, based on screening positive on the basis of M chat score, in 688 (98.3%) cases no autism spectrum disorder, mild form present in 11 (1.56%) cases and severe form in 01(0.14) cases.

Table no 10: incidence and Period Prevalence of autism spectrum disorder in the cases

Autism Disorder	Incidence	Period Prevalence
No (0 -1)	688	98.3%
Mild (2-8)	11	1.56%
Severe (8-20)	01	0.14

In the present study, incidence of severe autism spectrum disorder is 1 while the period prevalence of severe autism spectrum disorder is 0.14%.

DISCUSSION

The present study was conducted in the department of Medicine, conducted in the indoor patients of Pediatrics, Government Medical College, Amritsar for the period of 12 months. A total of 700 toddlers and their parents were

interviewed for the study and the observations were recorded and now they are being compared and discuss with the previous studies by various authors.

In the present study, majority of the cases were having age of 18 months which included 226 (32.3%) followed by 24 months having 175 (25%) and 20 months that had 144 (20.6%) cases. 105 (15%) cases had age of 20 months. The least no of cases 06 (0.85%) had the age of 21 months. The mean age of the cases is 20.66 months. The majority of the studies conducted included the children of same age group as that of present study though the frequency of toddlers in age was different in the various studies. The present study can be compared with studies conducted by **Kumar et al(2023)**, **Ping et al (2014)**, **Wang et al (2018)** and **Raina et al (2015)**. The findings of the present study are different from the studies conducted by **Zhang et al (2022)** where the mean age of the children was the mean age at diagnosis for children was 23.1 ± 4.55 months and **Hoang et al (2019)** where the screening study was conducted in the age group of 2 to 8 years. The probable reason for difference can be that full clinical features of ASD might not appear at this low age range and the diagnosis might be difficult at this age.

In the present study, 379 (54.14%) were males while 321 (45.86%) were females. The ratio of male to female was 1.2:1. The findings of the present study can be compared to the study conducted by **Hoang et al (2019)** where there were more boys (53.6%) than girls (46.4%) and **Ping et al (2014)** where majority of toddlers 51.8% were male in the study.

In the present study, based on screening positive on the basis of M chat score, in 688 (98.3%) cases no autism spectrum disorder, mild form presents in 11 (1.56%) cases and severe form in 01(0.14)

cases. The findings can be compared with study conducted by **Kumar et al (2023)** where Out of the 253 boys, majority of them, i.e., 52.52% fell in the range of mild-moderate autism. 85 boys, i.e. 28.6% were severely autistic while only 12 out of the 253 boys showed minimal or no symptoms of autism. Out of the 44 girls, only 2 of them, i.e., 0.67% were in the non-autistic range showcasing minimal to no symptoms of autism. 8.08 % of the 44 girls were in the mild-moderate autism spectrum range. Only 18 out of 44 participants i.e., 6.06 % of girls were in the severe autism range.

In the present study, incidence of severe autism spectrum disorder is 1 while the period prevalence of severe autism spectrum disorder is 0.14%. No statistically significant variances were observed in ASD prevalence across other socio-demographic factors. The outcomes of this study are open to comparison with research conducted in different global regions. The findings is similar to the study conducted by **Zeidan et al (2021)** which observed that approximately 1/100 children are diagnosed with autism spectrum disorder around the world. The present study can be compared with studies conducted by **Eom et al (2022)** which observed that Over the 11-year study period, there was an escalation in the prevalence of ASD among preschool children aged 2 to 5 years, rising from 0.06% to 0.23%.

Top of Form

In another study by **Hoang et al (2019)** where in urban settings, the prevalence of ASD stood notably higher at 1.238% compared to rural areas where it was 0.580%. Additionally, children whose mothers worked as farmers exhibited a significantly higher prevalence of ASD at 1.054% compared to children of mothers employed as government staff, where the prevalence was 0.497%.

The results of the present study are in concordance with the study conducted by **Salari et al (2022)** where The global prevalence of ASD was estimated at 0.6% with a 95% confidence interval ranging from 0.4% to 1%. Subgroup analyses revealed that the prevalence of ASD in Asia, America, Europe, Africa, and Australia was consistent at 0.4%. The present study is different from the study conducted by **Wang et al (2018)** where based on diagnostic criteria the pooled prevalence of ASDs was 39.23 per 10,000; specifically, the prevalence of autism was 10.18 per 10,000 and **Zhang et al (2022)** where In this community-based sample, the diagnostic rate of ASD was found to be 0.32%. Furthermore, during subsequent well-child visits and follow-up, 12 children initially screened as negative were later diagnosed with ASD. The average diagnostic rate of ASD increased to 0.43% when toddlers were followed up until 3 years old. The variance in sample size and environmental factors could potentially account for this difference. The prevalence reported in this study contrasts with the notably higher figures of 168 per 10,000 in a US survey and 264 per 10,000 in a South Korean survey. This difference could stem from the narrower age range considered in this study, potentially leading to challenges in diagnosing ASD when full clinical features may not yet be fully apparent. Other important causes of variation were the methodological differences in the case definition and case-finding procedures and diagnostic criteria.

CONCLUSION

Certainly, it is imperative to conduct national epidemiological studies utilizing alternative approaches to discern the trends in Autism Spectrum Disorder (ASD) prevalence. The results indicate anomalies in early brain development during the clinical progression of autism. Ongoing

research aims to comprehensively understand the mechanisms behind these structural abnormalities and their longitudinal evolution. In-depth investigations into brain structural irregularities are essential to accurately estimate the actual prevalence of autism, necessitating further studies to uncover the underlying reasons for these findings. This survey has the potential to facilitate the creation of an effective collaborative program between the government and non-governmental organizations (NGOs). Early identification of ASD in children could pave

the way for timely interventions, enabling these individuals to make significant contributions to society and the nation through proper training and education. Recognizing the rarity of autism in childhood, it's acknowledged that a larger sample size may be necessary for the study to more confidently determine the prevalence of autism in very young children.

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Motor Delay- A Diagnostic Dilemma, Will Molecular Genetics Help? A Case Series

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Abstract:

Congenital muscle disorders are a group of clinically, genetically, and histologically heterogeneous diseases characterized by congenital or early-onset muscle weakness of varying degrees with a static or slowly progressive clinical course. These disorders involve a constellation of clinicopathological features typically involving a child with early-onset motor delay, especially with walking, together with normal to slightly elevated creatine phosphokinase levels and characteristic histopathological findings on muscle biopsy. Considering the invasive nature, technical complexity, and often inconclusive results, muscle biopsies have almost become obsolete. Molecular genetics even though costly, has now been increasingly used for the diagnosis due to their specificity. We present a case series of 5 children with gross motor delay where a definite etiology could not be obtained. One child had associated Vitamin D deficiency, another had hypothyroidism and significantly elevated creatine kinase and two of them had brain MRI findings. Due to the diagnostic and prognostic dilemma, parents were counseled regarding the need for genetic evaluation. Results identified various common genetic causes like Duchenne muscular dystrophy, Limb-girdle muscular dystrophy, and not-so-common causes like Bethlem myopathy and Central core disease.



Parents were counseled for further management as appropriate. Hence it is desirable to identify genetic variations in muscle disorders where congenital cause is strongly suspected as it has the potential to improve family planning, aid in prognosis, and also start specific interventions, if any.

Keywords: Congenital myopathy, elevated creatine kinase, motor delay, genetic disorder, child, development.

Introduction:

Motor development is the ability to move which is essential in human development. It refers to the ability to improve our physical capabilities, both in the usage of lower (for locomotion and stability) and upper (for hand skills) limb extremities. Hence aberrations in motor development can affect the quality of life considerably. Isolated motor delay associated with several systemic conditions (PEM,

rickets, anemia) and benign hypotonia is usually self-limiting. However, diagnosis of motor delay associated with progressive or static weakness especially with elevated muscle enzymes is always a clinical dilemma. Considering the invasive nature, technical complexity, and often inconclusive results, muscle biopsies have almost become obsolete. A secure diagnosis based on molecular evidence has become possible for many syndromes previously only clinically defined, which has helped enormously in predicting children's-developmental progress, in allowing knowledgeable surveillance for potential associated health problems, in genetic counselling, and in prenatal diagnosis [2]. The discovery of new cytogenetic and molecular genetic techniques and principles has been explosive in recent years, resulting in ground breaking progress in the evaluation of rare diseases where genetic testing became helpful [3]. We present a case series of 5 children with predominant gross motor delay where a definite clinical etiology could not be obtained.

Subject and Method:

Children of the age group from 9 months to 5 years who came to child development centre. After detailed clinical evaluation, parents were counselled for genetic testing, blood samples were collected and sent for genetic analysis and results were interpreted.

CASES

Case 1

Master X born of non consanguineous marriage was seen at 10 months of age with concerns of no sitting. His assessment revealed hypotonia with developmental age of 3-4 months and unremarkable lab reports and was initiated on developmental therapy. By 2 years of age he had

started walking but with a lordotic gait. Hence family was counselled for genetic testing for definite diagnosis. It revealed a heterozygous two base pair duplication in exon 239 of the TTN gene and heterozygous missense variant in exon 198 of the TTN gene suggestive of Limb Girdle Myopathy.

Case 2

A 5-year-old boy, 1st born of consanguineous marriage with normal cognition was brought with an abnormal gait and difficulty in getting up from a sitting posture at 5 years of age. Mother also gives a history of recurrent muscle cramps. Clinical examination revealed pseudohypertrophy of calf muscles with positive Gower sign s/o a proximal limb girdle weakness. His blood investigations showed significantly elevated creatine kinase, Aspartate transaminase, TSH with low Vitamin D levels pointing towards a chronic muscle weakness. He was started on symptomatic treatment and gentle physiotherapy. Considering his normal cognition, hypothyroidism was not considered clinically as the cause for calf pseudohypertrophy. Genetic testing sent was confirmatory of DMD with Hemizygous deletion of exon 44.

Case 3

Master Y born of non consanguineous marriage was detected to have hypotonia with no sitting sitting by 1 year of age. Imaging studies and blood investigations were non-contributory. This child started to walk with waddling gait by the age of 2 years following developmental with the help of therapy and foot orthosis. Whole exome sequencing and revealed heterozygous missense variant in exon 23 of the RYR1 gene suggestive of Congenital myopathy, concluding his diagnostic dilemma and helped in prognosis.

Case 4

A 3-year-old girl born of non consanguineous marriage with noncontributing family and birth presented with global developmental delay at 1 year of age. She had subtle dysmorphism and on examination she had peripheral hypotonia and sluggish deep tendon reflexes. Laboratory workup showed Vitamin D deficiency and high normal CPK. MRI Brain showed benign CSF space enlargement with normal myelination. She started walking with support, with an awkward wide based gait by 2 years of age. Suspecting genetic etiology, investigations sent. a rare cause of muscular dystrophy with heterozygous missense variation in exon 26 of the COL6A2 gene s/o Ullrich congenital muscular dystrophy-1 and Bethlem myopathy-1.

Case 5

A 2-year-old boy born out of non consanguineous marriage was brought at the age of 9 months with unprovoked seizure and global developmental delay. On examination he was found to have hypotonia, stereotyped behaviors, proximal and distal muscle weakness and hyperextensive joints. Imaging revealed nonmyelination of anterior limb of internal capsule in MRI and right posterior slowing on EEG. He didn't show much improvement despite developmental therapy. Whole exome sequencing revealed a heterozygous missense variation in exon 100 of the RYR1 suggestive of another another rare disorder, Central core disease.

Discussion:

Case 1: Limb-girdle muscular dystrophy is a term for a group of diseases that cause weakness and wasting of the muscles in the arms and legs. Signs and symptoms may first appear at any age and generally worsen with time, although in some cases they remain mild.[5]

Case 2 : Duchenne muscular dystrophy (DMD) affects both skeletal and heart muscle. Early signs may include delayed ability to sit, stand, or walk and difficulties learning to speak. Symptoms of this disease may start to appear in early childhood (2-11 years)[6]. It leads to progressively worsening disability, and most children with DMD need to use a wheelchair by the age of 12[7].

Case 3: Congenital myopathy is a term for any genetic muscle disorder that is typically noticed at birth and includes weakness and lack of muscle tone. Some symptoms may remain stable or progress slowly. There is no cure for congenital myopathy.[8]

Case 4: Ullrich congenital muscular dystrophy (UCMD) is a rare hereditary muscle condition that manifests at birth or a few months after birth. It belongs to a group of disorders called collagen type 6-related myopathies and characterized by abnormalities in collagen type 6, a major protein that supports skeletal muscles[9]. **Bethlem myopathy** is a rare disease affecting the skeletal muscles and connective tissue. The disease is characterized by slowly progressive muscle weakness and joint stiffness (contractures). Signs and symptoms may begin before birth (with decreased fetal movements), shortly after birth (with low muscle tone or torticollis), in early childhood (with delayed motor skills, muscle weakness, and contractures), or in adulthood (with weakness, Achilles tendon, or finger contractures)[10]

Case 5: Central core disease (CCD) is an inherited condition that involves muscle weakness, skeletal abnormalities. Symptoms of this disease may start to appear from early childhood(around 2 years).Muscle weakness ranges from mild to severe and typically affects muscles in the trunk and upper legs[11]

Conclusion:

In the case of a child with motor delay, there is no single approach to diagnostic evaluation. The clarification of the etiological diagnosis is necessary in order to prognosticate, to consider the possibilities for therapeutic intervention and to assess the risk of recurrence. Families can be offered genetic counselling regarding the mode of inheritance and are supported to take informed

family planning decisions, based on the implied risk of recurrence. To conclude, molecular genetics will alleviate the diagnostic dilemma to isolated motor delay. A reduction in the cost of next-generation sequencing will likely lead to its widespread use.

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Conflicts of interest : There are no conflicts of interest.

Table 1: Summary of the cases

Case no	Age/ Gender	Consanguinity	Walking initiated by	Hypotonia, Muscle weakness	Other features	Para clinical findings	Genetic test	Diagnosis
1.	2years /boy	No	2 years	Hypotonia+, Proximal muscle weakness	Frontal bossing, lordotic walk	-	Heterozygous duplication in exon 239 and missense variant in exon 198 of the TTN gene	Limb Girdle myopathy
2	5 years /Boy	YES	1 year	Normal tone	Gower sign positive, pseudohypertrophy of calf +	Highly elevated CKMB, hypothyroidism, Vitamin D deficiency	Hemizygous deletion of exon 44	Duchenne Muscular dystrophy

3	2 years / boy	No	2 years	Hypotonia+	Frontal bossing +, Waddling gait + mild intellectual disability, macrocephaly	Increased CKMB, MRI normal	Heterozygous missense variant in exon 23 of the RYR1 gene	Congenital myopathy
4	3 years / girl	No	2 years	Hypotonia+	Floppy from at birth	Vitamin D deficiency, Benign CSF space enlargement, Myelination normal.	Heterozygous missense variation in exon 26 of the COL6A2 gene	Ullrich congenital Muscular Dystrophy, Bethlem myopathy
5	2 year / boy	No	2 years	Hypotonia+	Recurrent seizures, Hyper-extensive joints, Autistic traits	Absence of myelination of anterior limb of internal capsule on MRI, right posterior slowing on EEG.	Heterozygous missense variation in exon 100 of the RYR1 gene	Central core disease.

Genetic Test Reports:

Gene [#] (Transcript)	Location	Variant	Zygosity	Disease (OMIM)	Inheritance	Classification ⁵
TTN (-) (ENST00000589042.5)	Exon 239	c.44252_44253dup (p.Lys14752LeufsTer13)	Likely compound Heterozygous	Limb-girdle muscular dystrophy-10 (OMIM#608807)	Autosomal recessive	Pathogenic (PVS1, PM2, PP3)
	Exon 198	c.38755G>A (p.Ala12919Thr)				Uncertain Significance

Case 1:

Sl. No.	Deletions /Duplications	No. of exons deleted/duplicated †	MLPA probe ratio (Dosage quotient) #	Disease (OMIM)	Inheritance	Classification
1.	Hemizygous deletion	1 (Exon 44) †	0.00	Duchenne muscular dystrophy/Becker muscular dystrophy	X-linked recessive	Pathogenic

Case 2:

RYR1 (+) (ENST00000359596.8)	Exon 23	c.2812G>A (p.Val938Met)	Heterozygous	Congenital myopathy-1A with susceptibility to malignant hyperthermia (OMIM#117000)	Autosomal dominant	Uncertain Significance (PM2)
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Case 3:

Gene [#] (Transcript)	Location	Variant	Zygosity	Disease (OMIM)	Inheritance	Classification ⁵
COL6A2 (+) (ENST00000300527.9)	Exon 26	c.2227A>T (p.Asn743Tyr)	Heterozygous	Ullrich congenital muscular dystrophy-1 (OMIM#254090) Bethlem myopathy-1 (OMIM#158810)	Autosomal dominant/ Autosomal recessive	Uncertain Significance

Case 4 :

Gene [#] (Transcript)	Location	Variant	Zygosity	Disease (OMIM)	Inheritance	Classification
RYR1 (+) (ENST00000359596.8)	Exon 100	c.14420A>G (p.Asn4807Ser)	Heterozygous	Central core disease	Autosomal dominant / Autosomal recessive	Uncertain Significance

Case 5:

References:

1. Motor delay in children: Symptoms for early identification and how therapy helps by Dr Pooja Sharma And Dr Arpan Kumar.
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3. Article by Juliann M. Savatt and Scott M. Myers on Genetic Testing in Neurodevelopmental Disorders.
4. <https://medlineplus.gov/genetics/condition/limb-girdle-muscular-dystrophy>
5. <https://rarediseases.info.nih.gov/diseases/6291/duchenne-muscular-dystrophy>
6. <https://my.clevelandclinic.org/health/diseases/23538-duchenne-muscular-dystrophy-dmd>
7. <https://www.ninds.nih.gov/health-information/disorders/congenital-myopathy>
8. <https://muscular dystrophynews.com/muscular-dystrophy-types/ullrich-congenital-muscular-dystrophy>
9. <https://rarediseases.info.nih.gov/diseases/873/bethlem-myopathy>.
10. <https://rarediseases.info.nih.gov/diseases/6014/central-core-disease>

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