Child India

Monthly e-Newsletter of Indian Academy of Pediatrics

June
2022

IAP EXECUTIVE COMMITTEE - 2022

PRESIDENT	DR REMESH KUMAR R
PRESIDENT-ELECT	DR UPENDRA S KINJAWADEKAR
IMM. PAST PRESIDENT	DR PIYUSH GUPTA
VICE-PRESIDENT (CENTRAL ZONE)	DR K RADHAKRISHNA
VICE-PRESIDENT (EAST ZONE)	DR SUDHIR MISHRA
VICE-PRESIDENT (NORTH ZONE)	DR HARINDER SINGH
VICE-PRESIDENT (SOUTH ZONE)	DR SUBRAMANYA NK
VICE-PRESIDENT (WEST ZONE)	DR CHETAN B SHAH
SECRETARY GENERAL	DR VINEET K SAXENA
TREASURER	DR SAMIR HASAN DALWAI
EDITOR-IN-CHIEF, IP	DR DEVENDRA MISHRA
EDITOR-IN-CHIEF, IJPP	DR S THANGAVELU
JT. SECRETARY - LIAISON	DR ALOK BHANDARI
JT. SECRETARY - ADMIN	DR PURNA A KURKURE

Executive Members

DR ANTHATI S KIREETI
DR P ANIL KUMAR
DR R RAMAKRISHNA PARAMAHAMSA
DR MRITUNJAY PAO
DR CHANDRA MOHAN KUMAR
DR SHEO BACHAN SINGH
DR ARUN PRASAD
DR SUSHIL KUMAR
DR AJAY KUMAR GUPTA
DR LALAN K BHARTI
DR MANISH GUPTA
DR VIRENDRA SADANAND GAOKAR
DR KANAKSINH U SURMA
DR RAMESH M BAJANIA
DR SAMIR R SHAH
DR AVS RAVI
DR MAHAVEER PRASAD JAIN
DR RAVINDER K GUPTA
DR JOY BHADURI
DR GEETA PATIL
DR MADHU S PUJAR
DR SN PRASHANTH
DR SHIVA PRAKASH SOSALE C
DR JOSE OUSEPH
DR M NARAYANAN
DR MK NANDAKUMAR
DR RIAZ I
DR KEWAL KISHORE ARORA
DR MAHESH MAHESHWARI
DR NARENDRA R NANIVADEKAR
DR PRAMOD M KULKARNI
DR RAMAKANT D PATIL
DR SANJAY B DESHMUKH
DR BELA VERMA
DR SHYAMKUMAR LAISHRAM
DR SANTANU DEB
DR PRASANT KUMAR SABOTH
DR SUSRUTA DAS
DR GURDEEP SINGH
DR HARPREET SINGH
DR ANURAG TOMAR
DR RAMESHWAR L SUMAN
DR A CHENTHIL
DR A SOMASUNDARAM
DR J BALAJI
DR R SOMASEKAR
DR G VIJAYA KUMAR
DR KOTTOORU SRISAILAM
DR S SRIKRISHNA
DR DHIRAJ M GUPTA
DR OM SHANKAR CHAURASIYA
DR RAJEEV KRASHAK
DR UTKARSH SHARMA
DR ASOK KUMAR DATTA
DR KAUSTAV NAYEK
DR SUTAPA GANGULY
DR SHEILA S MATHAI (SERVICES)

CONTENT

1. Editor's Note. 3

2. President's Address. 4

3. Secretary's Message 5

4. President's Engagements 6

5. Early detection of Cerebral Palsy and its management 12
Dr. Jewel Chakraborty, Dr. Anjan Bhattacharya

6. Exploring the Difficulties of Lived Experiences in Cerebral Palsy 17
Utilising Discarded Data from Set Researches and Thematic Analysis :
A Qualitative Systematic Review
Dr. Pulama Mitra, Dr. Anjan Bhattacharya,
Dr. Arunita Chakraborty, Dr. Shreya Ghosh

7. A Training Module on Accident Prevention for Parents 26
of Children with Cerebral Palsy
Dr. Arunita Chakraborty, Dr. Aishee Ghosh,
Dr. Shalinee Sarkar, Dr. Anjan Bhattacharya

8. Visual Function Classification System in Cerebral Palsy 30
Dr Deepika Jain

9. Role of Botulinum Toxin in Cerebral Palsy. 33
Prof. Dr P A M Kunju, Dr. Anitha Vijayan, Dr. Anjitha Mallasserry

10. Orthopaedic Surgery In Cerebral Palsy - An Outline 36
Dr C Cheriyan Kovoor

11. Genetics of Cerebral Palsy 38
Dr. Upasana Mukherjee, Dr. Anjan Bhattacharya

12. Parental Perspectives of Environmental Factors Acting as Facilitators . . 43
or Barriers in Cerebral Palsy, with reference to the International
Classification of Functioning, Disability and Health (ICF)
Dr. Arunita Chakraborty, Dr. Shreya Ghosh, Dr. Paulama Mitra,
Dr. Aishee Ghosh, Dr. Jewel Chakraborty, Dr. Anjan Bhattacharya

13. Assistive Technology and Devices for Habilitation and 48
Early Intervention of Children with Cerebral Palsy
Dr. Sindhu Vijayakumar

14. Branch Activities at a Glance 54

Editor's Note

Dear colleagues,

Greetings from Child India with the June issue.

This month we are again dealing with some issues regarding Cerebral Palsy (We had discussed this very common handicap in the Oct 2021 issue of Child India).

Methodology of collection and interpretation of the data in various studies of children with cerebral palsy is different.

Many studies have been restricted to centres with facility and capability to conduct research and so are not representative of the ground situation.

Age of children included in studies varies. As late diagnosis is the norm, studies involving very young would miss out many. Those studies including older children would not include children who died in early childhood. Some studies include acquired causes and others do not.

All cerebral palsy cases need to be in one basket as only with inclusive and appropriate designation and identification can service delivery be provided effectively for all these children.

We hope that these articles by experts will arm pediatricians and care-givers with sufficient information to help children with cerebral palsy.

Regards,

Dr Jeeson C Unni

Editor-in-Chief

President's Address

Dear friends,

Greetings to all my dear ones through our monthly e newsletter – Child India.

Cerebral palsy is a reality that we face with increasing NICU graduate survivors and we need to be knowledgeable of all issues that these children encounter as their life unfolds.

Nearly 15-20% of the total physically handicapped children suffer from cerebral palsy. The estimated incidence for our country is around 3/1000 live births; this is more likely to be an underestimate.

Early diagnosis and comprehensive management require a multidisciplinary team including pediatricians, developmental pediatrician, neurologist, orthopedic surgeon, speech and language therapist, physiotherapist, occupational therapist, ophthalmologist, psychologists and psychiatrist, dietician, gastroenterologist and a geneticist. Very few children with cerebral palsy in our country have access to all these specialists and it is our bounden duty to ensure this becomes a reality.

We need to be aware of our National programs like DISHA, VIKAS, Gharaunda, Niramaya, Sahyogi, Prerna, Sambhav and Badthe kadam. District early intervention centres (DEIC) is well staffed in most districts. We must support and create awareness about activities of the National Trust and RBSK.

Let us all put our might behind these programs.

Jai IAP,

Dr Remesh Kumar
National President, IAP 2022

Secretary's Message

Dear Friends,

We are in the midst of the Presidential tenure of Dr Remesh Kumar. First few months are consumed in presentation of the Action Plan and organizing TOTs for various academic activities which are envisioned for the whole year. It's only after three months or so that the roll out of various action plans begins and it's by this time the vision of the President starts taking a form and start making an impact. Charting this course we are reaching the crescendo with a huge number of modules running in physical mode, all across the country.

A total of 155 workshops of NTEP, the most prestigious and of great importance and with MOHFW, Govt of India, have been done till now. In June alone we did 20 workshops. 43 workshops of ECD, yet another path breaking project of IAP, have been conducted till now including one in Kochi of which 13 came in June. 5 Workshops of Pediatric Emergency Care & Resuscitation Training Module (PECART), 4 of Demystifying Allergic Disorders (DAD), 3 of Pyrexia of Infection & Non Infection (POINT), 1 of Ped Gastro, 3 of Pulmostar, 1 each of Growth & Puberty and use of Medications in Pediatrics (UMP) have taken place in this month. A remarkable feat for which our President Dr Remesh, Team IAP 2022 and each organizing Branch deserves huge applause.

Then there was a program of Training each and every Intern in UP in NRP, graduated from any of the Medical Colleges. This was a massive workshop, where 176 Faculty Members from all the Medical Colleges of UP were trained to be the Trainers in NRP and were assigned their roles. They will in turn train each and every Intern in their college. This will definitely contribute in bringing down the under Five mortality in India.

So Friends keep organizing and attending the various Academic Bonanza about to follow in coming

months.

Long Live IAP, Jai IAP.

Warm Regards,

Dr Vineet Saxena
Hon. Secretary General 2022 & 23

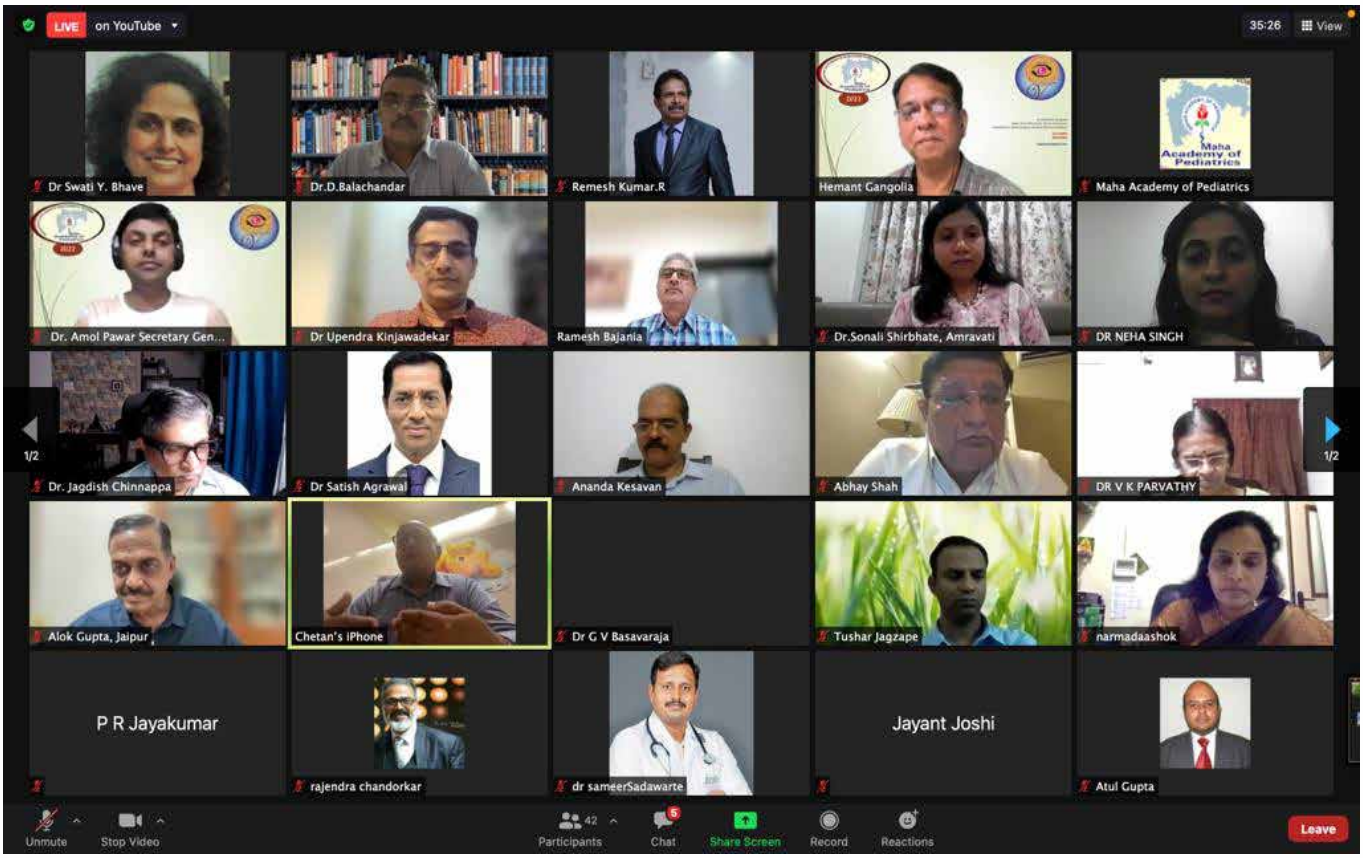
President's Engagements

June 5th inauguration of with UP Deputy Chief Minister Sree Brijesh Pathak of Neonatal Resuscitation Training Program for all interns in UP

President's Engagements

5th June inaugurated IAP Chikkaballapur branch .. the 332nd IAP branch in India

President's Engagements



World Environment Day observed on 9/5/22, by IAP AMRAVATHI , MAHARASHTRA in association with ECHG CIAP. Inaugural address by Dr Remesh Kumar stressed on the importance of sustainably living in harmony with nature.

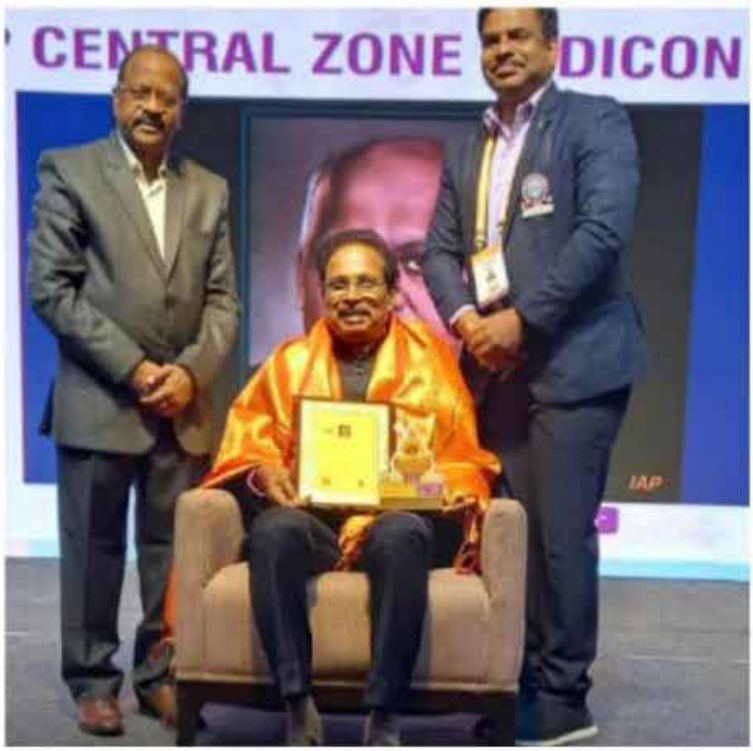
President's Engagements

Chief Guest at inaugural function of 14th Annual CME of IJPP at Chennai June 12th

President's Engagements

19th June Chief Guest at Pulmostar Patna and faculty Under 5 wheezers

President's Engagements



Delivered the Dr Harishchandra Oration at Central Zone Pedicon July 3rd at Hyderabad

Early detection of Cerebral palsy and its management

DR. JEWEL CHAKRABORTY[1]

DR. ANJAN BHATTACHARYA[2]

Introduction: Cerebral palsy (CP) refers to a group of posture and movement disorders occurring as a result of a non- progressive lesion of the developing central nervous system during the prenatal, perinatal, or postnatal period (up to 2 years) 1,2,3. CP can lead to global dysfunction but always includes motor problems 4.

CP has been classified based on the type of motor disorder, with variable numbers and descriptions of types. The revised classification now in use defines the following four main categories of motor disorder 5: Spastic (70-80% of cases): quadriplegia (10-15%): all four extremities are affected equally along the trunk; diplegia (30-40%): lower extremities are affected to a greater degree than the upper extremities; hemiplegia (20-30%): involvement is noted in one side of the body, including the arm and the leg; monoplegia (rare): involvement is observed on one limb, either the arm or the leg; Dyskinetic or athetoid (10-15% of cases); Ataxic (< 5% of cases); and Mixed forms (most often spasticity and athetosis, less often ataxia and athetosis).

CP is caused by an insult to the immature brain at any time prior to birth up to 2 years of age. The early central nervous system (CNS) damage results in chronic physical disabilities and often includes sensory impairments. Cerebral insult produces alterations in muscle tone, muscle stretch reflexes, primitive reflexes, and postural reactions. Other associated symptoms may be involved secondary to the neurological insult (mental retardation, speech, hearing and vision problems, perceptual disturbances, epilepsy). 54% of children have more than one associated disability 6.

The etiology of such cerebral insults includes vascular, hypoxic-ischemic, metabolic, infectious, toxic, traumatic, and genetic causes. The pathogenesis of CP involves multifactorial causes, but much is still unknown. Different mechanisms of CP pathogenesis have been associated with pre-term and term births. The prevalence of congenital CP is approximately 2 per 1,000 births 7..

Early detection of Cerebral palsy:

Early diagnosis of CP is extremely difficult. Often, it is impossible to diagnose CP under the age of four months, and even less than six months of age in slightly affected children with 'soft neurological signs'. In a majority of cases, there is an abnormal birth history such as prematurity, anoxia, asphyxia, hyper- bilirubinemia, prolonged or precipitated labour, a small- for-dates baby, twinning, multi-gravid mother, etc.8. These are

1. *Consultant Paediatric physiotherapist, Child Development Center, Apollo Multispecialty Hospital, Kolkata*

2. *Consultant Developmental Pediatrician, Child Development Center, Apollo Multispecialty Hospital, Kolkata*

the babies at risk, who will need a careful follow-up. Neurological assessments are frequently used to monitor development of high-risk infants.

The best known neuromotor assessment is the general movement assessment (GMA). General movements are the most frequently used movements from early fetal age until 3–4 months post-term8. The quality of these movements provides information about the integrity of the brain, possibly especially about the connectivity in the periventricular white matter9. Typical general movements are characterized particularly by variation and complexity; in abnormal general movements these characteristics are reduced or absent 8,9. Prediction of CP with the GMA is excellent when based on longitudinal series of assessments 9. When a single assessment is used, prediction is best when GMA is carried around 3 months post-term [median sensitivity 98% (range 50–100%), specificity 94% (range 35–100%) 10,11,12. Other motor assessments used to predict CP in infancy are the motor assessment of infancy [MAI 13], the test of infant motor performance [TIMP 14], the Alberta infant motor scale [AIMS (15)] the infant motor profile [IMP 16], and – less frequently – the psychomotor index of the Bayley scales of development 17. However, calculation of predictive values for CP is precluded due to the limited data on prediction available, or due to the fact that studies evaluating the predictive properties used more global "abnormality" outcomes 12, 10, 18. The neurological and neuromotor assessments are relatively cheap instruments, and therefore, may be applied in many settings across the world.

The Early intervention of Cerebral Palsy:

The aim of treatment for children with CP or other conditions involving the upper motor neuron of the CNS, regardless of etiology, is to lead them towards the greatest degree of independence possible, and so to prepare them for as normal an adolescent and adult life as can be achieved. This is the aim of all schools of treatment 19.

The effect of early intervention has been studied predominantly in infants at high risk for developmental disorders, i.e., in groups of preterm infants only 20, or in mixed groups of high-risk infants 21. On the effect of early intervention in preterm infants after term age more information is available. A meta-analysis 22 and a systematic review 20 indicated that early intervention by means of general developmental programs is associated with a positive effect on cognitive development until the age of 3 years. Wallander et al 23 applied the concept of early developmental intervention in asphyxiated infants in the Low-middle income setting. The results of this study were similar to those of the early intervention studies in preterm infants in more affluent settings: intervention promoted development until the age of 3 years, and the effect on cognitive development was larger than that on motor development.

The treatment of cerebral palsy is directed at repair of the injured brain and at the management of the impairments and disabilities resulting from developmental brain injury. Management options include physiotherapy, occupational and speech therapy, orthotics, device-assisted modalities, pharmacological intervention, and orthopedic and neurosurgical procedures. 35

It involves establishing a total management program for the child in which a specialized physiotherapy forms an essential part. 36

Treatment should start only when signs of abnormal tonus and movement patterns are seen. In most babies, this happens after a 'silent' period, during which no treatment is necessary, but if suspicious signs develop, treatment must start immediately.

First symptoms may appear immediately following, or even during, a stormy perinatal

period, but these cases present no particular diagnostic problem. In other instances, there may have been some abnormalities during the pregnancy, followed by a relatively normal perinatal period of varying length, after which symptoms appear. These cases may present diagnostic problems. There is great difficulty in differentiating the pathology from permissible signs of deviation from nor mal development. There are babies with unusual symptomatology who subsequently develop normally. Be- cause of this, it is very important to repeat examination and assess the baby's rate of development, especially in babies under four months of age . In a baby with suspected brain damage, the intervals between seeing the baby should be short, not longer than 3 or 4 weeks after the appearance of suspicious signs. During the first year of the baby's life, the development is at its fastest and 'soft signs' may become 'hard signs' over a very short time.

Early intervention in general comprises in addition to the therapeutic developmental interventions targeting the infant, some form of parental support, including psychosocial support and parent education. As a result, general developmental programs are also associated with a reduction of maternal anxiety and depression, improved maternal self-efficacy, and – presumably – less maternal stress 24. Possibly, the effect of the programs on the mother is one of the mediators of the effect of early intervention on the infant's development. However, the way in which parents are involved in early intervention differs considerably. Traditionally, parents have been assigned the role of co-therapist. But gradually, awareness of family autonomy arose, leaving room for individual parenting and educational styles in early intervention. 25, 26 The concept of family coaching as opposed to parent training emerged26. Family coaching in early intervention implies that families set the goals for intervention and that the coach provides – by means of an open dialog – hints and suggestions how the goals may be achieved during daily routines, such as feeding and bathing 25,27. A recent study in high-risk infants indicated that family coaching during early infancy was associated with improved motor development and functional mobility at 18 months CA28, 29. This suggests that family coaching may be one of the potentially effective factors in family centered care.

Palmer et al. study 39 provided moderately strong evidence that intervention by means of an infant-stimulation program provided twice per month was associated with better motor outcome than equally frequent intervention by means of NDT.

Goal directed functional therapy may offer one of the means to improve the success of early intervention. 42, 43

Mattern-Baxter et al. 44 recently studied the effect of 6 weeks of intensive home-based treadmill training in 12 young children with CP (aged 9–36 months, mean: 21 months; Gross Motor Function Classification System levels I and II). The intervention group of six infants received twice daily during 6 days/week treadmill training sessions of 10–20 min. During the intervention period of 6 weeks, the infants continued to receive their usual therapy. The six control infants received only their usual therapy. Direct after the intervention, but also 4 months post-intervention function in daily life of the infants who had received treadmill training was significantly better than that of the control group.

References

1. Reid DT. Benefits of a virtual play rehabilitation environment for children with cerebral palsy on perceptions of self-efficacy. Pediatr Reh 2002;5:141-8.
2. Bobath K. A neurophysical basis for the treatment of cerebral palsy. Mac Keith Press, London, 1991:30-98.
3. Vojta V. The movement disorders in infant - early diagnosis and early therapy. Hippokrates Verlag GmbH, Stuttgart, 2000. (in Germany)

4. Chang JJ, Wu TI, Wu WL, Su FC. Kinematical measure for spastic reaching in children with cerebral palsy. Clin Biomech 2005;20:381-8.
5. Majnemer A, Mazer B. New directions in the outcome evaluation of children with cerebral palsy. Semin Pediatr Neurol 2004;11: 11-7.
6. Bhatia M, Joseph B. Rehabilitation of cerebral palsy in a developing country: the need for comprehensive assessment. Pediatr Reh 2001;4:83-6.
7. Fernandez-Alvarez E, Aicardi J. Movement disorders in children. Mac Keith Press, London,2001;216-27
8. Prechtl HRF. Qualitative changes of spontaneous movements in fetus and preterm infant are a marker of neurological dysfunction. Early Hum Dev (1990) 23:151–8. doi:10.1016/0378-3782(90)90011-7
9. Hadders-Algra M. Putative neural substrate of normal and abnormal general movements. Neurosci Biobehav Rev (2007) 31:1181–90. doi:10.1016/j.neubiorev.2007.04.009
10. Heineman KR, Hadders-Algra M. Evaluation of neuromotor function in infancy – a systematic review of available methods. J Dev Behav Pediatr (2008) 29:315–23. doi:10.1097/DBP.0b013e318182a4ea
11. Burger M, Louw QA. The predictive validity of general movements – a systematic review. Eur J Paediatr Neurol (2009) 13:408–20. doi:10.1016/j.ejpn.2008.09.004
12. Bosanquet M, Copeland L, Ware R, Boyd R. A systematic review of tests to predict cerebral palsy in young children. Dev Med Child Neurol (2013) 55:418–26. doi:10.1111/dmcn.12140
13. Harris SR. Early neuromotor predictors of cerebral palsy in low-birthweight infants. Dev Med Child Neurol (1987) 29:508–19. doi:10.1111/j.1469-8749.1987.tb02511.x
14. Barbosa VM, Campbell SK, Sheftel D, Singh J, Beligere N. Longitudinal performance of infants with cerebral palsy on the test of infant motor performance and on the Alberta infant motor scale. Phys Occup Ther Pediatr (2003) 23:7–29. doi:10.1080/J006v23n03_02
15. Piper MC, Darrah J. Motor Assessment of the Developing Infant. Philadelphia: Saunders (1994). 222 p.
16. Heineman KR, Bos AF, Hadders-Algra M. Infant motor profile and cerebral palsy: promising associations. Dev Med Child Neurol (2011) 53(Suppl 4):40–5. doi:10.1111/j.1469-8749.2011.04063.x
17. Weiss LG, Oakland G, Aylward GP. Bayley-III, Clinical Use and Interpretation. Amsterdam: Elsevier BV (2010). 256 p.
18. Spittle AJ, Doyle LW, Boyd RN. A systematic review of the clinimetric properties of neuromotor assessments for preterm infants during the first year of life. Dev Med Child Neurol (2008) 50:254–66. doi:10.1111/j.1469-8749.2008.02025.x
19. Sine R, Liss SE, Roush RE. Basic rehabilitation techniques. Gaithersbur, Aspen, 2000: 313-38.
20. Spittle A, Orton J, Anderson P, Boyd R, Doyle LW. Early developmental intervention programmes post-hospital discharge to prevent motor and cognitive impairments in preterm infants. Cochrane Database Syst Rev (2012) 12:CD005495. doi:10.1002/14651858.CD005495
21. Blauw-Hospers CH, Hadders-Algra M. A systematic review on the effects of early intervention on motor development. Dev Med Child Neurol (2005) 47:421–32. doi:10.1017/S0012162205000824104. Guzzetta A, D'Acunto MG, Carotenuto M, Berardi N, Bancale A, Biagioni E, et al. The effects of preterm infant massage on brain electrical activity. Dev Med Child Neurol (2011) 53(Suppl 4):46–51. doi:10.1111/j.1469-8749.2011.04065.x+
22. Vanderveen JA, Bassler D, Robertson CM, Kirpalani H. Early interventions involving parents to improve neurodevelopmental outcomes of premature infants: a meta-analysis. J Perinatol (2009) 29:343–51. doi:10.1038/jp.2008.229
23. Wallander JL, Bann CM, Biasini FJ, Goudar SS, Pasha O, Chomba E, et al. Development of children at risk for adverse outcomes participating in early intervention in developing countries: a randomized controlled trial. J Child Psychol Psychiatry (2014). doi:10.1111/jcpp.12247
24. Benzies KM, Magill-Evans JE, Hayden KA, Ballantyne M. Key components of early intervention programs for preterm infants and their parents: a systematic review and meta-analysis. BMC Pregnancy Childbirth (2013) 13(Suppl 1):S10. doi:10.1186/1471-2393-13-S1-S10
25. Dirks T, Blauw-Hospers C, Hulshof H, Hadders-Algra M. Differences between the family-centered 'COPCA' program and traditional infant physical therapy based on neurodevelopmental treatment principles. Phys Ther (2011) 91:1303–22. doi:10.2522/ptj.20100207
26. Dirks T, Hadders-Algra M. The role of the family in intervention of infants at high risk for cerebral palsy – a systematic analysis. Dev Med Child Neurol (2011) 53(Suppl 4):62–7. doi:10.1111/j.1469-8749.2011.04067.x

27. Hwang AW, Chao MY, Liu SW. A randomized controlled trial of routines-based early intervention for children with or at risk for developmental delay. Res Dev Disabil (2013) 34:3112–23. doi:10.1016/j.ridd.2013.06.037

28. Blauw-Hospers CH, Dirks T, Hulshof LJ, Bos AF, Hadders-Algra M. Pediatric physical therapy in infancy: from nightmare to dream? A two arm randomized trial. Phys Ther (2011) 91:1323–38. doi:10.2522/ptj.20100205

29. Hielkema T, Blauw-Hospers CH, Dirks T, Drijver-Messelink M, Bos AF, Hadders-Algra M. Does physiotherapeutic intervention affect motor outcome in high-risk infants? An approach combining a randomized controlled trial and process evaluation. Dev Med Child Neurol (2011) 53:e8–15. doi:10.1111/j.1469-8749.2010.03876.x

30. Nelson MN, White-Traut RC, Vasan U, Silvestri J, Comiskey E, Meleedy-Rey P, et al. One-year outcome of auditory-tactile-visual-vestibular intervention in the neonatal intensive care unit: effects of severe prematurity and central nervous system injury. J Child Neurol (2001) 16:493–8. doi:10.1177/088307380101600706

31. Ohgi S, Fukuda M, Akiyama T, Gima H. Effect of an early intervention programme on low birthweight infants with cerebral injuries. J Paediatr Child Health (2004) 40:689–95. doi:10.1111/j.1440-1754.2004.00512.x

32. Weindling AM, Hallam P, Gregg J, Klenka H, Rosenbloom L, Hutton JL. A randomized controlled trial of early physiotherapy for high-risk infants. Acta Paediatr (1996) 85:1107–11. doi:10.1111/j.1651-2227.1996.tb14226.x

33. Hielkema T, Hamer EG, Reinders-Messelink HA, Maathuis CGB, Bos AF, Dirks T, et al. Learn 2 move 0-2 years: effects of a new intervention program in infants at very high risk for cerebral palsy – a randomized controlled trial. BMC Pediatr (2010) 10:76. doi:10.1186/1471-2431-10-76

34. Balshem H, Helfand M, Schünemann HJ, Oxman AD, Kunz R, Brozek J, et al. GRADE guidelines: 3. rating the quality of evidence. J Clin Epidemiol (2011) 64:401–6. doi:10.1016/j.jclinepi.2010.07.015

35. McDermott s, Nagle R, Wright HH, Swann S, Leonhardt T, Wouri D. Consultation in paediatric rehabilitation for behaviour problems in young children with cerebral palsy and/or developmental delay. Pediatr Reh 2002;5:99-106.

36. Kemper HC. Is physical exercise good for the brain of a child? Pediatr Reh 2001;4:145-7.

37. Scherzer A, Mike V, Ilson J. Physical therapy as a determinant of change in the cerebral palsied infant. Pediatrics (1976) 58:47–52.

38. Mayo NE. The effect of physical therapy for children with motor delay and cerebral palsy. A randomized clinical trial. Am J Phys Med Rehabil (1991) 70:258–67. doi:10.1097/00002060-199110000-00006

39. Palmer FB, Shapiro BK, Wachtel RC, Allen MC, Hiller JE, Harryman SE, et al. The effects of physical therapy on cerebral palsy. A controlled trial in infants with spastic diplegia. N Engl J Med (1988) 318:803–8. doi:10.1056/NEJM19880331318130

40. Reddihough DS, King JA, Coleman GJ, Catanese T. Efficacy of programmes based on conductive education for young children with cerebral palsy. Dev Med Child Neurol (1998) 40:763–70. doi:10.1111/j.1469-8749.1998.tb12345.x

41. Law MC, Darrah J, Pollock N, Wilson B, Russell DJ, Walter SD, et al. Focus on function: a cluster, randomized controlled trial comparing child- versus context-focused intervention for young children with cerebral palsy. Dev Med Child Neurol (2011) 53:621–9. doi:10.1111/j.1469-8749.2011.03962.x

42. Löwing K, Bexelius A, Brogren Carlberg E. Activity focused and goal directed therapy for children with cerebral palsy – do goals make a difference? Disabil Rehabil (2009) 31:1808–16. doi:10.1080/09638280902822278

43. Löwing K, Bexelius A, Carlberg EB. Goal-directed functional therapy: a longitudinal study on gross motor function in children with cerebral palsy. Disabil Rehabil (2010) 32:908–16. doi:10.3109/0963828090335342

44. Mattern-Baxter K, McNeil S, Mansoor JK. Effects of home-based locomotor treadmill training on gross motor function in young children with cerebral palsy: a quasi-randomized controlled trial. Arch Phys Med Rehabil (2013) 94:2061–7. doi:10.1016/j.apmr.2013.05.012

Exploring the Difficulties of Lived Experiences in Cerebral Palsy Utilising Discarded Data from Set Researches and Thematic Analysis : A Qualitative Systematic Review

DR. PULAMA MITRA
M.Sc Clinical Psychology, Christ (Deemed to be) University, Delhi NCR

DR. ANJAN BHATTACHARYA
Developmental Paediatrician, Child Development Centre
Apollo Multispeciality Hospital, Kolkata

DR. ARUNITA CHAKRABORTY
Ph.D. Scholar, Amity University, Kolkata
Psychologist, Child Development Centre, Apollo Multispeciality Hospital, Kolkata

DR. SHREYA GHOSH
Psychologist, Child Development Centre, Apollo Multispeciality Hospital, Kolkata

Abstract

Aims and Objectives: Researchers conducting Qualitative Researches often collect transcripts and discards data which do not meet their criteria for their study. This is a source of frustration in many researchers, since many times they feel that the discarded data contained valuable information. The present study analyses that discarded data to see, if there is really any information that are valuable for clinical use.

Methods and Materials: Parents of ten children with Cerebral Palsy (CP) and one treating professional (clinical psychologist) were interviewed for their Lived Experiences and ICF Coding by two separate researchers. Data they have discarded were analysed to find out if these contained any clinically relevant information using standardized coding techniques.

Results: 12 additional problems of relevance were identified and interestingly 3 positives were captured, which would have been discarded by the studies for which these data were originally captured. There were some known issues found in literature, which did not surface in our dataset. These findings and their relevance were discussed in detail.

Conclusions: This innovative study demonstrates how collected data from other studies can be utilised without discarding them, to the best use clinically. This study has wider applications, thus.

Introduction

Cerebral Palsy (CP) is an umbrella term for a group of disorders that typically affects newborns. The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) and International Classification of Diseases (ICD) classify CP under unspecified neurodevelopmental disorder. The onset of Cerebral Palsy is often insidious and the child is usually affected during the prenatal period or shortly after birth during the postnatal period. Cerebral Palsy is a lifelong condition that often requires prolonged treatment. CP does not get worse over time and is therefore considered to be a non-progressive disorder. However, with the child's development, nature, perception, and degree of their problems change. Cerebral Palsy is associated with multiple comorbid and secondary medical conditions, consequently following a multidisciplinary team approach for its treatment and affects individuals in more ways than one. Based on the existing literature on CP, research has been conducted to explore the symptomatology, etiology, and comorbidity. However, CP has innumerable complications and is associated with additional problems and difficulties that cause significant distress and impairment in patients and their basic ADLs. Qualitative researchers often collect data, which researchers discard not because they are clinically insignificant but because such data are beyond the remit of their studies. The crux of the present study is to study the value of such data, usually meticulously collected and seldom used, to see if this novel way of researching discarded data can pave the way for the best utilisation of the researcher's efforts and do full justice to the data set collected. The aim of this article is to provide an updated overview of CP and review the additional problems associated with it, utilising the data discarded by researchers not relevant to their study.

Purpose

In the present study, the additional difficulties associated with Cerebral Palsy are explored. The study is based on reviewing the previous findings of the literature on CP. Additionally, the subjective experiences of individuals and families with Cerebral Palsy were explored through interviews, and the qualitative data was used to find out the correlation between existing and newfound difficulties faced by patients with CP.

The qualitative data that was obtained through interviews is put to use in two differnt studies on CP. However, the data that is put to use in the present study is built on the eliminated data of researchers that were irrelevant to their studies which they felt were otherwise clinically important. The purpose of the present study is thus, to explore the emerging themes obtained from the data that hold clinical significance in CP that are not useful for the original studies.

Method

Design

This research design included focus groups with (i) immediate caregivers of children diagnosed with CP and (ii) healthcare professionals with expertise in the management of CP. Thematic analysis, a commonly used descriptive qualitative methodology that is not conceptually bounded, was used as the analytical methodology to enable the collection of relevant and rich data from both parents and professionals.

Procedure

During the period of observatory clinical internship in a Child Development Centre, in Kolkata, there has been exposure to clinical cases of CP. The qualitative enquiry of the focus group was conducted upon approval received from the superintendent in charge of Barasat District Hospital and the Clinical Psychologist, who conducted the original research. Informed consent was obtained from the participants before taking part in the study. For the ones who

were not comfortable with the interview being audio recorded, running notes were taken on the patients' history with prior consent. Ethical consideration was taken into account since the study deals with a special population and the participants were debriefed thoroughly. Data was collected and utilised anonymously. Based on the interactions with families and patients with CP and the conduction of qualitative interviews while shadowing the researchers for the study, relevant conclusions have been drawn through cross-referencing with the existing literature on CP.

The data that has been used for the study is the discarded information that remained unutilized by researchers, only because it did not fit their research objective (a common and possibly frustrating experience for the researchers). Thus, the innovative methodology and the present study hold originality, making it possible to use data obtained during the short duration of the observatory internship to be utilised efficiently and its applicability to a larger sample in the future.

Data Analysis

The data obtained from the focus groups were analysed qualitatively using thematic analysis. The interviews and discussions were transcribed verbatim and coding was done utilising the standard Qualitative Methodology coding system. A thematic analysis was conducted which led to the emergence of relevant themes reflecting associated difficulties in CP, as experienced by the patients, immediate caregivers, and healthcare professionals. These were then cross-referenced with the available information in the literature to find out, if discarded data, thus analysed, hold value for the clinical research field. The themes are summarised in Table 1.

Results and Discussion

Analysis was organised according to the two major methodological approaches of the study. Analysis following the first approach, to identify the additional challenges associated with CP resulted in the emergence of nine themes. Analysis following the second approach, to explore relevant literature on CP and its associated difficulties resulted in correlated and additional findings with the themes.

Literature Search highlighting Associated Difficulties in CP:

To give an overall view of the associated difficulties in CP, the themes obtained as a result of literature search revealed the following list which are summarised in Table I:

Qualitative Analysis of Data highlighting Associated Difficulties in CP:

Analysing discarded data from the two original studies using 10 families with a child with CP, we found the following, which is summarised in Table 2.

One of the biggest finds in using discarded data was a set of positives, which were unexpected. These data are tabulated in the Table 3.

Discussion

Discarded data, if analysed, yields valuable information. This study highlights an innovative manner in which discarded data can be utilized optimizing researchers' toil and effort, without losing valuable resources.

While the original studies utilized relevant data as per their set criteria (here these were Lived In Experiences and ICF Coding, as two separate studies), left overs may contain pearls, that do not necessarily need to be thrown away.

In fact, while setting up the study (so that we can take informed consent from parents and eligible minors), so much yield was hardly anticipated. In future studies, preparation for capturing more data out of the discarded lot is envisioned and the study repeated with larger sample size is already planned.

Table I

Summary of the themes emerging from the focus group post thematic analysis

Theme	Sub-themes	Definition and Summary of Theme Content
Intellectual Disability (ID)		ID pertains to the intellectual difficulties of children with Cerebral Palsy which vary greatly. Despite their physical limitations, some patients will demonstrate the same ability as others. Others will have some form of intellectual disability, which can range from minor to severe. Parents and healthcare professionals reported that children diagnosed with CP have ID.
Educational Difficulties		Educational difficulties highlight the obvious academic challenges in patients with CP that may affect their academic progress.
Health-related Quality of Life (HRQOL)	Ideation of Disability Quality of Life and Progress **Associated Clinical Conditions**	HRQOL focuses on the overall quality of life while incorporating all factors that impact a child's life with CP, taking into consideration their physical and mental health.
Physical Difficulties and Pain Neurogenic Difficulties		The associated problems such as orthopedic pain are consequent of persistent gait patterns, and motor and postural difficulties in CP. Difficulties like bowel and bladder incontinence are associated with CP.
Functional and Social Difficulties	Functional Impairment Social Factors Social Difficulties	Impairments in ADL and routine activities of daily life associated with the disability and consequent social problems such as bullying, lack of social support, etc.
Associated Birth Complications and Irregularities in Check-ups		Birth complications are major red flags of CP and delayed or irregular intervention worsens the condition of CP.
Treatment and Dependency Issues	Treatment and Therapeutic Intervention Financial Burden Dependency Difficulties	Multidisciplinary treatment approach of CP and increased financial burden on patients' families accompanied by a lifelong dependency on the primary caregiver and its associated problems.
Psychosocial Problems faced by Professionals		Highlights the challenges faced by healthcare professionals dealing with patients and families of CP.

Table 2

Additional Problems	Number (Out of 10 cases)	Severity (Dysuntio-nality)	REMARKS (Highlighting some statements made by parents but not usable in other studies)
Intellectual Disability	5	Schooling/ Grades	"He is an intelligent boy, if only his friends realized that"
Educational Difficulties	10	Academic optimality	"He is intelligent, still he is not doing well in studies due to his physical issues"
Health Related Quality of Life	10	Recurrent ailments	"He misses so much school due to his recurrent UTI/Cough & Cold/Tummy aches"
Physical difficulties	10	Activity Limitation	"Only if they let him participate, he could have felt so much better about himself"
Pain	9	Activity Limitation	"It pains her to go from classroom to classrooms, so she needs to be carried"
Neurogenic Difficulties	1	Activity & Participation limitation	"She is incontinent, she needs frequent changing. Moreover she started her periods and she smells. So friends avoid her"
Functional Impairments	3	Multiple Functional Limitations	"He is so busy supporting himself, he forgets every other task"
Social Impairment	1	Bullying	"He is an intelligent boy, but his friends keep bullying him for his awkward gait"
Management Related Difficulties	4	Mild to Moderate	"There are so many problems with him that we need to go to so many doctors"
Anticipation Decision Regret	10	Unmeasurable	"We wish we were told early. It is only later that we learnt about what we should have done with him. Wish doctors told us before"
Family related difficulties	1	Single mother	"Father left knowing his disability so I am the sole carer left for him"
Professional's Difficulty	1	Communication on Breaking News	"It is daunting to face parents to tell them that their child has a lifelong condition"

Table 3

Additional Facilitators/ Positives	Number (Out of 10 cases)	Degree (Impact)	REMARKS (Highlighting some statements made by parents but not usable in other studies)
Inclusivity	5	Full Inclusion	"It is nice to see that nowadays people around are sympathetic towards his needs"
Resilience	1	Full Access	"Of course, I will cater to all his needs"
Life Course Approach	10	Learning in family	"We have learnt so many things while getting her treated"

Some of the highlights are left below for better perception of this utility in Qualitative manner as follows:

Social Difficulties

Interestingly, what was reported during the interview was that the patients with CP were mostly a part of an inclusive and accepting family and peer group, and received enough support from their educational institutions as well. This is perhaps due to the reduced stigma and increased awareness of CP. However, it was also reported that individuals with disabilities like CP are at a higher risk of being bullied and one of the patients shared negative experiences due to social impairment. The patient insisted on consistent efforts from service providers to include discussions on the challenges of young adults with disability and its consequent impaired social relationships while delineating the importance of adequate social support in battling the disability. There is a scarcity of relevant literature that highlights the relevance of social factors and patients' feelings of exclusion and social isolation that individuals with CP experience as evidenced by our study.

Functional Impairment

Spasticity present in CP can result in functional problems with daily living activities (ADL) as reported by the healthcare professional during the qualitative interview. He reported patients having problems related to gait, feeding, and eating problems, common in CP. One of the parents interviewed reported that his child was unable to focus his attention or remember things told to him. The child also showed a lack of adaptive functioning and was unable to take care of himself.

Treatment Issues

Treatment of CP follows a multidisciplinary and interdisciplinary approach involving physiotherapists, occupational therapists, speech therapists, psychologists, family counsellors, and educators who work together in a clinical setting. The demographic details of the families of patients who were interviewed for the study reflected belonging to the lower socioeconomic class. Since the treatment for CP is persistent for a long duration and multidisciplinary, the costs of treatment and therapeutic interventions become an economic burden for most families.

Dependency Issues

During the interview, one of the parents reported being the primary caregiver of her child, with the father being ignorant. The child was solely dependent on the mother and she carried her child on her back and consequently, faced problems like shoulder and back pain. She also reported having an irregular sleep pattern as she had to regularly wake up and check on her child every night who had a risk of seizures. Additionally, exploring the psychosocial problems, she was continuously accused and blamed for giving birth to a child with a disability and had to fight relentlessly for the treatment of her daughter.

Psychosocial Problems faced by Professionals

An important factor that shows a paucity of literature is the challenges faced by healthcare professionals with expertise in CP as reported during the qualitative enquiry. The healthcare professional reported that the biggest difficulty or challenge that seems daunting to him is to be upfront with the patients' families in communicating that their child has a neurodevelopmental disability like CP and that it is a lifelong clinical condition.

Neurogenic Difficulties

The age of bladder and bowel continence in children with bilateral Cerebral Palsy (BCP), as well as its relationship with intellectual impairment (II) and the severity of a motor

disability, were investigated in a study. The findings revealed that children with BCP achieved bladder and bowel continence more slowly and incompletely than controls, with 60.8 percent being continent during the day and 54.6 percent being continent at night by the age of 17 years (Wright et al., 2016). The one child in the present study was thus, typical of what literature shows but could have been missed out by the other studies, since they either did not focus on medical issues or looked at it only from the coding perspective.

Associated Medical Difficulties

The literature review supports our qualitative findings while listing out additional problems such as irregularities in sleep, drooling, toilet training, etc present in patients with CP.

Children with Cerebral Palsy (CP) may lose or regress in their functional ability. Systematic research on CP reveals that children, adolescents, and young adults with CP lose motor and oral function. Oral dysfunction often leads to dental problems that affect their oral hygiene.

Dental Problems

Wasnik et al. (2020) reported that oral problems in patients with CP are common and may be manifested in the form of Malocclusion, Bruxism that persistently causes the teeth to wear away prematurely, Dental Erosion and Dental Caries due to inadequate oral hygiene. Our data were completely devoid of this issue, since we did not introduce or prompt any ideas and only accepted participants' free flowing divulgence, as per Qualitative Research Standards.

Feeding, Nutrition, and Growth

Sullivan (2013) highlighted that feeding difficulties in children with Cerebral Palsy can be caused by a variety of factors. Oropharyngeal incoordination, which is related to the slowdown in the rates of feeding, lengthy feeding periods, excessive spillage of food, and damage to the swallowing safety, causes a considerable loss in nutritional intake. Vomiting, poor dentition, early satiety, communication problems, and behavioural disorders all contribute to the undernutrition seen in many children with severe Cerebral Palsy. Surprisingly, this common theme in parental discussion did not surface during our data collection. This may be due to relatively small sample size, opening remark bias or a genuine shift in community focus and perception over time.

Sleep Disturbances

In a study, the Sleep Disturbance Scale for Children (SDSC), sleep problems in children with CP (age range: 3–5 years, mean: 3.8 years). Thirteen percent of children with CP had an abnormal overall sleep score, while 35 percent had an abnormal score on at least one SDSC category, with pre-school children being more predisposed to developing sleep disturbances. (Romeo et al., 2014). All data were used up in the other two studies on this. Hence, there were no discarded data available for the present study on this.

Drooling

Tahmassebi and Curzon (2003) investigated the relation between drooling and the type of CP using $\chi 2$ analysis. The study was conducted on one hundred and sixty children and adolescents (91 males, 69 girls; mean age 10 years 10 months, SD 4 years 2 months; mean age 10 years 10 months, SD 4 years 2 months; mean age 10 years 10 months, SD 4 years 2 months; mean age 10 years 10 months, SD 4 years 2 ranged in age from 4 to 18 years) with Cerebral Palsy who attended special schools. The presence or absence of drooling was determined by the naturalistic observation of the participants while demographic details and other relevant data such as LD and type of CP were collected using questionnaires. Drooling was found in 93 of 160 children with Cerebral Palsy (58 percent), with 53 (33 percent) having severe drooling.

In another study, Tahmassebi and Curzon (2003) further explored the causes of drooling in children with CP, trying to determine whether or not drooling in children with Cerebral Palsy is due to hypersalivation. The study included ten children with Cerebral Palsy who had been diagnosed with significant drooling, as well as a matched control group of ten children with no known physical or mental problems. The chin-cup collecting drool measurement method established by Sochanjwskyj was used to assess the salivary flow rate between cerebral palsied children and the control group. Based on statistical analysis, it was found that children with Cerebral Palsy who drool do not appear to produce excess saliva. Their salivation is similar to the control children.

Further research exploring cases and treatment approaches found that biofeedback training caused a significant decrease in drooling rates and a small increase in swallowing rates (Koheil et al., 1987). This did not surface in our data, teaching us not to assume anything in scientific researches.

Financial Issues

A recent study exploring several factors influencing the financial burden in the treatment of CP was consistent with our study. The socioeconomic status of the families with ongoing child treatment for CP was found as an important determinant factor, and the findings suggested that financial assistance should not be limited to low-income families, as many middle-income families also struggle financially to care for children with CP. (Ismail et al., 2022).

The literature review proved to be purposefully relevant in studying the associated difficulties in CP based on the analysis of the narratives of lived experiences in CP. It facilitated further exploration of the obtained themes from the qualitative enquiry, while at the same time reflecting a gap in the existing literature on CP.

While factors like physical difficulties due to the motor and postural problems, potential birth complications, acting as a predisposing factor in developing CP, and the alike are well-established facts of the neurodevelopmental disorder, there has been limited research on intricate areas identified as themes in the study such as irregularities in check ups and the crucial role of timely intervention in CP. The psychosocial problems faced by professionals dealing with patients and families with CP also encounter several difficulties in their professional careers as highlighted in the qualitative enquiry. A major aspect of it is psychological, covering a myriad of emotional challenges that need to be addressed and explored so that healthcare professionals are able to serve to the best of their potential.

Therefore, this study proposes that researchers use as much data collected as possible to capture the essence and complexity of neurobiological problems like CP. This innovative approach can reduce wastage of valuable data captured painstakingly.

Conclusion

The study holds significance in the utility of discarded data in contributing to relevant findings, suggestive of the fact that the qualitative data collected can always be relied upon for research and hardly gets thrown away. Based on the information obtained from qualitative interviews and thematic analysis, several themes highlight the clinical concerns and associated difficulties of CP, adding to the literature on CP.

Several clinical implications and future research perspectives can be drawn from this study. First, improved documentation of the difficulties associated with CP as facilitated by the study should be ascertained. Second, the information floating around ought to be captured in its totality, as much as feasible and an innovative approach is broached upon here. And third, along with the associated difficulties the study largely highlighted the psychological

and emotional burden of the disorder and the paucity of literature on these factors makes future research paramount to ensure increased awareness of CP and improved quality of life of the patients and families, aiding their difficulties.

Acknowledgment

Gratitude is extended to the families, patients, and healthcare professionals of the Barasat District Hospital who participated in this study. We thank Child Development Centre, Apollo Multispeciality Hospital, Kolkata for being a knowledge and practice clinical hub for interns and researchers.

References

Ismail, A., Sk Abd Razak, R., Suddin, L. S., Mahmud, A., Kamaralzaman, S., & Yusri, G. (2022). The Economic Burden and Determinant Factors of Parents/Caregivers of Children with Cerebral Palsy in Malaysia: A Mixed Methods Study. International Journal of Environmental Research and Public Health, 19(1), 475. https://doi.org/10.3390/ijerph19010475

Jenks, K. M., de Moor, J., & van Lieshout, E. C. (2009). Arithmetic difficulties in children with cerebral palsy are related to executive function and working memory. Journal of Child Psychology and Psychiatry, 50(7), 824–833. https://doi.org/10.1111/j.1469-7610.2008.02031.x

Koheil, R., Sochaniwskyj, A. E., Bablich, K., Kenny, D. J., & Milner, M. (1987). Biofeedback techniques and behaviour modification in the conservative remediation of drooling by children with Cerebral Palsy. Developmental Medicine & Child Neurology, 29(1), 19-26.

Reid, S. M., Meehan, E. M., Arnup, S. J., & Reddihough, D. S. (2018). Intellectual disability in Cerebral Palsy: a population-based retrospective study. Developmental Medicine & Child Neurology, 60(7), 687-694.

Romeo, D. M., Brogna, C., Musto, E., Baranello, G., Pagliano, E., Casalino, T., ... & Mercuri, E. (2014). Sleep disturbances in preschool age children with Cerebral Palsy: a questionnaire study. Sleep medicine, 15(9), 1089-1093.

Sullivan, P. B. (2013). Nutrition and growth in children with Cerebral Palsy: setting the scene. European journal of clinical nutrition, 67(2), S3-S4.

Tahmasebi, J. F., & Curzon, M. E. J. (2003). Prevalence of drooling in children with Cerebral Palsy attending special schools. Developmental medicine and child neurology, 45(9), 613-617.

Tahmasebi, J. F., & Curzon, M. E. J. (2003). The cause of drooling in children with Cerebral Palsy–hypersalivation or swallowing defect?. International Journal of Paediatric Dentistry, 13(2), 106-111.

Wasnik, M., Chandak, S., Kumar, S., George, M., Gahold, N., & Bhattad, D. (2020). Dental management of children with Cerebral Palsy-a review. Journal of Oral Research and Review, 12(1), 52.

Wright, A. J., Fletcher, O., Scrutton, D., & Baird, G. (2016). Bladder and bowel continence in bilateral Cerebral Palsy: A population study. Journal of pediatric urology, 12(6), 383-e1.

A Training Module on Accident Prevention for Parents of Children with Cerebral Palsy


DR. ARUNITA CHAKRABORTY[1]

DR. AISHEE GHOSH[2]

DR. SHALINEE SARKAR[3]

DR. ANJAN BHATTACHARYA[4]


Abstract:

Introduction: Cerebral Palsy (CP) affects the potential for movement and maintaining balance and posture in an individual. Accidents can be defined as any casual event that results from a group of factors that make its occurrence often predictable by determining a recognizable injury. Children with cerebral palsy tend to have more issues with falls due to imbalance and non-voluntary movements than teens and children with other disorders. In this study, impact of a structured Parent Training Program is tested to see its preventative potential. Patients and methods: The data was collected via semi-structured interviews with parents of children suffering from Cerebral Palsy. They were asked to state the difficulties that they face, in caring for their child and preventing them from engaging in accidents while performing activities of daily living. Based on their answers and a review of the rate of accidents, impact of a standard training module has been tested to see, if it can prevent incidences of accidents related to cerebral palsy. Results: This section states the preventive techniques demonstrated in this model of training and parents have been made aware of these through psycho-education. The module was designed to help children have fewer injuries, both physically and psychologically. Physical injuries can result from continuous falling, whereas psychological issues can result from constant rebukes from parents, bullying from peers, or social judgement. The accident prevention model, therefore, was based on the concept of prevention. Prevention can be divided into two-time frames- taking preventive measures during pregnancy and taking precautionary methods after the child is born. Measures can be taken to prevent both congenital and acquired Cerebral Palsy, but more options seem to be effective in curtailing acquired cases. Conclusions: This model can be considered as a preventive technique measure in

1 *Psychologist, Child Development Centre, Apollo Multispeciality Hospital, Kolkata*

2 *Undergraduate Student, Department of Psychology, Amity University Kolkata*

3 *Student, M.Sc in clinical psychology*

4 *Consultant Developmental Paediatrician and Head, Child Development Centre, Apollo Multispeciality Hospital, Kolkata*

dealing with accidents of children suffering from cerebral palsy.

Keywords: Cerebral Palsy, Accident, Psycho-education, Preventive Techniques, Parenting Training

Introduction:

Cerebral Palsy (CP) affects the potential for movement and maintaining balance and posture in an individual, and is the most common motor disability in childhood.

Accidents can be defined as any casual event that results from a group of factors that make its occurrence largely predictable by determining a recognizable injury. Accidents are among the leading, but preventable causes of death, and injury affecting children and adolescents with cerebral palsy. According to the National Institutes of Health (NIH), children with cerebral palsy tend to have more issues with falls due to imbalance and non-voluntary movements than teens and children with other disorders.

Patients and Methods:

The data was collected via semi-structured interviews with parents of children suffering from Cerebral Palsy. They were asked to state the difficulties that they faced till date before a standard structured Parent Training Program was imparted. Additional information was collected on their difficulties in caring for their child and preventing them from engaging in accidents while performing activities of daily living. Based on their answers and a review of the rate of accidents, the modular training was given to parents to prevent accidents related to cerebral palsy. It is a part of the Program of Care (PoC) which is a systematic procedure of providing psycho-education to the parents at the outset of any intervention at our centre. This psycho-education model focuses on educating the parents about the different aspects of dealing with children with special needs, like language management, behaviour management, sleep, eating and nutrition, accident prevention, screen time, physical challenges, vision, etc. After the training sessions, parents were also asked about their understanding of accident prevention and how it was going to help their child lead a better life. The rates of accidents were reviewed one month after the training to see if there was any reduction.

Results:

The training module seem to have successfully stated prevented incidences of accidents of children with cerebral palsy. It has been noticed that by applying the techniques of this module, accidents from instances of falling, burning, shoulder dislocations, and getting cuts or bruises have been prevented in several children. Over the years from 2016 May till 2022 May, these techniques have eliminated such risks for over 276 children, which has prompted us to formulate a compulsory training module for all parents of children with special needs. Moreover, we found that dealing with their treatment complexities also improved through this training before starting any diagnosis or treatment.

A table has been given below which roughly estimates the percentage of cases of each accident and the success rate of implementation of these techniques:

Physical Injury Prevention

Physical Injury Prevention

Type of Accident	Prevalent Rate (in percentage) Before training	Prevalent Rate (in percentage) One month after training	Prevalent Rate Reduction (in percentage)
Accidental Falls	80	10	87.5
Bruises	54	3	51
Burning	1	0	100
Shoulder dislocation	20	0	100

Psychosocial Injury Prevention

Physical injuries can result from continuous falling, whereas psychological issues can result from constant rebukes from parents, bullying from peers, or social judgement.

Type of Accident	Prevalent Rate (in percentage) Before training	Prevalent Rate (in percentage) One month after training	Prevalent Rate Reduction (in percentage)
Constant rebukes from parents	90	1	99
Bullying from peers	18	3	83
Social judgement	7	0	100

Discussion

This section states the preventive potential through psycho-education. The importance of screening tests and genetic counselling have also been highlighted through this model. The effect of accidental falls in the first few years of life on acquired Cerebral Palsy alone is remarkable.

The goal of psycho-educating the parents is to make them aware of their child's issues as well as their abilities. It ensures that parents have the basic knowledge regarding the disorder and the process of dealing with their child effectively. Parent psycho-education intervention can decrease stress and lead to parent empowerment. The module was designed to help children have fewer injuries, both physically and psychologically. Physical injuries can result from continuous falling, whereas psychological issues can result from constant rebukes from parents, bullying from peers, or social judgement. The accident prevention model, therefore, was based on the concept of prevention, rather than cure. Prevention can be divided into two time frames: i) taking preventive measures during pregnancy and ii) taking precautionary methods after the child is born. Measures can be taken to prevent both congenital and acquired Cerebral Palsy, but more options seem to be effective in curtailing acquired cases.

If a baby is suffering from cerebral palsy, then early intervention is extremely crucial for their proper treatment, which in turn, would enable the child to have more chances of leading an independent life. Parental psychoeducation might have untold benefits in subsequent pregnancies or in pregnancies in close family members, which we could not even measure.

Although Cerebral Palsy results from foetal development and in about 30% cases from complications during pregnancy and delivery, this condition can also be caused by head injuries due to motor accidents, falls, drowning, or shaken baby syndrome, during early childhood as acquired CP. To avoid such accidents, parents should adopt Accident Prevention measures. Few examples include securing their child using the appropriate car seat for their height and weight. This will eliminate any possibility of a child slipping through their seat in the case of an accident. While riding a bike, skateboard, motorcycle, etc, children should always wear protective helmets to avoid a risk of brain damage. Parents should never leave their children unattended while in a pool or bathtub, as they are at risk of drowning. Additionally, parents should never shake their baby, as there are cases of CP related to the shaken baby syndrome. Often when children are learning to walk, they tend to fall after a few steps, this can often lead to brain injury. To avoid such falls, parents need to keep the child under supervision and should have items like pillows and carpets in places where the child tends to practice walking.

Accidents can be prevented by actively and positively supervising the child by knowing their abilities, establishing clear and simple safety rules, being aware of potential hazards involved, and focusing on the positives rather than the negatives. Making safe space arrangements, by demarcating the space for play and arranging the sleeping area cautiously can prevent accidents. It is important that the indoor setting is child-friendly. This can be achieved by keeping the furniture in good repair and free of sharp edges, storing heavy objects on lower shelves, and ensuring the area is clear of toys or other items that might pose a tripping hazard. Wheelchair-related injuries can also be avoided by proper parental supervision.

Parents were also advised to not engage in unnecessary rebuke or taunts toward the child. Instances of physical punishment should also be eliminated. Parents should protect their child from bullies. If such instances occur, immediate actions should be taken, as these instances have a deep impact on the psychological well-being of the child.

We are encouraged by our preventative effectivity and therefore, our accumulated data over last 7 to 8 years have empowered us to empower parents, which we advocate for all and sundry.

Conclusion

This model can be considered as a preventive technique measure in dealing with accidents of children suffering from cerebral palsy. However, this model is in its pilot stage and further research should be conducted to understand the effectiveness of this model in a more detailed manner and to develop new techniques to eliminate any shortcomings of this model.

References:

Renee Warmbrodt. May 02, 2022. Cerebral Palsy and Falling Issues

Poonam Sachdev. September 29, 2021. What Is Cerebral Palsy?

Mohammed M. S. Jan. Mar-Apr 2006. Cerebral Palsy: Comprehensive Review and Update

Kristin Proctor. (n.d.). Cerebral palsy prevention

Suravi Patra, Priti Arun, and Bir Singh Chavan. Oct-Dec 2015. Impact of psychoeducation intervention module on parents of children with autism spectrum disorders: A preliminary study.

Visual Function Classification System in Cerebral Palsy

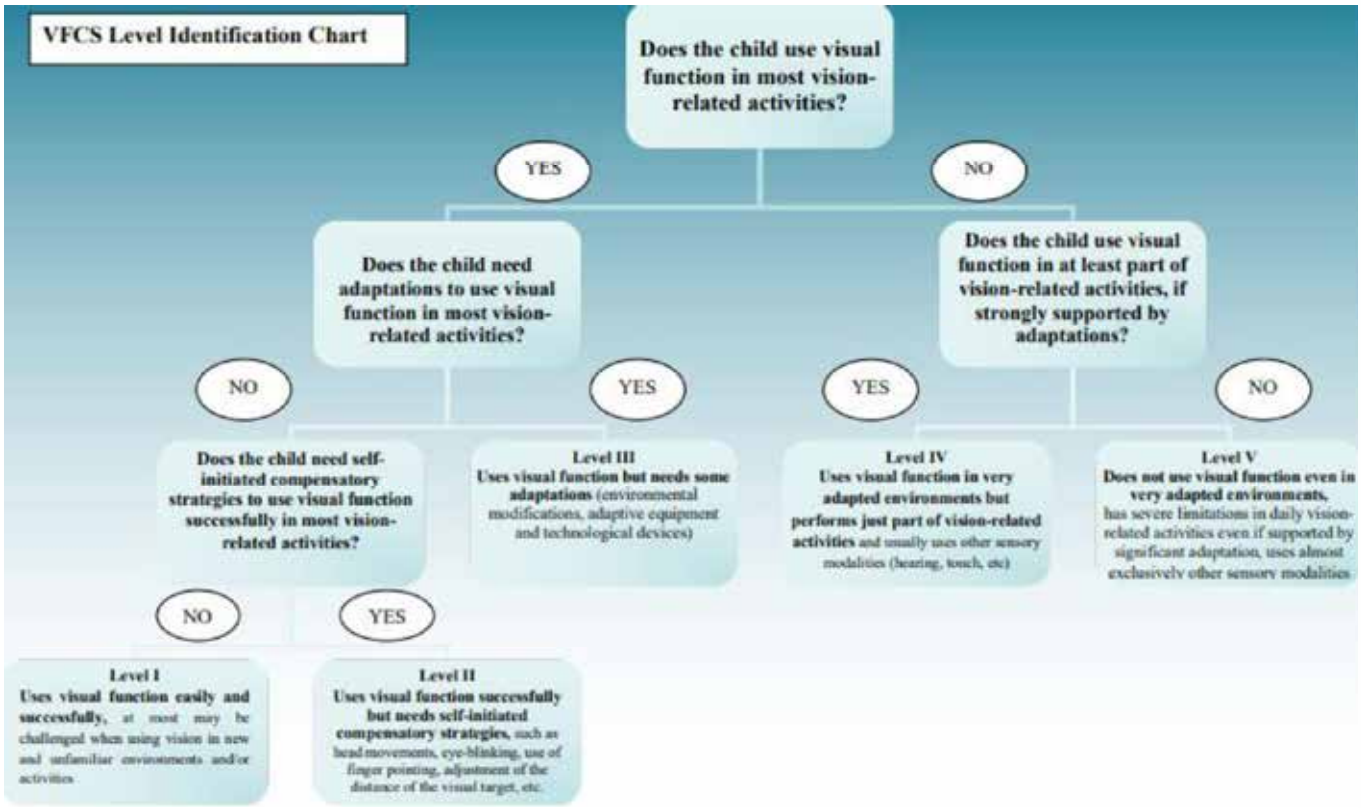
DR DEEPIKA JAIN
Shishu Child Development & Early Intervention Centre
Ahmedabad

Introduction: Cerebral Palsy (CP), according to current definition is a "group of permanent, but not unchanging, disorders of movement and/ or posture and of motor function, which are due to a non-progressive interference lesion, or abnormality of the developing/ immature brain". Although it is a motor disorder, it is frequently accompanied by co-morbidities such as: epilepsies, intellectual disabilities, gastrointestinal disorders, visual impairments, behavioural disorders etc[1] Visual impairments either Ocular Visual Impairment (strabismus, hyperopia) or Cerebral Visual Impairment (damage to visual pathway, cerebral cortex) are frequently associated with CP (50-90%). Over the years, Visual Pathway assessment (Visual Evoked Potential) and MRI scans to see cortical impairment has been an integral part of CP assessments to assess "visual function". In 2001 WHO endorsed the ICF (International classification of functioning, disability and health) model which conceptualizes "level of functioning as s dynamic interaction between person's health conditions, environmental conditions and personal factors" and focuses on "activity and participation"2] The Visual Function Classification System (VFCS) has been developed by Pisa SMILE Lab- Dr Bennett and team, as a 5-level classification system, on ICF model to describe how children with CP use their visual abilities in their daily environment [3.4.5]

Visual Function Classification System (VFCS): levels [3.4]
Visual function classification. SMILE Lab. (n.d.). https://www.pisasmilelab.it/vfcs

Level 1	**Uses visual function easily and successfully in vision related activities** At most, children in Level I may be challenged when using their vision in unfamiliar and/or crowded environments and/or new activities, but they do not consistently need compensatory strategies or adaptations.
Level 2	**Uses visual function successfully but needs self-initiated compensatory strategies.** Children in Level II consistently need self-initiated compensatory strategies to perform vision-related activities. They may avoid or rush through some activities requiring visual skills; however, their visual difficulties do not restrict or only mildly restrict their independence in daily life.
Level 3	**Uses visual function but needs some adaptations.** Children in Level III need, in addition to self-initiated compensatory strategies, some adaptations to consistently use vision functionally and perform most vision-related activities in daily life. Adaptations include any modifications made to the visual environment, and the use of adaptive equipment and/or technological devices in order to enhance visual function.
Level 4	**Uses visual function in very adapted environments but performs just part of vision-related activities.** Children in Level IV can use vision when significantly supported through adaptations, however their use of vision is inconsistent, they perform part of vision-related activities, and they often use other sensory modalities to help initiate and maintain visual function.
Level 5	**Does not use visual function even in very adapted environments.** Children in Level V have severe limitations in daily vision-related activities even when supported by significant adaptations; they use almost exclusively other sensory modalities (hearing, touch, etc)

Visual Function Classification System (VFCS): Parameters [3.4] As per the guidelines given by the developers, VFCS is not an assessment tool. It doesn't give cause for impairment in visual function. It describes what child can perform and focuses on abilities. Lower the level, better is the functioning. Corrective spectacles are worn to calculate the level. It can be scored by parent, child himself or herself, therapists or doctors. Overall, VFCS is a classification system to test use of "visual function" in daily life.



Visual function classification. SMILE Lab. (n.d.). https://www.pisasmilelab.it/vfcs

References:

1. Sadowska M, Sarecka-Hujar B, Kopyta I. Cerebral Palsy: Current Opinions on Definition, Epidemiology, Risk Factors, Classification and Treatment Options. Neuropsychiatr Dis Treat. 2020;16:1505-1518. Published 2020 Jun 12. doi:10.2147/NDT.S235165 2. Alford, V. M., Remedios, L. J., Webb, G. R., & Ewen, S. (2013). The use of the international classification of functioning, disability and health (ICF) in indigenous healthcare: a systematic literature review. International journal for equity in health, 12, 32. https://doi.org/10.1186/1475-9276-12-32

3. Visual function classification. SMILE Lab. (n.d.). https://www.pisasmilelab.it/vfcs 4. Baranello, Giovanni et al. "Visual Function Classification System for children with cerebral palsy: development and validation." Developmental medicine and child neurology vol. 62,1 (2020): 104-110. doi:10.1111/dmcn.14270 5. Peter Rosenbaum, Visual Function Classification System for children with cerebral palsy: development of a new tool, Developmental Medicine & Child Neurology, 10.1111/dmcn.14279, 62, 1, (14-14), (2019).

Role of Botulinum Toxin in Cerebral Palsy

PROF. DR P A M KUNJU
MD(Ped) DM(Neuro), WHO Fellowship Ped Neuro (USA), FIAP
Consultant, KIMS Health, Trivandrum

DR. ANITHA VIJAYAN, DR. ANJITHA MALLASSERRY
Neuro-Development Fellowship Residents
Child Development Centre, Trivandrum

When is botulinum toxin (BTX) appropriate for cerebral palsy

Major Problems in spastic cerebral palsy

- Muscle under tension does not grow

- Bone continues to grow

- Relative muscle shortening occurs, and thus fibrosis ensues. So if treatment for CP is limited to physiotherapy alone dynamic contractures progress to fixed contractures and skeletal deformities. During the dynamic spastic stage injections of botulinum toxin type A (BTX) will be helpful.

Botulinum toxin is basically a neurotoxin produced by the bacteria clostridium botulinum a gram positive anaerobic bacterium . Botulinum toxin acts by binding on the presynaptic to high affinity recognition sites on the cholinergic nerve terminals and decreases the acetyl choline release causing a neuromuscular blocking effect .Botulinum toxin when injected into the spastic muscle leads to reduction of increased tone and provides a time frame to the therapist to strengthen the antagonist muscle. Because of rapid and high-affinity binding to receptors at the neuromuscular junction of the target muscle, little systemic spread of toxin occurs. However, it is important to note that some systemic spread occurs following every injection and this can also can be useful like the remote effects like reduction of drooling of saliva.

Role of BTX in lower limb spasticity

3 Major primary complaints in cp in lower limbs where BTX is useful are described below:

The three primary complaints we encounter in children with lower extremities affected by CP include (a) toe walking (excessive ankle-plantar flexion), (b) crouched gait (dynamic knee contracture with excessive knee flexion, and (c) scissoring (excessive adductor tone)

Toe Walking

Although children who manifest toe walking generally have excessive plantar flexion tone, hamstring tone also can contribute to the condition.

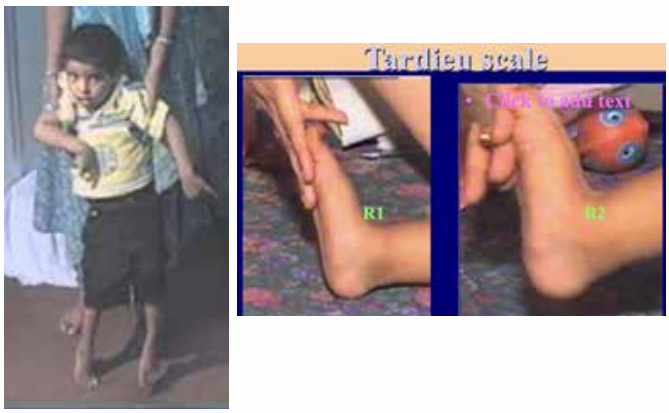


Figure 1 Tardieu Scale assessment for Equinus

The selection of the muscle groups to be injected is somewhat empirical, and we use modified Tardieu Scale results and our assessment of the gait pattern to guide our selection.

We try to distinguish spasticity from dystonia, although they commonly coexist.

We consider children with excessive plantar flexion who demonstrate normal range of movements (ROM) and mild spasticity (modified Ashworth Scale Score 1, modified Tardieu Scale R2 . 10°) to have hypertonicity primarily due to dystonia. These children typically receive sufficient benefit from BTX and physical therapy.

Children with more prominent spasticity (modified Ashworth Scale Scores 2-4, modified Tardieu Scale R2, 10°) may receive orthotic devices in addition to BTX.

Although we routinely evaluate patients' conditions by using both the modified Ashworth Scale and the modified Tardieu Scale, we prefer using the latter for the basis of treatment decisions because the test-retest reliability is significantly higher.

Measurements for the modified Tardieu Scale are obtained in both the knee flexed (soleus) and knee extended (gastrocnemius) positions by using a handheld goniometer with the patient lying prone.

In general, measurements taken in the knee-extended position dictate the treatment plan. If the R2 on the modified Tardieu scale fails to reach neutral (R2 , 0°), the child is referred for serial casting after BTX therapy.

Crouched Gait

Patients who present with dynamic knee contracture usually have a crouched gait, although not all such children are ambulatory.

Like children who exhibit toe walking, children who have hypertonicity primarily caused by dystonia are also treated with BTX and physical therapy.

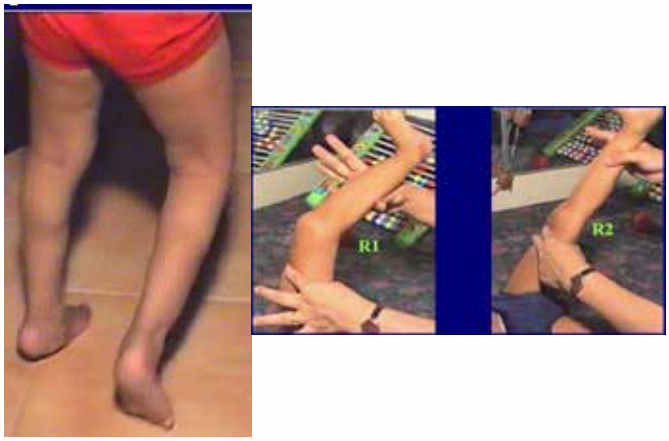


Figure 3 crouched gait;
Tardieu Scale assessment for hamstring spasm

On the basis of modified Tardieu Scale criteria, the condition of patients for whom the majority of their hypertonicity is secondary to spasticity is classified into mild, moderate, or severe categories.

Modified Tardieu Scale measurements are obtained with a handheld goniometer while the child lies supine with the hip flexed at 90° (90/90 position), and then the leg is fully extended (terminal knee extension).

In the 90/90 position, the knee is extended to R1 (first catch) and R2 (end range). Patients who have mildly increased tone (modified Tardieu Scale R2 . -25) are treated with physical therapy and knee immobilizers.

Patients who have moderately increased tone (modified Tardieu Scale R2 -25 to -40) are considered candidates for BTA injections, knee immobilizers, and physical therapy.

Patients who have severely increased tone (modified Tardieu Scale R2 , -40) who are unable to reach a neutral position (R2 , 0) in terminal knee extension are referred for splints in addition to BTX and physical therapy.

Scissoring

In patients who experience scissoring (excessive adductor tone), hypertonicity is categorized according to the clinician's interpretation of movements.

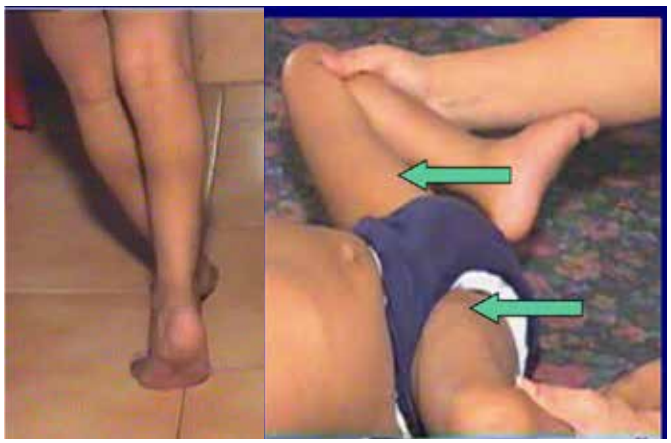


Figure 4 injection sites for adductors

Patients who have prominent dystonia (nearly normal ROM on the modified Tardieu Scale) are treated with BTA and physical therapy.

Patients primarily demonstrating spasticity (reduced ROM as shown by modified Tardieu Scale) are divided into categories of mild, moderate, or severe on the basis of modified Tardieu Scale criteria.

Each child's adductor ROM is measured using a handheld goniometer while the patient lies supine with the knee flexed and then extended.

Patients suffering from moderate or severe spasticity are considered candidates for adductor BTA injection and physical therapy in addition to orthotic interventions.

Patients experiencing moderately increased tone and hip dislocation and all patients who have severely increased tone receive Ultraflex splints, physical therapy, and BTA injections.

Adductor muscles are injected starting approximately 1 to 2 cm below the pubis symphysis and extending about two thirds of the distance along a line drawn to the medial epicondyle.

The initial dose is BTX at 5 to 10 U/kg of body weight in each extremity, with a maximum total dose of 20 U/kg.

The BTX is diluted into 2 ml preservative-free normal saline for these injections, and no more than 50 U is injected at each site. Just as with those who have crouched gait, children with a good response receive injections every 3 to 6 months. Patients who fail to respond are referred for possible surgical intervention.

Parents Role

Motivated parents can assist in maximizing BTX outcomes. They must be involved in the decision making process, by understanding what the team is attempting to achieve. Parents can assist by communicating changes to the caring team

Summary of role of BTX in CP

Calf muscle BTX injection given for dynamic equinus

Hamstring injection for crouch gait

Injection of adductors and hamstrings in severely involved children to improve seating.

Also, for specific muscles of focal limb dystonia

Correct patient selection, correct target muscle selection, continued adjunctive treatments and fixing definitive goals is the major step in usage of BTX in CP.

Orthopaedic Surgery In Cerebral Palsy - An Outline

DR C CHERIYAN KOVOOR D.Orth, DNB[Orth]
Fellow Limb lengthening and reconstruction [Lecco, Italy]
Consultant, Division of Paediatric Orthopaedics & Limb Reconstruction
Aster Medcity, Kochi

In cerebral palsy orthopaedic surgery plays an important part in the rehabilitation of the child but it must be remembered by all concerned it is another cog in the overall management wheel OF treatment. It is absolutely important to remember the dictum by all concerned "decision is more important than the incision".

The parameter that is to be taken into account considering surgery in cerebral palsy is the Gross Motor Function classification system [GMFCS] level. Levels 1-3 are ambulant patients and 4-5 are non-ambulatory patients. It would be unrealistic to expect a level 4or 5 patients to progress to level 3 or above by doing orthopaedic surgery, in fact a wrong surgery can convert an ambulant patient to a non-ambulant one.

The aims of orthopaedic surgery in ambulatory patients include improve gait, diminish energy expenditure and reduce support while in non-ambulant children is to facilitate toilet care, improve sitting balance and reduce pain due to hip dislocation. It is of utmost importance to see that a patient does not drop down to the next GMFCS level,

Various types of orthopaedic surgical treatments which can be offered to patients are:

1. Muscle tendon surgeries- include muscle and tendon lengthening, tenotomies [cutting a tendon] and tendon transfers. These surgeries weaken spastic and shortened muscles and balance muscle power. These are mostly done inn lower limbs around foot and ankle , knee, occasionally hips. Such surgeries in upper limbs must be more judiciously done
2. Osteotomies- cutting and re aligning the bones are done to correct bony and joint deformities
3. Joint fusions especially triple fusions are quite commonly done in the foot to correct deformities. Occasionally they are done in the upper limb mainly wrist joint to improve function.
4. Spinal surgeries include spine fusions and scoliosis corrections

The age at which these surgeries are performed vary from patient to patient, in general soft tissue surgeries are performed between 4-6 years of age, bony procedures around puberty. In

certain cases, these may have to be done earlier such as during hip instability, severe femoral anteversion and for bone and joint deformities interfering with function.

Post operative management includes pain relief by means of oral or epidural analgesics and care of the wound and immobilization splints. Adequate provision must be made for perineal care and hygiene. After the period of immobilization is over it must be kept in mind by parents and the treating personal that improvement occurs over a period of time with regular physiotherapy by the therapist and parents ,use of splints to prevent recurrence .

In summary orthopaedic surgery in cerebral palsy should be carefully tailored to patient taking into consideration age, type of cerebral palsy, GMFCS level. It must be understood orthopaedic surgery doesn't treat the cerebral palsy but only improves function. Also, parents and care givers must realize that long term follow up is mandatory for all patients

Genetics of Cerebral Palsy

DR. UPASANA MUKHERJEE
Sr. Genetic Counselor, Child Development Centre,
Apollo Multispecialty Hospital, Kolkata

DR. ANJAN BHATTACHARYA
Consultant Developmental Paediatrician and Head
Child Development Centre, Apollo Multispecialty Hospital, Kolkata

Introduction

Cerebral palsy (CP) is a complex heterogeneous neurodevelopmental disorder characterized by a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to nonprogressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior, by epilepsy, and by secondary musculoskeletal problems. The worldwide incidence of CP is approximately 2 to 2.5 cases per 1000 live births. [1] In India, it is estimated at around 3 cases per 1000 live births; however, being a developing country the actual figure may be much higher than probable figures.

Patients with CP are often classified clinically into spastic, hypotonic, dystonic (also called "dyskinetic"), ataxic, and mixed subgroups and by the limbs involved (diplegia, hemiplegia, or quadriplegia, and occasionally other patterns) [2,3]. Each of these clinical subgroups and patterns of involvement is also etiologically and genetically heterogeneous, and while certain major genetic forms of CP characteristically produce only one particular kind of involvement, the clinical presentation of other genetic forms of CP is variable.

Risk factors of Cerebral Palsy:

There are numerous risk factors that have been identified, but for many individuals identifying the etiology of CP is challenging. Risk factors of CP are often subdivided into groups based on timing: preconception (maternal), prenatal and postnatal (Table 1). A 2013 systematic review described the following postnatal risk factors as significantly associated with CP in term infants: neonatal respiratory distress syndrome, meconium aspiration, instrumental or emergency cesarean section, birth asphyxia, neonatal seizures, hypoglycemia, and neonatal infections [2]. Together these factors indicate that the pathophysiology of CP may result from a combination of genetic, environmental factors. Other CP risk factors, such as congenital anomalies or intrauterine growth restriction, may also reflect underlying genetic etiologies. Determination of genetic factors as the underlying cause of CP, has become a rapidly developing field.

Table 1
Risk factors for cerebral palsy

Maternal	Prenatal	Perinatal	Postnatal
• Epilepsy • Thyroid disease • Advanced maternal age • Low socioeconomic status • Smoking • Intellectual disability • History of premature delivery • History of multiple miscarriages	• Placental abnormalities • Poor fetal growth • Cardiac anomalies • Maternal disease during pregnancy (eg, diabetes, thyroid disease, epilepsy) • Poor prenatal care • High or low amniotic fluid level • Preeclampsia • TORCH infections • Chorioamnionitis • Twin gestation	• Prolonged delivery • Traumatic delivery • Breech presentation • Meconium • Fetal hypoxia • Low APGAR scores • Seizures • Infection • Low blood sugar • Jaundice	• Stroke • Abusive head trauma • Meningitis

Table 1: From DiCarlo S, Schwabe A. Cerebral palsy and static encephalopathies. In: KlineMW, editor. Rudolph's pediatrics. 23rd edition. New York: McGraw-Hill; 2018. p. 2672–5; with permission.

Genetics of Cerebral Palsy:

The diagnosis and classification of CP is mainly clinical. However there is considerable evidence that has been established as genetic factors for CP. The prevalence of congenital anomalies in children with CP is about 11% to 32%, significantly higher than the general population prevalence of 2% to 3%[3]. Hence it is important to determine the genetic etiology of CP to understand the neurogenetic routes of CP which in turn has potential to influence the patient's care. Human genome sequencing, including whole exome sequencing, X-chromosome exome sequencing, and chromosomal analysis in population studies, has led to the identification of various gene mutations that are linked to the development of CP, indicating that no single CP genes exist but that multiple genes are involved [4,5].

Numerous Mendelian disorders inherited as autosomal dominant, recessive, as well as X-linked can present with characteristics that are distinct to CP. Some of these conditions are rare as individual disorders, but others are not all that uncommon as a group and should be taken into account when assessing children with CP. Genome wide sequencing studies have identified a list of genes associated with CP and CP like disorders. Plausible genetic variants associated with CP can be grouped into several categories. Such as single gene mutations, candidate cerebral palsy genes and Copy no variations.

When to consider genetic testing?

In patients who present with a clinical picture concerning a diagnosis of cerebral palsy, thorough clinical history, family history and physical examination should be performed. Patients with significant birth history including birth asphyxia, neonatal jaundice, respiratory distress and/or with positive family history of similar phenotypic presentation, MRI findings (if done) suggestive of genetic etiology, should be offered genetic testing. Genetic counselors play a significant role of the multidisciplinary team to help obtain thorough histories and pedigrees as well as to provide families with both pretest and

posttest counseling of genetic tests.

Why consider genetic testing?

Genetic testing is indicated if there is the presence of other risk factors such as a suspicious family history for other affected family members, MRI findings inconsistent with the patient's clinical presentation, or the presence of other congenital anomalies. Making a genetic diagnosis helps a patient in the below following ways:

a. Find out possible treatment options: There are specific treatments available for conditions like inborn error metabolisms or dopa-responsive dystonia or restricted diet and ammonia scavenging agents for arginase deficiency. There are more specific treatments such as enzyme replacement therapy or gene therapy for disease like Spinal muscular atrophy.

b. Helps to understand prognosis: A genetic diagnosis can aid in guiding prognosis in conditions that were previously thought to be static but may be progressive; for example, a primary mitochondrial disorder or a disorder of brain iron accumulation.

c. Inheritance of the disease: Often clinical diagnosis fails to justify the inheritance of the disease. However genetic diagnosis provides an accurate information inheritance of the disease and helps the patient's family to identify the at risk members and to plan their future generation. It also helps to decide on reproductive technologies.

d. Provides closure: A diagnostic closure to a patient family helps them to better understand the disease. It prepares the family for needful management and encourages better care of their patient.

Genetic tests options:

Genetic variation results in gene function disruption leading to protein damage. Variations can occur either on a chromosomal level, such as with either microdeletions or microduplications on the chromosome, also known as copy number variants (CNVs), single nucleotide variants (SNVs), or repeat expansions. Microdeletions or microduplications have been reported in patients with diagnoses of cerebral palsy. Previous studies have reported between 10% and 12% detection rate of likely pathogenic CNV in patients with cerebral palsy [6]. Variations can also occur secondary to single DNA nucleotide variants (SNV) that can be detected with DNA sequencing methods, such as Sanger sequencing or next-generation sequencing (Table 2).

Discussion:

Cerebral palsy was once thought to be related to acquired brain injury, however the scope of the diagnosis of cerebral palsy has been broadening significantly in recent years to include patients with genetic disorders. There are more than 800 genetic conditions in the OMIM mendelian genetic database that include cerebral palsy as a part of the phenotype. This number is expected to increase further with the improved methods for expanding the knowledge of the cause of cerebral palsy with growth of fetal medicine and genetics. At present the focus is on genetic conditions that mimic cerebral palsy motor phenotypes; however, there is ongoing work to assist with possibly identifying susceptibility genes for acquired types of cerebral palsy in the future.

Genetic testing options

Genetic Test	Indications	Pros	Cons/Limitations
Karyotype	Specific dysmorphic features History of multiple miscarriages in mother	Trisomies including mosaicism Large chromosomal deletions Balanced chromosomal rearrangement, ring chromosomes	Does not detect microdeletions or microduplications
Chromosome microarray	Dysmorphic features Multiple congenital anomalies Associated developmental delay Nonspecific phenotype	Microdeletions and Microduplications SNP arrays: detect areas of homozygosity and uniparental disomy	Does not detect small deletions, duplications or insertions Does not detect balanced rearrangements or ring chromosomes if balanced, variants of unknown significance
Gene panel/single gene	Specific phenotypes	Better coverage than WES, may be able to detect mosaicism	Limited number of genes
WES	Nonspecific phenotype specific phenotype but possibility of gene discovery	Broad coverage of genes Medically actionable findings	Variants of unknown significance, incidental findings, does not detect CNVs or repeat expansions
WGS	Nonspecific phenotype specific phenotype but possibility of gene discovery	Detect single base variant (SNV), microdeletion and duplication, repeat expansions	Insurance coverage Variants of unknown significance, incidental findings
mtDNA	mtDNA-specific conditions	Specific to mtDNA genome	Heteroplasmic difference in blood and other tissues, variants of unknown significance
Repeat Expansion Panels: ataxia panel	Specific disorder	No variants of unknown significance	Limited number of genes if panel or single-gene testing

Table 2- Genetic testing options

References:

1. Report of the Australian Cerebral Palsy Register Birth years 1995–2012 (2018) Available online at: https://cpregister.com/wp-content/uploads/2019/02/Report-of-the-Australian-Cerebral-Palsy-Register-Birth-Years-1995-2012.pdf (accessed October 7, 2020).
2. A. Michael-Asalu, G. Taylor, H. Campbell, L.L. Lelea, R.S. Kirby Cerebral palsy: diagnosis, epidemiology, genetics, and clinical update Adv. Pediatr. Infect. Dis., 66 (2019), pp. 189-208,
3. M. Sadowska, B. Sarecka-Hujar, I. Kopyta Cerebral palsy: current opinions on definition, epidemiology, risk factors, classification and treatment options Neuropsychiatr. Dis. Treat., 16 (2020), pp. 1505-1518,
4. Fahey MC, Maclennan AH, Kretzschmar D, et al. The genetic basis of cerebral palsy. Dev Med Child Neurol 2017;59(5):462–9.
5. Schaefer GB. Genetics considerations in cerebral palsy. Semin Pediatr Neurol 2008;15(1): 21–6.
6. Friedman JM, van Essen P, van Karnebeek CDM. Cerebral palsy and related neuromotor disorders: Overview of genetic and genomic studies. Mol Genet Metab. 2021 Nov 8:S1096-7192(21)00819-2. doi: 10.1016/j.ymgme.2021.11.001. Epub ahead of print. PMID: 34872807.
7. Fahey MC, Maclennan AH, Kretzschmar D, et al. The genetic basis of cerebral palsy. Dev Med Child Neurol 2017;59(5):462–9.

Parental Perspectives of Environmental Factors Acting as Facilitators or Barriers in Cerebral Palsy, with reference to the International Classification of Functioning, Disability and Health (ICF)

DR. ARUNITA CHAKRABORTY[1]
DR. SHREYA GHOSH[2]
DR. PAULAMA MITRA[3]
DR. AISHEE GHOSH[4]
DR. JEWEL CHAKRABORTY[5]
DR. ANJAN BHATTACHARYA[6]

ABSTRACT:

Objective: To understand the parental perspective of environmental factors acting as facilitators or barriers in cerebral palsy, with reference to the International Classification of Functioning, Disability and Health (ICF). Patients and Methods: The search included qualitative studies and personal interviews taken by the researcher from parents of children with cerebral Palsy with informed consent. This study includes children age 8-18 years with a diagnosis of cerebral palsy with or without mobility restrictions. Multiple databases were searched for 'ICF', 'children', environmental', 'facilitators' and 'barriers' 'Cerebral Palsy'. Results: The study results supports the effect of environment including the immediate family the extended family, community support and service providers. The children with disabilities and their parents identified a range of barrier and facilitator factors. These included family pressures, school pressures, financial difficulties, and inadequate public services. This study also suggests that various personal and environmental factors play a key role in determining the extent to which children with CP are affected by these environmental factors. The facilitators and barriers identified provide important theoretical insights into the problems faced by the children and their parents. The identification of the focul role played by environmental factors has

1 *Psychologist, Child Development Centre, Apollo Multispecialty Hospital, Kolkata*
2 *Psychologist, Child Development Centre, Apollo Multispecialty Hospital, Kolkata*
3 *Intern, Child Development Centre, Apollo Multispecialty Hospital, Kolkata*
4 *Undergraduate Student, Department of Psychology, Amity University Kolkata*
5 *Consultant Paediatric Physiotherapist, Director, Nabajatak Child Development Centre, Salt Lake, Kolkata*
6 *Consultant Developmental Paediatrician and Head, Child Development Centre, Apollo Multispecialty Hospital, Kolkata*

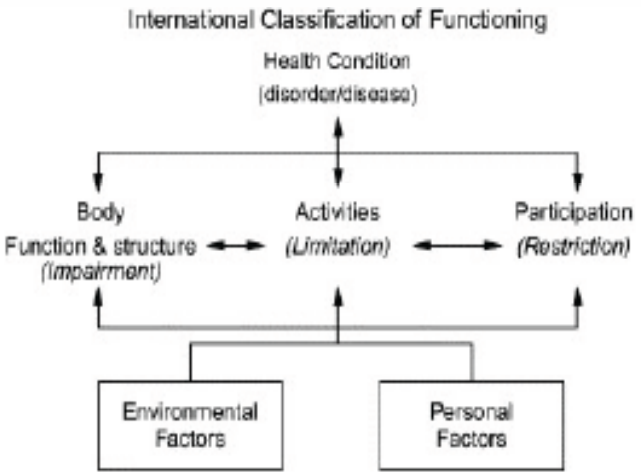
changed the locus of the problem and, hence, focus of intervention, from the individual to the environment in which the individual lives. Disability now is no longer understood as a feature of the individual, but rather as the outcome of an interaction of the person with a health condition and the environmental factors. Conclusion: The studies supported positive impact of environmental factors as facilitators on overall development. However, previous researches suggest that environmental factors can often act as barriers for such children.

Keywords-ICF, cerebral palsy, environmental factors, barriers, facilitators.

Introduction:

The International Classification of Functioning, Disability, and Health (ICF) is a framework for describing and organizing information on functioning and disability. It provides a standard language and a conceptual basis for defining and measuring health and disability. It can discover any possible pattern present in patients suffering from similar disorders. It allows professionals to get a holistic view of their patient's problems as it encompasses physical, psychological, social, and environmental factors. It is based on the biopsychosocial model which is an integration of medical and social models or synthesis of different perspectives of health, biological, individual, and social. According to ICF, disability, and health is an outcome of interactions between health conditions and contextual factors. ICF coding domains include body function, structures, activities, participation, and environment. Environmental factors which include natural environment and human-made changes to the environment, products and technology, services, systems, and policies, support, relationships, and attitudes, are coded as barriers and facilitators.

Cerebral Palsy (CP) affects the potential for movement and maintaining balance and posture in an individual. It is the most common motor disability in childhood. The words 'cerebral' is associated with the brain and 'palsy' means weakness or problems with using the muscles. Common causes of cerebral palsy include, Bacterial and viral infections such as meningitis, Bleeding in the brain, Head injuries sustained during birth or within the first few years of infancy, etc. Cerebral palsy is broken down into different types to help describe how brain damage affects motor skills. Each type of cerebral palsy is categorized by the type of movement issues and body parts affected. The types are Spastic, Mixed, Athetoid, Hypotonic, and Ataxic. Children, suffering from cerebral palsy have copious physical and neurological problems. The issues vary for each child depending on the location and severity of brain damage. Symptoms are contractures, drooling, exaggerated or jerky reflexes, floppy muscle tone, gastrointestinal problems, incontinence, involuntary movements or tremors, lack of coordination and balance, problems swallowing or sucking, problems with movement on one side of the body, stiff muscles, behavioural problems, delayed motor skill development, difficulty with speech and language.



Patients and Methods:

Patients and Methods:

For the present study, the data was collected from 10 parents of children with cerebral palsy. They were interviewed at the Barasat District Hospital. The parents of children aged between 8-18 years were included in this study. Consent was taken at the preliminary stages. The interviews were audio recorded and later utilized for drawing conclusions.

Results:

From the data, the Environmental factors such as the physical, social and attitudinal environment in which people live and conduct their lives were observed. both the Natural environment and human-made changes to the environment affected an individual's functioning. Support and relationships and attitudes acted as facilitators of the person's functioning. Functioning is an umbrella term used here for body function, body structures, activities, and participation. Family forms the core environment of the child and therefore family factors affect the child's functioning.


ICF e.jpg

An example shown on Environmental Factor of ICF Core Set CP (Patient No. 6 in Table)

It was seen that environmental noise in public places and loud voices topped the list of factors hindering the children. The participants valued support from family, friends, and community members and see practical assistance as a means to improve participation while a lack of assistance created severe barriers to participation. Similarly, health care service providers were seen as a source of support that assisted the facilitation of participation by some since they provided the necessary support needed whereas it acted as a barrier to participation by others. Friendship played a pivotal role in dealing with their disability.

The following Table 1 brings out the spread of this rainbow, capturing evidence of increasing support for children with disability in our society including legal support, which is tabulated at the next Table 2:

Conclusion:

Reconceptualizing the environmental factors component supports a more holistic interpretation of it as both facilitator and barrier. In doing so, it strengthens the ICF's utility in identifying and measuring health-facilitating natural environmental factors. According to ICF, integral parts of the environment are the physical environment and societal attitudes, and it is clear that certain factors such as economy, policies, and social norms will vary tremendously across different countries and cultures. So, environmental factors may differ in the impact of hindrance or facilitation on a patient's daily functioning, especially for those with lifelong disabling conditions such as cerebral palsy. The sample size was small, hence the general applicability of the results may not be feasible.

References:

1 Ridga,Dan.The causes and classification of the cerebral palsies." The lancet neurology 11.3 (2012): 283-292.

2 Kent, Athol. "Cerebral Palsy and Genetic Predisposition." Reviews in Obstetrics and Moreno-De-Luca, Andres, David H. Ledbetter, and Christa L. Martin. "Genetic insights into Gynecology 1.3(2008): 148.

3 Wynia K,, Middel B,, van Dijk JP,, De Keyser JHA,, Reijneveld SA. The impact of disabilities on quality of life in people with multiple sclerosis. Mult Scler. 2008

4 Benito-León J,, Morales J,, Rivera-Navarro J,, Mitchell A. A review about the impact of multiple sclerosis on health-related quality of life. Disabil Rehabil. 2003

5 McDonald WI,, Compston A,, Edan G, Recommended diagnostic criteria for multiple sclerosis: guidelines from the International Panel on the Diagnosis of Multiple Sclerosis. Ann Neurol. 2001

Table 1

P1			P2			P3			P4			P5			P6			P7			P8			P9			P10		
E	F	B	E	F	B	E	F	B	E	F	B	E	F	B	E	F	B	E	F	B	E	F	B	E	F	B	E	F	B
e110	+1	-	e110	-	-1	e110	+1	-	e110	-	-	e110	-	-	e110	+1	-	e110	-	-	e110	+1	-	e110	+1	-	e110	+1	-
e111	+1	-	e111	-	-1	e111	+1	-	e111	-	-	e111	-	-	e111	-	-	e111	-	-	e111	+1	-	e111	+1	-	e111	+1	-
e112	+1	-	e112	-	-	e112	+1	-	e112	-	-	e112	-	-	e112	-	-	e112	-	-	e112	-	-1	e112	+1	-	e112	0	0
e113	+1	0	e113	-	-1	e113	+1	-	e113	0	0	e113	+1	-	e113	0	0	e113	+1	-	e113	-	1	e113	+1	-	e113	+1	-
e114	+1	-	e114	-	-1	e114	+1	-	e114	0	0	e114	+1	-	e114	+1	-	e114	+1	-	e114	+1	-	e114	+1	-	e114	+1	-
e115	+1	-	e115	-	-1	e115	+1	-	e115	+1	-	e115	+1	-	e115	-	-1	e115	+1	-	e115	0	0	e115	+1	-	e115	+1	-
e116	-1	-1	e116	+1	-	e116	+1	-	e116	0	0	e116	+1	-	e116	-	-	e116	-1	-1	e116	-	-	e116	-	-1	e116	+1	-
e117	+1	-	e117	+1	-	e117	+1	-	e117	-	-1	e117		1	e117	+1	-	e117	-	-1	e117	+1	-	e117	+1	-	e117	-	1
e118	+1	-	e118	+1	-	e118	+1	-	e118	+1	-	e118	0	0	e118	+1	-	e118	-	-1	e118	+1	-	e118	+1	-	e118	+1	-
e119	+1	-	e119	+1	-	e119	-	-1	e119	+1	-	e119	+1	-	e119	+1	-	e119	+1	-	e119	0	0	e119	+1	-	e119	+1	-
e120	+1	-	e120	+1	-	e120	+1	-	e120	+1	-	e120	+1	-	e120	+1	-	e120	+1	-	e120	+1	-	e120	+1	-	e120	+1	-
e121	+1	-	e121	-	-1	e121	+1	-	e121	+1	-	e121	+1	-	e121	+1	-	e121	+1	-	e121	+1	-	e121	+1	-	e121	+1	-
e122	+1	-	e122	-	-1	e122	+1	-	e122	-	1	e122	+1	-	e122	+1	-	e122	-	1	e122	+1	-	e122	+1	-	e122	+1	-
e123	+1		e123	-	-1	e123	+1	-	e123	+1	-	e123	-	-1	e123	-	-1	e123	-	-1	e123	-	-1	e123	+1	-	e123	+1	-
e124	+1	-	e124	+1	-	e124	+1	-	e124	-	1	e124	+1	-	e124	+1	-	e124	-	1	e124	+1	-	e124	+1	-	e124	-	1
e125	+1	-	e125	+1	-	e125	-	-1	e125	+1	-	e125	0	0	e125	+1	-	e125	-	-1	e125	+1	-	e125	+1	-	e125	+1	-
e126	-	-1	e126	-	-	e126	+1	-	e126	-	-1	e126	-	-1	e126	-	-1	e126	-	-1	e126	-	-1	e126	-	-1	e126	-	-1
e127	-	-1	e127	-	-	e127	+1	-	e127	-	-1	e127	-	-1	e127	-	-1	e127	-	-1	e127	-	-1	e127	-	-1	e127	-	-1
e128	-	-	e128	0	0	e128	+1	-	e128	-	-	e128	0	0	e128	0	0	e128	0	0	e128	0	0	e128	+1	-	e128	+1	-
e129	-	-	e129	-	-	e129	+1	-	e129	-	-	e129	0	0	e129	0	0	e129	-	-1	e129	0	0	e129	-	-1	e129	-	-1
e130	-	-1	e130	+1	-	e130	+1	-	e130	+1	-	e130	-	-1	e130	-	-1	e130	-	-1	e130	-	-1	e130	-	-1	e130	-	-1
e131	-	-1	e131	+1	-	e131	+1	-	e131	+1	-	e131	-	1	e131	-	-1	e131	+1	-	e131	-	-1	e131	+1	-	e131	-	-1
e132	-	-	e132	-	-	e132	-	-	e132	-	-	e132	0	0	e132	0	0	e132	-	-	e132	0	0	e132	+1	-	e132	-	-

Total Facilitators										
14 (40)	9 (29)	19 (41)	8 (20)	8 (25)	9 (32)	6 (14)	9 (16)	18 (63)	14 (46)
Total Barriers									
5 (15)	9 (19)	2 (8)	5 (6)	5 (9)	6 (9)	10 (13)	6 (7)	4 (7)	7 (24)

E = Environmental Factors; F = Facilitators; B = Barriers Facilitators have (+) sign, Barriers have (-) Total Number (Total Scores)

Thus, the following themes could be summarized for applied purposes for each child as follows:

Table 2

Patients	Facilitation Theme	Barrier Theme
P1	Strongly supportive family and system support	Negative attitude of society despite of assistive devices
P2	Strongly supportive social, educational and authorities	Negative impact & attitude of immediate and extended family
P3	Supportive family, education, authority, legal and society	Extremely negative impact and attitude of Health Professional
P4	Supportive professionals and a little caring extended family	Lackadaisical immediate family, unaware of products
P5	Supportive education and family systems	Slightly difficult authority, family unaware of technogies
P6	Supportive Immediate Family with Products & Technologies	Extended Family; Lack of knowledge of Social Policies
P7	Supportive family, education services & professional others	Authority, Health Professional & Social
P8	Supportive immediate family and professionals with physical support and products	Poor support for education; poor social support including extended family
P9	Strongly supportive family, education and professionals Needed legal support for gainful employment	Indifferent or slightly negative social experiance including friends and societal support
P10	Strong family and social support to access legal services for educational access	Unreasonable barrier to education

ENVIRONMENTAL FACTORS		Facilitator Barrier								
		+4	+3	+2	+1	0	1	2	3	4
e110	Products or substances for personal consumption									
e115	Products and technology for personal use in daily living					9				
e125	Products and technology for communication					9				
e130	Products and technology for education									
e310	Immediate family									
e315	Extended family									
e325	Acquaintances, peers, colleagues, neighbours and community members					9				
e330	People in positions of authority									
e340	Personal care providers and personal assistants									
e355	Health professionals									
e360	Other professionals									
e410	Individual attitudes of immediate family members									
e415	Individual attitudes of extended family members									
e430	Individual attitudes of people in positions of authority									
e450	Individual attitudes of health professionals									
e460	Societal attitudes									
e465	Social norms, practices and ideologies									
e550	Legal services, systems and policies									
e570	Social security services, systems and policies									
e575	General social support services, systems and policies									
e585	Education and training services, systems and policies									
e590	Labour and employment services, systems and policies									

6 Khan F,, Turner-Stokes L,, Ng L,, Kilpatrick T. Multidisciplinary rehabilitation for adults with multiple sclerosis. Postgrad Med J. 2008

7 Oskoui M, Coutinho F, Dykeman J, et al. (2013) An update on the prevalence of cerebral palsy: a systematic review and meta-analysis. Developmental Medicine and Child Neurology 55(6): 509–519.

8 Pashmdarfard M and Amini M (2017) The relationship between the parent report of gross motor function of children with cerebralpalsy and their participation in activities of daily livings. Journal of Modern Rehabilitation 11(2): 93–102

9 Pashmdarfard M and Amini M (2017) The relationship between the parent report of gross motor function of children with cerebral palsy and their participation in activities of daily livings. Journal of Modern Rehabilitation 11(2): 93–102.

Assistive Technology and Devices for Habilitation and Early Intervention of Children with Cerebral Palsy

DR. SINDHU VIJAYAKUMAR
MD, DNB, Certified Assistive Technology Professional
Associate Professor, Dept. of Physical Medicine and Rehabilitation (PMR)
Amala Institute of Medical Sciences, Amalanagar, Thrissur

Rehabilitation (or Habilitation in case of children) is defined as "a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment". Put simply, rehabilitation helps a child, adult or older person to be as independent as possible in everyday activities and enables participation in education, work, recreation and meaningful life roles. It does so by addressing underlying conditions and improving the way an individual functions in everyday life, supporting them to overcome difficulties with thinking, seeing, hearing, communicating, eating or moving around.

Early interventions are the educational and neuro-protection strategies aimed at brain development. It nurtures the developing brain early on when neuroplasticity or the capacity of brain to form more interconnecting neurons, neural networks and synapses, and pruning happens in response to outward stimuli. Early Intervention is the most important aspect in Habilitation of children with Cerebral Palsy. As it is a non-progressive disorder, habilitation efforts and appropriate interventions in all domains of neurological development should be initiated in all high-risk babies. The goal is to achieve age-appropriate developmental milestones in all domains and avoid any likely anticipated delays. A dedicated trans-disciplinary team [including Developmental Paediatrician, Physical Medicine and Rehabilitation (PMR) specialist, also known as Physiatrist, Paediatric Neurologist, Paediatric Orthopaedic Surgeon, Paediatric Ophthalmologist, Paediatric ENT Surgeon, Developmental therapist, Physiotherapist, Occupational Therapist, Audiologist and Speech Language Pathologist (ASLP), Prosthetist-Orthotist, Pscyhologist, Dietician, Assistive Technology Professional along with Medical Social Worker and/or Care Coordinator] is able to make children with mild to moderate delay achieve all domains of development well before the school-going age. Thus the key for early intervention is to prevent any delays, rather than waiting to confirm any developmental delay to start before intervening.

In cerebral palsy, the most common motor disability of childhood, there are disorders of the development of movement and posture, often associated with intellectual disability (ID), Seizures, Problems with vision, hearing, or speech or feeding difficulties. In order to achieve the habilitation goals, along with appropriate medications and therapies, assistive devices are often used, which are "any item, piece

of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities". The primary purpose of assistive devices and technologies is to maintain or improve an individual's functioning and independence to facilitate participation and to enhance overall well-being. Many of the commonly available children's toys as well as day-to-day objects could serve as assistive devices, if implemented in proper manner. Specific prescription devices like orthoses, seating or standing systems, ambulatory aids, etc. are required for specific indications. It is extremely important to make sure that the devices are enhancing the individuals child's existing functions and facilitating independence and skill development, rather than hindering the available functions. To give an example, the readily available sitting walkers in the market may delay the development of trunk balance, standing and walking as the child's pelvis is supported and does not allow for the pelvis to be stabilized on the lower extremities.

Classification of Assistive Devices for Habilitation or Early Intervention of children with CP could be based on function.

For Vision Impairment

Human faces, Vision stimulation charts (Fig 1, 2), bright coloured objects, etc. may be used right from the NICU. These objects, placed 8 – 12 inches away from the baby produces best results. Care should be taken to avoid extremely bright lights and to avoid over stimulation which may produce seizures. If vision impairment is diagnosed, it is best to involve a paediatric ophthalmologist in the team to guide visual stimulation therapies and strategies along with early and timely introduction of eye glasses and low vision aids as appropriate. If there is complete vision loss or blindness, early introduction of tactile strategies, counselling and introduction of braille should be offered to parents. Tactile and Braille toys (Fig 3, 4) are available in market.

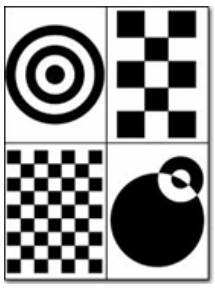


Fig 1, 2: Visual Stimulation Charts

Fig 3: Tactile/textured toy

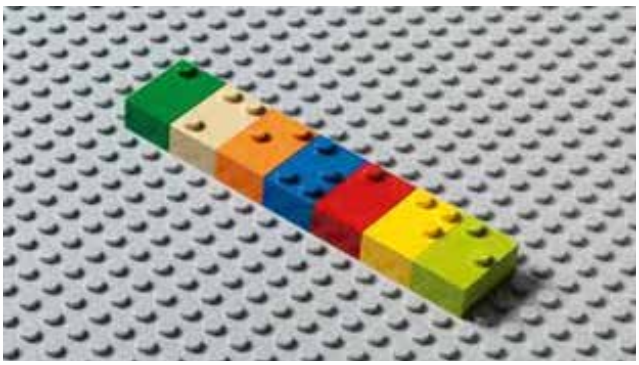


Fig 4: Braille toy

For Hearing Impairment

Hearing screening is now routinely done in all hospitals for all new-borns. If hearing impairment is suspected, early intervention, early use of hearing aids (Fig 5, 6) and in appropriate candidates, cochlear implants are

done. Referral to a centre specialized in treating children with hearing impairment is often indicated. Soft rattles and auditory stimulation may be tried from an early stage, taking care not to do overstimulation. As a rule of thumb, babies should not be exposed to noise levels over 60 decibels. The noise level recommended for hospital nurseries is actually lower, at 50 dB. For reference, a quiet conversation is between 50 and 55 dB and an alarm clock is 80 dB. There are different types of hearing aids available in the market now and a clear understanding of how the hearing aid works is important to ensure adherence to its use. Most often, parents and treating team members do not realise the fact that most hearing aids amplify all sounds, including that of the fan or AC in the room and may be extremely disturbing to the child. Hence, it is important to understand what the child is trying to communicate and offer most appropriate solution. The hearing aid technology is very well advanced and sophisticated instruments are now available.

Fig 5, 6: Hearing aids

For Speech and Language Impairment or Communication

Non-verbal communication starts early in children, when they start recognising faces and smiling or crying appropriately. Although verbal communication or saying single word is anticipated only by 12 months, cooing by the 2nd month, babbling and copying sounds by the 4th month, etc are communication milestones that may be monitored. Many practitioners still provide wrong advice to parents, asking them to wait for two to three years, before starting therapy for speech delay. The key is not to wait and do detailed evaluation as early as possible. Adequate environmental stimulation is required for children to achieve speech, which is the reason many a times. Talking toys, games with repetition of names of objects, etc. are excellent for children to who have isolated speech delays. For children with associated hearing impairments, it will have to be corrected. If in detailed evaluation, speech in not anticipated, parents and children should be offered Alternative and Augmentative Communication (AAC) as soon as possible. There are a variety of interventions available like Picture Exchange Communication System (PECS) (Fig 7), Symbol systems like gestures and sign language, Communication Devices like books, speech output devices (Fig 8, 9), computers, talking word processors, etc. Avaz (Fig 10) is a software application that is available in many Indian languages and can be easily installed. Children are advised to carry these AAC options with them to augment spontaneous communication and those who may not develop speech.

Fig 7: Easy to carry PECS

Fig 8, 9: Communication devices

Fig 10: Avaz app

For Motor Impairment – Head control, Sitting Balance, Standing Balance and Walking

Nesting and positioning in the NICU is important to manage tone abnormalities and to facilitate neural recovery. In babies who have increased tone, preventing contractures is an integral part of this and could be started in the ICU itself with gentle passive movements and placing babies' trunk and extremities in particular positions, using soft pillows and cushions as far as possible, and avoiding hard splints. The positioning techniques are different for those who have reduced muscle tone and excessive passive movements should be avoided and causes other than CP should be carefully looked into. Carrying techniques (Fig 11, 12) have to be taught to caregivers that address the tonal abnormalities and synergy patterns.

Fig 11, 12: Carrying and sitting options for children with hip adductor contractures

Orthoses are devices that support the extremities that have impaired function and are often used to prevent contractures and enhance function. They are named according to body part used for. For example, foot orthoses (FO), ankle foot orthoses (AFO) (Fig 13), knee ankle foot orthoses (KAFO), wrist hand orthoses (WHO) (Fig 14), etc. The prescription of these devices should only be done an experienced PMR Specilaist (Physiatrist) who make sure that the child function is enhanced with the orthoses at the same time, allowing for development.

Fig 13: AFO

Fig 14: WHO

Early developmental therapy helps children to achieve the various motor developmental milestones. Assistive devices are only prescribed if there is great delay anticipated or in those with severe CP. Head bands or attachments to seats are given if children do not have head control. Corner seats (Fig 15, 16) facilitate sitting balance and CP Chairs (Fig 17) provide overall support including supporting the head in those children who do not develop head control. Standing frames and devices are prescribed later on if needed (Fig 18, 19, 20).

Different varieties of paediatric sized canes, crutches (Fig 21) and walkers (Fig 22, 23) are available to support the ambulatory child, which is prescribed only as needed. Wheelchairs are only prescribed if the child does not attain walking by 6 years of age or the child is heavy for the parents to carry. However, sitting and positioning devices with wheels may be given according to the individual child and parents' involvement.

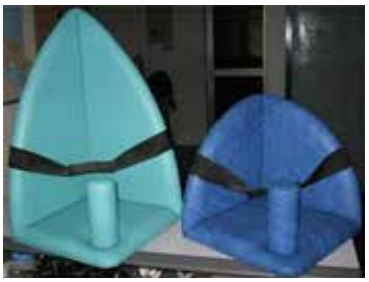



Fig 15, 16: Corner seats

Fig 17: CP Chair

Fig 18, 19, 20: Standing Frames

Fig 21: Forearm crutch


Fig 22, 23: Paediatric Walkers

For Hand Function

Built up handles, and other modifications based on individual needs may be custom made to enhance hand function (Fig 24, 25).

Fig 24: Swivel spoon and fork

Fig 25: Adapted utensils for better grip

For Behavioural and Sensory Issues, Intellectual Disability and Early Learning

Fig 26, 27, 28: Sensory and Educational Toys

Commercially available sensory toys, educational toys (Fig 26, 27, 28), etc. may effectively used by expert therapists as devices to overcome behavioural and sensory issues. Early learning toys are also available. If indicated puzzles, cards, etc. can be modified to suit the child. Each child needs individual education and learning plans and devices need to be made in a customized fashion.

Summary

Appropriate use of Assistive devices is a useful adjunct to early intervention and habilitation of children with cerebral palsy. There are many myths and stigma associated with its use. These devices have to be prescribed by trained professionals, customized to the individual child, trialled and modified from time to time to assess effectiveness and should enhance function. Gradation of services is important as the child attains specific goals.

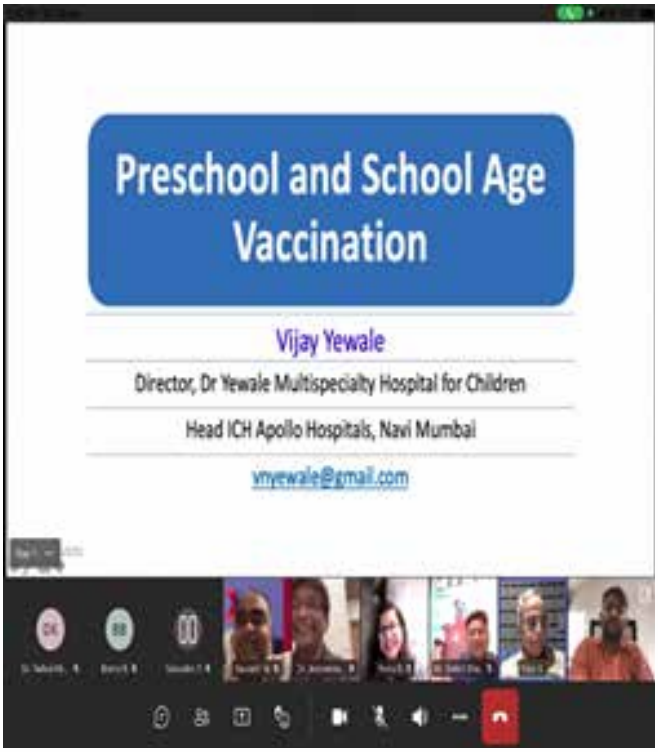
References

1. World Health Organization: Rehabilitation, 10 November 2021. https://www.who.int/news-room/fact-sheets/detail/rehabilitation Accessed on June 29, 2022
2. Developmentally Supportive Positioning Policy for Preterm Low Birth Weight Infants in a Tertiary Care Neonatal Unit: A Quality Improvement Initiative. Jaya Upadhyay, Poonam Singh, Kanhu Charan Digal, Shantanu Shubham, Rajat Grover, Sriparna Basu. Indian Pediatr 2021; 58: 639-642.
3. Chapter 12. Lower Limb Orthoses. Douglas P. Mruphy, Joseph B. Webster, William Lovegreen, and Andrew Simoncini. Braddom's Physical Medicine and Rehabilitation. 6th edition. Chief Editor: David X. Cifu. 2021: 281 – 299.
4. Chapter 11. Upper Limb Orthotic Devices. Brian M. Kelly, Atul T. Patel, and Carole Dodge. Braddom's Physical Medicine and Rehabilitation. 6th edition. Chief Editor: David X. Cifu. 2021: 261 – 280.
5. Chapter 19. Assistive Technology and Environmental Control Devices. Shih-Ching Chen, Cathy Bodine, and Henry L. Lew. Braddom's Physical Medicine and Rehabilitation. 6th edition. Chief Editor: David X. Cifu. 2021: 450 - 465.

IAP Navi Mumbai

IAP Navi Mumbai

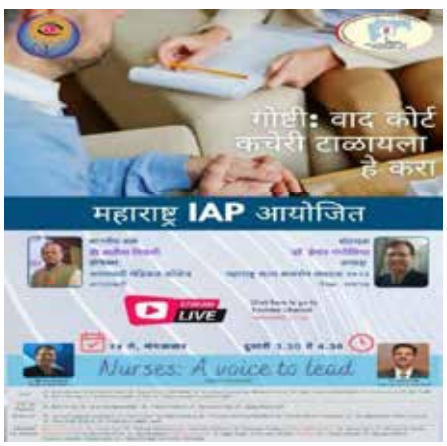
IAP Navi Mumbai



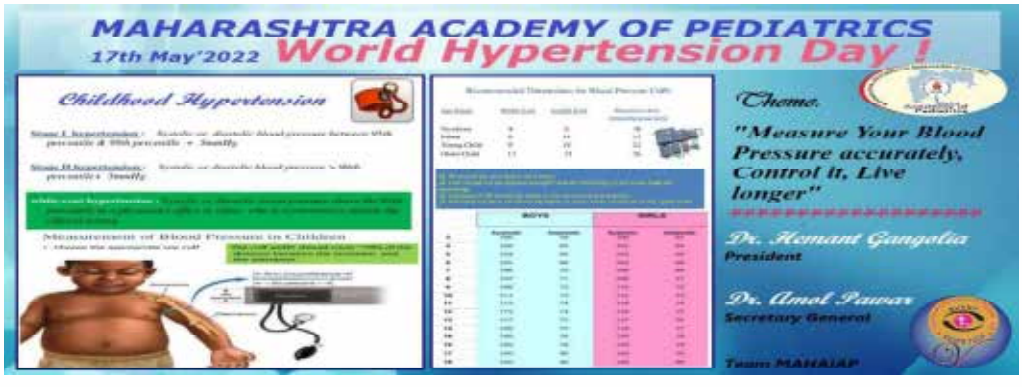
IAP Maharashtra

IAP Maharashtra

IAP Maharashtra



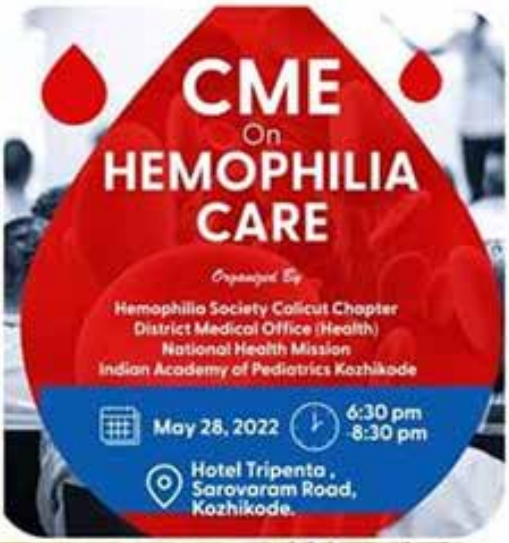
IAP Maharashtra



IAP Maharashtra

IAP Kerala

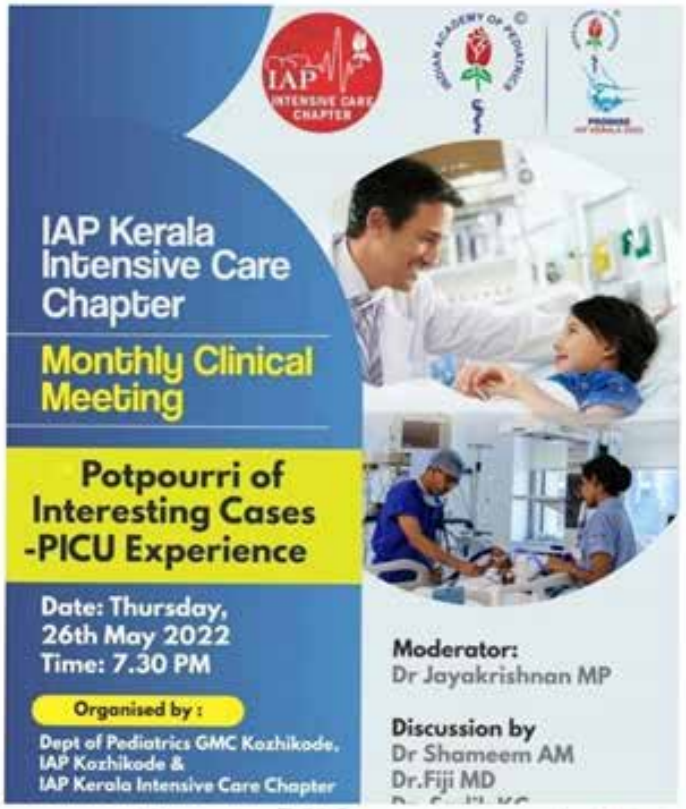

HEMO
CONTINUING
HEMOPHILIA CARE

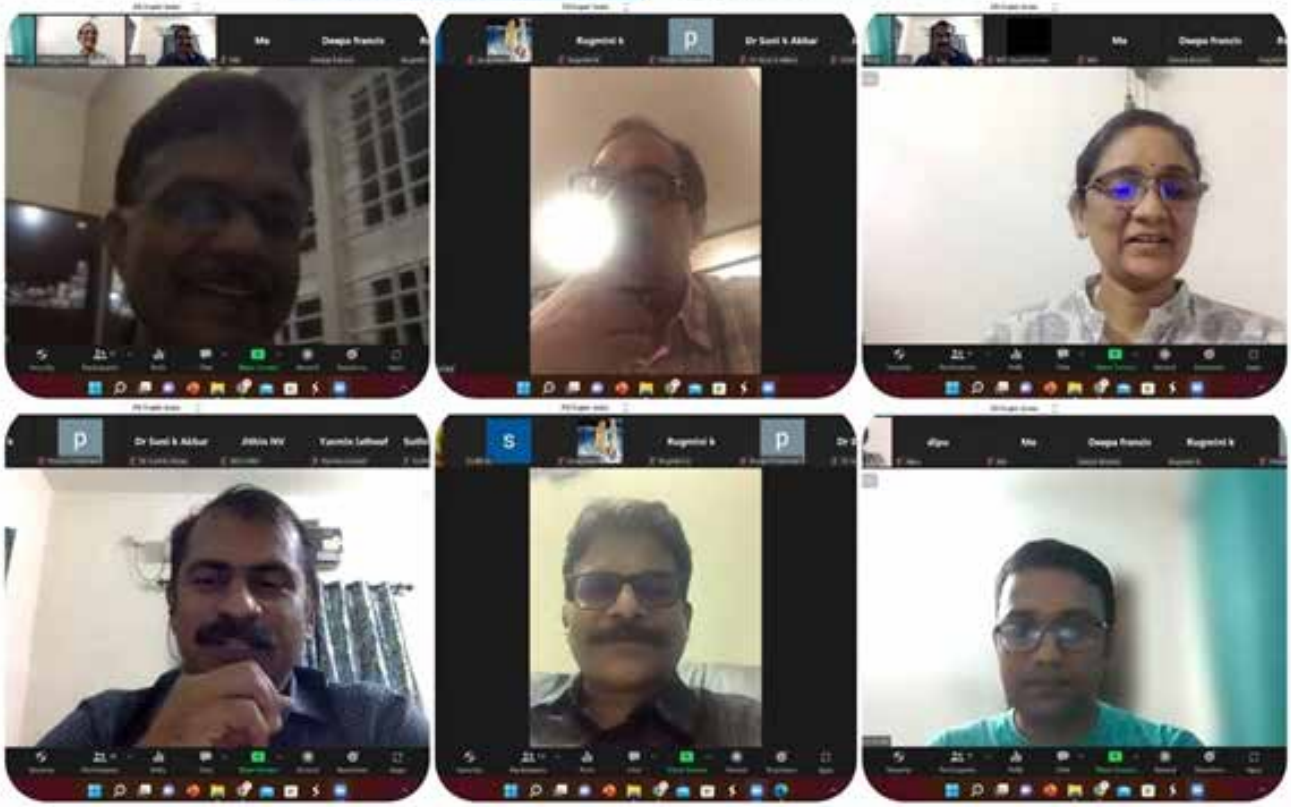

CME
On
HEMOPHILIA
CARE
Organised By
Hemophilia Society Calicut Chapter
District Medical Office (Health)
National Health Mission
Indian Academy of Pediatrics Kozhikode
May 28, 2022
6:30 pm
-8:30 pm
Hotel Tripenta ,
Sarovaram Road,
Kozhikode.


HEMOPHILI
CONTINUING MEDICAL EDUCATIO
Organised By
Hemophilia Society Calicut Chapter, Distri
National Health Mission, Indian Academy
2022 MAY 28 6.30 PM
HEMOPHILIA CARE


HEMOPHILIA CARE

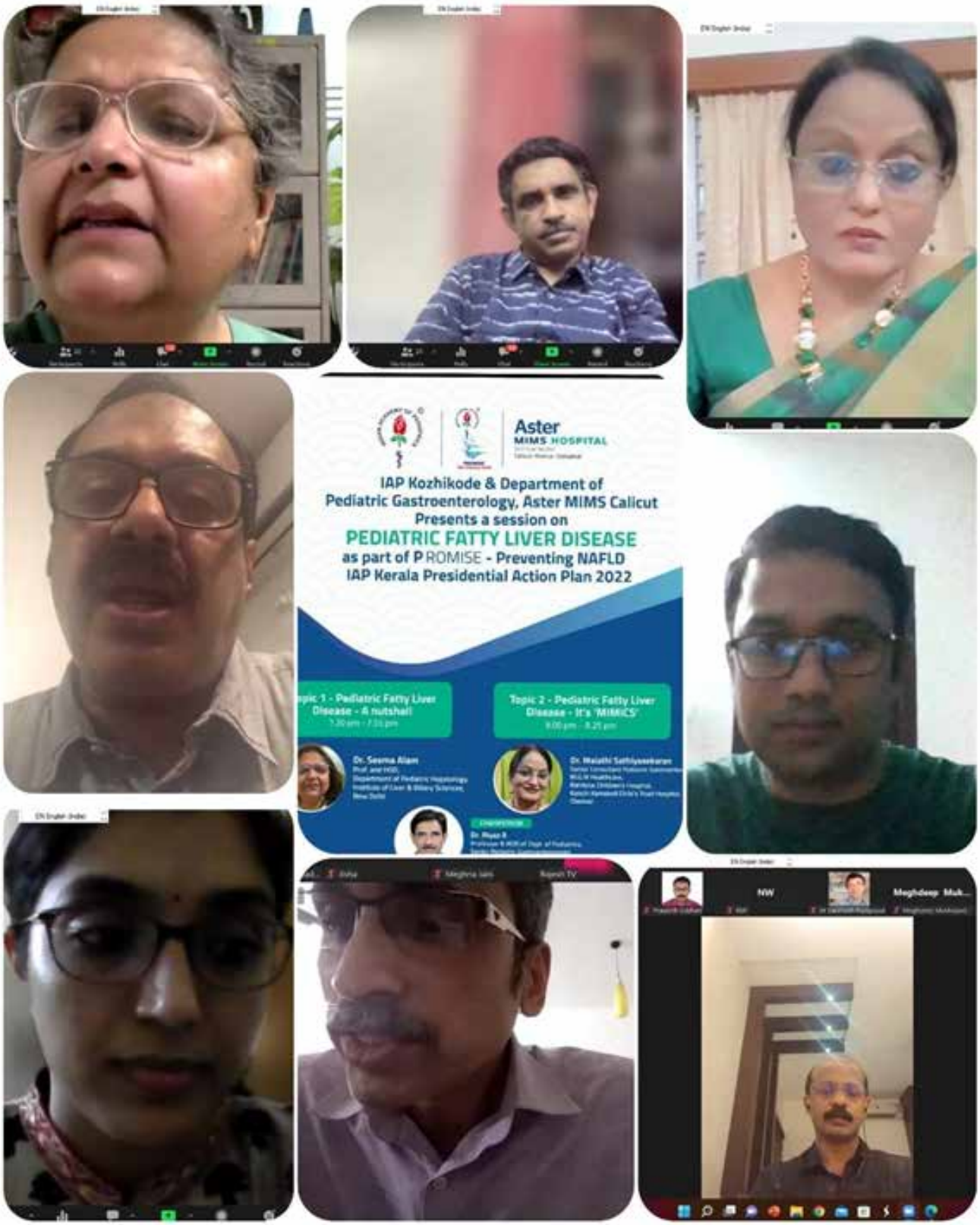
IAP Kerala


IAP
INTENSIVE CARE CHAPTER
IAP Kerala Intensive Care Chapter
Monthly Clinical Meeting
Potpourri of Interesting Cases -PICU Experience
Date: Thursday, 26th May 2022
Time: 7.30 PM
Organised by :
Dept of Pediatrics GMC Kozhikode, IAP Kozhikode & IAP Kerala Intensive Care Chapter
Moderator:
Dr Jayakrishnan MP
Discussion by
Dr Shameem AM
Dr.Fiji MD



IAP Kerala

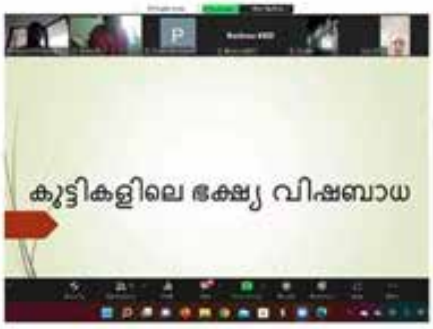
IAP Kerala


Aster
MIMS HOSPITAL
IAP Kozhikode & Department of
Pediatric Gastroenterology, Aster MIMS Calicut
Presents a session on
PEDIATRIC FATTY LIVER DISEASE
as part of PROMISE - Preventing NAFLD
IAP Kerala Presidential Action Plan 2022
Topic 1 - Pediatric Fatty Liver Disease - A nutshell
Topic 2 - Pediatric Fatty Liver Disease - It's 'MIMICS'
Dr. Seema Alam
Dr. Malathi Sathiyasekaran

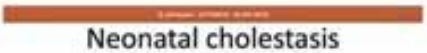
IAP Kerala

Speaker
Dr Sreela P
Assistant Surgeon
Paediatrician
CHC Thalakkulathur

zoom meeeting
Meeting ID:
333 678 2020
Password:
IAPCALICUT



IAP Kerala



Dr Vishnu, Final year MD, KMC

Dr. A.Riyaz MD DCH DNB DM (Gastroenterology) F
Pediatric Gastroenterologist
Professor & Head of Pediatrics
MCT Medical College, Calicut
Kerala

IAP Kerala

IAP Kerala


ACADEMY OF
PEDIATRICS


CADEMY OF
EDIATRICS


ACADEMY OF
PEDIATRICS


ACADEMY OF
PEDIATRICS


ACADEMY OF
PEDIATRICS
KOTTAYAM


ACADEMY OF
PEDIATRICS

IAP Kerala

SAFE SOUND INDIA

INDIAN MEDICAL ASSOCIATION
KANNUR, BRANCH

In association with National initiative of Safe sound, AOI Kannur, IAP Kannur

Inaugural function for the cycle rally
May 6th Friday at 07.30 pm at IMA hall Kannur.

Inauguration by,
Smt. P. P. Divya
District Panchayat President

Address by,
Sri. P. P. Sadanandan
Additional S P Kannur

Flag off,
Sri. Rethnakumar. T. K
Asst. Commissioner of Police
Kannur

Cycling From Kannur to Kozhikode.
" Safe Sound, Right of Every Citizen "
Certificate & Medal for all finishers
Breakfast & Lunch will be served

SILENT WHEEL 22

IAP Kerala


IAP WAYANAD
in association with
Wayanad O&G Society
WAYANAD O&G SOCIETY
IAP KERALA PRESIDENTIAL ACTION PLAN 2022
PROMISE
5 - Screening for Congenital Hypothyroidism for all neonates
Guest Speaker
Topic :
Newborn screening for Congenital Hypothyroidism
Date & Time
6th May 2022,Friday
@7.30pm
INDIAN ACADEMY OF PEDIATRICS
WAYANAD BRANCH
GUTGERMINA