"IMPACT OF INTERVENTIONAL THERAPIES ON THE QUALITY OF LIFE IN CHILDREN WITH CEREBRAL PALSY: A ONE YEAR HOSPITAL BASED INTERVENTIONAL STUDY"

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LIST OF ABBREVIATIONS USED

CP	:	Cerebral palsy
QoL	:	Quality of Life.
WHO	:	World health organization.
ICF	:	International classification of functioning, disability and health.
PROM	:	Premature rupture of membranes
PVL	:	Peri-ventricular leukomalacia
LBW	:	Low birth weight
VLBW	:	Very low birth weight
GMFCS	:	Gross motor function classification system
MACS	:	Manual ability classification system
BPRS-C	:	Brief psychiatric rating scale in children
QALY	:	Quality adjusted life years.
DALY	:	Disability adjusted life years
PT	:	Physiotherapy
OT	:	Occupational therapy
NSAIDs	:	Non-steroidal anti-inflammatory drugs
PEDI	:	Pediatric Evaluation of Disability Inventory.
PedsQL	:	Pediatric Quality of Life Inventory.
TACQoL	:	TNO-AZL Children's Health-Related Quality of Life
LAQ-CP	:	The Life style assessment Questionnaire-CP

ABSTRACT

IMPACT OF INTERVENTIONAL THERAPIES ON THE QUALITY OF LIFE IN CHILDREN WITH CEREBRAL PALSY: A ONE YEAR HOSPITAL BASED INTERVENTIONAL STUDY.

Introduction: Cerebral palsy(CP) denotes a group of heterogeneous disorders with permanent ailments of tone and posture causing activity limitation. It's a debilitating disease of childhood with varied co-morbidities, which have a grave effect on the economy, psycho-social aspects and quality of life of these children, family and society at large. Because of the notion that CP is a non treatable disease, most of these children are not provided with adequate care and treatment.

Objectives: the primary objective of this study was to assess the impact of interventional therapies on the Quality of life in children living with cerebral palsy. This study also looks at the co-relation of different modalities of effective interventional therapies with respect to various types of cerebral palsy and also assesses the impact of co-morbidities on quality of life in children with CP.

Methods: This study was conducted in the child development clinic(CDC) of KLES Dr Prabhakar Kore hospital and Medical research centre. All newly registered and treatment naïve children with CP attending CDC from January 2018 to September 2018 were enrolled. After taking appropriate history and thorough neurological and other systematic evaluation they were classified into respective type of CP. They were subjected to necessary interventional therapies like physiotherapy, speech therapy, oro-motor stimulation, medications and treatment of co-morbidities for 6 months. The patients were followed up every month for a duration of 6 months. The Quality of

life(QoL) was assessed based on Lifestyle assessment Questionnaire(LAQ-CP) pre and post interventions.

Results: 51 patients were enrolled in our study(M:F=1.8:1). Dystonic Quadriplegic CP was the most common type with 18 patients(35.2%) with perinatal asphyxia being the commonest cause in 22(50.8%). Majority patients i.e 25(49.01%) had moderate disability LAQ-CP scores. The mean final LAQ-CP score pre and post intervention were 52.78 and 46.91 respectively($p<0.0001$). The median number of co-morbidities reduced from 9.5 to 5.5 after interventions. Drooling of saliva reduced in 27/28 patients followed by seizures which showed reduction in 20/23 patients.

Conclusion: There is a notion that CP is non-treatable disease. Many of these children are neglected both by parents and treating physicians. Our study shows that timely and appropriate interventions can significantly improve the Quality of life of these children.

Key words: Cerebral palsy, life style assessment questionnaire – cerebral palsy, interventional therapies, co-morbidities

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CHAPTER 1- INTRODUCTION

The Term Cerebral palsy (CP) denotes a heterogeneous group of permanent ailments of posture and movement causing activity limitation due to non-progressive damage to developing fetal and infant brain. Most of the times, the motor abnormalities are associated with disturbances in sensory perception, behavioural and psychosocial problems, cognition, epilepsy or other co-morbidities. [1]

The global incidence of cerebral palsy ranges from 2 to 3 among 1000 live births. Though the Indian data is lacking in this regard, cerebral palsy constitutes major proportion of childhood neurological disorders in our country. Traditionally attributed to birth asphyxia, there are wide variety of causative factors for cerebral palsy, ranging from intrauterine life till age group of 3 to 5 years.[2,3]

Cerebral palsy impacts a child's functioning as a whole, affecting not only the bodily functions, but also affects his participation and intellectual ability leading to limitation in activity and participation. In a study by Ozkan, quadriplegic children had poor Quality of life (QoL) scores than hemi- or diplegic children, thereby laying an emphasis on the affect of disability on their life's quality.[4] Research has proven that not only do the disabilities affect the Quality of life of these children, they also have a negative influence on the families and society at large.

While bringing up a child is a task in itself, bringing up a child with CP causes not only an enormous psychological and emotional burden but also a financial burden with huge health care costs. Time and again there has been a wrong notion that cerebral palsy is not a treatable disease. Though not curable, the interventions directed at mitigating these morbidities, will enhance the quality of life of these children and

their families. The interventions available today have had a paradigm shift from exclusive physical rehabilitation and orthopaedic surgeries to a more holistic and family centred approach along with community participation to maximize their immediate environment and independence in daily activities. Physiotherapy with goal directed training, medical management of co-morbidities, occupational therapy, speech and psychotherapy are a few of them. [5,6]

The impact of these interventions on the disability has been assessed in terms of improvement in symptoms or functional ability (viz. GMFCS and QALY) at various centres in the past, mostly in the Western countries.[5] But owing to the detrimental effect of this disorder on the children and their caregivers specially in a country like India, there is a necessity to evaluate the impact of the interventions in terms of improvement in these children's Quality of life to dispel the myth of non-treatable nature of this disorder and give hope to those families crippled by it. Hence, the present study was contemplated to assess the impact of interventions on the Quality of life of children with Cerebral Palsy.

CHAPTER 2- OBJECTIVES

The objectives of this present study were:

Primary objectives:

To assess the impact of interventional therapies on the Quality of life in children living with cerebral palsy.

Secondary objectives:

1. To study the co-relation of different modalities of effective interventional therapies with respect to various types of cerebral palsy.
2. To assess the impact of co-morbidities on quality of life in children with CP.

CHAPTER 3 - REVIEW OF LITERATURE

HISTORICAL PERSPECTIVE:

In the primitive era, due to lack of knowledge, deformities have always been attributed to supernatural causes. Various superstitions existed in the Babylonian and Chaldean societies where the children with deformities were thought to have caught God's wrath or occurred due to evil's eye or witchcraft.[7] Midwifery negligence and maternal miswatching during pregnancy were also attributed as causes for cerebral palsy.

While Charles Ollivier in 1827 described about the immature fetal brain and liquefaction, Bednar first spoke about periventricular Leukomalacia in 1851.[7] In his distinguished lecture in 1861 for the Society of Obstetrics, William John Little proposed difficult labour as a reason for spasticity in children.[8] The word Cerebral palsy came in to use after William Osler coined the term to describe 140 children with spasticity in 1889.[9] Sigmund Freud later in 1897, proposed antenatal and postnatal causes leading to cerebral palsy, thereby countering little's hypothesis of perinatal asphyxia as its major cause.[10]

The ancient indian physician Susrutha, in his compendium wrote about *ritu* (time of conception), *kshetra* (Uterus), *ambu* (Amniotic fluid) and *beeja* (sperm and ovum) as the causes leading to Cerebral palsy.[11] Another ancient indian text, Charaka Samhita, mentions about *Garbhopaghatakarabhava* which means factors associated with fetal development, *Garbha Vriddhikarabhava* meaning the monthly fetal development and *Garbhini Paricharya*, the do's and don'ts of a pregnancy, as some

of the causes for deformities in an infant, there by shedding light on the understanding of these diseases by our fore fathers.[12]

DEFINITION

Cerebral palsy was defined by various working groups and eminent minds in order for its better understanding and outreach. The difficulty in doing so can be apprehended by the various attempts that have been made since mid 20th century.

In 1959, Mac Keith and Polani from the 'Little Club' defined CP as

''a persisting but not unchanging disorder of movement and posture, appearing in the early years of life and due to a non-progressive disorder of the brain, the result of interference during its development.'' [13]

In 1964, Bax and his group in an effort to put forth a universally acceptable definition, successfully stated CP as

"a disorder of movement and posture due to a defect or lesion of the immature brain.'' [14]

In the early half of 1990's, after understanding the concepts of pathology in early brain damage and complexities of disorders under CP, Mutch and colleagues reiterated the emphasis on motor involvement and non-progressive nature of disorder as annotated previously by modifying the definition as:

''an umbrella term covering a group of non-progressive, but often changing, motor impairment syndromes secondary to lesions or anomalies of the brain arising in the early stages of development''. [15]

In the wake of understanding of newer concepts of developmental neurobiology, functional status of these children, participation and the realisation of association of other developmental and behavioural disorders with cerebral palsy, an

International Workshop was held in 2004 for defining and classifying Cerebral palsy. They published the definition in 2006 report as :

"Cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture causing activity limitation that are attributed to non-progressive 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 behaviour; by epilepsy, and by secondary musculoskeletal problems."

This definition also highlighted the idea of a comprehensive multi-disciplinary approach to treat Cerebral palsy. [1]

EPIDEMIOLOGY

According to WHO estimation, the global prevalence of disability stands at 15%, with those individuals suffering from some or the other form of disability.[16] In India 3.8% of the population suffers from disabilities.[12] Cerebral palsy is the most common disabling illness of the childhood. The prevalence of Cerebral palsy is 2-3 for every 1000 live births globally.[17] Cerebral palsy prevalence on the whole has not changed over the years despite the advancement in perinatal medicine due to increased survival of preterm babies.[18] The prevalence in developed countries is 2.11 for every 1000 live births, and 2.0 to 2.8 in middle and low income countries. [19,20] With 17 million individuals affected worldwide, the incidence and prevalence differs across countries based on prenatal care, intra partum and postnatal medical facilities available. [21] Though robust data is lacking from our country, the prevalence is estimated at 3/1000 live births and there are about 25 lakh individuals living with cerebral palsy as per the recent statistics.[12,22]

RISK FACTORS:

Birth asphyxia or difficult labour has always been perceived as a foremost cause of cerebral palsy. But disproving this common belief, studies have found perinatal asphyxia to be causative factor for only 10% of cerebral palsy cases.[23] Post natal events such as infections, stroke, hypoglycaemia and trauma, which were recent attributions to the aetiology of Cerebral palsy, accounted for 10% of the cases. [18] The majority i.e around 80% of the causative factors of Cerebral palsy are believed to be intra-uterine events, such as chorioamnionitis, prematurity, genetic factor etc.

The following table depicts the Causative/Risk factors for CP [24-29]

Prenatal (80%)
• Prematurity (less than 37 weeks Gestation) • Low Birth weight (weighing less than 2.5kgs) • Intra Uterine restriction of fetal growth • Multiple births • Intracranial Haemorrhage, Periventricular leukomalacia • Maternal Age of more than 35 years • Maternal hypotension, Sepsis, Diabetes Mellitus • Severe maternal Iodine deficiency • Intra uterine infections like TORCH group • Genetic defects causing lissencephaly, schizencephaly, polymicrogyria and porencephalic cysts etc.
Perinatal causes (10%)
• Perinatal asphyxia • Maternal infections • Stroke • Hyperbilirubinemia leading to kernicterus • Hypoglycemia, Dyselectrolytemia • Septicemia
Postnatal Causes (10%)
• Meningitis / Meningoencephalitis or other febrile encephalopathies • Stroke • Head trauma • Hypoxic events

Disturbances in the foetus before 20 weeks gestation, due to maternal infections or recently identified genetic defects which lead to brain malformations by neuronal migration abnormalities, lead to severe phenotype of CP causing spasticity and dystonia. [24,30]

Disturbances to the growing fetal brain between 24-32 weeks periods of gestation lead to injury of peri-ventricular white matter due to its vulnerable blood supply. This leads to characteristic spastic diplegic presentation owing to the representation of legs on the homunculus on periventricular cortex. Prematurity and Low birth weight have been attributed as one of major causes of Cerebral palsy, where the prevalence is as high as 40 to 100 for every 1000 live births and with a risk 70 fold high if the birth weight is lesser than 1.5kgs. [17,31,32]

Intra partum damage to the brain commonly affects the highly metabolic areas such as basal ganglia due to the vigorous vascular development. This usually leads to dyskinetic type of CP. But, if the damage is extensive, can also present as spastic and dyskinetic variant.[24]

Strokes usually present with unilateral involvement as middle cerebral artery territory is usually involved, with arms being more affected than the legs.[33]

CLINICAL FEATURES AND DIAGNOSIS:

Early recognition of symptoms of cerebral palsy is necessary to intervene at the earliest with interventions. Identification of CP is generally made based on clinical features. This can be done at an earlier age, when coupled with appropriate antenatal, perinatal and postnatal history and imaging findings. It is prudent to know the early clinical features in order not to miss the golden period of a child's life where the

neurodevelopment may be amenable to interventions. Only after eliminating other causes of neuro-disability by reasonable certainty is the diagnosis of CP made. As the features are subtle and may be missed, one should always refer the child to a specialist when in doubt, for a better assessment. [34]

Healthy infants from 6 weeks till 20 weeks of age develop small, elegant and transient fidgety movements involving the neck, limbs and trunk. These movements are best seen when an infant is awake, alert in supine or semi recined position and can be sustained up to as long as an hour. These movements disappear once the child cries or fusses in hunger. Prechtl HF et al[35] proposed that absence or lack of these normal fidgety movements were associated with abnormal neurodevelopment outcome. These features when used along with Magnetic resource imaging of preterm brains, have a diagnostic accuracy of 100% in predicting Cerebral palsy.[36]

Motor disability is a predominant symptom in a child with CP. In most of these children, the motor abnormalities present by or become apparent by 18-24 months of age. Early hints of CP in an infant usually include:[25,31]

- Delay in motor milestones: probably the most important symptom of CP. Children usually present with delayed milestones

Milestones	**Red flag sign**
Head control	Not attained by 6 months of age
Sitting without support	Not attained by 9 months of age
Walking	Not attained by 18 months of age

- Tone and Posture: Hypotonia, hypertonia or normal tone can be seen. Lack of head control, floppiness, hand fisting, oromotor pattern abnormalities like tongue thrusting and grimacing, early hand preference (before 15 months), commando crawl, apparent early head control in some cases due to increased axial muscle tone.
- Abnormal Reflexes: exaggeration of neonatal reflexes or delay in their disappearance.
- Abnormal neurobehavioral signs: irritability, lethargy, difficult handling, excessive or difficulty in sleeping.

When a child comes with above mentioned signs and symptoms, after a thorough examination and history, imaging studies can be obtained which will aid in the diagnosis. According to American Academy of Neurology, MRI is abnormal in 86% of Cerebral Palsy cases. Before labelling a child as a case of CP, one needs to eliminate the likelihood of progression of symptoms or worsening of existing symptoms, in order not to miss out on diagnoses of neuro-regressive or metabolic disorders.[37]

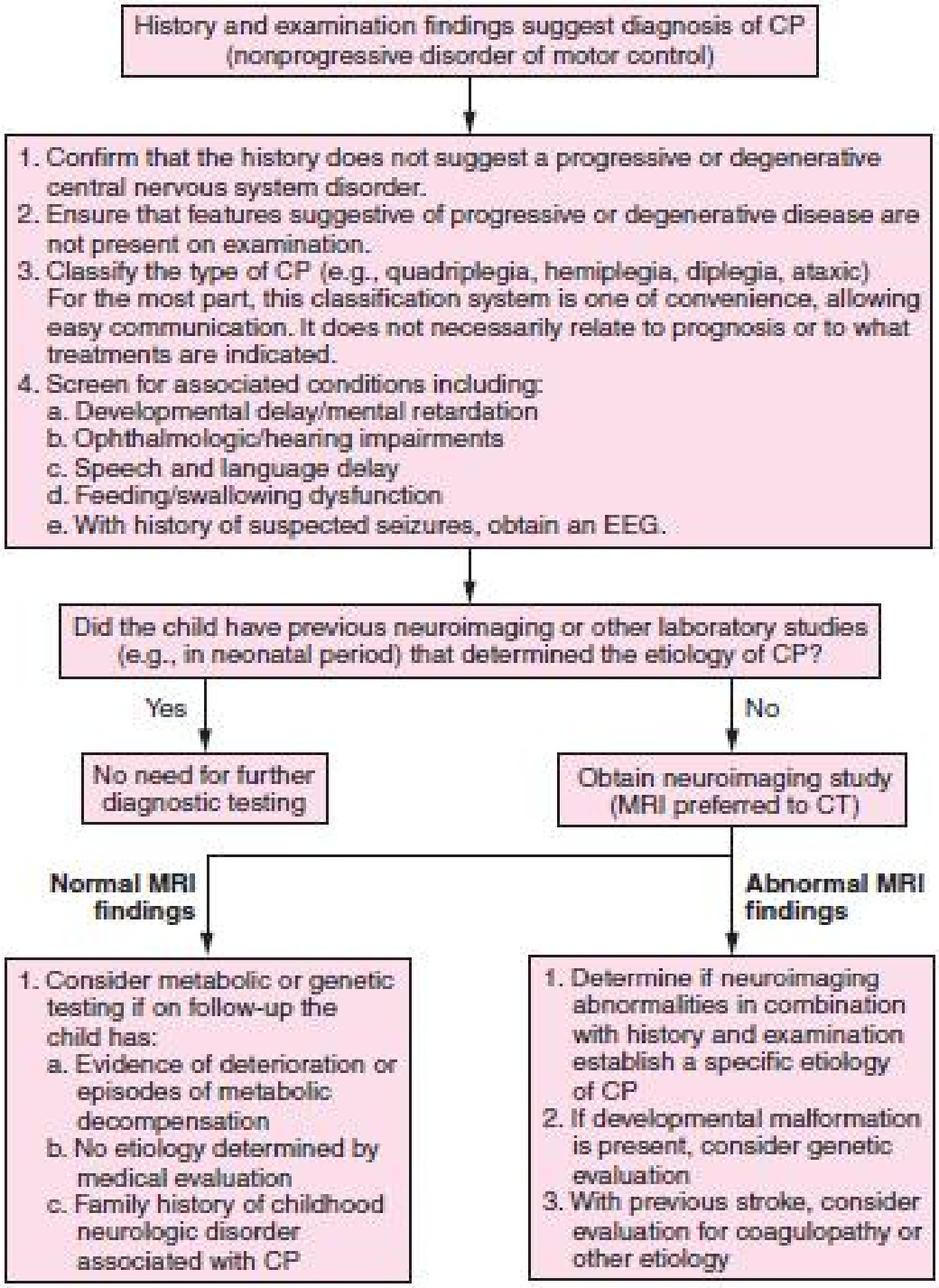


Fig 1. Algorithm for cerebral palsy (CP) child evaluation. [37]

As per the current accepted definition of CP, almost all the cases are complicated by associated co-morbidities.[18] The following table enlists the common co-morbidities of a Child with CP based on a systematic review done by Novak et al.[38]

Co-morbidity	**Remarks**
Intellectual disability (ID)	• Seen in 50% patients • Spastic quadriplegics are severely affected
Epilepsy / seizures	• Seen in 25-45% patients • Most common in spastic quadriplegics and hemiplegics. • Children with CP and ID have more possiblity to have epilepsy.
Neurobehavioral disorders	• Occurs in 25% CP children. • Children with CP and ID are prone to have behavioural problems
Visual disorders	• noted in 30% children having cerebral palsy. • Commonly associated with Prematurity. • Retinopathy of prematurity, Amblyopia, Refractive errors, strabismus, Myopia are common causes.
Hearing and Speech impairment	• Seen in 30-40% cases • Aphasia or dysarthria are common.
Gastrointestinal disorders	• 90% of the children are associated with GI problems. • Constipation, bulbar palsy causes swallowing difficulties, Gastro-esophageal reflex disease (GERD) and vomiting are commonly seen. • One in fifteen CP children have feeding difficulty. • Mostly seen in children with severe physical disability. • Leads to malnutrition and growth failure.
Growth failure	• Poor nutrition and GI difficulties are the causes
Pulmonary disorders	• Recurrent aspiration due to GERD, bony deformities like scoliosis etc are associated with chronic lung diseases
Pain	• 75% children with CP are associated with pain in one or the other form. • Orthopaedic and muscular pains, dental caries, constipation are common causes. • Regardless of severity of disability, these patients are prone to develop pain as per high quality evidence in studies.
Urinary problems	• Upto 60% children with CP can have disturbances in voiding, like enuresis, increased frequency, dribbling etc
Sleep disturbances	• Exact prevalence not known • But seen commonly in CP children.

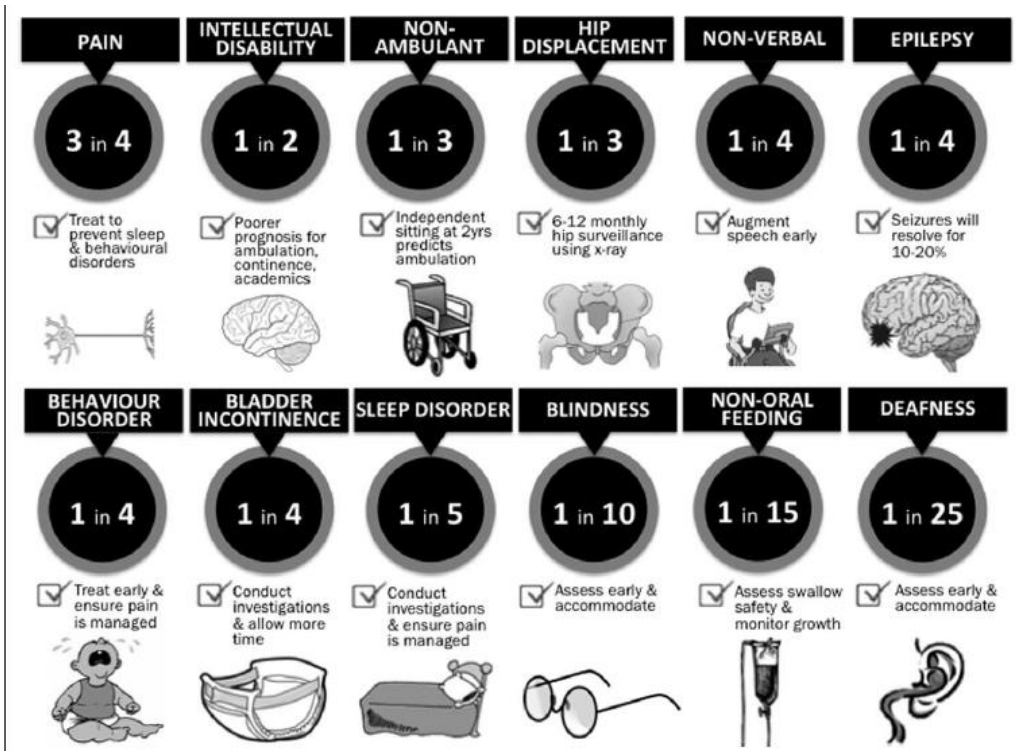


Fig 2. Pictographic depiction of Co-morbidities of children with CP.[39]

CLASSIFICATION:

Cerebral palsy was earlier classified only in terms of physical and motor abnormalities. Functional classifications are a better method of classifying CP children as they deal with what can be done to patient to improve his activity and participation. "Surveillance of Cerebral palsy in Europe" collaboration topographically classifies CP:[40]

- Unilateral or
- Bilateral

Based on tone and movement:

1. Spastic
2. Dyskinetic
    a. Dystonic
    b. Choreo-athetoid

3. Ataxic
4. Mixed forms

According to Nelson Textbook of Paediatrics, first South Asian edition, volume 3: Cerebral palsy can be classified into four major syndromes: [41]

1. Spastic Diplegia
2. Spastic Quadriplegia
3. Spastic Hemiplegia
4. Extrapyramidal CP (choreo-athetoid and Dystonic)

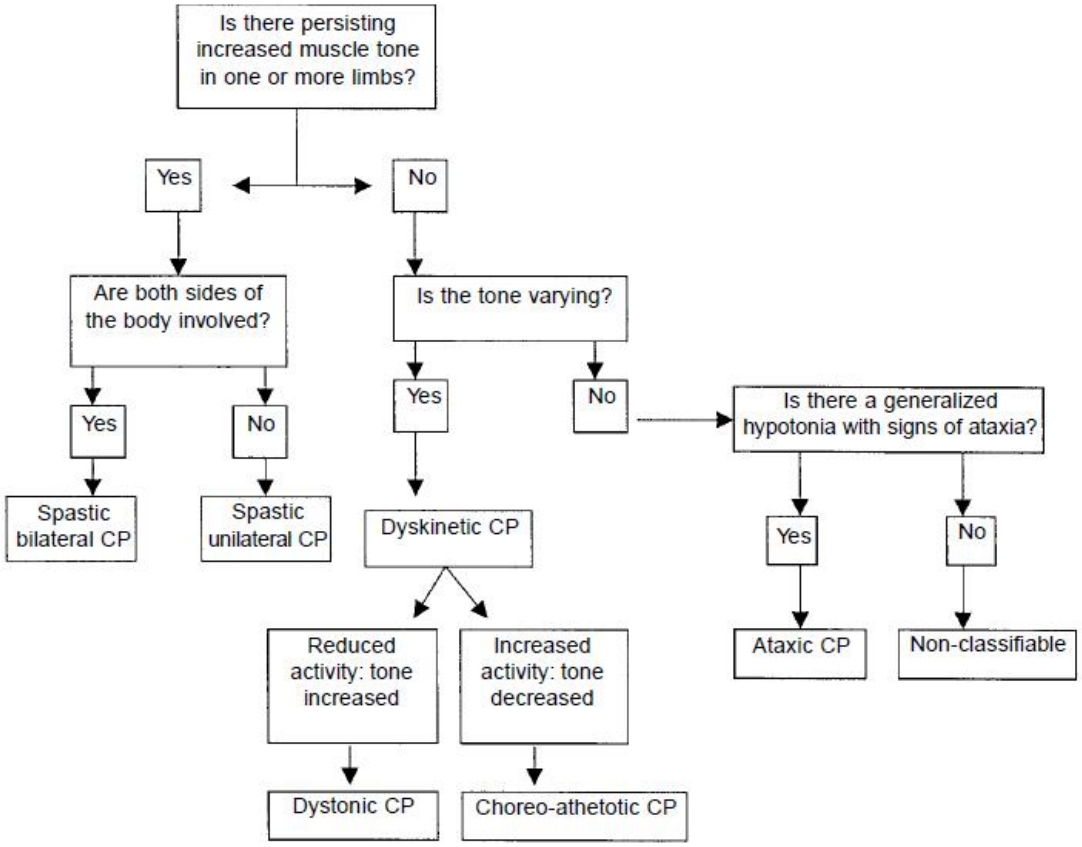


Fig 3. Hierarchical classification tree- the cerebral palsy sub-types[40]

Following are the the major clinical features of CP Syndromes:[25,41]

CP Syndromes	Proportion	Causes and Risk factors	Clinical features
Spastic Diplegia	15-25%	• Prematurity • Ischemia, infections • Endocrine causes ↓ • Peri Ventricular Leukomalacia • Periventricular cysts or scars	• Clasp Knife Spasticity • Brisk Deep tendon reflexes (DTR) • Extensor plantars • Contractures • Commando Crawl • W-sitting • Toe walking • Preserved upper limb function and cognition
Spastic hemiplegia	20-40%	• Term • Thrombophilic disorders • Infection • Genetic causes ↓ • Stroke: neonatal or in utero • Focal infarct causing cortical damage • Cortical malformations	• Asymmetrical moro's reflex • Assymetrical hand movements • Early hand dominance (before 12 months) • Reduced muscle bulk on the affected side
Spastic Quadriplegia	20-40%	• Preterm/ Term • Perinatal asphyxia • Cerebral malformations • Genetic causes ↓ • Periventricular leukomalacia • Multicystic encephalomalacia • Cortical malformation	• Severe motor delay and cognitive impairment • In the initial months there may be hypotonia • Slowly evolves into spasticity by 9-12 months • Feeding difficulties • Seizures and chronic respiratory problems are common.
Dyskinetic CP	10-15%		• Variable tone • Reduced spontaneous movements • Involuntary movements • Drooling • Involuntary grimace

• Dystonic CP • Choreo-athetoid CP		• Perinatal Asphyxia • Term • Severe Hyperbilirubinemia	• Striatal Toe • Dysarthria • ID • Contractures less common • Dystonia present • Tendon reflex may or may not be present • Chorea and athetotic movements • Athetosis more common.
• Ataxic	5-10%	• No specific aetiology • May be genetic or early prenatal.	• Hypotonia • Delayed milestones • Ataxia • Slow jerky speech.

The physical classification doesn't provide any information regarding the child's capacity to participate and also the extent of his activities.[42] With the advent of World health Organization's (WHO) INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH (ICF), clinicians outlook on cerebral palsy has had a drastic change.[43] Functional classification systems have come into vogue.

The Gross motor function classification system (GMFCS) is a pattern recognition system devised to gauge the motor ability of a child with CP. It Is divided into five levels and was validated for the age group of 2 to 12 years way back in 1997. Various age specific descriptions available for use.[44,45]

A brief outline of GMFCS:

"Level I: walks without any limitations

Level II: Walks without assistive devices, but with limitations (ex: limitations in walking long distances, stairs and balancing)

Level III: Walks using a hand held mobility device (ex: crutch or walker)

Level IV: limited self mobility; child uses powered mobility device independently (ex: a joystick operable wheel chair)

Level V: Child transported in a manual wheel chair. Has severe activity limitations."

Similarly, the Manual ability classification system (MACS) was designed to grade the functional ability of using the hands. Which was tested and validated for the ages of 4 to 18 years. A brief outline of MACS levels: [46]

"Level I: Handles objects easily and successfully

Level II: Handles most objects but with somewhat reduced quality and ⁄ or speed of achievement

Level III: Handles objects with difficulty; needs help to prepare and ⁄ or modify activities

Level IV: Handles a limited selection of easily managed objects in adapted situations

Level V: Does not handle objects and has severely limited ability to perform even simple actions"

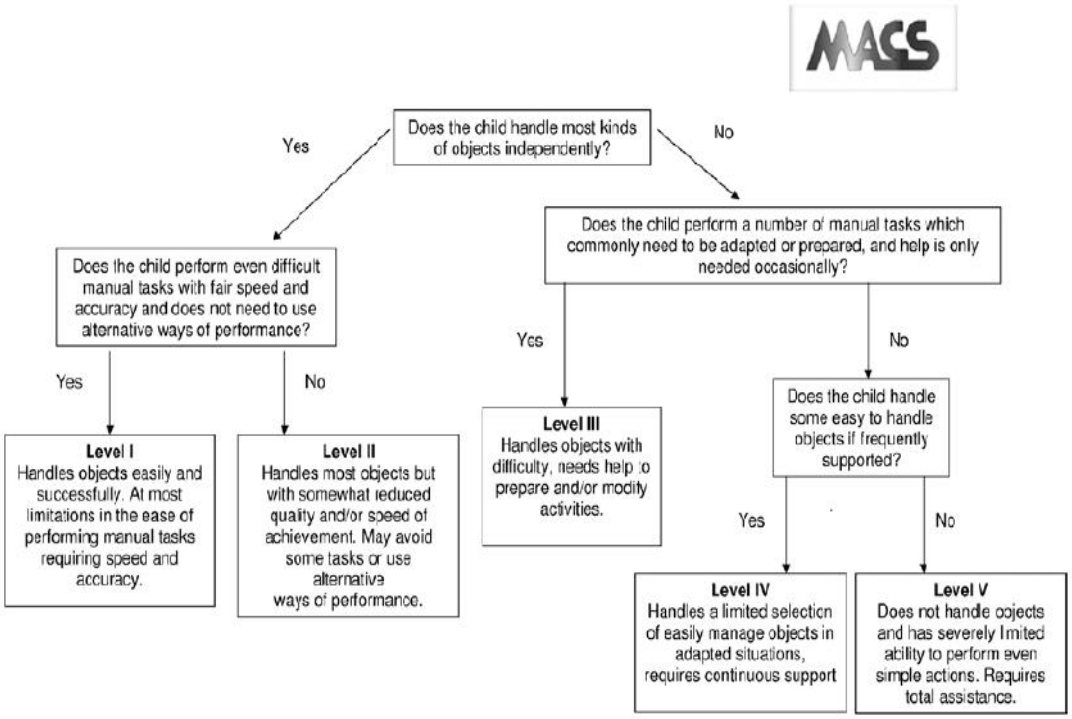


Fig 4. MACS classification

Similarly, a Communications function classification system (CFCS) was designed to classify the functional ability of communication for an easy and reliable usage by practitioners and research personnel.[47]

IMPACT OF CP:

After looking at the types and classifications of CP, it is prudent to know its impact. It is known that cerebral palsy is a debilitating illness of paediatric population which transits into adulthood.[48,49] The impact of cerebral palsy on Quality of life, survival and economy has been thoroughly studied in various countries by researchers and paediatric societies. In the year 2014, under the onus of "Royal college of Obstetricians and Gynaecologists" a study was published which looked at the number of Quality adjusted life years (QALY) lost (1 QALY equivalents to "one year of life in perfect health") due to cerebral palsy secondary to asphyxia. The above mentioned

study estimated an individual with GMFCS-I to live 23.4 QALY which reduced to a mere 2.0 QALY for an individual with GMFCS-V. when gauged in terms of loss of QALYs, there were a loss of 29.5 QALYs for a severely disabled individual with GMFCS-V in comparison to 1.6 QALY loss in an individual with GMFCS-I. The same study also estimated a decline in Quality of Life with worsening GMFCS level, with a 5% reduction in an individual with GMFCS-I to 92% in QoL over life time in an individual with GMFCS-V.[50]

"Disability adjusted life years" (DALY) is another method of measuring the impact of a chronic disease. In a study done in Australia, the total DALYs in one year were 14,768 for all the cerebral palsy cases.[51]

The implications of chronic illness like CP on the economy of a family and the nation need not be emphasized. "Center for disease control and prevention" in the year 2004, estimated a lifetime costs of 15 billion US dollars i.e 1.2 million per an individual living with cerebral palsy.[52,53] The costs estimated not only takes into account direct medical costs, but also the costs of equipment, consultations, indirect costs in the form of travel for consultations, work holidays and also productivity losses.[54] Kruse *et al* reported a life time costs of 1.2-1.3 million US dollars in Denmark for Cerebral Palsy.[55] From an Asian country like Taiwan, Chang *et al* reported annual health care costs in CP child exceeded other children by 773 US dollars.[56] Whereas the health care expenditures in a developed country like the united states by an individual with Cerebral palsy averaged at a staggering 18,433 US dollars more than that spent by those without Cerebral palsy.[57] In two different studies done in Australian continent, it was found that the health care costs positively co-related to

the increase in disability, i.e, individuals with GMFCS IV and V had high health care expenditures.[58,59]

Studies have also categorised the areas of expenditure in these children, with home care expenditure leading the tally followed by costs incurred for buying special equipment for these children, therapy, rehabilitation and transportation et cetera.[60]

Impact of CP on the Quality of life of care givers has also been an area of particular interest for researchers recently. The care giver burden in CP is often overlooked with emphasis only on the individual with CP. The indirect cost estimates due to care giver burden, in form of work holidays, quitting employment and their health status has also been studied. Mothers who take care of CP children have reported poor health, reduced work participation and contribution to family income.[61]

In addition to the above mentioned costs, the burden of disability on the national economies is well known. Various countries across the globe, including India, provide funds, grants and aids to these children with cerebral palsy to help them self-sustain and cover the costs for their therapy and rehabilitation.[62,63]

Management of cerebral palsy:

CP has long been perceived as a non-treatable disease. Though not curable, the symptoms and co-morbidities can be mitigated there by improving the quality of life of these children. Managing a case of cerebral palsy is a huge task to a paediatrician as it involves not only treating the child, but also to alleviate the undue stress borne by the families and caregivers. Also, the wide spectrum of symptoms and co-morbidities associated with CP, mandate a multi-disciplinary approach in its management.[64]

A multi-disciplinary team in CP management usually involves the paediatrician at the centre of decision making responsibilities along with a team of neurologist, orthopaedic surgeons, occupational therapists, physiotherapists, speech therapists, nurses, counsellors, psychologists and health care works among the others.

The management of CP child has had a philosophical shift over the years. WHO's ICF has been instrumental in changing the view and approach of clinicians in treating Cerebral palsy. CP affects the body structure and function, activity and as well as participation. Traditional management goals in CP were more towards addressing the structural abnormalities but currently, the focus is mainly on maximizing the child's environment by activity improvement and enhancing their participation in the community. Evidence has shown the benefits of family-centred services in treatment and approach to a case of CP, focusing on the goals of child and caregivers and not just from a clinician's perspective. Family centered approach is also unique in a way that it respects the needs and wishes of each family and transcends the boundaries of different cultures and it also lays emphasis on the fact that a family is the constant unit of context for these children. [3,65-69]

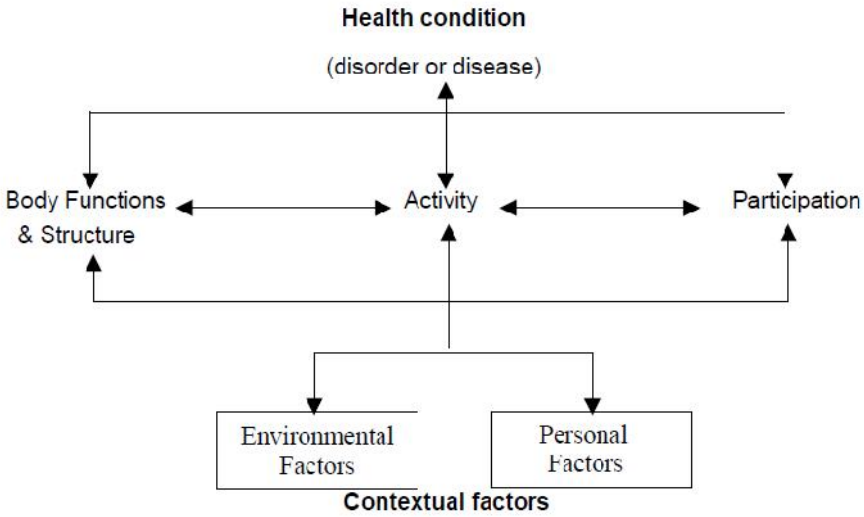


Fig 5: WHO classification of functioning, disability and health

Historically, CP has always been considered as a disease of childhood. But with improving medical facilities and rehabilitation therapies, the number of individuals with CP living into adulthood has substantially increased in the recent past. But at the same time, the training and orientation of internal physicians and surgeons who deal with adult patients has not been evolved to accommodate CP as a disease transcending into adulthood. Many a time patients and their caregivers also are more comfortable visiting the treating paediatricians rather than physicians, way into the adulthood.[67,70]

The goal of an intervention should be to modify the disease course. Novak et al, in their exhaustive review, opined that among 64 intervention techniques, 24% were effective, 70% were uncertain regarding the outcomes and 6% were ineffective. Physical therapy, medications and occupational therapy were the most effective of the interventions. Psychology, speech therapy, social work and education etc had a low quality of evidence for effectiveness. Though most of these interventions focused at body functions and activity but not participation of the above mentioned WHO's ICF, lack of evidence in this particular context doesn't mean they offer no benefit. But it should also be borne in mind that it is ultimately both activity and participation that impact the quality of life of these patients. [5,24]

To summarize, the interventions used should affect the following

- To correct tone and posture.
- Improve mobility
- Focus on mitigating co-morbidities
- To improve care given to the child
- Improve quality of life

- Provide comfort to both the child and family
- Make the child as self-sufficient as possible.

The factors to be considered before initiating the treatment are:

- Goals and expectations of patient and family and not just of clinician.
- The age of the patient
- Financial status
- Willingness for regular follow up and compliance.

Management of Motor impairments:

Before beginning the treatment modalities to correct the tone of a patient, it is important to evaluate the usefulness of tone, as hypertonia sometimes is beneficial. In a child with severe hypotonia in lower extremities, increase in central tone will help him to stand up on his feet and reducing tone in this patient may pose a negative effect. Broadly speaking, the aims of tone reducing treatment should be, to ease and maximize patient's functions and reduce the complications like pain, contractures, dislocations and subluxations. It is also prudent to always have a discussion with the family members before initiating any intervention and during the treatment in order to have **realistic and attainable goals** and to curtail any over expectations from the care givers or family members.[71]

Physiotherapy (PT) and Occupational therapy (OT):

This ranges from simple exercises to electrical stimulation. Although many modalities under PT lack conclusive evidence, they aid in helping the caregivers to learn to handle, wash, toilet and also feed their children and improve their posture and optimize the tone and mobility.

Among the various modalities, the ones with conclusive evidence include:

- Bimanual training for hemi-plegic CP: here patients are trained to use both the hands to improve functioning.[72,73,74]
- Constraint induced movement therapy (CIMT): unaffected limb usage is reduced in order to improve the function of affected side. Used in hemiplegics.[75,76]
- Context focussed therapy: here the environment or task is changed.[77]
- Goal directed functional training: improved gross motor function.[78,79]
- Strength training [80,81,82]
- Stretching: used for contracture prevention.[83]

Among those with ineffective evidence for improvement include:

- Hydrotherapy: aquatic based exercises to improve gross motor activities.[84,85]
- Neurodevelopmental therapy: direct, passive handling to optimize the functions. Used to prevent contractures, normalize the movements, enhances social and cognitive functions.[86,87]
- Sensory integration: they include activities to enhance adaption and also to organize sensations from both body and environment.[88]
- Electrical stimulation: stimulation of muscles through skin electrode to produce passive contraction to improve gait and muscle strength.[89,90]

Medications for spasticity:

Oral medications: Easy to administer and have better compliance**.** The availability of evidence for the effectiveness of these drugs is either inconclusive or of low quality. Used in patients with mild and widespread tone abnormality.[91]

Drug	Mechanism of action	side effect
Baclofen[92,93]	Binds to $GABA_B$ receptors and inhibits excitatory neurotransmitters	• Worsens hypotonia • Causes Constipation
Tizanidine[91,94]	Central α-2 agonist acting at spinal and supraspinal level	• Hypotension • Agitation • Depression • GI problems
Diazepam[94]	Binds to $GABA_A$ receptor enhancing endogenous inhibitory activity	• Drowsiness • Hypersalivation • Respiratory depression • Tolerance and dependence.

Other medications for spasticity:

Botulinum toxin type A:[95]

- Intramuscular injections are given to reduce spasticity
- Given at dose of 4U to 16U/kg
- Produces chemo denervation
- Best results are seen when given in children younger than 4 years without fixed contractures.
- Has high quality evidence with strong recommendations of use for lower limb spasticity.[96,97]

- When used along with occupational therapy has shown to improve hand functions.[98]
- Systemic weakness, ptosis, urinary incontinence etc are among the side effects.

Phenol and alcohol:[91]

- Perineurally injected using the guidance of electrical nerve stimulation under sedation or anaesthesia.
- Painful procedure
- Results are temporary.

Intrathecal baclofen:[25]

- Administered via subcutaneously implanted pump.
- Higher levels are attained in CSF compared to oral drugs.
- May cause coma, respiratory depression.

Surgical therapy:

Selective dorsal rhizotomy:[99,100]

- Severs dorsal lumbo-sacral roots in the spinal cord in order to relieve spasticity.
- Candidates are those with GMFCS II and III, between ages 4-7 years with good cognition, adequate strength and minimal dystonia
- Familial commitment to rigorous daily physical therapy for 12 months is mandatory.

Orthopaedic surgery and orthoses:

- Surgical correction or prevention of contractures like equinus foot deformity.
- Research showed poor quality evidence with chance of recurrence after early surgery.[101]
- Plaster casts to the limbs improves passive range of movements for lower limbs.[102]
- AFOs significantly reduce the ankle excursion and also increase the dorsiflexion angle to improve the transition from sitting to standing postures.[103,104]

Medications for dystonia:

Oral medications for dystonia:

Drug	**Mechanism of Action**	**Side effects**
Trihexyphenidyl [24]	Anticholinergic drug	• Dry mouth • Blurring of vision • Retention of urine • Reduced Gut motility

Surgical therapy for dystonia:

Deep brain stimulation: studies in adults with dyskinetic CP have shown beneficial results. Data in paediatric population is lacking in this regard.[105]

Feeding and nutrition:

- Feeding difficulties that arise due to bulbar/pseudobulbar palsy and dyskinesias are usually treated with oromotor exercises but the evidence for these interventions is of low quality. Sensory stimulation is given to jaw, lips, tongue, larynx, soft palate.[106]
- Gastrostomy will be needed in few patients with severe swallowing difficulties with inability to swallow food or water for 6 weeks, recurrent aspiration pneumonias etc. Adverse events have been reported due to feeding tube. [107,108]
- Dietary modification, change in food consistency, antacids etc may help in gastro esophageal reflux disease.
- Fundoplication for severe Gastro-oesophageal reflux may be done. No specific evidence is available with regard to CP children.[109]
- Supplementation of Vitamin D, Calcium and other micronutrients is needed to improve the child's nutritional status.

Drooling:

- One of the major co-morbidities of CP, drooling poses significant impedance to social acceptance.
- Various treatment modalities for drooling include
    - Oro-motor exercises
    - Pharmacotherapy includes drugs like Glycopyrrolate or trihexyphenidyl: act by reducing salivary flow and Botulinum toxin type A injected into salivary glands.[110]

- Surgery: ligation of submandibular and parotid ducts, removal of sublingual glands have all been tried but acceptance is low due to complications like ranula, dry mouth etc.[111]
- Behavioral therapy: For older children who are able to understand commands, a trial of behavioural therapy is initiated.[25]

Behaviour therapy:

Children with chronic illness like cerebral palsy may develop unhealthy thoughts, suicide ideation and depression.

Cognitive behaviour therapy has been helpful in identifying these thoughts and helps in restructuring of cognition and promotion of constructive thinking and actions. Though no strong supportive evidence is found in CP children, due to its high quality evidence in children without CP may be beneficial in CP.[5]

Conducive therapy: facilitates learning and rehabilitation.[112]

Adaptive assistive approach: supportive aids are used to improve daily functioning and also communication.[113]

Epilepsy management:

Being the most common co-morbidity of CP children, epilepsy management should be prioritised. Many times seizures are under recognised due to their partial/ focal nature.[114]

Appropriate oral anti epileptic drugs and a compliance are required for epilepsy management.

Pain Management:

Pain is almost always associated with vast majority of CP patients. Pain affects motor abilities and reduces sleep time there by affecting the quality of life of CP children. Its always important to communicate with the children who have good cognition or the parents regarding pain as it can be mitigated.[115-117]

The various causes of pain and their management in CP is as follows:[3]

Causes	Symptoms/signs	Management
Spasticity	Motor tone abnormality	• Protect the joints and neck during abnormal spasms; • Physiotherapy • diazepam for acute spasms • Baclofen • Botulinum neurotoxin type A • orthopaedic surgery
Gastro-Esophageal reflux	Poor feeding, lethargy, irritability, vomiting, poor weight gain, aspiration pneumonia	• upright posture • regular small meals • H2 blockers and PPIs
Hip subluxation	Pain during walking, sitting and activities involving hip movements	• Orthotic changes • NSAIDs • Anti depressants • Surgical correction
• Scoliosis • back pain	Pain in the sitting posture or complaints of shape changes in the back	• Orthotic changes • NSAIDs • Anti depressants • Surgery
Constipation	Solid and infrequent stools	• Optimal tone management • Regular intake of water, fruits and high fibre diet • Laxatives • suppositories
Physiotherapy associated	After or during physiotherapy	• Paracetamol or NSAIDs

Speech and language difficulties:

Many children with CP have development delay. So speech and language delay are common in them. A Cochrane review showed positive inclination, but low evidence for beneficial effects of using a speech and language therapy in CP.[118,119.]

Bowel and Bladder Dysfunction:

Constipation is a problem primarily due to tone abnormalities, poor feeding practices and immobility. Adequate tone management, excessive water and fibre diet are used to treat. Laxatives and suppositories may be given.

Bladder dysfunction leading to incontinence may be treated with bio feedback mechanisms, drugs, and occasionally surgery. [120,121]

Intellectual impairment:

30% of the patients with CP show intellectual impairment. A large well documented review has shown how intellectual impairment has a negative effect on a child's Quality of life and this becomes particularly difficult during the transition phase into adulthood. [122]

Parental counselling:

It's a very important aspect of caring for a child with CP. The impact CP has on the families of children is detrimental. Parental mental health issue has to be taken care off. There is a weak evidence of how it helps the parents of these children but nonetheless should be adapted into practice. Fostering the understanding of problems faced by them due to the condition of their children leading to undue stress in life

from relationships to work, to improve interpersonal and communication skills and to promote positive mental health is the need of hour.[123]

Despite so many modalities of interventions, there is a startling lack of evidence from global perspective to improve the participation of a child in the community. As Novak et al reviewed in their research work, no single intervention worked at more than one level of ICF. More research should give precedence to this domain with emphasis on activity and participation of the child which have long been ignored due to undue importance given to body structure and function level of ICF for decades.[5]

The impact of the above mentioned interventions has been quantified in different ways from subjective improvement of symptoms and signs to objective assessment in terms of functional classifications like GMFM scores to quality of life assessment. World Health Organization Quality of Life Assessment Group defined quality of life (QoL) as

‘‘an individual’s subjective perception of their satisfaction across various domains in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.’’

QoL in particular is one of the most important methods of quantification of the impact of these interventions as ultimately it is the improvement in quality of life is what both the patients and care givers strive for.[124]

QoL is multidimensional and the components vary as per the variables desired. Various researchers have used different components over the years. In 2002, Stewart proposed that QoL should be defined in terms of five domains, namely “material well-being, health, education and literacy, participation in the productive and social

sphere"; whereas Pollard & Lee in 2003 defined QoL in another five different domains of well-being: "physical, cognitive, psychological, social and economic. There has been a surge in usage of QoL based assessment in the recent years as it is a real-world indicator of the impact of interventions and helps in prioritizing the health related issues and monitoring the changes.[125-127]

Various QoLs have been used in the past by researches to measure the impact of interventional therapies in CP children.

- Pediatric Evaluation of Disability Inventory (PEDI).[125,128]
- Pediatric Quality of Life Inventory (PedsQL)[129]
- TNO-AZL Children's Health-Related Quality of Life (TACQOL) scale[130]
- the Caregiver Priorities and Child Health Index of Life with Disabilities[131]
- the Life style assessment Questionnaire-CP (LAQ CP)[132]

In 2009, Hoving and colleagues reported using a child health questionnaire that baclofen treatment had improvement in psychosocial domain of the QoL. Using exercise training program as the intervention, improvements were found in motor domain of TACQoL. Stiller in 2003, assessing the behavioural aspect of interventions using PEDI score, found that the group using intensive combination therapy had better impact than the group using conducive therapy alone as intervention.[133,134,135]

Many researches have quantified individual interventions in terms of QoL improvement but no study has quantified the improvement of child's Quality of life after subjecting them to a set of standard and systematic interventions. Among the many questionnaire's available for QoL assessment the LAQ-CP was validated for indian population in Delhi.[135,136]

Thus, with our study we aim to quantify the impact of a set of standard and systematic interventional therapies on the quality of life in children with cerebral palsy with an intention to dispel the myth of non-treatable nature of this disease and to show how if intervened early the interventions can certainly change the quality of life of these children, reducing their co-morbidities and making them and their families to lead a life as close to normalcy as possible.

CHAPTER 4 – METHODOLOGY

This study was conducted from January 2018 to December 2018 in the Child Development clinic(CDC) of KLES Dr Prabhakar Kore Hospital and Medical Research centre(MRC), Belagavi, a 2400 bedded hospital including super-specialities.

Study Design:

Hospital based Interventional study / Observational study

Study duration and study period:

One year duration from January 2018 to December 2018

Place:

Study was conducted in the department of Paediatrics, KLES Dr Prabhakar Kore Hospital and Medical Research Centre, Belagavi, a teaching hospital affiliated to Jawaharlal Nehru Medical College, Belagavi.

Source of Data:

Children with cerebral palsy between 3-10 years of age attending Child Development Clinic of KLES Dr. Prabhakar Kore Hospital and MRC were included in the study at their first visit.

INCLUSION CRITERIA:

All types of newly registered cases of Cerebral Palsy between 3-10 years of age were included as the Life style assessment Questionnaire – CP has been validated for the age group 3-10 years.

EXCLUSION CRITERIA:

The following children will be excluded from the study-

- Cerebral palsy cases already receiving interventional therapy
- Cases suspected to or diagnosed to have
  - Metabolic disorders
  - Genetic disorders
  - Chromosomal disorders
- Children with Cerebral palsy whose parents haven't consented for the study.

Sample size :

A convenient sampling of 50 children with cerebral palsy attending Child development clinic between 1st January 2018 to 30th September 2018 fulfilling the criteria.

Ethical clearance:

Prior to the commencement, study was approved by the institutional ethical committee, Jawaharlal Nehru Medical College, Belagavi.

Informed Consent:

Parents of the children with cerebral palsy who fulfilled the eligibility criteria were briefed about the nature of the study. Also, prior to the enrolment a written informed consent was obtained in the language known to them.

METHODOLOGY:

Once the child was registered in the CDC out patient clinic, he/she was examined after taking a thorough history and classified into the respective type of cerebral palsy.

If the child fulfilled the eligibility criteria he/she was enrolled into the study after taking an informed consent from the parents. Children known or suspected to have any metabolic, genetic disorders were excluded from the study after thorough investigations.

After taking the consent, relevant data was obtained from the parents and recorded in a structured proforma along with the details of examination.

The demographic details, presenting complaints, antenatal, perinatal and postnatal history, infancy history, relevant family history, anthropometry, details of thorough CNS examination and other systemic examination, relevant investigation reports like MRI, EEG, BERA were all obtained.

The child was classified into respective type of CP– anatomical, topographic, etiological classifications. He or she was also classified as per functional classification systems – Gross Motor Functional Classification system (GMFCS), Manual ability classification system (MACS). They were also subjected to Brief psychiatric rating

scale – children (BPRS-C). The neurological assessment of each patient was confirmed by paediatric neurologist.

The parents/care-takers were subjected to a questionnaire – the Lifestyle assessment Questionnaire-CP (LAQ-CP) (*vide infra*) and the score was calculated after ensuring that the parent/care-taker understood it in detail. Translators were used whenever necessary. The questionnaire was filled by the investigators based on the answers given by the care-givers.

After the final diagnosis, he or she was subjected to interventional therapies as required:

- Physiotherapy
- Pharmacotherapy
- Nutritional Rehabilitation
- Speech therapy
- Oro-motor stimulation
- Management of Co-morbidities

The physiotherapy was administered to the patients in the department of physiotherapy of the hospital as per the needs of the child and the parents were taught regarding method and timing of administering physiotherapy to the children as per the requirement. Similarly, speech therapist in child development clinic taught the parents regarding the various techniques like oro-motor stimulation, articulation therapy *et cetera* as per the requirements. Nutritional advice was given to the parents/caretakers of all the children enrolled. Medications were prescribed to the children as per the co-morbidities present.

Follow up:

The cases were all followed up every month ± 7days, for a period of six months. Reminder calls were made for follow up every month. The compliance to interventions was evaluated based on the improvement in the neurological and developmental assessment of the children on follow up. An indirect way used to assess the compliance was by the number of medications remaining with the patient every month. The information regarding the compliance to other interventional was taken at parent's word. During each follow-up the child was thoroughly examined and clinical details, improvement in symptoms and new complaints were noted and treatment was provided accordingly.

Towards the end of six months the parents/care-takers were once again subjected to LAQ-CP questionnaire, to assess the impact of interventions. The children were re-assessed based on GMFCS, MACS and BPRS-C.

Outcome variables:

1. Type of Cerebral palsy
2. Functional diagnosis of Cerebral palsy
3. Etiology of CP
4. Co morbidities associated with CP
    a. Epilepsy
    b. Global developmental delay
    c. Hearing impairment
    d. Gastrointestinal problems
    e. Dental problems
    f. Respiratory and urinary infections

g. Clinical evidence of malnutrition

h. Contractures and deformities.

5. Quality of life:

LAQ-CP questionnaire is used to evaluate the impact of disabilities in children with CP and their families. It has simple questions, systematized into six dimensions: clinical burden, physical independence, mobility, schooling, economic burden and social integration. Among these, clinical burden, physical independence, and mobility are directly concerned with the child's neurological status. Based on scores in each dimension, dimensional scores were calculated and a final standard score was obtained. They are expressed as a percentage score. This questionnaire was validated by in Delhi by Dobhal et al for Indian Patients.

The scores were analyzed as below

- ❖ Good- scores < 30%
- ❖ Mildly affected- scored between 30-50%
- ❖ Moderately affected – scores between 51-70%
- ❖ Severely affected- scores >70%

The impact of interventions was assessed based on pre and post intervention LAQ-CP scores, which is tested for significance on the basis of improvement of post intervention scores over pre intervention scores.

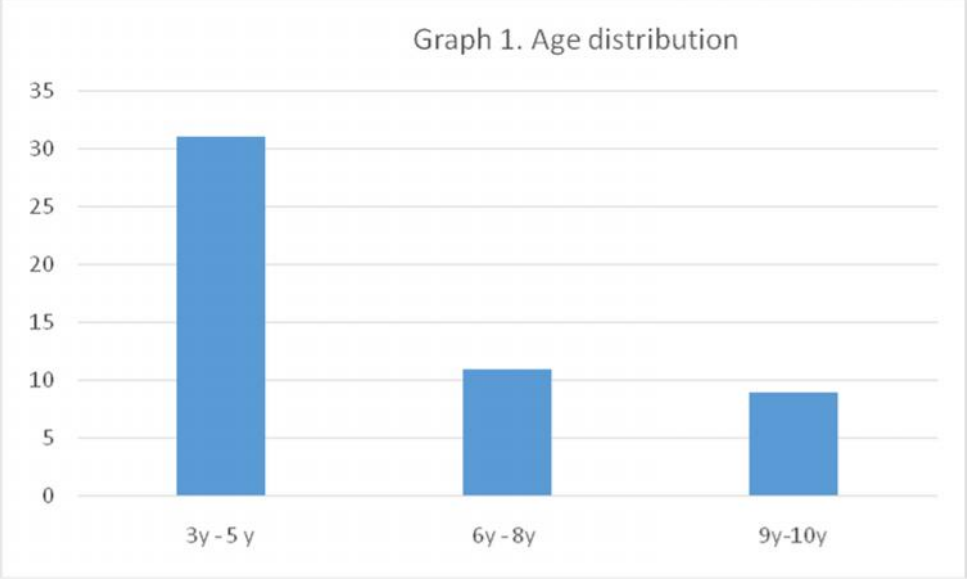
Data analysis:

The data which was obtained was coded and entered into Microsoft excel worksheets and analyzed using SPSS version 23. The continuous data was expressed as mean ± Standard deviation (SD). The LAQ-CP scores were calculated before and after interventions and compared using mean and standard deviations and student paired T test was used to find any statistical difference. The p value of < 0.05 was treated as significant. Functional classifications were also assessed based on similar statistical methods. The spearman's rank co-relation co-efficient was calculated between the LAQ-CP scores and the number of co-morbidities. For the categorical data frequencies will be calculated and expressed as percentages. The association of any pair of variables were tested for independence using Chi Square test.

CHAPTER 5- RESULTS

TABLE 1. Distribution of study population as per age.

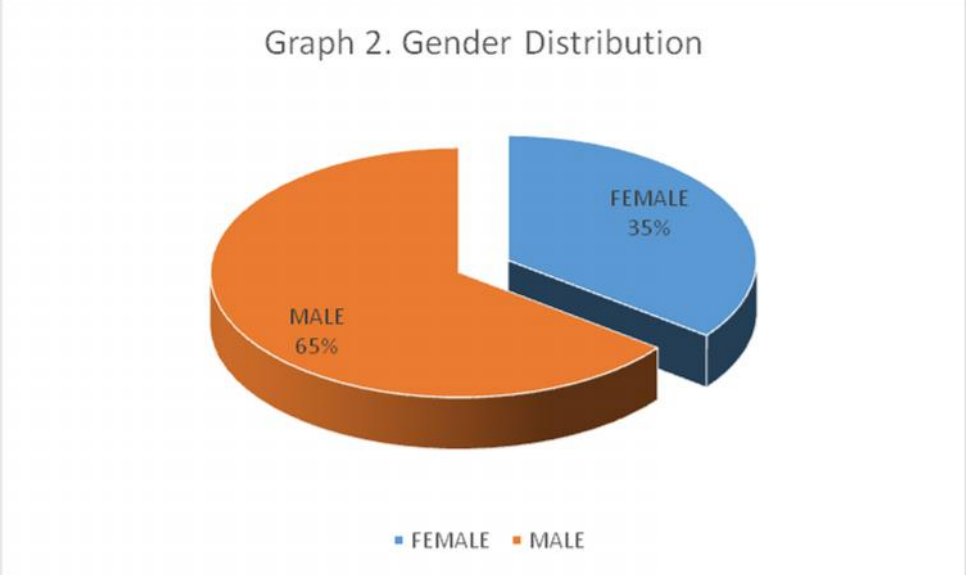
	Distribution n = 51	
AGE (in years)	Number	Percentage (%)
3-5	31	60.78
6-8	11	21.57
9-10	9	17.65
Total	51	100.00



In this study, most of the children were aged between 3-5 years (60.78%) followed by 6-8 years (21.57%). Children aged less than 3 years weren't enrolled as the Questionnaire wasn't validated for that age group.

TABLE 2. Distribution of study population as per gender

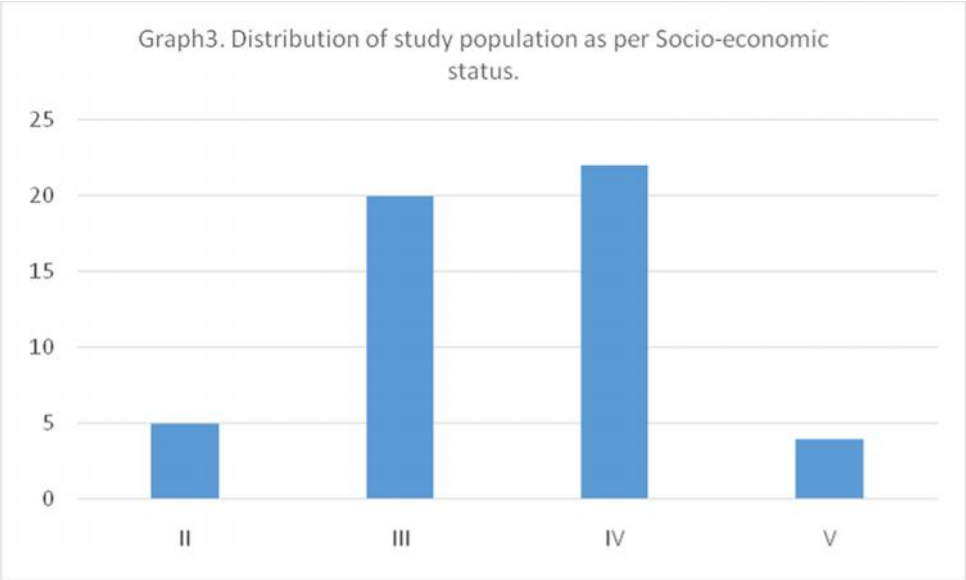
Gender	Distribution n = 51	
	NUMBER	PERCENTAGE
FEMALE	18	35.29
MALE	33	64.71
TOTAL	51	100.00



In the present study, Majority of the patients were boys (n=33) (65%); Male to female ratio was 1.8:1.

Table 3. Distribution of study population as per socio-economic status.

SOCIO ECONOMIC STATUS (CLASS)	Distribution n = 51	
	NUMBER	PERCENTAGE
II	5	9.80
III	20	39.22
IV	22	43.14
V	4	7.84
TOTAL	51	100.00



In this study, 22 children (43.14%) belonged to Class IV socio economic strata according to modified B.G Prasad's classification, followed by 20 children (39.22%) in class III.

Table 4. Distribution of patients according to maternal and family history

	Distribution n = 51		
	Findings	**NUMBER**	**PERCENTAGE**
Mother's Age (during child birth)	<20 years	7	13.72
	20-25 years	33	64.7
	25-30 years	9	17.64
	>30 years	2	3.92
Birth order	**1**	36	70.59
	2	9	17.65
	3	5	9.80
	4	1	1.96
DEGREE OF CONSANGUINITY	0	31	60.78
	1	0	0
	2	11	21.56
	3	9	17.65
FAMILY HISTORY	YES	3	5.88
	NO	48	94.11

In our study, the most common maternal age at birth was between 20-25 years (64.7%) followed by 25-30 years (17.64%). Most of the children i.e 36/51 were of first birth order (70.59%). 2nd degree consanguinity was seen in 11 (21.56%) patients, followed by 3rd degree consanguinity in 9 patients (17.65%). No consanguinity was seen in 31 patients. Family history of cerebral palsy was seen in 3 patients (5.88%) of which two of them are siblings enrolled in our study.

Table 5. Distribution of patients according to place of delivery.

PLACE OF DELIVERY	Distribution n = 51	
	NUMBER	PERCENTAGE
HOME	3	5.88
HOSPITAL	48	94.12

In our study, mothers of 38 children (74.50%) had more than 3 Ante natal check-ups. Forty eight of our patients (94.12%) were born in hospitals and three (5.88%) of them were born at home.

Table 6. Distribution of patients according to mode of delivery.

MODE of Delivery	Distribution n = 51	
	Number	Percentage
Vaginal	40	78.43
LSCS	11	21.56

In our study, Forty patients (78.43%) were born by vaginal route, of which 3 (7.5%) were forceps assisted. 11 (21.56%) patients were born via C-section.

Table 7. Distribution of patients according to maternal risk factors.

		Number	Percentage
Maternal Risk Factors	YES	44	86.2
Primigravida		36	70.58
PROM		5	25
Breech		1	5
Non Progression of Labour		9	45
Urinary tract infection		1	5
Ante partum Haemorrhage		1	5
Pregnancy induced hypertension		3	15

We observed from our study that 44 patients (86.2%) had maternal risk factors with Primigravida mother being a major risk factor seen in 36 patients (70.5%) followed by Non progression of labour, seen in 9 patients (45%) followed by Premature rupture of membranes in 5 (25%), Pregnancy induced hypertension in 3 (15%), breech presentation, Urinary tract infection and Ante partum haemorrhage in one patient each. Five of these patients (9.8%) had meconium stained amniotic fluid in utero.

Table 8. Distribution of patients according to birth weight

BIRTH WEIGHT	Distribution n = 51	
	NUMBER	PERCENTAGE
< 1kg	0	0.00
1 - 1.5Kg	8	15.69
1.5-2.5kg	22	43.14
>2.5kg	20	39.22
Unknown	1	1.96

In our study, 22 children out of 51 had Low birth weight, weighing between 1.5 to 2.5kgs (43.14%) followed by 20 babies (39.22%) with normal birth weight of > 2.5kgs and 8 babies (15.69%) with very low birth weight i.e 1 to 1.5kgs. There were no babies <1kg in our study.

Table 9. Distribution of patients according to duration of pregnancy.

	DISTRIBUTION n = 51	
Duration of Pregnancy	**Number**	**Percentage (%)**
TERM	40	78.43
LATE PRETERM	4	7.84
EARLY PRETERM	7	13.73

Forty (78.43%) children were term gestation, followed by 7 children (13.73%) who were early preterm (<34w+6d) and 4 (7.84%) children who were late preterm (35w to 36w+6d).

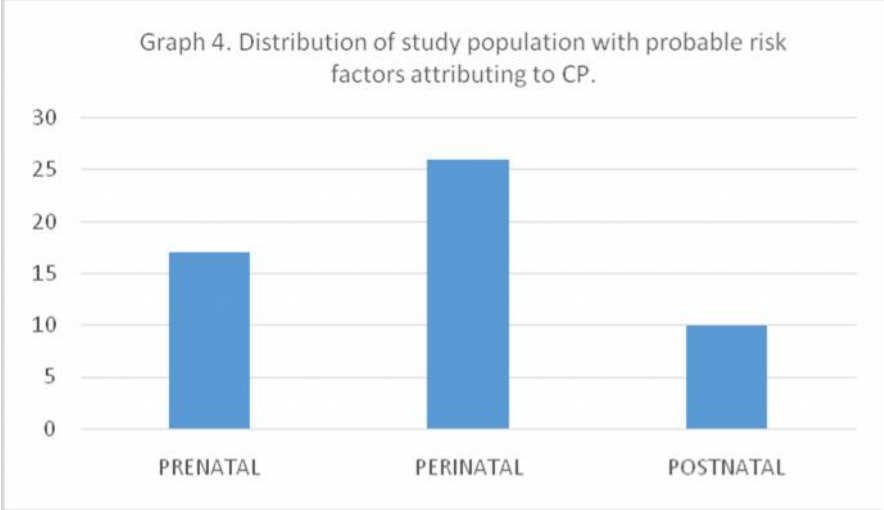
Table 10. Distribution of study population as per post natal risk factors in the new born period.

	Distribution n = 51	
POST NATAL EVENTS	NUMBER	PERCENTAGE
Delayed cry at birth	22	43.13
MECONIUM	5	9.80
JAUNDICE	6	11.76
SEPTICEMIA	3	5.88
SEIZURES	17	33.33
Respiratory distress	9	17.65
FEEDING	2	3.92
NICU Admission	38	74.5

Twenty two (43.13) of children enrolled in our study didn't cry at birth and required resuscitation, the objective details of which aren't known. Thirty eight patients (74.5%) had NICU admissions in the neonatal period. Seizures (33.33%) were the most common Post natal event seen in 17 patients of which 13 patients had delayed cry at birth, followed by Respiratory distress syndrome in 9 (17.65%). Five of our patients had meconium stained amniotic fluid in utero (9.80%).

Table 11. Distribution of study population with probable risk factors attributing to CP in prenatal, perinatal and postnatal period.

RISK FACTORS	NUMBER	PERCENTAGE
PRENATAL	17	33.33
PERINATAL	26	50.90
POSTNATAL	10	19.60



In the present study, the predominant risk factors were perinatal as seen in 26 children (50.98%), while post natal and prenatal risk factors were noted in 10 (19.60%) and 17 children (33.33%) respectively. Among Perinatal risk factors, 22 had delayed cry (43.13%), 3 had Premature rupture of membranes (PROM) (5.88%) of which two of them had associated prematurity with delayed cry, 1 patient had delivered at home with unknown resuscitation details. Among prenatal risk factors- 9 patients were LBW (1.5kgs – 2.5kgs) (17.64%), 5 patients were Very low birth weight babies (1-1.5kgs Birth weight) (9.80%) with two of these patients having an associated PROM, prematurity in 11 (21.57%) with delayed cry in 2 of those patients, one had Urinary tract infection (1.96%). In our study, 1 patient had no known risk factor (1.96%).

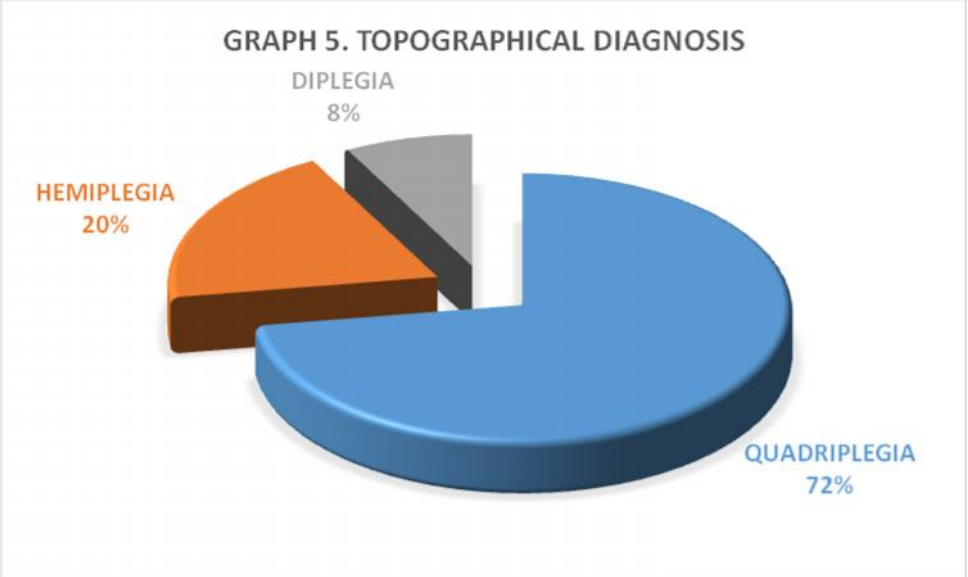
Table 12. Clinical Presentation of study population.

Clinical Presentation	Number	Percentage
MOTOR DELAY	46	90.20
LANGUAGE DELAY	40	78.43
SOCIAL MILESTONES DELAY	32	62.75
ABNORMAL MOVEMENTS	32	62.75
SEIZURES	22	43.14
INFECTION	9	17.65
EXCESSIVE CRY	14	27.45
BEHAVIOUR PROBLEMS	27	52.94
FEEDING PROBLEMS	26	50.98
DROOLING of Saliva	24	47.06
VISUAL DISTURBANCES	8	15.69
HEARING ABNORMALITIES	4	7.84
DENTAL CARIES	9	17.65

It is observed that, most of the children presented with developmental delay, among which motor delay was seen in 46 children (90.20%) followed by language delay in 40 children (78.43%) and social milestone delay in 32 children(62.75%). Development delay is followed by abnormal movements in 32 children (62.75%), behavioural problems in 27 children (52.94%) with 15(55.55%) showing hyperactivity, 5(18.5%) being autistic and 2 patients showing apathy(7.1%), feeding problems in 26 (50.98%), drooling of saliva in 24(47.06%), seizures in 22(43.14%), excessive cry in 14 (27.14%), infections in 9(17.65%), dental caries in 9 (17.65%), visual abnormalities in 8 (15.69%), hearing abnormalities in 4 children (7.84%).

Table 13. Distribution of study population according to the Topographical diagnosis.

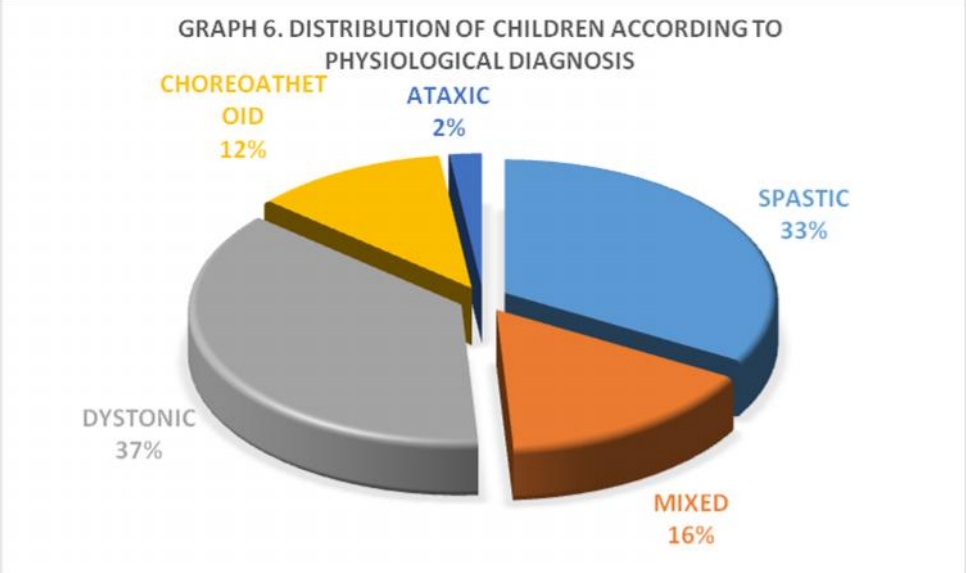
	Distribution n = 51	
Diagnosis	**Number**	**Percentage**
QUADRIPLEGIA	37	72.55
HEMIPLEGIA	10	19.61
DIPLEGIA	4	7.84
TOTAL	51	100.00



In the present study, Quadriplegic CP was commonest type seen in 37 children (72.55%) followed by hemiplegic CP in 10 children (19.61%) and diplegia in 4 (7.84%). There were no cases of triplegic or monoplegic CP cases in our study.

Table 14. Distribution of children as per physiological type of CP.

Type of CP	Distribution n = 51	
	Number	Percentage
DYSTONIC	19	37.25
SPASTIC	17	33.33
MIXED	8	15.69
CHOREOATHETOID	6	11.76
ATAXIC	1	1.96
TOTAL	51	100.00



In our study, Dystonic type of CP was the commonest with 19 (37.25%) cases, followed by Spastic CP with 17 cases (33.33%), Mixed CP with 8 (15.69%), Choreo-athetoid CP with 6 (11.76%). Ataxic CP was seen only in 1 child (1.96%).

Table 15. Distribution of children according to the Gross motor function classification system (GMFCS) - Pre intervention.

	Distribution n = 180	
Level	**NUMBER**	**PERCENTAGE**
1	12	23.53
2	10	19.61
3	8	15.69
4	12	23.53
5	9	17.65
TOTAL	51	100.00

The Gross Motor Function Classification System for CP is based on self-initiated movement with specific emphasis on sitting and walking. Level 1- signifying "CP of minimal severity" was seen in 12 (23.53%) patients, while level 4 & 5 signifying "CP of maximum severity" was noted in 12 (23.53%) and 9 (17.65%) of the children.

Table 16. Distribution of children as per Manual Ability Classification Systems (MACS) – Pre intervention.

	DISTRIBUTION n = 51	
MACS	**NUMBER**	**PERCENTAGE**
1	12	23.53
2	11	21.57
3	9	17.65
4	8	15.69
5	11	21.57
TOTAL	51	100.00

The Manual Ability Classification System describes how children with CP use their hands to handle objects daily. It has five levels. The levels are based on the child's self-initiated ability to handle objects and their need for support, with level 1 being easy handling of the objects to level 5 being severely restricted ability to complete simple actions. In our present study, 12 (23.53%) children had level 1 ability, whereas 11 (21.57%) of them had severely limited ability.

Table 17. Distribution of study population as per Brief Psychiatric Rating Scale children (BPRS-C) - Pre intervention.

BPRS-C score	Distribution n =51	
	Number	Percentage
1-3	4	7.8
4-6	22	43.13
7-9	14	27.45
10-12	9	17.64
>13	2	3.92

In our present study, many of the patients were clustered around the scores of 4-6 on the BPRS-C with 22 in number (43.13%), followed by scores of 7-9 with 14 in number (27.64). 11 patients had a score of more than 10. After the interventional therapy, the number of children with lower scores less than 6 improved by 3 patients, where as the number of children in high score group(score >10) signifying high behaviour problems reduced from 11 to 5.

Table 18. Distribution of study population as per co-morbidities.

	Distribution n = 51	
CO-MORBIDITIES	**NUMBER**	**PERCENTAGE**
Neurological Co-morbidities		
SEIZURE episodes in last six months	23	45.10
Global Development delay	43	84.31
HEARING Abnormalities	6	11.76
VISUAL Disturbances	6	11.76
SPEECH Abnormalities	30	58.82
BEHAVIOUR problems	20	39.22
Non Neurological Co-morbidities		
GI abnormalities	10	19.61
Respiratory infections	8	15.69
DROOLING of saliva	28	54.90
UTI	0	0.00
DEFORMITIES	5	9.80
DENTAL CARIES	4	7.84

In our study, Global development delay was the major co-morbidity associated with CP children as seen in 43 patients (84.31%). Among the other neurological co-morbidities, speech difficulties were reported in 30 (58.82%), followed by Seizure episodes in last 6 months in 23 children(45.1%), behavioural abnormalities in 20 children (39.22%), visual abnormalities in 8 (15.6%) with squint being commonest (6/8) followed by refractive error (2/8). Hearing abnormalities were seen in 4 children (7.8%). Among the non-neurological abnormalities, drooling in 28 (54.9%) was the commonest followed by constipation as seen in 10 children (19.61%), recurrent respiratory infections in 8 (15.65%), deformities in 5 (9.8%) and dental caries in 9 (7.84%).

Table 19. Distribution of study population as per Lifestyle assessment questionnaire –CP scores (LAQ-CP score) - Pre intervention.

	Distribution n = 51	
Score	**Number**	**Percentage**
Good	10	19.60
Mild	8	15.68
Moderate	25	49.01
Severe	8	15.68
total	51	100

In our present study, we found that most of the study population i.e 25(49.01%), had moderate disability LAQ-CP scores, followed by Good scores in 10 children (19.60%), Mild in 8 children (15.68%) and severe in 8 children (15.68%).

Table 20. Parameters of Life style assessment Questionnaire (LAQ) – CP – Pre and Post interventions

	PRE INTERVENTION					POST INTERVENTION					
	MEAN	**S.D.**	**MEDIAN**	**MINIMUM**	**MAXIMUM**	**MEAN**	**S.D.**	**MEDIAN**	**MINIMUM**	**MAXIMUM**	**p VALUE**
CLINICAL BURDEN	0.50	0.26	0.38	0.15	1.35	0.39	0.20	0.30	0.08	0.90	< 0.0001
ECONOMIC BURDEN	0.98	3.24	0.00	0.00	13.67	0.66	2.68	0.00	0.00	13.67	0.1208
PHYSICAL INDEPENDENCE	21.74	10.07	25.29	1.49	33.47	18.62	9.95	20.08	0.74	31.24	< 0.0001
MOBILITY	15.75	7.05	16.39	3.86	30.86	14.55	7.00	14.52	2.89	30.86	< 0.0001
SCHOOL	0.34	0.30	0.40	0.00	0.80	0.31	0.30	0.40	0.00	0.80	0.0545
SOCIAL INTEGRATION	9.54	3.58	10.50	1.40	16.77	8.57	3.41	9.10	1.40	15.40	< 0.0001
FINAL LAQ	52.78	20.11	56.15	12.57	92.67	46.91	19.74	49.59	12.42	91.67	< 0.0001

The LAQ-CP questionnaire, had six Domains: clinical burden, physical independency, mobility which directly deal with the neurological abnormalities and three other domains, the economic burden (Cost associated with treatment), Schooling and social integration, which indirectly depend on the severity of the neurological abnormalities.

In our present study, the primary objective was to study the impact of interventional therapies on the Quality of life in children with CP. At the end of our study, we noticed that there is significant effect of interventional therapies on the Quality of life in CP children, especially in neurological domains, with Clinical features ($p < 0.0001$), physical dependency ($p < 0.0001$) and mobility ($p < 0.0001$) showing significant improvement as tested by student paired t-test. Among the non-neurological Domains, social integration which dealt majorly with the parental impact of CP showed significant improvement after the interventional therapies ($p < 0.0001$).

Table 21. Impact of intervention on Clinical burden domain

Domain	**Mean (Pre intervention)**	**Mean (Post intervention)**	**P value**
Clinical Burden	0.50	0.39	<0.0001
Parameter	**Number of patient's showing improvement**		
Reduction in visits to the doctor	26		
Reduction in Hospital stay	10		
Reduction in Seizure episodes	20		

When the domains were analysed individually to assess the parameters, we observed that in the clinical burden domain noteworthy improvement was seen in the reduction of number of visits to a doctor and length of hospital stay. These two questions in the questionnaire dealt with the occurrence and severity of co-morbidities, which have shown improvement with the intervention therapies. Seizure episodes have shown a significant reduction in our study with anti-epileptic medications as 23 patients have reported reduced seizure episodes in last six months after initiating the antiepileptic medications.

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Table 22. Impact of interventions on physical independency domain

Domain	**Mean (Pre intervention)**	**Mean (Post intervention)**	**P value**
Physical independency	21.74	18.62	<0.0001
Parameter	**Number of patient's showing improvement**		
Improvement in Fine motor activities	3		
Improvement in Gross motor activities	10		
Reduction of Burden of lifting the child	35		
Reduction in night awakenings	23		

Among the physical independency domain, there were certain questions which dealt with day to day activities and could be categorised as fine and gross motor activities. There was an improvement in gross motor activities in 10 subjects and fine motor activities in 3. Much improvement was seen in the question which dealt with weight associated burden of lifting and carrying the child with 35 patients showing reduction and frequencies of sleep disturbances with 23 subjects showing reduction

Table 23. Impact of interventional therapies on mobility domain

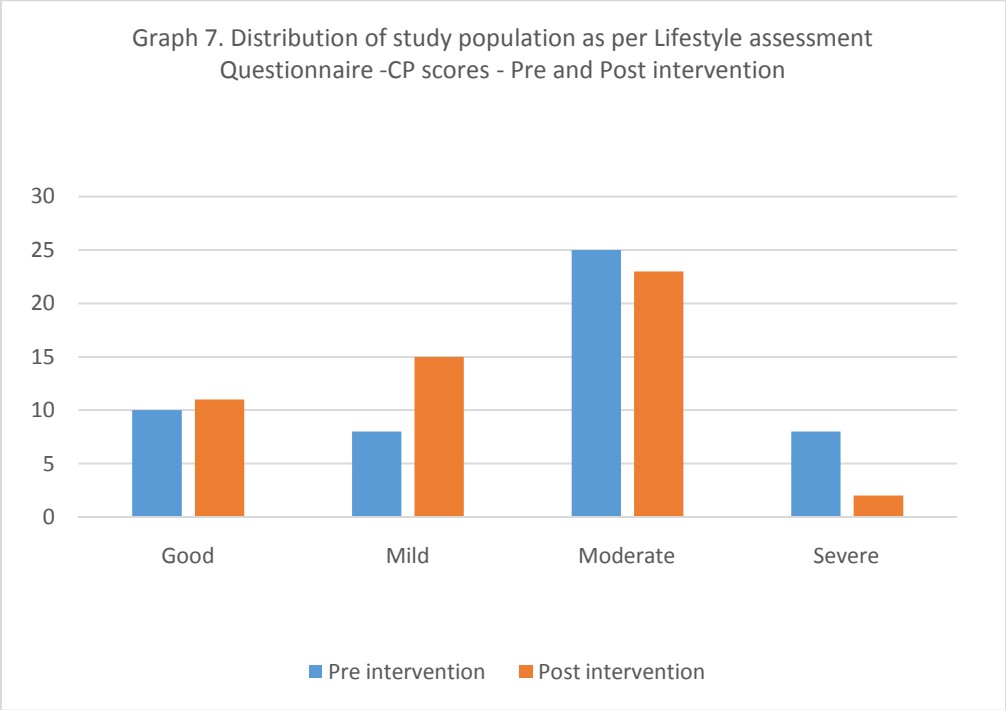
Domain	**Mean (Pre intervention)**	**Mean (Post intervention)**	**P value**
Mobility	15.75	14.55	<0.0001
Parameter	**Number of patient's showing improvement**		
Improvement in frequency of unaccompanied outings	6		
Increase in Frequency of outings.	17		

Among the mobility domain, note-worthy improvement was seen in increased frequency of outings in 17 subjects and increased frequency of unaccompanied outings in 6.

Table 24. Impact of interventions on social integration domain.

Domain	Mean (Pre intervention)	Mean (Post intervention)	P value
Social Integration	9.54	8.57	<0.0001
Paramter	**Number of patient's showing improvement**		
Reduction in stress on parents life	22		

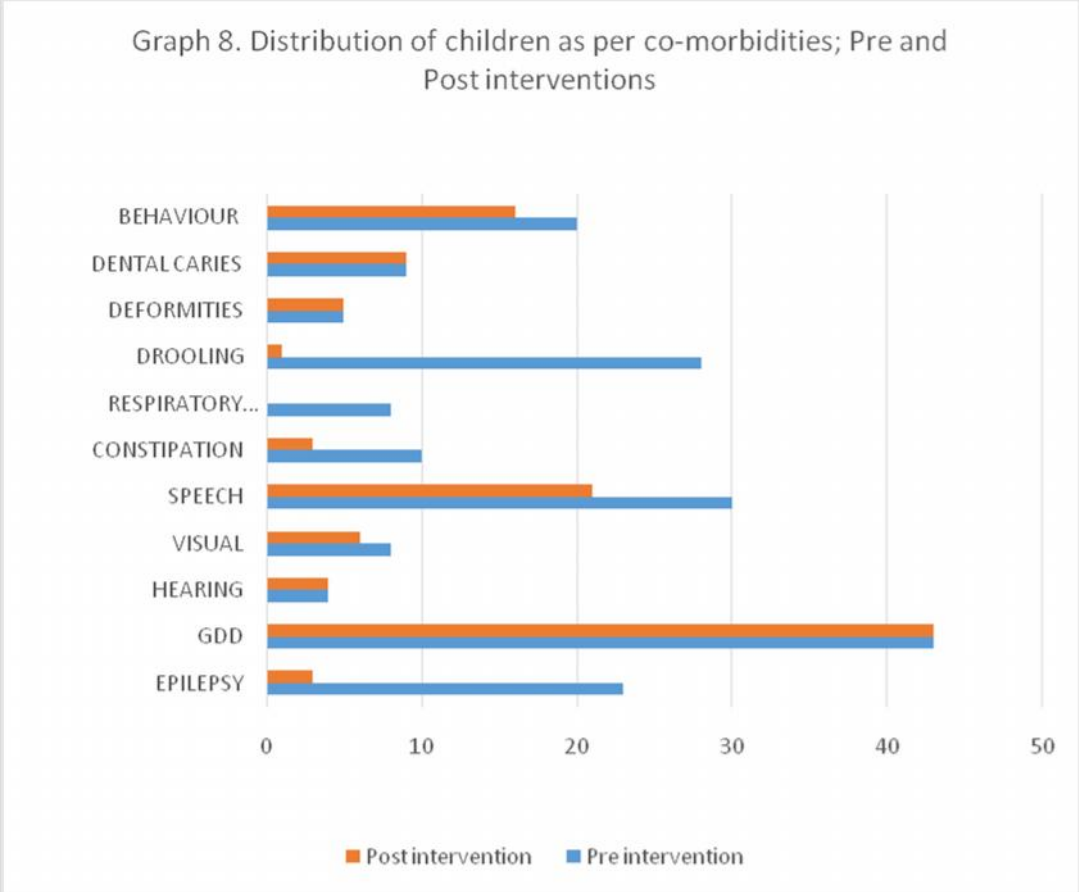
Among the social integration domain, 22 parents reported reduced stress on their lives after six months of interventions.



In the above graph, we can see the improvement in the scores of subjects. Total number of subjects with good scores improved from 10(19.6%) to 11 (21.5%), mild scores from 8(15.68%) to 15(29.41%). The number of subjects with moderate disability scores reduced from 25(49.01%) to 23(45.09%) and In the severe disability group from 8(15.68%) to 2 (3.92%).

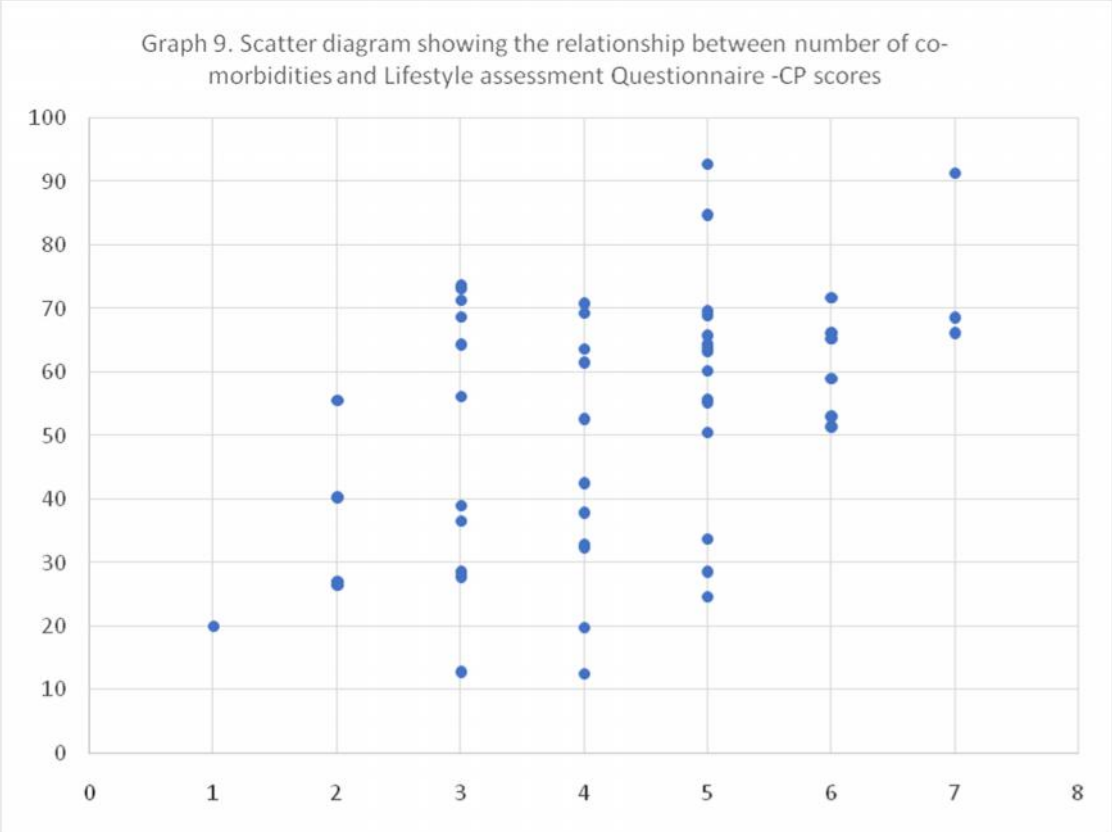
Table 25. Comparison of co-morbidities in the study population- Pre and Post intervention.

	PRE INTERVENTION		POST INTERVENTION	
CO-MORBIDITIES	**NUMBER**	**PERCENTAGE**	**NUMBER**	**PERCENTAGE**
Neurological Co-morbidities				
SEIZURE EPISODES in last 6 months	23	45.10	3	5.88
GDD	43	84.31	43	84.31
HEARING ABNORMALITIES	4	7.8	4	7.8
VISUAL ABNORMALITIES	8	15.6	6	11.7
SPEECH DIFFICULTIES	30	58.82	21	41.18
Non-neurological Co-morbidities				
CONSTIPATION	10	19.61	3	5.88
RESPIRATORY INFECTIONS	8	15.69	0	0.00
DROOLING	28	54.90	1	1.96
DEFORMITIES	5	9.80	5	9.80
DENTAL CARIES	9	7.84	9	7.84
BEHAVIOURAL ABNORMALITIES	20	39.22	16	31.37



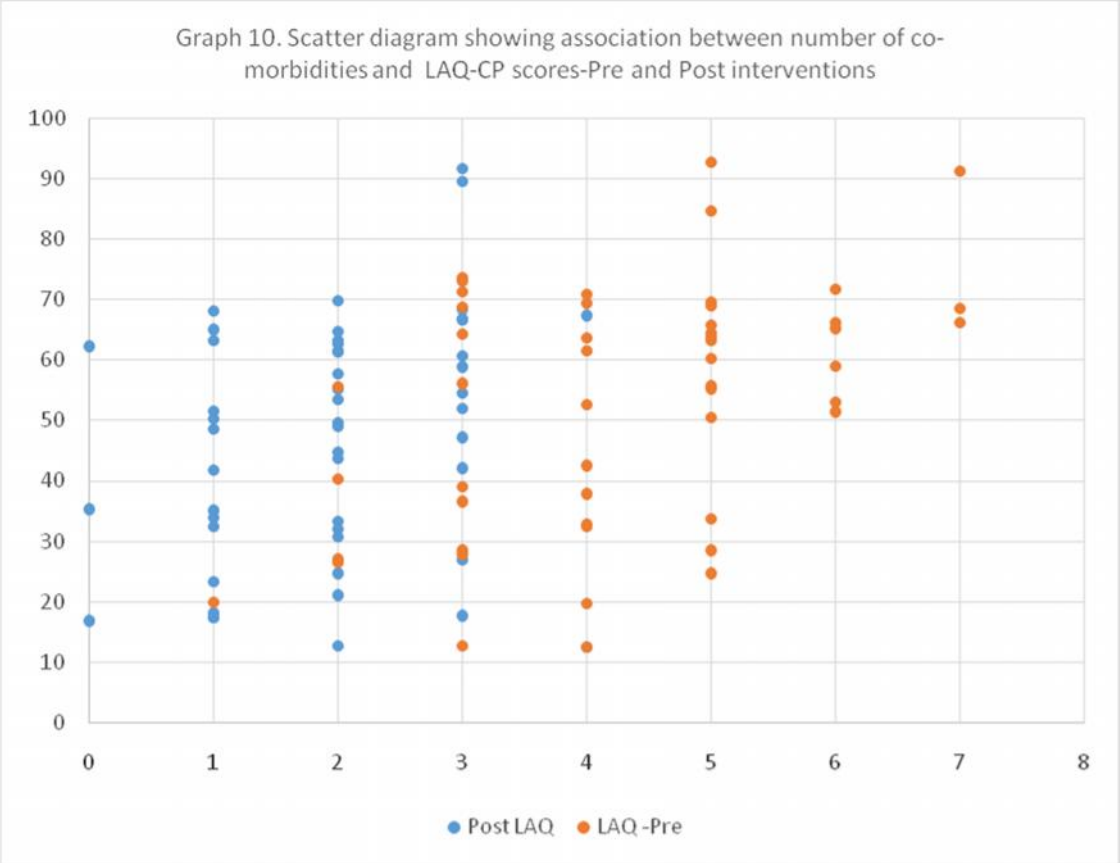
Following the interventional therapies, noteworthy reduction has been seen in various co-morbidities. The median number of co-morbidities reduced from 9.5 to 5.5 after interventional therapies. Among the non-neurological co-morbidities, Incidence of Recurrent respiratory infections has reduced to 0%. Drooling of saliva which was taken into account based on the presence of wetting of dress and skin changes around mouth, improved substantially with 27/28 patients showing improvement. Seven out of 10 patients also showed improvement in constipation after interventions. Among the neurological co-morbidities, Seizure frequency was considerably reduced in many children with 20/23 children showing reduced frequency or being seizure free during six months after subjecting them to interventions.

Graph.9 Showing rank co-relation between number of co-morbidities and Lifestyle assessment Questionnaire –CP scores. (Spearman's Rank Co-relation co-efficient)



In our study, we found that there is a significant co-relation between number of co-morbidities and the LAQ-CP scores with a spearman rank co-efficient of 0.3789 and p value of 0.0059.

Graph 10. Graph showing the comparison between the Co-morbidities and Pre and Post intervention Lifestyle assessment Questionnaire CP scores.



In the above scatter diagram, we can see a comparison between the co-morbidities pre and post interventions, where a noteworthy improvement in the number of co-morbidities post intervention therapies.

Table 26. Association between GMFCS (Gross motor function classification system) and LAQ-CP (lifestyle assessment questionnaire –CP) scores-pre intervention.

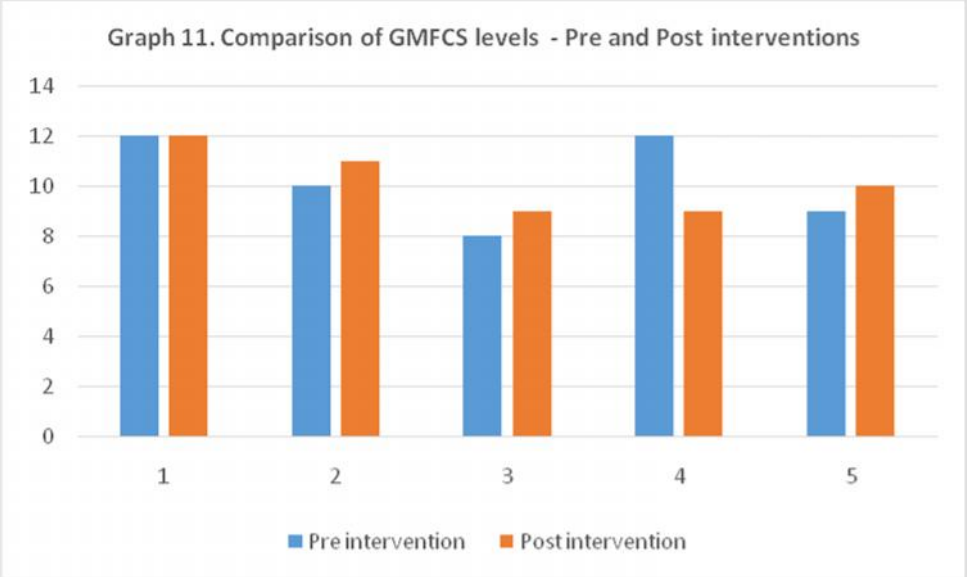
	LAQ-CP scores				
GMFCS	**Good**	**Mild**	**Moderate**	**Severe**	**TOTAL**
1	9	2	1	0	12
2	1	5	4	0	10
3	0	1	5	2	8
4	0	0	9	3	12
5	0	0	6	3	9
TOTAL	10	8	25	8	51

In our study, we found a significant association between the GMFCS grade and LAQ-CP scores. (p value <0.0001). i.e higher the GMFCS scores, Higher is the LAQ-CP score and worse the disability.

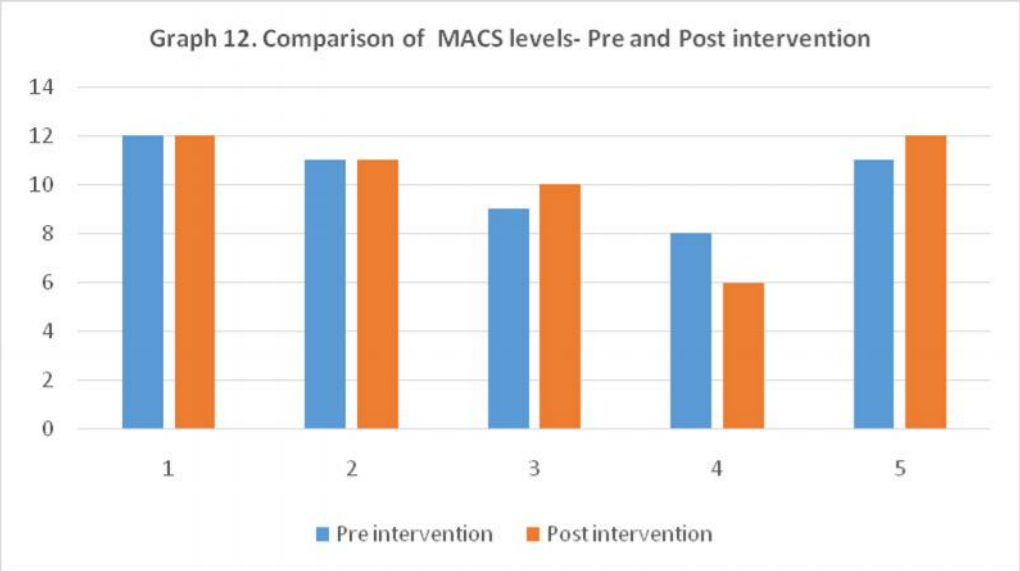
Table 27. Association between MACS (Manual ability classification system) and LAQ-CP (Lifestyle assessment questionnaire –CP) scores Pre-intervention.

	LAQ-CP scores				
MACS	**Good**	**Mild**	**Moderate**	**Severe**	**TOTAL**
1	9	1	1	1	12
2	1	5	4	1	11
3	0	2	7	0	9
4	0	0	5	3	8
5	0	0	8	3	11
TOTAL	10	8	25	8	51

In our study, we found a significant association between the MACS grade and LAQ-CP scores. (P value < 0.0001) i.e higher the MACS scores, higher is the LAQ-CP score and worse the disability.



In our study, following the interventional therapies, 2 patients in the GMFCS class 4 have shown improvement, with one improved to class 3 and another to class 2. One patient in class 4 has worsened to class 5. Rest of the patients had no change in GMFCS grades.



Following the interventional therapies, one patient in class 4 has improved to class 3. Whereas one patient who also had a worsened GMFCS grade to class 5 post intervention, worsened to class 5. Rest of the patients had no change in MACS grade.

Table 28. Comparison of Brief Psychiatric Rating Scale children (BPRS-C) - Pre and Post intervention.

BPRS-C score	Pre intervention		Post intervention	
	Number	Percentage	Number	Percentage
1-3	4	7.8	7	13.72
4-6	22	43.13	22	43.13
7-9	14	27.45	17	33.33
10-12	9	17.64	4	7.84
>13	2	3.92	1	1.96

After the interventional therapy, the number of children with lower scores less than 6 improved by 3 patients, whereas the number of children in high score group(score >10) signifying high behaviour problems reduced from 11 to 5.

Table 29. Association of Topographical diagnosis with Quality of life (LAQ-CP scores) - Pre-intervention

TOPOGRAPHY	LAQ – CP scores (Pre intervention)								
	Good	%	Mild	%	Moderate	%	Severe	%	TOTAL
QUADRIPLEGIA	5	13.51	4	10.81	20	54.05	8	21.62	37
HEMIPLEGIA	4	40.00	4	40.00	2	20.00	0	0.00	10
DIPLEGIA	1	25.00	0	0.00	3	75.00	0	0.00	4
TOTAL	10	19.60	8	15.68	25	49.01	8	15.68	51

(p value = 0.0382)

In our study, we noted that children with Quadriplegic CP have higher LAQ-CP scores with 20 (54.05%) and 8 (21.62%) children having moderate and severe disability respectively, followed by diplegic CP where 3 patients (75%) have moderate disability and hemiplegics where 2 patients(20%) have moderate disability. This difference was statistically significant as 100% of all the severely disable children belonged to quadriplegia group (p=0.0382).

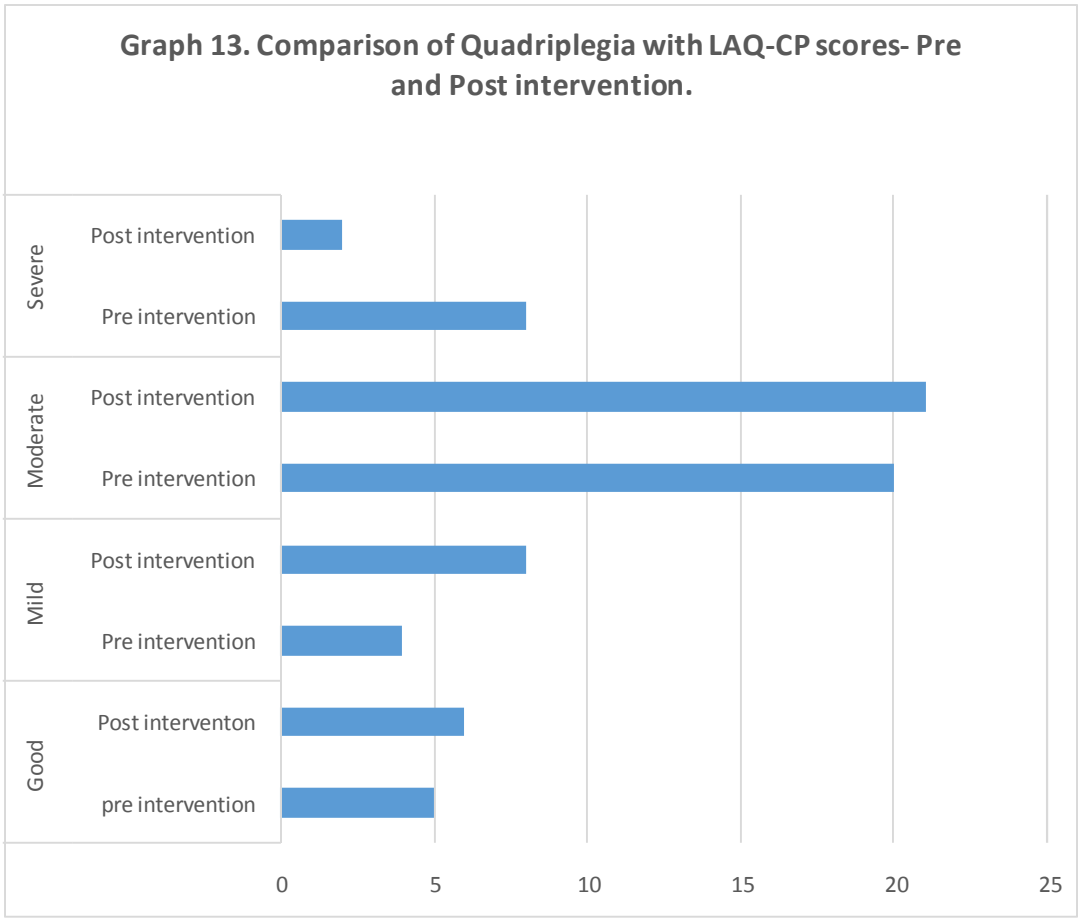
Table 30. Association of Topographical diagnosis with LAQ-CP scores post interventional therapies.

	LAQ-CP scores (Post intervention)								
	Good	**%**	**Mild**	**%**	**Moderate**	**%**	**Severe**	**%**	**Total**
QUADRIPLEGIA	6	16.2	8	21.6	21	56.7	2	5.4	37
HEMIPLEGIA	4	40.00	5	50.00	1	10.00	0	0.0	10
DIPLEGIA	1	25.00	2	50.00	1	25.00	0	0.0	4
TOTAL	11	21.50	15	29.41	23	45.09	2	3.92	51

Post interventional study, we found improvement among Quadriplegic CP children as the number of patients from severe disability reduced from 8 to 2 after interventions. Similar trend was seen among hemiplegic and diplegic CP children.

In Hemiplegic CP group, one patient from moderate disability group improved to mild disability; there was no change seen among the others.

Among the diplegic CP group , 2 patients from the Moderate disability group improved to mild disability with no change among the rest.



We noted that post interventions, there was improvement in disability among Quadriplegics from 8 (21.62%)to 2 (5.4%) among severe disability group, followed by increase in number in mild disability group from 4 (10.81%) to 8 (21.6%).

Table 31. Association of Physiological diagnosis with LAQ-CP scores- Pre interventions

Physiological diagnosis	Pre intervention LAQ scores								
	Good	**%**	**Mild**	**%**	**Moderate**	**%**	**Severe**	**%**	**TOTAL**
DYSTONIC	1	5.26	3	15.79	11	57.89	4	21.05	19
SPASTIC	6	35.29	4	23.53	7	41.18	0	0.00	17
MIXED	0	0.00	0	0.00	6	75.00	2	25.00	8
CHOREOATHETOID	3	50.00	1	16.66	0	0.00	2	33.33	6
ATAXIC	0	0.00	0	0.00	1	100.00	0	0.00	1
Total	10	19.60	9	15.68	25	49.01	8	15.68	51

(p=0.1549)

Among the severely disable group, we found that 4/8 belong to dystonic CP. Among dystonic CP, 11 (57.89%) patients had moderate score with 4 (21.05%) having severe scores. Among Spastic CP, 6 (35.29%) patients had a good score, followed by 4 (23.53%) with mild and 7 (41.18%) with moderate scores. Among mixed CP, 6 (75.00%) patients had Moderate score and remaining 2 (25.00%) had severe score. Choreo-athetoid group, 3 (50%) had good scores, followed by 2 (33.33%) with mild and 2(33.33%) with severe scores. We had only one patient in ataxic group and had moderate disability. There was no statistically significant association noted between the type of CP and LAQ-CP scores.

Table 32. Comparison of physiological Type of CP with LAQ-CP scores, Pre and Post interventional therapies.

		Good	Mild	Moderate	severe	TOTAL
SPASTIC CP	**PRE intervention**	6	4	7	0	17
	POST intervention	6	8	3	0	17
MIXED CP	**PRE intervention**	0	0	6	2	8
	POST intervention	0	0	7	1	8
DYSTONIC CP	**PRE intervention**	1	3	11	4	19
	POST intervention	4	4	9	2	19
CHOREOATHETOID CP	**PRE intervention**	3	1	0	2	6
	POST intervention	3	1	2	0	6
ATAXIC CP	**PRE intervention**	0	0	1	0	1
	POST intervention	0	0	1	0	1

Among the spastic CP group, the number of children with moderate disability improved from 7 to 3, as four of them had improved LAQ-CP scores from moderate to mild. Amongst Mixed CP one patient improved from severe disability to moderate group, while the rest showed no change. Among the dystonic CP group, 3 patients with mild disability improved to LAQ-CP score-good, where as 4 patients from moderate group improved to mild and two from severe disability group improved to moderate disability. Among the Choreo-athetoid group 2 patients with severe disability improved to moderate disability scores.

CHAPTER 6- DISCUSSION

In the year 2006, the International Workshop on Definition and Classification of Cerebral Palsy defined CP as

"Cerebral palsy(CP) describes a group of permanent disorders of the development of movement and posture causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour; by epilepsy, and by secondary musculoskeletal problems".[1]

CP is one of the commonest childhood neurological disorders associated with varied spectrum of clinical presentation and co-morbidities which have a detrimental effect on a child's quality of life. Varied interventions have been used to alleviate these symptoms and co-morbidities. The effect or impact of these therapies can be assessed using various tools based on the problem being dealt with. One of the objective methods of assessing the impact would be by measuring the individual's quality of life pre and post interventions. World Health Organization Quality of Life Assessment Group has defined quality of life (QoL) as

''an individual's subjective perception of their satisfaction across various domains in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns." [124]

Health related-QoL scores are used to distinguish health related issues from environmental and social issues affecting the QoL. Our study was aimed to assess the impact of standard and systematic interventions on health related QoL.

This study was conducted in KLES Dr Prabhakar Kore hospital and Medical Research Centre, Belagavi from January 2018 to December 2018. 54 patients with Cerebral palsy attending the CDC OPD between the ages 3-10 years were enrolled after meeting the inclusion criteria. They were subjected to Life style assessment Questionnaire- CP (LAQ-CP) after the thorough assessment and were given necessary interventional therapies. They were followed up monthly for six months and were subjected to the LAQ-CP once again at the end of six months to look at the impact of these interventions on the quality of life. Three patients were lost to follow up.

In our study, we found a male preponderance with the majority of the patients being boys with 33 in number (64.71%) as compared to girls who were 18 in number (35.29%). These findings were consistent with Najar et al [137] from Kashmir and Dobhal et al [136] from Delhi where 64.91% were males and 35.08% females & 64% males and 36% females respectively. Where as in a study by Yamada et al [138] females were predominant (60.52%). The male to female ratio was 1.8:1 which was close to the ratio of 2.19:1 as reported by Subramaniam ND et al [139] from Chettinad. This difference may be difficult to explain but could be due to the fact that male child gets more preference in our society and thus are taken to health services for treatment more often than girls.

We enrolled patients over 3 years as the Questionnaire was validated for the age group of 3-10 years. It was documented in our study that majority of the children belonged to an age group of 3-5 years with 31 in number (60.78%) followed by 6-8

years with 11 children (21.57%) and 9-10 years with 9 children (17.65%). Najar et al [137] reported similar distribution pattern among their patients, with maximum cases between 2-5 years age group with 78.94%. The mean age in our study was 58.8 months which was similar to the finding by Dobhal et al. [136]

In our study, we found that majority of the cases were clustered among middle (class III) and lower middle classes (Class IV), with 20(39.22%) and 22 cases(43.14%) respectively as per Modified B.G Prasad classification and 4 patients in lower class (Class V). These findings are in concordance with Dobhal et al [136], who reported 32% and 49% patients in lower middle class and upper lower class respectively. Sundrum et al [140] from UK, reported similar results, where they noted significant attribution between socio-economic results and Cerebral palsy. Wu et al [141] from the United States reported increased incidence of Cerebral palsy among Black population who have low socioeconomic status.

Our study also noted second degree consanguinity in 11 patients (21.5%) and 3rd degree in 9 patients (17.65%). Consanguinity didn't have any association with type of CP (p value of 0.36 for topographic diagnosis and 0.76 for physiological type). Subramaniam ND et al [139] from southern India reported 23.33 percent consanguinity in their study whereas Bangash et al [142] reported 50% consanguinity from Pakistan among CP children in their study. We found family history of cerebral palsy in only three cases out of fifty one (5.88%). Two of three cases were siblings and both of them had dyskinetic CP secondary to birth asphyxia.

To conclude, among the socio-demographic factors, low socio-economic status and male gender were the major risk factors associated with CP in this study.

In our study, 44 patients had maternal risk factors (86.2%). We found that 36 children were born to primigravida mothers (70.59%). McIntyre et al [143] reviewed 6 studies which didn't report any conclusive evidence of association between birth order and CP and 4 studies which found a significant association. First birth order was followed by non-progression of labour, seen in 9 patients (45%) followed by Premature rupture of membranes (PROM) in 5 (25%), Pregnancy induced hypertension (PIH) in 3 (15%), breech presentation, Urinary tract infection and Ante partum haemorrhage in one patient each. The overall incidence of maternal risk factors from other Indian studies were low compared to our study. Najar et al [137] from Srinagar reported an incidence of 29.82% of maternal risk factors with PIH and multiple gestation being the commonest with 29.49%, followed by hypothyroidism (17.64%), Toxoplasma infection (11.76%), Rubella(11.76%), UTI(11.76%), Diabetes Mellitus(3.5%). Subramaniam ND et al [139] reported 35.3% maternal risk factors with Prolonged labour in 45.2%, followed by toxaemia in 28.3%, Ante partum haemorrhage in 18.8% and diabetes in 7.5%. None of them reported any statistically significant association between the risk factors and occurrence of cerebral palsy. The difference in incidence of maternal risk factors could be explained by the fact that in our study birth order was taken as a risk factor while the above quoted Indian studies didn't consider first birth order as a risk factor for CP. Five of these patients had meconium stained liquor in utero. McIntyre et al [143] found strong association between Antepartum Haemorrhage, PIH, meconium stained liquor and occurrence of Cerebral palsy, but didn't report any conclusive evidence of association in their review regarding PROM, breech presentation and CP.

In our study, majority of the mothers during child birth were between ages of 20-25 years i.e 33 in number (64.7%). Only 2 (3.92%) mothers were over 30 years

during the child birth. This data was in contrast to a study by Wu Yw et al [29] where a maternal age of >35 years was reported as a risk factor for CP. In a systematic review by McIntyre et al [143], maternal age of > 40years was associated with increased risk.

In our study we found that 48 (94.12%) patients were born in hospitals with access to basic medical facilities but the availability of a paediatrician during birth wasn't known. This was in stark contrast to results found by Subramaniam ND et al [139], where 40% of the deliveries were at home and Bangash et al [142] where 25% were home and assisted vaginal deliveries. In our study, 40 (78.43%) patients were born via vaginal route with three of them being forceps assisted and 11 (21.56%) deliveries were via Lower segment Caesarean section (LSCS). This wasn't in agreement with Subramaniam ND et al [139] who reported only 13% of deliveries via LSCS. A vast systematic review by McIntyre et al [143] reported LSCS and forceps as a risk factor for CP.

Perinatal risk factors were reported to be the commonest cause for developing cerebral palsy (50.9%) followed by prenatal risk factors (33.3%) and postnatal risk factors (19.60%) respectively. Among the perinatal risk factors, asphyxia was the commonest (22/26 i.e 84.6%) followed by Premature rupture of membranes (11.5%). Perinatal asphyxia was also the common overall risk factor for CP in our study with 22 patients (43.13%). This result was in substantial agreement with the reported values by Dobhal et al [136] (40.00%) and higher than the values reported by Najar et al [137] (31.8%). Sugimoto [137] from Japan reported perinatal asphyxia as a risk factor in only 12.8% of the enrolled patients. This relatively higher values from a developing country like ours could be attributed to the sub-optimal perinatal facilities.

We also noticed from our study that prenatal risk factors account for 33.33% cases of CP. Among the prenatal risk factors we associated to CP, prematurity was the commonest (21.57%) followed by Low birth weight (17.64%), Very low birth weight (9.80%) and urinary tract infection (1.96%). Dobhal et al [136] reported 26% cases with prematurity as a risk factor and Subramaniam ND et al [139] reported 11% incidence of prematurity. These findings were low compared to the reported incidence in the west. Bax et al [137] reported 34.3% cases with prematurity as a risk factor. The relatively higher incidence of cases with prematurity in the western studies could be due to the higher survival rates among preterm babies in developed countries owing to good perinatal health services and better neonatal survival rates. This proposition can also be supported by another study by Gulten et al [144], where LBW(45.1%) and prematurity (40.5%) were major causes over birth asphyxia(34.6%). Wu et al [141] also reported increased incidence of CP in LBW and Premature babies in their study from the United states. McIntyre et al [143] in their review also found significant association between low birth weight and occurrence of cerebral palsy.

Among the post natal events which could be attributed as risk factors for CP, neonatal hyperbilirubinemia was seen in 6 (11.76%) patients, respiratory distress in 9 (17.6%) and septicemia in 3 (5.88%) patients. Though seizures were seen in 17 (33.33%) patients in post-natal period, it is attributed to perinatal asphyxia in 13 (25.49%) patients. Similar observations were made by Najar et al [137] (13.6%) and Subramaniam ND et al [139] (10%) with respect to hyperbilirubinemia. Subramaniam ND et al [139] reported neonatal sepsis in 21% patients, whereas Najar et al [137] reported sepsis in 21.7% patients. McIntyre et al [143] found a strong association between neonatal sepsis, seizures and cerebral palsy.

In our study, we observed that development delay was the commonest presentation, with motor delay seen in 46 (90.2%) subjects followed by language and social milestones delay which were seen in 40 (78.43%) and in 32 (62.75%) respectively. Among the neurological problems developmental delay was followed by abnormal movements and posture in 32 (62.75%) children, behavioural problems in 27 (52.94%) children with 15(55.55%) showing hyperactivity, 5(18.5%) being autistic and 2 patients showing apathy (7.1%). Seizures were seen in 22 (43.13%) patients, visual disturbances in 8 (15.69%), hearing abnormalities in 4 (7.84%). Among the non-neurological problems feeding difficulty in 26 (50.98%) children, drooling of saliva in 24 (47%), excessive cry in 14 (27.45%), infections in 9 (17.65%), dental caries in 9 (17.65%) children were present in descending order.

When we looked into the topography of the disease, Quadriplegic CP was the most common type of CP as seen in 37 (72.55%) patients followed by hemiplegic CP in 10 (19.61%) and diplegic CP in 4 (7.84%). There were no triplegic or monoplegic CP children in our study. Among the physiological type of CP, dystonic CP was the commonest with 19 (37.25%) patients, while Spastic CP was seen in 17 (33.33%) followed by mixed CP in 8 (15.69%), choreo-athetoid in 4 (11.76%) and ataxic CP in 1 (1.96%) child. After assessing the results, we noted that dystonic quadriplegia was the commonest type of CP with 18 children (35.2%) followed by Spastic hemiplegia, mixed quadriplegia, choreoathetoid quadriplegia, spastic quadriplegia, spastic diplegia, ataxic CP with 10 (19.6%), 8(15.6%), 6(11.7%), 5 (9.8%), 2 (3.9)%, 1 (1.9%) respectively.

Dobhal et al [136] in their study in Delhi, found that Spastic CP was the commonest with 83% patients which was in stark contrast to our study where

spasticity was seen in only 33.33%. Dobhal et al [136] also reported Spastic diplegia with 35% incidence followed by spastic quadriplegia with 32% and spastic hemiplegia in 18%, Ataxic CP was seen in 3%, hypotonic in 4%, Mixed CP in 9% patients. All types of CP except spastic hemiplegia weren't in concordance with our study. Our reported incidences of different type of CP were also divergent from the values reported in Srinagar by Najar et al [137] , where Spastic diplegia was the commonest with 49.10% patients followed by spastic quadriplegia and hemiplegia in 19.29% patients. Bax et al [137] in their study also reported spastic hemiplegia as the commonest with 26.2% followed by spastic quadriplegia (81.6%). These findings aren't confirmatory with our study. In our study Dystonic Quadriplegia was the commonest type of CP, which wasn't in agreement with various studies done in our country, as Najar et al[137] and Dobhal et al[136] didn't report even a single case of Dystonic CP. Our study also had a relatively higher incidence of mixed CP with 8 (15.8%) cases, as Bax et al[137] and Najar et al[137] reported 2.6% and 5.26% cases of mixed CP respectively. The relatively high incidence of dystonic and mixed CP in our study can be attributed to the basal ganglia damage due to perinatal asphyxia, the most common risk factor in our study. The low incidence of dystonic and mixed CP from other studies could probably be due to lack of recognition of dystonia which goes under reported frequently.

Gross motor function classification system for cerebral palsy is based on self-initiation of movement where sitting (truncal control) and walking are particularly emphasized. GMFCS was developed to take into consideration the anticipated change in motor functioning of a child with age and development. It can be used to prognosticate and to assess the improvement in motor function after an intervention. It is divided into five levels.[44] Level I signifies "minimal brain dysfunction" and level

five signifies "maximal brain dysfunction." In our study children were equally distributed among various levels of GMFCS with 12 patients in level 1 and 4 (23.53%). 10 patients (19.61%) and 9 patients (17.65%) were in level 2 and 5 respectively. 8 patients had a GMFCS level of 3 (15.69%). Dobhal et al [136] reported maximum patients in level 4 and 5 with 28% and 30% respectively.

The Manual ability classification system classifies a child's ability to handle objects in daily activities. It is also classified into five levels. Level 1 signifies "ease of handling the objects successfully" and level 5 "severely limited ability to perform simple actions." In our present study even the MACS levels almost had an equal distribution across various levels drawing parallels with the findings on GMFCS levels.

The Brief Pyschiatric rating scale children (BPRS-C) was developed to provide a succinct profile on childhood behavioural and emotional symptomatology. Higher the score more is the severity of the problems.[145] In our study, many patients were clustered around the scores of 4-6 on the BPRS-C with 22 in number (43.13%), followed by scores of 7-9 with 14 in number (27.64). 11 patients had a score of more than 10. Hyperactivity was the most common behavioural problem observed in our study.

In this study all the children (100%) had one or the other associated co-morbid condition. The commonest neurological co-morbidity was Global development delay as noted in 84.31% of the patients followed by speech difficulties (58.82%), seizures (45.10%), behaviour problems (39.22%), visual disturbances (15.6%), hearing abnormalities (7.8%). Among the non-neurological conditions, drooling of saliva was the commonest (54.90%) followed by constipation (19.61%), recurrent respiratory

infections (15.65%), deformities (9.8%) and dental caries (7.84%). Subramaniam ND et al [139] reported delayed milestones as the commonest neurological co-morbidity in 57% of the patients, Mental retardation and behaviour abnormalities in 45% and seizures in 31%. Dobhal et al [136] also reported GDD to be the most common neurological abnormality (81%) followed by visual disturbances(43%), seizures (31%). Among the non-neurological co-morbidities drooling was the commonest, which was similar to the findings in our study.

In our study, we found that most of the study population i.e 49.01% had moderate disability LAQ-CP scores, followed by Good scores in 19.60%, Mild in 15.68% and severe in 8 children (15.68%). The LAQ-CP manual was first designed and validated in the United kingdom.[132] The Questionnaire has been categorised into six domains and takes into account very minute details of the child's condition-clinical burden, economic burden, physical independency, mobility, schooling and social integration. The score measures at any given point, the impact of disabilities on the lives of children with CP, as perceived by the parents/ care-givers. The scores obtained in our study were similar to the ones noted by Dobhal et al [136], where majority of the children were in moderate (37%) and severe (30%) disability groups. But in Malaysia, where a study using the same questionnaire showed a disparity as majority of that study population had good Lifestyle assessment scores(LAS).[136] This disparity can be explained by the difference in the health care facilities, demographic profiles and also psycho-social factors.

In our study, prior to the enrolment, out of 51 patients, 18 never received any treatment for CP and rest of the patients received treatment only for any acute health related condition. After the enrolment all these treatment naïve patients (100%)

received necessary medications and treatment for associated co-morbidities. Physiotherapy was received by 44 (86.27%), speech therapy in 39 (76.47%) subjects. At the end of six months of interventions, there was significant improvement in the scores. Total number of subjects with good scores improved from 19.6% to 21.5%, mild scores from 15.68% to 29.41%. The number of subjects with moderate disability scores reduced from 49.01% to 45.09% and in the severe disability group from 15.68% to 3.92%. The mean LAS score of all the subjects reduced from 52.78% to 46.91% after subjecting them to interventional therapies, which was highly significant (student paired t-test; $p < 0.0001$). Among the individual domains, clinical burden, physical independency, mobility and social integration have shown significant improvement (p value <0.0001). In our study we noted that with appropriate treatment, these children can have a significant improvement in their clinical condition and the overall quality of life.

Among the clinical burden domain, various questions dealing with number of hospital visits and weeks of hospital stay have shown improvement in 26 and 10 subjects respectively, with weeks of hospital stay and seizure frequency worsening in one subject. These two questions in the questionnaire dealt with the occurrence and severity of co-morbidities, which have shown improvement with the interventional therapies. Seizure episodes have shown a significant reduction in our study with anti-epileptic medications as 20 patients have reported reduced seizure episodes in last six months after initiating the appropriate antiepileptic medications. This probably can be attributed to the good compliance to the drugs. Though there was no statistically significant improvement in economic burden domain, the reduction in hospital visits, hospital stay and seizure frequency have all contributed to indirect reduction in economic burden in the treatment of these children.

Among the physical independency domain, there were certain questions which dealt with day to day activities and could be categorised into fine and gross motor activities. There was an improvement in gross motor activities in 10 subjects and fine motor activities in 3. This small number of improvement among the motor activities could be due to short time of study period as the impact of interventions was assessed after six months. Much improvement was seen in the question which dealt with weight associated burden of lifting and carrying the child with 35 patients showing reduction which could be attributed to medications and physiotherapy directed to improve the muscle strength and tone and also the medications used to calm the child. Appropriate nutritional advice could also have played a role in improving the muscle strength of these children. Night time awakenings were reduced in 23 subjects showing good compliance to medical therapy.

Within the mobility domain, note-worthy improvement was seen in increased frequency of outings in 17 subjects and increased frequency of unaccompanied outings in 6 all of which could be attributed to the medications calming the child and home based physiotherapy interventions. Among the social integration domain, 22 parents reported reduced stress on their lives after six months of interventions. This reported reduction could be attributed to the improvement in the above mentioned parameters of physical independency i.e reduction in night awakenings and weight associated burden of lifting and carrying the child and also due to the mobility parameters of increased unaccompanied outings and increased number of outings.

Various studies have quantified the outcomes of interventions on the basis of improvement in quality of life. Verschuren et al [134] evaluated the impact of exercise training program on the health-related quality of life measure, autonomy (P = .02),

motor (P = .001), and cognition (P = .04) domains have shown significant improvement. Similarly Hoving et al [133] in their study showed a significant improvement on psychosocial domain of QoL scale after subjecting the patients to intrathecal baclofen therapy. In a study done by Russo et al [128] assessing the effect of combination therapy of Botulinum toxin and low intensive occupational therapy though showed significant improvement on body structure and self-worth, didn't show much improvement on PEDsQL. In another study done by Stiller et al [135] significant improvement was reported in self-care domain of PEDI scores following a combination of intensive therapies as compared to one intervention alone.

Though several studies have assessed the impact of a single intervention in terms of Quality of life improvement, only few studies have looked at the improvement in Quality of life on the whole after subjecting the child to a set of interventions. Also, no other study has used LAQ-CP scores to this effect.

In our study, we found a positive co-relation (spearman's rank co-efficient r=0.3789) between number of co-morbidities and LAQ-CP score which means that as the number of co-morbidities increase the disability worsens as evidenced by increasing LAQ-CP scores (p = 0.0059). This statement is self-explanatory, as the number of co-morbidities increase in an individual with CP, there will be an associated increase in clinical and economic burden, increased physical dependency, reduced mobility and increased stress on the life of care-givers. These findings were similar to those found by Tessier DW et al.[147] Among the neurological co-morbidities, we found a significant association between the Global development delay and LAQ-CP score (p=0.0104). Global development delay implies increased dependency of the child on the parent/care-giver and may also have an associated increase in clinical and

economic burden. However, in our study we didn't see any significant association of seizures (p=0.12) or behavioural problems (p=0.92) with LAQ-CP scores. Among the non-neurological abnormalities, Drooling of saliva was significantly associated with LAQ-CP scores (p=0.02). Drooling of saliva is associated with increased feeding difficulties, soiling of clothes, increased clinical burden thereby increasing the economic burden, dependency on parents which explain the worsening of QoL. Other non-neurological abnormalities didn't show any significant association with LAQ-CP scores.

Following interventional therapies, the median number of co-morbidities reduced from 9.5 to 5.5. We found that seizure frequency was reduced in 20/23 patients among the non-neurological co-morbidities in six months after subjecting them to anti-epileptic drugs. Speech difficulties reduced to 41.18% following speech therapy, visual abnormalities reduced in two patients after refraction correction. Hearing defects remained the same as they were sensory-neural hearing defects and the patients couldn't afford the cost of treatment. Among the non-neurological co-morbidities, recurrent respiratory infections have fallen down to 0%, and Drooling of saliva which causes negative impedance to social acceptance has reduced to 1.96% and constipation reduced to 5.88%. All these signify compliance to medications.

In our study we found that LAQ-CP scores were significantly high in patients with severely affected GMFCS levels ($p < 0.0001$) i.e higher the GMFCS, higher is the LAQ-CP score and worse the disability. These findings were in concordance with Dobhal et al [136], who found a strong positive co-relation between LAQ-CP score and GMFCS levels ($r=0.907$, $p < 0.001$). In our study levels 4 and 5 co-related well with LAQ-CP score where 100% patients had moderate to severe disability. But among the

level 2 and 3, 40-87% had moderate to severe disability, thus signifying that GMFCS if applied alone in evaluating a child with CP can miss these severely affected children because there are other important factors like clinical burden, physical independency and social integration which affect the Quality of life apart from motor manifestations. MACS levels were also similarly associated with LAQ-CP scores ($p<0.0001$). Likewise, as with GMFCS, MACS levels 2 and 3 if used alone can miss 45 to 77 percent of severely disabled individuals as these are functional classifications which take only the motor ability into account.

In our study following the interventional therapies, only two patients in level 4 showed improvement to level 3 and level 2, and one patient worsened from level 4 to 5 due to an acute illness. Though there was an overall significant improvement in the mobility domain of the LAQ-CP, many patients remained at the same level of GMFCS post interventions probably due to the variables like age, as our study group included patients over 3 years. Secondly, it could also be due to variable intensity of home based interventions and also the short duration of study period. The same came be told regarding the changes in MACS levels, where only one patient improved to class 3.

Among the BPRS-C scores, after interventional therapies, the number of children with lower scores less than 6 improved by 3 patients and the number of children in high score group(score >10) signifying high behaviour problems reduced from 11 to 5. Though they were not subjected to any specific behaviour therapies, the medications used to calm the child have affected hyperactivity related problems in many of these children.

In our study, LAQ-CP scores were significantly higher in Quadriplegic CP group (p=0.0382) with 100% patients among the severe disability group having quadriplegia. This finding was in agreement to the one by Dobhal et al [136] where LAQ-CP scores was significantly high in subjects with quadriplegic CP. At the same time, these findings were in disagreement with the findings by Tessier DW et al [147] who found no association between psychosocial QoL and type of CP. In our study we didn't find any statistically significant association between the physiological type of CP and LAQ-CP scores.

Overall, the present study showed a significant association of co-morbidities on the quality of life i.e with increasing number of co-morbidities, the QoL worsened in these children. The study also showed a significant improvement in the quality of life of these children when subjected them to systematic interventions including treatment of the co-morbidities. This is especially true for non-neurological co-morbidities like drooling of saliva, which showed a significant impact on the child's QoL but can be tackled with medications and oro-motor stimulation. Epilepsy, though not significantly affected the QoL in CP children in our study, can be controlled if treated promptly. Speech therapy is another major intervention in our study which substantially improved the speech difficulties in these children. Physical independency of the children improved with medications used to calm them and also due to the medications and home based physiotherapy used to improve muscle strength and alleviate the tone abnormalities. Apart from the clinical burden and physical independency and mobility domains, social integration also showed a significant improvement as the above parameters indirectly increased stress levels in care-givers and thus the stress levels reduced with an improvement in them.

In our study, though there was significant improvement in overall LAQ-CP scores pre and post interventions, statistically significant improvement pertaining to topographic and physiological types of CP was lacking owing to a small sample size. The co-relation of different modalities of interventional therapies with respect to various types of CP could not be studied for the same reason. This remains the major limitation of our study. Another limitation was the short duration of our study as it wasn't enough to notice significant improvement in the motor domain.

Hence, we recommend this questionnaire to assess the Quality of life. However a longer duration of study will be required to assess the motor domain.

CHAPTER 7- CONCLUSION

Cerebral palsy is a debilitating neurological disease of childhood associated with various co-morbidities. The impact of the disease and its co-morbidities is so severe that it causes a great psycho-social, clinical and economic burden to the family and society at large. There is a notion that cerebral palsy is a non-treatable disease and many a times these children don't receive appropriate treatment and adequate care for various reasons and are often neglected by the family and physicians. The purpose of this study was to assess the change in quality of life of these children following interventional therapies so as to refute the notion regarding the non-treatable nature of cerebral palsy.

The present one year interventional study was conducted at Child development clinic and department of Paediatrics of KLES Dr Prabhakar Kore hospital and Medical Research Centre, Belagavi from January 2018 to December 2018. A total of 54 children attending CDC OPD were enrolled in the study and were subjected to interventions. At the end of study period 3 children were lost to follow up. The impact of the interventions on quality of life was assessed using LAQ-CP questionnaire after a period of six months.

There was a strong positive co-relation between the number of co-morbidities and the Quality of life signifying the worsening of disability with increasing number of associated co-morbidities. Among the co-morbidities, GDD and drooling of saliva had significant association with LAQ-CP scores. GMFCS and MACS levels were also significantly associated with LAQ-CP scores. As their levels increased, the LAQ-CP scores also worsened. Though GMFCS and MACS are good to assess the motor

ability of a child, they don't look at the other parameters like clinical burden, physical independency, social integration which affect a child's QoL. This questionnaire with its simple questions addresses this and can be used effectively for this purpose. After subjecting them to interventional therapies, these children showed a significant improvement in quality of life. Especially the non-neurological comorbidities like drooling of the saliva have significant impact on the quality of life and can be tackled easily with medications and oro-motor stimulation. Epilepsy, another common co-morbidity in these children can be controlled promptly with anti-epileptic medications. Speech difficulties are overlooked quite often, which can be improved with simple speech therapies. All these children prior to the enrolment in our study were treatment naïve and hadn't received proper care and treatment for the co-morbidities and motor problems. But with appropriate medications and home based therapies, there was a significant improvement in physical independency, mobility, reduction in clinical burden and improved social integration. These results imply that it is prudent to identify these children with CP and their associated co-morbidities and address them early in life with timely and appropriate interventional therapies in order to improve their quality of life

CHAPTER 9- SUMMARY

Cerebral palsy has long been regarded as a non-treatable disease with motor disabilities and associated co-morbidities, which affects not only an individual's growing brain but also has an impact all through his life. These co-morbidities significantly dampen an individual's quality of life and have a grave impact on the person, his/her family and society at large resulting in clinical, social and economic burden. Such children are often neglected both by parents and physicians and are not given adequate care and treatment owing to its perceived non-treatable nature. The present study was aimed to disprove this misconception and to assess the impact of interventional therapies used in this children, on their quality of life.

The present one year interventional study was conducted at Child development clinic and department of Paediatrics of KLES Dr Prabhakar Kore hospital and Medical Research Centre, Belagavi from January 2018 to December 2018. A total of 54 children attending CDC OPD were enrolled in the study and were subjected to interventional therapies. They were followed up every month for a period of six months. At the end of study, 3 children were lost to follow up. The impact of the interventions on quality of life was assessed using LAQ-CP questionnaire. The study results are summarised below:

- Males outnumbered the females with M:F ratio of 1.8:1. Most of the children were aged between 3-5 years (60.78%) followed by 6-8 years (21.57%).
- Majority of the children (43.14%) belonged to Class IV socio economic strata according to modified B.G Prasad's classification, followed by class III (39.22%).

- 2^{nd} degree consanguinity was seen in 21.56% of patients, followed by 3^{rd} degree consanguinity in 17.65%. No consanguinity was seen in 60.7% patients.
- Family history of cerebral palsy was seen in 3 patients (5.88%) of which two of them are siblings enrolled in our study
- Most common maternal age at birth was between 20-25 years (64.7%) followed by 25-30 years (17.64%).
- Most of the mothers received atleast three Ante natal check-ups (74.5%).
- 94.12% of the children were born in hospitals whereas 5.88% of them were born at home.
- Vaginal delivery was the commonest mode of delivery seen in 78.43% patients. Forceps assisted vaginal delivery was seen in 7.5% patients and 21.56% of patients were born via C-section.
- Maternal risk factors were observed in 86.2% with first birth order (primigravida mother) being a major risk factor seen in 70.5%, followed by non progression of labour in 45%, Premature rupture of membranes in 25%, Pregnancy Induced Hypertension in 15% and breech presentation, urinary tract infection and ante partum haemorrhage in one patient each.
- Meconium stained amniotic fluid in utero was seen in 9.8% of patients.
- Low birth weight was seen in 43.14%, followed by normal birth weight in 39.22% and 15.69% with very low birth weight.
- 78.43% were term gestation, followed by 13.73% who were early preterm (<34w+6d) and 7.84% children who were late preterm (35w to 36w+6d).
- 43.13% of children enrolled in our study required resuscitation.
- NICU admission was needed in 74.5%.

- Perinatal risk factors associated with CP were the commonest as seen in 50.98% children, while post natal and prenatal risk factors were noted in 19.60% and 33.33%.
- Among the perinatal risk factors, Asphyxia was the commonest risk factor accounting for 84.6% patients, followed by PROM in 11.5%. Overall Asphyxia was the commonest risk factor (43.13%).
- Prematurity was the commonest prenatal risk factor for CP (21.57%) followed by LBW (17.64%), VLBW (9.80%) and UTI (1.96%).
- Among the post natal events attributed to CP in our study, neonatal hyperbilirubinemia was seen in 11.76% patients followed by respiratory distress in 17.6% and septicemia in 5.88%.
- Though seizures were seen in 33.33% patients post natally, in 25.49% patients it was attributed to perinatal asphyxia.
- Clinical presentation with Developmental delay was the commonest with 90.2% showing motor delay followed by 78.43% language delay and 62.75% with social milestones delay. Among the other presentations, abnormal movements (62.75%), behavioural problems (52.94%), feeding difficulty (50.98%), drooling of the saliva (47%), seizures (47%), excessive cry (27.45%), repeated infections (17.65%), dental caries (17.65%), visual disturbances (15.69%), hearing abnormality (7.84%) were seen in descending order of frequency.
- Topographically, Quadriplegic CP (72.55%) was the commonest followed by hemiplegic CP (19.61%) and diplegic CP (7.84%). No triplegic and monoplegic CPs were seen.

- Among the physiological type, Dystonic CP was the commonest type (37.25%) followed by spastic CP (33.33%), mixed CP (15.68%), choreo-athetoid (11.76%) and ataxix CP (1.96%).
- Dystonic Quadriplegic type of CP was overall the commonest type of CP accounting for 35.2% of the cases, followed by Spastic hemiplegia, mixed quadriplegia, choreoathetoid quadriplegia, spastic quadriplegia, spastic diplegia, ataxic CP accounting for 19.6%, 15.6%, 11.7%, 9.8%, 3.9%, 1.9% cases respectively.
- Not much difference was seen in distribution of children among GMFCS levels with 23.53% patients in level 1 and 4, 19.61% in level 2 and 17.65% in level 5.
- MACS levels drew parallels with GMFCS levels. 23.53% children had level 1 ability, whereas 21.57% of them had severely limited ability i.e level 5.
- Many of the patients were clustered around the scores of 4-6 on the BPRS-C (43.13%), followed by scores of 7-9 (27.64%). 21.56% patients had a score of more than 10.
- All the children had one or the other co-morbidity. (100%)
- Most common neurological co-morbidity observed was global developmental delay in 84.31%.
- After GDD, Speech abnormalities (58.82%) were the commonest followed by seizure episodes in last six months (45.1%), behavioural abnormalities (39.22%), visual abnormalities (15.6%), hearing abnormalities (7.8%).
- Among the non-neurological abnormalities, drooling of saliva was present in 54.9% which was the commonest followed by constipation (19.61%),

recurrent respiratory infections (15.65%), deformities (9.8%) and dental caries (7.84%).

- Most of the study population had moderate disability LAQ-CP scores (49.01%), followed by Good scores in 19.60%, Mild in 15.68% and severe disability in 8 children 15.68%.
- Prior to enrolment in our study, 35.29% haven't received any treatment. Rest 64.7% received treatment for acute conditions.
- Among the interventions, Medications were received by 100%, Nutritional advice in 100%, Physiotherapy was advised in 86.27%, speech therapy in 76.47% patients.
- At the end of six months of interventions, total number of subjects with good scores improved from 19.6% to 21.5%, mild scores from 15.68% to 29.41%.
- The number of subjects with moderate disability scores reduced 49.01%) to 45.09% and In the severe disability group from 15.68% to 3.92%.
- There is significant effect of interventional therapies on the Quality of life in CP children, especially in the neurological domains, with Clinical features ($p<0.0001$), physical independency ($p<0.0001$) and mobility ($p<0.0001$) showing significant improvement as tested by student paired t-test.
- Among the non-neurological Domains, social integration which dealt majorly with the parental impact of CP showed significant improvement after the interventional therapies ($p <0.0001$).
- Mean LAQ-CP scores of all the subjects reduced significantly from 52.78% to 46.91% after interventions. ($p < 0.0001$)
- Among the clinical burden domain, 26 patients showed improvement in questions dealing with hospital visits and weeks of hospital stay. These dealt

with the occurrence and severity of co-morbidities, which reduced with interventional therapies.

- Seizure frequency reduced in 86.9% patients after anti-epileptic medications.
- Among the physical independency domain, Gross motor activities improved in 10 and fine motor in 3. This small number in improvement could be due to short duration of our study.
- Other parameters in physical independency domain like weight asociated burden of lifting the child and carrying the child reduced in 35 subjects. Night awakenings showed improved in 23 patients. This was attributed to medications and physiotherapy used to strengthen the muscle and improve the tone and medications to calm the child.
- Among mobility domain, 17 subjects showed improved frequency of outing and improved frequency of unaccompanied outings is seen in 6. This was attributed to medications used to calm the child and home based physiotherapy.
- The improvement in above parameters have reduced the stress levels on care givers as reported by parents of 22 children.
- There was a strong positive co-relation between the number of co-morbidities and LAQ-CP scores. (spearman's rank co-relation co-efficient r = 0.3789, p = 0.0059)
- Among the neurological co-morbidities, GDD was significantly associated with LAQ-CP scores (p=0.0104).
- Seizure frequency in last six months didn't show any significant association with LAQ-CP scores (p=0.12)

- The same was with behavioural problems where there was no significant association with LAQ-CP scores (p=0.92)
- Among the non-neurological problems, drooling of the saliva was associated significantly with LAQ-CP scores (p=0.02)
- Following the interventional therapies, seizure frequency reduced in 86.9% owing to good compliance to antiepileptic medications; Speech difficulties reduced to 41.18% following speech therapy; visual abnormalities reduced to 11.7% following refraction correction; hearing abnormalities (sensory neural hearing loss) remained the same as the patients couldn't afford the cost of treatment.
- Among the non-neurological co-morbidities, recurrent respiratory infections reduced to 0%; drooling of saliva reduced to 1.96% due to medications and oro-motor stimulation; constipation reduced to 5.88% due to medications and high fibre diet.
- The LAQ-CP scores were significantly high in patients with severely affected GMFCS levels ($p < 0.000p$) i.e higher the GMFCS, higher is the LAQ-CP score and worse the disability. However, many patients in GMFCS levels 2-3 had moderate to severe LAQ-CP scores, indicating that if GMFCS applied alone could miss these severely affected children.
- MACS levels were also similarly associated with LAQ-CP scores ($p< 0.0001$). However, many patients in GMFCS levels 2-3 had moderate to severe LAQ-CP scores, indicating that if MACS applied alone could miss these severely affected children.
- Not many improvements have seen in GMFCS and MACS levels post interventional therapies, this could be due to the variables like age group as all

our patients are over 3 years of age. Secondly it could be due to the variable intensity of home based interventions and also the short duration of study.

- After interventional therapies, the number of children with lower BPRS-C scores less than 6 improved from 7.8% to 13.7%, whereas the number of children in high score group(score >10) signifying high behaviour problems reduced from 21.56% to 9.8%. Though they were not subjected to any specific behaviour therapies, the medications used to calm the child have affected hyperactivity related problems in many of these children.
- There was a significant association between LAQ-CP scores and Quadriplegia ($p=0.0382$) as 100% patients in severe disability group had quadriplegia.
- No significant association was found between LAQ-CP scores and physiological type of CP ($p>0.05$).

The present study showed that number of co-morbidities have a detrimental effect on the QoL of CP children. When these children were subjected to systematic interventions and treatment of co-morbidities, these children showed significant improvement in their QoL especially in the domains of clinical burden, physical independency, mobility and social integration. This LAQ-CP questionnaire is a simple tool which can be used for this purpose. Small sample size and short duration of the study are the major limitations of this study.

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ANNEXURE I – CONSENT FORM

IMPACT OF INTERVENTIONAL THERAPIES ON THE QUALITY OF LIFE IN CHILDREN WITH CEREBRAL PALSY: ONE YEAR HOSPITAL BASED OBSERVATIONAL STUDY

Principal Investigator: _____

Guide: _____ **Co-Guide: _____**

You are hereby requested to involve you child in the above said research to be conducted at KLE'S Dr. Prabhakar Kore Hospital and Medical Research Centre, Belgaum from January 2018 to December 2018 by Dr. Nalla Anuraag Reddy, Post Graduate Student in the Department of Paediatrics at Jawaharlal Nehru Medical College, Belagavi.

Purpose of the study:

Although Cerebral Palsy is primarily a movement disorder, many children affected with it may have other impairments that may affect their function, quality of life, and life expectancy. With recognition and proper management of these co morbidities, we can improve the quality of life in children with cerebral palsy. Through this study we aim to look at that improvement in quality of life of these children by a multidisciplinary care.

Procedure Involved:

If you agree, your child will be enrolled in the study and a thorough clinical examination will be done, associated co-morbidities will be assessed and you will also

be subjected to an LAP-CQ Questionnaire to assess the Quality of life of your child. Based on the child's condition and associated co morbidities, he will be given necessary interventional therapies such as physiotherapy, pharmacotherapy, speech therapy, nutritional rehabilitation, oro-motor stimulation etc. you will be called for the follow up everyone for which reminder phone calls will be made. On each follow up, the child's current complaints if any, will be looked into and will also be assessed based on the follow up proforma. At the end of six months, the will be reassessed based on LAP-CQ for the Quality of life and grading based on GMFCS, MACS and BPRS-C will be done.

Voluntary participation:

Your child's participation in this study is your voluntary decision. Whether to participate or not to participate will not affect your current or future relationship with the KLES Dr. Prabhakar Kore Hospital and Medical Research Centre, Belgaum.

You are free to discontinue the participation in the study at any time for any reasons and you will not be paid any reimbursement for participation in the research.

Risk and benefits

There are no major risks involved in this study. All the interventions used have been scientifically tried and tested.

Privacy and Confidentiality

The only people who will know that your child is a research participant are members of the research team. No information about you or provided by you, during research will be disclosed to others without your written consent. When the results of

the research are published or discussed in the conferences, no information will be disclosed that would reveal your identity. Any information obtained in connections with this study and that can be identified with you remain confidential and will be disclosed only with your permission.

Queries

If you have any questions about your rights or research participation you may contact

Dr. Roopa M Bellad

Chairperson of Ethical Committee

JNMC Belgavi-590010

Phone No.9448113403

You will be given a copy of this form for your information and to keep for your records.

STATEMENT OF CONSENT

I hereby voluntarily agree for my child to take part in this study. I understand that even if I choose to allow my child to take part in this study I have the liberty to withdraw at any time. My signature below indicates that I have read or have been told about this entire consent form including the risks and benefits and have had all my questions answered. I will be given a copy of this consent form.

Signature of the authorized representative/ parent: _____

Date: _____

Name: _____

Relation to the Subject: _____

Signature of the witness: _____

Date: _____

Name: _____

Signature of investigator: _____

Date: _____

Name: _____

ANNEXURE-II

PROFORMA

Proforma for the study

Name:

Age/ Sex: phone no.:

Hosp no:

Religion: 1. Hindu 2. Muslim 3. Christian. 4. Other

Date of evaluation:

Percapita income:

Mother's age:

Primary care giver:

Presenting complaints:

- Development delay: 1. Motor 2. Language. 3. Social.
- Abnormal posture/movements: 1. Absent 2. Present
- Seizures 1. Absent 2. Present 3. GTCS 4. Clonic
  5.Myoclonic 6. Spams
- Infections: 1. Respiratory 2. Gastrointestinal 3. Urinary
- Excessive crying: 1. Present 2. Absent
- Behavioral problems: 1. Hyperactive 2. Autistic 3. Pathetic
  4.depressed
- Feeding problems 1. Constipation 2. Vomiting
- Drooling of saliva 1. Present 2. Absent
- Vision abnormalities: 1. Squint 2. Poor vision

- Hearing abnormalities: 1. Present 2. Absent
- Dental caries: 1. Present 2. Absent
- Hand preference: 1. Left 2. Right

Family history: Consanguinity: 1.yes 2. No

if yes $1^{st}/2^{nd}/3^{rd}$

Age of the mother at child birth: married life:

Birth order:

Seizure: yes/no

Development delay: yes/no

Cerebral palsy: yes/no

Birth history:

Antenatal care: ANC taken 1. <3 2. 3 3. No ANC

Duration of pregnancy: 1. Term 2. Late preterm 3. Preterm

Natal history:

Place of delivery: 1. Home 2. Hospital.

Events: 1. PROM 2.Difficult labour 3.Abnormal presentation.

4.APH 5.precipitate labour 6. Forceps

7.Ventouse 8.Breech 9. LSCS 10. Others

Multiple pregnancy:

Meconium: 1. Yes 2. No

Cry at birth: 1. Normal 2 weak 3. Delayed

Resuscitation required 1. Yes 2. No

Birth weight: 1. <2 2. 2-2.5 3. 2.5-3 4. >3

Postnatal history:

Events: 1. Jaundice 2. Cyanosis 3. Septicemia 4. Seizures

5.RDS 6.feeding problems

NICU stay:

Infancy: 1.trauma. 2.infections 3. Meningitis 4. Infection

Development milestones

Social smile

Recognition of mother

Rolling over

Sitting

Cooing

Crawling

Monosyllables

Standing

Two word sentences

Walking

Total vocabulary

Examination:

Vital signs

HR: RR BP: Hydration:

Anthropometry	Measured	comments
Height		
Head circumference		
weight		
CC		

Central Nervous System Examination:

Interaction with the examiner: 1. Good 2. Fair 3. Poor.

Interest in the surrounding: 1.good 2.fair 3.poor.

Schooling: 1. Normal 2. Spl school 3. No school

Speech and articulation:

Comprehension

Expression

Behavioral problems: 1. Hyperactive 2. Autistic 3. pathetic 4. Depressed

Cranial nerves:

Vision: 1. Present 2. Absent.

1.Tracking 2. Fixation 3. Squint 4.abnormal function

5. involuntary movement

Hearing: 1. Normal 2. Abnormal 3. Cannot be ascertained

Others:

Motor system: deformitites:

Involuntary movements: 1.chorea 2.athetosis 3. Dystonia

4.myoclonus 5.mixed

Body part	TONE	Voluntary contraction
1.shoulder		
2.elbow		
3.wrist		
4.hand		
5.hip		
6.knee		
7.ankle		

1.normal/2.flaccid 1. absent

3.spastic/ 4. Rigid 2.impaired 3.normal

GAIT: 1.possible 2. Not possible

1.Hop 2.Tandem walk 3. Toe walk 4. Kneel walk

Rise from sitting; 1. Independent 2. With assistance 3. Absent

Gait paatern: 1. Non ambulant 2. Spastic 3. Ataxic

4.Dystonic 5. Mixed 6. Normal

Hand function: 1. Absent 2. poor 3. Fair 4. Good

Grip: 1. Cylindrical 2. Spherical 3. Conical 4. Opposition 5. Pincer

Reflexes:

Deep tendon reflexes: 1. Present 2. Absent 3. Exaggerated

Biceps

Supinator

Triceps

Knee jerk

Ankle jerk

Primitive:

Moro's

Placing

Grasp

Suck

Rooting

Other systems:

CVS:

RS:

P/A:

Investigations:

CT/MRI: 1.PVL 2. Cystic enceph 3. Parasaggital injury

4.BG changes 5.Par occ gliosis 6. Cerebellar atrophy

EEG: 1. Normal 2. Abnormal

1.gen. epileptiform 2. Focal/LRE

3.Hypsarrythmia 4. Slow background

BERA: 1.normal 2. Abnormal 3. Threshold

1.50-70 2.70-100 3.100-120 4.>120

Barium studies:

GER 1. Present 1. Absent Grade: 1/2/3/4

CPQoL rating:

Final diagnosis:

Topographical: 1. Quadri 2. Hemi 3. Diplegia
4.Double hemi 5. pseudobulbar 6. Facial palsy

Physiological: 1. Spastic/dyskinetic 2.choreo athetoid 3. Dystonic
4.hypotonic 5.ataxic

Etiological: 1.antenatal 2. Perinatal 3. Postnatal

Functional: GMFCS 1/2/3/4/5

MACS: 1/2/3/4/5

BPRS-C:

Associated co-morbidities:

1.seizures 2.GDD 3.hearing abnormalities
4.visual abnormalities 5.GI abnormalities 6.Respiratory infection
7.Drooling 8.UTI 9.Deformities 10.dental caries

Assessment at the end of six months.

Functional: GMFCS 1/2/3/4/5

MACS: 1/2/3/4/5

BSCR-P: 1. 2. 3. 4. 5. 6. 7. 8. 9.

Associated co-morbidities:

1.seizures 2.GDD 3. Hearing abnormalities
4.visual abnormalities 5.GI abnormalities 6. Respiratory
7. Drooling 8. UTI 9. Deformities 10. dental caries

LIFESTYLE ASSESSMENT QUESTIONNAIRE FOR CHILDREN WITH CEREBRAL PALSY.

About this questionnaire and how you can help us:

we are trying to get a better understanding of families who are caring for their child with movement difficulties. You could help us by letting know your views and completing this questionnaire. These questions are all about the impact your child's disability has on the everyday life which you and your child experience.

If you complete this questionnaire your answers will be treated in total confidence. Although we will use the information you give us. neither you nor your child will be identified.

HOW WILL WE USE THE INFORMATION YOU GIVE US?

information given by you and other parents will help us decide whether we can provide differently in a way that is better for children and families.

WHO SHOULD FILL IN THE QUESTIONNAIRE?

The questionnaire should be filled in by the parent or care giver who is most involved with the day to day care of the child. Please answer the questions realisitically based on what you know your child can do and does every day and not on what you think he or she should do.

We have tried to make filling in this questionnaire as simple as possible. For most of the questions, all you need to do is circle the appropriate response from those given. There are also spaces for comments and we are interested in what you have to say.

Please give us some details about your child.

Child's name:……

Sex:……...

Child's D.O.B:…….....

Date of completion of the form:……

Child's place of birth:……...

Home address at birth:…….

……..

Current address:……

……..

Child's birth weight if known:……...

Child's current weight:……..

What is relationship to your child:……..

Name of the nursery or school attended by your child:……

This information about your child will be kept confidentially on a secure computer. In any analysis or reports, neither you nor your child's identity will be revealed.

1. How many times has your child been seen over the last year by a children's doctor- either a consultant or a senior children's doctor u der the consultant? (please circle one of the following)

0 1 2-5 6-12 13+

2. Has your had to stay in the hospital for any length of time over the last year? Please indicate in weeks the total amount of time spent in the hospital.
   (please circle one of the following)

   0 less than 1 1- 3 4-26 27+

3. How many operations have been carried out on your child over the last year?
   (please circle one of the following)

   0 1 2 3 4+

4. Has your had a leg, arm or any other body part of his or her body in the plaster over the last year? Please indicate in weeks the total time your child has spent in plaster.
   (please circle one of the following)

   0 6 or less 7-11 12-17 18+

5. Has your child had to wear some form of body or leg support over the last year? Please indicate in weeks the total time the support was worn. (please circle one of the following)

   0 1-16 17-32 33-51 52

6. How many pills, tablets or doses of medicines did your child take yesterday?
   (please circle one of the following)

   0 1-4 5-8 9-12 13+

7. Is your child currently receiving a special diet for any reason? (please circle one of the following)

   YES NO

8. How many time has your child experienced any epileptic seizures over the last year? (please circle one of the following)

   No epileptic seizures at all.

   Occasional epileptic seizures during the day averaging one per month.

   Some epileptic seizures most weeks, day or night.

   Many epileptic seizures on most days and nights.

   Constant epileptic seizures in frequent succession.

9. Has your child been seen by a specialist about difficulties in his/her behavior over last one year? (please circle one of the following)

   YES NO

10. How often has your child been seen by any sort of therapist over the last one year? (please circle one of the following)

    0 1 2-12 13-52 53+

11. Which of the following services/ allowances is your child currently receiving? (please circle one of the following)

Visits from health visitor visits from home help visits from social worker visits from community nurse

Voluntary services disability living allowance mobility allowance direct payments personal budget

12. How many items of special equipment are there in the home which are currently, or have been, essential for your child? (please circle one of the following)

0 1-3 4-7 8-10 11+

13. What has been the financial cost to the family for your child over the last year in purchasing and maintaining such special equipment? (please circle one of the following)

£0 £1-150 £151-250 £251-350 £351+

14. What has been the extra financial cost to your family over the last one year other than purchasing special equipment, which was not covered by grants and allowances?

(please circle one of the following)

£0 £1-150 £151-250 £251-350 £351+

15. Has your child's present home been adapted in any way over the last one year because of your child? (please circle one of the following)

YES NO

If yes, how many adaptations have been made? (please circle one of the following)

1-3 4-7 8-10 11+

16. Please indicate how many further adaptations have been planned or considered necessary? (please circle one of the following)

0 1-3 4-7 8-10 11+

17. For each of the following activities, please tick one of the spaces to indicate how much help you would normally give to your child to complete that activity.

	No help given	some help supervision given	has to be done for him/her
washing hands	…….	……..	…...……
eating a bowl of cereal	…….	……..	…...……
putting a vest/t shirt	…….	……..	…...……
doing up buttons or buckles	…….	……..	…...……
getting out of bed	…….	……..	…...……
getting out of bath	…….	……..	…...……
going to the toilet	…….	……..	…...……
climbing stairs	…….	……..	…...……
getting in and out of car	…….	……..	…...……
opening doors	…….	……..	…...……
picking up objects from the floor	…….	……..	…...……
carrying a drink around the length of the room	…….	……..	…...……

18. How many times did you need to lift your child on the last occasion you spent full day with him/her?
19. How often has your child required assistance during the night over the last week? (please circle one of the following)

0 1-3 4-7 8-10 11+

20. Please list any other areas your child requires assistance in the course of a normal day? (please circle one of the following)

21. a) how many rooms(excluding halls and passages) are there in your child's place of residence?

    b) over the past week, how many of these did your child go into?

    c) how many of these did your child enter unassisted?

22. Does your child normally need help in getting in and out of the house? (please circle one of the following)

    YES NO

23. What is the farthest distance your child has gone outside without resistance over the past week? (please circle one of the following)

    0 1-100yards 101-440yards ¼- ½ mile more than ½ mile

24. How often has your child been out of the house by himself/herself over the past week? (please circle one of the following)

    0 1-7 8-13 14-20 21+

25. Excluding trips to and from the school/nursery, how many times has your child been on a longer outing over the past week, which required some form of transport? (please circle one of the following)

    0 1-3 4-7 8-10 11+

26. What type of nursery/ school is your child attending?

    None

    Pre school

Special pre school

Infant/primary without special support unit attached

Infant/primary with special support unit attached

Special school: physical disability

Special school: learning difficulties

Home teaching (including portage)

Others (please specify) …….

27. How often does your child attend school? (please circle one of the following)

Part time : daily:

Weekly boarding: full time boarding:

28. Approximately how long does it take for your child to travel from home to school? (please circle one of the following)

0-15minutes 16-30minutes 31-45minutes

46minutes-1 hour more than one hour

29. How many friends does your child has seen outside of school hours over the past one week? (please circle one of the following)

0 1-3 4-7 8-10 11+

30. Do you have any friends or family locally to whom you can turn to for help if necessary? (please circle one of the following)

YES NO

31. Do you think that the people in your local area are generally supportive and understanding where your child is concerned? (please circle one of the following)

YES NO SOMETIMES

32. Do you think your child's disabilities restrict your social life in any way? (please circle one of the following)

YES NO SOMETIMES

33. Do you have any difficulties organizing family holidays because of your child's disabilities? (please circle one of the following)

YES NO

34. Who does your child live with? (please tick one of the following)

Lives with both birth parents ……

Lives with one birth parents …….

Lives with neither birth parents …….

Eg. Grandparents, foster parents, adoptive parents.

35. Please describe if any member of the family has had to change their employment situation to make caring for your child easier.
36. Do you think that your child's disabilities have placed any extra stress on you as parents/care givers? (please circle one of the following)

None:

Slight:

Severe:

37. Do you think that your child's disabilities have placed any extra stress on any other children in the family? (please circle one of the following)

NO OTHER CHILDREN NONE SLIGHT SEVERE

Thank you for your time and co-operation in completing this questionnaire. Please feel free to add comments.

……..

……..

……..

……..

ANNEXURE-III- ETHICAL CLEARANCE LETTER

K.L.E.UNIVERSITY'S
JAWAHARLAL NEHRU MEDICAL COLLEGE,
NEHRU NAGAR, BELAGAVI-590010 (KARNATAKA-INDIA)
(Accredited 'A' Grade by NAAC)

Website: http//www.jnmc.edu
E-Mail : dome@jnmc.edu

Phone: (+ 91-(0)831 Office : 2471350
Principal: 2471701
Fax No. +91 (0)831 – 2470759

Ref: MDC/DOME/72 **Date: 22/11/2017**

(REG NO. BM0117003)

Sub: Institutional Ethical Clearance for the study.

With reference to the above, we wish to inform you that your proposed research project titled **"IMPACT OF INTERVENTIONAL THERAPIES ON THE QUALITY OF LIFE IN CHILDREN WITH CEREBRAL PALSY: ONE YEAR HOSPITAL BASED INTERVENTIONAL STUDY"**, is ethical and justifiable. The proposed research project has been cleared by the JNMC Institutional Ethics Committee on Human Subjects Research.

(Dr. Arathi Darshan)
Member Secretary
JNMC Institutional Ethics Committee
on Human Subjects Research,
J.N.Medical College, Belagavi.

(Dr. Roopa M Bellad)
Chairman,
JNMC Institutional Ethics Committee
on Human Subjects Research,
J.N.Medical College, Belagavi.

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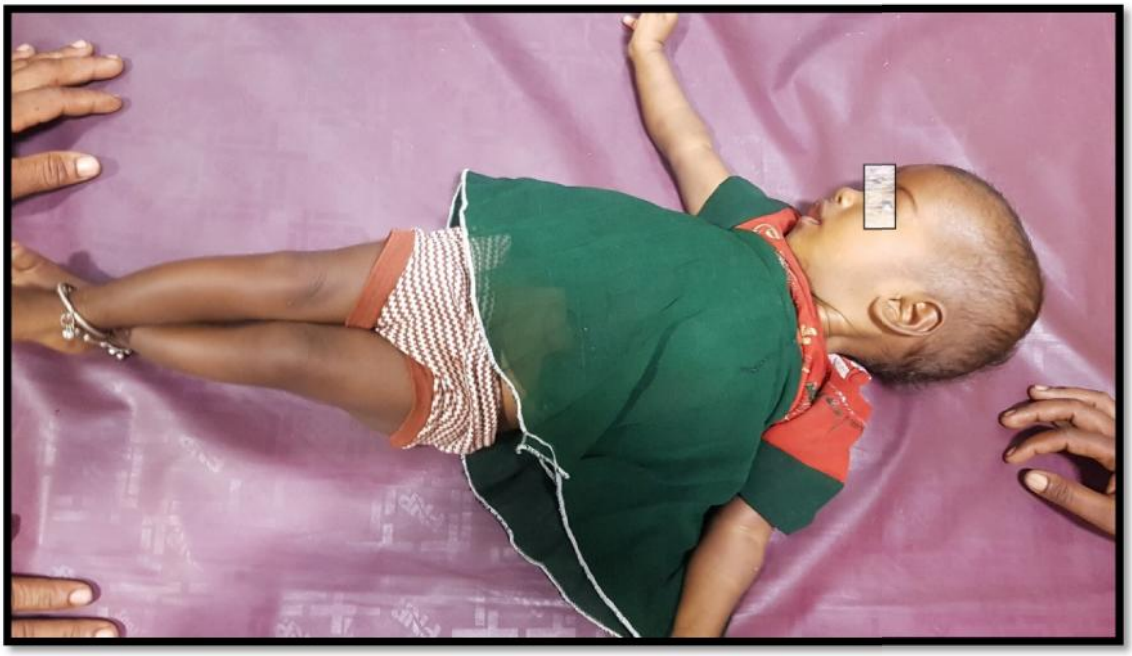
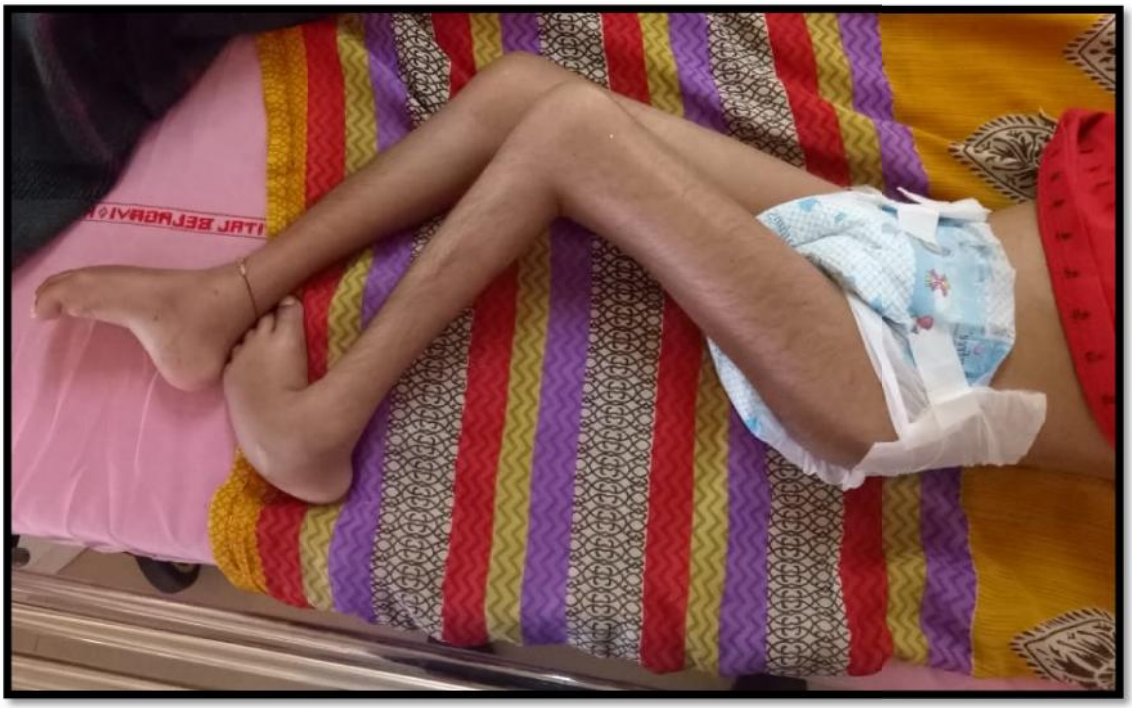
ANNEXURE IV– PHOTOGRAPHS



Pic 1. Photograph of a girl child with spastic diplegic cerebral palsy.



Pic 2. Photograph of a child with spastic quadriplegic cerebral palsy with windswept deformity.

Pic 3. Photograph depicting clinical examination of a child with CP

Pic 4. Photograph showing filling of the questionnaire.

ANNEXURES V - MASTER CHART

	basic details				presenting complaints																		family history				Birth history				Natal history												Post natal history						infancy				final diagnosis																						
Sl.no	name	age	sex	SE class	developmental delay			abnormal movements	seizures	infection	Excessive cry	Behaviour				feeding problems		drooling	vision		hearing	dental	degree of consanguinity	mother's age at birth	birth order	family history CP	regular ANC	duration of pregnancy			place of delivery		Events and type of delivery	multiple pregnancy	meconium	cry at birth		resuscitation	B.wt				events						trauma	stroke	infection	meningitis	topographical			physiological					risk factors				GMFCS	MACS	BPRS-c	co-morbidities							
					motor	language	social					hyperactive	autistic	pathetic	depressed	contripation	vomiting		squint	poor vision							taken = 1	Term	late preterm	preterm	home	hospital				normal	delayed		< 1kg	1 - 1.5Kg	1.5-2.5kg	>2.5kg	Jaundice	cyanosis	septicemia	seizures	RDS	feeding					Quadri	hemi	diplegic	spastic	mixed	dystonic	choreoathetoid	ataxic	prenatal	perinatal	postnatal					epilepsy	GDD	hearing	behaviour	visual	speech	GI	respiratory
1	shrinidhi	4	F	IV	1	1	1	1	0	1	0	0	0	1	0	1	0	1		0	1	1	I	21	I	0	1	0	1	0	0	1	A	0	0	0	1	0	0	0	1	0	1	0	0	0	0	0	0	0	0	0	1	0	0	0	1	0	0	0	1	1	0		V	V	7	0	1	1	0	0	1	1	0
2	Zakiya	7	F	IV	1	1	1	0	1	0	0	0	0	0	0	0	0	1	0	0	0	0	N	18	I	1	1	1	0	0	0	1	A	0	0	0	1	1	0	0	1	0	0	0	0	0	1	0	0	0	0	0	0	0	1	1	0	0	0	0	0	1	0		III	IV	6	1	1	0	0	0	1	0	0
3	bhagesh	8	M	III	1	1	1	1	0	0	1	0	0	1	0	0	0	1	0	0	0	0	N	20	I	0	0	1	0	0	0	1	A	0	0	0	1	1	0	0	0	1	0	0	0	1	0	0	0	0	0	0	1	0	0	0	0	1	0	0	0	1	0		V	V	6	0	1	0	1	0	1	0	0
4	Shabira	3	F	IV	1	1	1	1	0	0	0	0	0	0	0	0	0	1	0	0	0	1	II	22	II	1	1	1	0	0	0	1	A	0	0	0	1	1	0	0	0	1	0	0	0	1	1	0	0	0	0	0	1	0	0	0	1	0	0	0	0	1	0		IV	III	3	0	1	0	0	0	1	0	0
5	Nirav	3.5	M	III	0	0	0	1	0	1	0	1	0	0	0	0	0	1	0	0	0	0	II	28	IV	0	0	1	0	0	1	0	A	0	0	1	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	1	0	0	1	0	0	0	0	NK	0	0		III	III	7	0	0	0	0	0	0	1	1
6	shivanand Mahantesh	3.5	M	IV	1	1	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	1	III	20	I	0	1	1	0	0	0	1	A	0	0	1	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	1	0	0	0	1	0	0		V	V	3	0	1	0	0	0	0	0	0
7	darshan	10	M	IV	1	1	1	1	0	0	0	0	0	1	0	0	0	1	0	0	0	1	N	16	II	0	1	0	0	1	0	1	B	0	0	0	1	1	0	1	0	0	0	0	0	0	1	1	0	0	0	0	1	0	0	0	0	0	1	0	1	1	0		IV	IV	5	0	1	0	0	0	0	0	1
8	Basavaraj Nagappa	7	M	IV	1	1	1	1	0	0	0	0	0	1	0	1	0	1	1	0	0	0	III	25	II	0	1	0	1	0	0	1	A	0	0	1	0	0	0	0	1	0	1	0	0	0	0	0	0	0	0	0	1	0	0	0	1	0	0	0	1	0	0		III	III	12	0	1	0	1	1	0	0	0
9	Shivanand	4y 3m	M	IV	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	N	22	II	0	0	1	0	0	0	1	A	0	0	1	0	0	0	0	0	1	0	0	0	0	0	0	0	1	0	0	0	1	0	1	0	0	0	0	0	0	1		I	I	5	0	0	0	0	0	0	1	0
10	Samya	5y 9m	F	III	1	1	0	0	0	1	0	1	0	0	0	0	0	0	0	0	0	0	N	25	III	0	0	1	0	0	0	1	D	0	0	0	1	1	0	0	0	1	0	0	0	1	0	0	0	0	0	0	1	0	0	1	0	0	0	0	0	1	0		I	I	11	0	1	0	0	0	0	1	1
11	Manjunath	6	M	V	1	1	1	1	0	0	1	1	0	0	0	1	1	0	0	0	0	0	II	18	I	0	0	1	0	0	0	1	A	0	0	1	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	1	0	0	1	0	0		I	V	17	1	1	0	1	0	0	1	0
12	Samaiyya	5	F	IV	1	1	0	1	0	1	0	1	0	0	0	0	0	1	0	0	0	0	N	22.5	III	0	1	1	0	0	0	1	A	0	0	0	1	1	0	0	0	1	0	0	0	1	0	0	0	0	0	0	1	0	0	0	0	0	1	0	0	1	0		I	I	11	0	1	0	1	0	1	0	1
13	Sameena	3	F	IV	1	0	0	0	1	1	0	0	0	0	0	0	0	1	0	0	0	0	III	19	III	0	0	1	0	0	1	0	A	0	0	1	0	0	0	0	NK	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	1	0	0	0	1	0		III	I	5	0	1	0	0	0	0	0	0
14	Pranav	3y 2m	M	II	1	1	1	1	0	0	1	0	0	0	0	0	1	1	0	0	0	0	II	22	II	0	0	1	0	0	0	1	C	0	1	0	1	1	0	0	1	0	0	0	0	0	1	0	0	0	0	0	1	0	0	0	0	1	0	0	0	1	0		V	V	5	0	1	0	0	0	1	0	0
15	Karthik	3	M	III	1	0	1	0	0	1	0	0	0	0	0	1	0	1	0	0	0	0	N	19	I	0	0	1	0	0	0	1	A	0	1	0	1	1	0	0	0	1	0	0	0	0	1	0	0	0	0	0	1	0	0	0	1	0	0	0	0	1	0		IV	III	3	0	1	1	0	0	0	1	0
16	Afifa	4	F	IV	0	1	0	1	1	0	0	0	0	0	1	0	0	0	0	0	0	0	N	30	I	0	0	1	0	0	0	1	A	0	0	1	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	1	0	1	0	0		I	I	6	1	0	0	1	0	1	0	0
17	Pradeep	6y 6m	M	III	1	0	0	1	1	0	0	0	0	0	0	0	0	1	0	0	0	0	N	21	I	0	1	0	0	1	0	1	B	0	0	1	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	1	0	0	0	1	0	0		IV	III	5	1	1	0	0	0	1	0	1
18	Basamma Nagappa	4	F	III	1	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	III	18	I	0	1	1	0	0	0	1	A	0	0	1	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	1	0	0	0	0	1		II	I	7	0	1	0	0	0	0	0	0
19	Pallavi	6	F	III	1	0	1	1	1	0	0	0	0	1	0	0	0	1	1	0	0	0	II	19	I	0	1	1	0	0	0	1	A	0	1	1	0	0	0	0	1	0	0	0	0	0	1	0	0	0	0	0	0	1	0	0	1	0	0	0	0	0	1		IV	IV	5	1	0	0	1	1	0	1	0
20	Sanjana	7	F	II	1	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	II	20	I	0	1	1	0	0	0	1	A	0	0	1	0	0	0	0	0	1	0	0	0	0	0	0	0	0	1	0	0	1	0	1	0	0	0	0	0	0	1		I	I	8	0	1	0	1	0	1	0	0
21	Vinayak	3	M	III	1	1	1	0	0	1	1	1	0	0	0	0	0	0	0	1	0	0	N	29	II	0	1	1	0	0	0	1	C	0	0	1	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	1	0	0	1	0	0	0	0	1	0	0		V	V	10	0	1	0	1	1	1	0	0
22	Sujatha	8	F	IV	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	III	20	I	0	1	0	0	1	1	0	A	0	0	1	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	1	0	0	0	0	1	0	0		II	I	5	0	0	0	0	0	0	0	0
23	Veeha	3y 9m	F	II	1	1	0	1	1	1	1	1	0	0	0	0	0	0	0	0	0	0	N	25	I	0	1	1	0	0	0	1	C	0	0	1	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	1	0	0	0	0	1		V	V	10	0	1	0	0	0	1	0	0
24	Pruthvi Raj	4	M	III	1	1	1	1	1	1	1	0	0	0	0	1	0	1	1	0	0	0	N	20	I	0	1	1	0	0	0	1	A	0	1	0	1	1	0	0	1	0	0	0	0	1	1	0	0	0	0	0	1	0	0	0	0	1	0	0	0	1	0		V	V	4	1	1	0	0	0	1	1	1
25	Parvati	10	F	III	1	1	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	II	24	I	0	1	1	0	0	0	1	A	0	0	0	1	1	0	0	0	1	0	0	0	1	0	0	0	0	0	0	1	0	0	0	0	1	0	0	0	1	0		II	II	6	1	1	0	0	0	1	0	0
26	Vedant	4	M	II	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	N	20	I	0	1	1	0	0	0	1	A	0	0	1	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	1	0	1	0	0	0	0	1	0	0		I	I	4	0	1	0	0	0	0	0	0
27	Sai Raj	10	M	II	1	1	1	0	1	0	1	1	0	0	0	0	0	0	0	0	0	0	N	25	II	0	1	0	1	0	0	1	C	0	0	1	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	1	0	0	0	0	1	0	0		II	II	6	1	1	0	0	0	0	0	0
28	Satish Hanumanth	3	M	V	1	1	1	1	0	0	1	0	0	0	0	0	0	1	0	0	0	0	N	27	I	0	1	1	0	0	0	1	A	0	0	0	1	1	0	0	0	1	0	0	0	0	1	0	0	0	0	0	1	0	0	0	0	0	0	1	0	1	0		IV	IV	7	0	1	0	0	0	1	0	0
29	Ashrith Gurunath	3y 2m	M	V	1	1	1	1	1	0	1	0	0	0	0	0	0	1	0	0	0	0	N	21	I	0	1	1	0	0	0	1	C	0	0	0	1	1	0	0	0	1	1	0	0	1	-	-	0	0	0	0	1	0	0	0	0	1	0	0	0	1	0		V	V	4	1	1	0	0	0	1	0	0
30	Dhanush Fs	3y 7m	M	IV	1	1	1	1	1	0	0	0	0	1	0	0	0	0	0	0	0	0	N	24	I	0	0	1	0	0	0	1	D	0	0	0	1	1	0	0	1	0	0	0	0	1	0	0	0	0	0	0	1	0	0	0	0	1	0	0	0	1	0		II	II	13	1	1	0	1	0	0	0	0
31	Sumedh	4	M	IV	1	1	1	0	0	0	0	1	0	0	0	0	0	0	0	0	0	1	III	23	I	0	0	1	0	0	0	1	E,C	0	0	1	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	1	0	0	1	0	0	0	0	1	0	0		III	IV	10	0	1	0	1	0	1	0	1
32	Shevanthi	3y	F	IV	1	1	1	1	1	0	1	1	0	0	0	0	0	1	0	0	0	0	N	22	I	0	0	1	0	0	0	1	A,F	0	0	1	0	0	0	0	1	0	0	0	0	1	0	0	0	0	0	0	1	0	0	0	0	1	0	0	0	0	1		IV	II	6	1	1	0	1	0	1	0	0
33	DhanRaj	7	M	IV	0	1	0	1	0	0	0	0	0	0	0	0	0	1	0	0	0	0	N	20	I	0	1	1	0	0	0	1	C	0	0	1	0	0	0	0	0	1	0	0	0	1	0	0	0	0	0	0	1	0	0	0	0	0	1	0	0	0	1		I	II	5	0	1	1	0	0	0	0	0
34	Md Maaz	3	M	V	1	1	1	1	1	0	0	0	0	0	0	0	0	0	0	0	1	1	III	19	II	0	1	1	0	0	0	1	C	0	0	1	0	0	0	0	1	0	0	0	1	0	0	0	0	0	0	0	1	0	0	0	0	1	0	0	0	0	1		V	V	4	1	1	1	0	0	0	0	0
35	Lalasab	10	M	IV	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	N	20	I	0	1	1	0	0	0	1	A	0	0	1	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	1	0	1	0	0	0	0	0	1	0		I	I	8	0	1	0	0	0	1	0	0
36	Shreyas Rajendra	7	M	III	1	1	1	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	N	20	I	0	1	0	1	0	0	1	B,D	0	0	0	1	1	0	0	1	0	0	0	0	1	0	0	0	0	0	0	1	0	0	0	0	1	0	0	0	1	0		IV	III	4	1	1	0	0	0	1	0	0
37	Shivam Sholapure	5	M	III	1	1	1	1	0	0	0	1	0	0	0	0	0	0	1	0	0	0	N	27	I	0	1	1	0	0	0	1	C,F	0	0	0	1	1	0	0	1	0	0	0	0	1	0	0	0	0	0	0	1	0	0	0	0	1	0	0	0	1	0		I	I	9	0	1	0	1	0	1	0	1
38	Radhika	9	F	III	1	1	1	1	1	0	0	0	0	0	0	0	0	0	0	0	1	0	N	23	II	0	1	1	0	0	0	1	A	0	0	0	1	1	0	0	0	1	0	0	0	1	0	0	0	0	0	0	1	0	0	0	0	1	0	0	0	1	0		IV	II	4	1	1	1	0	0	1	0	0
39	Sangamesh	3	M	IV	1	1	1	1	0	0	1	0	0	1	0	0	0	1	1	0	0	0	N	21	I	0	1	1	0	0	0	1	C,F	0	0	0	1	1	0	0	0	1	0	0	0	1	0	0	0	0	0	0	1	0	0	0	0	1	0	0	0	1	0		III	III	7	0	1	0	1	1	0	0	0
40	VedA	5	F	IV	1	1	1	1	1	0	0	1	0	0	0	0	0	1	0	0	0	0	II	30	III	0	0	1	0	0	0	1	C,F	0	0	0	1	1	0	1	0	0	0	0	0	0	1	0	0	0	0	0	1	0	0	0	0	0	1	0	0	1	0		II	III	10	1	1	0	1	0	1	0	0
41	HussainSab	9	M	IV	1	1	0	0	1	0	0	1	0	0	0	0	0	0	0	0	0	0	II	20	I	0	1	1	0	0	0	1	A	0	0	1	0	0	0	0	1	0	0	0	1	0	0	0	0	0	0	0	0	1	0	1	0	0	0	0	0	0	1		III	III	9	1	0	0	0	0	0	0	0
42	Shreya	4	F	III	1	1	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	N	20	I	0	1	0	0	1	0	1	B	0	0	1	0	0	0	0	1	0	1	0	0	0		0	0	0	0	0	0	1	0	0	0	1	0	0	0	1	0		I	II	4	0	1	0	0	0	1	0	0
43	Krishna	4	M	III	1	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	N	21	I	0	1	0	0	1	0	1	A	0	0	1	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	1	0	0	0	0	0	0	1		III	II	5	0	1	0	0	1	0	0	0
44	Keshav	5	M	IV	1	1	1	0	1	0	0	1	0	0	0	1	0	0	1	0	0	1	N	20	I	0	1	1	0	0	0	1	A	0	1	0	1	1	0	0	0	1	0	0	0	0	1	0	0	0	0	0	0	0	1	1	0	0	0	0	0	1	0		IV	IV	11	1	1	0	0	1	0	1	0
45	Ravi Gowda	3	M	IV	1	1	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	N	21	I	0	1	0	0	1	0	1	A	0	0	1	0	0	0	0	1	0	0	0	0	1	0	0	0	0	0	0	1	0	0	0	0	0	1	0	1	0	0		IV	IV	8	0	1	0	1	0	1	0	0
46	Somashekar	10	M	III	1	1	1	1	1	0	1	1	0	0	0	0	0	0		0	1	0	N	27	III	0	1	1	0	0	0	1	A	0	0	1	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	1	0	0	1	0	0		III	IV	8	1	1	1	1	0	1	0	0
47	Akshaya	10	M	IV	1	1	1	0	1	0	0	1	0	0	0	0	0	1	0	0	0	0	III	23	I	0	1	1	0	0	0	1	A	0	0	0	1	1	0	0	0	1	0	0	0	1	0	0	0	0	0	0	0	1	0	1	0	0	0	0	0	1	0		II	V	9	1	1	0	1	0	1	0	0
48	Samarth	4y 5m	M	III	1	1	0	0	0	0	1	1	0	0	0	0	0	0	0	0	0	0	II	21	I	0	1	1	0	0	0	1	G	0	0	1	0	0	0	0	0	1	1	0	0	0	0	0	0	0	0	0	0	1	0	1	0	0	0	0	1	0	0		II	II	10	1	0	0	1	0	1	0	0
49	Hanmavvva	10	F	III	0	1	0	0	1	0	0	1	0	0	0	0	0	1	0	0	0	1	N	20	I	0	1	1	0	0	0	1	F	0	0	1	0	0	0	0	0	1	0	0	0	1	0	0	0	0	0	0	1	0	0	0	0	1	0	0	0	1	0		I	I	7	1	0	0	1	0	1	0	0
50	Muthu	7	M	III	1	1	1	0	1	0	1	1	0	0	0	0	0	1	0	0	0	0	N	23	I	1	1	1	0	0	0	1	H	0	0	1	1	1	0	0	1	0	0	0	1	0	0	1	0	0	0	0	1	0	0	1	0	0	0	0	0	1	0		III	III	9	1	1	0	1	0	1	0	0
51	Mallappa	5	M	III	1	0	0	1	1	0	0	0	0	0	0	0	0	1	0	0	0	1	N	21	I	0	1	0	0	1	0	1	B	0	0	1	0	0	0	1	0	0	1	0	0	0	0	0	0	0	0	0	1	0	0	0	1	0	0	0	1	0	0		IV	III	3	1	1	0	0	0	1	1	0

					interventions adviced					LAQ- parameters																																
					physiotherapy	medical	nutritional	speech	treatment of co-morbities	Clinical	economic	physical	mobility	school	social integration	FINAL LAQ		CO morbities Post interven														pOst intervention			PARAMETERS of LAQ p							Post INtervention
drooling	UTI	deformities	dental caries	total														epilepsy	GDD	hearing	visual	speech	GI	respiratory	drooling	UTI	deformities	dental caries	behaviour	pain	total co-morbidities	GMFCS	MACS	BPRS-C	Clinical	economic	physical	mobility	school	social integration		FINAL LAQ
1	0	0	1	7	1	1	0	1	1	0.97503	13.666	30.4947	30.8568	0	11.2	91.2434		0	1	1	0	0	1	0	0	0	0	0	0	0	3	V	V	7	0.75	13.6667	29.7509	30.8568	0	12.6		91.6746
1	0	0	0	5	1	1	1	1	1	0.5262	0	19.3381	18.3212	0.6	7.7	50.5356188		0	1	0	0	0	0	0	0	0	0	0	0	0	1	III	III	6	0.5262	0	16.363	12.535	0.6	7.7		41.7748
1	0	0	0	5	1	1	1	1	1	0.6	13.666	30.4947	30.8568	0.6	12.6	92.6684		0	1	0	0	1	0	0	0	0	0	0	1	0	3	V	V	6	0.675	13.6667	29.0071	30.8568	0.6	11.2		89.6058
1	0	0	0	4	1	1	1	1	1	0.3	0	27.5196	21.2141	0	8.4	61.48375		0	1	0	0	0	0	0	0	0	0	0	0	0	1	III	III	3	0.3	1.025	20.0818	16.3927	0	8.4		50.2496
1	0	0	0	4	0	1	0	0	1	0.375	0	21.1975	10.607	0	6.3	42.5296		0	0	0	0	0	1	0	0	0	0	0	0	0	1	II	II	7	0.3	0	15.9911	8.6785	0	4.9		33.9185
1	0	1	0	3	1	1	1	0	1	0.3	0	28.2634	21.2141	0	10.5	64.3275		0	1	0	0	0	0	0	0	0	1	0	0	0	2	V	V	3	0.375	0	27.5196	20.2498	0	10.5		62.69
1	0	0	0	3	1	1	1	1	1	0.375	0	31.9822	19.2855	0.6	16.7731	73.0659		0	1	0	0	0	0	0	0	0	0	0	0	0	1	V	V	5	0.3	0	28.4384	19.2855	0.6	15.4		68.0739
1	0	0	0	5	1	1	0	1	1	0.4512	0	25.2883	16.39272	0.6	8.4	55.6822		0	1	0	0	0	0	0	0	0	0	0	1	0	1	II	III	12	0.3757	0	25.5445	14.5177	0.6	7.5		51.5879
0	0	0	0	2	0	1	0	0	1	0.675	0	8.9252	8.6785	0	4.2	26.5288		0	0	0	0	0	0	0	0	0	0	0	0	0	0	I	I	4	0.375	0	5.2064	2.8928	0	4.2		16.7243706
0	0	0	0	3	1	1	1	1	1	0.225	0	12.64415	6.7499	0.6	4.9	28.569		0	1	0	0	0	0	0	0	0	0	0	0	0	1	I	I	11	0.225	0	3.7188	5.7856	0	3.5		17.2795
0	0	0	0	5	1	1	1	1	1	0.675	0	20.825	19.2856	0.6	9.8	55.236248		0	1	0	0	0	0	0	1	0	0	0	0	0	2	I	V	17	0.525	0	14.1317	15.4284	0.6	8.4		43.63516
1	0	0	0	5	1	1	1	1	1	0.225	0	12.64415	6.7499	0.6	4.9	28.569		0	1	0	0	0	0	0	0	0	0	0	0	0	1	I	I	11	0.225	0	3.7188	5.7856	0	3.5		17.2795
1	0	0	0	3	1	1	1	0	0	0.45	0	28.2634	28.9283	0	11.9	73.5914		0	1	0	0	0	0	0	0	0	0	0	0	0	0	III	I	5	0.451	0	26.032	21.2141	0	10.5		62.2472
1	0	0	0	4	1	1	1	1	1	0.375	1.3666	33.4698	23.1426	0	8.4	70.8042		0	1	0	0	1	0	0	0	0	0	0	0	0	2	V	V	5	0.3	1.3667	31.2384	19.2855	0	8.4		64.64084
1	0	0	0	5	1	1	0	1	1	0.3	13.6667	27.5196	27.964	0	11.2	84.7004		0	1	1	0	0	0	0	0	0	0	0	0	0	2	III	II	3	0.3	0	26.7758	28.9283	0	9.8		69.8542
0	0	0	0	3	0	1	0	1	1	0.45	0	1.4875	4.8213	0.6	1.4	12.808948		0	0	0	0	1	0	0	0	0	0	0	1	0	2	I	I	5	0.225	0	1.4875	4.8213	0.6	1.4		12.58
1	0	0	0	6	1	1	1	1	1	0.45	0	26.7758	20.2498	0.6	14	66.1275		1	1	0	0	0	0	0	0	0	0	0	0	0	1	IV	III	5	0.375	0	25.2883	20.2498	0.6	12.6		63.1631
0	0	0	0	2	1	1	0	0	0	0.2255	0	23.8007	16.3927	0.6	10.5	55.569		0	1	0	0	0	0	0	0	0	0	0	0	0	1	II	I	6	0.15	0	20.8256	14.4641	0.6	8.4		48.4898
1	0	0	0	6	1	1	0	1	1	0.801	0.6833	25.2883	16.3927	0.6	11.2	59.0154		0	0	0	1	0	0	0	0	0	0	0	1	0	2	IV	IV	5	0.6013	0.6833	25.2803	16.3927	0.6	9.8		53.3657
0	0	1	0	4	1	1	0	1	0	0.3758	0	1.4875	3.8571	0	2.8	12.5705		0	1	0	0	1	0	0	0	0	1	0	1	0	4	I	I	8	0.2255	0	1.4875	3.857	0	2.8		12.4207
0	0	0	0	5	1	1	1	1	1	0.525	0	30.4947	15.4284	0	13.3	63.7981		0	1	0	1	1	0	0	0	0	0	0	0	0	3	V	V	8	0.3758	0	26.032	13.4998	0	10.5		54.4578
0	0	1	0	1	1	1	0	0	1	0.15	0	1.4875	5.7856	0.8	7.7	19.9732204		0	0	0	0	0	0	0	0	0	1	0	0	0	1	II	I	4	0.15	0	1.4875	3.8571	0.8	7.7		18.0446
1	0	0	0	4	1	1	0	1	0	0.6750216	2.0500164	33.469821	14.46417	0.6	14	69.309029		0	1	0	0	0	0	0	0	0	0	0	0	0	1	V	V	7	0.6750216	0	31.2384996	14.4617	0.6	14		65.0276912
1	0	0	0	7	1	1	0	1	1	1.35004	0	31.9822	19.2856	0.6	11.9	68.5678		0	1	0	0	1	1	0	0	0	0	0	0	0	3	V	V	4	0.60001	0	31.2384	18.3212	0.6	11.9		66.7098
0	0	0	0	4	1	1	0	1	0	0.3758	0	9.669	8.6785	0.4	13.3	32.4234		0	1	0	0	1	0	0	0	0	0	0	0	0	2	II	II	6	0.3	0	8.9252	7.7142	0.4	11.9		33.2895
0	0	0	0	2	1	1	1	0	0	0.3758	0	8.1815	8.6785	0.2	5.6	27.0858		0	1	0	0	0	0	0	0	0	0	0	0	0	1	I	I	4	0.375	0	6.6939	7.7142	0.2	4.2		23.2332
0	0	0	0	3	1	1	1	0	1	0.6013	0	13.3879	8.6785	0.4	11.9	39.0178		0	1	0	0	0	0	0	0		0	0	0	0	1	II	II	6	0.375	0	7.7142	13.3879	0.4	9.1		35.0271
1	0	0	0	3	1	1	0	1	0	0.150348	0	31.2384996	19.28556	0	14	68.7244076		0	1	0	0	1	0	0	0	0	0	0	0	0	2	IV	IV	7	0.150348	0	22.5	18.32129	0	12.6		57.62235
1	0	0	0	5	1	1	1	1	1	0.375012	0	29.75	19.28556	0	9.8	63.261524		0	1	0	0	1	0	0	0	0	0	0	0	0	2	V	V	3	0.3	0	29.007	18.3212	0	9.8		61.4784
0	0	0	0	4	1	1	0	0	0	0.9772	0.6833	20.0876	15.4284	0.2	11.2	52.6267		0	1	0	0	0	0	0	0	0	0	0	1	0	2	II	II	10	0.825	0.6833	16.363	13.4998	0.2	9.1		44.72133
1	0	0	0	6	1	1	1	0	1	0.902	0	31.2384	12.5356	0.8	3.5	53.0262		0	1	0	0	1	0	0	0	0	0	0	1	0	3	III	IV	8	0.675	0	27.5196	10.607	0.8	3.5		47.1517
1	0	0	0	5	1	1	1	1	1	1.05	0.6833	31.2384	18.3212	0	4.9	60.2426		0	1	0	0	1	0	0	0	0	0	0	1	0	3	IV	II	5	0.902	0.3416	27.5196	18.3212	0	4.9		51.9843
1	0	0	0	3	0	1	1	1	1	0.3006	0	8.1815	6.7499	0.8	7.7	27.7821		0	1	1	0	0	0	0	0	0	0	0	0	0	2	I	II	5	0.225	0	7.437738	5.7856	0.8	6.3		24.5984
1	0	0	0	5	1	1	0	1	1	0.3758	0	30.5035	18.32182	0	11.18208	64.4327		0	1	1	0	0	0	0	0	0	0	0	0	0	2	V	V	4	0.15	0	27.5196	18.3212	0	11.182		61.229
0	0	1	0	4	0	1	0	1	0	0.3758	0	1.4875	5.7856	0.4	7.7	19.799		0	1	0	0	1	0	0	0	0	1	0	0	0	3	I	I	8	0.3	0	1.4875	5.7856	0.4	5.6		17.62322
0	0	0	1	5	1	1	1	1	1	0.3758	0	28.2634	21.2141	0.6	11.2	65.7304		0	1	0	0	1	0	0	0	0	0	0	0	0	2	IV	III	4	0.225	0	22.313	17.357	0.6	8.4		48.895
0	0	0	0	4	0	1	1	1	1	0.45	0	13.3879	7.7142	0.2	7	32.8022		0	1	0	0	1	0	0	0	0	0	0	1	0	3	I	I	8	0.2255	0	9.0002	7.7142	0.2	5.6		26.790034
0	0	0	1	5	1	1	1	1	1	0.37501	0.6833	30.4947	22.1783	0.6	11.2	69.58146		0	1	1	0	0	0	0	0	0	0	0	0	0	2	IV	II	3	0.3006	0	16.363	21.2141	0.6	12.5879		55.1153
1	0	0	0	4	1	1	0	1	1	0.3	0	30.4947	18.3212	0	10.5	63.661		0	1	0	1	0	0	0	0		0	0	1	0	3	III	III	7	0.225	0	27.5275	18.3212	0	10.5		60.6238
1	0	0	0	5	1	1	0	1	1	0.225	0	16.363	9.64	0	3.5	33.7808		1	1	0	0	0	0	0	0	0	0	0	0	0	2	II	III	9	0.075	0	13.3879	9.6427	0	3.5		30.6557
0	0	0	0	2	1	1	0	0	1	0.525	0	16.363	9.642	0.6	9.1	40.2808		1	0	0	0	0	0	0	0	0	0	0	0	0	0	II	III	8	0.3	0	14.1317	8.6785	0.4	7.7		35.2602
0	0	0	0	3	1	1	0	1	1	0.825	0.6833	14.1317	10.607	0	6.3	36.5971		0	1	0	0	0	0	0	0		0	0	0	0	1	I	II	2	0.675	0	12.6441	8.6785	0	6.3		32.3477
0	0	0	0	3	1	1	1	0	0	0.675	2.05	25.2883	19.2855	0.6	4.2	56.1489		0	1	0	1	0	0	0	0	0	0	0	0	0	2	III	II	5	0.525	2.05	20.0818	19.2855	0.6	2.8		49.5925
0	0	1	0	5	1	1	0	1	1	0.375	0	31.9822	19.2855	0.6	12.6	68.8928		0	1	0	1	0	0	0	0	0	1	0	0	0	3	IV	IV	9	0.6747	0	30.4947	18.28558	0.6	12.6		66.705
0	0	0	0	3	1	1	0	1	1	0.3	0	31.2384	23.1426	0	12.6	71.3311		0	1	0	0	1	0	0	0	0	0	0	1	0	3	IV	IV	8	0.3	0	29.7509	23.1426	0	11.2		68.4436
0	0	0	0	6	1	1	0	1	1	0.3	0	32.726	22.1783	0.6	11.9	71.7544		0	1	1	0	1	0	0	0	0	0	0	1	0	4	III	IV	6	0.3	0	29.0071	22.1789	0.6	11.2		67.3361
1	0	0	0	6	1	1	0	1	1	1.125	0	20.0818	11.5713	0.6	14	51.4282		0	1	0	0	1	0	0	0	0	0	0	1	0	3	II	V	7	0.825	0	17.1067	9.6427	0.6	9.8		42.0246
0	0	0	0	4	1	1	0	1	1	0.375	0	14.875	9.4968	0	9.1	37.897388		0	0	0	0	1	0	0	0	0	0	0	1	0	2	II	II	8	0.3	0	11.1566	9.496	0	7		32.0035
1	0	0	0	5	0	1	0	1	1	0.525	0	2.2164	7.7142	0	10.5	24.7056		0	0	0	0	1	0	0	0	0	0	0	1	0	2	I	I	6	0.375	0	0.7437	6.7499	0	9.1		21.0187
1	0	0	0	6	1	1	0	1	1	0.6	0	23.8007	22.1783	0.6	14	65.2291		0	1	0	0	1	0	0	0	0	0	0	1	0	3	III	III	8	0.3	0	20.0818	21.2141	0.6	12.6		58.846
1	0	0	1	7	1	1	1	1	1	0.45	0	26.7758	20.2498	0.6	14	66.127		0	1	0	0	1	0	0	0	0	0	0	0	0	2	IV	III	3	0.375	0	25.2883	20.2498	0.6	12.6		63.1631592

ANNEXURE-VI

KEY TO MASTER CHART

Sex:

M- male

F- female

SE (socio-economic) class

I: Upper class

II: Upper middle class

III: Middle class

IV: Lower Middle

V: Lower class

Presenting complaints:

0- Not Present

1- Present

Degree of consanguinity:

N: no

I: 1st degree

II: Second degree

III: Third degree

Birth order:

I: first birth order

II: second birth order

III: third birth order

IV: fourth birth order

Family history

0- Not present

1- Present

Duration of pregnancy

0- No

1- Yes

Place of delivery

0- No

1- Yes

Events during delivery:

A- Normal delivery

B- PROM

C- LSCS

D- Forceps

E- Breech

F- Pregnancy induced hypertension

G- UTI

H- Difficult labour

Natal and post natal history:

0- No

1- Yes

Infancy

0- No

1- Yes

Final diagnosis

0- No

1- Yes

Risk factors:

0- No

1- Yes

GMFCS and MACS levels:

I- Level I

II- Level II

III- Level III

IV- Level IV

V- Level V

Co-morbidities:

0- No

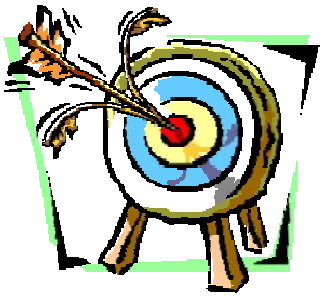
1- Yes

Interventions adviced:

0- No

1- Yes

Introduction



Objectives

Review of Literature

Methodology

Results

Discussion

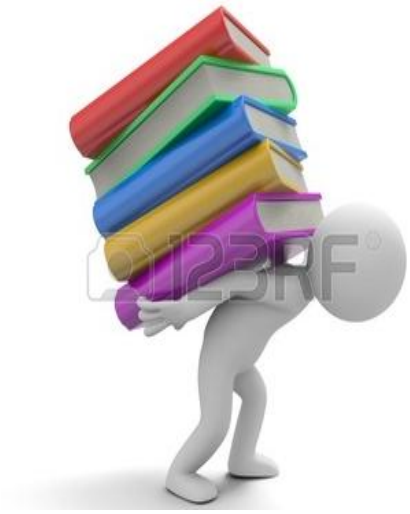
Conclusion

Summary

Bibliography

Annexure-I

Annexure-II



Annexure-III

Annexure-IV

Annexure-V

Annexure-VI