

Comprehensive Management of People with Cerebral Palsy: An Indian Perspective

Kavitha Raja^{1*}, Saumen Gupta², Priyanka Shirsath³

1. JSS College of Physiotherapy, Mysore, Karnataka, India

2. Sikkim Manipal College of Physiotherapy, Sikkim Manipal University, Gangtok, Sikkim, India

3. Physiotherapy Practitioner, Nashik, Maharashtra, India

ABSTRACT

Purpose: *Guidelines for the management of people with cerebral palsy are available from many countries. However, these cannot be adopted in their entirety in other countries due to socio-cultural differences and varied health systems. This study set out to develop guidelines for the management of people with cerebral palsy, throughout their lifetime, in India.*

Methods: *A mixed methodology with a multiphasic approach was used. The first phase involved an extensive literature review to compile current evidence about the management of people with cerebral palsy. In the second phase, a questionnaire was given to stakeholders in order to explore current practices. The third phase consisted of consensus-building meetings with stakeholders, to develop resolutions that incorporate global best-practice recommendations for India.*

Results: *Responses from the second phase were compiled and categorised based on discipline. Proceedings of the consensus meetings were transcribed verbatim and best evidence was synthesised to understand current global practice guidelines. Resolutions were formed within the framework of the results of phases I and II. These were ratified by experts and then formalised.*

Conclusion: *Sixty-four resolutions were formed, detailing a framework for multidisciplinary management of persons with cerebral palsy throughout their lifetime. A card with guidelines was developed to document all aspects of rehabilitation, development and care. However, the utilisation and application of these guidelines have not been explored as yet.*

Key words: SAKSHAMA, current practice of cerebral palsy care, lifelong care

* **Corresponding Author:** Kavitha Raja, JSS College of Physiotherapy, Mysore, Karnataka, India.
Email: kavitharaja62@gmail.com

INTRODUCTION

Cerebral palsy (CP) is defined as “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” (Torjesen, 2017). CP is a common cause of childhood disability with an estimated global incidence of 3/1000 live births (Arneson et al, 2009).

While the needs of people with CP are unique and extensive, a significant majority have the potential to live independent and productive lives despite functional challenges. To achieve this, management must be ongoing and systematic. The obvious goals would be early identification of potential morbidities and focussed management to minimise such complications (Herskind et al, 2015).

The management of people with CP varies throughout India, with the emphasis limited to the early years of life. Although cerebral palsy has recently been included as a separate entity under the category of physical disabilities, despite the high prevalence the condition is not considered a public health issue in India. The management of children with CP is currently undertaken in hospitals and special schools; interdisciplinary management is rare. Moreover, healthcare disciplines in India, with the exception of rehabilitation disciplines (physiotherapy, occupational therapy, and speech and language pathology) have very little content on CP in their curricula.

Due to these challenges, it is imperative that uniform practice guidelines be drawn up in order to improve the quality of care, and ultimately the quality of life of people with CP. Guidelines for the management of CP exist in other countries but cannot be used in India without contextualisation and modification due to differences in healthcare delivery, and other social institutional systems. Guidelines in India are sketchy and limited to individual disciplines (Purohit, 2008). The recommended method of developing guidelines for medical disciplines with reference to best research evidence is by using the GRADE framework (Bhaumik, 2017). However, the GRADE checklist for forming guidelines does not include the value of social sciences research methodologies and this has been acknowledged as a limitation (Wang et al, 2018). Therefore, the current study did not use the GRADE guidelines but relied on: 1) a review of global guidelines, and 2) consensus-building meetings for feasibility and adaptation to the unique circumstances of the Indian health delivery services.

Objective

The study aimed to:

- 1) Conduct an extensive literature review in order to identify known risk factors, causal factors, prognostic indicators, robust outcome measures and management strategies for cerebral palsy;
- 2) Identify current practices in the management of people with cerebral palsy in India with reference to the first objective;
- 3) Develop an evidence-based guideline that is feasible, acceptable and applicable for the lifelong management of people with cerebral palsy in India.

METHOD

Study Design

This study used a multiphasic mixed-method design.

Participants

The study participants were persons with CP involved in advocacy, parents of children with CP, and professionals representing all disciplines involved with rehabilitation and care of a person with CP.

Procedure

Phase I: Literature Review - This phase consisted of an extensive literature review in order to synthesise scientific evidence on risk factors, causes and management of cerebral palsy in the various disciplines involved in the care of an individual with CP.

Literature was sourced from all available clinical practice guidelines, limited to the preceding 10 years. In the case of the social sciences only articles published from India were considered. The level of evidence of individual articles/ opinions was categorised using the guidelines of the National Health and Medical Research Council (NHMRC), Australia (NHMRC,2009).

Phase II: Survey to understand current practice - This phase was conducted through informal surveys to gather information on the current management

strategies used for people with CP by practitioners of various disciplines. A questionnaire, based on the evidence identified in phase I, was developed separately for each discipline and sent to 50 professionals in various disciplines all across India, using a snowball sampling technique. The questionnaire listed the recommendations for practice guidelines and the responses consisted of four options - “consistently followed”, “sometimes followed”, “never followed”, and “not aware”. Respondents were requested to provide information if their current practice differed from the guidelines listed in the questionnaire.

Phase III: Guideline formation - In this final stage, the results synthesised from the previous phases were used as a framework to guide a consensus-building meeting with experts and draw up guidelines (Tables 1-3). Experts belonging to healthcare disciplines, rehabilitation and social sciences disciplines, people with CP, and parents of children and adults with CP were invited to form ‘consensus’ groups in core areas: medical sciences, rehabilitation sciences and social sciences. Meetings were conducted separately for each group. All invitees had a minimum of five years’ experience in working with people with cerebral palsy and were considered experts in their field. All the sessions were video-recorded and then transcribed verbatim, including nonverbal communication where possible. The transcriptions were synthesised to form Resolutions with a level of recommendation and sent to the participants for clarification and confirmation. Following this process, the guidelines were circulated for ratification by professionals who were not part of the previous phases.

Table 1: Guiding Framework for Consensus Meeting with Medical Professionals

From a purely medical point how relevant are the NICE guidelines for us?

What are the major challenges?

Which classification is most useful for a paediatrician? For an Orthopaedic surgeon? For a Psychiatrist?

How feasible is it to refer to a rehab professional in the neonate period?

What are early markers that would help in flagging an infant?

Which is the earliest milestone that you consider for referral to rehab?

Any addition to standard risk factors?

What is a feasible and necessary follow-up schedule for an infant at high risk for NDD?

Which is the most feasible and sensitive scale for assessment? Cost, validity for India, norms for India.

What is the method to decrease loss to follow-up? Give a card like immunisation schedule?

Is recording of movement in NICU in India feasible?

Ethics?

What are the recommendations for MRI?

What are parent counselling recommendations? Who should do it?

Medication in high-risk pregnancies?

Pre-natal vaccines, vaccines for the child

NICU access to OT/PT

Referral to genetic testing? When?

Indicators?

What will be the changes to CP terms if genetic problems are identified?

When should the doctor elicit regression from the parent?

Counselling about having other children? Who should do it?

When is the earliest to refer to psychiatrist? Parent? Child?

Any difference in diagnosis of GI/ LD in CP different from TDC?

DIAGNOSIS- change from DD to CP

Systemic disorders when to screen? All time period.

Spasticity medication guidelines? Same as everywhere else?

Osteoporosis - when to test?

Correct age for Botox? Nerve block? Orthopaedic surgery?

Indications

Questions to identify atypical seizures

When to send to ophthalmologist?

Botox frequency for major muscles

Ortho Surgery for specific deformities- indications. Guidelines same as elsewhere?

Botox less than prescribed dose?

Hip surveillance - indicators

How often should be x-ray be done?

Vit D indications? Frequency?

Growth chart same as TDC?

ORAL HYGIENE and referral to dentist

Supplemental feeding recommendations

Questions to be asked for aspiration, constipation

Specific concerns for CP bowel - Irritable bowel?

Child with CP with mobility restrictions - diet modifications/ ADHD identification

When to assess for depression/ ADHS/ LD? Any specific differences from usual?

Behavioural problems - when to send to psychiatry? Tool to assess specific to India? Norms?

Disinhibition, stress- when should they be referred to psychiatry from psychology?

Table 2: Guiding Framework for Consensus Meeting with Rehabilitation Professionals

International Classification of Functioning (ICF)

Child Protection

Family-Centred Practice

Team Approach

Early Planning for Transition Periods

Clinical Measurement Practical Guidelines for Service Providers

Cultural Considerations

Definition

How is Cerebral Palsy Classified?

Goal Setting

Canadian Occupational Performance Measure (COPM)

Goal Attainment Scaling (GAS)

Classification Tools

Functional Motor Ability

Gross Motor Function Classification System (GMFCS)

Functional Mobility Scale (FMS)

Upper Limb Classifications

Manual Ability Classification System (MACS)

Communication Classification

Communication Function Classification System (CFCS)

Eating and Drinking Ability Classification System (EDACS)

Activity and Participation Assessment

Gross Motor and Mobility Assessment

Gross Motor Function Measure (GMFM)

3 Dimensional Gait Analysis (3DGA)

Observational (2D) Gait Analysis

Gillette Mobility Scale

Walk Tests

Timed Up and Go

Timed Up and Down Stairs

Fine Motor and Upper Limb Assessment

Quality of Upper Extremity Skills Test (QUEST)

Assisting Hand Assessment (AHA) and Mini Assisting Hand Assessment (MINI-AHA)

Melbourne Assessment 2: A Test of Unilateral Upper Limb Function (MA2)

Shriners Hospital Upper Extremity Evaluation (SHUEE)

Children's Hand-Use Experience Questionnaire (CHEQ)

ABILHAND-Kids

Box and Blocks Test

Jebesen-Taylor Hand Function Test (JTHFT)

Speech and Language Assessment

Quality of Life Assessment

Table 3: Guiding Framework for Consensus Meeting with other professionals

Dental care

Referral for dental care, ear pain, facial pain, routine check-up

Dental hygiene is not a priority for parents

Dental curriculum to include

Type of dentist to refer

Early indicator of osteoporosis- OPG/ dental radiology Hyperactive gag reflex- type of toothpaste

Electric toothbrush after the age of

Nursing practitioners

PHC- screening and early identification of DD (TDS) AND EARLY IDENTIFICATION OF SECONDARY complications

Role of counsellor in hospital/ clinic OPD

Health education- personal hygiene, nutrition, skin, B&B, medication and side effects

Psychologists

IQ and ID are overestimation? Or accurate? Should parents consider that during school planning?

Early identification of learning precursors- when and who

Executive function evaluation and classification? Best way to assess

List of best tests for India and what they measure

Educational goal same as all children -RTE- Secondary school completion
Individual learning plan if not possible in mainstream, open schooling Therapy for cognition?

Aim for self-care/ participation?

RESULTS

The results of phase I are presented below in Table 4. The guidelines were extracted from the works of various authors (Ashwal, 2004; Adekoje et al, 2016; Anttila et al, 2008; Bax et al, 2006; Beckung et al, 2002; Blanchard, 2016; Byrne et al, 2017; Cerebral Palsy - Effective Health Care Program, 2011; Colvin, 2018; Hadders-Algra, 2014; Himmelmann et al, 2006; Morris et al, 2006; Morris, 2009; Novak et al, 2013; Padmakar et al, 2018; te Velde, 2019) for each group and these were considered as guiding documents during the consensus discussions.

Table 4: Sample List of Recommendations available from Existing Guidelines (results of phase1)

Factor	Age applicable
Established independent risk factors for cerebral palsy must be considered and children followed up consistently	Pre-natal and natal
Established causal factors for cerebral palsy must be documented and infants followed up consistently	Pre-natal and natal
General movement assessment must be used as a screening tool for all infants at risk for cerebral palsy	0-5 months
Multidisciplinary early intervention strategies must be begun in all children at risk/ screened positive for cerebral palsy	3-12 months

Parent education in the early months of the child's life is essential in children at risk / screened positive for cerebral palsy	3-12 months
Nutritional and energy evaluation must be done routinely especially for children with swallowing difficulties	1-12 years
Pulmonary evaluation must be done routinely especially for children with swallowing difficulties and those with total body involvement	0-6 years
Evaluation for gastrointestinal comorbidities must be done routinely	Lifelong
Cognitive behavioural issues must be identified	3-6 years
Evaluation for communication, speech and hearing, seizures, vision, oral hygiene must be conducted	0-3 years
Orthopaedic evaluation must be done for all children to screen for deformities/ pain	3 years - lifelong
Functional prognostic factors must be communicated to parents for future planning	18 months-3 years
Gross motor interventions, Assistive technology, Social support, Social interaction, Fine movement training, schooling and vocational assistance	12 months- lifelong

The results of phase II are given below in Table 5. The response rate was very low despite repeated attempts at eliciting responses. Moreover, responses were inconsistent even among professionals belonging to the same discipline.

Table 5: Distribution of Individuals who Responded (phase II)

Discipline	Number of Responders
Paediatrics	30
Physiotherapy	29
Occupational therapy	14
Speech language pathology	12
Special education	10
Orthopaedic surgeon	08
Medical social work	03
Clinical psychology	03
Nursing	03
Neurologist	01

Oral physician	01
Ophthalmology	01
Ear nose throat specialist	01
Psychiatry	01
Prosthetic & Orthotics	01

The results of the first two phases were discussed in phase III. The results of phase III are given below. Participant descriptions are depicted in Table 6.

Table 6: Distribution of Participants at the Consensus Meetings

Discipline	Number of Participants
Persons with CP	02
Parents of persons with CP	03
Paediatricians	03
Orthopaedists	02
Psychiatrist	01
Oral medicine specialist	01
Physiotherapists	09
Occupational therapists	04
Speech and language pathologists	04
Orthotic specialist	01
Clinical psychologists	02
Social workers	04
Special educators	04
Nurse	01

The Resolutions that were formed in the consensus meetings are presented according to the order of importance as deemed by the participants.

Resolution 1: Identification and registration - Classification of the child with CP was deemed essential by all participants, although different disciplines used various systems of classifications. Due to this inconsistency, it was opined that management was not consistent. One of the reasons was attributed to the lack of a national registry. It was resolved that until such time as a national registry is operational, a booklet similar to the immunisation card will be given to the parents of a child at risk for CP. This booklet will be considered as an identification/ registration card and will remain in the possession of the parents/ caregivers, and thereafter of the person with CP if the individual is competent to care for himself/herself. This booklet will give crucial timelines and information about the type of professionals to be consulted. It is expected that the booklet will

help to ensure that the relevant experts will evaluate the child/ person with CP at crucial intervals and thereby improve the care of the individual. Moreover, this booklet would form a record of the person's progress as well as the management provided.

The salient points of this booklet are given in the box below. The acronym SAKSHAMA (meaning "efficiency" in English) was considered appropriate.

SAKSHAMA bearing a unique registration number which can later be integrated into a registry:

Screening and surveillance includes early identification of neurodevelopmental delay, routine screening for secondary complications based on current evidence.

Assessment refers to assessment for formalisation of diagnosis and those undertaken by healthcare providers from time to time for various complications detected during screening.

Knowledge transfer refers to education about CP to parents and communication between professionals and inclusion of CP-specific content in curricula of healthcare providers.

Service provision refers to provision of healthcare and social services including assistive technology, social services and availability of required services.

Habilitation refers to optimisation of functional capabilities undertaken by rehabilitation professionals. This may happen in short spells throughout life.

Accommodation refers to the provision of and advocacy for reasonable accommodation at school, in public places and the workplace including accessibility, job modification and ergonomic solutions.

Management refers to strategies employed by all members of the team towards minimisation of disability and optimisation of function.

Assistance refers to the provision of human assistance in school, public places, work-places and care in the later years of life.

Resolution 2: The experts unanimously agreed that existing international guidelines are relevant and appropriate for India, provided the healthcare system is able to cope with it. The challenges that they faced were timely and correct screening of children. Therefore it was resolved that the guidelines in healthcare disciplines available from other countries, particularly from the National Institute

for Health and Care Excellence (NICE) (National Guideline Alliance, 2017) were relevant and applicable to India.

Resolution 3: The dental specialist and the psychiatrist opined that additional modules on CP should be integrated into their respective curricula. Alternatively, special course work should be made available, preferably through Massive Open Online Course (MOOC) platforms popular in India, such as SWAYAM, which is hosted by the Ministry of Human Resource Development.

Resolution 4: Government of India (GOI) to be petitioned to create a cadre of rehabilitation workers at the Primary Health Centre (PHC) level. These rehabilitation workers can undertake routine screening and ensure timely and appropriate referral. Moreover, they can also be trained to perform certain essential nursing and rehabilitation interventions. Trained professionals will supervise them on a consultancy basis, in line with the existing system of consultant rehabilitation professionals at the PHC level.

Resolution 5: The Trivandrum Developmental Scale can be used as a screening tool by Accredited Social Health Activists (ASHA)/ rural childcare workers (Anganawadi workers)/ PHC nurses to identify children with dysfunction during their first year of life, until a suitable alternative for a more valid tool like the General Movements Assessment (GMA) by Prechtl, (2005) can be developed.

Resolution 6: *The* GMA developed by Prechtl (2005) is the most valid tool available for early detection of neurodevelopmental dysfunction. Movements of babies at risk, who are in the neonatal intensive care unit (NICU) in secondary and tertiary level hospitals, must be video- recorded. A trained GMA practitioner must be available at these centres for screening and prescription of early intervention programmes.

Resolution 7: Magnetic Resonance Imaging (MRI) is indicated in children with clear risk factors and this must mandatorily be carried out two weeks after birth.

Resolution 8: As soon as a child is identified as “at risk for neurodevelopmental delay”, a psychiatrist with counselling skills must be involved in the team to prepare the parents for the future care of the child. The team must consist of the paediatrician, parents and other decision- making family members, a medical social worker and the psychiatrist. It is necessary to classify the parents’ receptiveness in order to plan for future counselling sessions/ flag in the SAKSHAMA booklet

Resolution 8 (alternative): If a psychiatrist is unavailable, the parents must be asked to fill out a translated version of the General Health Questionnaire (GHQ- 12), which must be assessed by a consultant psychiatrist and the need for counselling should be decided.

Resolution 9: Obstetrics and Gynaecology specialists must consider the use of steroids and magnesium sulphate supplements (MgSO₄) for high-risk pregnancies as per current evidence.

Resolution 10: Genetic screening should be done at age 9-12 months when syndromic features/any dysmorphisms are noticed. This is standard practice across the world to differentially diagnose CP.

Resolution 11: If a genetic disorder is diagnosed, the child must not be referred to as 'CP' in any health records thereafter. For purposes of social security only, the term 'CP' or any other suitable term may be used. This Resolution may be omitted once social security regulations are changed to include various other diagnoses. Currently all children with motor delay are termed 'CP' for purposes of disability certification in many states of India.

Resolution 12: The list of disabilities recognised by the GOI must be revised to include genetic conditions, in order to minimise the improper diagnosis of CP.

Resolution 13: CP should not be diagnosed as intellectual disability (ID) ,as is common now, unless the child does have intellectual disability as a comorbidity. This labelling forms a barrier for mainstream schooling.

Resolution 14: All children with CP who are unable to maintain sitting position and do not have independent mobility must be evaluated by a paediatrician / gastroenterologist for aspiration, gastroesophageal reflux disorder (GERD), and bowel dysfunction. This must be accomplished by the time the child is 12 months old. Nutritional assessment and need for alternate methods of feeding/ augmentation of nutrition must be considered.

Resolution 15: If a child is on parenteral/ gastric feeding, non-nutritive sucking must be encouraged and safety for conversion to oral feeding must be reassessed every three months. Gastrotomy site care must be taught to parents to avoid infection. PHC nurses must be taught to monitor and intervene when necessary.

Resolution 16: All children with CP, who are severely affected, must be assessed for malnutrition at three-month intervals. Anthropometry can be used as a screening

tool until 12 months of age but must be complemented with biochemistry analysis. After 12 months of age, anthropometry is unreliable as the child with CP who has severe mobility deficits is not expected to grow at typical rates. Hence other methods of screening must be utilised. As of now, anthropometric guidelines for children with CP do not exist for India. Guidelines from South Africa may be considered as a reference (Morris et al, 2006).

Resolution 17: Spasticity management using serial casting must be done only when the person undertaking this intervention is competent to cast and the child is monitored for 24 hours to ensure that there is no injury caused by casting. Children who appear to be malnourished must be handled gently to avoid risk of fracture. If the muscles do not yield with moderate pressure, casting must not be attempted and Botox is the safe solution.

Resolution 18: Indication for Botox must be assessed by two independent practitioners and the optimum dosage must be injected. Less than optimum dosage (currently done as an economical measure) must never be injected.

Resolution 19: In children with CP who are non-weight bearing, bone health must be assessed biannually. Radiographs and laboratory tests must be used to complement this evaluation. Vitamin D3 drops may have to be continued until three years of age for children with CP. Currently this is not a practice. Paediatricians must monitor at three-month intervals to avoid toxicity.

Resolution 20: Hip surveillance programme must be started biannually after four years of age for all non-ambulatory children. Physiotherapists must screen for clinical indicators and send for orthopaedic consultation if screening indicates a dislocation (decreased hip abduction range, limb length shortening). Hip radiograph must be taken in true antero-posterior (AP) view as per standard radiographic guidelines.

Resolution 21: Orthopaedic soft tissue surgical procedures must be performed only after seven years of age. Bony surgeries for alignment must be considered as elective and attempted only after the age of seven. An exception to this is in cases of painful hip dislocations which must be attempted as an emergency procedure.

Resolution 22: Mothers must be questioned on whether the child has seizures. These episodes can be upward rolling of eyes briefly, with crying normally immediately after waking up or prior to going to sleep. Other signs are upward rolling of eyes and sudden unresponsiveness and stiffening not related to normal

spasticity. Primary Health Centre nurses must be trained to identify and refer appropriately regarding this morbidity.

Resolution 23: All high risk babies must be screened for retinopathy of prematurity (ROP) at birth by a neuro ophthalmologist. Children with CP must undergo ophthalmological consultation for refractory errors such as strabismus at two years of age. Any error must be corrected immediately.

Resolution 24: Dental check-up must be done at the age of two years for developmental screening. Thereafter, annual check-up with the goal of preventive dentistry and management of oral hygiene and dental issues must be undertaken. One specific area of safety concern is posterior drooling which may cause aspiration. This must be evaluated and appropriate management commenced immediately.

Resolution 25: Children must be screened for attention deficit hyperactivity disorder (ADHD)/learning disability (LD) at age 4- 6 by a psychologist. Screening for depression must be done annually, especially during the transition years of 11- 18. If a teacher flags a child as a poor academic performer for intelligence, screening for LD must be done. Children with CP who have ADHD will not present in typical fashion due to mobility difficulties. Teachers and parents must be made aware of atypical presentations. If behavioural therapy is unsuccessful or inadequate, the child must be referred to a psychiatrist.

Resolution 26: The International Classification of Functioning (ICF) and the CP core sets form a relevant and easy to use framework for rehabilitation professionals but it was opined that the interpretation of ICF varies and hence training should be carried out among rehabilitation professionals. Such training can be offered in the form of a MOOC course. ICF core sets for cerebral palsy must be used as the guiding framework for assessment and goal setting.

Resolution 27: Local governments at district levels must be petitioned to stop the practice of giving out irrelevant and inappropriate assistive aids. These are cost intensive in terms of money and human effort, and counterproductive and often harmful to children with CP by increasing deformities and disability. Appropriate assistive technology providers must be solicited to provide appropriate aids and appliances.

Resolution 28: School-based therapies must be made available through the Sarva Shiksha Abhiyan, in addition to sensitising teachers on the abilities of children

with CP rather than focussing on their disabilities. Special training in current guidelines for management must be made mandatory through MOOC platforms for rehabilitation professionals working in the school system.

Resolution 29: Team goals, individually tailored to the child, must be formulated, keeping the child's social development in mind. Therapists must undertake holistic responsibilities to fulfil team goals and the use of ICF will aid this.

Resolution 30: Rehabilitation therapists must be vigilant to identify any signs of abuse and neglect and infringement on the child's human rights. This includes parents who insist on long hours of therapy at the expense of normal life roles, leisure, school and play. Identification of such parents and those who seem too tired must be done, for referral to a psychologist or social worker for counselling and assistance. Protection of the child includes counselling of parents and appropriate referral to social services/ advocacy groups for mainstreaming in education and employment for those with ability, and for supportive care for those with severe disability. Therapists must also be self-vigilant to avoid unnecessary and painful therapeutic procedures that may stimulate fear and crying in children. This must be avoided at all costs.

Screening of a school going child by a psychologist to identify bullying and / or neglect by teachers/ healthcare professionals/ family members and peers is also an important part of protection.

Resolution 31: Therapists must be aware of when and whom to refer to when they identify issues beyond their professional competence. These include potential seizures like stiffening, crying with eyes rolling back, lack of attention or seeming to "fade" during an otherwise engaging activity. When such behaviours are reported by parents or observed during therapy, children must be referred to a neurologist.

A child with failure to thrive or who seems to be tired and without enough energy must be referred for nutritional assessment.

A child who cries when a part (specifically the hip) is moved must be referred to orthopaedics to screen for potential fracture/ dislocation of the hip. A child with spasticity coming in the way of functional goals must be referred to a paediatrician/ neurologist/ orthopaedist as the case may be.

Children with dynamic spasticity and postural deviations must be referred to an assistive technology specialist for appropriate seating/ orthotic/ mobility devices.

Resolution 32: Physiotherapy must be undertaken regularly for the first three years of life and then the frequency must be reduced and the child must be seen intermittently when new goals surface or there is a new phase in the child's life. Therapeutic goals must be reviewed if a short-term goal is not met in 12 sessions.

After the first 8 sessions, parents must be efficacious enough to continue with routine management, and therapy time must be utilised for goal-oriented, active and skilful interventions so that there is optimum usage of time and financial resources. Goals must be focused towards functional independence to the extent that is possible based on functional classification systems (as relevant for the particular child).

Resolution 33: Parent education, conducted through focussed sessions, must form the most essential aspect of therapeutic intervention as one of the main goals of therapy is to increase the self-efficacy of parents and people with cerebral palsy. Parents and the adult with cerebral palsy must be educated to identify deficits/dysfunctions that require short-term therapy and seek appropriate therapy for intermittent short spells, including before and after orthopaedic intervention. Therapists must facilitate these short spells and not prolong therapy sessions with unreasonable goals and must counsel parents to have expectations reasonable with diagnosis, classification and comorbidities.

Resolution 34: Persons with CP must be followed up by relevant therapists weekly for the first three years, fortnightly until 6 years of age, every three months from 6-18 years of age, and annually thereafter in order to facilitate early identification of dysfunctions and optimum management. The exception would be if there is an acute dysfunction or elective surgery or other reasons that require intensive short spells of therapy to regain decreased function or optimise new gains.

Resolution 35: Following the fitting of any orthotic device or seating/ adapted device, the therapist must watch carefully for any pressure points or discomfort, and educate parents on don-doff schedules and how to keep a log of the child's behaviour in order to identify any discomfort and take remedial action immediately.

Resolution 36: Therapy goals must be individual-centred and must reflect the changing requirements and characteristics of the person, especially during transition periods. Goals must be broken down into short-term or micro goals, and must be specific, measurable, achievable, relevant and time bound (SMART). The Goal Achievement Scale (GAS) must be used to monitor progress.

The long-term goal must be articulated as a team goal and each professional must take up a part of it for their individual goal, e.g., the mothers may state that their goal is that the child must be able to join the family at mealtimes rather than be fed individually. Physiotherapy (PT) goal would be independent ambulation for 15 metres (to get ready and walk to the dining table). Occupational therapy (OT) goal would be independent sitting on chair and adequate fine motor function to perform eating. Speech and Language Pathology (SLP) goal would be appropriate or motor coordination for effective chewing, breath control and swallowing, while Psychology goal would be appropriate table behaviour. This will bring about integrated management.

Resolution 37: Therapists must use the SAKSHAMA booklet optimally to avoid using irrelevant therapeutic methods and draining emotional, temporal and financial resources. They must build on previous goals and interventions and must document these appropriately.

Resolution 38: The SAKSHAMA booklet must be issued only once. It must be issued by the first professional who identifies the need and challenges that require intervention. This may be the hospital where the birth takes place/ PHC or, in neglected cases, may be therapists. Prior to issuing the SAKSHAMA booklet, parents must be asked if they already possess one. All professionals must insist on seeing the booklet at every fresh visit.

Resolution 39: Linking the SAKSHAMA booklet with Aadhar (India's citizen card) is recommended as it is a lifelong requirement. However, confidentiality issues must be considered.

Resolution 40: Children with CP must be enrolled in the Anganawadi (community level pre- school system) as it is an important socialising environment. Prior to 3 years of age, a child must be trained to indicate wants and needs either through speech/ augmented/ alternative methods. The child must be trained to sit upright/ slightly reclined based on need for a period of time. Therefore, appropriate seating/ mobility device and communication methods must be taught to Anganawadi teachers and these must be provided to the children through insurance schemes. Currently, seating devices that have been appropriately designed for individual children are not provided.

Resolution 41: Assistive technology assessment must be undertaken with a multidisciplinary team consisting of physician, physiotherapist (PT), occupational therapist (OT), orthotic specialist, speech language pathologist (SLP) and medical

social worker (MSW). These assessments must be undertaken at 3 years, 6 years and thereafter annually until the age of 18, and then as needed. This provision must be made available at the district level and a camp method can be used if it is difficult to have consultant professionals. This is currently followed across large parts of the country.

Resolution 42: Occupational, employment and recreational needs must be assessed with a culture appropriate tool at the PHC level or school. A specific tool was not recommended.

Resolution 43: Each healthcare discipline must use sensitive and valid methods of assessment. These must include tools that measure body structure, function, activities and participation and contextual factors. Some of these include but are not limited to gross motor functional measure (GMFM), muscle strength measurement in functional methods, range of motion (ROM), activities of daily living (speech, swallowing, drooling, selective motor control, or motor function), behavioural measures, Edinburgh visual gait scale, energy expenditure index for GMFCS I-III, Melbourne hand assessment, breath holding time, cardio vascular endurance measures for older people, and language assessment using relevant language versions of Language Proficiency Profile (LPP) which is a standard language assessment tool used in India.

Resolution 44: Adolescents and adults with CP must be encouraged to engage in fitness programmes in adapted environments. This is an important preventive measure for lifestyle diseases. Gyms and swimming pools must be made wheelchair accessible and safe. Adolescents and adults must be assessed for pragmatic components of speech prior to enrolling in college/ joining work, and appropriate therapy initiated.

Resolution 45: People with CP living independently must be assisted by helping with access, ergonomics and reasonable accommodation by PT/OT/MSW. Employers must be given information and reasonable accommodation must be legislated.

Resolution 46: PHC workers and school teachers must be educated on selection of appropriate assistive aids. Companies engaging in corporate social responsibility activities for people with disability must be educated about giving appropriate and usable mobility and walking aids. Currently a “one size fits all” mechanism is used which is counterproductive.

Resolution 47: Mainstream schools must have provision for visiting therapists so that children can get therapy in school. This can be an extension of the current Sarva Shiksha Abhiyan programme which is a school inclusivity programme. The professionals must be appointed based on the number of children and must include all disciplines. The professionals will evaluate and make a plan of care to be followed by parents/ teachers/ assistants, and they will visit regularly for follow-up and revision. This is over and above the aforementioned Resolutions. Healthcare must also be addressed, including urinary tract infections, skin infections, etc., preferably by a nurse practitioner on the team.

Resolution 48: Community-level workers must be selected and appointed, and professionals must be involved in training them to screen, identify new onset dysfunctions, access government schemes and refer appropriately. They must have refresher courses annually on the lines of SSA teachers. In case of positive screening results or doubt, they must be trained to refer to the appropriate professional at the relevant healthcare level. They must be trained to create awareness and dispel the taboo of using a wheelchair/ walking aids.

Resolution 49: PHCs must have assistive aids like client hoists and special wheelchairs available for rent. Moreover, appropriate wheelchair transportable two-wheelers and four-wheelers must be manufactured at affordable costs. A list of resources must be made available to PHCs periodically.

Resolution 50: Parents of people with CP need respite. Therefore it was resolved that the PHC/ Anganawadi must have a day-care centre with a qualified nurse to supervise, and a ratio of 1:8 community worker to children with CP (also taking into consideration male/ female profile). This will have the added benefit of allowing the children to be routinely screened for health, hygiene and rehabilitation needs by the nurse.

To achieve this, nurses must be provided additional education in feeding, swallowing, gross motor and fine motor aspects. This service must be augmented by consultant therapists, dentists and physicians.

Resolution 51: At least two medical social workers must be appointed at each block level so that they will be able to counsel persons with CP and caregivers on social security schemes, healthcare access and schooling, employment and improving access.

Resolution 52: The curricula of special educators, nursing, dentistry, and medical social work must be augmented by a module on CP as this is a common cause of impairment.

Resolution 53: Accessibility must be achieved through participatory means. Local solutions to mobility aids and other devices must be developed at the community level to assist parents to take care of severely impaired individuals with cerebral palsy as they get older.

Resolution 54: Assisted living centres must be made available, keeping human rights, dignity, health and hygiene in mind, at Taluka/ district level based on necessity.

Resolution 55: Centres in India which have adopted best practices (e.g., Madhuram Narayanan Centre for exceptional children, in Chennai, has “Upanayanam” cards; Vidyasagar, in Chennai, has a module called “Let’s play”) can be emulated across the country with relevant translations.

Resolution 56: The PHC staff or community workers must ensure that all children at risk for CP are given the SAKSHAMA booklet immediately upon birth/ upon diagnosis.

Resolution 57: The community workers and PHC staff will mandate that every child with CP attend the day care or Anganawadi until the age of 6 years. After the age of 6 years the children must be enrolled in school or, for those with severe disability, they must continue to attend day care so that optimum screening takes place.

Resolution 58: The PHC nurse must do a routine nutrition, health and hygiene assessment every month and administer appropriate education to the caregiver.

Resolution 59: The PHC nurse or a nurse practitioner from the district level will conduct regular classes for parents on care, referrals, nutrition, immunisation, gastrointestinal problems and counsel them on therapy with the concerned specialists on mobility, self-care, hand function, eating, swallowing, oral health, communication and behaviour. They will play a crucial role in ensuring enrolment in the Anganawadi and school, and in having realistic expectations. They will also create awareness to dispel superstitious beliefs which can potentially be harmful to the child’s safety and security.

Resolution 60: Government schemes for CP must have dental professionals, nurse practitioners and special educators in addition to the existing professionals.

Resolution 61: A medical social worker with training in disability legislation must visit the necessary PHC and address parents on government schemes and provisions. Moreover he/she will facilitate access to these provisions.

Resolution 62: In the transitional ages, a clinical psychologist must assess the person and initiate counselling or therapy to minimise behavioural issues, anger and coping. Moreover he/ she along with the nurse practitioner and medical social worker will undertake counselling on sexual behaviour, substance abuse and refer appropriately as needed.

Resolution 63: The psychologist, occupational therapist, medical social worker and special educator will screen children at 12 years to decide on the future path – mainstream education/ vocational training/ custodial care/ assisted living options.

Resolution 64: The government must be petitioned to consider the rehabilitation needs and social needs of independently living persons with CP, and to bring out an insurance plan commensurate with their needs, from screening to custodial care and throughout their lifespan.

DISCUSSION

This project set out to develop feasible care guidelines for persons with CP. Although the condition is well recognised in India, no systematic method of assessment and management exists in the country for people with this disorder. One of the reasons that emerged from non- responders in phase II of the study was that professionals and parents had a pessimistic attitude towards CP as it cannot be cured. Moreover, there is an opinion that most people with CP have intellectual disability and hence not much progress can be achieved. These factors must be addressed through awareness programmes. This aspect was developed into a Resolution because it was considered to be beyond the scope of this project. The current project was limited to care of the person with CP, and governmental actions regarding policies were not within the ambit of the consensus group. Petitioning policy-makers will be taken up as a future direction. The evidence guiding medical care developed in other countries, particularly the UK, related to care of people with CP can be adopted in India without modification. Experts opined that the barriers to implementation of NICE (2017) guidelines in India

were the lack of training of professionals on care of persons with cerebral palsy, and economic and healthcare access.

In the case of dentistry, speech and language pathology, clinical/ rehabilitation psychology, medical social work and nursing, the curriculum does not deal adequately with cerebral palsy. Hence it is highly recommended that additional modules on CP should be incorporated into the curriculum. Until this is effected it is recommended that online tutorials through MOOC platforms be created to upskill professionals in these disciplines.

In the case of physiotherapy, occupational therapy, prosthetics and orthotics, there are multiple challenges. These challenges include inadequate exposure to evidence-based curricula, costly and culturally inappropriate measurement tools and outcome measures, and cost of training for CP specific management strategies.

The core members of the interdisciplinary team involved in care of persons with cerebral palsy must include dentists, psychiatrists, gastroenterologists, ophthalmologists, nurse practitioners and assistive technology specialists, in addition to the commonly accepted team members. These additional members would act as consultants and their services will be obtained through the SAKSHMA booklet.

The greatest challenge to providing adequate care to persons with cerebral palsy is the poor acceptance of the prognosis by parents, and their unreasonable expectations from therapies provided. Often, parents continue therapy for years hoping for normalcy, instead of enrolling the child as early as possible in regular or special schools. Awareness programmes, sponsored by the government and using mass media, as well as mandatory training for all healthcare professionals in counselling, may alleviate this challenge over time. This was beyond the scope of the current project and is a future goal.

The SAKSHAMA booklet with a unique number, along the lines of the immunisation card, is a feasible way to maximise professional assessment and management in a timely manner for people with cerebral palsy. This can be a precursor to a web-based registry.

Training of community-level workers and provision of an interdisciplinary professional consultancy team at each PHC level is an urgent need.

Provision of aids and appliances that are unsuitable and potentially unsafe is uneconomical and a waste of manpower, and must be replaced by individualised assessment and provision of appropriate assistive technology at regular intervals.

Limitations and Strengths

The major limitation of this study was the poor response for the phase II survey. Several attempts (maximum of 10) were made to contact the persons identified, but to no avail. One reason that is hypothesised is the overwhelming amount of work that clinicians normally handle, making it difficult for them to engage in research. A major strength was the success of the consensus-building meetings which allowed the researchers to develop methods that are feasible in India and will integrate into the existing healthcare system. The extensive literature review undertaken for best research evidence was another strong point. The consensus-building meetings were rich in content and the Resolutions were comprehensive. The active participation of all consensus group participants was an asset. The Resolutions developed in this project are the opinions of those who participated. It is possible that there might be differences of opinion from other practitioners. Efforts were made to get opinions from all over India, but due to poor response rates this was not achieved. This is acknowledged as a limitation of the study.

From the results of this study, it is evident that limitations in knowledge, poor awareness and inadequate social security remain the greatest challenges limiting participation of people with cerebral palsy and impacting their quality of life and their caregivers. These guidelines are an initial attempt to guide persons involved in the care of people with CP holistically.

CONCLUSION

Guidelines for early detection, early intervention and continuous evaluation and follow-up, as well as supportive care of persons with CP and their caregivers, have been formulated for India with the participation of multiple stakeholders. The 64 Resolutions provide a road map for community-level health practitioners on referral and provision of services within the existing healthcare system.

Implications for Rehabilitation

- The management of chronic conditions require a multidisciplinary approach and therefore the management guidelines should be developed by a broad group of stakeholders.

- Cerebral palsy is an important lifelong potentially disabling condition and requires a lifelong approach.
- Pure research evidence is inadequate for practical purposes as actual situations vary in different countries. Therefore, practice guidelines must include stakeholder preferences to make them acceptable and relevant to local situations.
- A management framework such as the guidelines which was developed with the input of all stakeholders is expected to be acceptable for all rehabilitation providers and is expected to result in more effective interventions.

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Appendix:

Sample Questionnaire used in phase II

Survey

Name (optional):

Speciality:

Type of Institution:

Average number of persons with cerebral palsy seen per month:

Do you follow the current guidelines (attached) of care for CP relevant to your discipline: Please note your answer against each recommendation using the following options:

Recommendation	Consistently followed	Sometimes followed	Never followed	Not aware
1				
2				
3				
4				
5				
6				
7				
8				
9				
10				

If not, please describe your routine care protocol:

What are the challenges that prevent you from adhering to guidelines?