

EXPERIENTIAL ARTICLES

Goal Oriented Activity Towards Life Skill Training: Preliminary Indications of a Task-intensive Approach to Manage Cerebral Palsy

Kavitha Raja^{1*}, Saumen Gupta²

1. Professor, Department of Physiotherapy, MCOAHS, Manipal University, Karnataka, India

2. Research Associate, Department of Physiotherapy, MCOAHS, Manipal University, Karnataka, India

ABSTRACT

Purpose: *To devise a viable programme of intervention for older people with Cerebral Palsy (CP).*

Method: *Using focus group interviews, a 'top down' model of intervention was devised among older children and adolescents with CP. Ten participants volunteered and a custom tailored approach was employed, in keeping with the participants' goals.*

Results: *The outcomes are described qualitatively.*

Conclusion: *There are preliminary indications that the programme is versatile and feasible. Further trials must be conducted before conclusive comments can be made.*

Keywords: *Participation, goals, adolescents and adults, activities of daily living, focus groups.*

INTRODUCTION

Cerebral palsy (CP) is a motor system disorder, and affected individuals require lifelong therapeutic intervention. Though children with CP receive therapy, it generally decreases as they grow into adolescence and adulthood. Due to the emphasis on academics, there is little time for specialised exercise sessions under supervision. Moreover, developing countries like India do not have school-based therapy services. Therefore, rehabilitation is effected as a home-based programme under the supervision of the caregiver.

***Corresponding Author:** Dr Kavitha Raja, PhD, Professor, Department of Physiotherapy, MCOAHS, Manipal University, Manipal 576104, Karnataka, India. Email:kavitha.raja@manipal.edu

Academic pressure and increased assistance in Activities of Daily Living (ADL) lead to reduction in the activity levels of children with CP. The need for ongoing or frequent treatment is very demanding for the children and their families (Hägglund et al, 2005). Other than in exceptional situations, compliance with home exercise programmes is less than satisfactory. This results in the need for repeated surgeries and increased assistance.

The appearance of new disabilities and the worsening of existing disabilities in the adult years are being documented in recent times (Bottos et al, 2001). It is not certain how far childhood therapeutic intervention contributes to these later complications, but it seems credible to assume that meaningful intervention in the growing years will help accustom the child to incorporating therapy in day-to-day life and will, in the long run, minimise dependence and late onset disabilities.

Traditional therapy has focussed on correcting atypical patterns of function or movement, as well as managing impairments (Butler & Darrah, 2001). While task-oriented practice is an established practise (Schneiberg et al, 2010), this is normally restricted to activity and does not extend to participation. It has been recognised globally that participation is the desirable end product of rehabilitation (Heinemann, 2010). Since lifelong exercise is essential for the individual to benefit, a sustainable programme must be envisioned. With this hypothesis, the authors developed a therapeutic approach.

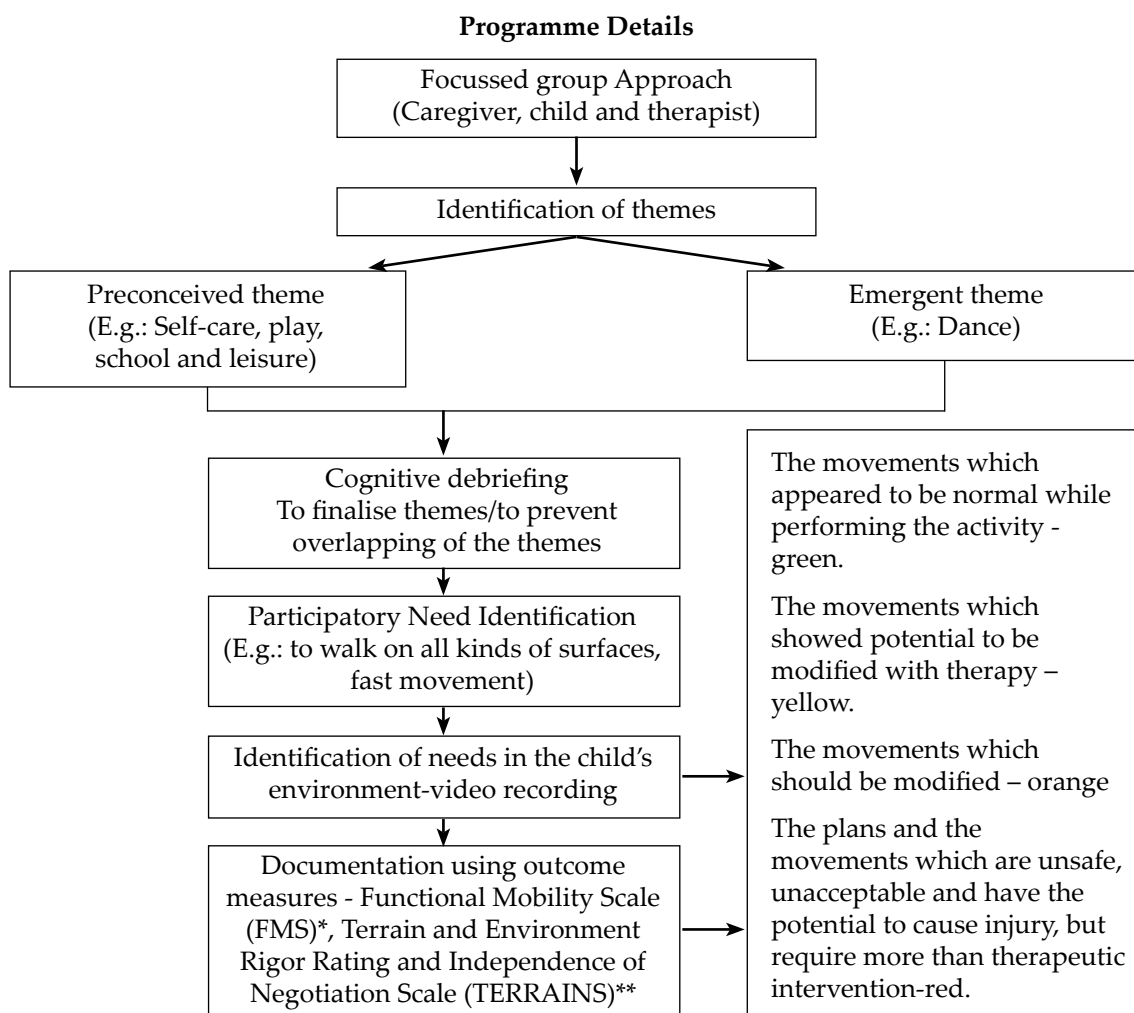
This programme employs a 'top down' approach, i.e. using contextual factors and participation as expected outcomes, and then problem solving to find the body structure/ function that can be addressed. This is situated in the conceptual framework of the International Classification of Functioning Health and Disability (ICF) (WHO, 2001). The ICF links the domains of body structure (e.g. muscle), body function (e.g. moving the limbs), activity (e.g. gait), participation (e.g. attending school), and also gives importance to contextual factors such as personal (e.g. overly protective parents) and environmental (e.g. stairs without balustrade). Typically, rehabilitation therapists employ a 'bottom up' approach wherein they identify body structure and dysfunctions, and then attempt to remedy these factors to effect a change in activity and participation. However, the professional concept of participation may be very different from the client's requirements. Therefore the authors followed the procedure called Goal Oriented Activity and Living Skills (GOALS) training. This study is a preliminary report on the components of the approach and on their observations of 10 adolescents and older children who underwent the programme.

METHOD

Programme Development

Initially, focus group interviews were conducted with the parents and children with CP, to identify areas which required their attention, their perceptions regarding on-going rehabilitation, and the feasibility and practicality of sessions. Following this, the authors proposed a “once a week supervised session - carry over to home” treatment programme which would enable the child and parent to become active problem solvers rather than passive therapy recipients.

Figure 1: Flow chart depicting Step I: Participation-based Need Identification (performance)



Step I: Participation-based Need Identification

Needs and expectations of the persons with CP and the parents are identified. The process is illustrated in Figure 1. The authors suggest that better outcomes can be expected from these conferences if multiple family units participate together. This allows for the emergence of a variety of scenarios and makes for clearer goal identification. However, focus may be lost if too many units are involved. Hence it is suggested that 3-5 is the optimum number. From these sessions, the most important expectations can be understood. For instance, a major expectation of parents may be their child's ability to perform ADL independently and walk on varied surfaces, as it is not always easy to use a wheelchair in India. Children may identify needs as the ability to participate in school activities (dance), attend school consistently and interact with peers. The results of the focussed group approach are given in Table 1.

Table 1: Example of Cognitive Debriefing and Identification of Themes

Parent	Children	Themes
Brush teeth - standing up	I want to brush my teeth like other people do	Standing for extended periods of time
Wash self - standing up	I want to wash my face while standing	
	I like to play like other children	Standing and Playing
	I want to stand and play, so that other children will involve me in playing	
Does he want to play with other children?	Unless I am standing, I do not want to join them for play	
Do other children want him to be in the play group?		

The children's homes and schools should be visited to identify activities that may need to be modified to fulfil expectations. This task can be achieved either by therapist visits or, where this is not feasible, the parents may be given the responsibility. It will aid repeated analysis and also ensure objective comparison at the end of the programme. Measures of participation must be administered to children and their parents [Functional Mobility Scale (FMS) (Harvey A et al, 2008), Terrain and Environment Rigor Rating and Independence of Negotiation Scale (TERRAINS) (Gupta S & Raja K, 2012)]. This will allow for quantification of change.

The results of the qualitative analysis of the videos and quantified outcome measures must be reconciled to identify priorities. A coding system for priorities is suggested:

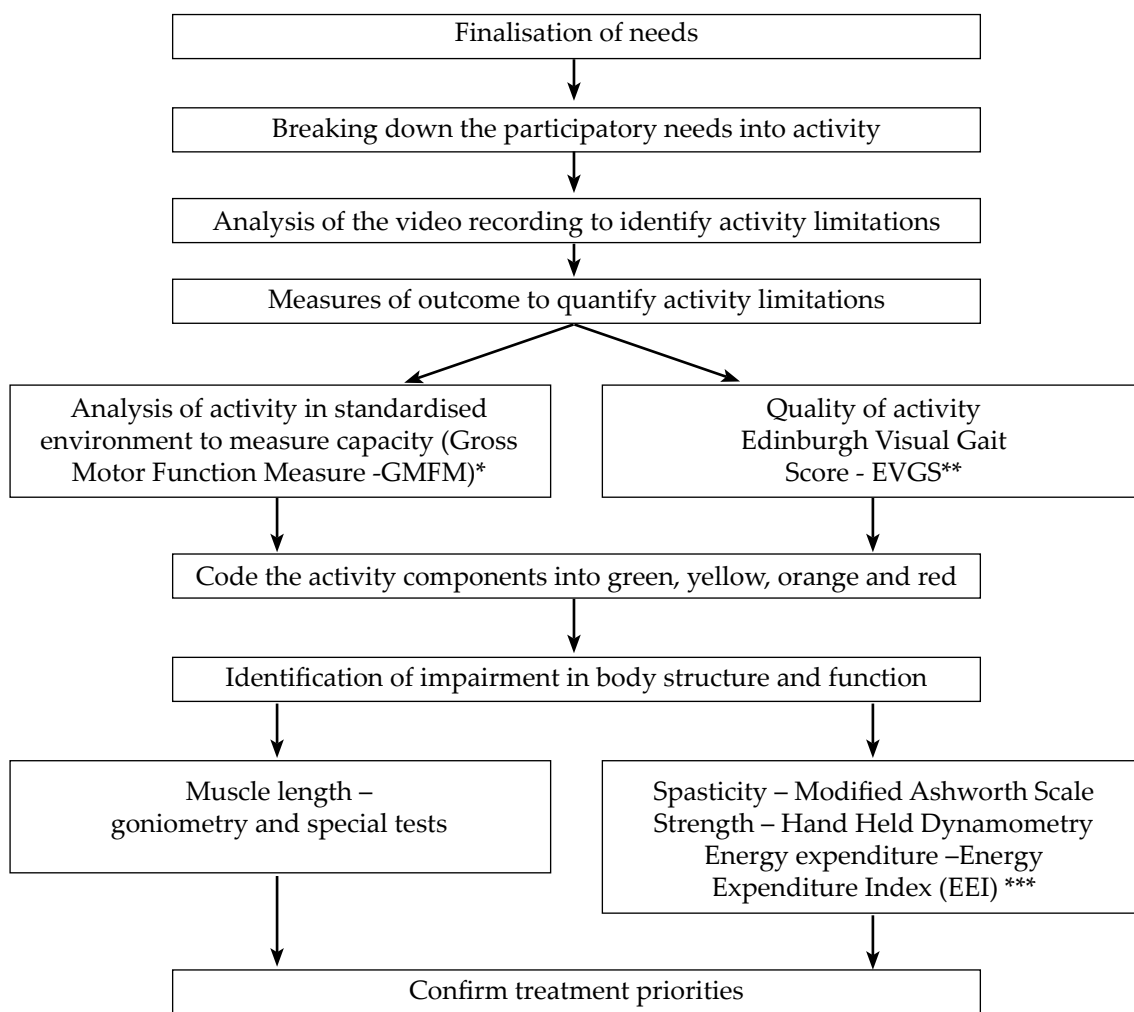
Green – Acceptable, safe, no need to intervene

Yellow – Not acceptable, high potential for improvement, high priority

Orange – Not acceptable, unsafe, potential for improvement, high priority

Red – Not acceptable, unlikely to change, therefore must be referred appropriately or compensated

Figure 2: Flow chart depicting Step II: Identification of Impairments



*Russell et al (2002); **Read et al (2003); *** Rose et al (1990)

Step II: This consists of analysing movement patterns associated with functional activity. Videos taken in Step I (which were considered as high priorities - yellow and orange) must be viewed by 2 or more therapists, and the difficulties identified. These must then be broken down into components and further analysed. The function or structure that requires assessment must be identified by consensus. The process is illustrated in Figure 2.

The movements and the plan must be further classified into 4 categories. Schematic representation of coding activity is given in Figure 3:

- The movements which appeared to be normal while performing the activity - green.
- The movements which showed potential to be modified with therapy – yellow.
- The movements which should be modified – orange.
- The plans and the movements which are unsafe, unacceptable and have the potential to cause injury, but require more than therapeutic intervention- red.

Following this objective evaluation, methods are to be employed to confirm the sources of impairment, e.g. tone, strength and range of motion (ROM).

Figure 3: Schematic representation of Coding Activity

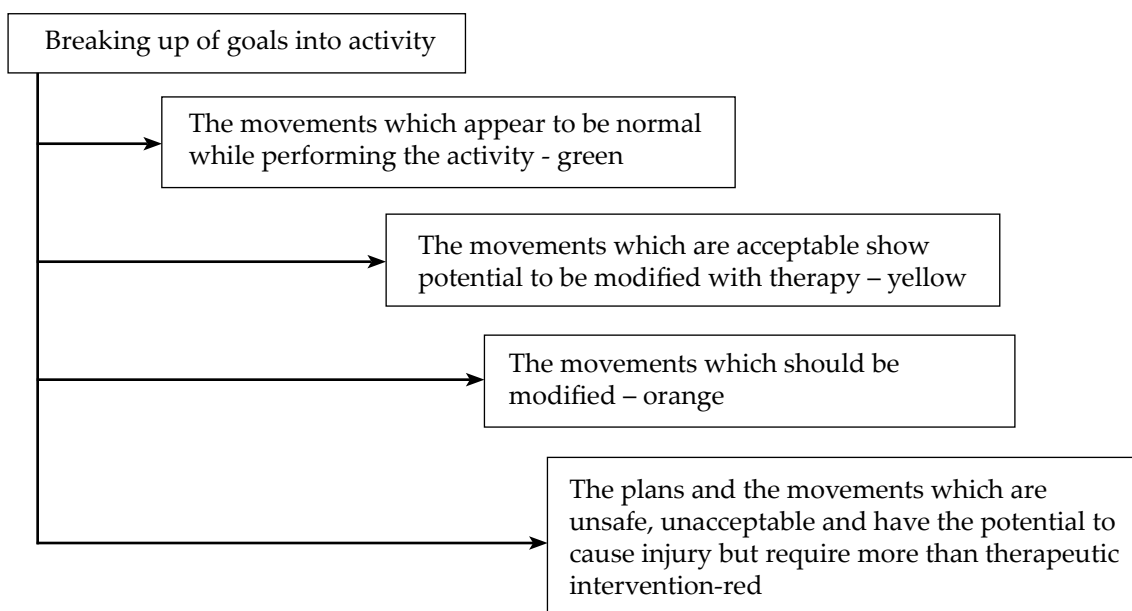
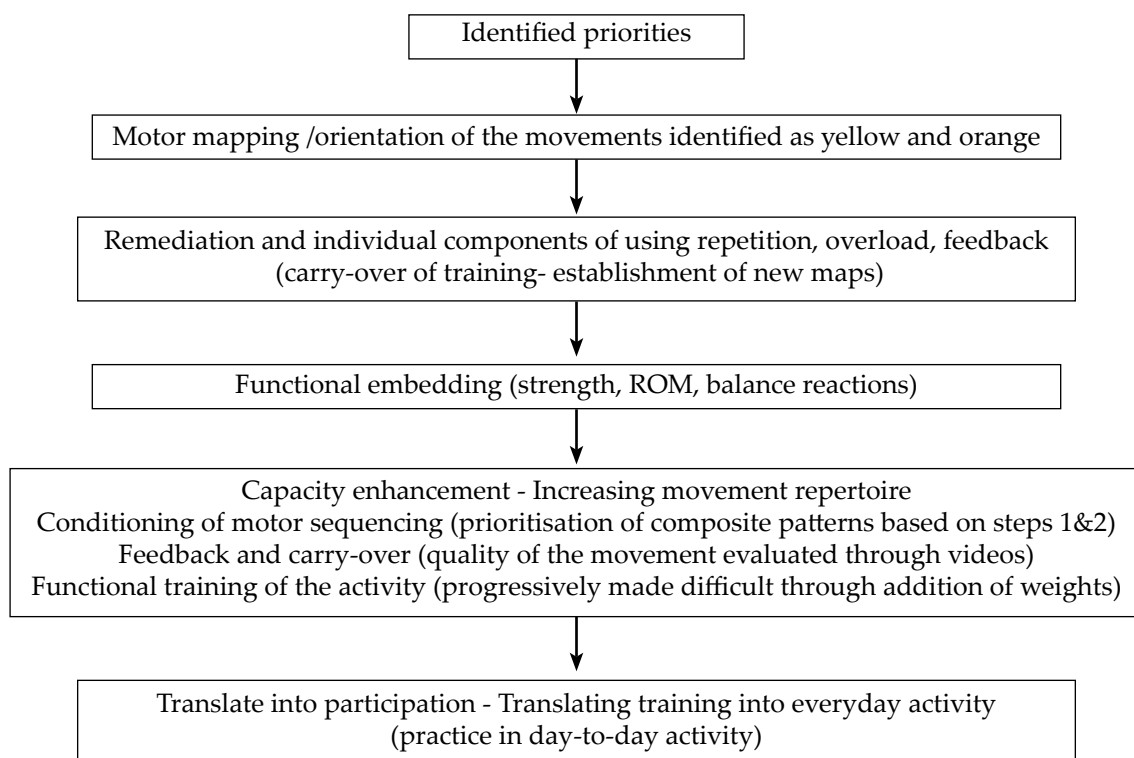


Figure 4: Flow chart of Step III: Identification and Remediation of Impairments



Step III: Remediation

Each movement function should be addressed. Remediation can be enhanced by using visual feedback or EMG biofeedback, etc. The target movement must be repeated 120-150 times. The authors suggest 75 % of 8 Repetition Maximum (RM) (Scholtes VA et al., 2010) as loading for strengthening movements.

The stages of remediation are illustrated in Figure 4.

Stage 1: Motor mapping/Cognitive orientation of the movements/Visual memory stimulation

This stage facilitates cognitive orientation to movements forming the activities which were coded as yellow and red. The child must be shown a video recording of him/her performing the activity, alongside a video recording of the same activity done by a typical child. Differences in performance are discussed with the child to help him/her identify the differences between his performance and that of a typical child. Potential for improvement are discussed and demonstrated.

During this phase, emphasis is to be given to two distinct tasks –

- 1) Moving the joint to perform functions which the child is able to do.
- 2) Moving or assisted movements of joints in the ranges which were never attempted by the child.

The whole sequence of the movement or the activity must be recorded by video camera. During breaks, the recorded videos must be shown to the child. This will enable the child to appreciate his/her effort to complete the movement, and will work as a motivator and feedback mechanism.

This phase will contribute to 50 % of a total session's time and will enable reduction of co-contraction and improve selective motor control of the muscle group.

The authors based progression of motor orientation activity from distal to proximal, keeping postural strategies as a priority in the programme (Shummway & Wollacott, 2007). Table 2 is an indicative chart.

Table 2: Various Positions for Activation of Muscles

	Position 1	Position 2	Position 3
Ankle plantar-flexion	Long-sitting position. Pressure given on calf muscle - trying to push a ball/ the foot is taken into extreme dorsiflexion and child is asked to push the foot in plantar-flexion. Compensatory movements are allowed.	High sitting position – pushing pressure bulb of sphygmomanometer. Emphasis on soleus activity.	Standing with support of a walker -performing toe stands
Knee extension	Pressing the popliteal fossa on pressure bulb of sphygmomanometer	Multiple angle Open Kinetic Chain movements	Maintain contraction of knee and hip in standing at loading phase (standing with support of a walker)
Hip extension	Prone on couch Hip extension – from 500 - 0 extension – 30 extension	Prone on couch Hip extension – both the legs off the couch. One leg resting on the floor.	Standing Hip extension (standing with support of a walker)

Stage 2: Increasing movement repertoire and functional strength / Training of components (strength, ROM, balance reactions), repetition, overload, feedback

Conditioning of motor sequencing: In this stage emphasis is on strengthening of the muscle groups which were activated in Stage 1. Leg press and treadmill walking may be utilised, the focus being on functional strength training.

Treadmill training helps to strengthen the movement repertoire at hip, knee and ankle joint in functional pattern. Inclination of the treadmill may be used to produce load on soleus muscles. This will help in the activation and strengthening of muscles.

In the early phases of functional training, walking may not be sustained for more than 3 minutes. Gait cycle facilitation (Figure 5) may be given by the therapist, to improve clearance of foot and stance phase duration.

Eccentric control can be established by applying resistance in functional positions using Thera-bands. Thera-bands as shown in Figure 6 may be used to apply resistance to large muscle groups like hip extensors while walking on the treadmill.

Feedback and carry-over: Six functional exercises were chosen, to improve endurance and strength and for carry-over of earlier steps into functionally meaningful activity.

The exercises were performed barefoot to ensure that the child got an opportunity to receive optimum sensory feedback from the ground.

The exercises were:

- Sit to stand
- Forward step ups
- Lateral step ups
- Kneel sit to stand
- Kneeling position to half kneel position
- Seated push-up
- Prone push-ups
- Toe stands
- Half kneel to erect standing
- Supine sit-ups

Appropriate techniques to perform the above exercises must be taught. The main aim of these exercises is to enable the child to perform the activities with the correct pattern of muscle activation and with proper eccentric control.

Stages 1-2 are precursors for subsequent stages. However the stages may overlap for some activities. The criteria for progression are as follows:

- Ability to demonstrate isolated movements of hip and knee extension
- Ability to ambulate for at least 5 minutes over ground, with or without assistive devices.
- Person should have established local muscle
- Ability to develop isolated contraction and hold the joint for at least 10 seconds

Stage 3: Functional embedding - Strength training in functional activities

8 RM must be calculated for progressive resistance training (Scholtes VA et al., 2010). This may be done by means of a weighted jacket. The activities described above may be utilised for functional strengthening. About 8-12 repetitions must be done.

Functional muscle grading was used to rate the strength gains. This was done by counting the number of repetitions performed over a specific period of time.

Stage 4: Translating training into activities and participation

Children must be trained to use the assistive devices optimally. The identified activities and load must be practised at 20 repetitions on alternate days of the week. The duration of the exercise programme must be at least 30-45 minutes.

Step IV: Carry-over of learning

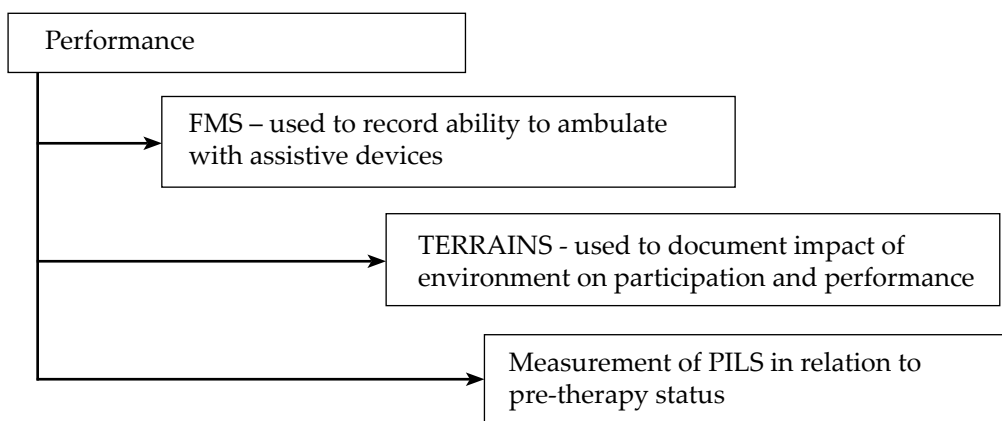
The child is given meaningful but untrained activity to assess carry-over of learning. If the child fails to perform, it is necessary to go back to the previous steps and start again at the necessary point. An example is to assess the ability to translate sit-stand activity into getting up from the toilet or opening the door. Similarly, climbing a bus or stairs can be used to assess the carry-over effects of step ups.

Step V: Performance: Generalisability of activity

This stage involves evaluation of performance within the framework of the child's environment and functional requirements. Identify further needs by exposing the child to a novel environment. Reassess the plans and the movement patterns which are brought into use by the child while performing the activity.

[FMS, TERRAINS, Participation in Life Scale (PILS) (Gupta S & Raja K, 2012)]

Figure 5: Flow chart showing order of documentation of performance through various scales



The authors suggest optimal benefits would be obtained with 24 sessions (6 months), and thereafter recommend 3-monthly follow-ups to evaluate new onset problems / plateaus / adherence and satisfaction. New functional demands may also be identified. It is suggested that parents can use videos and email to clarify doubts with the therapist. This is a feasible and cost-effective method.

RESULTS

Proof of Concept

Step I: Focussed Group Approach

P, a 16-year-old boy [Gross motor functional classification system (GMFCS III), Manual ability classification system (MACS I)], had a severe crouch and was prone to frequent falls. His house, situated in hilly terrain, was only accessible by a steep path. Both the boy and his parents identified as his primary requirement

the ability to walk for a “long” period without assistive devices on external surfaces and to stand erect for 30 minutes to 1 hour during his sister’s wedding.

Theme identification (only two themes are described for the ease of explanation)

1. Ability to stand for a long period at social functions
2. Ability to walk without assistive devices

Cognitive debriefing

Cognitive debriefing of “long” period found that 15 minutes of ambulation was required for the boy to reach his home from the main road. It was also revealed that he had to stand for about 10 minutes to catch a bus to go to school. Embarking and disembarking from the bus required the ability to climb steps with risers of 6-8 inches.

Participatory need identification

Participation needs identified were transportation and mobility. The activities identified were walking endurance, walking ability on uneven surfaces, standing endurance, and propulsive strength of lower limb.

Documentation using outcome measures – FMS 5 – 4, FMS 50 – 4, FMS 500 - 4
TERRAINS – 344

Step II: Finalisation of needs:

1. Ability to walk for long duration
2. Improve static and dynamic balance
3. Ability to climb steps

Functional breakdown of participatory needs was done as follows:

1. Walking on uneven surfaces: dynamic balance, strength, flexibility
2. Standing endurance: isometric strength, static balance
3. Reduction in toe drag
4. Propulsive strength: quadriceps strength, hip, knee ROM

Measures of outcomes to quantify limitations – GMFM 60.39, EVGS - 41

Table 3a: Depiction coding of Activities

Activity	Coding
Standing on level surface	Yellow
Walking on unstable surface	Orange

Identification of impairment of body structure and function:

1. Weakness of plantar flexors, knee extensors, hip extensors.
2. Tightness of plantar flexors
3. Tone

Ankle plantar flexors

	ROM	Tone	Strength
Code	Yellow	Yellow	Yellow

Knee extensors

	ROM	Tone	Strength
Code	Green	Yellow	Yellow

Step III: Remediation of identified priorities**Motor Mapping by orientation of the movements:**

Open kinetic muscle activation was performed for all the joints of the lower limb. Motor activity was facilitated against manual resistance with visual feedback. The number of repetitions was 120 -150 for each of the joints. The distal joints were activated first.

The following muscles were targeted –

Ankle – soleus, gastro soleus and tibialis anterior

Knee – quadriceps and hamstrings

Hip – Gluteus Maximus and medius

Different positions of motor orientation utilised:

- High sitting and long sitting
- High sitting and prone
- Prone, lying sideways, on the edge of the couch

Functional embedding and capacity enhancement – by improvement of ROM, strength

Strength training

Leg press without resistance for endurance and activation of muscles – 50 repetitions in one session

Leg press – 8 RM

Progression of weight was done by 8 RM method measured every week.

Movement repertoire

Treadmill training which was initiated for 5 minutes to start with, at the lowest speed possible, was gradually extended to 30 minutes. P was allowed to hold the rails of the treadmill. His perceived exertion was taken into account while increasing the speed. Once he achieved over ground speed on the treadmill, the inclination was increased to maximum grade.

Simultaneously, over ground walking was practised on both level and uneven surfaces, to improve the functional speed. To mimic school scenarios, the child was also given loaded over ground training with the help of a backpack and assistive devices. The weight in the backpack was based on 10% of 8 RM weight used to perform resisted functional activity training of sit to stand activity.

Fear and anxiety reduction techniques were employed by replicating social scenarios, to give the child the confidence to walk without assistive devices.

Functional activity training

- Sit to stand
- Forward step ups

- Lateral step ups
- Kneel sit to stand
- Kneeling position to half kneeling position
- Prone push up

The above mentioned positions were used for strength training.

Step IV

The child was trained to cross hurdles and jump over them, with and without the loaded bag. This simulated community participation needs.

Step V: Reassessment of the outcomes

At 6 months, P used only a crutch for support outdoors. At the 1-year follow-up, he was walking unaided in his immediate surroundings.

Documentation of participation – FMS 5 = 6, FMS -50 = 5, FMS 500 =5, TERRAINS = 600

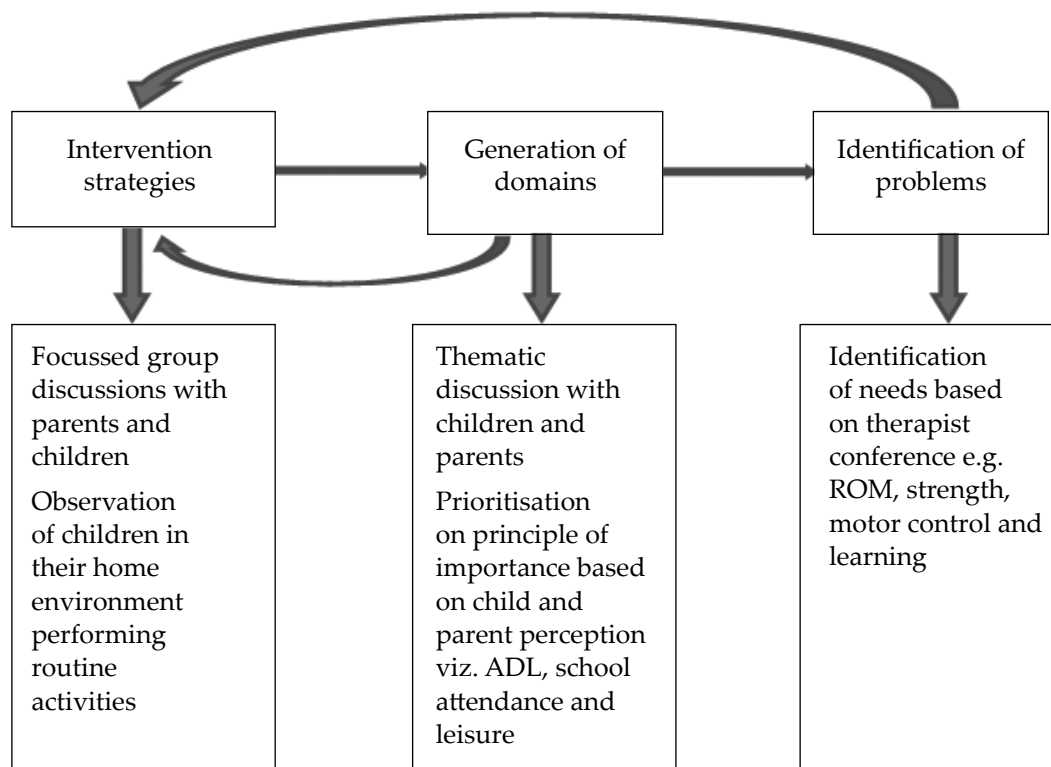
Documentation of outcomes to quantify limitations – GMFM 74.39, EVGS - 13

Nine other participants were similarly managed. Measurable improvement was found in participation, adherence and parent satisfaction with treatment outcomes.

DISCUSSION

The process of development of this programme is described in Figure 6 below:

Figure 6: Depiction of focussed group approach generates themes and identification of impairments and intervention strategies



This model of rehabilitation / approach stems from the identification of participation restriction and the needs identified from focussed interviews with the parents and children. It directly addresses what the client needs from rehabilitation and management in cerebral palsy.

Earlier programmes were instituted to bring about change in spatial and temporal parameters of gait, and were recommended without emphasising how the programme would improve participation of children with CP.

Parent and child involvement in management decisions will lead to greater efficiency, and thus keep both the client and the service provider well informed regarding the success of the rehabilitation programmes.

This rehabilitation programme conforms to ICF as all the stages are interconnected and bi-directional in nature. Involvement of the parent and child helps to gain insight into the personal and contextual factors affecting participation. It helps to keep them motivated and sustains participation in rehabilitation which is essential. This is a bigger step than merely targetting impairments as it allows for the recognition of barriers which were unknown to earlier methods of management.

A coding system was introduced in this interventional programme to keep a check / to prioritise a workable goal. This system helps to go beyond the traditional notion that “we only provide intervention for things that we happen to think of measuring” (Campbell SK, 2006). For example, the red colour code helps in decision-making regarding when to refer the case for surgical procedures. The traffic light system suggested here may be modified into any culturally identifiable system (+++ or ---).

Although there was demonstrable success in the areas of compliance and strength gains and measurable gains in participation, controlled trials are required to assess the effectiveness of this programme in comparison to routine therapy. The authors have followed up cases for 1 year. Regular follow-up will be required for on-going evaluation and repudiation of management. As CP is a disorder characterised by motor impairments that change constantly, the researchers suggest that this programme will work for a lifetime. No particular school of treatment is recommended as the purpose of this strategy is to increase participation and decision-making, and management guidelines have been laid out by compiling the available approaches in rehabilitation. Any method chosen to meet the goals will be acceptable.

As these are only guidelines, it is suggested that they can be used in a variety of therapeutic goal setting exercises and need not be exclusively physiotherapy focussed. A weekly exercise programme is feasible and economical. The children who participated in the study ranged in age from 9 to 16 years, and had varied difficulties, expectations and academic and social demands. It is encouraging that despite these differences, all of them showed excellent compliance. This is all the more noteworthy as parents pay for the therapy sessions in India and are unlikely to continue unless there are perceived benefits. Another point to note is that 4 of the children travelled over distances as far as 250 km to reach the authors over the weekend. It is unlikely that they would have done so unless results were perceived. In addition, parents were able to understand the principles of the

programme as they could articulate their needs and difficulties. Parents must be instructed to return for follow-up to the therapist if there is:

- Decrease in functional level,
- Change of expectations, or
- New onset dysfunction.

As the final vindication of any therapeutic approach is translation to function, and this is best represented by parent / child reports and compliance, the authors are optimistic that this programme is meaningful throughout the life of an individual with CP. Future studies will provide evidence. No adverse effects were reported except for minor complaints of delayed onset muscle soreness (DOMS) after the initial sessions. These are to be expected after any strengthening regimen and hence are of no great concern. It was also noticed that strength increased objectively after the once-a-week strength training session. This is another aspect that requires further study.

Implications

As the parents and the child are active participants in the treatment planning, the authors believe this is more meaningful, sustainable and economical than formal institution based therapy.

CONCLUSION

The supervised intensive task-oriented approach, following participatory need identification, is able to show measurable gains in participation.

Acknowledgement

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Complete evaluation tools can be obtained from the authors on request.

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