

Effectiveness of the Home-based Habilitation Programme for Children with Cerebral Palsy

Maja Racic¹, Srebrenka Kusmuk², Vesna Krstovic-Spremo³

Abstract

Objective. This study was undertaken with the aim to compare the effects of home-based habilitation programmes with the effects of hospital-based habilitation programme for children with cerebral palsy (CP) on motor performance and daily functioning.

Patients and methods. The study was conducted on a sample of 60 children with cerebral palsy. First group included 30 children, 5 to 12 years old, who had a continued physical home treatment and education in public/special school. The second group consisted of 30 children, from Banja Luka region, who continued inpatient habilitation programme and training. Habilitation outcomes were analysed by measuring muscle tone (using original Tardieu Scale), muscle strength, range of motion (ROM), gross motor functions (gross motor function measure-88) and the Barthel Index of activities of daily living (ADL).

Results. The proportion of clinically significant change in gross motor functions, ADLs, ROM and muscle strength didn't show major differences between the two groups.

Conclusion. There were no significant differences in effectiveness between home-based and hospital-based habilitation programmes according to the treatment outcomes. The effectiveness of home-based programme increases when supplemented by frequent consultations with the rehabilitation team members and occasional out-patient physical therapy treatment, education as well as counselling and support for parents.

Key words: Cerebral palsy, home-based habilitation, interdisciplinary care.

Introduction:

The term habilitation has been used to describe ongoing care and multiple medical, therapeutic and educational interventions that children with developmental disabilities receive through their lives. One way to approach this issue is to define habilitation

in terms of participation. The term participation broadly characterises the core mechanism that operates at each stage of the human cycle. Disability is the loss of opportunities for participation in the goods of society, so working to enhance a child's ability to participate in settings and to be engaged in relationships and age appropriate activities presents a good way of increasing the probability that an improvement will occur.

In order for habilitation to be successful, different approaches to care are often necessary. Two such approaches are the interdisciplinary approach and the family centred approach. Both approaches involve drawing on the expertise of other individuals in order to provide optimal health care for the patient^{1,2}.

The interdisciplinary approach involves teams of medical professionals from such backgrounds as physicians. The team identifies specific problems and issues which must be addressed, and collaborates with one another to find optimal therapeutic solutions. Treatment of children with CP requires a long-term process during growth by an interdisciplinary team, focusing on all developmental

Author's affiliations:

¹ MD, PhD (Family Medicine, postgraduate studies in Physical medicine and rehabilitation), Assistant Professor

² MD (Family Medicine), Family Medicine Department

³ MD, PhD (Occupational medicine), Assistant Professor

Department of Occupational Medicine, Medical faculty, University of East Sarajevo, Bosnia and Herzegovina.

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Correspondence:

Dr Maja Racic
Medicinski fakultet, Studentska 4, 73300 Foca, Bosnia
E mail : majaracic@excite.com

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aspects of the child and planning interventions in relation to the most urgent needs of the child and the family. The long-term goal is the optimal functioning in adulthood³.

The family centred approach involves drawing on the life expertise of family members and other care-givers who are involved in the patient's life. Realising that these individuals are the ones most intimately familiar with the patient's overall health, it would be remiss to not involve them in the overall treatment programme^{4,5}.

Some habilitation programmes in Bosnia and Herzegovina have even included families as faculty members in educating medical professionals on the care and treatment of individuals with disabilities. Such persons not only have a great deal of knowledge regarding the patient, but often have unique and different perspectives on what may work best in terms of treatment. In this stage, families determine the interventions that are appropriate based on their knowledge of their child and their own circumstances.

Very often, interdisciplinary care is institution-based, so the children with CP needing some therapeutic intervention have to be hospitalised in order to obtain it, what means that they will be placed away from their families and absent from their schools and communities for extended period of time. The underlying assumption in these instances is that therapeutic procedures will generally prevent future limitation, enhance better quality of life and improve function or future participation in the society. But, for many children these short or long-term hospitalisations accumulate until they represent a pattern of lost opportunities⁶.

In order to overcome this problem, different home-based habitation programmes, aiming to support and assist with the acquisition, retention, or improvement in skills for living successfully in the community through ongoing daily home programmes, have been introduced.

This study was undertaken with the aim to compare the effects of home-based habilitation programmes with the effects of hospital-based habilitation programme for children with CP on reducing the impairment and improving the function.

Materials and Methods:

This prospective study included sixty children with cerebral palsy divided into two groups. The first group consisted of 30 children, from Sarajevo region, who were included in the home-based habilitation programme after initial institutional treatment.

Before the hospital discharge, the members of interdisciplinary team have educated parents to address education and therapeutic needs of their child, through the individually tailored, daily home-based programme of physical, task-oriented and speech improvement exercises.

During the first six weeks, the home-based habilitation programme included daily visits by physiotherapists to a child and family at home, helping family members to adopt and to comply with the programme activities.

During the next three years, the parents themselves continued to provide the treatment programme for their children, which consisted of physical therapy based on Bobath concept, occupational therapy focusing on everyday tasks and emotional resources and speech therapy. Beside three patients with spastic CP who were receiving botulinum toxin injections annually, none of other children used any kind of medications. The treatment programme was followed by the GPs and community-based nurses.

Every six months, children were referred to community-based rehabilitation centres or local hospitals for follow up, additional physical treatments, occupational and speech therapy and orthopaedic consultation or treatment, respectively. The children attended school for the children with special needs.

This programme was conducted in the period from 2008 to 2011.

The second group consisted of 30 children, from Banja Luka region, who continued inpatient habilitation programme and training in institution for physical medicine and rehabilitation, including the daily individual work with a physical therapist, occupational therapists, special educators, psychologists, speech therapists and orthopaedists.

Matching of the children in the two groups was performed with predefined inclusion and exclusion criteria. Inclusion criteria were children with a diagnosis of CP, aged 5-12 years. Exclusion criteria were severe mental retardation defined (IQ<20) according to International Classification of Diseases⁷, severe visual impairment and severe hearing impairment.

Habilitation outcomes were analysed by measuring muscle tone (using original Tardieu Scale)^{8,9}, muscle strength, range of motion (ROM), gross motor functions (gross motor function measure-88)¹⁰ and the Barthel Index of activities of daily living (ADL)¹¹. Intellectual functions were assessed using the standardised set of

tests. Clinical assessments and examinations were done at the beginning of habilitation programmes and three years later.

Data obtained from the clinical examination was recorded and interpreted.

Chi-square test was done to see proportion of change. All analyses were performed using the SPSS statistical software package.

Results:

Male:female ratio 39 : 21.

Majority of the children had spastic type of CP (88%). Mental retardation was found in 27 children (45%) (Table 1).

The proportion of change on GMFM-88 total score and dimension A-E after the period of three years did not

show any statistically significant difference between two groups (Table 2).

There were no statistically significant differences between the children with normal intelligence and different degree of mental retardation when it came to GMFM-88 total score ($p>0.5$).

The parent who took the role of care-giver in home-based habilitation programme was the mother in all 30 children involved with the programme. Four mothers (13%) had basic or primary school education (8 grades), 17 (57%) high school education and 9 (30%) held a university degree.

The most significant improvement was found in the children whose mothers had university education (Fig 1).

Muscle tone of both legs and left arm was significantly

Table 1: Distribution of Children according to the Type of Cerebral Palsy and Degree of Mental Retardation

Type of cerebral palsy	Home-based habilitation programme			Hospital-based habilitation programme		
	Normal intelligence N (%)	Mild MR N (%)	Moderate MR N (%)	Normal intelligence N (%)	Mild MR N (%)	Moderate MR N (%)
Spastic	14 (47%)	8 (27%)	4 (14%)	12 (40%)	12 (40%)	3 (10%)
Ataxic	1 (3%)	0	1 (3%)	0	2 (7%)	0
Athetoid	1 (3%)	0	0	0	0	1 (3%)
Mixed	1 (3%)	0	0	0	0	0

Table 2: A Comparison of the Proportion of Change on GMFM-88 Total Score and Dimension A-E after the Period of Three Years for Both Groups

GMFM-88	Change	Home-based habilitation	Hospital-based habilitation	Chi-square	P-value
Total score	Improved	8	10	3,471	0.05
	Unchanged	22	20		
	Deterioration	0	0		
Lying and rolling	Improved	16	17	0,0673	0.5
	Unchanged	14	13		
	Deterioration	0	0		
Sitting	Improved	7	9	0,14066	0.5
	Unchanged	23	21		
	Deterioration	0	0		
Crawling, kneeling	Improved	6	8	0,37267	0.5
	Unchanged	24	22		
	Deterioration	0	0		
Standing	Improved	10	8	0,31746	0.5
	Unchanged	20	22		
	Deterioration	0	0		
Walk, run, jump	Improved	8	10	0,15098	0.5
	Unchanged	19	19		
	Deterioration	3	1		

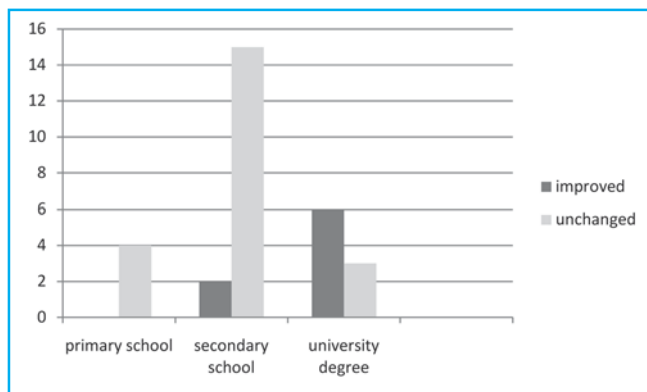


Fig 1- The Proportion of Change on GMFM-88 Total Score according to the Care-giver's Education

higher in children who were included in home-based habilitation programme after three years, while the proportion of change on muscle strength and range of motion was not statistically significant (Table 3).

The proportion of change on bathing and managing the stairs was statistically different between the groups, while the proportion on change on bowel, bladder managing, toileting, feeding, mobility, transfer and dressing was not statistically different between two groups after three years (Table 4).

There were no statistically significant differences between the children with different degree of mental retardation when it came to the proportion of change on the ADL.

Proportion of change in intellectual functioning was statistically different between the groups (H_i^2 20.37, for df 1 and p 0.005). Children on home-based habilitation treatment had more significant improvement in intellectual functioning compared with the group treated in the hospital.

Discussion:

Although the survey group who had home care had observable higher muscle tone and were less independent in bathing and managing the stairs, the proportion of change in gross motor function, muscle strength, ROM and other daily functions was not statistically significant between the two groups after the period of three years.

The parents were key participants in the team and were very important in the child's development, and the integration of their knowledge and experience in the rehabilitation process was beneficial to the child's physical therapy, mental development, and socialization (tasks are more often successfully completed at home

than under the observation of others in an institutional setting). In any case, the treatment of CP represents a long and exhausting process that requires close collaboration of an interdisciplinary team along with the parents, as indicated by the fact that children who are treated at home and had the opportunity of regular follow-up with a physical medicine doctor and occasional participation in outpatient physical treatment showed better functional progress and significant reduction in muscle tone than children who didn't have the same opportunity.

Although the sample size was small, the level of care-giver's education was an important factor in the whole process of habilitation. Many families develop the power needed to effectively overcome the problems that occur with CP, but a number of parents are not able to adapt to the needs of a child with development disabilities and to the demands of the new socio-economic conditions which lead to a lack of co-operation with other team members and neglect of the whole rehabilitation process. The problem of lack of co-operation of the parents has become more extensive over the last few years due to the restrictions put in place by the Health Department and a lack of education of parents about the nature and course of the disease, the available forms of treatment, and the available forms of treatment that a child with CP can obtain. The need for continuing education through collaboration with the parents which is indicated by the fact that the majority of parents of children who were treated at home realise that professional help in physical therapy leads to a more effective rehabilitation, ease of care, lessening liability and offers the opportunity to be better informed.

Rehabilitation organisations and clinics base their treatment on interdisciplinary collaboration of experts and offers along with other things, a greater possibility of integration of therapies which is most often lacking in home care and which could have significant impact on muscle tone reduction.

According to the literature, mothers of children with developmental disabilities spend more time feeding, clothing and bathing than mothers of children who are developing normally. Over time an overprotective relationship by the parents develops leading to the lessening of the child's independence. Occupation and work therapy are helpful in the assessment and treatment of functional limitations which have an effect on performing fine motor skills, cognitive and perceptual development as well as psychosocial adaptation essential for the acquisition of self-care skills. By selecting

Table 3: A Comparison of the Proportion of Change in Muscle Tone, Muscle Strength and ROM after the Period of Three Years for Both Groups

Measure	Change	Home-based habilitation	Hospital-based habilitation	Chi-square	P-value
Muscle tone					
Left arm	Improved	9	17	7,77	0.02
	Unchanged	16	13		
	Deterioration	5	0		
Right arm	Improved	12	17	5,86	0.5
	Unchanged	13	13		
	Deterioration	5	0		
Left leg	Improved	9	15	6,53	0.02
	Unchanged	16	15		
	Deterioration	5	0		
Right leg	Improved	9	19	9,5	0.001
	Unchanged	16	11		
	Deterioration	5	0		
Muscle strength					
Left arm	Improved	14	17	0,6	0.5
	Unchanged	16	13		
	Deterioration	0	0		
Right arm	Improved	17	17	0,00	0.5
	Unchanged	13	13		
	Deterioration	0	0		
Left leg	Improved	14	15	0,07	0.5
	Unchanged	16	15		
	Deterioration	0	0		
Right leg	Improved	14	19	1,68	0,4317
	Unchanged	16	11		
	Deterioration	0	0		
Range of motion					
Left arm	Improved	14	17	0,6	0.5
	Unchanged	16	13		
	Deterioration	0	0		
Right arm	Improved	17	17	0,00	0.5
	Unchanged	13	13		
	Deterioration	0	0		
Left leg	Improved	14	15	0,07	0.5
	Unchanged	16	15		
	Deterioration	0	0		
Right leg	Improved	14	19	1,68	0,4317
	Unchanged	16	11		
	Deterioration	0	0		

stimulating objects and activities, by education and support services to parents, the therapist encourage the introduction of therapeutic principles and techniques in their activities of daily living. Occupational therapy in rehabilitation centres is one of the basic components of habilitation and rehabilitation, while in a home care setting it is often neglected due to a lack of co-operation between the therapist and the parents after inpatient

treatment as well as the limited number of outpatient occupational therapy clinic in the primary care setting. The opportunity to have home-based occupational therapy visits or outpatient consultations is an important factor for improving the effectiveness of home treatment¹²⁻¹⁴.

The estimates of the initial and highest achieved levels of intellectual functioning were significantly different

Table 4: A Comparison of the Proportion of Change on the ADL after the Period of Three Years for Both Groups

ADL	Change	Home-based habilitation	Home-based habilitation	Chi-square	P-value
Bowels	Improved	12	14	0,27149	0.01
	Unchanged	18	16		
	Deterioration	0	0		
Bladder	Improved	12	14	0,27149	0.01
	Unchanged	18	16		
	Deterioration	0	0		
Grooming	Improved	12	14	0,27149	0.5
	Unchanged	18	16		
	Deterioration	0	0		
Toileting	Improved	12	14	0,27149	0.5
	Unchanged	18	16		
	Deterioration	0	0		
Feeding	Improved	10	11	0,00568	0.5
	Unchanged	18	19		
	Deterioration	2	0		
Dressing	Improved	12	14	0,27149	0.5
	Unchanged	18	16		
	Deterioration	0	0		
Transfer	Improved	10	8	0,31746	0.5
	Unchanged	20	22		
	Deterioration	0	0		
Mobility	Improved	8	10	0,15098	0.5
	Unchanged	19	19		
	Deterioration	3	1		
Stairs	Improved	6	14	6.88	0.02
	Unchanged	21	16		
	Deterioration	3	0		
Bathing	Improved	6	13	5.22	0.05
	Unchanged	22	17		
	Deterioration	2	0		

between the experimental and control groups. The mental development of children in home care was faster (and they had equally developing character) indicating the important role of the family in the process of cognitive and social development. It is interesting to note that children from families with three or four senior members of the household (total number of respondents) showed the most significant improvement over the three-year follow-up rehabilitation in terms of intellectual functioning and independence. Multiple stimulations through various activities lead to better adaptation of the child to the environment and positive responses to it as well, and the majority of authors agree that the home care setting is much more stimulating than the conditions that the best rehabilitation centre can offer¹⁵⁻¹⁷.

The patients who had neurological symptoms diagnosed in the first or second month of life, and then included in

a rehabilitation treatment programme, showed significant functional improvement compared with the patients where cerebral damage was diagnosed after the first year of life. The experiences of various authors suggest that the success of rehabilitation of children with CP depends primarily on the age of the child when their rehabilitation began and then on the severity of damage. The patients of this study with severe brain damage (quadriplegia), involved in rehabilitation during the first three months of life, began walking by early adolescent and fully or partially mastered the activities of daily living. In the first three months of life, a child with cerebral damage does not show any abnormal activities nor has developed motoric symptoms which allows for the development of normal positioning and movement. Whereas an older child comes with already established abnormal behaviours, cerebral damage is more complicated and their progress is slower. As a result, there is a need for a

process of thorough psychomotor screening for every child in the primary care setting in order to identify neurological symptoms and provide the opportunity of early inclusion in treatment¹⁸.

Conclusion:

There were no major differences in effectiveness between home-based and hospital-based habilitation programmes according to outcomes on motor performance and daily functioning.

The effectiveness of home-based programme increases when supplemented by frequent consultations with the rehabilitation team members and occasional outpatient physical therapy treatment, continuing and comprehensive education as well as counselling and support for parents.

Home-based programmes should be rigorous, daily, and stimulating with the goal of eliciting co-operation from the child, encouraging development as the child grows and tailored to the priorities of the family.

Family members are cornerstone in the process of motor, cognitive and social development.

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Conflict of Interest: The authors declare no conflict of interest.

Carry home message: Rigorous home-based habilitation programmes supplemented by frequent consultations with interdisciplinary team members and outpatient physical treatments, represents an immensely effective medical treatment of children with CP.

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