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Family as a Factor in Cerebral Palsy Prevention

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ABSTRACT

The aim of the study was to assess maternal perception of family impact on the course and outcome of rehabilitation in children with cerebral motor impairment. The study included 135 children with cerebral motor impairment. Their motor development was followed-up over a one-year period by use of structured interview with the children's mothers after 12-month rehabilitation. The course of rehabilitation was assessed by the method of locomotor system functional evaluation. The improvement achieved in motor development was significantly better in the group of children whose mothers found their relationships with extended family excellent than in those whose mothers considered it good or poor. The study showed that mothers to children with cerebral motor impairment frequently feel the lack of extended family support, being it real or perceived as such by the mothers due to their emotional sensitivity, suggesting the need of additional studies of the reasons for this. These findings indicate that greater attention should be paid by health professionals to the psychological support offered to these mothers.

Key words: cerebral motor impairment, rehabilitation, extended family, psychological support

Introduction

Cerebral palsy is a nonprogressive disorder of the central nervous system (CNS). Although CNS pathology is not progressive, the resulting physical deficits and functional restrictions change during the period of growth and development¹. The treatment of cerebral palsy is long lasting and difficult, since cerebral palsy is a definitive condition, a chronic disease where only palliative interventions including physiotherapeutic and surgical orthopedic procedures along with patient education and symptomatic therapy are possible². However, some preventive actions can be taken in the treatment of cerebral motor impairment (CMI) in order to prevent the onset of cerebral palsy or at least to alleviate the clinical picture severity. In contrast to cerebral palsy, the diagnosis of CMI is based on the evidence of risk symptoms, i.e. clinical signs of a specific pattern of CNS damage (e.g., tetraparetic, paraparetic, etc.). The risk symptoms are signs of deviation from the normal condition due to CNS lesion³. In a child with CNS lesion, the process of rehabilitation is very complex, necessitating full parental engagement. Inappropriate parental attitudes that are incompatible with the goal of rehabilitation can consi-

derably hinder and slow the process of rehabilitation down⁴. According to literature reports, up to 50% of parents fail to comply with the rehabilitation treatment prescribed⁵.

Low socioeconomic status has been demonstrated to have an unfavorable impact on many aspects of pediatric morbidity and mortality⁶. Neither should the issue of family influence on the health state of a child with CMI be overlooked, as maternal depression is known to have unfavorable effect on the child's behavior and development, parental attitudes, and mother to child relationship during the first three years of life⁷.

The aim of this study was to assess the maternal perception of family impact on the course and outcome of rehabilitation in children with CMI.

Subjects and Methods

The study was performed at Professor Milena Stojčević-Polovina Polyclinic for Physical Medicine and Rehabilitation, Zagreb, Croatia. The study included 135 chil-

dren with CMI. Study patients were divided into two groups according to clinical picture severity. Group 1 consisted of 27 male and 40 female children with moderate forms of CMI and functional locomotor system evaluation score 30–39. In this score group, motor development deviations need not manifest at infancy. Group 2 included 33 male and 35 female children with functional locomotor system evaluation score 20–29 indicating severe forms of CMI. In this score group, deviation from normal motor development is fully evident from infancy. Average age of the children in the whole sample at the beginning of the rehabilitation treatment was 6,43 months with minimal age being 1 month and maximal 48 months in both groups. Average age at the beginning of treatment in the group of children with moderate CMI was 5,49 and in that with severe CMI was 7,35 months.

The children presented for regular control examinations and parents were advised to have the children exercise for at least 3 hours daily. Exercises were performed according to the child's developmental stage within the diagnosis. Exercises were performed according to the method of Vojta and Bobath. Method of Vojta is based on the reflex locomotion. It is a reciprocal activity of global character. Method of Bobath emphasizes the need for the person's own more effective activity and repetition for learning. Parents are trained in ways to assist their child to achieve best performance. The children were examined by the method of functional evaluation of the locomotor system at the beginning of the study and 12 months later. The method of functional evaluation is based on recording risk symptoms classified according to 10 criteria: general locomotor impression; attitude and posture in supine position; attitude and posture in pronation; attitude and posture in antigravity position; assessment of active mobility; assessment of passive mobility; assessment of muscle tone; specific reactions; position reflexes; and developmental retardation. Each criterion is scored 1–5, where 5 denotes normal finding, 4 mild deviation, 3 moderate deviation, 2 severe deviation, and 1 very severe deviation from normal. Summing up the scores for all 10 criteria gives a sum of 10–50, where 50 indicates normal development according to all criteria, 40–49 mild deviation, 30–39 moderate deviation, 20–29 severe deviation, and 10–19 very severe deviation from normal. Functional evaluation of the locomotor system has been introduced by Stojčević-Polovina⁸. On 12-month examination of the study children, their mothers underwent a structured interview, describing their opinion of and experience with their family attitudes to their children's health problems.

Statistics

The following statistical methods were used on data processing: descriptive statistics for distribution of study variables; χ^2 -test for differences in the values of quantitative variables; Kolmogorov-Smirnov test for normality of distribution of quantitative variables; nonparametric Mann-Whitney test and Kruskal-Wallis ANOVA for differences in the values of quantitative variables; and Spearman correlation coefficients for correlation of quantitative variables.

Results

Demographic data showed a slightly older parental age in the group of children with severe CMI. The proportion of mothers with elementary and secondary level of education was greater than the proportion of mothers with university education in both groups of patients, whereas the proportion of fathers with elementary and secondary level of education was higher in the group of children with severe CMI and that of fathers with university education in the group of children with moderate CMI.

When asked about regular performance of the rehabilitation treatment prescribed, 95% of mothers gave affirmative answer, and only 5% stated they did not comply with the rehabilitation treatment. When questioned about the extended family's attitude towards the diagnosis and rehabilitation, 45 mothers to children with moderate CMI and 41 mothers to children with severe CMI stated they received full support and help from their families; 48 mothers, 20 and 24 of them to children with moderate and severe CMI, respectively, said they had support but no help from their families; and only five mothers, two and three to children with moderate and severe CMI, respectively, answered their extended families were indifferent. Four of the children whose extended families showed no concern for their rehabilitation failed to achieve any improvement of their condition.

Sixty-five mothers reported daily contact, 39 mothers frequent contact, 20 occasional contact, and eight no contact with their extended families (Figure 1).

The group of children with severe CMI had a lower rate of excellent relations and higher rate of good or poor relations with their extended families as compared with the group of children with moderate CMI. The rate of condition improvement was statistically significantly lower in the group of children whose mothers perceived their relationship with extended families as poor than in

TABLE 1
ASSESSMENT OF MOTOR DEVELOPMENT AFTER 12-MONTH REHABILITATION

CMI severity	n	Improvement	Normal finding	Unchanged	Aggravation
Moderate	67	10	41	15	1
Severe	68	27	8	33	
Total N	135	37	49	48	1

TABLE 2
RELATIONS WITH EXTENDED FAMILY RELATIVE TO MOTOR DEVELOPMENT

Difference in motor development	Relations with extended family			Total
	Excellent	Good	Poor	
n	62	70	3	135
χ	11.14	9.46	2.33	10.07
S	6.62	6.54	2.08	6.64
Minimum	1	-2	0	-2
Maximum	30	26	4	30
Q ₁	6	5	0	5
Median	10	8.5	3	9
Q ₃	15	15	4	15

Kruskal-Wallis ANOVA: $H(2, N=135)=7.273$; $p=0.026$.
Post-hoc test: excellent:good $p=1.000$; excellent:poor $p<0.001$; good:poor $p<0.001$

TABLE 3
IMPROVEMENT IN MOTOR DEVELOPMENT OF CHILDREN TO MOTHERS STATING THEY WOULD HAVE BETTER COMPLIED WITH PHYSICIAN'S INSTRUCTIONS HAD THEY RECEIVED STRONGER SUPPORT FROM THEIR EXTENDED FAMILY

Difference in motor development	Better compliance with higher family support		Total
	No	Yes	
n	97	38	135
χ	10.77	8.29	10.07
S	6.80	5.93	6.64
Minimum	-2	0	-2
Maximum	30	20	30
Q ₁	5	3	5
Median	10	7.5	9
Q ₃	15	11	15

Mann-Whitney test: $U=1442.5$; $Z=-1.959$; $p=0.050$

the group of children whose mothers found it good or excellent (Table 2).

The group of children with severe CMI had a higher proportion of those whose extended families paid more attention to either healthy or affected children as compared with the group of children with moderate CMI. The highest proportion of children with unchanged condition at the end of one-year rehabilitation period was found in the group of CMI children whose families paid more attention to healthy children. Also, the latter was the case in the only child whose condition aggravated after one-year rehabilitation. On an average, the greatest improvement in motor development was recorded in children whose extended family paid equal attention to both healthy and diseased children, somewhat lower improvement in children whose extended family paid more atten-

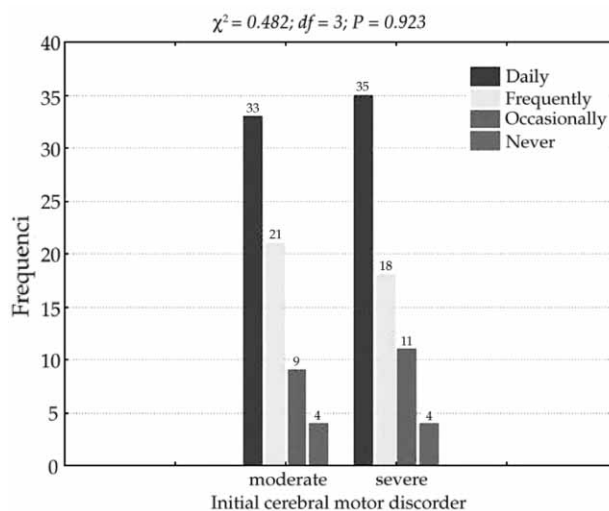


Fig. 1. Contact with extended family.

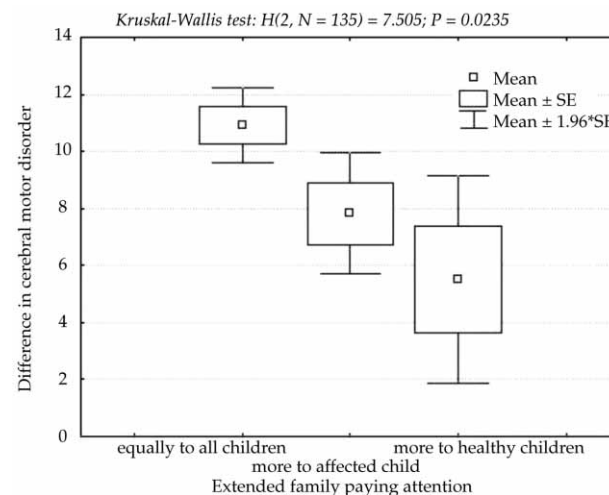


Fig. 2. Improvement in motor development relative to extended family attitude towards children in the family.

tion to healthy children, and lowest improvement in those whose extended family paid more attention to affected children (Figure 2).

Fourteen mothers to children with moderate CMI and 24 mothers to children with severe CMI believed they would have more strictly followed physician's instructions had they received greater support from their extended families (table 3). Improvement in motor development of children to mothers stating they would have better complied with physician's instructions had they received stronger support from their extended family is shown in figure 3.

When asked whether their extended families were adequately included in the rehabilitation of their children, 68 mothers including 33 and 35 mothers to children with moderate and severe CMI, respectively, gave negative an-

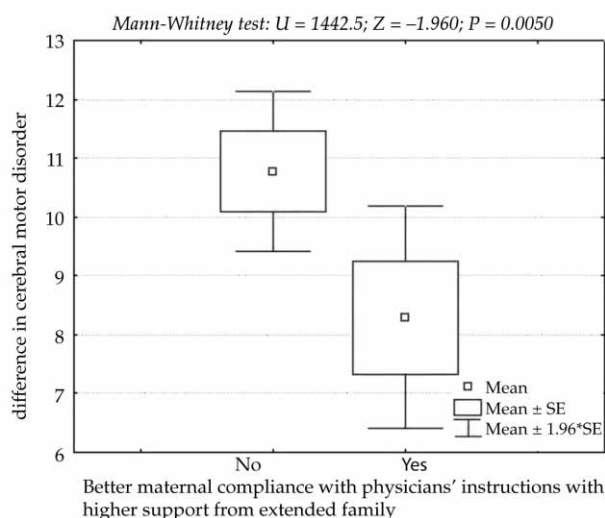


Fig. 3. Improvement in motor development relative to better maternal compliance with physician's instructions with higher support from extended family.

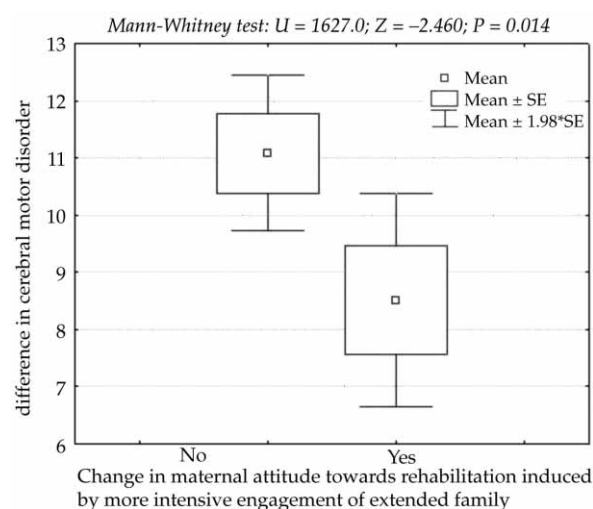


Fig. 4. Improvement in motor development relative to change in maternal attitude towards rehabilitation induced by more intensive engagement of extended family.

swer, and 67 mothers including 34 mothers to children with moderate CMI and 33 mothers to children with severe CMI gave affirmative answer. Fifty-three mothers, i.e. 23 and 30 to children with moderate and severe CMI, respectively, considered that more extensive engagement of their extended families would influence their attitude towards rehabilitation. This group of children exhibited a lower level of improvement in their motor development after 12 months of rehabilitation on an average (Figure 4).

If they could, 44 mothers would have changed their extended family attitudes towards their children's diagnosis, and 49 mothers would have modified their attitude towards rehabilitation.

Discussion

The results obtained confirmed the need of rehabilitation in children with risk symptoms in order to influence their motor development. Similar results have been reported from the prospective study conducted at Department and Polyclinic for Children's Rehabilitation, Dr. Mladen Stojanović University Hospital in Zagreb from 1966 to 1978, pointing to general benefits of rehabilitation treatment irrespective of its timing, as the development of motor deficit was halted in almost all cases, whereas leaving a handicap to itself and untreated is known to always entail unfavorable consequences. That study also demonstrated the use of ultra-early rehabilitation to be justified, along with full success of very early and early rehabilitation, in contrast to the limited possibilities of rehabilitation medicine in the delayed and late stage of the disease⁹. Ultra-early rehabilitation refers to the rehabilitation initiated while the child is still under intensive care treatment. Very early rehabilitation is the rehabilitation started within the first three months of the child's life. Early rehabilitation begins between the third and ninth month, delayed rehabilitation between the ninth and eighteenth month, and late rehabilitation after the eighteenth month of the child's life.

Currently, ever more attention has been paid to the participation of parents in the rehabilitation of children with chronic physical deficits. This opinion is substantiated by two arguments: first, therapeutic activities have to be incorporated in daily practice in order to extrapolate them from rehabilitation institutions to the child's daily life; and second is the impact of such an approach on the parents. The parents taking active part in their child's rehabilitation get better insight in the child's abilities, they get better adapted in the care for their child, which eventually upgrades their self-confidence concerning their own abilities and reduces the stress caused by their child's handicap¹⁰. Many studies have tackled the issue of parental participation in the rehabilitation of children with cerebral palsy, however, they generally used too different methodological approaches to yield definitive recommendations¹⁰. However, it should be emphasized that the treatment of children with CNS lesion requires persistent and longstanding efforts, yet knowing that no spectacular results can be expected. Great endeavors, patience, collaboration, and above all love and faith are needed to reach some results⁹. Hinojosa and Anderson carried out a qualitative study of maternal perception of home treatment of their children with cerebral palsy. Almost all mothers admitted they did not perform complete rehabilitation program, mostly because it was too demanding for the mothers, the children and their families. So, the mothers chose those activities that could have been more easily incorporated in their daily routine¹¹. In contrast to this, Von Wendt et al. investigated parents who performed physical therapy according to the method of Bobath and Vojta in their children at home, only a few of them reporting difficulties encountered on home treatment. The author concluded that parents were not overloaded with the program as long as they re-

ceived appropriate economic and emotional support¹². In our study, only six parents said they had not complied with physician's instructions. Similar answers were obtained to the questions of whether a more intensive engagement of extended family would influence their attitude to rehabilitation, and whether they would have followed the instructions more strictly had they received stronger support from extended family. Although there was no statistically significant difference in the distribution of answers between the two groups of children, and no difference in motor development between the groups of children with moderate and severe CMI, the children whose mothers gave affirmative answer showed a statistically significantly lower improvement of motor development after 12-month rehabilitation on an average, as indicated by difference in the locomotor system functional evaluation score recorded initially and at 12 months of rehabilitation treatment. Lambrenos et al. investigated the effect of the child's handicap on the mother's mental health. In the first year of life, the prevalence of depression was identical in the mothers to premature infants at risk of cerebral palsy and mothers to term newborns. At the age of six months, however, depression was much more pronounced in the mothers who felt lonely, those lacking support from the family and friends, those having problems with their own parents, those that were unemployed or experienced household problems¹³. These data appear to raise the question of whether these mothers would have followed physician's instructions more strictly, thus making the child's improvement more evident, had they received greater support from their extended families. Isn't the very feeling of inadequate support from the environment an important element, perhaps one of the crucial ones for the reduced maternal responsiveness to their child's rehabilitation treatment? Catell (1964), Stančić (1968), Richardson (1972) and many others point to parents as a highly relevant factor in the rehabilitation of children with cerebral palsy, confirming that inappropriate parental attitudes are the source of frustration for handicapped children, thus hampering their rehabilitation². Poor relations with ex-

tended family can be and frequently are the source of frustration for parents, and constitute grounds for the development of unfavorable attitudes.

Parents should be approached in an open and sincere manner, since they have to be aware that rehabilitation of children with CNS lesion is longterm and very often emotionally and physically demanding, not only for those working with the children but for the family as a whole. The outcome and chance to persist in rehabilitation are frequently questioned, yet the goal one is striving to should always be remembered. On the long way to reaching the goal, one should consider the following, said by parents to an affected girl: «... and we would like to warn the parents not to expect to become 'perfect parents', the more so as they will find themselves in a situation requiring from them the patience of a saint, the wisdom of gods, and the energy of a humming-bird. Day by day, we find emotional and physical sources for many variable Patricia's needs and needs of other family members»¹⁴.

The present study demonstrated the importance of daily rehabilitation performed at home by parents to children with CMI for the prevention of cerebral palsy. Due support from extended family to the child's parents and attention equally paid to all children in the family were found to be of utmost relevance for proper rehabilitation performance. Mothers to CMI children were found to frequently perceive the lack of support from extended family, suggesting the need of additional studies to investigate the reasons for this, i.e. whether support from extended family is really lacking or mothers experience it as such because of their emotional sensitivity. Therefore, considering the role of maternal perception of the support offered by extended family and specific maternal emotional state, the child's health condition as well as the more extensive family factors should all be taken into account when initiating rehabilitation in a child with CNS lesion. Mothers should be offered full psychological support from health professionals in order to obtain optimal parental response, thus maximally influencing the outcome of the child's rehabilitation.

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ULOGA OBITELJI U PREVENCIJI CEREBRALNE PARALIZE

S A Ž E T A K

Cilj studije bio je ispitati majčinu percepciju utjecaja obitelji na tijek i ishod rehabilitacije djece s cerebralnim poremetnjama. U ispitivanje je bilo uključeno 135-ero djece s cerebralnim poremetnjama kretanja čiji je motorički razvoj praćen kroz godinu dana. Primjenjena je metoda usmjerenog strukturiranog intervjua s majkama nakon 12 mjeseci provođenja rehabilitacije, a tijekom rehabilitacije procjenjivan je metodom funkcionalne evaluacije lokomotornog sustava. Analizom podataka pokazalo se da je u skupini djece s teškim oblikom cerebralnih poremetnji kretanja veći udio majki koje doživljavaju svoj odnos s širom obitelji dobrim i lošim, a manje odličnim nego u skupini majki djece s srednje teškim oblikom cerebralnih poremetnji kretanja. U djece čije majke doživljavaju svoj odnos s širom obitelji dobrim i lošim zabilježen je manji napredak u motoričkom razvoju. U djece čije majke doživljavaju podršku od strane šire obitelji zabilježen je značajno bolji napredak u motoričkom razvoju djece. Najveći je napredak u motoričkom razvoju zabilježen u djece čija šira obitelj prema doživljaju majki jednaku pažnju posvećuje i bolesnoj i zdravoj djeci. U djece s oštećenjem središnjeg živčanog sustava neophodno je provođenje rehabilitacije od strane roditelja. Studija je pokazala da majke djece s cerebralnim poremetnjama kretanja često osjećaju izostanak podrške od strane šire obitelji, bilo da ona zaista izostaje ili ju majke takvom doživljavaju zbog svoje emocionalne osjetljivosti, što navodi na potrebu daljnjeg istraživanja tih razloga. Imajući to u vidu, neophodno je potrebno da zdravstveni djelatnici više pažnje posvete psihološkoj podršci majci.