

# Expectations from Rehabilitation of Children with Cerebral Palsy: The Agreement between the Physiotherapists and Mothers

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**Abstract.** [Purpose] The aim of this study was to examine the agreement between physiotherapists (PTs) and mothers (Ms) about the treatment of children with cerebral palsy (CP) who received treatment in special education and rehabilitation centers. [Subjects] Ms of 130 children with CP (75 boys, 55 girls) and 130 PTs who applied rehabilitation programs were interviewed. [Methods] Clinical types and gross motor function levels of the children were recorded. A questionnaire consisting of 6 open-ended questions was used to describe the expectations and views of the PTs and Ms about the physiotherapy and rehabilitation programs for the children. [Results] The mean age of the children was 89.80±52.05 months. The mean treatment period for the children was 73.62±42.11 months. The mean age of the mothers was 35.47±5.79 years, and the mean age of the PTs was 28.07±7.28 years. We found a statistically moderate level of agreement between the PTs and Ms regarding the appropriateness of the treatment provided to the children. There was statistically insignificant agreement regarding the applied treatment methods and the appropriateness of the applied rehabilitation programs. [Conclusion] We believe that the views and expectations of the Ms should be taken into account by the PTs when preparing a treatment program for children with CP.

**Key words:** Cerebral palsy, Physiotherapist, Mother

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## INTRODUCTION

Rehabilitation for the cerebral palsied children should be given thought a team work including parents as a model refers to patient centered treatment regimens<sup>1-3)</sup>.

This idea encourages considering parent's opinions about physiotherapy and rehabilitation for their children with CP. For this reason, health providers, especially physiotherapists (PTs), should talk with the parents of a disabled child before planning a specific treatment or intervention in order to establish the most suitable program for the child<sup>4-7)</sup>.

The parents of disabled children seek to learn all details, both positive and negative aspects, about a physiotherapy and rehabilitation program that will be applied to their children. This is necessary for the parents to understand the mission and goal of the program. Moreover, the PTs and mother (M) or father of a disabled child should evaluate the child together so that they can define the needs of the child. For this reason, the parents of children with CP should also

be included in making decisions in the rehabilitation process<sup>4, 5, 8, 9)</sup>

The purposes of this research were (1) to understand perceptions of Ms and PTs regarding the rehabilitation programs their children receive and (2) to report the current knowledge of Ms and PTs, highlighting consensus and disagreement.

## SUBJECTS AND METHODS

The study was conducted between January and April 2012. One hundred and thirty children (75 boys, 55 girls) who were being treated in special education centers in different parts of Turkey and their Ms and 130 PTs who were treating them were included in the study.

Informed consent was obtained from Ms and PTs, written approval was obtained for the study from the managers of the schools, and the study was completed in accordance with the principles of the Helsinki Declaration.

The inclusion criteria were as follows: all participants agreed to participate, the children had been diagnosed with CP by a pediatric neurologist, and the caregivers of the children had to be Ms.

Demographic data of children, Ms, and PSTs were recorded.

The Gross Motor Function Classification System (GM-

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FCS) was used to determine the functional level appropriate for the age of the child and score it between 1 and 5. While a score of 1 indicates that the child may easily achieve indoor ambulation without the need for adjunctive mobilization devices, a score of 5 indicates that the child is totally dependent for mobilization. The reliability and validity of the classification system have been determined for children aged between 2 months and 12 years, and studies have also been done for adults with CP<sup>10, 11</sup>.

The questionnaire form was composed of 6 open-ended questions asking about the expectations and opinions of the Ms and PTs with regard to the physiotherapy and rehabilitation programs being used. The questionnaire form was created by experienced PTs who were working in the pediatric rehabilitation units of university hospitals and special education rehabilitation centers.

In the present study, power analysis revealed that 90% power would be obtained with a reliability of 95% if 130 people were included in the study. SPSS 18.0 was used for data analysis. Characteristics of the children with CP, Ms, and PTs are presented as mean  $\pm$  standard deviation, numbers, and percentages. The views of the PTs and Ms are presented as numbers and percentages. The level of statistical significance was set at  $p < 0.05$ . The kappa coefficient (K) was used to analyze agreement with regard to the views of the PTs and Ms. The kappa coefficient ranged between 0 and 1. A kappa coefficient for two values of between 0.0 and 0.20 was considered to indicate statistically insignificant concordance, and one between 0.21 and 0.40 was considered to indicate statistically moderate concordance.

## RESULTS

The mean age of the children who participated in the study (75 boys, 55 girls) was  $89.80 \pm 52.05$  months, and the mean duration of treatment was  $73.62 \pm 42.11$  months. The mean age of the Ms was  $35.47 \pm 5.79$  years. The mean age of the PTs was  $28.07 \pm 7.28$  years, and their mean number of working years was  $6.84 \pm 7.51$ . Of the Ms, 83.1% had 12 years or less of education, 14.6% had 12 or more years of education and 2.3% were illiterate (Table 1). The distribution of clinical types of CP cases and levels according to the GMFCS are shown in Table 1.

According to the results of the questionnaire that asked about the opinions of the Ms and PTs, while 33.1% ( $n=43$ ) of the PTs and 32.3% ( $n=42$ ) of the Ms defined the health status of the children as "good", the concordance was found to be 13.1%. In addition, while 38.5% ( $n=50$ ) of the PTs and 39.2% ( $n=51$ ) of the Ms defined the health status of the children as "moderate", the concordance was found as 18.5%. Statistically insignificant correlation was found ( $K=0.129$  and  $p=0.015$ ) (Table 2).

When the awarenesses of the Ms and PTs about the therapies the children received were analyzed, 86.9% ( $n=113$ ) of the PTs and 40% ( $n=52$ ) of the Ms stated that the children were receiving Bobath therapy, and the concordance was found to be 36.2%. Statistically insignificant concordance was found between the Ms and PTs ( $K=0.077$  and  $p=0.016$ ) (Table 2).

**Table 1.** Characteristics of the children with CP, Ms, and PTs

Children with CP	X $\pm$ SD	Min–Max
Age (months)	89.80 $\pm$ 52.05	18–300
Treatment period (months)	73.62 $\pm$ 42.11	18–240
Gender	n	%
Boys	75	57.70
Girls	55	42.30
Mother	X $\pm$ SD	Min–Max
Age (years)	35.47 $\pm$ 5.79	23–49
Physiotherapist	X $\pm$ SD	Min–Max
Age (years)	28.07 $\pm$ 7.28	22–51
Length of service (years)	6.84 $\pm$ 7.51	1–30
Education level of mother	n	%
12 years or less	108	83.1
12 years or more	19	14.6
Illiterate	3	2.3
Clinical types of the children with CP	n	%
Spastic	111	85.4
Dyskinetic	7	5.4
Ataxic	6	4.6
Hypotonic	4	3.1
Mixed type	2	1.5
GMFCS		
Level 1	10	7.7
Level 2	21	16.2
Level 3	38	29.2
Level 4	36	27.7
Level 5	25	19.2

While 94.6% ( $n=123$ ) of the PTs and 83.1% ( $n=108$ ) of the Ms stated that they found the therapy appropriate, the concordance was found to be 82.3%. Moderate concordance was found between the PTs and Ms when all answers about the appropriateness of therapy were evaluated ( $K=0.338$  and  $p=0.0001$ ) (Table 2).

When asked about the ability to walk with/without help, 31.5% ( $n=41$ ) of the PTs and 38.5% ( $n=50$ ) of the Ms stated that they wanted the children with CP to walk with/without help, and the concordance was found to be 17.7%. Statistically insignificant concordance was found between the PTs and Ms when all expectations were evaluated ( $K=0.187$  and  $p=0.0001$ ) (Table 3).

When asked about additional therapy, 18.5% ( $n=24$ ) of the PTs and 32.3% ( $n=42$ ) of the Ms stated that it was not necessary. The concordance was found to be 6.2%. Statistically insignificant concordance was found between the PTs and Ms with regard to additional therapies ( $K=0.136$  and  $p=0.001$ ) (Table 3).

Finally, when questioned about the efficacy of the physiotherapy and rehabilitation programs, 25.4% ( $n=33$ ) of the PTs and 30.8% ( $n=40$ ) of the Ms defined the applied therapy as "very good", and the concordance was found to be 10.0%. Statistically insignificant concordance was found between the PTs and Ms in terms of opinions about the efficacy of

**Table 2.** Description of the health of the children with CP, awareness about the received treatments, and views about the appropriateness of the treatments

Description of the health of the children with CP*	Physiotherapist		Mother		Physiotherapist-mother agreement	
	n	%	n	%	n	%
Perfect	4	3.1	3	2.3	1	0.8
Very good	12	9.2	13	10.0	1	0.8
Good	43	33.1	42	32.3	17	13.1
Moderate	50	38.5	51	39.2	24	18.5
Bad	21	16.2	21	16.2	7	5.4
Awareness about the received therapies*						
Bobath	113	86.9	52	40.0	47	36.2
Vojta	2	1.5	4	3.1	1	0.8
Special education	5	3.8	50	38.5	4	3.1
Reflexology	5	3.8	4	3.1	2	1.5
Botox	3	2.3	2	1.5	-	-
I have no idea	2	1.5	18	13.8	-	-
Views about the appropriateness of the treatment**						
Yes	123	94.6	108	83.1	107	82.3
No	3	2.3	9	6.9	3	2.3
I have no idea	4	3.1	13	10.0	2	1.5

\*Statistically significant ( $p < 0.05$ ), kappa coefficient; \*\*Statistically significant ( $p < 0.01$ ), kappa coefficient

**Table 3.** The views of the physiotherapists and the mothers about the expectations from the treatment the children with CP receive, additional therapies and effectiveness of the physiotherapy and rehabilitation program

Expectations from the treatment**	Physiotherapist		Mother		Physiotherapist-mother agreement	
	n	%	n	%	n	%
Walking with/without help	41	31.5	50	38.5	23	17.7
Standing with/without help	15	11.5	8	6.2	4	3.1
Sitting with/without help	31	23.8	13	10.0	8	6.2
Independency in daily life activities	20	15.4	46	35.4	8	6.2
Increased balance and postural control	23	17.7	13	10.0	5	3.8
Additional therapies**						
Not necessary	24	18.5	42	32.3	8	6.2
Speech therapy	34	26.2	37	28.5	14	10.8
Water exercise	23	17.7	24	18.5	9	6.9
Special education and psychosocial support	20	15.4	14	10.8	6	4.6
Reflexology	12	9.2	5	3.8	2	1.5
Vojta	3	2.3	3	2.3	-	-
Surgical	5	3.8	3	2.3	-	-
Sensory-perception motor education	9	6.9	2	1.5	-	-
Effectiveness of the physiotherapy and rehabilitation program**						
Perfect	13	10.0	12	9.2	3	2.3
Very good	33	25.4	40	30.8	13	10.0
Good	69	53.1	59	45.4	35	26.9
Moderate	10	7.7	11	8.5	2	1.5
Bad	5	3.8	8	6.2	3	2.3

\*\*Statistically significant ( $p < 0.01$ ), kappa coefficient

the programs ( $K=0.141$  and  $p=0.009$ ) (Table 3).

## DISCUSSION

The results of our study showed that while statistically insignificant concordance ( $K=0.0-0.20$ ) was found between the PTs and Ms regarding the definition of the health statuses of the children, treatment methods applied to the children, required additional therapies, and appropriateness of the rehabilitation programs, statistically moderate concordance was found regarding the appropriateness of the therapies ( $K=0.21-0.40$ ).

For families with a disabled child, it is quite difficult to accept the disability and rearrange lifestyles to adapt to the child's condition<sup>12-14</sup>.

Ms who are the primary caregivers of disabled children and interact more often with them represent a risk group for mental health due to anxiety and worries about the problems of their disabled child<sup>15, 16</sup>. The significance of participation of the family in treatment and education of a disabled child is emphasized in the literature<sup>17-19</sup>.

It has been emphasized that early application of physiotherapy to a child with CP are important for motor development of the child and that the mother perceives the condition of the child<sup>20</sup>. Considering that all rehabilitation processes should be realized in the natural environment of the child, involving the family in this process is inevitable. Informing the family about the care and rehabilitation of the child and providing help are as effective as directly educating the child<sup>21</sup>. According to the results of our study, we consider that it is necessary to increase the contribution of mothers to treatment, to educate them in order to apply the therapies at home and to better understand their children, and to increase the cooperation with PTs.

In a study of Karaduman et al., families graded the treatment methods applied to their children as special education, physiotherapy, speech therapy, drug therapy, and surgical therapies, respectively<sup>22</sup>.

In our study, the mothers stated that Bobath therapy and special education treatment were the most appropriate and most beneficial treatment types for their children. Low concordance was found between PTs and Ms in terms of the therapies applied to the children and degree of benefit from treatment.

In the study of Karaduman et al., the outcomes expected by families from treatment were attainment of the most efficient level of the disability or total elimination of the disability<sup>22</sup>. In our study, 38.5% of Ms wanted their children to walk with/without help, and 35.4% wanted their children to perform daily activities independently. These results are similar to the aforementioned results. High concordance was found between PTs and Ms in terms of expectations from therapies. However, 67.72% of the Ms and 81.5% of the PTs considered alternative treatment methods to be necessary (Table 3).

The importance of a high education level of families for adequate care and treatment of a disabled child is known. In studies investigating the relations between families and health teams in early and later periods, Ms stated that

they did not understand the explanations their child's disease<sup>23, 24</sup>. In our study, 83.1% of Ms had 12 years of education or less (Table 1).

Insignificant concordance was found between PTs and Ms regarding the expectations from treatments. We consider that this resulted from the fact that families are not sufficiently informed about their child's health and treatments or that they cannot understand enough of the information they are given.

Taaniala et al. emphasized that having enough knowledge about the condition of the child is important for adaptation to the child and care, education, and rehabilitation of the child<sup>25</sup>.

One of the most important factors that positively affects the ability to cope with difficulties is education<sup>26</sup>. In the study of Singer et al. conducted with families of disabled children, families with a higher education level reportedly cared for their children better; in other words, awareness about the disease was higher<sup>27</sup>. In our study, the concordance between Ms and PTs regarding the appropriateness of therapy was 82.3%, and it was found to be 36.2% for treatment awareness. These concordance rates show the importance of informing and educating the mothers of children with CP.

In conclusion, participation of the Ms in the treatment program and awareness about the treatment are important. We consider that health staff involved in the care of disabled children should consider the opinions of the Ms about the therapy when determining the most appropriate and most beneficial treatment.

We consider that Ms should cooperate with PTs in the course of rehabilitation and receive education about the condition of their children in order to increase their awareness of their child's disease, find the most appropriate treatment option, practice the therapy at home in the most effective and most appropriate way, and obtain better results from rehabilitation programs.

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