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

INTRODUCTION

Rehabilitation for the cerebral palsied children should be given thought a team work including parents as a model refers to patient centered treatment regimens1–3). 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 child4–7). 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 process4, 5, 8, 9). 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-
(Table 2). was found between the Ms and PTs (K=0.077 and p=0.016) found to be 36.2%. Statistically insignificant concordance were receiving Bobath therapy, and the concordance was of the PTs and 40% (n=52) of the Ms stated that the children received were analyzed, 86.9% (n= 113) of the PTs and 32.3% (n=42) of the Ms defined the health status of the children as “good”, the concordance was found as 18.5%. In addition, while 38.5% (n=50) of the PTs and 32.3% (n=42) of the Ms stated that it was not necessary. 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 when all expectations were evaluated (K=0.187 and p=0.0001) (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

| Children with CP | X±SD | Min–Max |
|------------------|------|---------|
| Age (months)     | 89.80±52.05 | 18–300  |
| Treatment period (months) | 73.62±42.11 | 18–240 |
| Gender           | n    | %       |
| Boys             | 75   | 57.70   |
| Girls            | 55   | 42.30   |
| Mother           | X±SD | Min–Max |
| Age (years)      | 35.47±5.79  | 23–49   |
| Physiotherapist  | X±SD | Min–Max |
| Age (years)      | 28.07±7.28  | 22–51   |
| Length of service (years) | 6.84±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).

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).

RESULTS

The mean age of the children who participated in the study (75 boys, 55 girls) was 89.80±52.05 months, and the mean duration of treatment was 73.62±42.11 months. The mean age of the Ms was 35.47±5.79 years. The mean age of the PTs was 28.07±7.28 years, and their mean number of working years was 6.84±7.51. Of the Ms, 83.1% had 12 years or less 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.

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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 |
|---------------------------------------------------|-----------------|--------|----------------------------------|
| Description of the health of the children with CP* | 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 |
|----------------------------------|-----------------|--------|----------------------------------|
| Expectations from the treatment** | 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[12–14].

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[15, 16]. The significance of participation of the family in treatment and education of a disabled child is emphasized in the literature[17–19].

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[20]. 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[21]. 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[22].

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[23, 24]. In our study, 38.5% of Ms wanted their children to develop of the most beneficial treatment types for their children and that the mother perceives the condition of the child[20]. 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[21]. 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.

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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[23, 24]. 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[23, 24]. In our study, 83.1% of Ms had 12 years of education or less (Table 1).

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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