Mothers' Expectations from Rehabilitation Program of Children with Cerebral Palsy

Annelerin Serebral Palsili Çocukların Rehabilitasyon Programından Beklentileri

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ABSTRACT

Objective: The purpose of the study was to evaluate the mothers' expectations from rehabilitation programs of children with cerebral palsy (CP).

Methods: One hundred eight children with CP and their mothers were taken into an inpatient rehabilitation program in the hospital. The Gross Motor Function Classification System was used to determine the severity of CP. Maternal age and education levels were recorded. Mothers were asked to indicate their expectations from the rehabilitation program in order of their priority. For this purpose, a form containing 11 items.

Results: The first expectations for the mothers at all educational levels were walking of the child or increasing the quality of walking. A poor correlation was determined between severity of CP and the mother's expectations ($r=0.34$, $p<0.001$). There was no significant statistical difference between length of stay in the hospital for rehabilitation of children with CP and the mothers' expectations ($p=0.297$).

Conclusion: The first expectations of mothers' of children with CP from rehabilitation programs are increasing the quality of the child's walking or increasing of the quality of walking in the first place. It is observed that the increase in the severity of CP did not change the expectations of the mother. We believe that more informing the parents of children with CP about CP and the goals of the rehabilitation program would be helpful incrising in terms of the efficiency of the rehabilitation program.

Keywords: Cerebral palsy, rehabilitation, mothers' expectation

ÖZET

Amaç: Çalışmanın amacı annelerin serebral palsi (SP) rehabilitasyon programından beklentilerini değerlendirmektir.

Yöntemler: Hastane de yatan 108 SP'li çocuk ve anneleri rehabilitasyon programına dahil edildi. SP şiddetini belirlemek için Kaba Motor Fonksiyon Sınıflama Sistemi (KMFSS) kullanıldı. Anne yaşı ve eğitim düzeyi kaydedildi. Annelere öncelik sırasına göre rehabilitasyon programından beklentilerini belirtmesi istendi. Bu amaçla 11 madde içeren bir form hazırlandı.

Bulgular: Tüm eğitim düzeylerinde annelerin birinci beklentisi SP li çocuklarının yürümesi yada yürüme kalitesinin artması idi. SP şiddeti ile annelerin beklentileri arasında zayıf korelasyon saptandı ($r=0.34$, $p<0.001$). Hastanede kalış süresi ile annelerin beklentileri arasında istatiksel anlamlı farklılık saptanmadı ($p=0.297$).

Sonuçlar: SP'li çocukların annelerinin birinci beklentisi çocuklarının yürümesi ya da yürüme kalitesinin artması idi. SP şiddetinin annelerin beklentisini değiştirmediği gözlemlendi. SP'li çocukların ailelerinin SP ve rehabilitasyon hedefleri konusunda daha fazla bilgilendirilmesinin rehabilitasyon programının verimliliğini arttırabileceğini düşünmekteyiz.

Anahtar sözcükler: Serebral palsi, rehabilitasyon, annelerin beklentisi

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Introduction

Cerebral palsy (CP) is one of the most common disorders of childhood (1), and its prevalence is reported to be 2-3 per 1000 live births (2) and in Turkey is reported to be 4.4 per 1000 live births (3). CP describes a group of permanent disorders of the development of movement and posture, causing activity limitation, which are attributed to non-progressive disturbances occurring in the developing fetal or infant brain. Motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior, by epilepsy and by secondary musculoskeletal problems (4). Although impaired motor function is the hallmark of the CP, many children may have complex limitations in self-care functions because of the sensory, communicative, and intellectual impairments. Although care-giving is a normal part of being the parent of a young child, this role takes on an entirely different significance when a child experiences functional limitations and long-term dependence. One of the main challenges for parents is to manage their child's chronic health problems effectively and perform this role along with the requirements of everyday living (3,4). Current management of CP is based on a multidisciplinary team approach. However, close attendance and active participation of the family during all phases of the child's treatment is a vital part of the overall management (5). However, based on our clinical experience, we observe that determined rehabilitation objectives might not overlap with the expectations of parents. Yet, it is very crucial for the effectiveness of the program. The purpose of this study is to investigate the expectations of mothers' of children with CP from rehabilitation programs.

Material and Method

This study was conducted at Ankara Physical Medicine and Rehabilitation, Education and Research Hospital, with a capacity of 200 beds, which is one of the largest national rehabilitation centers in Turkey.

During the rehabilitation period of children with CP, their mothers or close relatives are allowed to accompany the child. Since the primary care following their discharge is generally carried out by mothers, children with CP who were accompanied by their mothers during hospitalization period were included in the study. The study included a total of 108 children with CP comprised of 48 girls and 60 boys, together with their mothers. Informed consent was obtained from all mothers and the study protocol was approved by the local ethics committee of our institution.

Inclusion criteria for the mothers of children with CP was: having a child with CP and living with him or her. Maternal age and education levels were recorded.

The cases of CP were classified, using the Swedish classification, into spastic (tetraplegia, diplegia and hemiplegia), ataxic and dyskinetic (including athetosis and dystonia) and mixed (6).

Rehabilitation programs include conventionel exercises (range of motion exercises, strengthening exercises), neuromotor treatment approaches (Bobath neurodevelopmental treatment and Vojta method), speech therapy and occupational therapy, which are performed to child with CP. Personal treatment schedule is ordered for each child with CP and these treatments are performed patients in the rehabilitation program 2 times a day.The goal is to improve existing neuromotor capacity function for optimal perform and to reduce complications of CP.

The Gross Motor Function Classification System (GMFCS) was used to determine the severity of the cerebral palsy (7). The Gross Motor Function Classification System improved by Palisano et al. in order to classify objectively the motor disability between 1-12 years old children (8); GMFCS classifies the severity of the CP in 5 grades and evaluates the patients according to 4 age groups (under 2 years age, between 2-4 age, 4-6 age and 6-12 age). The classification is based on the child's self-initiated movement with an emphasis on sitting, transfers and mobility. The differences are based on the necessity to functional constraints, hand-held vehicles (walker, crutch or walking stick) or wheeled mobility vehicles and to a lesser extend to the quality of movement.

Level I: The most independent motor function. It works without any constraint. The only limitation is whith fine motor skills.

Level II: Individuals walk without any walker but there is a limitation on walking out of house and in the community.

Level III: Walks with assistive mobility devices, limitations walking outdoors and in community.

Level IV: Self mobility with limitations, children are transported or use power mobility outdoors and in the community.

Level V: All fields of motor function are restricted. Volitional act control is the worst level in saving the posture of head and body against gravity. The functional constraints on staying and standing cannot be provided completely by using equipment and assistant technology (7).

According to GMFCS, CP was classified as; at level 1 and 2 the cases were mild, at level 3 the cases were moderate and at level 4 and 5 the cases are severe.

Mothers were asked to indicate their expectations from the rehabilitation programs in order of their priority. For this purpose, a form which contained 11 objects (I want him/her to run, I want him/her to walk and to increase the quality of walking, I want him/her to stand up, I want him/her crawl, I want him/her sit, I want him/her to keep his/her head, I want him/her to speak, I want him/her to eat his/her own food, I want to reduce stiffness in his/her legs, I want him/her to hold a pen, other) was created.

Statistical Analysis

SPSS 15.0 packed software was used. Descriptive statistics were used for the evaluation of the demographic data. Children with CP were grouped according to the severity of the illness as; the cases in level 1 and 2 were mild, the cases in level 3 were moderate, the cases in level 4 and 5 were severe. The relationship between CP severity and the first demand of mothers was evaluated with Spearman correlation analysis. The patients were separated into 3 groups according to their total hospitalization duration. Group 1: rehabilitation program duration about 0-3 months, Group 2: rehabilitation program duration about 3-6 months, Group 3: rehabilitation program duration longer than 6 months. Whether there was a difference between the first demands of mothers in 3 groups was evaluated by using Kruskal-Wallis One-Way Analysis of Variance. The difference between the first expectation of mothers and severity of CP was evaluated using the Spearman Correlation analysis.

Results

The mean age of the mothers was 31,96±6,1 (21-45) years old. Determined education level of mothers is depicted in Table 1. The mean age of the children with CP was 6,14±2,38 (2-13). Patients who classified according to CP types and GMFCS levels are depicted in Table 2.

When mothers were questioned about their expectations of the rehabilitation program, 52.8% reported that their first expectation was for him/her to gaining the ability to walk and to increase the quality of walking, 13.9% reported that their first expectation was to him/her to run, 9.3% reported that their first expectation was to him/her to stand up, 4.6% reported that their first expectation was to him/her to reduce stiffness in his/her legs, 1.9% reporte their first expectation was for to him/her to eat his/her own food, 0.9% reported their first expectation was to him/her to have the ability to communicate. The distribution of first 5 expectations of mothers'of children with CP is depicted in Table 3.

Table 1. Education levels of mothers.

Education levels	n	Percentage
Illiterate	11	10,2%
Primary school	57	52,8%
Secondary school	18	16,7%
High school	16	14,8%
University	6	5,6%

Table 2. CP types and GMFCS levels.

CP Types	n	Percentage
Diplegic	48	44,4%
Hemiplegic	4	3,7%
Tetraplegic	10	9,3%
Ataxic	12	11,1%
Dyskinetic	6	5,6%
Mixed type	28	25,9%
Severity		
Mild (GMFCS 1-2)	26	24,1%
Modorate (GMFCS 3)	36	33,3%
Severe (GMFCS 4-5)	46	42,6

The first expectation of 69.2% (18) of mothers of children with mild cases, determined by GMFCS, is an increase in the quality of childrens' walking ability. The first expectation of 50% (18) of mothers of children with moderate cases is an increase in the quality of children walking ability or gaining the ability to walk. The first expectation of 45,7% (21) of mothers of children with severe cases is an increase in the quality of children walking ability or gaining the ability to walk.

The difference between the first expectation of mothers and severity of CP was evaluated using the Spearman Correlation analysis. A poor correlation was determined between severity of CP and mother's first expectation ($r=0.34$, $p<0.001$). Based on this result mothers' expect of mild and moderate cases is realistic, but mothers' expect of severe cases is unrealistic.

Also when mothers were classified according to their education level, it was determined that; 6 (54,5%) of illiterate mother's, 25 (43,9%) of primary school graduated mother's, 12 (66,7%) of secondary school graduated mother's and 3 (50%) of university graduated mother's first expectations were walking or increased quality of walking of their children. It was seen that the first and foremost expectation among mothers in all education levels was walking or an increase in quality of the walking.

Table 3. **The distribution of first 5 expectations of mothers of children.**

	1.expectation (%)	2.expectation (%)	3.expectation (%)	4.expectation (%)	5.expectation (%)
I want him/her to run	13.9	13	7.4	14.8	21.3
I want him/her to walk and to increase the quality of walking	53.7	25.9	6.5	2.8	4.6
I want him/her to stand up	8.3	17.6	14.8	4.6	12
I want him/her crawl	2.8	4.6		5.6	6.5
I want him/her to keep his/her head		2.8			0.9
I want him/her to speak	0.9	7.4	11.1	9.3	2.8
I want him/her to eat his/her own food	1.9	9.3	34.3	23.1	8.3
I want to reduce stiffness in his/her legs	4.6	8.3	18.5	20.4	16.7
I want him/her to keep the pen		1.9	2.8	11.1	7.4

Only 5 mothers (4,6%) out of 108 children with spasticity stated that their first expectation was a decrease in spasticity, one mother (1,01 %) of 99 children, who had a communication problem, stated that her first expectation was to communicate with her child.

The mean of the hospitalization time of patients with CP was 87,30±83,26 (10-460) days. The total hospitalization time is classified in to 3 groups. They are named as; Group 1: patients who participated in the rehabilitation program for 0-3 months (Figure 1), Group 2: patients who participated in the rehabilitation program for 3-6 months (Figure 2), Group 3: in-patients who participated in the rehabilitation program for more than 6 months. In these 3 groups it was determined that the first expectation was to walk (Figure3). There was no significant statistical difference of the first demands between these 3 groups (p=0.297).

Discussion

We have demonstrated that the first expectation of mothers of children with CP for their child to gain walking ability or increase the quality of walking ability and also an increase in the severity of CP does not effect the mothers' expectations.

The aim in CP rehabilitation is to reduce the CP complications and to gain optimum function that the child can achieve with his/her current neuromotor capacity, not the treatment of brain damage (9). Cerebral palsy rehabilitation contains physiotherapy, occupational therapy, speech therapy, orthosis therapy, auxiliary devices, adaptive technology, sports and recreation (9,10,11). Parents should be well informed about predicted, possible gains of the child's ability. Health specialists and families should work together to decide

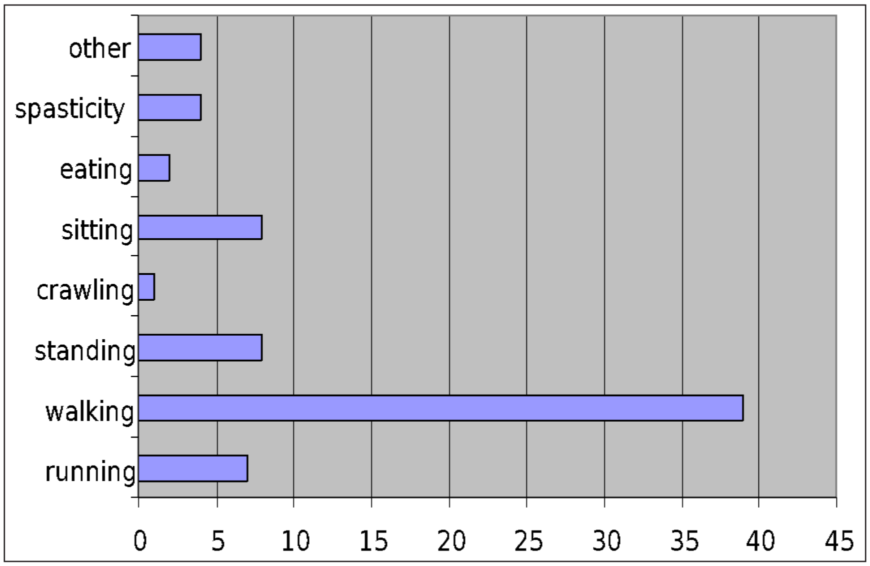

Figure 1. **Group 1 (0-3 months hospitalization time of patients with CP).**

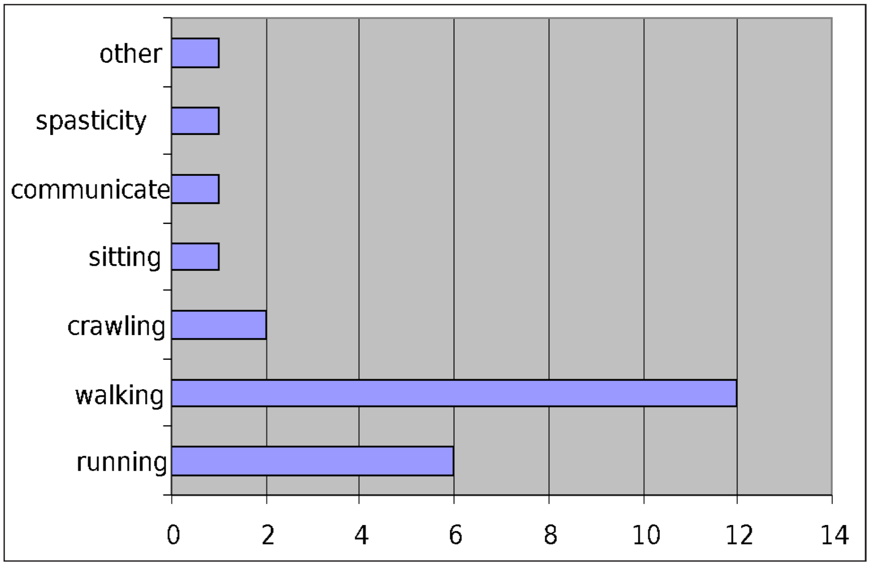

Figure 2. Group 2 (3-6 months hospitalization time of patients with CP).

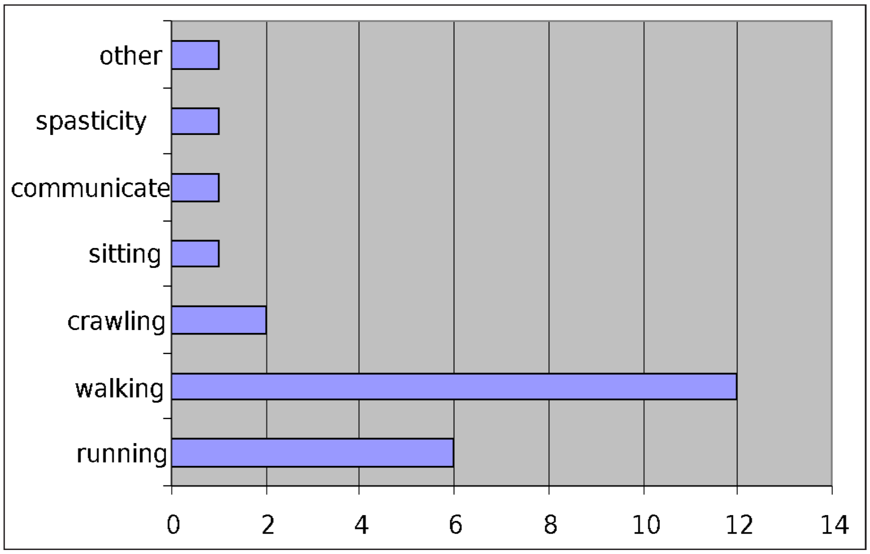

Figure 3. Group 3 (more than 6 months hospitalization time of patients with CP).

the objectives of a rehabilitation program. A patient specific treatment plan should be established according to patient specific needs. Generally, at the beginning of the rehabilitation program the first question which comes from the family is whether she/he will walk. This question can be difficult to answer by health professionals (12). Prior to answering this question, the severity level of CP should be determined and families should be informed about current status of the child. Information should be emphasized on therapy goals that focus on a child's success in completing functional activities that are meaningful to the child and the family (13,14,15,16).

In our study, 52.8 % of mothers expressed that the first outcome they wished to see was an improvement in the quality of walking or just to be able to walking of their child. When mothers were classified according to their education levels, it was determined that mothers' first expectations were walking or an increase in the quality of walking in all groups. Linstrand et al. had emphasized that the expectations of the family can vary according to their demographical and sociocultural properties (17).

In a study in which the mothers of a children with CP were asked to explain their expectations from the rehabilitation programs and they reported that they expected much more than their children can do, they cannot get enough information and cannot obtain satisfactory results from rehabilitation programs. However, it has been demonstrated that mothers have much more expectations from what their children can reach according to their current situations. In this work, carried out by Brodin et al., it was shown that the first expectation of mothers is for their child to speak (17,18,19). We have also determined in our study that the expectation of the mothers' did not change with regard to education level, the severity of CP and length of hospital stay for rehabilitation. In all groups it was noted that the first expectation was always walking of the child. When we classified the patients according to their attendance time to the rehabilitation program, it was noted that the first expectations were walking or increasing the quality of walking in all groups.

There is no such study in the literature investigating the relationship between the severity of CP and parents' expectation from rehabilitation programs. This study is unique with regard to this information. However we found out that there is a mild correlation (r=0.34, p<0.001) between the severity of CP and parents' first expectation from the rehabilitation program. This result indicates that informing parents about the severity of CP and in accordance with possible outcomes of rehabilitation program is crucial for the effectiveness of the rehabilitation program.

Contemporary literature discussing rehabilitation services for children with cerebral palsy highlights two important concepts. First, there is an emphasis on family-centred service that encourages collaborative decision-making among the health specialists, child and family, and conveys respect for the uniqueness of each family's life situation (19,20). Second, there is an emphasis on therapy goals that focus on a child's success in completing functional activities that are meaningful to the child and the family (13,14,15,16).

Active involvement of parents throughout the process of setting and implementing goals seemed to increase their feeling of competency and partnership with professionals. Concrete goals based on families' preferences and concerns, participatory observation, and discussions with professionals, came out as valuable means for practice of functional tasks (21). Goal Attainment Scaling (GAS) was used in this study, as a method for individual goal-setting. When GAS was introduced by Steenbeek et al in a training programme for an interdisciplinary paediatric rehabilitation team 70% of the therapists and 60% of the parents reported that GAS was a suitable tool to improve the quality of rehabilitation intervention (14).

This study was planned as a cross-sectional study, the aim was determined the expectations of mothers from rehabilitation program. Furthermore new researches are required to reveal relation with mothers' expectation and obtained goals of rehabilitatıon program.

Conclusion

Our findings showed that the first and foremost expectation from rehabilitation programme for mothers' with a child with CP was always to see an improvement in the quality of walking or just being able to walk, and that the severity of CP did not make any change in the expectations of mothers. Therefore, when a final diagnose is established, the general condition of the child, CP and potential problems should be explained in detail to the parents. Health specialist must work as a team and give detailed information about the targets to the family. The most important factor to achieve the aim is the neurological capacity of the child.

The success in achieving expected goals is highly dependent on several factors such as ensuring active participation of the family and child to the rehabilitation programme, enforcement of physiotherapy programs applied at clinics to the daily activities carried out at home, and also apply them at home (22,23).

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