Fizyoterapi Rehabilitasyon. 2007;18(2):51-58

An investigation of parents' problems according to motor functional level of children with cerebral palsy

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[Kerem Gunel M, Mutlu A, Livanelioğlu A. An investigation of parents' problems according to motor functional level of children with cerebral palsy. Fizyoter Rehabil. 2007;18(2):51-58]

Research Report

Purpose: This study was planned to determine the problems of families of children with Cerebral Palsy (CP) and to investigate whether they had differed according to motor functional level. Material and methods: The study included 348 male and 212 female, totally 560 children with CP and their families. Group I included children in Level I, II, III of Gross Motor Function Classification System (GMFCS) and their families while Group II included Level IV and V of GMFCS and their families. Aetiology of CP, consanguinity between mother and father, age of diagnosis, clinical type, and extremity distribution of children were recorded from hospital files. Age of the mothers and the fathers, work status, educational status, number of children in the family, monthly income, living location, lack or existing social insurance were asked. The families were requested to fill a questionnaire about care of children, source of CP information, problems that the disabled children bring to family, problems while meeting the needs of children and emotional problems. **Results:** Families of Group II had more percentage of problems whom disabled children bring to family, had major difficulties in meeting the needs of disabled children, and emotional problems ($p<0.05$). **Conclusion:** It is a necessity to define the problems of families in order to maintain rehabilitation goals. We believe that investigation of children with CP and their families, determination of their needs, problems, and difficulties will guide rehabilitation and education of children with CP as well as social support for families.

Key words: Cerebral palsy, Rehabilitation, Family, Parents, Social problems.

Serebral paralizili çocukların motor fonksiyon seviyelerine göre ailelerinin problemlerinin araştırılması

Amaç: Bu çalışma, serebral paralizili (SP) çocuğa sahip ailelerin problemlerini belirlemek ve bu problemlerin çocukların motor fonksiyonel seviyelerine göre farklılık gösterip göstermediğini belirlemek amacı ile planlandı. **Gereç ve yöntem:** Çalışmaya 348 erkek, 212 kız, toplam 560 SP'li çocuk ve aileleri dahil edildi. Gross Motor Fonksiyon Sınıflandırma Sistemi'ne (GMFCS) göre Seviye I, II ve III'teki çocuklar ve aileleri Grup I'i oluştururken, Seviye IV ve V'teki çocuklar ve aileleri Grup II'yi oluşturdu. SP'nin nedeni, anne-baba arasında akrabalığın varlığı, tanı konulan yaşı, klinik tip ve ekstremite dağılımı hastane dosyalarından kaydedildi. Anne ve babanın yaşları, iş durumları, eğitim durumları, ailedeki çocuk sayısı, aylık gelir, yaşadıkları yer ve sosyal güvenceleri sorgulandı. Ailelerden çocukların bakımı, SP ile ilgili edindikleri bilginin kaynağı, özürlü çocuğun aileye getirdiği problemler, özürlü çocuğun ihtiyaçlarını karşılamada yaşanılan problemler ve emosyonel durumları ile ilgili soruları içeren anketi doldurmaları istendi. **Sonuçlar:** Özürlü çocuğun aileye getirdiği problemler, özürlü çocuğun ihtiyaçlarını karşılama ve emosyonel problemlerin Grup II'deki ailelerde daha sık görüldüğü saptandı ($p<0.05$). **Tartışma:** Rehabilitasyon hedeflerinin sağlanması için SP'li çocukların ve ailelerinin problemlerinin kesin olarak ortaya konması gereklidir. SP'li çocuklar ve ailelerinin zorluklarının araştırılarak belirlenmesi, bu çocukların rehabilitasyonlarına yol göstermekle beraber sosyal destek almalarına da yardım edecektir.

Anahtar Kelimeler: Serebral paralizi, Rehabilitasyon, Aile, Ebeveyn, Sosyal problemler.

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The cerebral palsy (CP) incidence in the Third World is much higher and potentially preventable causes, especially peri-natal etiologies, are much more common in developing countries.[1] Albright informed that 1.5-2.5 of 1000 live birth in United States were CP. American CP Association declared CP in 1.2-1.5 of 1500 children.[2] The prevalence of CP was determined as 4.4 per 1.000 live births and included postnatal acquired CP in Turkey.[3] These rates are higher in Turkey as the important factors such as the insufficiency of periodic follow up and care in prenatal period, unfavorable conditions during delivery, disease high fever and malnutrition occurring after delivery, and parental consanguineous marriage.[4]

Families of children with CP may have social, economical, and psychological problems due to age of the children, severity of CP, age of mother and father, psychological structure, lack of social insurance, environmental factors, and many others. Definition of problems in families may provide solutions in rehabilitation process because families have significant role in rehabilitation approaches, and active role of families may enhance success of the rehabilitation.[5,6] The purpose of the study was to determine the problems of families of children with CP and to investigate whether they have differed according to motor functional level.

Materials and method

This study included 348 male and 212 female, totally 560, children with CP and their families referred to Hacettepe University, School of Physical Therapy and Rehabilitation for assessment, physiotherapy, and home exercise program. The mean age of children was 5.68±3.45 years (3-15 years) (Table 1).

Families were informed about the study including assessments and questionnaires. Written consent was taken from the families. Estimated etiology of CP, consanguinity between mother and father, diagnosis age, clinical type, and extremity distribution of children were recorded from hospital files. Functional motor levels were determined by the authors using Gross Motor Function Classification System (GMFCS). GMFCS classifies the motor involvement of children with cerebral palsy on the basis of their functional abilities, their need for assistive technology, and wheeled mobility. GMFCS has five levels or groups for describing differences in severity of motor abilities.[7]

Table 1. The characteristics of children with cerebral palsy (CP) (N=560).

	X±SD
Age (years)	5.68±3.45
	n (%)
Gender	
Male	348 (62.1)
Female	212 (37.9)
Presumed timing of CP	
Prenatal	172 (30.7)
Perinatal	333 (59.4)
Postnatal	55 (9.9)
Parental consanguinity	
1st degree	23 (4.1)
2st degree	19 (3.3)
Diagnosis age	
0-3 years	502 (89.7)
3-6 years	58 (11.3)
Clinical subtypes	
Spastic	429 (76.7)
Dysknetic	108 (19.3)
Ataxic	15 (2.6)
Mix	8 (1.4)
Extremity distributions	
Diparetic	321 (57.3)
Quadriparetic	169 (30.1)
Hemiparetic	70 (12.6)
GMFCS	
Level I	94 (16.8)
Level II	57 (10.1)
Level III	226 (40.3)
Level IV	107 (19.1)
Level V	76 (13.6)
Treatment status	
Regular physiotherapy program	101 (18)
Home program	459 (82)

GMFCS: Gross Motor Function Classification System.

Age of mothers and fathers, work status, educational status, number of children in the family, monthly income, living location, and lack or existing social insurance of the families were inquired. The families were requested to fill a questionnaire. The questionnaire was developed by authors considering the problems of families having children with CP. It included questions about the care of the children, source of CP information, and problems that the disabled children bring to family, problems while meeting the needs of children, and emotional problems (Appendix).

It was also addressed whether the problems of families were changed according to functional motor level of their children. In this respect, we classified the patients in two groups. Group I, included the children in Level I, II, III and their families while Group II consisted of the children in Level IV and V of GMFCS and their families. The answers to the questionnaire of Group I and II were compared (problems that disabled children bring to family, the major difficulties in meeting the needs of disabled children, and emotional problems of families).

Statistical analysis:

Analysis of data was performed using the SPSS Statistical Package (Version 11.0). Results of questionnaire were defined as the percentages. Relation of groups was assessed by cross tables using Chi-square test. Statistical significance was accepted at the $p<0.05$ level.

Results

General characteristics of children are shown in Table 1. Majority of subjects were spastic CP (76.7%), and diparetic according to extremity distribution (57.3%) and in Level III (40.3%). The 1st and 2nd degree consanguinity in the families was found as 7.4% of children (Table 1). Work status of mothers and fathers were examined, 74.16% of mothers were housewife while 94% of fathers were working. Mothers were commonly graduated from primary school and fathers from high school and university. Majority of the families lived in big cities (40.2%). Although 61.5% of the children had health insurance, and monthly incomes of families were low (Table 2).

Group I consisted of 377 children and Group II had 183 children according to GMFCS. We compared the results of Section 3, 4 and 5 of the questionnaire between the groups. Problems that disabled children bring to family were mentioned as economical problems, poor relation between environment, poor relation between relatives, poor relation between husband and wife, lack of time for other children, lack of time for mother self and father self. The major difficulties were in meeting the needs of disabled children, economical difficulties, communication difficulties, insufficiency of health services, being sorry about future of child and feeling sadness were higher in Group I when compared to that of the answers of Group I ($p<0.05$). Among other questions of the two groups, no significant difference was found although "Yes" answers in Group II were higher than Group I (Table 3).

Discussion

One of the most comprehensive studies about CP prevalence in Turkey was performed by Serdaroglu et al, and was found 4.4 per 1000; this rate is comparably higher than that reported for other developed and developing countries.[3] Therefore, it is assumed that one million people with CP were living in Turkey.

As American Academy Cerebral Palsy Developmental Medicine (AACPDM) and European Academy of Childhood Disability (EACD) aim to investigate disabled population ratio in developing countries, we thought that this study would bring a new perspective from Turkey, about the information related to also search the needs of disabled children and their families, and difficulties in their social life.

As the most important member of team, families of children with CP, have major role in the rehabilitation process of their children. The problems within the family may effect rehabilitation of children negatively. Nevertheless, we may better understand the significance of defining these problems.[8,9]

Table 2. Characteristics of families having children with cerebral palsy (CP) (N=560).

	Mother Mean±SD	Father Mean±SD
Age (at birth of children) (years)	26.8±7.3	30.5±8.1
Age (current) (years)	32.5±5.4	36.7±7.8
	n (%)	n (%)
Parent filled the questionnaire	374 (66.8)	186 (33.2)
Working		
Yes	142 (25.3)	526 (94)
No	418 (74.6)	34 (6)
Education Status		
Primary	290 (51.8)	93 (16.6)
Secondary	70 (12.5)	94 (16.7)
High School	105 (18.7)	186 (33.3)
University	95 (17)	187 (33.4)
Number of children	2.6 (range: 1-6)	
	n (%)	
Living locations of families		
Village	54 (9.6)	
Town	112 (20)	
City	169 (30.2)	
Big City	225 (40.2)	
Monthly income of family		
Low (<2000$)	250 44.6	
Moderate (2000-5000$)	248 (44.3)	
High (>5000$)	62 (11.1)	
Social insurance support (for family)		
Yes	344 (61.5)	
No	216 (38.5)	

A disabled child may be a huge disappointment and an intensive source of anxiety for the families.[10] Anxiety levels of families are affected from psychological, social, economical and cultural structures as well as severity of the disability of the children.[11] Clinical type, extremity distribution, functional status, intelligence level, sensory problems, and motor development level may be determinative in the severity of CP. In this study, we found that the families of children with severe CP had more family problems.

In our country, many problems related to disabled children raise anxiety and stress in families. Those are mainly defined as care and economical difficulties, access to rehabilitation centers, fear for future, retardation from peers, and care of their children after them.[12] Families experiencing anxiety, stress, and economical problems had reduced quality of life in the family members. At the same time, it is also known that all of these problems restrict to achieve rehabilitation goals. Determination of social and psychological problems in families and finding solutions has great importance in families of children with CP.[13]

Table 3. Problems, needs, and difficulties of families having children with cerebral palsy (CP).

	n (%)
1. Care of disabled children	
Mother and father	275 (49.1)
Grand mother and grand father	212 (37.8)
Relatives	35 (6.2)
Siblings	7 (1.2)
Caregiver	31 (5.5)
2. Information about CP	
Doctor	136 (24.2)
Physiotherapist	114 (20.3)
Newspaper	14 (2.5)
Radio	0 (0)
Television	7 (1.2)
Internet	14 (2.5)

	Group I N: 377 n (%)	**Group II N: 183** n (%)	**Total N: 560** n (%)
3. Problems that disabled children bring to family			
Economical problems	80 (21.2)	74 (40.4)*	154 (27.5)
Poor relation between environment	8 (2.1)	24 (13.1)*	32 (5.7)
Poor relation between relatives	18 (4.7)	22 (12)*	40 (7.1)
Poor relation between husband & wife	19 (5.0)	37 (20.2)*	56 (10)
Lack of time for other children	12 (3.2)	30 (16.4)*	42 (7.5)
Lack of time for mother self & father self	21 (5.6)	40 (21.8)*	61 (10.8)
4. The major difficulties in meeting the needs of disabled children			
Economical difficulties	90 (23.9)	96 (52.4)*	186 (33.2)
Communication difficulties	60 (16)	76 (41.5)*	136 (24.2)
View of community to disabled child	25 (6.7)	30 (16.4)	55 (8.9)
The lack of play fields	20 (5.3)	32 (17.5)	52 (9.8)
Insufficiency of health services	100 (26.5)	101 (55.2)*	201 (35.8)
Insufficiency of social prosperity	25 (6.7)	26 (14.2)	51 (9.10)
5. Emotional problems of families			
Pity for his/herself	20 (5.3)	15 (8.2)	35 (6.3)
Accuse his/herself	40 (10.6)	35 (19.1)	75 (13.3)
Accuse husband/ wife	10 (2.7)	6 (3.2)	16 (2.9)
Accuse doctors	64 (16.9)	40 (21.8)	104 (18.5)
Fate	33 (8.7)	13 (7.1)	43 (7.6)
Love child, happy for living	178 (47.2)	100 (54.6)	278 (49.6)
Worry about future of child	67 (17.7)	75 (40.1)*	142 (25.3)
Feel punishment of God	10 (2.7)	13 (7.1)	23 (4.1)
Feeling sadness	43 (11.4)	40 (21.8)*	78 (13.9)

* $p<0.05$ Chi-square test. Group I: Level I, II, and III according to GMFCS. Group II: Level VI and V according to GMFCS.

Rehabilitation of CP consists of a multidisciplinary team, which is composed of several experts, for example, physiotherapist, occupational therapist, speech therapist, social worker, and psychologist.[14] Rehabilitation of disorders of speech and auditory impairments were performed carried in a few centers in Turkey, and there were not enough related health professionals. Families in rehabilitation had major roles and form the most important participant of the team.[15]

Multidisciplinary approach of CP indicates that rehabilitation is a hard, long, and an expensive period for this group of disability. The most important component of rehabilitation, physiotherapy was applied to the patients that have social assurance for workers and employees in pediatric rehabilitation units of university and state hospitals. In addition there were many special rehabilitation centres, and the most of the centers are located in big cities. In our study although 29.64% of the families were living in town and villages, they preferred Ankara for the rehabilitation of their child. Ankara is the capital city of Turkey and it is in the center of the country. The most patients though come from close periphery of Ankara; an equal amount of patients were admitted from various parts of Turkey. Although the number of pediatric rehabilitation services are rapidly increasing, they are still insufficient in many regions of Turkey.

In Turkey, due to insufficient number of rehabilitation centers in small cities, high incidence of CP, lack of social assurance, physiotherapy was commonly performed as home exercise program. As direct therapy services become less available due to funding cuts, the home program may become a more common mode of service delivery. Families joining physiotherapy increases success of the rehabilitation, effects psychosocial development of the child positively, and enhances acquisition of motor development and functionality.[16]

Success of rehabilitation continuing at home is related to the education and social- cultural levels of the family. In this study, 66.6% of the fathers and 83% of the mothers did not attend to a university, 74.6% of mothers and 6% of fathers were not currently working.

Home exercise program is one of the approaches of physical therapy in children with CP. Family compliance is one of the most important factors in this process. In this study, majority of subjects with 84% ratios, did not attend to a rehabilitation center regularly and were cared at home by the families. The families who had higher educational status had more compliance to home program compared with families who had lower education status. In addition, the families wanted and needed more information regarding to their children difficulties. This had been parallel with streams of work carried out in both the United Kingdom and Australia recently, regarding parental need for information, and the best way of receiving this information. Interestingly, the authors asserted that they did not think that children and families got what they need in parallel with the United Kingdom.[17] The ratio of rehabilitation taken by home exercise program (82%) was also supported this situation in Turkey.

In our study 275 of the mothers (49.1%) were responsible for the children and 212 of (37.8%) whole families (including grandmother and grandfather) were responsible for the child. An interesting result was grandmother and grandfather together cared the disabled child in our country. We thought that this was a special cultural characteristic of our country. In our country, many parents live with their mother and fathers home particularly in the rural areas of country. In care of mother and father, mother had the major responsibility and effort although we could not reflect this issue in our results. When we look relations of the parents having disabled children, relations between parents as well as other children were affected negatively. Because care of disabled children took more time, requires more financial needs and physiological support, and siblings might have problems when the parents were more interested in the disabled children.

Families had not enough information about CP. They had information from pediatric neurologists, pediatricians, and physiotherapists. Many families accused of doctors, insufficiency of health conditions and they had stated that they were not directed to right professionals on time. McKay and Hensey investigated causes of dissatisfaction of parents of 83 children with CP, and 58% reported lack of explanation from the health professions.[18] Most parents had little information of CP. Parents are the central and key figures in the life long management of their children disability, and we thought that they should be well informed. Although with many financial and communication difficulties, 49.6% of the parents loved their child and tried to do the best for their child.

In Hirose and Uedda study, 28 mothers and fathers who had sons or daughters with CP were interviewed with a semi-structured method. The reactions to diagnosis were emotional, and mothers took care of children while the fathers provided income. Therefore, most mothers seemed to be more emotional in their reactions.[19]

We thought that the reasons for the worry about their child were their future life, insufficiency of support in social and occupational area, isolation due to not having private education, occupation, and not having economical independence. All these reasons could bring social isolation in the community. The investigation of children with CP and their families and determination of their difficulties would guide rehabilitation of children with CP and should be taken into consideration of social support for families.

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Appendix. Family of Cerebral Palsied Children Questionnaire.

Family of Cerebral Palsied Children Questionnaire

Date: ....

(Please check the appropriate choice)

Who is filling the questionnaire?: Mother Father

I. Care of disabled children

Mother and father
Grand mother and grand father
Relatives
Siblings
Caregiver

II. Do you have enough information about cerebral palsy? Yes No

(If yes, please answer the question below)

Whom did you take the information?

Physiotherapist
Newspaper
Radio
Television
Internet

III. What are the problems that disabled children bring to your family? *(You may check more than one)*

Economical problems
Poor relation between environment
Poor relation between relatives
Poor relation between husband and wife
Lack of time for other children
Lack of time for mother self &father self

IV. The major difficulties in meeting the needs of your disabled children. *(You may check more than one)*

Economical difficulties
Communication difficulties
View of community to disabled child
The lack of play fields
Insufficiency of health services
Insufficiency of social prosperity

V. Emotional problems of families. *(You may check more than one)*

I pity for my children
I accuse of myself
I accuse of my husband or wife
I accuse of doctors
Fate
I love my child, happy for living
I worry about future of child
I feel punishment of God