Original Article
DOI: 10.5152/tftrd.2015.70745
Turk J Phys Med Rehab 2015;61:320-5

Assessment of Family Environment and Needs of Families Who Have Children with Cerebral Palsy

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Abstract

Objective: The aim of the study is to identify family needs and to assess the family environment of children with cerebral palsy (CP).
Material and Methods: Participants were the primary caregivers of 103 children between the age of 4 and 12 years with a diagnosis of CP. The parents of the children completed the Family Environment Scale (FES) and the modified version of Family Needs Survey (FNS). The Gross Motor Function Classification System (GMFCS) and Manual Ability Classification System (MACS) levels of children were determined. The medical history of the participants accompanying disorders and characteristics of families are questioned.
Results: According to the results of FNS, the most cited requirement was need for information (84.3%) and the least cited requirements were needs for babysitting while having a meeting (62.1%) and payment for childminders (74.8%). Neither the FES nor the FNS results was correlated to the GMFCS or MACS levels or accompanying disorders.
Conclusion: Regardless of education level, parents reported need for information about their children's conditions and future services. If families are informed about their children's health condition and are aware of present or future resources, better outcomes will be seen. Understanding the needs of families who have children with CP and assessment of family characteristics and environment are important for family-centered services.
Keywords: Cerebral palsy, family needs, family environment

Introduction

Cerebral palsy (CP) is a nonprogressive neuromuscular disorder that affects the developing brain (1). It is the most common cause of disability during childhood, and its prevalence in school-age children is 2–2.5/1,000 (2, 3). Neuromuscular deficits observed in children with CP are abnormal muscle tone causing an imbalance between agonist and antagonist muscles, loss of voluntary motor control, sensory and coordination disturbances, and muscle weakness (4). In addition to motor deficits, mental retardation, epilepsy, sensory disorders (visual or auditory loss), urinary system disorders, learning disabilities, communication and behavioral disorders, and emotional problems can be seen (5, 6).

Knowledge about the etiology, CP type, and other accompanying medical problems in affected patients enables the determination of a rational and comprehensive treatment program that includes services such as prognosis and special education, psychological support, and family counseling.

Families facing these problems occurring at birth or shortly after the birth of a child with CP a serious compliance problem.

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Received: April 2014 Accepted: November 2014

Cite this article as:
Karadağ Saygı E, Giray E, Peynirci Cerşit H, Ulutatar F, Aydın R. Assessment of Family Environment and Needs of Families Who Have Children with Cerebral Palsy.
Turk J Phys Med Rehab 2015;61:320-5.

The physical and emotional health of parents of children with CP is worse than that of parents of children growing healthily (7). They need to obtain information and receive psychological and social support.

The fact that family plays an important role in the lives of children with disabilities is a view that has increasingly gained importance. Family education level, sociocultural status, and psychological approach of parents play an important role in the development of children with CP (8).

Families of children with CP have troubles in providing care and using public services for their children's care. In a family-centered approach, the needs and priorities of these families should also be known (9).

The profile of the family needs of children with CP and information on the factors affecting these requirements are very limited (10). These children show marked differences in terms of the development of gross motor function and its final status, and the needs of families markedly vary on the basis of these functions. Lack of awareness on resources and their distribution issues cause serious problems in patients with CP. Determination of the overall needs of families and the determination of its relation according to the child's age, family income, gross motor function, and dexterity classification assist families and healthcare professionals in determining goals and ensuring the coordination of services (9, 10).

The aims of this study were to (1) identify family needs; (2) assess the family environment of children with cerebral palsy and (3) determine their relation with factors such as CP type, gross motor function and family income.

Material and Methods

Working group

One-hundred three patients diagnosed with CP at 4–12 years of age admitted to the Physical Medicine and Rehabilitation, Pediatric Rehabilitation Outpatient Clinic of Marmara University between November 2013 and April 2014 were evaluated; primary caregivers were also included. A primary caregiver was defined as a person who provided for the daily needs of the child at home for at least 1 year. After obtaining written informed consent, the Family Environment Scale (FES) and Family Needs Survey (FNS) were administered to each participant with a face-to-face interview. The medical history of each child and family characteristics (the birth weight, the mode of delivery, the age of the parents and their child, the educational status of the parents, their occupation, the housing status, the monthly family income, the number of individuals living in household people living at home, and the CP type of the child and accompanying findings) were questioned in detail. In addition, each patient's motor activity levels were evaluated using the Gross Motor Function Classification System (GMFCS) and hand functions with Manual Ability Classification System (MACS). The study was conducted after the approval from the Ethics Committee of Marmara Univercity School of Medicine (approval number: 092013.0351) and oral and written informed consents were obtained from the parents of children.

Assessment Scales

Gross Motor Function Classification System

GMFCS developed for children with CP is a five-step classification system. Children with CP under the age of 12 years were divided into five levels according to gross motor functions such as self-initiated actions, sitting, and walking. As children's motor functions vary depending on age, functions were defined for children in the following age groups: <2 years, 2–4 years, 4–6 years, and 6–12 years. Level differences were determined on the basis of functional limitations, hand-held mobility aids (walker, crutches, or canes), or the need for wheeled mobility vehicles and the quality of movement. The aim is to provide information about the child's gross motor function, and it cannot be used to evaluate the child's personal function and his/her potential of development (11).

Manual Ability Classification System

MACS identifies how children with CP use their hands while holding the objects in daily activities. It was defined by Eliasson et al. in 2006 and the validity and reliability studies of the Turkish version were conducted by Akpınar et al. (12) in 2010. MACS describes five levels. The determination of the levels is based on the child's ability to hold objects on his/her own and the need for help and adaptation in performing hand-related activities of daily living. Those objects are nearby the child, not far away from he or she as like he or she can not reach. The child is classified according to capability of handling objects in daily activities (eating, dressing, playing, drawing and writing etc.) which are compatible with the child's functional status. In addition, these objects are not beyond the reach of the child, and they are around him/her. MACS is available for children aged 4–18 years, but certain concepts suitable for the child's age should be included. Five levels ranging from 1 to 5 with a gradual limitation of correct functional hand use are determined.

Family Environment Scale

FES was developed by Fowler in 1982, and the reliability and validity studies of its Turkish version were conducted by Usluer (13) in 1989. It is a pencil and paper test composed of a total of 26 items and is administered to family members. It consists of two subtests; one of these subsets has 16 items on interpersonal relationships and the other has 10 control items. FES evaluates the extent of the necessity of activity plan and family rules for the sustainability of family life.

Family Needs Survey

FNS created by Bailey and Simeonsson in 1988 assesses the needs of the families of children with developmental disability. The reliability and validity studies of its Turkish version were conducted by Sucuoğlu (14) in 1995. The tool is generally divided into two parts:

Part 1: In this part, there are 35 items gathered in six groups to enable parents to be aware of their needs.

These 35 items are examined in six separate categories according to the type of needs:

1. Information requirement (seven items)
2. Support requirement (Article 7)

3. Explaining to others (five items)
4. Social services (five items)
5. Financial requirements (Article 5)
6. Family function (Article five)

Parents are requested to give answers to each question as 1. No, 2. Not sure, and 3. Yes.

Part 2: This has the open-ended question "Please list the five most basic needs of your family". It is intended to determine more private needs, which are not covered in the first section, for the family.

Statistical Analysis

Data analysis was performed using the SPSS 16.0 (Statistical Package for the Social Sciences Inc., Chicago, IL, USA) for Windows. Chi-square and Mann–Whitney U-tests were used for comparisons. Relations were assessed by Spearman correlation analysis. P<0.05 was considered as statistically significant.

Results

The mean age of the patients was 6.5±2.7 (3–13) years; 57 (55.3%) of them were females and 46 (44.7%) were males. The distribution by the CP type was 42.7% hemiplegic, 26.2% diplegic, and 25.2% quadriplegic. The distribution of patients according to GMFCS, MACS, and disease-related findings has been summarized in Table 1.

Because all children came to polyclinic controls with their mothers, FES and FNS questionnaires were completed by their mothers. The family education level, care, and the economic status were also questioned (Table 2). It was determined that only 7.8% of mothers worked and that 91.8% of caregivers were mothers. The average age of mothers was 33.8 (22–51) years, and that of fathers was 37.4 (26–55) years. It was found that subsistence was provided by the father at a rate of 98.1%, and the monthly income of more than half the families was in the range of 500–1,000 Turkish Liras. A total of 94.2% of the parents were married, and 5.8% of them were divorced. It was observed that the monthly income was associated with the mother's and father's educational levels (r=0.358, p<0.01 and r=0.345, p<0.01; respectively). It was also found that as the mother's education level increased, the number of siblings decreased (r=0.227, p=0.013).

According to the results of FNS, information requirements were observed in families the most (Table 3). Under this heading, information needs about the condition of the child (93%), information needs about the institutions that the child can benefit in the future (92%) and today (90%) came into prominence.

Table 1. Gross motor function, manual dexterity, and additional findings

GMFCS	**n (%)**
Stage 1	27 (20.4%)
Stage 2	31 (30.4%)
Stage 3	15 (14.6%)
Stage 4	23 (22.3%)
Stage 5	13 (12.6%)
MACS	
Stage 1	34 (33%)
Stage 2	32 (31.1%)
Stage 3	19 (18.4%)
Stage 4	14 (13.6%)
Stage 5	4 (3.9%)
Additional disorders	
Mental retardation	42 (40.8%)
Vision problems	35 (34%)
Epilepsy	31 (30.1%)
Dental problems	31 (30.1%)
Salivation	29 (28.2%)
Swallowing difficulty	20 (19.4%)
Behavioral problems	19 (18.4%)
Breathing difficulty	15 (14.6%)
Speech impairment	15 (14.6%)

GMFCS: gross motor function classification system
MACS: manual ability classification system

Table 2. Characteristics of family members

Maternal education level	**n (%)**
Illiterate	5 (4.9%)
Primary school	66 (64.1%)
Secondary school–High School	25 (24.3%)
University	7 (6.8%)
Paternal education level	
Illiterate	1 (1%)
Primary school	46 (44.6%)
Secondary school–High School	42 (40.8%)
University	14 (13.6%)
Income status (TL)	
<500	7 (6.8%)
500–1000	55 (53.4%)
1000–3,000	39 (37.9%)
>3,000	2 (1.9%)
Number of siblings	
None	25 (24.3%)
1	42 (40.8%)
2	25 (24.3%)
≥3	11 (10.7%)
Housing	
Own house	45 (43.7%)
Rent	42 (40.8%)
With family elders	15 (15.5%)

Table 3. Tool for identifying the needs of families

	Yes	No	Not sure
Information requirements	84.3%	10.3%	5.4%
Support needs	56.8%	28.4%	14.8%
Explaining the child's situation to others	45.4%	45.6%	9%
Public services	45.4%	46%	8.6%
Financial requirements	44.5%	46.8%	8.7%
Overall family functioning	39.6%	48.5%	11.9%

Table 4. Mean score of family environment survey subcategory according to GMFCS

	Independent (GMFCS 1) Mean- SD (min–max)	Partially dependent (GMFCS 2 and 3) Mean-SD (min–max)	Fully dependent (GMFCS 4 and 5) Mean-SD (min–max)	p value
Interpersonal relationships	26.4±6.5 (5–34)	26.7±7 (5–42)	25.3±7.3 (6–40)	0.668
Control	15.8±3.2 (10–23)	16.4±3.2 (7–24)	16±4.2 (8–30)	0.481

GMFCS: gross motor function classification system; min: minimum value; max: maximum value; SD: standard deviation

Table 5. Comparison between expectations and the family environment survey

		FNS					
		Information requirement	Support requirement	Explaining the condition of child	Expectation for social service	Financial needs	Family function
FES	Interpersonal relations in family	r=0.081 p=0.461	r=0.067 p=0.504	r = 0.100 p=0.317	r=-0.020 p=0.844	r=-0.089 p=0.370	r=-0.178 p=0.072
	Control in family	r =-0.034 p=0.735	r=-0.052 p=0.599	r=0.065 p=0.511	r=0.032 p=0.751	r=-0.078 p=0.436	r = 0.126 p=0.204

FES: Family Environment Scale; FNS: Family Needs Survey; r: correlation

In particular, the need for information was not found to be associated with maternal or paternal education level (r=-0.117, p=0.239). In contrast, it was found that as the child grows up, the need for information about organizations that can be utilized in the future increased (r=-0.239, p=0.015). It is seen in the support requirement section that they need to read materials such as books and articles written about the families of children with CP (79.6%). Under the titles of explaining the condition of the child with less commonly experienced problems to others, services related to the society, financial needs, and overall family functioning, emphasis on the need for dentists was remarkable (71.8%). Under these headings, the least experienced problems were identified as the need for a daycare center to leave the child when they were required to participate in a meeting (62.1%) and the need for money for caregiver wages (74.8%).

Although the mean score of the interpersonal relationship subscale in FES was 26.2±7, the control subscale score was 16.1±3.5. While there was no statistically significant difference in comparison between intra-family relationships and control in fully dependent (GMFCS 4 and 5), partially dependent (GMFCS 2 and 3), and independent (GMFCS 1) patients, the compliance of both subscales was high ($r=0.473$, $p<0.01$; Table 4). With regard to the scoring of interpersonal relationships in the family, no correlation was found among the GMFCS stage of the child, score of manual activity, and presence of additional problems. Neither subscales of FES nor subscales of FNS were correlated to each other (Table 5).

Discussion

In this study, demographic data of the patients with CP, concomitant symptoms, levels of dexterity and motor activity, characteristics of families, family environment, and requirements were determined. In the research with an intensive hemiplegic group, the motor activity levels of most patients were found as GMFCS stage 2 and hand functions as stage 1. When the accompanying symptoms were examined, mental retardation, vision problems, epilepsy, and dental problems were detected, in the order of decreasing frequency. When the family education level, care, and the economic status were queried in family characteristics, the number of working mothers was found to be quite low; it was found out that the number of working mothers was quite low; the caregivers were mostly mothers and monthly incomes of most families were too low. It was observed that families needed to obtain information the most and that they needed money for care and the caregiver of the child the least. In the assessment of the needs of families and family environments, no correlation was found among the GMFCS stage, MACS stage, and the existence of concomitant problems.

It is known that the most common CP type is spastic and that the most common spastic CP type is diplegic (6, 15-18). In our study, the spastic type was the most encountered, which conforms to the literature. However, hemiplegic was detected to be the most common among spastic type (42.7%), and diplegic was the second most common type (26.2%). Hagberg et al. (16) conducted a CP prevalence study in Sweden and observed that the overall frequency remained the same but that the distribution varied in the CP types; similar to our study, the frequency of the hemiplegic type was 44% and that of the diplegic type was 29%.

In the comparison of GMFCS and hand function according to the CP types, the motor activity levels of patients with CP were most commonly found as stages 1 and 2 in GMFCS; the stage of the hand function was most frequently found to be stages 1 and 2 in MACS (18-20). In accordance with the literature, the majority of cases in this study were children with hemiplegic CP type, and the most frequent GMFCS and MACS stages were 2 and 1, respectively.

Additional problems that are most commonly observed in children with CP are mental retardation, visual impairment, epilepsy, and speech disorder (17, 18, 21). In our study, the most common additional problems were mental retardation, visual impairment, and epilepsy, in accordance with those in the literature. However, in addition to these, dental problems were observed with a close frequency. Tooth decays and gum problems are more frequent in patients with CP than in healthy children (22-25). Spasticity in the facial muscles; disorders in the control of the lips and tongue; decrease in salivary secretion; high consumption of fluids, sweet foods, and medicines; long elapsed time between ingestion and swallowing because of chewing and swallowing disorders; and malocclusions cause dental problems (22-25). No correlation was found between the CP type and dental plaque and tooth decay incidence (23). Although the majority of CP patients were of hemiplegic type in this study, dental problems stood out as a common problem in all patients with CP. Dental caries affects the life quality of both children with CP and their caregivers in a negative way (22, 24, 25). Considering the frequency and the problems dental caries causes, these children need regular oral and dental health screening.

Walker et al. (26) reported that 91% of parents whose children have chronic health problems need to obtain information about the situation, treatment, and long-term effects of the disease of their child. In a study conducted in the United States, it was found that the families of children with CP mostly needed information about planning the future of their children (53%) and about institutions that they can benefit from (51%) (27). Similarly, in another study, families expressed that they had information needs about planning the future of themselves and their children, regardless of their child's age (10). In this study, according to the results of FNS, it was found that families mostly needed information about their child's condition (93%) and institutions that they can benefit in the future (92%) and today (90%). More importantly, it was made clear that these requirements are not related to the educational level of the mothers and fathers. In the support needs subscale, families stated that they needed to read materials such as books and articles written about children with CP. However, 71% of mothers and 47% of fathers were found to be illiterate or primary school graduates. At this point, to ensure a family-oriented treatment of patients with CP, instead of giving information in an outpatient room in a short time or through books and articles with intensive medical information, it would be more appropriate to give information through seminars. This would clearly meet the information needs.

The results of FNS clearly showed that families need help to find dentists who will help their children. This need is because dental problems are much more common in children with CP than in healthy children, and their dental problems cannot usually be treated in primary care centers because of additional problems of children with CP. A greater number of institutions that will provide tertiary care service are required for the treatment of these children's dental diseases. Families should be informed about how they can reach the required centers.

In a study conducted on children having developmental disabilities at 3–16 years of age, the needs of families with children at a younger age were more than those of families with older children. However, in the study by Bailey (28) and Farmer (29), there was no correlation between the needs of the family and the child's age (30). In our study, it was determined that as the child grows up, the information need of the family about the institutions that can be utilized in the future increased. This can be explained by the emergence of different critical needs, such as speaking, communication, nutrition, dental problems, and information about reproductive health, as children with CP grow up (31).

Only 7.8% of the mothers of children with CP in this study were employed, and 91.8% of the caregivers were mothers. Among the family needs, the financial support for babysitting and a daycare center to leave their children when mothers had to attend a meeting were reported as the less needs. It is assumed that the rationale for this result was that the primary caregivers of children were mostly mothers and most of them were unemployed.

It was stated in the literature that although families with a high monthly income need financial and social support and less resources, the families of children with limited functional mobility (GMFCS grades 4 and 5) need them more (9,10). However, although the monthly income of 62% of the families in our study was under 1,000 Turkish Liras, no correlation was found between monthly income and the needs. Similarly, there was no correlation between motor activity levels of the children with CP and the family needs. The reason may be that 15% of the families live with family elders and 45% of them live receiving support from family elders in their homes. A positive correlation was detected among social function, emotional function, and psychosocial health of the children with CP and FES interpersonal relationships scores (32). Laforme et al. (33) examined the family ecologies of young children with CP according to the GMFCS stage and did not determine any relationship between FES scores and GMFCS stages. In this study, no correlation was found among the child's GMFCS stage, manual activity score, and the presence of additional problems with interpersonal relationships scoring. The reason for this is that the characteristic features of the families were very similar.

Conclusion

In family-oriented care, identifying the needs of families of the children with CP is essential. Determination of the family needs helps in the cooperation of health personnel with the family and the detection of therapeutic targets, and it is important for authorities to allocate financial resources for treatment and care (10). Family function was found to affect the results of the treatment of children with disabilities (7). Family education, sociocultural structure, and psychological approach of the parents play an important role in the development of these children. At this point, the evaluation of family environment and determination of parents' service expectations will positively affect the approach of the rehabilitation team and will facilitate the family-oriented establishment of the approach to patients with a diagnosis of CP.

Ethics Committee Approval: Ethics committee approval was received for this study from the ethics committee of Marmara University Faculty of Medicine.

Informed Consent: Written and verbal informed consent was obtained from the parents of the patients who participated in this study.

Peer-review: Externally peer-reviewed.

Author Contributions: Concept - R.A.; Design - R.A.; Supervision - E.K.S.; Resources - E.K.S.; Materials - E.K.S.; Data Collection and/or Processing - E.G., H.P.C, F.U.; Analysis and/or Interpretation - E.K.S.; Literature Search - E.G.; Writing Manuscript - E.K.S., E.G., H.P.C, F.U.; Critical Review - R.A, E.K.S

Conflict of Interest: No conflict of interest was declared by the authors.

Financial Disclosure: The authors declared that this study has received no financial support.

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