



RESEARCH ARTICLE

Investigation of the Effect of Functional Levels of Children with Cerebral Palsy on Parents' Quality of Life in Northern Cyprus

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Abstract

The aim this research, determine the level of influence of families with children with cerebral palsy in Northern Cyprus and to reveal the difference in being affected between parents. The study was carried out on 49 children with CP and 49 couples of parents. Pediatric Functional Independence Measure (WeeFIM) was used to evaluate the functional status of children, and the Impact of Family Scale (IFS) and the Quality of Life Scale (SF-36) were used to measure the influence of families. Those with WeeFIM total score between 18-90, the group requiring observation (CNO) (n = 34), and those between 91-126 were divided into independent group (IC) (n = 15). No relationship was found between IFS, SF-36 score of parents and functional level of their children. There was a positive correlation between mothers and fathers in IFS and SF-36 scores within groups (CNO IFS p: 0,021 r: 0,394; CNO SF-36 p: 0,001 r: 0,546; IC IFS p: 0,038 r: 0,602; IC SF-36 p: 0,001 r: 0,825). When the levels of influence and quality of life of the mothers and fathers within the groups were compared, it was observed that there was not a significant difference between the mothers and fathers in the group CNO and in the IC group (p>0.05). According to this study family influences of parents with children with cerebral palsy in Northern Cyprus are not affected by their functional levels. The fact that there was no difference between mothers and fathers in terms of quality of life and level of influence revealed the geographical cultural difference in favor of women.

Keywords

Family Influence, Functional Level, Cerebral Palsy

INTRODUCTION

The birth of a child with developmental disabilities is a great stress for the family. After parents learn that they have a disabled child, they may experience many psychological problems such as anxiety, shock, denial, sadness, anger, avoiding confrontation with the attitude of the social environment, and feelings of decreased self-confidence and respect (Akmeşe et al., 2007).

Many studies have shown that; these tensions experienced by families cause problems in relationships, isolation from the social

environment and deterioration of intra-family relationships (Olawale et al., 2013). Collaboration with a professional team is needed for the necessary medical interventions and rehabilitation process to combat the functional deficiencies of the child and the addictions arising from these disabilities in the long term. Parents of children with cerebral palsy (CP), who are the most important and inseparable part of this team, experience many physical, social, and emotional problems (Panteliadis, 2004; Raina et al., 2005).

Different results have been found in studies investigating the relationship between the

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functional level of the child with CP and the stress experienced by the family and the level of life quality. In Bosnia and Herzegovina, it has been stated that the quality of life of the mothers of children with CP is lower than the mothers of healthy children, and as the functional status of the child deteriorates, the general quality of life of the mothers is negatively affected (Glinac et al., 2017). In a study examining the psychological distress experienced by Jordanian parents, severe disability in the child with CP was related to higher mental distress in the parents. In the study, when the perceived stress and depression scores between mothers and fathers were compared, it was reported that the results were similar and the parents experienced moderate stress and depression (Al-Gamal and Long, 2013). Parkes et al. in the works carried out in 9 regions of Europe; It has been observed that the motor effects of children with CP do not cause stress on the family alone, but can cause stress when a secondary problem is added (Parkes et al., 2011).

Although psychosocial exposure and impaired quality of life have clinical significance for parents, there is no evidence of the condition of parents with children with CP in the northern part of Cyprus. This study was planned to reveal how the functional levels of children with cerebral palsy living in the northern part of Cyprus affect the family and change the quality of life of the family, as well as whether there is a difference between mother and father influence.

MATERIALS AND METHODS

Participants

In this study, 49 children with CP who were diagnosed with CP by a pediatric neurologist and who were living in Northern Cyprus and were trained in physiotherapy and rehabilitation, and their parents were included. Inclusion criteria in the study while it was determined as being diagnosed with CP and living in the north of Cyprus, non-voluntary families were not included in the study. Children with CP with a mean age of 8.45 ± 4.74 years and between 4-16 years of age participated in the study. Work permits and consents were obtained from the families of the children. For the study, ethics committee approval, dated 24.02.2017 and numbered YDU/2017/44-370, was obtained.

After the demographic information of the participants was obtained using the demographic information form and face-to-face interview method, the mothers and fathers were explained about the contents of the scales to be filled out separately.

Data Collection Tools

The Pediatric Functional Independence Scale (WeeFIM) was used to evaluate the functional status of children, the Impact of Family Scale (IFS) to evaluate the level of influence of families, and the Quality of Life Scale (SF-36) to evaluate the quality of life of the children.

Pediatric Functional Independence Measure (WeeFIM)

The pediatric physiotherapist with the functional independence scale WeeFIM evaluated the independence level of the children in daily life. WeeFIM is to measure the degree of independence performance of the child's daily living skills. It is a valid and reliable test for both disabled and healthy children to assess the functional independence of all children aged 6 months to 7 years and to monitor their development. This test can be applied to children with developmental retardation until the age of 21. It aims to question the child's self-care, transfer activities, movement activities, sphincter control, communication skills, and cognition skills under 18 headings.

In the scoring of WeeFIM sub-items, the functions of the child from 1 to 7 are scored: 7: fully independent, 6: modified independent, 5: 4: minimum assistance with observation, 3: light assistance, 2: maximum assistance and 1: full assistance. Scores from 1 to 4 indicate the child's level of assistance required to complete an activity. 5 points indicate the observation of the child to do the skill or the hint given by the adult. A score of 6 demonstrates the child can complete the activity independently however needs an assistive tool. The lowest total score that can be obtained from the test is 18 (fully dependent on all skills), the highest total score is 126 (fully independent in all skills), (Msall et al., 1994).

Children with cerebral palsy with a total score of 18-90 on the Pediatric Functional Independence Criterion taken in our study were divided into two groups as "requiring observation (CNO)" and those between 91-126 as "independent (IC)" (Çetin et al., 2017).

Impact of Family Scale (IFS)

Families' levels of affection were evaluated using the Impact of Family Scale (IFS). Developed for families or caregivers with a disabled child, this scale evaluates the burden of the child's illness on the family. The family impact scale consists of four subtitles, which measure the family's level of influence: financial support, general impact, deterioration in social relations and coping, and a total effect that includes all sub-headings. In the scale, families were asked to give appropriate answers such as 'totally agree 1, 'agree 2, 'disagree 3, and disagree 4. The scale has a Likert type assessment ranging from 1 to 4. A minimum of 24 and a maximum of 96 points can be obtained on the scale (Stein and Riessman, 1980).

Short Form-36 (SF-36)

The quality of life of mothers and fathers was evaluated with the Short Form-36 (SF-36). The SF-36 questionnaire is a valid and frequently used criterion for assessing the quality of life. It includes 36 questions on eight subscales of physical function, physical role restriction, emotional role restriction, body pain, mental health, vitality, social function, and general health. There are two subsections of the Physical

Component Scale (PCS) and the Mental Component Scale (MCS). The physical section summary scale; physical function, body pain, physical role, and general health subscales; the mental section summary scale consists of vitality, emotional role, social function, and mental health subscales (Ware and Sherbourne, 1992).

Statistical Analysis

IBM SPSS Statistics 22 program was used for the statistical analysis (IBM Corp., New York, USA). Pearson correlation test was used in correlation. The normal distribution of the data was evaluated with the Kolmogorov Smirnov test. The data were suitable for normal distribution. Independent samples t test was used to compare two independent groups. In statistical analysis, $p \leq 0.05$ was set as statistical significance.

RESULTS

Demographic and clinical information of children and parents are shown in the first table (Table 1). The study was carried out on 49 children (mean age: 8.45 ± 4.74 years) with CP, 24 mothers (age: 40.05 ± 7.79) and 25 fathers (mean age: 43.25 ± 6.85 years).

Table 1. Demographical and clinical information of children and parents

Variable	Group	Mean \pm SD
Height	Child	125,69 \pm 27,57
Weight	Child	26,40 \pm 13,32
Age	Child	8,45 \pm 4,74
	Mother	40,05 \pm 7,79
	Father	43,25 \pm 6,85
Gender	Male	25 (%51)
	Female	24 (%49)
Weefim Groups	CNO	34 (%69.4)
	IC	15 (%30.6)

CNO: children who need observation IC: Independent children SD: Standart Deviation

There was no difference between mothers and fathers within IFS and SF-36 scores that CNO (IFS: $p=0.52$; SF-36: $p=0,59$) and IC groups (IFS: $p=0.54$; SF-36: $p=0,06$) (Table 2). When the IFS and SF-36 scores were compared according to the functional level of the children within mothers (IFS: $p=0.31$; SF-36: $p=0,22$) and fathers (IFS:

$p=0.43$; SF-36: $p=0,52$), no difference was found (Table 3). No relationship was found between the level of influence of mothers and fathers with children with cerebral palsy and the functional level of their children (Table 4).

Table 2. Comparison of parents' IFS scores within and between groups

Variables	CNO (n=34)	IC (n=15)	p*
	Mean (Min-Max)	Mean (Min-Max)	
Total IFS score mothers	45,6 (21 - 90)	49,6 (30 - 76)	0,310
Total IFS score fathers	42,8 (24 - 64)	46,5 (33 - 72)	0,430
p**	0,525	0,547	

CNO: children who need observation IC: Independent children IFS: Impact of Family Scale Min: Minimum, Max: Maximum p*:comparison IFS scores of CNO and IC groups within mothers and fathers, p**: comparison of mothers and fathers IFS scores of CNO and IC group

Table 3. Comparison of parents' SF-36 scores within and between groups

Variables	CNO (n=34)	IC (n=15)	p*
	Mean (Min-Max)	Mean (Min-Max)	
Total SF-36 score mothers	67 (37,2 - 93,9)	71,8 (44,2 - 92,4)	0,225
Total SF-36 score fathers	73,2 (41,4 - 95,1)	75,1 (41,7 - 96,7)	0,523
p**	0,590	0,061	

CNO: children who need observation, IC: Independent children, Min: Minimum, Max: Maximum, p*: comparison SF-36 scores of CNO and IC groups within mothers and fathers, p**: comparison of mothers and fathers SF-36 scores of CNO and IC group

Table 4. Correlation between groups within mothers and fathers in IFS and SF-36 scores

		CNO (n=34)	IC (n=15)
Total IFS score mothers	r	-0,046	0,207
	p	0,795	0,519
Total IFS score fathers	r	0,152	0,294
	p	0,389	0,354
Total SF-36 score mothers	r	-0,016	0,018
	p	0,928	0,957
Total SF-36 score fathers	r	-0,059	-0,151
	p	0,738	0,639

CNO: children who need observation IC: Independent children IFS: Impact of Family Scale

There was a positive correlation between mothers and fathers IFS scores in CNO ($r=0,39$; $p=0,02$) and IC group ($r=0,60$; $p=0,03$). SF-36 scores in CNO ($r=0,54$; $p=0,00$) and IC ($r=0,82$; $p=0,00$) group had a positive correlation between the of mothers and fathers (Table 5). When the

levels of influence and quality of life of the mothers and fathers within the groups were compared, it was observed that there was no significant difference between the mothers and fathers in the group CNO and in the IC group ($p>0,05$).

Table 5. Correlation between IFS, SF-36 scores of mothers and fathers within groups

		CNO(n=34)	IC(n=15)
Total IFS score	r	0,394*	0,602*
mother/father	p	0,021	0,038
Total SF-36 score	r	0,546*	0,825*
mother/father	p	0,001	0,001

CNO: children who need observation IC: Independent children IFS: Impact of Family Scale

DISCUSSION

This study was planned to reveal how the functional levels of children with cerebral palsy in the northern part of Cyprus affect the mother and father, how it changes the quality of life of the family, and whether there is a difference between the influence of the mother and father.

In the literature, there are studies showing that the functional level of the child with CP is not as affected as the studies showing that it affects the life parameters of the family (Ramanandi et al., 2019). In the study of Rodrigues et al. examining the relationship between the functional status of children with CP and the quality of life of the first-degree caregivers, it was observed that the relationship between WeeFIM and SF-36 total scores was positive, and there was a negative effect on the quality of life of caregivers (Rodrigues dos Santos, 2009). It was stated that the effect was due to problems related to physical, behavioral, psychological and social functioning. In Turkey Albayrak et al. found that mothers with children with CP had higher caregiving burden, depression scores, and poorer sleep and life quality compared to mothers with healthy children (Albayrak et al., 2019). It was stated that this result was most likely due to mothers providing home care for their children with CP all day long and being exposed to long-term stress factors. They were evaluated the quality of life of mothers with 424 children with CP and their children's motor levels in Iran. As a result, they stated that children with worse gross motor function need more support and this support may cause injuries to the musculoskeletal system of the mother. Thus, in general, they suggested that if the gross motor functions of children with CP are at low levels, the physical health of mothers might also be negatively affected (Dehghan et al., 2016). Contrary to these studies, Davis et al. examined the quality of life of mothers and fathers with children

with CP, and it was found that the functional level of the child did not make a significant difference in financial, social and physical issues, including parental stress (Davis et al., 2010). Riberio et al. in their study conducted in Brazil, they compared the stress of mothers with children with CP and their functional level classified according to GMFCS, but it was observed that the deterioration of the functional level of the child with CP did not increase the mother's stress (Riberio et al., 2014).

In the study, they argued that the deterioration in the health and quality of life of mothers depends on how the family copes with adverse situations and how they organize themselves against their children's illness rather than the child's level of disability. In a study conducted in Korea, determinants affecting health-related quality of life in parents were examined and it was found that the severity of disability was not an important quality of life determinant for mothers of children with CP. In the study, the physical quality of life of the child to have less secondary diseases; On the other hand, it was stated that social support and having sufficient free time of the mother increased the mental life quality (Lee et al., 2019). In a similar study involving 270 children with CP, IFSs were administered to mothers without including the questions of the coping domain to evaluate the disease status, and as a result, none of the IFS factors laid the groundwork for a significant relationship between the functional status of the children and the depression of the mothers. It has been reported that only the lack of perceived social support has an important role in the relationship between the functional status of the child and maternal depression (Manuel et al., 2003). In our study, no relationship was found between the WeeFIM score of the children and the IFS total effect scores of the parents and the SF-36 Form mean scores. This is a case consistent with social comparison theory. Parents of children with mild disabilities think

their quality of life is good when they compare themselves with the parents of severely disabled children. Because comparing oneself with the less fortunate is common among individuals with disabled children. In this regard, we need to mention the following point: The North of Cyprus is a geography where both broad and nuclear family relations are tight. Even after marriage, it is very common for families to provide financial and moral support to their children, care for grandchildren, and help with household chores. In this sense, the social support provided by other members of the family to the parents of children with CP in Northern Cyprus helps both to reduce the burden on the child and to provide time for the family. This is the biggest reason why families are less affected by this situation.

In the literature, there are quite a few studies comparing the changing quality of life and exposure levels of mothers and fathers due to having children with CP (Barreto et al., 2020). Parisi et al. applied a scale to parents of children with cerebral palsy to determine how much this disease affected them in Italy (Parisi et al., 2016). It was observed that mothers got higher scores than the father group in subscales related to the influence of the sick child and the family life and other family members due to the disease.

Pelchat et al. in the evaluation of 13 couples with children with CP, investigated the adaptation and transformation processes of parents in their personal, marital and parenting roles and drew attention to the differences and similarities between them in these processes (Pelchat et al., 2009). While mothers were more inclined to reveal their feelings to cope with this situation and sought both social and informative support, fathers often showed emotional reactions such as avoidance and denial to distance themselves from the situation emotionally. In our study, the mothers, and fathers of children with "requiring observation" and "independent" CP were compared among themselves, and the quality of life and impact scores of the mothers did not differ significantly compared to the fathers. This shows that the parents shared similar experiences and faced similar difficulties. There are no serious differences between mother and father's burden distribution in family structures in Northern Cyprus. Fathers also play an active role in childcare throughout the island of Cyprus, although mothers have slightly more

responsibilities for the child, as they are generally primary caregivers. Thus, the mother and father share the responsibility equally in the house. This situation explains why there is no difference between mother and father's quality of life and levels of influence.

Our study had some limitations. First, there was no control group in this study. Future studies should include a control group of parents with healthy children to allow comparisons of quality of life and levels of influence between groups. Second, there is a need for establishing causal relationships of the results and longitudinal studies that examine the changes in the physical and mental quality of life of the parents over time. Finally, the data we obtained has led us to the impression that families in small communities do not want their children with disabilities to appear as a burden on them. In such a situation, we think that the environment will misunderstand families; they will be thought to be dislike their children when they give negative answers, and they may be worried about social stigma and avoid objectively answering questions.

As a result, we have seen that due to the Mediterranean climate of Northern Cyprus, the low population, and the presence of close family and social relations, families with children with CP are not affected as much as parents in other countries. Our study supports the clinical necessity of family / patient-centered biopsychosocial approach. We believe that providing environmental, social and physical support to families can help their children minimize the impact of their illness on their lives and change the health outcomes of the caregiver. For this reason, we consider and recommend that it is important and necessary to provide all kinds of support to families with disabled children in state policies.

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Conflict of interests

The authors have no conflict of interests to declare. No financial support was received for this study

Ethical Consideration

The study protocol was carried out in accordance with the Helsinki Declaration of 1975 and an approval was obtained from the University of Near East, Scientific Research Ethics Committee, Cyprus (Ref: YDU/2017/44-370).

Written informed consent forms were obtained from all participants prior to the study.

Author Contributions

Study Design, MB, BBC; Data Collection, MB; Statistical Analysis, MB, BBC, TY; Data Interpretation, MB, BBC, TY, UC; Manuscript Preparation, MB, BBC; Literature Search, MB, TY. All authors have read and agreed to the published version of the manuscript

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