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The effect of motor and functional independence of disabled children on musculoskeletal disorders in pediatric caregivers: A cross-sectional study

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This study was reviewed and approved by the İnönü University Clinical Research Ethics Committee (Decision number: 2020/163).
All procedures in this study involving human participants were performed in accordance with the 1964 Helsinki Declaration and its later amendments.

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Abstract

Background/Aim: There are conflicting results regarding the effect of motor and functional independence levels of disabled children on the burden of care. In addition, this burden, as well as musculoskeletal problems of pediatric caregivers, has not been examined in detail. The aim of this study is to examine the effects of motor and functional levels of the disabled child.

Methods: The study was planned as a single-blind, multicenter, cross-sectional study. Children between ages 1-12 with physical disabilities from various problems, and 65 caregivers over the age of 18 who cared for them for at least 6 months, were included. Caregivers were divided into two groups, as per the BAKAS Caregiver Impact Scale score as high care burden (n = 33) or low care burden (n = 32). The motor level of the disabled child was determined by the Gross Motor Function Classification System, and the functional level of the Pediatric Functional Independence Measurement. The Nordic Musculoskeletal Questionnaire was used to evaluate musculoskeletal problems in caregivers.

Results: There was no significant difference between the Gross Motor Function Classification System levels of children in groups ($P > 0.05$). The Pediatric Functional Independence Measurement scores of children in the high care burden group were significantly lower than those in the low care burden group ($P < 0.05$). According to a comparison of pain in parts of the body for 12 months, using the Nordic Musculoskeletal Questionnaire, the percentage of pain in the neck, shoulder, back, elbow, hand, hip, and foot regions of caregivers was significantly higher in the group with a high care burden ($P < 0.05$). There was no significant difference between percent of low back and knee pain in the last 12 months ($P > 0.05$). A weak positive correlation was found between the BAKAS Caregiver Impact scores and the Pediatric Functional Independence Measurement of children with disabilities ($r = 0.26$; $P = 0.03$).

Conclusion: The lower functional level of the disabled child may cause an increase in caregiver burden of both the caregivers and musculoskeletal disorders.

Keywords: Caregivers, Caregiver burden, Disabled child, Musculoskeletal pain

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Introduction

Disability is a situation that limits or prevents activities by gender, age, social, and cultural situation of the individual due to damage or disability [1]. The rate of disability is increasing gradually with congenital anomalies, increased survival rate in preterm births, and some genetic disorders [2]. Disability can be seen separately or combined as psychological, physical, developmental, and mental problems. According to the World Health Organization, it is estimated that 5.1 percent of children aged 0-14 (approximately 93 million children) have a disability and 0.7 percent [approximately 13 million children] have a serious disability [3]. Approximately 12% of 6.6 million children in the US have a disability [4].

It is also estimated that there are approximately 9 million children with special needs or disabilities between the ages of 0-18 in Turkey. This highlights that there is 1 disabled child or adult in every 7 to 8 families [5]. The family who learns their child is disabled or the family whose child has a disability after birth experiences profound grief. Families may go through many negative psychological processes such as denial, anger, crisis, depression, and shame [6]. Families are obliged to care for their disabled children physically, socially, emotionally, and financially – and as such, this situation creates a burden of care due to difficulties experienced in the care process, feeling under stress, or under a burden [7]. It creates many psychological and physical problems for the caregivers [8]: studies report that they have psychological health conditions, e.g., high stress and depression [9]. The caregiver undertakes physically demanding tasks, like assisting with the child's transfers and personal needs [10].

Within the scope of these interventions, a change from normal posture causes biomechanically incorrect positions. The prolonged caregiving period and worsening of the motor level of the disabled children cause fatigue, headache, and back pain, i.e., low back pain [11]. It was found that 84% of caregivers of neurological patients have physical problems themselves [12]. Despite this, few studies have addressed the effects of care burden on quality of life in the caregivers for children with disabilities. When studies are assessed, they relate to difficulties experienced by the families and related psychological factors [13-15].

Towards this goal, our aim was to examine the effects of motor and functional level of the disabled child on care burden and musculoskeletal system disorders in pediatric caregivers.

Materials and methods

This study is a multicenter, cross-sectional study, which was reviewed and approved by the Inonu University Clinical Research Ethics Committee (Decision No. 2020/163); this study was conducted according to the principles of the Declaration of Helsinki. Informed consent was obtained from the parents of participants before the study started.

Research data were collected between 6 July and 6 August 2020. Children aged 1-12 years with physical disabilities and caregivers over the age of 18 who took care of them for at least 6 months were included in this study. Individuals in institutions were selected by the non-probability random sampling method, as caregivers with a musculoskeletal injury or surgery linked to their musculoskeletal system in the last 6 months, or who had low back-back-neck pain due to rheumatological diseases were excluded from the study.

Private hospitals and special education centers were chosen by drawing lots among 33 centers (special education and rehabilitation centers, physical therapy centers, and private hospitals) in the city center of Malatya, for rehabilitation services by the independent researcher. This research consisted of disabled children and their families who had applied for assistance. Demographic variables of all participants (the disabled child and caregiver), including age, gender, weight, and height, were recorded. In addition, caregivers were asked about their employment status, how long they had been working, and whether they engaged in exercise. The burden of caregivers was evaluated with the Bakas Caregiver Impact Scale, which consists of 15 questions with scores between +3 (best possible score) and -3 (worst possible score). A lower score can occur with a negative change, while a higher score can occur with a positive change [16, 17]. This impact scale was conducted through face-to-face interviews with caregivers. The median score was calculated to be 55, so individuals over 55 constituted the group with low care burden (n = 32) and those below that had a high care burden (n = 33).

The mobility and functional level of the disabled child was determined according to the Gross Motor Function Classification System (GMFCS). This system offers age-appropriate scoring between 1-5. Level 1 allows ambulation indoors and outdoors without the need for assistive devices, while level 5 is defined as completely dependent in terms of mobility [18, 19].

The Pediatric Functional Independence Scale (WeeFIM) was used to assess the level of functional independence of those with disabilities between 6 months and 21 years of age. This scale consists of a total of 18 items that evaluate 3 areas: self-care, mobility, and cognitive function. Scores ranged between 1 and 7 points for each item, with 7 points indicating activities performed by the disabled individual independently, and 1 indicating activities that had to be done with full assistance [20, 21]. Their status for sub-parameters of the WeeFIM was evaluated in conjunction with information from the physiotherapist and caregiver.

The Nordic Musculoskeletal Questionnaire was used to evaluate musculoskeletal problems in caregivers: it included 27 items to assess the presence of musculoskeletal symptoms over a 12-month period, covering nine different parts of the body (neck, shoulders, elbows, hands/wrists, back, waist, hips/thighs, knees, and ankles). All answers were based on a binary "yes/no" answer [22]. In this study, part of the questionnaire related to the presence of pain, suffering, and discomfort in the last 12 months in 9 body regions.

Statistical analysis

The Shapiro-Wilk test was used to assess normality of the data. Descriptive statistics (frequency, mean, standard deviation) were applied to characterize individuals within groups. Differences between two groups were compared with the Independent Sample T-test (normally distributed variables) and the Mann-Whitney U test (for non-normally distributed variables). Categorical variables were evaluated with the Chi-squared test. The relationship between the BAKAS Caregiver Impact scores and the WeeFIM scores of children with disabilities was evaluated with Spearman's correlation test (parameters that do not show normal distribution). Correlation values ≥ 0.4 were considered satisfactory (r ≥ 0.81–1.0 excellent, 0.61–0.80 very good, 0.41–0.60 good, 0.21–0.40 fair, and 0.00–0.20 poor). The significance level was set at $P < 0.05$. Statistical analysis was performed with SPSS software v. 25.0. Power analysis was performed before starting the study with α = 0.05 and 1-β (power) = 0.80. Considering that the prevalence of disabled individuals in society is 12.3% (39%), it was calculated that at least 63 people should be included in this research. The public statistical software OpenEpi, v. 3 (http://www.openepi.com) was used to calculate the sample size.

Results

At the end of the study period, 69 disabled children and caregivers were included, but four individuals who filled in evaluation forms incompletely were excluded. A total of 65 individuals, 33 individuals in the high care burden group and 32 individuals in the low care burden group, were included in our analysis. The characteristics of both groups are examined in Table 1. Groups were similar in terms of age, gender, and body mass index of caregivers ($P > 0.05$), and were also similar in terms of the ages of disabled children ($P > 0.05$). However, the body mass index was higher in the group with a high care burden ($P < 0.05$), but in groups with high and low care burdens, 9.1% and 21.9% of caregivers engaged in exercise activities, respectively. There was no difference between the groups' duration of care and the working status of caregivers ($P > 0.05$).

Table 1: Characteristics of caregivers and children with disabilities

	High Care Burden (n = 33) Mean (SD)	Low Care Burden (n = 32) Mean (SD)	*P*-value
Caregiver Age, year	34.90 (7.31)	36.96 (7.48)	0.26^{a}
Caregiver BMI, kg/m²	27.14 (3.41)	26.81 (5.54)	0.77^{a}
	Median (min/max)	Median (min/max)	
Child Age, year	4.0 (1/12)	5.0 (1/12)	0.09^{b}
Child BMI, kg/m²	(10.94/38.78)	15.86 (9.17/23.44)	0.03^{b}
	n (%)	n (%)	
Caregiver Sex			
Female	30 (90.9)	30 (93.75)	1.00^{c}
Male	3 (9.1)	2 (6.25)	
Exercise Habits			0.18^{c}
Yes	3 (9.1)	7 (21.9)	
No	30 (90.9)	25 (78.1)	
Care Time			0.26^{c}
6 months-4 years	23 (69.7)	18 (56.3)	
5 years and above	10 (30.3)	14 (43.8)	
Working status			0.47^{c}
Yes	6 (18.2)	3 (9.4)	
No	27 (81.8)	29 (90.6)	

BMI: body mass index, SD: standard deviation, ^{a} Independent Sample T-test, ^{b} Mann-Whitney U test, ^{c} Chi-squared test

Comparison of WeeFIM scores, GMFCS levels, and the Nordic Musculoskeletal Questionnaire for children with disabilities in groups with high and low care burden, is shown in Table 2. The WeeFIM scores of children with high care burden were significantly lower than the group with low care burden ($P < 0.05$). Yet, there was no significant difference between the GMFCS levels of disabled children in groups ($P > 0.05$). In comparison to pain in different parts of the body over the last 12 months, while using the Nordic Musculoskeletal Questionnaire, the percent of pain in the neck, shoulder, back, elbow, hand, hip, and foot regions of the caregivers was found to be significantly higher in those with a high care burden ($P < 0.05$). There was no significant difference between groups with low back and knee pain over the last 12 months ($P > 0.05$). There was a weak positive correlation between the BAKAS Caregiver Impact scores of caregivers without grouping and the WeeFIM scores of children with disabilities (r = 0.26; $P = 0.03$).

Table 2: Comparison of participants' functional independence, motor level, and musculoskeletal problems according to care burden

		High care burden (n = 33)	Low care burden (n = 32)	*P*-value
WeeFIM, Median		29 (12/116)	40 (18/119)	0.03^{a}
GMFCS		n (%)	n (%)	0.90^{b}
Level I- III		15 (45.5)	15 (46.9)	
Level IV- V		18 (54.5)	17 (53.1)	
NORDIC				
Neck	Yes	17 (51.5)	7 (21.9)	0.01^{b}
	No	16 (48.5)	25 (78.1)	
Shoulder	Yes	14 (42.4)	6 (18.8)	0.03^{b}
	No	19 (57.6)	26 (81.3)	
Back	Yes	22 (66.7)	6 (18.8)	0.00^{b}
	No	11 (33.3)	26 (81.3)	
Elbow	Yes	8 (24.2)	1 (3.1)	0.02^{b}
	No	25 (75.8)	31 (96.9)	
Hand	Yes	19 (57.6)	7 (21.9)	0.00^{b}
	No	14 (42.4)	25 (78.1)	
Waist	Yes	24 (72.7)	17 (53.1)	0.10^{b}
	No	9 (27.3)	15 (46.9)	
Hips/Thighs	Yes	9 (27.3)	2 (6.3)	0.02^{b}
	No	24 (72.7)	30 (93.8)	
Knee	Yes	13 (39.4)	7 (21.9)	0.12^{b}
	No	20 (60.6)	25 (78.1)	
Ankle	Yes	7 (21.2)	1 (3.1)	0.05^{b}
	No	26 (78.8)	31 (96.9)	

WeeFIM: Pediatric Functional Independence Scale, GMFCS: Gross Motor Function Classification System, ^{a} Mann-Whitney U test, ^{b} Chi-squared test

Discussion

In this study, effects of the motor and functional level of the disabled child on burden of care and musculoskeletal disorders in pediatric caregivers were assessed. Results showed that functional levels of disabled children with a high burden of care were lower, but their motor levels were similar. Moreover, it was found that those with a high care burden had more musculoskeletal disorders.

The functional level of children is one of the most important factors affecting burden of care. As the level of independence increases, the need for caregivers decreases. Henry et al. [23] reported that as the level of independence decreased for caregivers, back pain increased and their mood was negatively affected; accordingly, physical functionality of the caregiver decreased. Similarly, Rigby et al. [24] observed changes in the burden of caregivers between onset and the first year of taking care of stroke patients, and found that as the level of functional disability increased, the burden of care also increased. The pediatric functional independence scale was used to determine function levels, and it was found that the burden of care decreased as functional independence increased, akin to other studies in the literature.

Until now, the psychological traits of caregivers for those with disabilities, and changes that occurred in the caregiving process, were extensively researched [25]. When the studies are examined, care burden for many diseases such as stroke, cerebral palsy, and autism spectrum disorder were examined, with a positive relationship observed between care burden, depression, and anxiety [26-28]. Kavlak et al. [29] found that caregivers of children with cerebral palsy had a high burden of care, but no significant relationship was found between gross motor function level and caregiver burden. Özden et al. [28] showed there is a highly significant relationship between spasticity levels of children with cerebral palsy and burden of care, but no significant relationship was established between levels of gross motor function and burden of care. In our study, there was no significant relationship between care burden and gross motor level of the child, which strongly coincides with the literature.

In our study, it was observed that more women had the responsibility of caregiving in the family. As such, since individuals who care for disabled children must stand in a flexed posture for long periods to lift them and meet their needs for a transfer, it was observed that they experienced problems when the load was more exposed, such as the waist, back, and wrist. The physical health of caregivers was assessed with different methods, including computer-assisted sensor dosimetry, three-dimensional postural exam, video recording, and the Nordic Musculoskeletal Assessment [30-33]. In our study, pain levels were higher in the neck, shoulder, back, elbow, hand, hip, and foot, in line with the literature, to evaluate the musculoskeletal system [10]. The percent of pain in caregivers' lumbar region was higher in the group with a high burden of care, but was not significant. Since low back pain is seen as a common problem in our society, it reduces the difference between the groups.

Limitations

Our study has some limitations, which is related to the number of samples. Scanning with larger samples would yield more generalizable results. Since pain status over the last year was evaluated, it could affect generalizability of the results. Prospective, longer-term follow-up studies may be useful in assessing the effect of caregiving on isolated musculoskeletal disorders. The low exercise activities in the groups prevented understanding the effect of exercise on preventing musculoskeletal problems.

Conclusions

As a result, our study will make significant contributions to a limited number of literature reports that evaluate children's motor and independence levels on caregivers' musculoskeletal problems. It was shown that the functional level of a disabled child is related to the burden of care for the caregiver and functional level of the disabled child – which relates to musculoskeletal disorders. Our results show that caregivers can have severe problems in terms of musculoskeletal disorders. Raising awareness for caregivers and explaining appropriate ergonomics would be effective in preventing musculoskeletal disorders.

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