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ORIGINAL ARTICLE

Fiziksel engelli çocukların bağımsızlık düzeyleri ile ebeveynlerinin fiziksel sağlık, yaşam kalitesi ve aldıkları sosyal destek arasındaki ilişki

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Amaç: Araştırma, fiziksel engelli çocukların ebeveynlerinin fiziksel sağlık, yaşam kalitesi ve aldıkları sosyal destek ile çocukların bağımsızlık düzeyleri arasındaki ilişkiyi incelemek amacıyla yapılmıştır.
Yöntem: Çalışmaya yaşları 18 ile 50 arasında değişen 61 engelli çocuk annesi dahil edildi. Olguların kas kuvveti ve dayanıklılığı, kas-iskelet sistemi ağrısı, yaşam kalitesi ve aldıkları sosyal destek değerlendirildi. Kas kuvveti ve kas enduransı, sırasıyla dinamometre ve McGill protokolü kullanılarak değerlendirildi. Yaşam kalitesini değerlendirmek için Kısa Form-36 anketi, kas iskelet sistemi ağrısını değerlendirmek için Cornell Kas İskelet Sistemi Rahatsızlığı Ölçeği, algılanan sosyal desteği değerlendirmek için ise Çok Boyutlu Algılanan Sosyal Destek Ölçeği kullanıldı. Engelli çocukların fonksiyonel bağımsızlık düzeyini belirlemek için Çocuklar için Fonksiyonel Bağımsızlık Anketi kullanıldı.
Bulgular: Çocukların Fonksiyonel Bağımsızlık Ölçeği puanları ile annelerin Kısa Form-36 ölçeğinin sosyal fonksiyon alt ölçeği puanları arasında istatistiksel olarak anlamlı ve pozitif korelasyon bulundu ($p < 0,05$). Çocukların Fonksiyonel Bağımsızlık Ölçeği skorları ile annelerin değerlendirilen 33 kas gurubunun 21'inin kas kuvveti arasında anlamlı ve negatif ilişki vardı ($p < 0,05$).
Sonuç: Engelli çocuklar günlük yaşamlarında daha bağımsız olmaları annelerin fiziksel ve sosyal durumlarını etkilemektedir. Fizyoterapi ve rehabilitasyon programlarında çocukların bağımsızlığına artırmaya odaklanmak önemlidir.
Anahtar kelimeler: Engelli Çocuklar, Ebeveynler, Sağlık, Yaşam kalitesi, Sosyal destek.

Relationship between the independence level of children with physical disabilities and physical health, quality of life and social support of their parents

Purpose: The study was conducted to examine the relationship between physical health, quality of life and social support of the parents of children with physical disabilities and the independence level of these children.
Methods: Sixty-one mothers of disabled children aged between 18 and 50 years were included in the study. Their muscular strength and endurance, musculoskeletal pain, quality of life and received social support were evaluated. A hand-held dynamometer and McGill protocol were used to assess muscle strength and endurance, respectively. The Short Form-36 questionnaire was used to assess the quality of life, Cornell Musculoskeletal Discomfort Questionnaire was used to assess musculoskeletal pain and Multidimensional Perceived Social Support Scale was used to assess social support perceived. Wee Functional Independence Measure questionnaire was used to determine the functional independence of children with disabilities.
Results: There were statistically significant and positive correlations between Wee Functional Independence Measure scores of children and scores of mothers' social function subscale of Short Form-36 scale ($p < 0.05$). There was a significant and negative relationship between Wee Functional Independence Measure scores of children and in 21 out of 33 of muscle group muscular strength of mothers ($p < 0.05$).
Conclusion: Children who are functionally more independent in their daily lives influencing physical and social well-being of their mothers. Physiotherapy and rehabilitation programs should focus on increasing the independence level of children with disabilities.
Keywords: Disabled children, Parents, Health, Quality of life, Social support.

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A disabled child is a person who needs care, rehabilitation and support services to do his/her social role as he has functional loss in physical, mental or psychological health.[1, 2] There are various effects of having and caring for a disabled child.[2, 3] Studies showed that mothers who have a disabled child have more psychosocial and physical problems than the mothers who have typically developed child.[4-6] Determination of the problems of the parents who have a disabled child or children and raising awareness are required to decrease the gaps in essential services and supports.[7] Little are these problems investigated, so this inhibits the improvement of services.[8]

The burden of care of disabled child causes musculoskeletal problems as well as pain in various regions.[4] Activities like bending, reaching, carrying, picking up which negatively affect body mechanics lead to pain in musculoskeletal system.[9,10] Mothers of disabled children who have long-time static posture, repeated trunk flexion, carrying movements are exposed to multiple postural stresses.[9] Severity of pain is affected by body mass of mother, age of child, locomotor skills and level of independence of child, the necessity of carrying child, and issues belonging to mother.[4]

Continuous effort in specific time intervals is required for various daily life activities so both muscular strength and endurance are important aspects of physical performance and they should be assessed while examining the musculoskeletal functions.[10] A decrease in core endurance may result in injuries and education regarding core muscles may decrease the risk of injury.[11] Therefore, the level of muscular strength and endurance of mothers who care for their disabled children should be assessed and the strategies should be improved to prevent chronic illnesses. No adequate study has been found to present this information.

As disability causes physical, psychological, and social changes in families' lives, their quality of life has been started to be investigated.[3,12,13] Quality of life of mothers with a disabled child is affected more negatively in all aspects than fathers.[3] Studies showed that mothers have mostly cared for the disabled child and left their other roles like businesswoman and friend and they become less social to care for their child.[3] While the practices and policies are determined and improved about the rehabilitation of these children, the quality of life concept should also be more detailed investigated.

Social support decreases anxiety and despair feelings, increases the feeling of confidence, provides motivation to try new ways to cope with stress, and provides managing psychological problems.[8,14,15] Social support taken from environment especially from their relatives is important for the parents who have a disabled child. The success of coping with the problems which parents of disabled children live have parallels with social support mechanisms.[14,15]

Planning and evaluating health services for children with disabilities requires information about families. Paths that require family-oriented biopsychosocial frameworks should be supported, rather than technical and short-term rehabilitation interventions focusing on the child.[3,14,16] The extent of support required to satisfy the child's biological and psychosocial needs depends on the severity of the disability. Caregiver of the child must cope with the child's motor and sensory disabilities and, in addition to that, he/she must enable implementation of a wide range of necessary medical interventions and rehabilitation[15]. This study aims to investigate the relationship between physical health, quality of life and social support of the families of children with physical disabilities and physical independence level of children.

METHODS

The study was conducted at Dr Burhan Nalbantoğlu State Hospital, Physiotherapy and Rehabilitation Unit, at Northern Cyprus. 84 primary caregivers of children were reached and 61 mothers who were primary caregivers and who accepted to participate were included according to inclusion/exclusion criteria. Mothers who are 20-50 years old, who have a child with 40% physical disability level or above (according to the evaluation of Ministry of Health), who have no surgery for the last year were included in the study. The mothers who have neurological disorder were excluded from the study. All participants signed informed

consent approved by the European University of Lefke, Institute of Graduate Studies &Research, Ethical Committee (11.04.2017, registration number ÜEK/03/02/04/1617/8).

Age, weight, height, occupation, education level, number of children, ages of children of mother and existence of any person in the family who could help her were asked. Muscular strength, muscular endurance, musculoskeletal discomfort, quality of life and social support information of mothers were also assessed by standardized tests. Then, age, gender, weight, the height of the child, diagnosis of disability, education level of the child, ambulation level and independence level were recorded. Study materials were supplied by the Department of Physiotherapy and Rehabilitation, Faculty of Health Sciences, European University of Lefke.

Functional Independence Measure for Children (Wee FIM)

The WeeFIM (Functional Independence Measure for Children) which is a valid outcome measure was used to assess the level of functional independence of the children. It consists of 18 items, divided into six categories. Each task is scored from 1 (total assist) to 7 (complete independence). The maximum total score is 126, whereas the lowest score is 18.[17]

Quality of Life - Short Form-36 (SF -36)

The SF-36, which is one of the most widely used and studied generic Health-Related Quality of Life tool, was used.[18] It measures health status with subscales consisting of physical functioning, role limitations due to physical health, role limitations due to emotional problems, energy/fatigue, emotional well-being, social functioning, pain, and general health. The points of subscales range from 0 to 100 points. High points indicate better health status.[19]

Cornell Musculoskeletal Discomfort Questionnaire (CMDQ)

The CMDQ, which has been developed by Hedge et al.[20], is a 54-item questionnaire containing a body map diagram and questions about the prevalence of musculoskeletal ache, pain, or discomfort in 18 regions of the body during the previous week. High scores indicate an increase in musculoskeletal system problems. Erdinç et al.[21] showed the validity and reliability of the Turkish version of the CMDQ.

Social support

The Multidimensional Scale of Perceived Social Support (MSPSS) which has been developed by Zinet et al. is a brief scale used to assess the adequacy of social support from three sources; the family, friends, and a significant other.[22] Eker et al. showed its Turkish validity and reliability. It has 12 items and high scores indicate high perceived social support.[23]

Muscular strength

A handheld dynamometer (Lafeyette Hand-held Dynamometer, New York, USA) which measures maximum isometric muscle strength was used.[24] Participants were first informed about positioning and muscle contraction. They were then asked to contract the muscle against the hand of the therapist to feel and be sure the contraction of correct muscles before starting the test.[25]

33 groups of muscles were evaluated of which 28 of them were extremity muscles. For extremity muscles, participants were asked to contract that muscle against gravity (according to Manual Muscle Testing Protocol[26]) and dynamometer measured the resistance at that point. Testing of the remaining five groups of muscles is explained below:

Back extensors: Participants were instructed to lift their back in the prone position and with the arms extended up parallel to the head. The dynamometer was placed on the erector spina muscles of the lumbar region and pelvis was fixed. The participants were then asked to apply strength against it for five seconds and measurement was repeated 3 times that their average was taken.[25]

Upper abdomen: Participants were instructed to lift their trunk forward in the supine position and with the arms extended in front. The dynamometer was placed on the Rectus Abdominus muscle parallel to the head. The participants were then asked to apply strength against it for five seconds and measurement was repeated three times that their average was taken.[25]

Lower abdomen: Participants were instructed to lift their legs in 30-60 degree angles while lying back in the supine position. The dynamometer was placed on the anterior femur. The participants were then asked to apply strength against it for five seconds and measurement was repeated 3 times that their average was taken.[25]

Neck flexors: Participants were asked to hang their head from the bed in the supine position. The dynamometer was placed on the forehead and lower thorax was stabilized. The participants were then asked to apply strength against it for five seconds and measurement was repeated three times that their average was taken.[25]

Neck extensors: Participants were asked to hang their head from the bed in the prone position. The dynamometer was placed on the occiput and lower thorax was stabilized. The participants were then asked to apply strength against it for five seconds and measurement was repeated three times that their average was taken.[25]

Muscular endurance tests

The endurance of the core muscles was assessed by using Mc Gill Protocol as trunk extension test, trunk flexion test and lateral bridge test. The endurance of the lower extremity was evaluated by a squat test.

Side bridge test

The lateral bridge test assesses the endurance of lateral core muscles. Participants were asked to lie on their sides with legs extended. The top foot was placed in front of the lower foot for support. They were then asked to support themselves on the elbow and their feet, and lift their hips off the surface to maintain a straight line over their full-body length. The nonsupporting arm was held across the chest with the hand placed on the opposite shoulder. The test ended when the participants lose this position and duration was recorded in seconds.[27]

Endurance test for trunk extensors

Static endurance of trunk extensors was assessed in this test. The participants were positioned prone with pelvis, hips and knees on the table. They were then asked to lift their trunk up starting from the table side and protect the position as long as possible. The duration was recorded in seconds.[27]

Endurance test for trunk flexors

The participants were positioned with 60º trunk, and 90º knee and hip flexion. Edge placed at the back was used for positioning. When the edge starts to be removed, participants were asked to protect their position as long as possible. The duration was recorded in second.[27]

Endurance test for lower limbs

The participants were asked to stand up vertically and squat respectively in 1 minute. Total number of squatting was recorded.[27]

Statistical analysis

This is a correlational, cohort study. The data were analyzed using SPSS for Windows 21.0 (IBM SPSS Statistics Version 21.0 64 Bit Edition, 1989-2012). Variables were presented with descriptive statistics and the data was not normally distributed. So, Spearman Correlation Analysis was used to determine the correlations among WeeFIM scores of children and anthropometric measures of mothers and their children, mothers' muscular strength, mothers' muscular endurance, quality of life (SF-36) values, social support scores.

Power analysis of your study was performed with G*Power v 3.1.9.2 (Universitat Kiel, Germany, 1992-2014). The power value calculated for our sample of 61 people with an effect size of 0.5 was found to be 99% (1-ß err probe=0.9947945).

RESULTS

The mean age of participants was 37.40±8.73 years, mean height was 161±0.05 cm, and mean weight was 68,38±15,41. BMI was 26.39±6.07 kg/m^2. The descriptive characteristics of the mothers are presented in Table 1.

Children of mothers had different ages and medical characteristics. Twenty-four children were pre-school age (0-6 years old) and rest had a 7-18 years old range. Children (31 girls, 30 boys) mostly had congenital disabilities (80.33%). 38 of them had cerebral palsy (62,31%), 5 of them had genetic diseases, (8.20%), seven of them had epilepsy (11,48%), three of them had Down Syndrome (4.92%), other eight of them had a different diagnosis (13,09%).

According to Table 2, correlations between children's WeeFIM scores and the muscular endurance, quality of life, social support scores, and pain were indicated. Only social function subheading of the SF-36 was found to be significantly correlated with the WeeFIM score of the children (r=0.31, p=0.01). Significant correlations between WeeFIM scores of the children and the muscular strengths of the participants at 21 out of 33 muscle groups had been shown. Table 3 shows r and p values of

these correlations.

DISCUSSION

Caring for a disabled child for long years and all day negatively affect physical and psychological health in many ways.[6,12] This study aimed to investigate the relationship between the independence level of children with disabilities and physical health, quality of life and social support of the primary caregivers of children. Physical health assessments included muscle strength, muscle endurance and pain level at different parts of the body which were the parameters not have been formerly investigated in detail for this population. The mothers were found to be the main person who cares for the disabled child in this study. Similarly, many papers have indicated that mothers have a major role in caring for the disabled child of a parent.[3,10,11] 86.89% of the mothers included in the study did not work and 90.16% did not take any other support about caring for their child. Doğru vd. similarly found that mothers of disabled children generally preferred part-time works or did not work to care for their child. [28]

Muscular strength and endurance are essential parameters for the musculoskeletal problems and also activities of daily living.[29] In this study, while the independence level of the children increased, average muscular strength decreased at 21 out of 33 muscle groups.

Table 1. Descriptive characteristics of the participants.

	n (%)
Age group	
30 year and below	14 (23.0)
31-39 years	24 (39.3)
40 year and above	23 (37.7)
Education status	
Illiterate	4 (6.6)
Primary school	30 (49.2)
Secondary school	9 (14.8)
High school	12 (19.7)
University	6 (9.8)
Marital status	
Married	54 (88.5)
Not-married	7 (11.5)
Working status	
Working	8 (13.1)
Not working	53 (86.9)
Income (monthly)	
1.800 TL- 2.800 TL	44 (72.1)
2.800 TL - 3.800 TL	14 (23.0)
3.800 TL - 4.800 TL	3 (4.9)
Child number	
One	9 (14.8)
Two	25 (41.0)
Three and more	27 (44.3)
Assistant person	
Yes	6 (9.8)
No	55 (90.2)
Total	61 (100.0)

Table 2. Correlations among functional independence scores of disabled children and endurance, quality of life, perceived.

	WeeFIM r (p)
McGill Endurance	
Trunk flexor	-0.09 (0.50)
Right lateral trunk	-0.18 (0.17)
Left lateral trunk	-0.15 (0.26)
Trunk extensor	-0.05 (0.69)
Repetition number in 1 min	-0.02 (0.86)
Quality of Life Scale (SF-36)	
Physical functioning	0.01 (0.91)
Role physical	0.20 (0.13)
Role emotional	0.11 (0.39)
Vitality	0.06 (0.65)
Mental health	0.07 (0.60)
Social function	0.32 (0.01)*
Bodily pain	-0.10 (0.45)
General health	0.12 (0.37)
Multidimensional Perceived Social Support	
Family	-0.16 (0.21)
Friends	0.11 (0.38)
Special person	0.11 (0.41)
General	0.07 (0.60)
Cornell - Pain	0.01 (0.92)

*p<0.05, r: Spearman correlation analysis, SF-36: Short From-36.

Table 3. Correlation between functional independence scores of disabled children and muscle strengths of participants.

	WeeFIM
Trunk	
Flexion (upper abdominals)	-0.31 (0.01)*
Flexion (lower abdominals)	-0.28 (0.03)*
Lumbar extensors	-0.29 (0.02)*
Toracal extensors	-0.36 (<0.001)
Hip	
Flexion	-0.32 (0.01)*
Extension	-0.27 (0.03)*
Abduction	-0.33 (0.01)*
Adduction	-0.41 (<0.001)
Internal rotation	-0.44 (<0.001)
External rotation	-0.37 (<0.001)
Sartorius	-0.34 (0.01)*
Tensor fascia latae	-0.13 (0.32)
Knee	
Flexion	-0.27 (0.04)*
Extension	-0.27 (0.04)*
Ankle	
Plantar flexion	-0.35 (0.01)*
Dorsal flexion and inversion	-0.34 (0.01)*
Plantar flexion and inversion	-0.22 (0.09)
Eversion	-0.40 (<0.001)
Scapula	
Abduction	-0.18 (0.17)
Adduction	-0.04 (0.78)
Elevation	-0.33 (0.01)*
Depression	-0.19 (0.14)
Shoulder	
Flexion	-0.41 (<0.001)
Extension	-0,11 (0.40)
Abduction	-0.35 (0.01)*
Horizontal abduction	-0.13 (0.31)
Adduction	-0.20 (0.12)
External rotation	-0.30 (0.02)*
Internal rotation	-0.13 (0.33)
Elbow	
Flexion	-0.18 (0.17)
Extension	-0.07 (0.60)
Neck	
Flexion	-0.32 (0.01)*
Extension	-0.24 (0.07)

*p<0.05, r: Spearman correlation analysis.

When we look at the correlated muscle groups, it is seen that 16 out of 21 muscle groups are the trunk and lower extremity muscles. It seems that as children need less support, mothers have less muscular strength at the trunk and lower extremities, but at only a few upper extremity muscles which were elevators of scapula, shoulder flexors, abductors and external rotators. This was an unexpected result as we thought to have more correlations for upper extremity muscles, especially elbow flexors which is an important group of muscle for lifting and carrying movements. We think that the relation of the independence level of children with disabilities with the upper extremity strength should be investigated in more detail.

Quality of life of the parents of disabled children who have functional inadequacy is negatively affected.[3,12] While the care for disabled children becomes difficult, psychological problems of mother's increase.[30,31] Gowen et al.[31] stated that decrease in the level of functional independence of children increases mothers' psychological problems and Telci et al.[30] also showed that the decreased independence level of children makes mothers more hopeless. Similarly, a significant correlation was found between WeeFIM scores and social function subscale of SF-36 in our study. Thus, it is possible to state that independence level of disabled children, apart from the type of disability, directly influences the quality of life of parents. A study done by Aybar et al.[32] in 2014 stated that the independence level (WeeFIM scores) of children with physical disabilities should be increased by physiotherapy programs which will lead to increase the quality of life of families.

Looking at the other correlations between WeeFIM and other parameters, except the parameters mentioned above, no significant correlation was obtained. Pain is multidimensional so since its biopsychosocial structure, the pain was not affected by the independence level of children. On the other hand, the cause of the absence of correlation with muscular endurance and social support should be discussed as this is a surprising result. Multiple papers investigated and compared the musculoskeletal disorders, physical fitness between the mothers/parents of children with and without disabilities.[33-35]

However, to our knowledge, muscular endurance has not been researched and this can be explained that the parents have short duration loads in daily life so the level of muscular endurance was found to be similar in all participants.

Social support is essential in the primary caregivers of a child with special needs. Both social security and moral support from friends and health professionals are required for social support. Management capability of the people who have strong and wide social support is seen to have an increase.[36,37] Parents of disabled children need help and support in various areas while caring for their children and sustaining their daily life activities.[11,38] Multiple papers are indicating positive correlation among social support, psychological and physical health.[39,40] Psychological status of mothers who took social support has been stated to be significantly better than mothers who did not. A recent randomised controlled study done by Gugula B. et al.[15] indicated that one of the main factors associated with the intensity of anxiety and depression in the parents of disabled children is lack of social support. Cuzzocrea et al. also emphasized the importance of social support in the management of stress seen in the parents of disabled children.[14] Although the importance of social support was explained in various papers, to our knowledge, this is the first paper investigating the correlation between independence level of disabled children and level of social support perceived by their parents. It was possible to get a negative correlation, but "no correlation" indicated that perceived social support was independent of the capabilities of the children.

Limitations

There are several limitations of this paper. Firstly, some field tests like muscular endurance tests which were used in the study may cause bias so more objective tests can be preferred in further papers. Secondly, some sensorial problems like auditory or visual loss were not recorded that they could be important parameters. Lastly, more details about the responsibilities in the daily living of the mothers could be examined which may affect the social life of participants.

Conclusion

There are not enough studies investigating the relationship between physical health, social health and many other health-related parameters of primary caregivers of children with disabilities. Also, within the purpose, the relationships between these parameters and independence level of children were determined. Our results indicated that functional independence level of children in their daily lives influences the physical and social well-being of their mothers who are mostly primary caregivers. These findings will guide health professionals to follow a holistic approach and highlights the importance of physiotherapy and rehabilitation programs to focus on increasing the independence level of children with disabilities.

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