H.Ü. Sağlık Bilimleri Fakültesi Dergisi
Cilt:10, Sayı:3, 2023
Doi:10.21020/husbfd.1229106

Özgün Araştırma

Engelli Çocuklara Bakımverenlerin, Çocuklarının Hastalığı, Fizyoterapi ve Spor Aktiviteleri Hakkındaki Farkındalık Düzeylerinin Belirlenmesi

Hatice Adıgüzel[1], Pinar Kuyulu[2], Nevin Ergun[3]

Gönderim Tarihi: 3 Ocak, 2023 **Kabul Tarihi:** 14 Haziran, 2023 **Basım Tarihi:** 31 Aralık, 2023
Erken Görünüm Tarihi: 23 Ekim, 2023

Öz

Amaç: Çalışmanın amacı engelli çocukların bakımverenlerinin, çocuklarının hastalığı, fizyoterapi ve spor aktiviteleri hakkındaki farkındalık düzeylerini belirlemekti.
Gereç ve Yöntem: Çalışmaya yaş ortalaması 6,50±5,29 olan, Serebral Palsi (SP), Spina Bifida (SB), Down Sendromu (DS), Musküler Distrofi (MD) tanılı çocukların bakımverenleri (n= 65) dahil edildi. Bakımverenlere araştırmacılar tarafından hazırlanan hastalık gruplarına özgü, çoktan seçmeli 12 sorudan oluşan 'Hastalık, Fizyoterapi ve Spor Farkındalık Anketi' yapıldı.
Bulgular: Çalışmaya katılan yaş ortalaması 34,43±10,16 olan bakımverenlerin (n=65) %83'ü anne, %4,6'sı baba, %4,6'sı kardeş, %7,7'si ise diğer kişilerden oluştu. Hastalık tanımının DS'lu grupta %92,9, SP'li grupta % 63,6, SB'da %85,7, MD'de %72,7 oranında doğru yapıldığı bulundu. SB'da duyu problemlerinin ise %26,7 oranında bilindiği saptandı. Fizyoterapi içeriği açısından DS'lu grupta %85,7, SP'de %62,5, SB'da %40, MD'de %45,5 oranında doğru bilgiye sahip olunduğu saptandı. Bakımverenlerin engel gruplarına göre spor katılımı yapabilme yanıtları karşılaştırıldığında gruplar arasında anlamlı fark bulunmadı (p>0,05). DS'lu çocukların bakımverenlerin %92,9'unun, SP'lilerin %75'i, MD'lerin %58,3'ü, SB'lıların %92,9'u çocuklarının spor yapabileceğini ifade etti.
Sonuç: Tüm bakımverenlerin sporun çocuklarının genel iyilik hali, motivasyon ve fiziksel kapasite artışı açısından olumlu etkileneceğini düşündüğü bulundu. Engelli çocukların bakımverenlerinin hastalık farkındalık düzeylerinin ve spor aktiviteleri ile ilgili fikirlerinin iyi düzeyde olduğu fakat yeterli olmadığı saptansa da, fizyoterapi süreci hakkındaki bilgi düzeylerinin arttırılması gerektiği görüşüne varıldı.

Anahtar Kelimeler: *Engelli çocuk, Bakımveren, Fizyoterapi, Spor, Farkındalık*

---

[1] **Hatice Adıgüzel, PT, PhD (Sorumlu Yazar),** Kahramanmaraş Sütçü İmam Üniversitesi, Sağlık Bilimleri Fakültesi, Fizyoterapi ve Rehabilitasyon Bölümü, Kahramanmaraş/Türkiye, fzthatis@gmail.com
[2] **Pınar Kuyulu, PT, MSc.** SANKO Universitesi, Sağlık Bilimleri Fakültesi, Fizyoterapi ve Rehabilitasyon Bölümü, Gaziantep/Türkiye, pinar.kuyulu@gmail.com
[3] **Nevin Ergun PT, PhD.** SANKO Universitesi, Sağlık Bilimleri Fakültesi, Fizyoterapi ve Rehabilitasyon Bölümü, Gaziantep/Türkiye, nevinergun53@gmail.com

H.Ü. Sağlık Bilimleri Fakültesi Dergisi
Cilt:10, Sayı:3, 2023
Doi:10.21020/husbfd.1229106

Original Research

Determination of Awareness Levels of Caregivers for Children with Disabilities About Their Children's Disease, Physiotherapy, and Sports Activities

Hatice Adıgüzel[1], Pinar Kuyulu[2], Nevin Ergun[3]

Submission Date: January 3rd, 2023 **Acceptance Date:** June 14th, 2023 **Pub.Date:**December 31st, 2023
Online First Date: October 23st, 2023

Abstract

Objective: The aim of the study was to determine the awareness levels of caregivers of disabled children about their child's illness, physiotherapy, and sports activities.
Materials and Methods: Caregivers (n=65) of children with a mean age of 6,50±5,29 diagnosed with cerebral palsy (CP), spina bifida (SD), Down syndrome (DS), and muscular dystrophy (MD) were included in the study. The 'Disease, Physiotherapy, and Sports Awareness Questionnaire' consisting of 12 multiple-choice questions specific to disease groups was applied.
Results: Of the caregivers (n=65) with a mean age of 34.43±10.16 who participated in the study (83% mothers, 4.6% fathers, 4.6% siblings, and 7.7% others). The definition of the disease was made correctly at 92.9% in the DS, 63.6% in the CP, 85.7% in the SB, and 72.7% in the MD group. Sensory problems in SB were known at a rate of 26.7%. 85.7% of the DS, 62.5% of the CP, 40% of the SB, and 45.5% of the MD group had accurate information in terms of physiotherapy content. There was no significant difference between the groups ($p>0.05$) when caregivers' responses about participation in sports activities were compared according to disability groups. Of caregivers for children with DS, 92.9%, 75% of CP, 58.3% of MD, and 92.9% of SB stated that their children could do sports.
Conclusions: All caregivers thought that sports would positively affect their children's general well-being, motivation, and increase in physical capacity. Although it was identified that the disease awareness levels of caregivers for children with disabilities and their ideas about sports activities were at a good level.

Keywords: *Children with disabilities, Caregiver, Physiotherapy, Sports, Awareness*

---

[1] **Hatice Adıgüzel, PT, PhD (Corresponding Author),** Kahramanmaras Sutcu Imam University, Faculty of Health Sciences, Department of Physiotherapy and Rehabilitation, Kahramanmaras/Turkey, fzthatis@gmail.com
[2] **Pınar Kuyulu, PT, MSc.** SANKO University, Faculty of Health Sciences, Department of Physiotherapy and Rehabilitation, Gaziantep/Turkey, pinar.kuyulu@gmail.com
[3] **Nevin Ergun PT, PhD.** SANKO University, Faculty of Health Sciences, Department of Physiotherapy and Rehabilitation, Gaziantep/Turkey, nevinergun53@gmail.com

Introduction

Disability is a general term that includes disorder, activity limitation, and participation restriction. Disability defines the outcome of the interaction between a health condition and the environmental and personal factors in which the person with this health condition is present. According to the International Classification of Functioning, Disability and Health (ICF), disability is a complex and multidimensional phenomenon (Rom Perenboom& Astrid Chorus, 2003; Karande et al., 2008). The impact of both individual characteristics and social factors is essential for understanding the disability and performing the correct interventions (Karande et al., 2008).

Disability is a condition that impacts not only the child but also the whole family and caregivers in terms of physical, emotional, and social expectations. Having a disabled child creates considerable challenges for families in their social environment, lifestyles, psychological health, business life, relationships with the family and financial situation (Basaran et al., 2013; Beaton et al., 2000; Costa & Pinto-Gouveia, 2013; Schneidert et al., 2003). In this respect, all caregivers develop numerous coping strategies. Developing these strategies begins with knowledge about the disease and therapy period well. In addition, the knowledge of caregivers about physiotherapy and rehabilitation approaches and sports activities that their children can participate in, positively affects the participation parameters of both caregivers and children. Also cultural and ethnic factors are among the factors determining the adaptation of families (Kim et al., 2021).

Family has a fundamental role in the development and support of disabled children (Kim et al., 2021). It is easier for families to seek government and social support services when they are more aware of their children's status, sufficiency, or shortcomings. So reducing the levels of despondency among families may get easier (Jensen et al., 2014). Hence, it is necessary to assess the awareness of the social integration of individuals with disabilities. These assesments can provide information for healthcare professionals to perform necessary interventions (Beaton et al., 2000). It is important for them to know what extent parents are familiar with physical education and sports and at what level they directly or indirectly affect their children's physical, mental, psychological, and social development in terms of directing children with disabilities, who maintain their lives more or less dependently, to sports activities (Devereux et al., 2015).

Family-centered approaches are currently known as the most successful therapy models in terms of physiotherapy and rehabilitation of disabled children (Konukbay & Arslan, 2015).. Since the family is known to be of great importance in terms of ensuring the child’s active participation in life (Konukbay & Arslan, 2015). Therefore, the success of rehabilitation depends on providing family interaction, identifying and supporting their needs and problems. It has been observed that studies generally emphasize the inadequacy of physical activity and sports participation levels of children with disabilities, or focus on increasing the level of consciousness by providing training on physiotherapy (Karande et al., 2008; Martin Ginis et al., 2016). However, as far as is known, no studies have been found comparing the disease, physiotherapy and sports awareness levels of caregivers in children from different disabled populations. Recent studies has emphasized indivudual psychological factors (negative emotions, attitudes, selfperceptions, and behaviour change strategies), support for interpersonal factors (social support; others' attitudes toward people with disabilities, knowledge of people within institutions; rehabilitation processes; design and construction of public buildings; and program factors, products and technology for recreational activities) were frequently related to inadequate physical activity participation for disabled children (Martin Ginis et al., 2016). Gender, family income, and household structure, financial burden and lack of opportunities were noted as the leading barriers to physical activities (Memari et al., 2015). Studies shown that parents' priorities for their children and youth with cerebral palsy differed depending on age and gross motor function level; however, the most frequent priority for all age groups was daily activities (Chiarello et al., 2010). One of the studies about the physiotherapy knowledge of disabled children, determined that mothers were aware of the benefits of therapy and and how crucial it was for it to continue at home (Domenech et al., 2016). Read et al.'s study revealed that the siblings of children who have been diagnosed with DMD learn more about the disease from their parents (Read et al., 2011).

Studies have indicated that despite the success of sports and paralympic programs for children with disabilities, opportunities to participate in physical activity, exercise or competitive sports are limited (Carbone et al., 2021). The barriers to participation are child, family, social barriers and inadequate advocacy at the local, state and federal levels (Carbone et al., 2021). Studies have shown that parents' physiotherapy and occupational therapy goals; demonstrated that movement for functionality, physical health and fitness, happiness by increasing acceptability by others, and therapy should be balanced with the needs of daily life and facilitate responsibility or role change (Wiart et al., 2010). In this respect, the aim of the present study is to determine the awareness levels of caregivers for children with disabilities about their participation in sports activities by identifying their levels of knowledge about their children's disease and physiotherapy processes.

Materials And Methods

Research Design and Subjects

The current research is a qualitative survey study. This survey study was consisted of the Disease, Physiotherapy, and Sports Awareness Questionnaire. This questionnaire was prepared by the two experienced pediatric physiotherapists (PTs) and one sports' PT at least 5 years experienced. Only three themes were selected for the questions. The questions was designed with the interview of the partners's of rehabilitation centers. Partners gave information about having difficulties for orienting families for these themes. The themes were selected according to the caregivers' awareness of the disease, physiotherapy and sports activities and the children's mobility levels. The study was carried out with the six rehabilitation centers determined in Gaziantep between April and August 2019. In this context, face-to-face interviews were conducted with 65 caregivers. Data were collected through face-to-face interviews based on guideline questions in a multiple-choice questionnaire about the level of understanding of the role, effectiveness, and different physiotherapy modalities of physiotherapy in the treatment of children with CP, awareness of sports activities apart from outpatient treatment. All interviews were recorded and analyzed. The study was conducted with caregivers (n= 65) of children with a mean age of 6.50±5.29 years, diagnosed with cerebral palsy (CP), spina bifida (SD), Down syndrome (DS), and muscular dystrophy (MD) and having active therapy in rehabilitation centers. The children participating in the study had the independent mobility of daily living transfer activities, also they could walk independently with an mobility aid or independently. Caregivers of children who lives in Gaziantep, diagnosed with SB, DS, MD, and CP, with the GMFCS (Gross Motor Function Classification System) level I-IV and aged 4-20 years who voluntarily participated in the study were included in the research. Caregivers who diagnosed by mental disorder were excluded. All caregivers signed the informed consent form.

Measurements

The 'Disease, Physiotherapy and Sports Awareness Questionnaire' was applied to caregivers of disabled children. The demographic information of caregivers and children was recorded. This questionnaire consisted of 12 multiple-choice questions about the disease, physiotherapy, and sports specific to each disease group. Questionnaires were applied by the researchers to all parents through face-to-face interviews. The survey design was adapted from Karende et al.'s study for CP children to other disabled children (Karande et al., 2008). The survey was piloted by several pediatric PTs, and the partners of rehabilitation centers external to the research team, to ensure understanding of the text by caregivers. The final version of the questionnaire was created by the researchers according to these interviews.

Approval for the research was received the Clinical Research Ethics Committee of SANKO University (2019/03-17). The study was performed in accordance with the Declaration of Helsinki. The clinical trial number is NCT05228405.

Statistical Analysis

IBM SPSS 24 package program was used for statistical analyses (SPSS Inc., Chicago, IL, USA). When the power analysis was performed with alpha: 0.05, power: 0.80 in the G-Power program using the pre-training Parental Responses to Questionnaire averages in the Questionnaire according to Karande et al.'s studies, it was calculated as at least 12 people for each group. (Karande et al., 2008). The conformity of the data to the normal distribution was tested by the Shaphiro-Wilk test. Mean and standard deviation values were given for continuous variables as descriptive statistics. Frequency and percentage values were calculated for qualitative variables. The chi-square test was used for group comparisons of qualitative variables. P value <0.05 was accepted as statistically significant.

Results

Of the caregivers participating in the study with a mean age of 34.43±10.16 (n=65), 83% were mothers, 4.6% were fathers, 4.6% were siblings, and 7.7% were other people. The children's mean age was 6.50±5.29, and their physiotherapy duration was 6.68±7.06. Table 1 contains all other sociodemographic characteristics of caregivers and children. Of 92.9%, caregivers for children with DS, 75% of caregivers for children with CP, 58.3% of caregivers for children with MD, and 92.9% of caregivers for children with SB stated that their children could do sports. No significant difference was found between the groups upon comparing responses about participation in sports activities according to the disease groups (p>0.05) (Table 2).

Table 1. Demographics of the children and caregivers

Caregivers n (%) (n=65)	Mother 54 (83.1) Father 3 (4.6) Siblings 3 (4.6) Other 5 (7.7)
Caregivers' Sex n (%)	Male 7 (10.8) Female 58 (89.2)
Caregivers' Occupation n (%)	Housewife 58 (73.8) Working 7 (10.8)
Caregivers' Education n (%)	None 3 (4.6) Primary School 25 (38.5) Secondary School 17 (26.2) High School 16 (24.6) Bachelor' Degree 4 (6.2)
Caregivers' Marital Status	Married 58 (89.2) Single 6 (9.2) Divorcee 1 (1.5)
Caregivers' Income Level	less than expenses 28 (43.1) income equals expense 29 (44.6) more than expense 8 (12.3)
Number of the children of the Caregivers'	None 2 (3.1) One children 2 (3.1) Two children 18 (27.7) >Two children 43 (66.1)
Children Sex n (%)	Male 36 (55.4) Female 29 (44.6)
Disability classification n (%) (n=65)	Down Syndrome 14 (21.5) Cerebral Palsy 24 (36.9) Muscular Dystrophy 12 (18.5) Spina Bifida 15 (23.1)
Comorbidities n (%)	Yes 22 (33.85) No 43 (66.15)
Comorbidity type n (%)	Heart 4 (6.2) Hearing 2 (3.1) Vision 7 (10.8) Other 9 (13.8)
Previous Surgery n (%)	Orthopedic 8 (12.3) Brain and Spinal Cord 10 (15.4) Heart 1 (1.5) Other 2 (3.1)
PT Frequency n (%)	One day per week 7 (10.8) 2 days per week 52 (80) 5 days per week 6 (9.2)
	Mean±SD (min-max)
Children's age (year)	6.50±5.29 (4-20)
Children's weight	23.77±20.28 (7-90)
Children's height	109.12±34.36 (60-177)
Caregivers' age	34.43±10.16 (14-63)
Caregivers' weight	65.78±10.42 (45-90)
Caregivers'height	160.67±16.22 (63-180)
Children's PT duration from birth	6.68±7.06 (0.5-20)

n: Number, **%:** Percent, **PT:** Physiotherapy

	Yes (n/%)	**No (n/%)**	**Don’t know (n/%)**	**Total (n)**	**p değeri**
DS	13 %92,9	1 %7.1	0 %0	14	0.182
CP	18 %75	3 %12.5	3 %12.5	24	
MD	7 %58.3	4 %33.3	1 %8.3	12	
SB	13 %92.9	1 %7.1	0 %0	14	
Total (n)	51 %79.7	9 %14.1	4 %6.3	64	

Table 2. Comparison of responses to sports participation according to disease groups

*p<0.05, **n:** Number, **%:** Percent, **DS:** Down Syndrome, **CP:** Cerebral Palsy, **MD:** Muscular Dystrophy, **SB:** Spina Bifida

Of caregivers for children with DS, 92.9% defined the disease correctly, 21.5% found physiotherapy beneficial, 71.4% indicated immediately after birth as the age of onset of physiotherapy, 85% indicated the purpose of physiotherapy correctly, 21.4% stated health problems as cardiac disease, 14.3% as orthopedic problems, and 64.3% as all. It was found that 85.7% of caregivers for children with DS had correct information about the content of the physiotherapy program. It was seen that 7.1% of caregivers for children with DS thought their children could participate in Boccia, 7.1% in horse riding, and 85.7% in all sports branches. In terms of determining the disability type, 14.3% of the caregivers gave correct answers, and 57.1% thought that their child did not have a disability (Table 3).

Of caregivers for children with DS, 92.9% defined the disease correctly, 21.5% found physiotherapy beneficial, 71.4% indicated immediately after birth as the age of onset of physiotherapy, 85% indicated the purpose of physiotherapy correctly, 21.4% stated health problems as cardiac disease, 14.3% as orthopedic problems, and 64.3% as all. It was found that 85.7% of caregivers for children with DS had correct information about the content of the physiotherapy program. It was seen that 7.1% of caregivers for children with DS thought heir children could participate in Boccia, 7.1% in horse riding, and 85.7% in all sports branches. In terms of determining the disability type, 14.3% of the caregivers gave correct answers, and 57.1% thought that their child did not have a disability (Table 3).

Table 3. Questionnaire used for the Down Syndrome Children Interview

Questions	Answers	n (%)
1. Which of the following is true for Down syndrome?	Occurs after high fever	0 (0)
	Disease related to chromosomes	13 (92.9)
	Occurs in people with jaundice after birth	1 (7.1)
	There is extreme stiffness in the joints	0 (0)
2. Do you think physical therapy is beneficial for individuals with Down syndrome?	Yes	14 (21.5)
	No	51 (78.5)
3. When should the physiotherapy program start in individuals with Down syndrome?	immediately after birth	10 (71.4)
	after 2 years 3	3 (21.4)
	After puberty	1 (7.1)
	Immediately after starting to speak	0 (0)
4. In your opinion, which one is true about the physical therapy program applied to individuals with Down syndrome?	The arms and legs are moved regularly in the supine position.	0 (0)
	The muscles should be lengthened by stretching the arms and legs while lying on the back regularly.	1 (7.1)
	In order to accelerate normal motor development, sitting, kneeling, standing up and walking exercises should be done with active participation.	11 (85.7)
	It should swing regularly on the swing and on the ball.	2 (14.3)
5. Which of the following health problems do individuals with Down syndrome have?	Heart diseases	3 (21.4)
	Obesity	0 (0)
	Orthopedic problems	2 (14.3)
	All	9 (64.3)
6. Can individuals with Down syndrome participate in any sports activities other than physiotherapy?	Yes	13 (92.9)
	No	1 (7.1)
7. What sports can individuals with Down Syndrome do?	Swimming	0 (0)
	Football	0 (0)
	Boccia (game similar to bowling)	1 (7.1)
	Shooting	0 (0)
	Horseback riding (equestrian/hipotherapy)	1 (7.1)
	table tennis	0 (0)
	All	12 (85.7)
	Swimming	0 (0)
8. Can individuals with Down syndrome have a job?	Yes	12 (85.7)
	No	2 (14.3)
9. What kind of disability do you think Down syndrome is?	Mental disability	2 (14.3)
	Physical disability	1 (7.1)
	I don't think he has a disability	8 (57.1)
	I think he has both mental and physical disabilities	2 (14.3)
	I think they are autistic	1 (7.1)
10. Which of the following is not a physical characteristic of Down syndrome?	curly hair	12 (85.7)
	Wide forehead	0 (0)
	Nape thickness more than	1 (7.1.)
	Flat nose	1 (7.1)
11. Can Down syndrome be diagnosed before birth?	Yes	12 (85.7)
	No	2 (3.1)
12. Which methods are used in the prenatal diagnosis of Down syndrome?	Ultrasound	0 (0)
	Double test	1 (7.1)
	Triple test	0 (0)
	All	13 (92.9)

Of caregivers for children with CP, 63.6% knew the disease definition correctly, 70.8% gave correct answers for the accompanying diseases, and 62.5% answered correctly about the content of the physiotherapy program. It was found that 62.5% of the caregivers thought that sports activities could contribute to children in terms of social support, motivation, and disciplined working skills in terms of gains. The caregivers indicated 26.1% of the physiotherapy and rehabilitation methods as sensory integration therapy, 4.3% as aquatherapy, 13% as manual or suit therapy, and 8.7% as neurodevelopmental therapy (NDT). Of the caregivers, 47.8% stated that their children could participate in swimming, 13% in gymnastics, and 13.8% in all of them (Table 4).

Among the caregivers, it was observed that the disease diagnosis was made correctly only at a rate of 26.7% in children diagnosed with SB. It was revealed that 26.7% of caregivers for children with SB stated that their children could prefer swimming, 13.3% could prefer Boccia, shooting, or horse riding, and 26.7% could do all of them. All caregivers agreed that 46.7% of the children could improve on issues such as motivation, communication, and physical capacity increase by participating in sports activities. Of the caregivers, 85.7% correctly determined the comprehensive definition of SB. In terms of physiotherapy, 33.3% of the caregivers thought that hippotherapy, 26.7% suit therapy, 26.7% taping, and 13.3% thought that sensory integration therapy would not be applied. The caregivers thought that sports activities could improve social support, motivation, and diciplined working abilities in 53.3% of these children (Table 5).

Among caregivers for children diagnosed with MD, 72.7% made the disease definition correctly, 45.5% thought that the disease progressed slowly but it progressed rapidly in the cardiac muscle, and 36.4% thought that the diseases displayed different severity in each child. Concerning physiotherapy practices, 36.4% of the caregivers stated that their children could do resistance exercises, 18.2% electrotherapy, 9.1% aquatherapy, and 36.4% pilates. Of the caregivers, 6.7% stated that exercise, 25% electrotherapy, and 16.7% respiratory rehabilitation was not one of the physiotherapy approaches. The caregivers thought that with sports, their children's general well-being would increase by 16.7%, physical capacity would increase by 25%, and 58.3% thought that their children would be positively impacted in every aspect. The caregivers agreed that their children required attention in terms of fatigue at a rate of 45.5% in sports activities (Table 6).

Table 4. Questionnaire used for the Cerebral Palsy Children Interview

	Questions	**Answers**	**n (%)**
1.	**Which of the following is true for cerebral palsy?**	It is a non-progressive disease of the brain, in which movements and posture (body shape and alignment) cannot be changed	3 (13.6)
		It is a progressive disease of the brain, movements and posture may change	2 (9.1)
		It is a non-progressive disease of the brain, movements and posture may change	14 (63.6)
		It is a progressive muscle disease, movements and posture may change.	3 (13.6)
2.	**Which of the following does not accompany cerebral palsy?**	Gait disorders	2 (8.3)
		Balance problems	2 (8.3)
		Bone fractures	17 (70.8)
		Difficulty in movements	3 (12.5)
3.	**Which of the following should be included in the physiotherapy program for cerebral palsy?**	Exercises to increase balance	1 (20.8)
		Hippotherapy	1 (4.2)
		Muscle strengthening exercises	1 (4.2)
		Orthosis	1 (4.2)
		Standing Table	2 (3.1)
		All	15 (62.5)
4.	**Can individuals with cerebral palsy participate in sports activities?**	Yes	18 (75)
		No	3 (12.5)
		I don't know	3 (12.5)
5.	**What do you think with which of the following characteristics sports can provide children with cerebral palsy?**	Social support	4 (16.7)
		Motivation	4 (16.7)
		Disciplined work	1 (4.2)
		All	15 (62.5)
6.	**In your opinion, which of the following does not accompany cerebral palsy?**	Communication problems	5 (21.7)
		Behavioral disorders	1 (4.3)
		Seizures	2 (8.7)
		All	8 (34.8)
7.	**Do you think siblings of children with cerebral palsy may also have the same disease?**	Yes definitely	2 (8.7)
		Maybe	6 (26.1)
		No it won't	10 (43.5)
		I don't know	5 (21.7)
8.	**When do you think treatment should start in individuals with cerebral palsy?**	as soon as diagnosed	18 (78.3)
		Medication is sufficient	2 (8.7)
		after puberty	3 (4.6)
		when physical losses begin	3 (4.6)
9.	**Which of the following is not a disorder that can accompany cerebral palsy?**	Diabetes	0 (0)
		Mental retardation (intelligence problems)	2 (9.5)
		Epilepsy (Seizure)	0 (0)
		Visual disturbances	2 (9.5)
		Hip dislocation	1 (4.8)
		Joint stiffness	1 (4.8)
10.	**Which of the following is one of the physiotherapy and rehabilitation practices in children with cerebral palsy?**	Sensory integration therapy	6 (26.1)
		Aquatherapy	1 (4.3)
		Space therapy	3 (13)
		Bobath therapy (Neurodevelopmental Therapy-NDT)	2 (8.7)
		Manual therapy	3 (13)
		All	8 (34.8)
11.	**Which sports do you think children with cerebral palsy can participate in?**	Swimming	11 (47.8)
		Gymnastics	3 (13)
		Tennis	0 (0)
		Can join all	9 (13.8)
12.	**In your opinion, what can children with cerebral palsy achieve by participating in sports?**	There is an increase in general well-being	2 (8.7)
		There is an increase in physical capacity	5 (21.7)
		Increasing communication skills	0 (0)
		Increased fatigue	0 (0)
		All	16 (69.6)

n: Number, **%:** Percent

Table 5. Questionnaire used for the Spina Bifida Children Interview

Questions	Answers	n (%)
1. Which of the following is true for the diagnosis of spina bifida?	There is a risk of osteoporosis	0 (0)
	There may be neurological findings (loss of sensation, loss of muscle strength, urinary problems, etc.)	4 (26.7)
	There is a risk of hip dislocation	7 (46.7)
	All	4 (6.2)
2. Which of the following is incorrect for shunt problems in children using shunts in spina bifida?	Squint eye (strabismus..etc)	2 (15.4)
	Vomiting	2 (15.4)
	Headache	3 (23.1)
	Frequent falls	6 (46.2)
3. What sports can children with spina bifida do?	Swimming	4 (26.7)
	Football	1 (6.7)
	Boccia	2 (13.3)
	Shooting	2 (13.3)
	Horse Riding	2 (13.3)
	All	4 (26.7)
4. What can be achieved by participating in sports in spina bifida?	General well-being	4 (26.7)
	Increase in physical capacity	3 (20)
	Increasing communication skills	1 (6.7)
	All	7 (46.7)
5. Do children with spina bifida have sensory problems (loss of sensation)?	No	4 (26.7)
	Can be in some cases	4 (26.7)
	Yes	5 (7.7)
	I don't know	2 (3.1)
6. Can children with spina bifida participate in various sports activities?	Yes	13 (92.9)
	No	1 (1.5)
	I don't know	0 (0)
7. Which of the following is a risk factor for spina bifida?	Folic acid deficiency	12 (80)
	Genetic predisposition	0 (0)
	Diabetes in pregnancy	0 (0)
	All	3 (4.6)
8. Which of the following is not true for children with spina bifida who have open wounds?	There is a risk of infection	4 (26.7)
	Surgical intervention should not be delayed	2 (13.3)
	Wound cleaning is important	1 (6.7)
	The injured part should be covered with taping	8 (53.3)
9. Which of the following is correct for the comprehensive definition of spina bifida?	It is a bone deformity that occurs in the womb	3 (21.4)
	Outward herniation in the lumbar region	5 (35.7)
	It is the closure problem of the central nervous system (brain and spinal cord) that occurs in the mother's womb	4 (85.7)
	Infection of the spine	2 (14.3)
10. Which of the following physiotherapy approaches is not used for sensory problems in children with spina bifida?	Hippotherapy	5 (33.3)
	Suit therapy	4 (26.7)
	Taping	4 (26.7)
	Sensory integration therapy	2 (13.3)
11. Which of the following physiotherapy approaches should not be performed in children with spina bifida who have open wounds?	Aquatherapy	7 (46.7)
	Balance-coordination exercises	1 (6.7)
	Capturing normal motor development and muscle strengthening	6 (40)
	Sensory integrity training	1 (6.7)
12. In your opinion, with which of the following characteristics can sports provide especially children with spina bifida?	Social support	3 (20)
	Motivation	2 (33.3)
	Disciplined work	2 (13.3)
	All	8 (53.3)

n: Number, **%:** Percent

Table 6. Questionnaire used for the Muscular Dystrophy Children Interview

Questions	Answers	n (%)
1. Which of the following is true for the definition of muscle diseases?	It is a progressive disease of the heart muscle	1 (9.1)
	It is a non-progressive disease of the heart muscle	1 (9.1)
	It is a progressive disease of skeletal muscles	8 (72.7)
	It is a non-progressive disease of skeletal muscles	1 (9.1)
2. Which of the following is true about the progression of muscle diseases?	It is a severe progressive disease	0 (0)
	It progresses slowly, progresses rapidly in the heart muscle	5 (45.5)
	The disease progresses slowly in the heart, progresses rapidly in the skeletal muscle	2 (18.2)
	The disease shows different severity of weakness in each child	4 (36.4)
3. Which of the following can primarily accompany muscle diseases?	Cardiac involvement	5 (55.6)
	Kidney involvement	0 (0)
	Lung involvement	0 (0)
	All	4 (44.4)
4. Which of the following is a problem that can cause limitations in muscle diseases?	All	4 (33.3)
	Perceptual problems	0 (0)
	Gait problems	7 (58.3)
	Respiratory problems	1 (8.3)
5. Which of the following is not a physical therapy practice for muscle diseases?	Electrical stimulation	2 (18.2)
	In-water applications	1 (9.1)
	Resistance exercises	4 (36.4)
	Pilates	4 (36.4)
6. What can cause decreased mobility in muscle diseases?	Obesity	4 (36.4)
	Osteoporosis (bone loss)	0 (0)
	Decreased general well-being	4 (36.4)
	All	3 (27.3)
7. Which of the following is not a secondary problem that may occur in wheelchair or bed-bound muscle disease patients?	Decubit ulsers	1 (10)
	Osteoporosis (bone loss)	3 (30)
	Scoliosis (curvature of the spine)	1 (10)
	Swallowing problems	5 (50)
8. Which of the following is not a physical therapy practice for muscle disease patients?	Exercise program	2 (16.7)
	Electrical stimulation	3 (25)
	Diet program	5 (41.7)
	Respiration exercises	2 (16.7)
9. In your opinion, can your child with muscle disease participate in sports?	Yes 7 (58.3)	
	No 4 (33.3)	
	I don't know 1 (8.3)	
10. What do you think your child with muscle disease can achieve by participating in sports?	Increasing general well-being	2 (16.7)
	Increasing physical capacity	3 (25)
	Improving communication skills	0 (0)
	All	7 (58.3)
11. Which of the following problems should children with muscle diseases pay attention to in sports?	Respiratory problems	0 (0)
	Rapid fatigue	5 (45.5)
	Joint and muscle problems	0 (0)
	All	6 (54.5)
12. Which of the following sports should be excluded in muscle diseases?	Weightlifting	11 (100)
	Gymnastics	0 (0)
	Swimming	0 (0)
	table tennis	0 (0)

n: Number, **%:** Percent

Discussion

The present research is the first study in Turkey that investigates the knowledge and familiarity of primary caregivers about the disease, physiotherapy, and sports activities in different disability groups. This study found that primary caregivers with DS, CP, SB, and MD in Turkey have knowledge about disease. However, caregivers for children with DS had the highest level of awareness about the diagnosis, followed by caregivers with MD and CP, whereas knowledge with the diagnosis was low in caregivers for children with SB. When caregivers with SB were questioned in terms of detailed prenatal identification, it was revealed that knowledge increased. The correct definition about physiotherapy and rehabilitation approaches were high in the groups receiving physiotherapy for at least 5 years, except for caregivers of the MD group. However, only low percentage of caregivers with DS found physiotherapy beneficial. It was determined that the highest level of knowledge in terms of physiotherapy content was in caregivers for children with DS, CP, SB, and MD, respectively. It was seen that over half of caregivers' responses about their children's ability to participate in sports activities were positive in all groups. It was observed that 75% of the caregivers, other than those for children with MD, thought that their children could easily participate in sports. Moreover, all caregivers thought that sports activities would increase motivation, communication, disciplined working skills, and physical capacity in these children. Domenech et al. stated that physiotherapy was perceived positively and mothers of children with CP cared about and had knowledge about physiotherapy by emphasizing that it provided physical, psychological, and social improvements in their children. The researchers also determined that mothers were aware of the benefits of therapy and and how crucial it was for it to continue at home (Domenech et al., 2016). Fereday et al. revealed that parents of children with chronic diseases such as cystic fibrosis and asthma had a good level of knowledge about the disease and they thought that their children's diseases did not adversely affect their participation in physical activity and sports (Fereday et al., 2009). In this study, parents stated that planning and structuring activities required attention to maximize their children's participation in physical activity and minimize possible complications that might arise from their diseases (Fereday et al., 2009). Parents in this study emphasized to the importance of being physically active with other children to promote normality, not just for the health benefits of physical activity. Due to these beliefs, it was observed that they actively encouraged their children to participate in physical activities and competitive sports (Fereday et al., 2009). Parental attitude is the most important factor influencing the belief in physical activity participation of children (Pianosi &

Davis, 2004). This finding was supported by the study by Lang et al. showing that when parents of children with asthma believed that exercise could relieve asthma, their children were more active (Lang et al., 2004).

Webb emphasized the importance of trusting parents in his study on families of individuals with Duchenne MD (DMD). This study stressed that it was difficult for parents to be knowledgeable. The researcher argued that the knowledge level of parents increased over time. It was indicated that parents shared information with experts on DMD and its outcomes to empower all patients (Webb, 2005). In the same study, it was stated that the first issue parents dealt with was the diagnosis process (Webb, 2005). It is thought that parents' acceptance of the diagnosis enables them to develop effective coping methods (Webb, 2005). There is a growing recognition in the literature that children need information and support to help them create personal and social meaning for illness and death. It is claimed that enabling children to assimilate disease knowledge ensures that they cope better and can reduce anxiety (Forrest et al., 2006; Scott et al., 2003). The study by Read et al. revealed that siblings of children diagnosed with DMD learned more about DMD from their parents over time in accordance with the evolving nature of the disease and the level of knowledge of siblings was variable (Read et al., 2011). Although the number of parents participating in our study was high, the disease knowledge levels of mothers were found to be quite high in the MD, DS, and CP groups, except SB. These results suggested that the disease knowledge levels of caregivers for children with SB should be increased.

Fereday et al. determined that participation in physical activity could not be prevented by a chronic disease (Fereday et al., 2009). In this study, the researchers revealed that children had beliefs and perceptions that they could 'do anything' that their peers did in relation to physical activity and parents had motivations that they 'would do anything' to make it happen (Fereday et al., 2009). In our study, caregivers thought that disability could not prevent their children from doing any sports. Therefore, if social policies to direct children with disabilities to sports are increased, it is suggested that caregivers in Turkey would not prevent their children from doing sports and families could support their children.

The study by Meldrum et al. revealed that although most families received genetic counseling, their genetic knowledge of spinal muscular atrophy (SMA) was highly variable. This study determined that most families received counseling from neurologists. However, it was reported that a consistent approach was required to facilitate how and when genetic counseling was received by families (Meldrum et al., 2007). Our study identified that caregivers for children with MD and DS had good knowledge about the genetic transmission of the disease (Meldrum et al., 2007). This demonstrated that the genetic knowledge and awareness levels of caregivers could vary in different muscle diseases and disability conditions. It is thought that these results may vary due to the small number of studies conducted with caregivers with MD.

Jobling et al. determined that although the majority of young people with DS had some awareness of basic hygiene, these behaviors were not yet at a level that they could realize without parental support (Jobling & Cuskelly, 2006). Furthermore, it was observed that the knowledge levels about substance use, exercise, and healthy nutrition were poor in young people with DS. Hence, it was revealed that individuals with DS had poor knowledge of most aspects of health (Jobling & Cuskelly, 2006). Our study examined the awareness levels of caregivers about their children’s disease, sports, and physiotherapy. It was concluded that, unlike children, parents' knowledge levels about their children's disability level, benefits of physiotherapy, and sports activities must be increased.

Studies have emphasized that responsibility for care and management can be taken if good knowledge is provided about the diagnosis, medications, medical care, and assistive devices suitable for the developmental level for the self-management of the disease in patients with MD (Colvin et al., 2018). It is also indicated that parent education should be managed. It is emphasized that this education required for awareness must be comprehensive, e.g., at a minimum level, modifications of activities that may be harmful to the muscles at school (such as a PE class), compensations to reduce energy consumption and fatigue (e.g., walking long distances until lunch), safety measures (e.g., playground activities), accessibility (e.g., adaptive technology and stair climbing), planning in advance for absences due to medical reasons, setting goals and planning for future education or occupation (Colvin et al., 2018). In this respect, our study showed on caregivers for MD children in Turkey needs education about respiratory problems and scoliosis.

Information was collected from mothers of children with DS in a study identifying parental perceptions of family support services (Van Riper, 1999). The results demonstrated that mothers were more satisfied with the care their children received and were more likely to seek help from health services when they believed their family's relationships with their health care provider were positive and family-centered. The findings of this study contribute to a better understanding of the role that healthcare providers play in individual and family adjustment to chronic conditions [22]. Although the philosophy and principles of family-centered care are frequently mentioned in the literature, it is more accepted that family-centered care is far from a reality (Van Riper, 1999). It is emphasized that most parents need family-centered care. There is a need for more studies to explain how families receive family-centered care. In this respect, it is thought that researching the awareness levels of families' perspectives on their children's disease in every aspect will also contribute to family-centered care systems.

The physiotherapy and rehabilitation programs for children with chronic physical disabilities points at increasing emphasis on parental involvement. Over time, the role of parents in physiotherapy has changed from a passive to an active role (Jansen et al., 2003). There are pieces of evidence in the literature indicating that parents of individuals with physical disabilities should be actively involved in their children's physiotherapy content and work in equal partnership with therapists in the goal-setting process (Jansen et al., 2003; Kolobe, 1991; Milner et al., 1996). Studies have reported significant differences between the perception of the functional level of their children by parents of children with CP and the performance of gross motor skills (Tieman et al., 2004). Accordingly, in our study investigating the awareness levels of parents and caregivers, although caregivers for children with DS knew the purpose of physiotherapy correctly, their belief that it could provide improvement in children was low, whereas the knowledge levels about physiotherapy methods were found to be high in caregivers for all children. Nevertheless, it was revealed that caregivers with MD had a low rate of accurate knowledge about the exercise methods used in physiotherapy, which was thought to have probably originated from providing less information due to a low number of children with MD in rehabilitation centers. While these results demonstrate that the levels of knowledge of caregivers with MD about physiotherapy approaches should be increased, it is recommended to organize various in-service training in order to show the effectiveness of physiotherapy for caregivers with DS and demonstrate its effectiveness by regular assesments.

Our limitations are that the number of caregivers is small and the study sample consists of only one province. Moreover, the awareness levels of caregivers were determined in the current study. In further research, it is recommended to determine the awareness levels of children with different disabilities, their caregivers or siblings of the disease, sports, and physiotherapy.

The results of the present study demonstrated that caregivers with CP, MD, and SB perceived physiotherapy as an important factor for developing social independence, which accelerates motor development in their children and prevents deformities by providing rehabilitation. However, DS group had low levels of the effectiveness of physiotherapy. Nevertheless, it was revealed that the knowledge of the disease was higher in the caregivers for children with DS, while caregivers for children with SB was the worst. It was found that the correct answers about physiotherapy and rehabilitation methods were high, except for caregivers for the MD group. Caregivers' responses to the questions about their children's ability to participate in sports activities were high in all groups. It was seen that 75% of the caregivers, apart from those for children with MD, thought that their children could easily participate in sports. It was also demonstrated that all caregivers thought that sports activities would increase motivation, communication, disciplined working skills, and physical capacity in these children. Accordingly, although it was detected that caregivers for children with disabilities in Turkey had a good level of awareness of the disease and their ideas about sports activities, it was concluded that the knowledge about the physiotherapy should be increased. If caregivers realize the importance of physiotherapy for their children, they will provide the necessary importance and participation in therapy. Thus, they can contribute significantly to the success of rehabilitation by ensuring continuity in physiotherapy in the clinic and integrating it into their daily lives. Also physiotherapists should demonstrate the effectiveness of therapy in this respect through regular assessments.

Acknowledgements

We acknowledge children and their parents who participated the study.

Funding

There is no funding for this study.

Declaration of interest

The authors report no conflicts of interest.

References

Basaran, A., Karadavut, K. I., Uneri, S., Balbaloglu, O., & Atasoy, N. (2013). The effect of having a children with cerebral palsy on quality of life, burn-out, depression and anxiety scores: a comparative study. *Eur J Phys Rehabil Med, 49*(6), 815-822. PMID: 24285025

Beaton, D. E., Bombardier, C., Guillemin, F., & Ferraz, M. B. (2000). Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine, 25*(24), 3186-3191. https://doi.org/10.1097/00007632-200012150-00014

Carbone, P. S., Smith, P. J., Lewis, C., LeBlanc, C. (2021). AAP Council on Children With Disabilities, Council on Sports Medicine and Fitness Promoting the Participation of Children and Adolescents With Disabilities in Sports, Recreation, and Physical Activity. *Pediatrics*, *148*(6), e202105466. https://doi.org/10.1542/peds.2021-054664

Chiarello, L. A., Palisano, R. J., Maggs, J. M., Orlin, M. N., Almasri, N., Lin-Ju Kang L. J., et al. (2010). Family priorities for activity and participation of children and youth with cerebral palsy. *Phys Ther*, 90, 1254 – 1264. https://doi.org/10.2522/ptj.20090388

Colvin, M. K., Poysky, J., Kinnett, K., Damiani, M., Gibbons, M., Hoskin, J., et al. (2018). Psychosocial management of the patient with Duchenne muscular dystrophy. *Pediatrics, 142*(2), 99-109. https://doi.org/10.1542/peds.2018-0333l

Costa, J., & Pinto-Gouveia, J. (2013). A new approach to explain the link between social support and depression in a 2-years arthritis rheumatoid sample. Is there any moderation effect of acceptance? *International Journal of Psychology and Psychological Therapy,* 13, 65-82. https://doi.org/10.1177/1359105313499807

Devereux, P. G., Bullock, C. C., Gibb, Z. G., Himler, H. (2015). Social-ecological influences on interpersonal support in people with physical disability. *Disability and Health Journal, 8*(4), 564-572. https://doi.org/10.1016/j.dhjo.2015.05.002

Domenech, A. C. P., Tavares, K. O., Ruedell, A. M., Nobre, J. R. D. S. (2016). Cerebral palsy: the meaning of physical therapy for mother caregivers. *Fisioterapia em Movimento,* 29, 757-766. https://doi.org/10.1590/1980-5918.029.004.ao12

Fereday, J., MacDougall, C., Spizzo, M., Darbyshire, P., Schiller, W. (2009). There's nothing I can't do–I just put my mind to anything and I can do it: a qualitative analysis of how children with chronic disease and their parents account for and manage physical activity. *BMC pediatrics, 9*(1), 1-16. https://doi.org/10.1186/1471-2431-9-1

Forrest, G., Plumb, C., Ziebland, S., Stein, A. (2006). Breast cancer in the family—children's perceptions of their mother's cancer and its initial treatment: qualitative study. *Bmj, 332*(7548), 998-1003. https://doi.org/10.1136/bmj.38793.567801.ae

Jansen, L. M., Ketelaar, M., Vermeer, A. (2003). Parental experience of participation in physical therapy for children with physical disabilities. *Developmental medicine and child neurology, 45*(1), 58-69. https://doi.org/10.1111/j.1469-8749.2003.tb00861.x

Jensen, M. P., Smith, A. E., Bombardier, C. H., Yorkston, K. M., Miró, J., Molton, I. R. (2014). Social support, depression, and physical disability: age and diagnostic group effects. *Disability and Health Journal, 7*(2), 164-172. https://doi.org/10.1016/j.dhjo.2013.11.001

Jobling, A., & Cuskelly, M. (2006). Young people with Down syndrome: A preliminary investigation of health knowledge and associated behaviours. *Journal of Intellectual and Developmental Disability, 31*(4), 210-218.

Karande, S., Patil, S., Kulkarni, M. (2008). Impact of an educational program on parental knowledge of cerebral palsy. *The Indian Journal of Pediatrics, 75*(9), 901-906. https://doi.org/10.1007/s12098-008-0160-0

Kim, J., Kim, J., Kim, Y., Han, A., Nguyen, M. C. (2021). The contribution of physical and social activity participation to social support and happiness among people with physical disabilities. *Disability and Health Journal, 14*(1), 100974. https://doi.org/10.1016/j.dhjo.2020.100974

Kolobe, T. (1991). Family-focused early intervention. *Pediatric Neurologic Physical Therapy.* (pp. 397-432) in. New York: Churchill Livingstone.

Konukbay, D., & Arslan, F. (2015). The analysis of hopelessness levels and problem solving skills of parents with the disabled children. I*nternational Journal of Caring Sciences, 8*(2), 344-355. http://internationaljournalofcaringsciences.org/docs/11_konukbay.pdf.

Lang, D. M., Butz, A. M., Duggan, A. K., Serwint, J. R. (2004). Physical activity in urban school-aged children with asthma. *Pediatrics, 113*(4), e341-e346. https://doi.org/10.1542/peds.113.4.e341

Martin Ginis, K. A., Ma, J. K., Latimer-Cheung, A. E., Rimmer, J. H. (2016). A systematic review of review articles addressing factors related to physical activity participation among children and adults with physical disabilities. *Health psychology review, 10*(4), 478-494. https://doi.org/10.1080/17437199.2016.1198240

Meldrum, C., Scott, C., Swoboda, K. J. (2007). Spinal muscular atrophy genetic counseling access and genetic knowledge: parents' perspectives. *Journal of child neurology, 22*(8), 1019-1026. https://doi.org/10.1177/0883073807305672

Milner, J., Bungay, C., Jellinek, D., Hall, D. (1996). Needs of disabled children and their families. *Archives of disease in childhood, 75*(5), 399-404. https://doi.org/10.1136/adc.75.5.399

Memari, A. H., Panahi, N., Ranjbar, E., Moshayedi, P., Shafiei, M., Kordi, R., et al. (2015). Children with autism spectrum disorder and patterns of participation in daily physical and play activities. *Neurology research international.* https://doi.org/10.1155/2015/531906

Pianosi, P. T., & Davis, H. S. (2004). Determinants of physical fitness in children with asthma. *Pediatrics, 113*(3), 225-229. https://doi.org/10.1542/peds.113.3.e225

Read, J., Kinali, M., Muntoni, F., Weaver, T., Garralda, M. E. (2011). Siblings of young people with Duchenne muscular dystrophy–a qualitative study of impact and coping. *European journal of paediatric neurology, 15*(1), 21-28. https://doi.org/10.1080/0963828031000137081

Rom Perenboom, J. M., & Astrid Chorus, M. J. (2003). Measuring participation according to the International Classification Of Functioning, Disability And Health (ICF). *Disability and Rehabilitation, 25* (11-12), 577-58. https://doi.org/10.1080/0963828031000137081

Schneidert, M., Hurst, R., Miller, J., Ustun, B. (2003). The role of environment in the International Classification of Functioning, Disability and Health (ICF). *Disability and rehabilitation, 25*(11-12), 588-595. https://doi.org/10.1080/0963828031000137090

Scott, J. T., Prictor, M., Harmsen, M., Broom, A., Entwistle, V. A., Sowden, A. J., et al. (2003). Interventions for improving communication with children and adolescents about a family member's cancer. *Cochrane Database of Systematic Reviews,* (4). https://doi.org/10.1002/14651858.cd004511

Tieman, B. L., Palisano, R. J., Gracely, E. J., Rosenbaum, P. L. (2004). Gross motor capability and performance of mobility in children with cerebral palsy: a comparison across home, school, and outdoors/community settings. *Physical therapy, 84(5)*, 419-429. https://doi.org/10.1093/ptj/84.5.419

Tough, H., Siegrist, J., Fekete, C. (2017). Social relationships, mental health and wellbeing in physical disability: a systematic review. *BMC public health, 17*(1), 1-18. https://doi.org/10.1186/s12889-017-4308-6

Van Riper, M. (1999). Maternal perceptions of family–provider relationships and well-being in families of children with Down syndrome. R*esearch in Nursing & Health, 22*(5), 357-368. https://doi.org/10.1002/(SICI)1098-240X(199910)22:5%3C357::AID-NUR2%3E3.0.CO;2-Q

Webb, C. (2005). Parents’ perspectives on coping with Duchenne muscular dystrophy. *Child: care, health and development, 31*(4), 385-396. https://doi.org/10.1111/j.1365-2214.2005.00518.x

Wiart, L., Ray, L., Darrah, J., Magill-Evans, J. (2010). Parents' perspectives on occupational therapy and physical therapy goals for children with cerebral palsy. *Disability and rehabilitation, 32*(3), 248-258. https://doi.org/10.3109/09638280903095890