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Evaluation of mechanical low back pain and quality of life in caregivers of individuals with neuromuscular diseases

Nöromüsküler hastalığı olan bireylere bakım verenlerde mekanik bel ağrısı ve yaşam kalitesinin değerlendirilmesi

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ABSTRACT

Objective: The aim of this study was to identify variables influencing mechanical low back pain and quality of life in caregivers of children with neuromuscular diseases, and to assess the association between caregivers' mechanical low back pain and quality of life.
Method: This cross-sectional study was conducted in the Muscular Diseases Center of an institute. Between February and July 2019, caregivers of the Muscle Disease Unit were included in the study. Caregivers' Visual Analogue Score (VAS), Functional Ambulation Scale (FAS) and pain treatment status, Revised Oswestry Low Back Pain Disability Questionnaire (ODI), and SF-36 Quality of Life Scale were evaluated using chi-squared and correlation analysis.
Results: The prevalence of low back pain among caregivers was 81.5% (n=135). The participants' VAS and Oswestry scores were 6.1 and 27.4, respectively. Dependency increased with age and duration of diagnosis. There was a positive correlation between caregivers' VAS and ODI scores. SF-36 scores were lower than average.
Conclusion: Neuromuscular diseases are chronic, progressive, often incurable and cause significant problems for paediatric patients and caregivers. As caregiver burden and back pain increase, caregivers' quality of life decreases. Multidisciplinary teams should be established to help caregiver cope with the difficulties.

Keywords: Caregiver burden; low back pain; neuromuscular diseases; paediatric patient; quality of life

ÖZET

Amaç: Bu çalışmanın amacı, pediatrik nöromüsküler hastalıklara bakım verenlerde mekanik bel ağrısı ve yaşam kalitesini etkileyen değişkenleri belirlemek ve bakım verenlerin mekanik bel ağrısı ile yaşam kalitesi arasındaki ilişkiyi değerlendirmektir.
Yöntem: Kesitsel tipteki bu çalışma enstitümüzün Kas Hastalıkları Merkezinde gerçekleştirildi. Araştırmaya Şubat-Temmuz 2019 tarihleri arasında kas hastalıkları ünitesine başvuran bakım verenler dahil edilmiştir. Bakım verenin görsel analog skoru (VAS), Fonksiyonel Ambulasyon Skalası (FAS) ve ağrı tedavi durumu, Revize Edilmiş Oswestry Bel Ağrısı Engellilik Anketi (ODI) ve SF- 36 Yaşam Kalitesi ölçeği kikare ve korelasyon analizi ile değerlendirildi.
Bulgular: Bakım verenlerde bel ağrısı görülme sıklığı %81,5 (n=135) idi. Katılımcıların VAS puanı ve Oswestry Puanları 6.1 ve 27.4 olarak belirlendi. Yaş ve tanı süresi arttıkça hastanın bağımlılığı da artmış olarak bulundu. Bakım verenlerin VAS ve ODI puanları arasında pozitif korelasyon vardı. SF-36 sonuçları ortalama puanların altındaydı.
Sonuç: Nöromüsküler hastalıklar kronik, ilerleyici, sıklıkla tedavi edilemeyen, pediatrik hastalar ve bakım verenler için önemli sorunlara yol açan bir hastalıktır. Bakım verme yükü ve bel ağrısı arttıkça, bakım verenlerin yaşam kalitesi düşmektedir. Bakım verenlerin zorluklarla başa çıkmalarına yardımcı olmak için multidisipliner ekipler oluşturulmalıdır.

Anahtar Kelimeler: Bakım veren yükü; bel ağrısı; nöromüsküler hastalıklar; pediatrik hasta; yaşam kalitesi

Introduction

Neuromuscular diseases are a heterogeneous group of disorders that can be either inherited or acquired and result from abnormalities in the anterior horn cells, peripheral nerves, neuromuscular junction or muscles. Most neuromuscular diseases are progressive in nature, and despite having different clinical features, their most important common feature is that they cause varying degrees of functional impairment and mobility

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limitations (Bekiroğlu & Gökçearslan Çifçi, 2017). The functional capacity of patients tends to decrease with increasing age and duration of the disease.

Mechanical low back pain is a term used to describe back pain that increases with frequent physical activity and decreases with rest. It is often the result of stress and strain on the back muscles, tendons and ligaments due to demanding daily activities (Karabudak, 2014).

Caregiving can range from occasional assistance to continuous, long-term support, and covers a wide range from family help to professional help. Long-term care of a patient has a significant impact on the caregiver and their close relatives in a number of ways. The need for extended care is particularly prevalent in paediatric patients with neuromuscular diseases and cerebral palsy. For caregivers, this responsibility can have several consequences, including depression, anxiety, burnout, poorer physical health, feelings of isolation and financial difficulties (Duggleby et al., 2016). In addition to these challenges, caring for a patient is also a risk factor for the development of back pain in caregivers (Altuntaş & Aydın 2014). The chronic nature of NMD has a profound impact on the quality of life of both patients and caregivers, resulting in numerous challenges in the physical, social and psychological domains (Ortega, Vázquez & Amayra Caro, 2023).

Recent literature emphasises the importance of a multidisciplinary approach to the management of neuromuscular diseases, in which both the patient and the caregiver play a central role and are actively involved in the treatment process. It is emphasised that maintaining the health of the caregiver is crucial for the effective management of the patient's condition (Landfeldt et al., 2016).

Due to the improvement in therapeutic treatments and the increase in life expectancy in NMD. In addition, the chronicity and dependency associated with NMD emphasise the need for a healthy caregiver. Identifying factors that affect caregivers is believed to contribute not only to the prevention and treatment of low back pain, but also to improving the quality of life of both caregivers and care receivers (Landfeldt et al., 2016). To address the physical and psychological challenges that caregivers face, particularly with regard to low back pain, recent literature has examined various aspects of caregiving and numerous studies are underway. However, despite the significant importance of back pain as a key issue, pain intensity, functional impairment and quality of life have not been adequately emphasised in the existing research. The aim of this study is to investigate the prevalence of mechanical low back pain in caregivers of children with neuromuscular disorders and to assess the relationship between mechanical low back pain and caregivers' quality of life.

Research Question

What variables influence mechanical back pain and quality of life in caregivers of children with neuromuscular disease, and is there an association between caregivers' mechanical back pain and their quality of life?

Methods

Study Design and Setting

This cross-sectional, descriptive study was conducted between February and July 2019 in the neuromuscular disease (NMD) unit of an institute. Primary caregivers of children under the age of 18 who were being followed up for neuromuscular diseases were included in the study.

The study aimed to enrol approximately 350 patients under the age of 18 registered in the unit over a six-month period. The inclusion criteria for caregivers is a clinical diagnosis of definite mechanical low back pain. When caregivers were asked about the presence of LBP, 30 out of 165 respondents said they did not have LBP and therefore did not want to participate in the study. In the end, 135 caregivers who agreed to participate within the timeframe and who were cognitively able to complete the survey were included in the study.

Data Collection Tools

Demographics

Age, weight, diagnosis and duration of NMD, ambulation status, functional activity level (Functional Ambulation Scale - FAS) and use of assistive devices were recorded. Based on their diagnosis, patients were classified into the following categories: Duchenne Muscular Dystrophy (DMD), Becker Muscular Dystrophy (BMD), Congenital Muscular Dystrophy (CMD), Limb Girdle Muscular Dystrophy (LGMD), Spinal Muscular Atrophy (SMA), Polineuropathy (PNP), and others (such as Myasthenia Gravis, Facioscapulohumeral Muscular Dystrophy, Nemaline Myopathy, etc.).

Caregivers' age, sex, occupation, marital status, relationship to the patient, level of education and income were recorded. Back pain characteristics and treatments were documented.

Functional Ambulation Scale (FAS)

Patients' functional ambulation was assessed using the FAS, which is based on the motor skills required to walk (Williams, 2011). The FAS scoring system was as follows: FAS 0: non-functional ambulation, FAS 1: walking with continuous assistance and supervision from another person, FAS 2: first level of dependency, FAS 3: independent walking on level ground, FAS 4: independent on level ground but requiring assistance on stairs and uneven terrain, FAS 5: independent ambulation at any speed and on any surface. The use of assistive devices was recorded, including ankle-foot orthosis (AFO), knee-ankle-foot orthosis (KAFO), cane, manual wheelchair and power wheelchair.

Visual Analog Scale (VAS) and Revised Oswestry Disability Index for Low Back Pain

The intensity of mechanical low back pain in caregivers was assessed using the Visual Analogue Scale (VAS), and the impact of low back pain on daily life was assessed using the Revised Oswestry Disability Index for Low Back Pain. The VAS pain score was numerically categorised from no pain (0) to the worst pain (Bijur, Silver & Gallagher, 2001). According to the World Health Organisation (WHO) pain intensity scale, VAS pain scores were grouped as follows <3 mild pain, 3-6 mild to moderate pain, >6 severe pain6. The Revised Oswestry Disability Index is a test developed to assess the degree of functional loss in low back pain. Its validity and reliability have been established and it consists of 10 items (Yakut, Düger & Öksüz 2004). These items ask about pain intensity, self-care, lifting/carrying, walking, sitting, standing, and sleep, degree of pain change, travel and social life. The maximum score is '100' and the minimum score is '0'.

Based on the total score, the level of disability is graded as follows
0-20 points: Low back pain does not significantly affect daily life.
21-40 points: Low back pain slightly limits the patient's daily life.
41-60 points: Low back pain moderately limits the patient's daily life.
61-80 points: Low back pain severely restricts the patient's daily life.
81-100 points: The patient is bedridden.
As the total score increases, so does the level of disability.

Short Form 36 (SF-36)

The Short Form 36 (SF-36) scale (Koçyiğit, Aydemir, Fişek, Ölmez & Memiş, 1999) is used to assess the caregiver's quality of life, self-perceived health, feelings and ability to perform activities of daily living. The SF-36 consists of 36 items and assesses quality of life over the previous four weeks. It measures eight dimensions: physical functioning, social functioning, role limitations due to physical health, bodily pain, mental health, role limitations due to emotional problems, vitality and general health perception. Each subscale represents a different dimension of health and each subscale score ranges from 0 to 100. A higher score indicates a better quality of life.

Data Analysis

The Statistical Package for the Social Sciences (SPSS 24 Inc, Chicago, IL, USA) was used for statistical analysis. Means and standard deviations were used for normally distributed numerical data. The Kolmogorov-Smirnov test was used to test the normal distribution of numerical data. The Pearson chi-squared test was used for categorical data, and Fisher's exact test for cases with small expected cell counts. Correlation analyses were performed. $p<0.05$ was considered statistically significant.

Ethical Approval

The study was approved by the local ethics committee (No:2019/2-15, Date:13/02/2019). Institutional permission was secured prior to the commencement of the research. Informed consent was obtained from all patients' caregivers, ensuring their voluntary participation and understanding of the study's objectives and procedures. The study was conducted in accordance with the ethical principles outlined in the Declaration of Helsinki, emphasizing respect for individuals, beneficence, and justice.

Study Limitations

The study also has certain limitations. The cross-sectional design limits the ability to establish causal relationships, and prospective or longitudinal studies would better capture the dynamic nature of caregivers' experiences. The reliance on self-report measures, particularly for pain intensity and quality of life, introduces potential response bias and subjective interpretation. The sample size of the study, while providing valuable insights, may limit the ability to detect more subtle differences in subgroups. Despite these limitations, this study provides valuable insights into the challenges faced by caregivers of children with neuromuscular disorders and suggests potential directions for future research and support interventions.

Results

In our study, 135 out of 165 caregivers (81.5%) of patients diagnosed with neuromuscular diseases had mechanical low back pain. Of the caregiver patients included, 47.8% (n=64) were aged 1-10 years and 52.2% (n=70) were aged 11-18 years, 75.6% (n=102) were male, the mean weight of the patients was 35.6 kg ± 18.5, and the mean duration of diagnosis was 6.8 ± 4.1 years. The most common diagnosis among the patients was DMD, with 58 patients accounting for 45% of the cases. Patients' diagnosis groups, functional ambulation and use of assistive devices are shown in Table 1.

Among the caregivers providing primary care to children with neuromuscular diseases, 89.6% (n=121) were aged between 25 and 45 years, 10.4% (n=14) were over 45 years, and 90.4% (n=122) were female. The mean age of the caregivers was 37.4 ± 6.9 years (min-max 25-71). The demographic data of the caregivers are shown in Table 2.

Table 1. Distribution of patients by diagnosis, Functional Ambulation Scale (FAS), and assistive device usage

	n	%
Diagnosis (n=129)		
DMD	58	45
CMD	18	14
BMD	12	9.3
SMA type 2	11	8.5
LGMD	7	5.4
PNP	6	4.6
Others	17	13.2

FAS (n=135)		
Nonfunctional ambulator	46	34.1
Ambulator, dependent on physical assistance – level I	9	6.7
Ambulator, dependent on physical assistance – level II	3	2.2
Ambulator, dependent on supervision	10	7.4
Ambulator, independent level surface only	45	33.3
Ambulator, independent	22	16.3
Assistive Device Usage	76	56.2
Foot Orthosis (AFO)	28	20.8
Powered wheelchair	28	20.8
Wheelchair	17	12.5
Knee-Ankle-Foot Orthosis (KAFO)	2	1.4
Cane	1	0.7
None	59	43.8

Duchenne Muscular Dystrophy (DMD), Becker Muscular Dystrophy (BMD), Congenital Muscular Dystrophy (CMD), Limb Girdle Muscular Dystrophy (LGMD), Spinal Muscular Atrophy (SMA), Polineuropathy (PNP), and others (Myasthenia Gravis, Facioscapulohumeral Muscular Dystrophy, Nemaline Myopathy, etc.).

All caregivers had experienced low back pain for more than 3 months. The mean duration of pain was 6 ± 4.4 years. 34.1% (n=46) of caregivers reported pain localised to the lumbar region, while 65.9% (n=89) had pain in both the lower back and legs (Table 3).

Table 2. Demographic characteristics of primary caregivers

(n=135)	**n**	**%**
Age		
25-45	121	89.6
>45	14	10.4
Sex		
Male	13	9.6
Female	122	90.4
Occupation		
Housewife	103	76.3
Private sector worker	17	12.6
Civil worker	11	8.1
Retired	2	1.5
Other/Unemployed	2	1.5
Marital status		
Married	128	94.8
Single	7	5.2
Relationship to the patient		
Mother	121	89.6
Father	13	9.6
Sister	1	0.8
Educational level		
Illiterate	6	4.4
Literate	2	1.5
Elementary school	60	44.4
High school	49	36.3
Higher education	18	13.3
Income status		
Less than expenses	77	57.0
Equals expenses	56	41.5
Exceeds expenses	2	1.5

60.7% (n=82) received no treatment, while 39.3% (n=53) received treatment. Of those who received treatment, 21.5% (n=29) received medical treatment, 14.8% (n=20) received physiotherapy and 3% (n=4) received surgical treatment.

Table 3. Visual Analog Scale, Revised Oswestry Disability Index for Low Back Pain and Short Form-36 scores of the caregivers

(n=135)	**Mean ± SD (min-max)/n(%)**
Visual Analog Scale	6.1 ± 2.2 (2-10)
Revised Oswestry Disability Index for Low Back Pain	27.4±12.7 (0-58)
Short Form-36	
Physical Functioning	76.8±13.4 (37-100)
Role Physical	45.5±35.2 (0-100)
Social Functioning	39.2±44.1 (12.5-100)
Role Emotional	37.5±17.2 (0-33.3)
Mental Health	54.1±18.7 (8-98)
Vitality	66.9±25.9 (0-85)
Bodily Pain	57.2±20.4 (10-100)
General Health	49.5±15.2 (25-90)

The caregivers' mean pain intensity was 6.1 ± 2.2 (min-max: 2-10, med: 6) on the VAS (Table 3).

There was no statistically significant relationship found between the caregivers' pain intensity and the type of assistive device used by the patients or the location of the pain (p>0.05) (Table 4). It was observed that 34.4% (n=22) of caregivers of patients aged 1 to 10 years had mild to moderate back pain, while 65.6% (n=42) had severe back pain. Among caregivers of patients aged over 10 years, 23.9% (n=17) had mild to moderate LBP, while 76.1% (n=54) had severe LBP. However, no significant difference was found between patient age and caregiver VAS score (p>0.05). It was found that 32.8% (n=19) of caregivers of non-ambulatory patients had mild to moderate pain, while 67.2% (n=39) had severe pain. Among caregivers of ambulatory patients, 26% (n=20) had mild to moderate pain, while 74% (n=57) had severe pain. However, there was no significant difference in pain intensity between caregivers of ambulatory and non-ambulatory patients (p>0.05). 26.4% (n=32) of caregivers aged 25-45 years had mild to moderate pain, while 73.6% (n=89) had severe pain. Among caregivers aged over 45 years, 50% (n=7) had mild to moderate pain, while 50% (n=7) had severe pain. There was no significant difference between the age of primary caregivers and the intensity of pain they experienced, nor between the intensity of pain experienced by caregivers and the type of assistive device used by patients or the location of the pain (p>0.05).

Table 4. Characteristics of lower back pain in primary caregivers of patients

(n=135)	**n**
Duration	
Acute (<6 weeks)	-
Subacute (6-11 weeks)	-
Chronic (≥12 weeks)	135
Location	
Localized to the lower back	46
In the lower back and legs	89
Severity (VAS)	
Mild (2)	14
Moderate (4)	25
Severe (6)	44
Very Severe (8)	39
Worst Pain Possible (10)	13

VAS: Visual Analogue Scale

Table 5. SF-36 Quality of Life Scale subdimensions and correlation analysis-1 with characteristics of patients and primary caregivers

	n	rho	*p*
Physical Function			
Patient’s age (years)	134	-0.08	*0.300*
Patient Wight (kg)	130	0.04	*0.590*
Duration of Diagnosis (years)	134	-0.11	*0.170*
Caregiver’s age (years)	135	0.02	*0.790*
Caregiver's Duration of Lower Back Pain (years)	135	-0.13	*0.120*
Caregiver’s VAS for Lower Back Pain	135	-0.48	***<0.001***
Caregiver’s Oswestry Scale	135	-0.64	***<0.001***
Physical Role Limitation			
Patient’s age (years)	134	0.004	*0.960*
Patient Wight (kg)	130	-0.009	*0.910*
Duration of Diagnosis (years)	134	-0.03	*0.700*
Caregiver’s age (years)	135	0.003	*0.970*
Caregiver's Duration of Lower Back Pain (years)	135	0.05	*0.530*
Caregiver’s VAS for Lower Back Pain	135	-0.37	***<0.001***
Caregiver’s Oswestry Scale	135	-0.54	***<0.001***
Pain			
Patient’s age (years)	134	-0.01	*0.840*
Patient Wight (kg)	130	-0.03	*0.730*
Duration of Diagnosis (years)	134	-0.006	*0.940*
Caregiver’s age (years)	135	0.04	*0.580*
Caregiver's Duration of Lower Back Pain (years)	135	-0.01	*0.820*
Caregiver’s VAS for Lower Back Pain	135	-0.39	***<0.001***
Caregiver’s Oswestry Scale	135	-0.64	***<0.001***
Emotional Role Limitation			
Patient’s age (years)	134	0.01	*0,910*
Patient Wight (kg)	130	0.05	*0,530*
Duration of Diagnosis (years)	134	0.10	*0,210*
Caregiver’s age (years)	135	0.12	*0,160*
Caregiver's Duration of Lower Back Pain (years)	135	0.11	*0,180*
Caregiver’s VAS for Lower Back Pain	135	-0.24	***0,005***
Caregiver’s Oswestry Scale	135	-0.37	***<0,001***

* Spearman’s Correlation, VAS: Visual Analogue Scale

A moderate negative correlation (rho=-0.492) but a highly significant one (p<0.001) was found between duration of diagnosis and FAS score. This suggests that as the patient's age and duration of diagnosis increases, so does the patient's level of dependency based on the Functional Ambulation Scale.

It was found that male caregivers had a mean Oswestry score of 19.69±13.11 (min-max: 2-50), while female caregivers had a mean score of 28.22±12.43 (min-max: 0-58). There was a statistically significant difference between the two groups (p=0.020). When examining the mean scores of the sub-parameters of the SF-36 Quality of Life scale according to some descriptive characteristics of the patients and caregivers, caregivers of children aged 1-10 years had statistically significantly lower scores for Energy-Vitality (p=0.030) and Mental Health (p=0.010) compared to caregivers of children aged over 10 years. There was no statistically significant difference (p>0.05) between the type of assistive device used by patients and caregivers' SF-36 subscores related to quality of life (Table 5-6).

Table 6. SF-36 Quality of Life Scale subdimensions and correlation analysis-2 with characteristics of patients and primary caregivers

	n	rho	*p*
Energy/Vitality			
Patient’s age (years)	134	0.14	*0.100*
Patient Wight (kg)	130	0.18	***0.030***
Duration of Diagnosis (years)	134	0.11	*0.170*
Caregiver’s age (years)	135	-0.064	*0.460*
Caregiver's Duration of Lower Back Pain (years)	135	0.08	*0.310*
Caregiver’s VAS for Lower Back Pain	135	-0.007	*0.930*
Caregiver’s Oswestry Scale	135	-0.13	*0.120*
Social Functioning			
Patient’s age (years)	134	0.01	*0.910*
Patient Wight (kg)	130	0.04	*0.640*
Duration of Diagnosis (years)	134	0.02	*0.740*
Caregiver’s age (years)	135	0.01	*0.820*
Caregiver's Duration of Lower Back Pain (years)	135	0.01	*0.890*
Caregiver’s VAS for Lower Back Pain	135	-0.23	***0.007***
Caregiver’s Oswestry Scale	135	-0.50	***<0.001***
Mental Health			
Patient’s age (years)	134	0.17	***0.040***
Patient Wight (kg)	130	0.20	***0.010***
Duration of Diagnosis (years)	134	0.16	***0.050***
Caregiver’s age (years)	135	0.20	***0.010***
Caregiver's Duration of Lower Back Pain (years)	135	0.02	*0.810*
Caregiver’s VAS for Lower Back Pain	135	-0.16	***0.050***
Caregiver’s Oswestry Scale	135	-0.29	***<0.001***
General Health Perception			
Patient’s age (years)	134	-0.06	*0.480*
Patient Wight (kg)	130	-0.03	*0.710*
Duration of Diagnosis (years)	134	-0.03	*0.730*
Caregiver’s age (years)	135	-0.01	*0.880*
Caregiver's Duration of Lower Back Pain (years)	135	-0.05	*0.490*
Caregiver’s VAS for Lower Back Pain	135	-0.35	***<0.001***
Caregiver’s Oswestry Scale	135	-0.46	***<0.001***

Physical function (p=0.008), physical role limitations (p=0.015) and mental health (p=0.003) scores were significantly lower for female caregivers on the SF-36. Caregivers aged 25-45 years had significantly lower mental health scores than caregivers aged over 45 years (p=0.030). Non-working caregivers had significantly lower emotional role limitations (p=0.020) compared to working caregivers.

There was a significant and weak positive correlation (rho=0.27, p=0.002) between the duration of LBP among primary caregivers and their VAS score. There was also a significant and weak positive correlation (rho=0.24, p=0.004) between the duration of LBP and their Oswestry Index score. These correlations suggest that as the duration of back pain in caregivers increases, the level of back pain measured by both scales also increases significantly. A significant and highly positive correlation (rho=0.60, p<0.001) was found between primary caregivers' VAS scores and Oswestry Index scores.

There were no significant correlations between physical function scores and patient age, patient weight, duration of patient diagnosis, primary caregiver age, and duration of primary caregiver back pain. However, there was a significant and moderate negative correlation (rho=-0.48, p<0.001) between caregivers' VAS scores and their physical function scores. There was also a significant and highly negative correlation (rho=-0.64, p<0.001) between primary caregivers' Oswestry Index scores and their physical function scores.

There were no significant correlations between caregivers' mental health scores and the duration of low back pain. However, there were significant but weak positive correlations with the patient's age, the patient's weight, the duration of the patient's diagnosis, and the primary caregiver's age. There was also a significant and weak negative correlation (rho=-0.16, p=0.050) between caregivers' VAS scores and their mental health scores. There was also a significant and weak negative correlation (rho=-0.29, p=0.001) between caregivers' Oswestry Index scores and their mental health scores.

Discussion

Our study includes a focused investigation of the impact of mechanical low back pain on primary caregivers of children with neuromuscular disease, a population often overlooked in research. The study's comprehensive assessment, combining measures of pain intensity, functional impairment and quality of life, provided a holistic understanding of caregivers' experiences. The study found that all participants experienced moderate long-term low back pain, and most caregivers did not seek treatment. Back pain was found to increase with the weight of the child. The study also found that low-income caregivers experienced mild limitations in their daily activities due to back pain. The SF-36 sub-parameters were below average, except for vitality. Female caregivers had significantly lower scores for physical function, physical role limitations and mental health compared to male caregivers. Caregivers aged between 25 and 45 years had significantly lower mental health scores. Anxiety also decreases as caregiver’s age.

In our study, almost 90% of primary caregivers for children with neuromuscular diseases were younger, female and mothers. Other studies also suggest that primary caregivers in the child age group are generally mothers, which explains their younger age compared to caregivers in the geriatric age group (Karahan & Islam, 2013; Türe, 2018; Bahadır Yılmaz & Ata, 2017). The emotional bond and trust towards mothers in childhood, as well as the nurturing and protective nature of women, lead to the assumption that mothers take on more responsibility in caring for children with chronic illnesses in our society (Türe, 2018; Bahadır Yılmaz & Ata, 2017). Studies conducted on caregivers in our country show that they are generally educated up to primary or high school level, and most of them are non-working women. While mothers take care of the child's well-being, fathers continue to work. Thus, it is inevitable that non-working housewives take on the caregiving role, in line with women's emotional attachment and protective qualities in childhood. This also suggests that mothers have a greater responsibility in caring for children with chronic illness (Fairfax et al., 2019). These findings highlight the critical role of mothers in the care dynamics of children with neuromuscular diseases, and emphasise the need for targeted support and resources to support these primary caregivers.

The study by Tong et al. of adult female caregivers of children attending paediatric physiotherapy and endocrinology clinics reported that 71% and 43% of them, respectively, had low back pain. Among female caregivers of physically disabled children, low back pain was significantly more common, with moderate pain intensity (Tong et al., 2003). Among caregivers, the duration of low back pain was chronic and of moderate intensity, lasting more than 3 months. The aetiological factors of acute and chronic LBP are different. While acute pain is primarily related to anatomical strains in the lumbar structures, chronic pain is influenced by the addition of psychosocial factors. This complexity in pain management can be challenging. Therefore, preventing pain from becoming chronic, implementing early preventative measures and planning appropriate treatment are crucial (Birnkrant et al., 2018). This highlights the importance of early intervention and comprehensive care strategies to address both the physical and psychosocial dimensions of caregiver back pain.

The study by Landfelt et al. on caregivers of patients with DMD showed no significant relationship between walking status and VAS scores, which is consistent with our findings (Landfelt et al., 2016). This unexpected finding may be due to caregivers' coping mechanisms with loss of ambulation and their increasing awareness of the progression of neuromuscular disease, leading to additional support from nurses and other healthcare professionals.

The study found that low back pain caused mild impairment in caregivers' activities of daily living, and that the rate of disability was higher in women than in men. In a study by Sherpa et al, they assessed low back pain in caregivers of people with spinal cord injuries, and the mean Oswestry Index score was 33, indicating mild limitations in daily life activities (Sherpa, Kitrungrote & Sae-Sia, 2018). However, Fırıncı et al. reported that caregivers of cancer patients did not experience significant restrictions in daily life activities due to low back pain (Fırıncı, Pehlivan, Durmuş & Özer, 2018). These findings highlight the variability in the impact of low back pain on daily activities among different caregiver groups, and emphasise the need for tailored interventions based on specific caregiving contexts.

Low back pain has a significant impact on quality of life (Kurban, 2018). When the SF-36 subscores of the participants in our study were compared with the Turkish norm, all subscores except vitality were lower than average. The largest differences were observed in physical role functioning, social functioning and emotional role functioning, with significant differences mainly among female participants. Contrary to the common belief that the level of dependency and the occurrence of physical, emotional and social problems would increase with the age of the child and the duration of the illness, our research did not support this notion (Özdinçer, 2002). However, the lower mental health scores of caregivers of younger children may be due to the recent diagnosis or the development of coping mechanisms over time. These findings highlight the complex and multifaceted impact of caregiving on quality of life and suggest the need for targeted support to address the physical, emotional and social challenges faced by caregivers, particularly women.

In terms of treatment seeking behaviour, our study found that more than half of caregivers did not seek treatment for their low back pain. Similar findings were reported by Alahan et al. in their study of caregivers of 500 paediatric chronic patients, where they found that caregivers often could not afford healthcare costs, frequently did not receive treatment, and lacked time to seek care (Alahan, Avlaz & Yetiş, 2015). In addition, caregivers of children over 10 years of age in this study described severe low back pain in 76% of cases, more than caregivers of younger children. These findings highlight the urgent need for accessible and affordable healthcare options for caregivers, as well as the importance of addressing the severe pain experienced by those caring for older children..

Oswestry Index scores were found to be higher in women in our study. This finding is consistent with the existing literature, which generally shows a higher prevalence of low back pain in women. Gül et al. reported that the frequency of pain was higher in females than in males in their study (Gül, Üstündağ, Kahraman & Purisa, 2014). Latina et al. also found that the risk of pain was higher and low back pain was more common in women (Latina et al., 2020). Consistent with the literature, our study found that low back pain was not a significant problem in the daily lives of male caregivers, whereas it caused mild limitations in the daily lives of female caregivers.

Conclusion and Recommendations

Neuromuscular diseases are chronic, progressive, often incurable and sometimes fatal conditions that cause significant problems for pediatric patients and their caregivers. Caregivers of children with neuromuscular diseases often do not receive adequate treatment or have the opportunity to rest, leading to chronic low back pain that is exacerbated by various psychosocial factors. As caregiver burden and back pain increase, caregivers' quality of life decreases. To help caregivers cope with these difficulties, multidisciplinary teams consisting of physiotherapists, rehabilitation specialists, nurses, psychologists, psychiatrists and physiotherapists should be established in neuromuscular disease centers to provide biopsychosocial support and education to families.

Researchers' Contribution Rate Statement

The contribution rates of the authors in the study are equal.

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The study has not received any support. There aren't any institutions or persons to acknowledge.

Disclosure of Interest

The authors report there are no competing interests to declare.

References

Alahan, N. A., Avlaz, R., & Yetiş, G. (2015). Kronik hastalığı olan çocuğa sahip ebeveynlerin bakım verme yükü. *Annals of Health Science Research*, 4(2), 1-5.

Altuntaş, O., & Aydın, M. (2015). Huzurevinde çalışan bakım verenlerde bel okulunun etkinliğinin incelenmesi. *Ergoter ve Rehabil Derg.*, 3(1), 1–6.

Bahadır Yılmaz, E., & Ata, E. E. (2017). Determining the relation between caregiver burden for individuals having neurological disease and their coping ways with stress. *J Psychiatr Nurs*, 8(3), 145–149. https://doi.org/10.14744/phd.2017.77699

Bekiroğlu, S., & Gökçearslan Çifci, E. (2017). Nöromüsküler hasta ailelerinin yaşadıkları güçlükler. *Türkiye Sosyal Araştırmalar Dergisi*, 21(3), 704–722. https://doi.org/10.20296/tsadergisi.322808

Bijur, P. E., Silver, W., & Gallagher, J. (2001). Reliability of the visual analog scale for measurement of acute pain. *Acad Emerg Med.*, 8(12), 1153. https://doi.org/10.1111/j.1553-2712.2001.tb01132.x

Birnkant, D., Bushby, K., Bann, C. M., et al. (2018). Diagnosis and management of Duchenne muscular dystrophy, part 2: respiratory, cardiac, bone health, and orthopaedic management. *Lancet Neurology*, 17(4), 347-361. https://doi.org/10.1016/S1474-4422(18)30025-5

Duggleby, W., Williams, A., Ghosh, S., Moquin, H., Ploeg, J., Markle-Reid, M., & Peacock, S. (2016). Factors influencing changes in health related quality of life of caregivers of persons with multiple chronic conditions. *Health Qual Life Outcomes*, 14(81). https://doi.org/10.1186/s12955-016-0486-7

Fairfax, A., Brehaut, J., Colman, I., et al.; Canadian Inherited Metabolic Diseases Research Network. (2019). A systematic review of the association between coping strategies and quality of life among caregivers of children with chronic illness and/or disability. *BMC Pediatr.*, 19(1), 215. https://doi.org/10.1186/s12887-019-1587-3

Fırıncı, B., Pehlivan, E., Durmuş, G. N., & Özer, A. (2018). Hasta bakıcılarda bel ağrısı ve yaşam kalitesinin değerlendirilmesi, Turgut Özal Tıp Merkezi örneği. *Sakarya Tıp Dergisi*, 8(2), 292-302. https://doi.org/10.31832/smj.411881

Gül, A., Üstündağ, H., Kahraman, B., & Purisa, S. (2014). Hemşirelerde kas iskelet ağrılarının değerlendirilmesi. *Sağlık Bilimleri ve Meslekleri Dergisi*, 1(1), 1-10. https://doi.org/10.17681/hsp.77225

Karabudak, R. (2014). Nöromusküler Hastalıklar. *Türk Nöroloji Derneği*. https://noroloji.org.tr/TNDData/Uploads/files/n%C3%B6rom%C3%BCsk%C3%BCler%20hastal%C4%B1klar.pdf

Karahan, A., & Islam, S. (2013). A comparison study about caregiver burden between physically disabled, pediatric and geriatric patients. *J Marmara Univ Inst Heal Sci.*, 1. Available from: http://www.clinexphealthsci.com/sayilar/102/buyuk/s1-s71.pdf

Koçyiğit, H., Aydemir, Ö., Fişek, G., et al. (1999). Kısa Form-36 (KF-36)'nın Türkçe versiyonunun güvenilirliği ve geçerliliği. *İlaç ve Tedavi Dergisi*, 12, 102-106.

Kurban, V. (2018). Tokat il merkezinde 6-14 yaş aralığında engelli çocuğa sahip ailelerin yaşam kalitesinin değerlendirilmesi ile yaşam kalitesini etkileyen faktörlerin belirlenmesi. *Gaziosmanpaşa Üniversitesi Tıp Fakültesi*. https://acikbilim.yok.gov.tr/handle/20.500.12812/255371

Landfeldt, E., Lindgren, P., Bell, C. F., et al. (2016). Quantifying the burden of caregiving in Duchenne muscular dystrophy. *J Neurol.*, 263(5), 906–915. https://doi.org/10.1007/s00415-016-8080-9

Latina, R., Petruzzo, A., Vignally, P., Cattaruzza, M. S., Vetri Buratti, C., Mitello, L., Giannarelli, D., & D'Angelo, D. (2020). The prevalence of musculoskeletal disorders and low back pain among Italian nurses: An observational study. *Acta Biomed.*, 91(12-S), e2020003. https://doi.org/10.23750/abm.v91i12-S.10306

Ortega, J., Vázquez, N., & Amayra Caro, I. (2023). Quality of life of Latin-American people with neuromuscular disorders and their families during the COVID-19 pandemic. *Adv Neurodev Disord.*, 8, 1-7. https://doi.org/10.1007/s41252-023-00328-3

Özdinçer, S. (2002). Nöromüsküler hastalıklı çocukların evde bakım gereksinimleri, ailelerin evde bakımda yaşadığı güçlükler ve olanakları. *Marmara Üniversitesi*. https://katalog.marmara.edu.tr/veriler/yordambt/cokluortam/E/E/D/D/B/T0047646.pdf

Sherpa, P. D., Kitrungrote, L., & Sae-Sia, W. (2018). Predicting quality of life among family caregivers of people with spinal cord injury having chronic low back pain in Nepal: A cross-sectional pilot study. *Spinal Cord Ser Cases*, 4(1). https://doi.org/10.1038/s41394-018-0110-7

Tong, H. C., Haig, A. J., Nelson, V. S., et al. (2003). Low back pain in adult female caregivers of children with physical disabilities. *Arch Pediatr Adolesc Med.*, 157(11), 1128. https://doi.org/10.1001/archpedi.157.11.1128

Türe, E. (2018). Kronik hasta çocuklara bakım verenlerin bakım verme yükünün değerlendirilmesi. *Bozok Tıp Dergisi*, 8, 46-53. https://doi.org/10.16919/bozoktip.403880

Williams, G. (2011). Functional ambulation classification. In: Kreutzer, J. S., DeLuca, J., & Caplan, B. (Eds.), *Encyclopedia of Clinical Neuropsychology* (pp. 1105–1106). New York, NY, USA: Springer.

World Health Organization. (1996). *Cancer Pain Relief with a Guide to Opioid Availability* (2nd ed.). Geneva, Switzerland: World Health Organization. https://apps.who.int/iris/handle/10665/37896

Yakut, E., Düger, T., & Öksüz, Ç. (2004). Validation of the Turkish version of the Oswestry Disability Index for patients with low back pain. *Spine*, 29(5), 581–585. https://doi.org/10.1097/01.brs.0000113869.13209.03