Investigation of care burden and musculoskeletal pain of parents of paediatric palliative care patients in Turkey

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Abstract

Background: Caring for a paediatric patient is associated with psychological, physical and social challenges. It may be easy to identify the emotional effects of caregiving burden on parents, but the physical effects are often not known.

Aims: We aimed to examine the relationship between caregiver burden and musculoskeletal pain in caregiver parents of children accessing palliative care services.

Methods: This was a cross-sectional study among caregiving parents of paediatric palliative care patients, conducted between 15 July 2020 and 15 January 2021. The care burden was examined using the Zarit Caregiver Burden Questionnaire, and the physical complaints of parents with the Extended Nordic Musculoskeletal Questionnaire.

Results: A total of 69 caregiving parents were included in the study. The median Zarit Caregiver Burden score was 54.0. In parents with pain complaints, the most common pain areas were lower back (62.3%), back (60.9%) and neck (42.0%). Pain was statistically significantly associated with the duration of the disease in the child, especially shoulder pain (P = 0.023) and wrist pain (P = 0.024).

Conclusion: Lower back pain was observed at a higher rate among caregiving parents. As the duration of the child's illness increased, the number of caregiver parents with shoulder and wrist pain increased. It is important to extend support to caregivers of paediatric palliative care patients to alleviate their physical difficulties.

Keywords: caregiver burden, musculoskeletal pain, parents, paediatric palliative care, Turkey

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Introduction

The prolongation of the lifespan of children with chronic and incurable diseases has led to an increase in the number of individuals requiring palliative care. Advances in palliative care have increased the importance of the concept of "caregiver" (1). Giving care may cause many difficulties despite its positive features such as increasing sincerity and love, finding meaning thanks to the experience of giving care, getting social support from other individuals, self-esteem and personal satisfaction (2). In Turkey, the care of patients and people in need of care is generally provided by family members; it is perceived as a family responsibility. Becoming a caregiver is involuntary and unplanned, therefore, resulting in the need to adjust to the situation (3,4). Reducing the caregiver's care burden may improve the quality of care given to the patient. Previous studies have indicated a correlation between care burden and psychological problems, reduced physical functionality, and a deterioration in quality of life of the caregiver (5,6). It has been shown that increased physical burden, such as bending or carrying loads, is often associated with lower back pain (7). Fatigue and back pain have been reported to be very common among caregivers (8). Due to a lack of education or awareness of how to move bedridden people, caregivers often use incorrect postures and uneven weight distribution when lifting or caring for patients (9).

Although caregivers are considered to be potential patients, the relationship between caregiver parents in paediatric palliative care and musculoskeletal diseases has not been studied (10). Protecting the health of caregiver parents is very important for the other children in the family. Data on the caregiving and physical burdens of parents of children with life-threatening or life-limiting diseases are very scarce. Most of the available studies have investigated lower back pain and emotional load. In this study we aimed to investigate the relationship between the burden of care and musculoskeletal pain of caregiver parents of children in paediatric palliative care. The study is important for determining the health problems of caregivers, protecting family and community health and supporting the family.

Methods

Study design

Izmir Behçet Uz Children's Research and Training Hospital is a tertiary hospital, with a Paediatric Palliative Care Centre which opened in November 2018. We conducted a cross-sectional survey involving the caregivers of children who applied to the Paediatric Palliative Care Centre between 15 July 2020 and 15 January 2021 and were followed up in the hospital. Paediatric palliative care patients and caregivers who met the inclusion criteria were included in the study. Among the caring parents, those who had been caregivers for at least 6 months, were not breastfeeding, had not had a musculoskeletal operation, had no chronic psychosocial problems and had no communication problems were included in the study. Children younger than 2 years, nursing children, children older than 18 years, nursing parents, parents with musculoskeletal surgery, parents with chronic psychosocial problems and parents with communication problems were not included in the study. Parents were informed about the study and were interviewed face-to-face for all assessments.

Data collection

Sociodemographic data were evaluated using a personal information form comprising 15 questions. Age, sex, education level, marital status, income level, employment status, whether the house is rented or owned, number of children, receipt of social security, receipt of spousal assistance, and health problems were covered. The child's age, sex, primary disease, duration of illness and level of need for care (mechanical ventilation, gastrostomy, mobility level) were recorded. Income level was determined according to the minimum wage in Turkey, and participants were classified as those whose income level was below or above the minimum wage. The number of cases to be included in the study and the statistical power of the study were calculated using G*Power (version 3.1.9.2) at 80% power and 0.05 alpha error probability.

Zarit Caregiver Burden Scale (ZCBS) is a widely used scale developed by Zarit, Reever and Bach-Peterson in 1980 (11). It is used to determine the difficulties that caregiving parents experience. The items in the scale are socially and emotionally oriented. The scale has a Likert-type assessment ranging from 1 to 5 (never, rarely, sometimes, often and almost always). The total score range is 22–110 points. The higher the score, the higher the caregiving burden. Although there are no data on the cut-off points, the scores are classed as mild (22–46), moderate (47–55) and heavy (\geq 56) burden. The Turkish validity and reliability study was conducted in 2006 by İnci et al. (Cronbach coefficient α = 0.95) (12).

The Extended Nordic Musculoskeletal Questionnaire (ENMQ) examines 9 pain areas (neck, shoulder, back, elbow, wrist/hand, waist, hip/thigh, knee, ankle/foot),

providing information on the onset, frequency and consequences of musculoskeletal pain. The questionnaire can be completed by the person on his own or through face-to-face interview (13). It was developed by Dawson et al. in a project funded by the Nordic Council of Ministers (14). It has yes/no questions regarding whether there is pain or discomfort for each body region in the last year, in the last month, and on the day of the evaluation. It is a reliable scale that evaluates the duration and region of the pain with 13 questions, and the severity of the pain with 3 questions, making a total of 16 questions. It evaluates pain intensity on a scale from 0 (lowest) to 10 (highest) points using a visual analogue scale. The Turkish validity and reliability study was conducted by Alaca et al. in 2019 (Cronbach $\alpha = 0.78$) (15).

Ethical approval

After approval by the institutional ethics committee, the study was conducted according to the Helsinki Declaration principles (number: 18/6/2020-107). Written consent was obtained from those who agreed to participate in the study after explaining the objectives to them

Statistical analysis

Statistical analysis was carried out using SPSS, version 21.0. The suitability of the variables to the normal distribution was evaluated using the Kolmogorov–Smirnov and Shapiro–Wilk tests, which showed that the variables did not fit the normal distribution. Discontinuous variables are presented as number and percentage, and continuous variables as median and interquartile range (IQR). Relationships between patient and parent characteristics and Zarit test total score, and patient and parent characteristics and Nordic test parameters were evaluated using Spearman correlation analysis. A P-value of < 0.05 was considered statistically significant.

Results

A total of 69 caregiving parent-child pairs were included in the study. The vast majority of the caregiving parents (92.8%) were female (Table 1). The largest age group for the parents was 30–40 years (43.5%). The majority of the caregiving parents received help from their spouses (65.2%).

More than half of the patients (52.2%) had cerebral palsy (Table 1). The median age at diagnosis was 1.0 year, and the median disease duration was 4 years. The level of care needed was classified according to respiratory support, nutritional support and activity level. Almost 50% were receiving spontaneous support (Table 1). For nutritional support, 39.1% had a nasogastric catheter. Almost 80% of the children were bedridden.

The median ZCBS scores was 54.0 (IQR = 20). The scores and score groups for the caregiving parents are shown in Table 2.

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Table 1 Characteristics of the participants, paediatric palliative patients and caregiver parents (n = 69 pairs), Izmir, 2020–2021

Sex Male 5 92.8 Female 64 7.2 Age (years) < 30 19 27.5 30-40 30 43.5 > 40 20 29.0 Education Primary/secondary school 52 75.4 High school/university 17 24.6 Married 61 88.4 Single/divorced 8 11.6 Received help from spouse 45 65.2 Chilter Median age at diagnosis (years) 1.0 (IQR = 1.0) Median disease duration (years) 4.0 (IQR = 7.0) Condition Cerebral palsy 36 52.2 Spinal muscular atrophy 13 18.8 Genetic disease 10 14.5 Inborn errors of metabolism 4 5.8 Other 6 8.7 Spontaneous Tracheotomy, O ₂ mask 21 30	Characteristic	No	%	
Male 5 92.8 Female 64 7.2 Age (years)		Pare	ents	
Female 64 7.2 Age (years) < 30	Sex			
Age (years) < 30	Male	5	92.8	
30	Female	64	7.2	
30	Age (years)			
Section Sect	< 30	19	27.5	
Education Primary/secondary school 52 75.4 High school/university 17 24.6 Marital status 30 38.4 Married 61 88.4 Single/divorced 8 11.6 Received help from spouse 45 65.2 Children Median age at diagnosis (years) 1.0 (IQR = 1.0) Median disease duration (years) 4.0 (IQR = 7.0) Condition Cerebral palsy 36 52.2 Spinal muscular atrophy 13 18.8 Genetic disease 10 14.5 Inborn errors of metabolism 4 5.8 Other 6 8.7 Respiratory support Spontaneous 34 49.3 Tracheotomy, O2 mask 21 30.4 Home-type mechanical ventilation 14 20.3 Nutritional support 20 29.0 Movement support Walking 6 8.7 Sitting/getting up <	30-40	30	43.5	
Primary/secondary school 52 75.4 High school/university 17 24.6 Marital status	> 40	20	29.0	
High school/university 17 24.6 Marital status Married 61 88.4 Single/divorced 8 11.6 Received help from spouse 45 65.2 Children Median age at diagnosis (years) 1.0 (IQR = 1.0) Median disease duration (years) 4.0 (IQR = 7.0) Condition Cerebral palsy 36 52.2 Spinal muscular atrophy 13 18.8 Genetic disease 10 14.5 Inborn errors of metabolism 4 5.8 Other 6 8.7 Respiratory support Spontaneous 34 49.3 Tracheotomy, O ₂ mask 21 30.4 Home-type mechanical ventilation 14 20.3 Nutritional support Oral 22 31.9 Nasogastric catheter 27 39.1 Gastronomy 20 29.0 Movement support Walking 6 8.7	Education			
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Married 61 88.4 Single/divorced 8 11.6 Received help from spouse 45 65.2 Children Median age at diagnosis (years) 1.0 (IQR = 1.0) Median disease duration (years) 4.0 (IQR = 7.0) Condition Cerebral palsy 36 52.2 Spinal muscular atrophy 13 18.8 Genetic disease 10 14.5 Inborn errors of metabolism 4 5.8 Other 6 8.7 Respiratory support Spontaneous 34 49.3 Tracheotomy, O ₂ mask 21 30.4 Home-type mechanical ventilation 14 20.3 Nutritional support Oral 22 31.9 Nasogastric catheter 27 39.1 Gastronomy 20 29.0 Movement support Walking 6 8.7 Sitting/getting up 9 13.0	High school/university	17	24.6	
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Median age at diagnosis (years) 1.0 (IQR = 1.0) Median disease duration (years) 4.0 (IQR = 7.0) Condition 36 52.2 Spinal muscular atrophy 13 18.8 Genetic disease 10 14.5 Inborn errors of metabolism 4 5.8 Other 6 8.7 Respiratory support Spontaneous 34 49.3 Tracheotomy, O2 mask 21 30.4 Home-type mechanical ventilation 14 20.3 Nutritional support Oral 22 31.9 Nasogastric catheter 27 39.1 Gastronomy 20 29.0 Movement support Walking 6 8.7 Sitting/getting up 9 13.0	Received help from spouse	45	65.2	
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Inborn errors of metabolism 4 5.8 Other 6 8.7 Respiratory support Spontaneous 34 49.3 Tracheotomy, O₂ mask 21 30.4 Home-type mechanical ventilation 14 20.3 Nutritional support Oral 22 31.9 Nasogastric catheter 27 39.1 Gastronomy 20 29.0 Movement support Walking 6 8.7 Sitting/getting up 9 13.0	Spinal muscular atrophy	13	18.8	
Other 6 8.7 Respiratory support Spontaneous 34 49.3 Tracheotomy, O2 mask 21 30.4 Home-type mechanical ventilation 14 20.3 Nutritional support Oral 22 31.9 Nasogastric catheter 27 39.1 Gastronomy 20 29.0 Movement support Walking 6 8.7 Sitting/getting up 9 13.0	Genetic disease	10	14.5	
Respiratory support Spontaneous 34 49.3 Tracheotomy, O ₂ mask 21 30.4 Home-type mechanical ventilation 14 20.3 Nutritional support Oral 22 31.9 Nasogastric catheter 27 39.1 Gastronomy 20 29.0 Movement support Walking 6 8.7 Sitting/getting up 9 13.0	Inborn errors of metabolism	4	5.8	
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Tracheotomy, O ₂ mask 21 30.4 Home-type mechanical ventilation 14 20.3 Nutritional support Oral 22 31.9 Nasogastric catheter 27 39.1 Gastronomy 20 29.0 Movement support Walking 6 8.7 Sitting/getting up 9 13.0	Respiratory support			
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Nutritional support Oral 22 31.9 Nasogastric catheter 27 39.1 Gastronomy 20 29.0 Movement support Walking 6 8.7 Sitting/getting up 9 13.0	Tracheotomy, O ₂ mask	21	30.4	
Oral 22 31.9 Nasogastric catheter 27 39.1 Gastronomy 20 29.0 Movement support Walking 6 8.7 Sitting/getting up 9 13.0	Home-type mechanical ventilation	14	20.3	
Nasogastric catheter 27 39.1 Gastronomy 20 29.0 Movement support Walking 6 8.7 Sitting/getting up 9 13.0	Nutritional support			
Gastronomy 20 29.0 Movement support Sitting/getting up 6 8.7 Sitting/getting up 9 13.0	Oral	22	31.9	
Movement support 6 8.7 Walking 6 9 13.0	Nasogastric catheter	27	39.1	
Walking 6 8.7 Sitting/getting up 9 13.0	Gastronomy	20	29.0	
Sitting/getting up 9 13.0	Movement support			
	Walking	6	8.7	
Bedridden 54 78.3	Sitting/getting up	9	13.0	
	Bedridden	54	78.3	

The ENMQ test results for caregiving parents are presented in Table 3. The most commonly reported pain regions in parents with pain complaints were the lower back (62.3%), back (60.9%), and neck (42.0%).

A moderate, statistically significant and negative relationship was found between parental age and ZCBS total score (Table 3), while other parameters were not significant. The correlations between the characteristics of children and their caregiving parents and the ZCBS total score are shown in Table 4. The duration of the error

Table 2 Zarit scores and score groups for caregiving parents of children in paediatric palliative, Izmir, 2020–2021

Zarit category	No. (%)	Median Zarit score (IQR)]
Mild	19 (27.5)	54.0 (20.0)
Moderate	20 (29.0)	
Severe	30 (43.5)	

IQR = interquartile range.

is the most important factor that appears to be associated with shoulder, back, elbow, wrist, and ankle pain (P = 0.023, 0.019, 0.015, 0.047, respectively). In the ENMQ test, the parameters having a significant correlation with the characteristics of the sick child and the caregiving parents are presented in Table 5. Parameters with no correlation are not presented.

No significant correlation was found between the pain severity scores for 9 different regions in the Nordic test and the Zarit test total score. The correlations between the pain intensity scores in the ENMQ test and the total score on the ZCBS are shown in Table 6. Internal consistency in our study was determined as Cronbach α coefficient = 0.82 for ZCBS and Cronbach α coefficient = 0.90 for ENMQ.

Discussion

Our study shows that most of the caregiving parents of the patients followed up in paediatric palliative care had moderate or severe care burden, and the care burden was negatively related to the parents' age. The most frequently reported pain symptom was lower back pain which was observed in 62% of parents, followed by waist, back, and neck pain. With the prolongation of the illness of the child, pain in the shoulder, wrist and ankle of the caregiving parent were more frequently observed.

Parents who have children with life-restricting or lifethreatening diseases often need to change their duties and responsibilities, financial resources, vital activities and behaviours (16,17). This situation causes emotional and physical difficulties, expressed as the care burden (2). Studies have shown that the care burden for the parents of children with chronic disease is greater than for those with acute disease, and the care burden of the parents of those with severe disease is higher than those with mild disease (18,19). It has been reported that the burden of care for children with chronic and complex problems is not related to the severity and type of medical equipment, such as mechanical ventilation (20). It has been reported that percutaneous endoscopic gastrostomy reduces the current care burden (21). In our study, no relationship was found between the duration of disease in the child, the child's disability level, diagnosis, the level of need for care or/and the care burden. Home-type mechanical ventilation, gastrostomy, and medical devices and applications used by our patient group may have made

Table 3 Nordic test results among caregiving parents of children in paediatric palliative, Izmir, 2020-2021

Region	Those with pain complaint	Age at onset of illness	Need to change job	Complaint in last 12 months	Complaint in last 1 month	Complaint today	Business disruption in last 12 months	Visited a doctor in last 12 months	Used medication in last 12 months
	No. (%)	Years (IQR)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)
Neck	29 (42.0)	29.0 (15.8)	7 (10.1)	23 (33.3)	23 (33.3)	19 (27.5)	9 (13.0)	9 (13.0)	15 (21.7)
Shoulder	17 (24.6)	37.5 (14.5)	2 (2.9)	11 (15.9)	7 (10.1)	6 (8.7)	3 (4.3)	1 (1.4)	6 (8.7)
Back	42 (60.9)	32.0 (13.0)	6 (8.7)	18 (26.1)	10 (29.0)	11 (15.9)	8 (11.6)	6 (8.7)	13 (18.8)
Elbow	7 (10.1)	40.0 (-)	2 (2.9)	5 (7.2)	4 (5.8)	3 (4.3)	4 (5.8)	1 (1.4)	3 (4.3)
Wrist	12 (17.4)	31.0 (16.0)	1 (1.4)	9 (13.0)	9 (13.0)	5 (7.2)	4 (5.8)	4 (5.8)	5 (7.2)
Waist	43 (62.3)	30.0 (12.0)	11 (15.9)	23 (33.3)	22 (31.9)	13 (18.8)	11 (15.9)	5 (7.2)	16 (23.2)
Hip	10 (14.5)	31.0 (28.5)	3 (4.3)	8 (11.6)	6 (8.7)	4 (5.8)	4 (5.8)	1 (1.4)	5 (7.2)
Knee	21 (30.4)	37.5 (5.0)	1 (1.4)	11 (15.9)	10 (14.5)	7 (10.1)	4 (5.8)	3 (4.3)	5 (7.2)
Ankle	18 (26.1)	34.0 (10.0)	1 (1.4)	7 (10.1)	7 (10.1)	7 (10.1)	3 (4.3)	1 (1.4)	3 (4.3)

IQR = interquartile range.

parents to perceive the burden of care as being much lower.

The relationship between care burden and various variables including family functions (to meet economic needs, to provide status, to plan the education of children, to protect each other and to create an environment of mutual love), parental age, working time, economic status, marital status, and educational status was examined. It has been reported that the care burden among working parents with low-income was greater than that for middle- and high-income parents and non-working parents (18,22). However, in our study, no relationship was found between the income level and working status of the parents and the burden of care. This may be due to the wider family structure of some study subjects, where other family members, mostly grandmothers and grandfathers, provide financial and emotional support in difficult situations such as having individuals with an incurable disease in the family. Contrary to research indicating that the age of the caregiving parent is not related to the care burden, this was negatively correlated in our study (2). This may be due to having more acceptance of their child, more experience in controlling their behaviour, and developing more coping strategies, as the parents get older.

It is difficult to explain the pain in a single statement. In studies on pain, the perception of pain is shown to be based on gender, age, generation, income, job, education, connection with the host country, degree of isolation of the person, ethnic origin of neighbours, physical inadequacy, depressive symptoms, environment, religious belief, and cultural characteristics as well as psychological factors (23,24). When the pain perception of caregivers was examined, depressive symptoms and musculoskeletal system pain, particularly lower back pain, were reported. Previous research has reported that lower back pain was associated with the increase in

the level of disability and the presence of other family members in need of care, and it has been emphasized that caregiving parents should be supported to protect their mental health (25,26). Consistently, the most common region reported by the caregiving parents in our survey for pain was the lower back.

In previous studies, shoulder, hand/wrist, knee, and foot/ankle pain have been reported as being related to type of job and working conditions, and long-term pain has been reported in individuals with high workloads, especially in the hands and feet. Hand-wrist-finger pain has been most frequently associated with repetitive tasks and work stress (27,28). Caregiver parents can be expected to have psychological problems as they have to deal with many additional issues related to the incurable ailments their children have. Supporting this, studies have shown

Table 4 Correlations between patient and parental characteristics and Zarit total score, Izmir, 2020–2021

Parameter		Zarit total score
Duration of sickness	r _s	0.117
	P-value	0.337
Respiratory support	r_s	0.141
	P-value	0.247
Nutritional support	r_s	0.033
	P-value	0.789
Parental age	r_s	-0.364
	P-value	0.002*
Parent education status	r_s	-0.127
	P-value	0.298
Spouse assistance	r_s	-0.207
	P-value	0.088

rs = Spearman correlation coefficient.

* $P \le 0.05$.

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Table 5 Parameters with significant correlation in the Nordic test according to certain characteristics of the patients and the

Parameter		Parental age	Parental education level	Duration of illness	Respiratory support	Nutritional support	Spouse assistance
Shoulder pain in last 12 months	r _s	-0.067	0.044	0.549	-0.290	0.342	-0.119
	P-value	0.798	0.866	0.023*	0.259	0.179	0.648
Shoulder pain in last 1 month	r_s	0.013	-0.258	0.496	-0.310	0.240	-0.099
	P-value	0.960	0.317	0.043*	0.226	0.354	0.704
Shoulder pain today	r_s	0.040	-0.030	0.536	-0.203	0.304	-0.171
	P-value	0.878	0.910	0.027*	0.434	0.236	0.512
Back pain today	r_s	-0.127	-0.314	0.038	-0.215	-0.047	0.271
	P-value	0.422	0.043*	0.810	0.171	0.766	0.083
Back pain intensity	r_s	0.081	0.321	-0.090	0.060	0.065	-0.151
	P-value	0.612	0.038*	0.570	0.704	0.683	0.340
Elbow pain in last 12 months	r_s	-0.176	0.300	0.820	-1.000	-1.000	-0.400
	P-value	0.705	0.513	0.024*			0.374
Wrist pain in last 12 months	r_s	0.263	0.031	0.525	-0.270	-0.358	0.048
	P-value	0.325	0.908	0.037*	0.312	0.174	0.861
Wrist pain in last 1 month	r_s	0.439	-0.157	0.594	-0.016	-0.098	0.048
	P-value	0.089	0.560	0.015*	0.953	0.719	0.861
Wrist pain today	r_s	-0.297	0.101	0.207	-0.764	-0.522	-0.153
	P-value	0.263	0.709	0.442	0.001*	0.038*	0.572
Wrist pain intensity	r_s	0.204	0.689	0.193	0.085	-0.101	0.275
	P-value	0.449	0.003*	0.475	0.755	0.709	0.303
Back pain today	r_s	0.039	-0.344	0.355	-0.208	-0.103	0.045
	P-value	0.803	0.024*	0.019*	0.181	0.513	0.773
Knee pain in last 1 month	r_s	0.154	-0.377	0.158	-0.440	-0.067	0.472
	P-value	0.504	0.092	0.493	0.046*	0.772	0.031*
Ankle pain in last 12 months	r_s	0.099	0.050	0.475	-0.342	-0.403	-0.014
	P-value	0.697	0.843	0.047*	0.165	0.098	0.956

Parameters with no correlation are not presented.

Table 6 Correlations between Nordic pain severity scores among caregiving parents and Zarit total score

Pain intensity score		Zarit total score
Neck	r _s	-0.046
	P-value	0.814
Shoulder	r _s	0.104
	P-value	0.690
Back	r_s	0.211
	P-value	0.180
Elbow	r_s	0.109
	P-value	0.816
Wrist	r_s	-0.160
	P-value	0.553
Waist	r_s	0.143
	P-value	0.360
Hip	r_s	-0.260
	P-value	0.468
Knee	r_s	0.077
	P-value	0.739
Ankle	r_s	0.081
	P-value	0.749

r_c = Spearman correlation coefficient.

that caregiving parents were 3.7 times more likely to experience depressive symptoms, and their physical burden was greater in relation to the level of disability (10,29). In addition to the emotional burden, lower back pain was found to be associated with the transfer of children who are being cared for, and the effect of the physical load has been demonstrated (30). We found that the duration of the disease was particularly associated with shoulder and wrist pain. It has been shown that as the duration of the illness, and therefore the care work, increases, lifting and turning tasks during the child's care lead to shoulder pain and increased physical burden for the parents. Shoulder, hand and wrist pain among caregivers may be a result of improper handling of their children and/or being overweight. Considering supports during the caregiving process, mechanical ventilation seems to affect knee and elbow pain negatively, gastrostomy negatively affects elbow pain, and spousal support positively affects knee pain. It is known that caregivers with high emotional burdens and significant social and psychological stress experience greater physical load when performing the same physical work with others (31). It is recommended to provide support for caregivers

 r_s = Spearman correlation coefficient. *P \le 0.05.

in order to reduce the burden of care. Thus, as their physical load decreases, their perception of load can also decrease (32). In our study, emotional and physical burden was found to be associated with different pain zones, but it was observed that the physical burden was reduced by providing support to the caregiving parent. However, we found no relationship between pain intensity and care burden.

This study had some limitations. The most important were the subjective assessment of care burden and pain and the lack of evaluation of activity types that cause pain.

Conclusion

The majority of the caregiving parents of children requiring paediatric palliative care appear to have

moderate or severe care burdens, and these seem to be negatively related to the parents' age. About two-thirds of caregiving parents suffer from back pain. Neck, knee, shoulder and ankle pains are other frequently reported symptoms by caregivers. Duration of disease seems to be associated with the frequency and intensity of pain. For parents of children in paediatric palliative care, providing caregiver support and intermittent rest for caregivers can be important in terms of a social responsibility and support for the family when there is a need for care for more than a certain period.

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Enquête sur la charge de soins et les douleurs musculo-squelettiques des parents de patients en soins palliatifs pédiatriques en Turquie Résumé

Contexte: La prise en charge d'un patient pédiatrique est associée à des défis aux niveaux psychologique, physique et social. Bien que les effets émotionnels de la charge de soins sur les parents soient évidents, les effets physiques ne sont souvent pas reconnus.

Objectifs : L'objectif de la présente étude était d'examiner la relation entre la charge des aidants et les douleurs musculo-squelettiques chez les parents aidants d'enfants qui ont recours aux services de soins palliatifs.

Méthodes: Il s'agissait d'une étude transversale réalisée auprès de parents aidants de patients en soins palliatifs pédiatriques, menée entre le 15 juillet 2020 et le 15 janvier 2021. La charge de soins a été examinée à l'aide de l'échelle de Zarit (ou Inventaire du fardeau) et les plaintes physiques des parents par le biais du questionnaire élargi de type « nordique » sur les troubles musculo-squelettiques.

Résultats: Au total, 69 parents aidants ont été inclus dans l'étude. Le score médian pour l'échelle de Zarit était de 54,0. Chez les parents souffrant de douleurs, les zones de douleur les plus fréquentes étaient le bas du dos (62,3 %), le dos (60,9 %) et le cou (42,0 %). La douleur était associée de manière statistiquement significative à la durée de la maladie chez l'enfant, en particulier la douleur à l'épaule (p = 0,023) et la douleur au poignet (p = 0,024).

Conclusion : La lombalgie a été observée à un taux plus élevé chez les parents aidants. Plus la durée de la maladie de l'enfant augmentait, plus les parents aidants souffrant de douleurs à l'épaule et au poignet étaient nombreux. Il est important d'apporter un soutien aux aidants des patients en soins palliatifs pédiatriques afin d'atténuer leurs douleurs physiques.

استقصاء العلاقة بين عبء الرعاية والآلام العضلية الهيكلية لآباء الأطفال المرضى الذين يتلقون الرعاية الملطِّفة في تركيا

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الخلاصة

الخلفية: إن رعاية الطفل المريض ترافقها تحديات نفسية وجسدية واجتهاعية. ربها يسهل تحديد ما يُلِم بالوالدين من آثار عاطفية ناجمة عن عبء تقديم الرعاية، ولكن الآثار الجسدية غالبًا ما تكون غير معلومة.

الأهداف: هدفت هذه الدراسة إلى دراسة العلاقة بين عبء مقدمي الرعاية والآلام العضلية الهيكلية التي تصيب الآباء من مقدمي الرعاية للأطفال الذين يتلقون خدمات الرعاية الملطّفة. طرق البحث: أُجريت هذه الدراسة المقطعية على آباء قائمين على تقديم الرعاية لمرضى الرعاية الملطِّفة من الأطفال، في الفترة ما بين 15 يوليو/ تموز 2020 و15 يناير / كانون الثاني 2021. وجرى النظر في عبء الرعاية باستخدام استبيان زاريت للأعباء على مقدمي الرعاية، وجرى تناول الشكاوى الجسدية للآباء باستخدام استبيان شهال أوروبا الموسع للجهاز العضلي الهيكلي.

النتائج: شملت الدراسة 69 مشاركًا. وبلغ متوسط درجة عبء الرعاية على مقياس زاريت 54.0. وأكثر مناطق الألم شيوعًا لدى الآباء الذين لديهم شكاوى بشأن الألم مرتبط ارتباطًا إحصائيًّا بارزًا بفترة الديهم شكاوى بشأن الألم مرتبط ارتباطًا إحصائيًّا بارزًا بفترة المرض لدى الطفل، ولا سيما ألم الكتف (P = 0.024) وألم المعصم (P = 0.024).

الاستنتاجات: لوحظت آلام أسفل الظهر بمعدل أعلى بين الآباء القائمين على تقديم الرعاية. وكلما طالت مدة مرض الأطفال، ارتفع عدد من يعانون آلام في الكتف والرسغ بين الآباء القائمين على رعايتهم. لذا، من المهم توسيع مجال الدعم ليشمل مقدمي الرعاية للأطفال المرضى الذين يتلقون الرعاية الملطِّفة لأجل تخفيف الصعاب البدنية التي يعانيها مقدمو الرعاية.

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