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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 (≥ 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 α = 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