

Research Article

Care Burdens and Burnout Status of the Caregivers of Patients Treated in Pediatric Palliative Care (PPC): A Mindful Measure to Improve Quality of Life of Children

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Abstract

Aim: Pediatric Palliative Care (PPC) is a developing specialization focusing on support to child and the quality of palliative care provided to these patients is very important. We aimed to investigate caregivers with these children contributing to medical and social service planning to meet their needs, ensuring the quality of PPC.

Methods: Patients admitted to the PPC inpatient clinic between ages of 3 months - 18 years were reviewed for 2 years. The demographics, number of siblings, educational level, monthly income, profession/job, and marital status of primary caregiver were recorded. The relationship between these and the care burden and burnout status perceived by the primary caregiver was evaluated. The burden of caregivers was calculated using Zarith Scale and the Maslach Burnout Inventory was used.

Results: Of the 103 patients; 55 were male (53.4%). The distribution was 40% for neuromuscular diseases mostly, ≈30% used more than 5 devices, and 5 or more drugs. The caregivers were 88.3% female and ≈60% at basic educational level. It was observed that emotional exhaustion and burnout, was higher in high level of education. Most of caregivers didn't have a job and burden of care perceived by individuals who have to work increased significantly. The burnout level of caregivers significantly increases when the number of medical devices or medications increases.

Conclusion: Since PPC patients need complex care with high responsibilities such as medical equipment, tracheostomy, and an elevated number of drugs, the care burden of primary caregivers and their burnout levels increase significantly. Increasing the number of professionally functioning PPC centers to meet the needs of the caregivers of children is required.

Keywords: Burden of care; Burnout; Caregiver; Child; Children with Special Healthcare Needs; Pediatric palliative care

Introduction

The number of children with special healthcare needs is increasing worldwide, and the number of chronic and life-limiting diseases is increasing day by day. In addition, the life expectancy of patients with congenital anomalies, prematurity, neurological and metabolic diseases, and oncological diseases is prolonged [1]. Developments in the field of medicine and technology, new treatment styles, and the improvement in biomedical, pharmacological, and bioengineering cause differentiation in the nature of diseases that were incurable a short time ago. PPC is defined as the provision of follow-up services for these children by the professional health team

in the environment they live with their families in a way to meet physiotherapy, rehabilitation, psychological and medical treatment [2]. Formerly, palliative care was seen as an approach that should be carried out with patients in the last stages of the disease, but now it is the opinion that it should be given together with therapeutic approaches beginning from the diagnosis [3]. According to data from the World health organization (WHO), it is necessary to provide palliative care services to 20 million people every year, and 9% of the patients who need palliative care are children [4]. WHO defines PPC as; the prevention and alleviation of the suffering of patients and their families facing the problems associated with life-threatening diseases. These problems are the physical, psychological, social, and spiritual suffering of the patients and their family members [5]. Therefore, it foresees the development of PPC centers in all countries [6]. The American Academy of Pediatrics (AAP), supports a palliative care model integrated with the health system that should be continued throughout, regardless of whether the disease is cured or fatal [7]. Therefore, PPC is a holistic approach to all problems of the patient and the family. There is no thought of accelerating or delaying death. Life and death are seen as natural processes. It is a care philosophy in which both the sick child and family are included, and it is important to increase the quality of the child's life rather than prolonging the life span and includes a comprehensive and effective approach [1,8]. This is a process with different dimensions and various difficulties for

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the patient and the caregiver. The caregiver assumes an extra financial and moral burden, and this burden can negatively affect the caregiver psychologically, socially, and physically over time. In the studies carried out on caregivers, it has been determined that the incidence of psychiatric disorders such as anxiety and burnout syndromes has increased [9]. These problems will cause the caregiver to disrupt the care and affect their health. As a result, the task of caring for a child with a disability who requires complex care at home/hospital can be daunting. Providing this type of care can be challenging for both the physical health and psychological well-being of their parents. Primary caregivers are likely to experience burnout as a result of these responsibilities and their work, and it is impossible for the child not to be affected. For this reason, it is important to evaluate caregivers in this context and unfortunately, the number of these studies in the literature is negligible. Hence, in this study, the care burden, and burnout status of individuals who care for patients hospitalized in PPC inpatient clinics for various reasons were evaluated, and the relationship between caregivers' sociodemographic status, chronic disease status, care burden, and burnout status was examined. By the way, it is aimed to contribute to medical and social service planning to meet the needs of both patients and primary caregivers.

Materials and Methods

The study was carried out with the approval of the Ethics Committee, on patients aged between 3 months and 18 years who were followed up in the 15-bedded Pediatric Palliative Care Unit of a tertiary Children's Research Hospital between March 2021, and April 2022. In the study, the patient's age, gender, diagnosis (congenital or acquired, metabolic, neurological, genetic, respiratory, gastrointestinal, cardiovascular, hematological/oncological, renal, endocrinological, trauma, and other causes) and the characteristics such as the medical technological devices they used and their number, disease duration, the number of drugs used, the presence of social security, and the number of siblings were recorded. In addition, demographic characteristics such as age, gender, degree of relationship, educational level, income, occupation, and marital status of the caregivers were determined. The relationship between these and the perceived care burden and burnout status of the primary caregivers was evaluated. The burden of care for the relatives of the patients was calculated using the "Zarith Burden Interview (ZBI)", which was developed by Zarith Reeve and Bach-Peterson. Again, to measure the burnout levels of caregivers, the "Maslach Burnout Inventory (MBI)" was developed by Maslach and Jackson. The validity and reliability analysis were performed in our country for both scales.

The ZBI is a 22-item tool used to measure the perceived burden of the caregiver. 22 items are evaluated on a 5-point Likert scale ranging from 0 = "never" to 4 = "almost always". All items are summed to give a total score ranging from 0 to the highest of 88, with higher scores indicating a greater perceived burden. The questions focus on key areas such as caregiver health, psychological well-being, financial status, social life, and the relationship between caregiver and patient [10]. The Maslach Burnout Inventory (MBI) is a 22-item questionnaire designed to assess and measure three scales of burnout syndrome. Burnout Syndrome Developmental Stages are defined under three subheadings; emotional exhaustion, depersonalization, and decreased personal success. It can be expressed as the tendency of a person to evaluate himself negatively [11,12]. The items were evaluated on a 5-point Likert scale ranging from 1 = "never" to 5 = "every day". Burnout is conceptualized as a continuous variable of experienced emotion ranging from low to high. A high degree of

burnout was reflected in high scores on the Emotional Exhaustion and Depersonalization scales and low scores on the Personal Achievement scale [13-15]. Those with a total score of 46 and below in all subgroups were considered a low load, and those over 47 were considered a heavy burden. The higher the emotional burnout and depersonalization scores and the lower the personal achievement scores, the higher the burnout [16].

A 20 min to 30 min face-to-face interview technique was applied to the families of the patients hospitalized in the PPC unit, voluntarily, with the multiple-choice questionnaire data form in which the demographic characteristics were questioned. In addition, Maslach-Burnout and Zarith Burden of Care Scales were completed and scored for each patient. Interventions such as home-type mechanical ventilation, tracheostomy, percutaneous endoscopic gastrostomy, permanent nasogastric tube, etc. are recorded. The caregivers over the age of 18 and able to understand the questions who lived with the child for at least 3 months and were directly responsible for the care of the child were included. Those who did not volunteer and the ones who wanted to quit or not complying with the aforementioned rules were excluded from the study.

Statistical evaluation

Data were evaluated using the IBM SPSS 26 (Statistical Package for the Social Sciences) program. Descriptive statistics were determined as the number, percentage (%), ratio, median, interquartile range, mean, standard deviation, median, minimum, and maximum. While evaluating the data, whether the parameters were suitable for normal distribution was evaluated with the Shapiro-Wilks test. The Kruskal-Wallis test was used to compare non-normally distributed Maslach parameters, and the Mann-Whitney U test was used to determine the group that caused the difference. The Chi-square test was used in the comparison of qualitative data. Logistic Regression Analysis was used to compare the Zarith burden of care score and other variables. Spearman Correlation Analysis was used for the comparison of non-normally distributed continuous variables. If the absolute value of the correlation coefficient is 0.00, there is no relationship; between 0.01 to 0.25 is weak; between 0.26 to 0.50 is moderate; A correlation between 0.51 and 0.75 was accepted as a strong correlation, and a correlation of >0.75 was accepted as a very strong correlation. Statistical significance was determined at the $p < 0.05$ level.

Results

In our study, a total of 103 patients hospitalized in the PPC unit and their caregivers were evaluated. Of the patients included in the study, 55 (53.4%) were male and 48 (46.6%) were female. Of these patients, 95 (92.2%) were citizens of Turkey, 3 (2.9%) were Syrian, and 5 (4.9%) were citizens of other countries (Iraq, Afghanistan, Pakistan, Djibouti). Diseases of patients included neuromuscular (40%), genetic (32%), cardiovascular (14%), metabolic (7%), respiratory (4%), hematological (2%), and endocrinological (1%) respectively.

Demographic data such as the residence of the patients, social security, medical technological devices they use, the number of siblings, and the drugs they use are shown in Table 1.

The disease duration of 32 (31.1%) patients was less than 12 months while 26 (25.2%) had a disease duration of 12-24 months. Forty-five (43.7%) needed care for more than 2 years. While the number of drugs used by 73 (70.9%) patients was less than 5, it was determined that 30 (29.1%) of the patients required 5 or more drugs.

Table 1: Demographic data of the patients and the medical devices they used.

	Variables	n = 103	Distribution (%)
Age	3-24 months	29	28.2
	25-60 months (2-5 years)	24	23.3
	61-120 months (5-10 years)	17	16.5
	>120 months (over 10 years)	32	32
Place of Residence	City Center	62	61.2
	Other Provinces	41	39.8
Child's Nationality	Turkish	95	92
	Syrian	3	2.9
	Other countries	5	4.9
Siblings	Yes	79	76.6
	None	24	23.4
Social Security	Fund	3	2.9
	Social Security Institution	65	63.1
	Limited security	13	12.6
	Private health insurance	5	4.9
	Disaster and Emergency Management Presidency (AFAD)	3	2.9
	None	14	13.6
Medical Technology	Nasogastric Tube	47	45.6
	Percutaneous Entero-Gastrostomy (PEG)	21	20.4
	Tracheostomy	56	54.4
	Non-Invasive Ventilator (BIPAP)	11	10.7
	Home Ventilator Dependent	44	42.7
	Central Venous Catheter	13	12.6
	Ventiulo-Peritoneal Shunt	7	6.8
	Wheelchair dependent	5	4.8
	Bedridden	93	90.2

When the data of caregivers were analyzed, it was found that 91 (88.3%) were female and 12 (11.7%) were male. In this group, the majority were women, 89 (86%) were mothers of sick children, 10 (9.7%) were fathers, and 4 (3.9%) were relatives or other nursing staff. The median and median values of the data are given in Table 2. Other demographics of caregivers are shown in Table 3.

When comparing the results of care burden and burnout, there was no statistically significant difference in the scales in terms of the gender of the caregiver of children ($p > 0.05$).

In the comparison made between the scales in the grouping of the patients according to the place of residence, a low level of significance was found in the Maslach total ($p = 0.048$), while no significance was found in the subtypes of depersonalization, emotional exhaustion, personal accomplishment and Zarith care burden ($p > 0.05$). In terms of the medical devices that the patients have to use to survive, the care and use of the medical devices by the caregiver were statistically significant highly on emotional exhaustion ($p = 0.002$). The total Maslach Burnout score of the families of the children with VP Shunt was also found to be statistically significant ($p < 0.05$). No statistically significant difference was found in other medical instruments like PEG, tracheostomy, NIV, home ventilation, wheelchair, or catheter ($p > 0.05$) (Table 4). When the relationship between the diagnosis and the burden of care/burnout was evaluated, no significant difference was found ($p > 0.05$).

There was no statistically significant difference between the

Table 2: The variables of patients and caregivers and the clinical scale scores.

	Mean±SD	Median (Min.-Max.)
Child's Age	6.3 ± 5.4	4(0.3-17)
Duration of Disease(months)	51.3 ± 57.5	24(3-204)
Caregiver's Age	34.3 ± 8.1	34(20-56)
Maslach Total	59.1± 10.9	60(19-81)
Emotional Exhaustion(DT)	19.2±7.5	17(9-39)
Depersonalization	7.2±2.8	6(5-17)
Personal Success	32.3±8.4	35(4-42)
Zarith Total	33.6± 12.8	30(14-72)

Mean: Mean; SD: Standard Deviation; Min.: Minimum; Max: Maximum

Table 3: Demographic data of caregivers.

	Variables	n = 103	Distribution (%)
Age	20-29 years	35	34
	30-39 years	37	35
	>40 years	31	39.1
Gender	Woman	91	88.3
	Male	12	11.7
The degree of the relationship	Mother	89	86.4
	Father	10	9.7
	Others	4	3.9
Marital status	Married	95	92.2
	Widow	3	2.9
	Divorced/Living Separated	5	4.9
Job	Housewife	76	73.8
	Employee	6	5.8
	Officer	5	4.9
	Self-employment	10	9.7
	Other	6	5.8
Educational Status	No education	10	9.7
	Primary education	54	52.4
	High school	22	21.4
	University/ Graduate	17	16.5
Income rate	<3000 ₺ (Below Minimum Wage)	53	51.5
	3000-5000 ₺	35	34
	5000-7000 ₺	7	6.8
	7000-10000 ₺	3	2.9
	>10000 ₺	5	4.9
Working	Yes	16	15.5
	No	87	84.5

caregiver burden perception and burnout scale and its subgroups in terms of the gender of caregivers ($p > 0.05$). While there was no statistically significant difference between the number of medical devices used by sick children and the burden of care perceived by caregivers ($p > 0.05$), a low level of significance was found between Maslach burnout total score ($p = 0.04$, $p < 0.05$), (Table 5).

A statistically significant difference was found between the Maslach Burnout total score and the Maslach subgroup Emotional Exhaustion, among the caregivers having secondary education and above (>8 years). It was determined that those with higher education levels had experienced more emotional burnout ($p < 0.05$). It was determined that the caregivers' working in a job additionally caring for their patients increased their care burden ($p < 0.05$), (Table 6).

Table 4: Comparison between the medical devices owned by the child and the scores of the Zarith Scale and Maslach Burnout Scale Subgroups.

Medical Technology	Maslach Total		DT		Depersonalization		NW		Zarith Total	
	median (Min.-max).	P*	median (Min.-max).	P*	median (Min.-max).	P*	median (Min.-max).	P*	median (Min.-max).	P*
NG										
YES	62(19-81)	0.081	20(9-39)	0.002	7(5-17)	0.153	34(4-41)	0.059	35(16-72)	0.011
NO	59(33-81)		16(9-32)		5.5(5-17)		35.5(9-42)		30(14-69)	
PEG										
YES	61(36-79)	0.557	17(9-29)	0.721	6(5-15)	0.719	36(16-40)	0.095	30(19-61)	0.746
NO	59(19-81)		17.5(9-39)		6(5-17)		34(4-42)		31(14-72)	
TRACHEOSTOMY										
YES	61.5(35-81)	0.099	20(9-39)	0.107	6(15-32)	0.948	35.5(15-40)	0.526	30(15-72)	0.91
NO	59(19-81)		16(9-32)		6(5-17)		34(4-42)		31(14-69)	
NIV										
YES	58(35-70)	0.269	17(13-29)	0.949	5(5-9)	0.123	34(14-40)	0.368	27(16-41)	0.165
NO	60(19-81)		17(9-39)		6(5-17)		35(4-42)		31(14-72)	
MV DEPENDENT										
YES	62(35-79)	0.055	20(9-39)	0.066	6(5-17)	0.963	36(15-40)	0.417	30(16-72)	0.973
NO	59(19-81)		16(9-33)		6(5-17)		34(4-42)		31(14-69)	
CVC										
YES	57(19-77)	0.167	17(9-37)	0.508	5(5-9)	0.287	34(4-40)	0.372	34(18-53)	0.505
NO	60(29-81)		17(9-39)		6(5-17)		35(9-42)		30(14-72)	
VP SHUNT										
YES	56(19-60)	0.031	14(10-17)	0.052	6(5-9)	0.569	35(4-40)	0.636	30(14-72)	0.262
NO	60.5(29-81)		18(9-39)		6(5-17)		35(9-42)		33(26-53)	
WHEELCHAIR										
YES	60(19-81)	0.87	17(9-38)	0.324	6(5-17)	0.459	35(4-42)	0.743	30(15-72)	0.599
NO	60(35-81)		19(9-39)		7(5-14)		34(14-40)		35(14-68)	

NG: Nasogastric feeding tube; PEG: Percutaneous Enteral Gastrostomy; NIV: Non-invasive Ventilator

CVC: Central Venous Catheter; VP Shunt: Ventriculoperitoneal Shunt

Table 5: Comparison between the scores of the Zarith Caregiver Burden Scale and Maslach Burnout Scale Subgroups according to the number of medical devices used by the child.

Number of Medical Devices Used	Maslach Total		EE		Depersonalization		PS		Zarith Total	
	median (Min.-max).	P*	median (Min.-max).	P*	median (Min.-max).	P*	median (Min.-max).	P*	median (Min.-max).	P*
>3	60(19-81)	0.04	17(9-39)	0.05	6(5-17)	0.8	34(4-42)	0.6	30(14-54)	0.985
<3	58(35-77)		17(9-30)		6(5-13)		35(14-41)		31(16-72)	

EE: Emotional Exhaustion; PS: Personal Success

Table 6: Comparison between the educational level and working status of the caregiver and the scores of the Zarith and Maslach Scale Subgroups.

Number of Medical Devices Used	Maslach Total		EE		Depersonalization		PS		Zarith Total	
	median (Min.-max).	P*	median (Min.-max).	P*	median (Min.-max).	P*	median (Min.-max).	P*	median (Min.-max).	P*
Education level										
>8 years	63(35-81)	0.033	22(9-39)	0.013	6(5-17)	0.574	35(14-40)	0.981	33(14-72)	0.246
<8 years	58(19-81)		16(9-38)		6(5-17)		35(14-42)		16(39-60)	
Work										
There is	61(46-70)	0.636	23(9-39)	0.116	5(5-17)	0.284	33(15-40)	0.257	38(15-72)	0.033
None	60(19-81)		17(9-38)		6(5-17)		35(4-42)		30(14-69)	

EE: Emotional Exhaustion; PS: Personal Success

When the effects of patient and caregivers variables on care load were evaluated, univariate binary logistic regression analysis was used to evaluate the effects of patients' medical devices and their number, the number of drugs they use, and the effects of caregiver sociodemographic data on Zarith Caregiver Burden. Those with a Zarith Care Burden score of 47 and above were considered to have an increased care burden. According to the logistic regression analysis results, a statistically significant result was obtained that; the use of NG owned by the patients and used by the caregivers, increased the burden of care [OR=0.97 95% CI (0.02 - 0.456), (p=0.003, p<0.05)], (Table 7).

It was determined that the patient's tracheostomy increased

the burden perceived by the caregiver [OR=0.250 95% CI (0.006-0.948), (p=0.041, p<0.05)], (Table 7). While there was a statistically significant statistical significance indicating that 5 or more drugs that the patient should use increase the burden of care (p=0.007, p<0.05), no statistically significant results were obtained regarding the use of other medical devices (p>0.05).

It was found that having a job for the caregiver increased the burden of care (p<0.05), and the lack of the caregiver's social security also increased the burden of care (p<0.05). The marital status of the caregiver, the degree of relationship, and the presence and number of siblings of the sick child were not found to affect the burden of care

($p > 0.05$), (Table 8).

The relationship between caregivers' burden of care and its subgroups was examined when the Zarith caregiving load scale and Maslach scores were compared. Since the data were not normally distributed, the relationship between them was analyzed by Spearman correlation analysis. A positive correlation was found between Maslach's total score and Zarith's total score ($R = 0.437$; $p = 0.000$), (Table 9). As the burden of care increases, the burnout rate increases.

When the relationship between disease duration and caregiver burden of care was compared with Spearman correlation analysis. It was observed that there was a positive relationship between disease duration and care burden. This relationship was considered statistically significant ($R = 0.216$, $p < 0.05$). As the duration of the disease increased, it was observed that the burden of care perceived by the caregivers increased, while no statistical significance was found between the duration of the disease and burnout ($p > 0.05$), (Table 9).

A positive correlation was found between IQ and Maslach's subgroup emotional exhaustion ($R = 0.679$; $p = 0.001$). Accordingly, as the burden of care increases, emotional exhaustion increases. Again, a positive correlation ($R = 0.370$; $p = 0.000$) was found between IMT

and Maslach subgroup depersonalization. Accordingly, as the burden of care increases, depersonalization increases. A negative correlation ($R = 0.346$; $p = 0.000$) was found between IQ and Maslach's subgroup, personal achievement. Accordingly, as the burden of care increases, Personal Success decreases (Table 9). All of these results show that as the burden of care increases, the level of burnout of the caregiver increases.

Discussion

PPC is a new area of expertise in the world and there is no publication on the burden of care in the pediatric age group in the literature. Since PPC is a newly developing field, the number of studies in this field is few, considering the adult age group with limited resources. For this reason, this study conducted in the field will be the first in the literature. Although the quality and quantity of care for pediatric palliative patients, the effect on the caregiver, and the quality of care that reaches pediatric patients in need of PPC are in line with all these effects, unfortunately, there is nothing to do other than comparing the data with adult palliative care patients in the current literature context.

Of the patients participating in the study, 55 (53.4%) were male and 48 (46.6%) were female. In the distribution of patients according

Table 7: The effect of medical devices on the burden of care.

Variables		Beta	SE	P value	OR	95% Confidence Interval
Medical Devices Used	NG	-2.33	0.79	0.003	0.097	0.021-0.456
	PEG	0.582	0.803	0.468	1,790	0.371-8.628
	Tracheostomy	-1.39	0.68	0.041	0.25	0.066-0.948
	NIV	19.57	1,	0.999	3,	0,000-.
	MV Dependent	-0.501	E+4	0.372	E+8	0.202-1.819
	Wheelchair	0.305	0.561	0.595	0.606	0.441-4.176
	CVC	-0.668	0.574	0.356	1,356	0.123-2.135
	Bedridden	-0.585	0.728	0.591	0.513	0.066-4.702
	VP shunt	-0.938	1,088	0.291	0.557	0.069-2.233
		0.888		0.392		
Number of Medical Devices >3		-0.577	0.565	0.307	0.562	0.186-1,700
Number of Drugs Used >5		-1.57	0.583	0.007	0.209	0.067-0.656

NG: Nasogastric feeding tube; PEG: Percutaneous Enteral Gastrostomy; NIV: Non-invasive Ventilator; CVC: Central Venous Catheter; VP Shunt: Ventriculoperitoneal Shunt; OR: Odds Ratio; SE: Standard Error

Table 8: The effect of Caregivers' Status on the Burden of Care.

Variables		Beta	SH	P	OR	95% Confidence Interval
Gender of the Caregiver		0.786	0.735	0.285	2,194	0.519-9.270
The degree of proximity	Mother			0.295		
	Father	-0.86	1,199	0.473	0.423	0.040-4.434
	Other	0.251	1,345	0.852	1,286	0.092-17.95
Educational Level (8>years)		-0.105	0.571	0.854	0.9	0.294-2.757
Marital status	Married			0.95		
	Widow	-0.369	1,155	0.749	0.691	0.072-6.649
	Divorced/Separate	-19.8	2, E+4	0.999	0,000	0,000-.
Working Status		-1.25	0.636	0.049	0.286	0.082-0.993
Number of Children	No other children			0.572		
	1-2	-1.01	0.981	0.302	0.364	0.053-2,487
	>3	-0.3	0.732	0.682	0.741	0.177-3.107
Social security	None			0.158		
	Pension fund	-1.61	1,360	0.237	0.2	0.014-2.876
	SSI	-1.39	1,732	0.423	0.25	0.008-7.452
	No insurance	-2.98	1,298	0.022	0.051	0.004-0.647
	Private insurance	-2.4	1,446	0.097	0.091	0.005-1.547
Monthly Income	AFAD	-21.9	2,E+4	0.999	0,000	0,000-.
		-0.97	1,075	0.365	0.378	0.046-3.107
Number of siblings	None			0.572		
	1-2	-1.01	0.981	0.302	0.364	0.053-2,487
	>3	-0.3	0.732	0.682	0.741	0.177-3.107

NG: Nasogastric feeding tube; PEG: Percutaneous Enteral Gastrostomy; NIV: Non-invasive Ventilator CVC: Central Venous Catheter; VP Shunt: Ventriculoperitoneal Shunt OR: Odds Ratio; SH: Standard Error

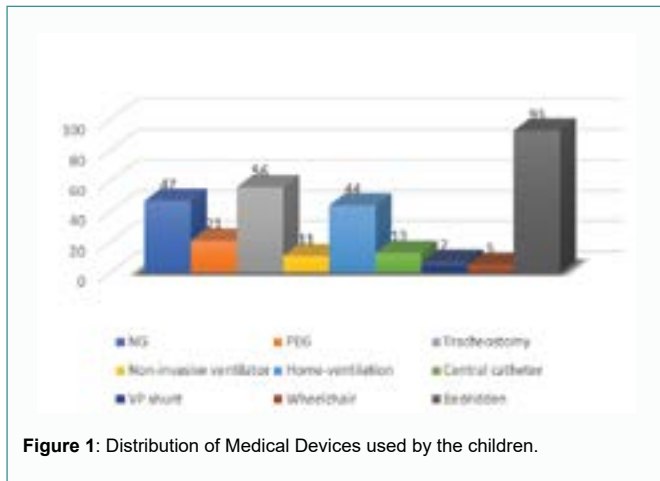


Figure 1: Distribution of Medical Devices used by the children.

Table 9: Comparison of Zarith Burden Scale, Maslach Burnout Scale, and its subgroups.

	Maslach Total		Zarith Total	
	r	p	r	p
Child Age	0.092	0.356	0.182	0.066
Caregiver Age	-0.043	0.667	0.116	0.242
Monthly Income Level	-0.025	0.804	-0.024	0.811
Education level	0.155	0.118	-0.011	0.909
Number of siblings	-0.07	0.485	-0.128	0.196
Emotional Exhaustion	-	-	0.679	0.001
depersonalization	-	-	0.37	0.001
Personal Success	-	-	0.35	0.001
Maslach Total	-	-	0.437	0.001
Zarith Total	0.437	0.001	-	-
Number of Drugs Used>5	0.156	0.115	0.113	0.254
Duration of the Disease	0.191	0.053	0.216	0.029

to disease groups, neuromuscular diseases were in first place at 40%, and genetic diseases were in second place at 33%. Similarly, in a prospective cohort study conducted in 6 centers, the majority of pediatric patients in need of palliative care consisted of 40.8% genetic congenital neuromuscular diseases with 39.2% [17]. Patients with hematological/oncological diseases are not sufficiently followed in PPC Units in our country compared to the literature, since the pediatric hematological/oncological inpatient units work actively and these patients prefer to be followed in these units [18]. In this respect, we think that the distribution of the diagnosis of the patients may differ in this regard. At the same time, our hospital is a leading center in the diagnosis and surgical treatment of congenital heart diseases and follow-up and treatment of SMA patients. Therefore, this may have increased the high distribution of neuromuscular and cardiovascular diseases. At the same time, genetic diseases, which have a large share of 32%, are in second place; due to the high number of second and third-degree consanguineous marriages in our country, with insufficient genetic counseling, and low educational levels.

It was determined that the number of drugs used by 73 (70.9%) patients were less than 5, while 30 (29.1%) of them required 5 or more drugs. Feudtner et al. [17] stated that patients who needed palliative care used an average of 9 drugs per day [17]. In our study, when the number of drugs that children have to use were five or more during the day, the caregiver's perceived burden of care significantly increases.

Of the 32 (31.1%) patients, the disease duration was less than 12 months. While 26 (25.2%) patients had a disease duration of 12 to 24 months, 45 (43.7%) were found to require care for more than 2 years, which was consistent with the literature [18]. When the relationship

between the duration of care of the caregivers and burnout/the burden of care was investigated, it was correlated with the duration of the disease of the patients. In addition, it was observed that the burden of care increased as the duration of the disease increased, but no effect was found on burnout. Similar to our study, data showing that the burden of care increases as the duration of the disease increases, in studies conducted with the caregivers of patients in the adult age group who need palliative care [19].

When the relationship between the number of medical devices children have to use, and the burden of care and burnout is verified, it was seen that the presence of a Nasogastric Tube (NG), increased the burden of care and significantly increased emotional exhaustion from Maslach Burnout subgroups. As far as we know, there is no previous study in the literature showing the effect of nasogastric tube feeding on the burden of care. The caregivers stated that they hesitated to feed the child with an NG tube, so they applied to the hospital frequently. Therefore, it has been determined that the NG catheter increases the burden of care, and although it does not require a difficult application, families are reluctant to use NG.

In our study, it was observed that the presence of a tracheostomy cannula which is among the medical devices that sick children have to use increases the burden of care in the same way. Baddour et al. [20] investigated the financial toxicity and burden of care in the families of children living dependent on tracheostomy [20]. In another cross-sectional study examining the quality of life in pediatric tracheostomy patients and their caregivers, it was shown that the burden of care is high, especially for children with tracheostomy and their families, when compared to other serious childhood diseases similar to our study [21].

In this study, while Maslach Burnout Scores were found to be significantly higher in families of children with VP shunt, no significant finding was obtained on care burden. As far as we know, there is no study in the literature about anxiety and burnout caused by VP shunts on families. However, we think that the fact that the VP shunt is directly related to the central nervous system increases the severity of its complications, and being aware of the early symptoms of increased intracranial pressure with shunt failure may increase the responsibility and anxiety on families in terms of early diagnosis and surgical intervention, and accordingly, increased burnout [22].

Children who had to use constantly three or more of these devices increased the burnout of caregivers. For example; costly and life-threatening responsibilities are having to aspirate the secretions of children with tracheostomy and controlling connection to a home mechanical ventilator at regular intervals. The maintenance of the tracheostomy cannula, replacement of the breathing circuit of the mechanical ventilator device, and the need for an aspirator, aspirator catheter, aspirator set, and tracheostomy cannula are very challenging for the caregiver, both in terms of anxiety and economic reasons. On the other hand, when we consider that the cost of permanent NG tube replacement, enteral feeding bags, injectors, and nursing diapers have to be partially afforded by the patient's relatives, it is possible to see that the economic burden of a child who is both on a mechanical ventilator and fed by NG increases. If we look from another perspective, that child patient who does not have many physiological functions such as chewing and swallowing; he/she should be fed with permanent NG or PEG every three to four hours during the day and each feeding will take 15 min to 20 min. Furthermore, if the medical treatments they have to take are calculated which is given in the same way, it is obvious

that the caregiver should spend at least 3 hrs to 4 hrs a day even for this job, which complicates the time management of the caregiver and seriously reduces the remaining time for their personal needs.

The caregiver who had another sibling besides the sick children and the number of these siblings did not affect the caregiver's perceived burden of care and burnout. In our study, when the distance the patients had to come for treatment was compared according to their place of residence, it was determined that the burnout score of those coming from far places other than center residences was higher. The main reason for this may be the small number of PPC centers and the need for such patients to come to the center from the periphery to benefit from special health services. Moreover, it is thought that it may be because patients experience various difficulties every time, such as providing appropriate vehicles during patient transport and providing stabilization during the transport period. In the interviews made with the relatives of the patients, it was determined that even the patients and caregivers residing in the center had difficulties in finding a fully equipped ambulance service for the transport of the patient to the hospital and during their return home since there are many medical devices that they have to use constantly.

When the characteristics of the caregivers of patients in need of PPC are evaluated; it was observed that 88.3% were female and 11.7% were male. Mostly, 86% was the mother of the sick child. Similar to many studies in the literature, when the caregivers of patients in need of palliative care are examined, it was seen that the female population is in the majority [23-26]. In our country, sociocultural values and gender judgments arising from the gender-based division of labor and patriarchal structure play a primary role since the birth of the child, and this situation places the burden and responsibility of care on the woman alone, which reaches serious dimensions in the presence of the child's illness and life-threatening diseases [27]. In a study by Grov et al. [28] conducted by women, who were caregivers of adult palliative care patients, it was determined that women had more anxiety and depression than men [28]. Although the majority of caregivers are women, many studies have shown that the perceived burden of care in men is higher than in women [29]. Unlike the literature, no statistically significant difference was found between the male and female genders in terms of care burden and burnout levels in our study. Although there was no significant difference between the sexes in our study, the reason why men perceive more care burden than women can be shown that they do not have previous experience in care and they feel inadequate in this regard.

When the relationship between the education levels of caregivers and their perceived care burden and burnout levels was examined in the literature, as in our data, the majority of the population providing palliative care consisted of people with a basic education level [30-32]. In our study, it was found that people with a secondary and higher education level experience more emotional exhaustion and, accordingly, more burnout at a statistically significant level. We think that this might be because, with the increase in the level of education, the awareness about the disease and its course increased, which in turn increased anxiety and emotional burnout. This brings to mind the saying of the ancient Greek philosopher Socrates, "Ignorance is bliss".

When the relationship between the status of having a job, which is another data of caregivers, and the burden of care and burnout, it was seen that the fact that the caregivers were working in any job (other than their responsibilities to care for their patients) was a factor

that greatly increased the care burden. Given et al. [33] examined the quality of life and depression status of individuals who care for cancer patients in the adult terminal period, it was reported that the burden of care and depression increased in those who had a job [33].

When the monthly income levels of caregivers were examined, it was seen that 51.5% of them had an income below the minimum wage. In our study, no statistically significant effect of income levels on care burden and burnout level was found. However; In many studies in the literature, data are showing that the low economic level of the caregiver increases the burden of care, and increases the level of burnout and depression [34,35]. According to WHO data, 98% of patients who need PPC live in low- and middle-income countries, and almost half are in Africa [36]. According to 2022 data, our country is among the low- and lower-middle-income countries. Many pediatric patients need palliative care due to factors such as immigration policy, refugees, health tourism, and war conditions in the region. In our study, in face-to-face interviews with families, many families stated that they were overwhelmed by the cost of maintenance and consumables for the medical instruments they had to use and that the support provided by the government was insufficient to supply these materials, which are constantly changing and increasing with current exchange rates [37]. This indirectly increases the burden of care and burnout.

In our study, while the majority of the patients had social security with a rate of 63.1%, 12.6% did not have any social security. When the relationship between the social security of the patients and their burden of care is evaluated, it has been observed that the care burden of the individuals who care for the patients without social security has increased considerably. We think that the main reason for this is the low income of these people.

In our study, the relationship between care burden and burnout levels of individuals who care for PPC patients was also investigated, and it was found that as the care burden increased, burnout and emotional exhaustion, and depersonalization, which are the subgroups of burnout, increased, and personal success decreased inversely. Using the same scales performed on adults, Egici et al. [38] stated that as the burden of care increased, the level of burnout increased [38].

Palos et al. [19] in the United States investigated the care burden of adult patients with advanced cancer and underserved minority groups, who needed palliative care, anxiety and depression symptoms were detected in caregivers rather than patients. At the same time, they stated that caregivers of patients with high symptom burden have a high burden of care, that psychologists and psychiatrists responsible for the palliative care service should screen patients' relatives early for negative physical and psychological symptoms, and that cross-cultural screening tools that can be applied in a short time should be developed and approved [19].

During our study, the general impression we got from the interviews was that the relatives of the patients needed more psychological and economic support. In particular, the families of SMA patients state that they are psychologically worn out during the campaigns they carry out to purchase the single-dose gene therapy Zolgensma, a new treatment method that is covered by payment in most countries in Europe and that they often cannot spare enough time for their sick children. In another study by Kalinkara et al. [20] investigating the care burden and burnout status of individuals who care for elderly patients, it was determined that an increase in the care

burden increases burnout and its subgroups, depersonalization, and emotional exhaustion while decreasing personal success. These data support the results of our study [20].

In another study by Salamara et al. [31] on disabled elderly individuals, a significant positive correlation was found between the degree of caregiver burden and the degree of burnout by using the Zarit Care Burden Scale and the Maslach Burnout Scale; heavy burden has been associated with high levels of burnout [31].

In Yıldızhan et al. [40] study on individuals caring for Alzheimer's patients, Zarit and Maslach scales were used, it was stated that as the care burden increased, there was an increase in depersonalization and emotional exhaustion, which are Maslach subgroups, and no significant change was found in the decrease in personal achievement [40].

To the best of our knowledge, our study is the first in the literature to include the pediatric population requiring palliative care and their caregivers. We have determined that the findings obtained in our study contain similar results with studies in adult groups that have been applied to different disease groups so far. We think that more meaningful data will be obtained in further studies in which pediatric oncological patients are included at a higher rate. Although it is known that PPC is quite different from adult palliative care, we think that the effect in caregiver groups was similar to each other. However, this field of profession is still untouched and more studies are needed because the distribution of the diseases and care strategies of PPC differ from adults.

Conclusion

Since PPC patients need complex care with high responsibilities such as medical equipment, tracheostomy, and an elevated number of drugs, the care burden of primary caregivers and their burnout levels increase significantly. As the burden of care and burnout increases, the quality of care that reaches the child decreases, and this circle affects the child negatively. Increasing the number of multidisciplinary and professionally functioning PPC centers will improve the quality of healthcare and the medical-social service planning to meet the needs of the caregivers of children who have special needs.

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