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Original Research

Determination of Burden of The Caregiver In Pediatric Liver Transplantation

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Abstract

Objectives: We aimed to determine the burden of care of individuals caring for pediatric patients who have undergone liver transplantation.

Methods: The study was conducted at the Inonu University Liver Transplant Institute pediatric liver transplantation ward between May 2022 and February 2023. Data were the "Zarit Care Burden Scale," and the "Beck Depression Scale," and demographic characteristics of the patients and their caregivers.

Results: The average age of the caregivers was 38.35±11.82 years; 72.7% were women, 69.7% were the child's mother, and 81.8% reported that caregiving impacted their daily lives. The effect of caregivers' burden of care on their daily lives was found to be statistically significant (p = 0.021). Among the pediatric recipients, 42.4% were aged 13-18 years, 60.6% were female, 45.5% had been post-transplant for more than 25 months, and 54.5% developed complications. The burden of care was severe at 38.87±10.21, and the depression was mild at 10.81±8.65. A moderate positive relationship was observed between burden of care and depression level (r: .602, p: 0.000). Simple linear regression analysis showed that caregivers' depression levels significantly affected their burden of care, (R^2=0.363).

Conclusion: The study concluded that caregivers of pediatric liver transplant patients experience a very high burden of care and mild depression. This high burden of care negatively impacts their daily lives and leaves them with less personal time. Providing social support to these families can improve caregivers' quality of life by reducing their depression levels.

Keywords: Pediatric Liver Transplantation, Burden of care, Zarit Care Burden Scale, Beck Depression Scale, Complications, Rejection, Biliary complications, Infections

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Hepatocellular Liver transplantation (LT) is the gold-standard treatment method for end-stage liver disease which is defined as the irreversible loss of liver functions beyond the physiologic limits.[1, 2] The patient who has end-stage liver disease and is confirmed to undergo liver transplantation is defined as the recipient. The individual who donates the liver is defined as the donor. The source of the liver graft may be from a deceased donor who is confirmed to have brain death. Under these circumstances, a whole liver graft is transplanted to the recipient. On the other hand, a partial left or right lobe liver graft can be transplanted from the living donors to the recipients. Living donor liver

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transplantation is usually performed between the next of kin and the recipient.[1, 2] The life expectancy following the LT procedure is prolonged because of the advancements in surgical technique and postoperative intensive care unit patient care.[3-5] The improved results have popularized LT, globally.[2, 3, 6]

The recipients need routine care after the liver transplant procedure and an increasing number of LT has resulted in an increased number of individuals requiring special care. The requirement for care is vital during the early postoperative period when patients cannot support themselves without their relative's care.[7] The values and the ethical standards of society determine the context of patient care requirements. In Turkey, patient care is the responsibility of the first-degree relatives of the patients.[8] Stone et al.[9] have defined the caregiver as the person who fulfills the care requirements of the patients and the person who is primarily responsible for their patient's care.

In LT recipients, the treatment period lasts a lifetime, which has detrimental effects on family members and caregivers. Furthermore, the caregivers may experience periodic psychosocial problems. Greenwood et al.[10] have shown that the caregivers experienced problems in sleep patterns, fatigue, and personality problems in addition to the difficulties encountered during the care of their patients. This was shown in direct relationship with the difficulty of the caregiving process.[10] It has been shown that the level of dependency of the patient on the caregiver was directly related to the burden of the caregivers.[11] The personal characteristics of the caregivers had a direct effect on the burden of the caregivers. Among these characteristics were the gender, age, and education status of the caregiver in addition to the presence of health problems, the degree of relation to the patient, the amount of time required for caring for their patient, and the amount of support provided by the peers to the caregiver.[12]

The LT recipient and their caregivers require psychosocial support. Studies have shown that nurses were expected to provide social support to patients.[13] Healthcare professionals focus on the physical, social, and psychological well-being of their patients; however, they should also provide the necessary support to their caregivers for a successful therapeutic outcome.[12] LT is a major abdominal surgery and caring for LT recipients is a demanding task. The nurses and other healthcare professionals must support the caregivers when they feel overwhelmed during the care of their patients. Only two studies have analyzed the burden of caregivers of LT recipients.[7,14] No studies analyze the caregivers' burden of pediatric liver transplant recipients.

In the present study, we aimed to evaluate the burden of caregivers in pediatric liver transplantation. Furthermore, we evaluated the relationship between the burden of the caregivers and the degree of depression of the caregivers. Our secondary aim was to determine the impact of the burden of the care for pediatric liver transplant recipients on the socioeconomic status of the relatives and we aimed to determine means of social support.

Methods

Study Design and Determination of the Study Population

The study is a descriptive and cross-sectional study. It is conducted between May 2022 and February 2023 in Inonu University Liver Transplant Institute pediatric inpatient ward. The power analyses were performed using the G-Power software (Düsseldorf, Germany). The power of the study was taken as 0.95 and the alpha-coefficient was determined as 0.05. The minimum number of participants was determined to be 33 in total. During the study period, 162 patients were admitted to the inpatient ward for various reasons. We included 33 of these patients and their caregivers in our study. All participants were informed by the researchers regarding the nature of the study and the patients who gave informed consent were included in the evaluation for our study. Initially, our study was approved by the Director of Inonu Liver Transplant Institute (Approval date: 23.02.2022, Approval number: E.148950). After the approval of the directorate of the Liver Transplant Institute, Institutional Review Board approval was obtained on 12.04.2022 (Approval number: 2022/1072).

Study Variables

All data are obtained using interview techniques to the patients and their caregivers in the pediatric inpatient ward. The study variables of the caregivers included age, gender, education level, occupation status, monthly income, degree of kinship to the patient, presence of any chronic illness, Zarit scale for burden of care, Beck’s depression scale, and eight questions evaluating the degree of interference of caregiving to the daily activities. The study parameters of the recipients included the presence of any complications, the interval between hospitalization and liver transplantation, age, and gender.

The Zarit Scale for Burden of Care

Zarit, Reever, and Bach-Peterson developed the scale in 1980.[15] The Turkish version was validated in 2006 by Inci et al.[16] It was initially designed to determine the burden of caregivers caring for ill or old individuals. Twenty-two questions assess the burden of care and are answered with a scale ranging between 0 to 4 (0=never, 1=occasional, 2=sometimes, 3=frequently, 4=always). Mainly, these questions evaluate the emotional and social aspects of the burden of care. The minimum score that can be obtained is 0 and the maximum score is 88. A higher score indicates the severity of the burden on the caregivers. The classification of the scores is as follows: a core ranging between 0 to 20 shows a low burden on caregivers, a score ranging between 21 to 40 indicates mild burden on the caregiver, a score ranging between 41 to 60 shows moderate burden on the caregiver, a score ranging between 61 to 88 indicates very severe burden on the caregiver.[17,18] The Cronbach alfa coefficient of the scale is 0.83.[17,18] The Cronbach alfa coefficient of scale in our study was 0.81. We used this scale to evaluate the burden of care for the relatives of the pediatric liver transplant recipients.

Beck’s Depression Scale

Beck’s depression scale was developed by Beck et al.[19] in 1961. Hisli et al.[20] validated the Turkish version of Beck’s depression scale in 1989. Twenty-one questions are evaluating the severity of depression of the individuals. Each question is answered on a scale from 0 to 3. The minimum and maximum scores obtained from the scale are 0 and 63, respectively. The classification of the scores of Beck’s depression scale is as follows: 0-9 points indicate no depression in the individuals, 10-16 points indicate mild depression in the individuals, 17-29 points indicate a moderate level of depression in the individual, and 30-63 points indicate a severe depression in the individuals.[21] The Cronbach alfa coefficient of the scale is 0.8. In the present study, we found the Cronbach alfa coefficient of the scale to be 0.86.

Statistical Analysis

Continuous variables are expressed as mean±standard deviation. Additionally, descriptive data such as gender and socio-economic status are presented as the number of individuals (n) and the percentage (%) in the study population. The normal distribution of continuous variables was assessed using the Kolmogorov-Smirnov Test. For continuous variables, comparisons among multiple groups were made using the One-Way ANOVA test, and comparisons between two groups were made using the Student’s T-Test. Furthermore, to investigate how caregiving burden and depression severity affect each other, Pearson correlation analysis was conducted, and R coefficients were calculated. An R coefficient between 0-0.3 indicates a weak relationship, 0.31-0.5 indicates a moderate relationship and >0.5 indicates a strong relationship. Differences identified in comparisons with p-values below 0.05 were considered significant. All statistical analyses were performed using the Statistical Package for Social Sciences (SPSS v27.0) software (IBM, USA).

Results

The average age of caregivers who took care of child transplant patients included in the study was 38.35±11.82 years. Additionally, 72.7% were women, and 51.5% had graduated from high school or higher. When looking at their income levels, it was found that 57.6% had an income above the minimum wage. 69.7% of the caregivers were the child's mother. It was observed that 72.7% of the caregivers were not working, 93.9% did not have a chronic illness, and 81.8% of the caregivers reported that the caregiving burden affected their daily lives (Table 1). The impact of the caregiving burden on the daily lives of caregivers was found to be statistically significant (p=0.021). However, when other variables were examined, no statistically significant difference was found for both caregiving burden and depression level (Table 1).

In our study, it was observed that 42.4% of the pediatric recipients were in the 13-18 age range, 60.6% were female, 45.5% had been more than 25 months since the transplant, and 54.5% had developed complications. Among those who developed complications, 24.2% had biliary complications, 84.8% did not develop rejection, and 93.9% did not develop an infection (Table 2). According to the results obtained between the transplant duration and the caregivers' caregiving burden and depression levels, it was observed that as time passed since the transplant, the caregivers' caregiving burden and depression levels statistically significantly decreased. However, when other variables were examined, no statistically significant difference was found for both caregiving burden and depression level (Table 2).

The average scores of caregiving burden and depression levels of caregivers and the correlation analysis between them are shown in Table 4.3. It was found that the caregiving burden level was severe with a score of 38.87±10.21, and the depression level was mild with a score of 10.81±8.65. Accordingly, it was observed that there was a moderate positive relationship between caregiving burden and depression level (r=0.602, p=0.000). In other words, as the depression level increases, the caregiving burden increases (Table 3).

A simple linear regression analysis was conducted to determine the effect of caregivers' depression levels on caregiving burden, and the model was found to be significant (F=17.649, p=0.000). The R^2 value, which expresses the explanatory power of the model, was found to be 0.363. This value indicates that 36.3% of the caregiving burden variable is explained by the independent variable depres-

Table 1. The burden of care and severity of depression in the caregivers in our study

Demographic characteristics of the caregivers	S	%	Burden of Care (Mean±SD)	Depression (Mean±SD)
Age				
18-30	5	15.2	40.20±8.52	12.80±12.27
31-45	20	60.6	38.35±11.82	9.55±8.81
46-60	8	24.2	39.37±7.32	12.75±5.84
Gender			F: .074, p: 0.929	F: .529, p: 0.595
Female	24	72.7	37.83±9.07	10.58±7.60
Male	9	27.3	41.66±12.97	11.44±3.84
			t: -.959, p: 0.432	t: -.251, p: 0.839
Education level				
Primary school or less	16	48.5	41.12±11.19	13.37±8.05
Highschool or more	17	51.5	36.76±9.01	8.41±8.73
		t: 1.236, p: 0.230	t: 1.697 , p: 0.100	
Income				
Minimum wage or less	19	57.6	40.52±9.54	13.36±7.15
More than minimum wage	14	42.4	36.64±11.00	7.35±9.55
		t: 1.059, p: 0.300	t: 1.980 , p: 0.060	
The degree of kinship				
Mother	23	69.7	38.34±8.91	10.56±7.78
Father	10	30.3	40.10±13.19	11.40±10.86
		t: -,384, p: 0.708	t: -.220, p: 0.829	
Occupational status				
Yes	9	27.3	38.44±12.84	10.55±11.17
No	24	72.7	39.04±9.35	10.91±7.80
		t: -.127, p: 0.901	t: -.089 , p: 0.931	
Chronic Illness				
Yes	2	6.1	51.00±5.65	21.50±3.53
No	31	93.9	38.09±9.98	10.12±8.45
		t: 2.943 , p: 0.143	t: 3.888, p: 0.067	
The effect on daily life				
Yes	27	81.8	40.77±9.14	11.66±8.87
No	6	18.2	30.33±11.20	7.00±7.01
		t: 2.434, p: 0.021*	t: 1.400 , p: 0.195	

*p<0.05; t: Independent Sample T test; F: One-way ANOVA; r: Pearson Correlation Test.

sion in the model. The Beta coefficient of the independent variable included in the regression model was (ß=0.602) (p=0.000). Accordingly, it is understood that the depression level has a significant effect on the caregiving burden of caregivers (p=0.000) (Table 4).

Discussion

Liver transplantation, a major surgical procedure, is quite complicated in the post-transplant period. For a helathy navigation of the process, patients and caregivers need professional support. After liver transplantation, patients may encounter problems such as infection, rejection, biliary complications, and bleeding. This process is especially stressful for families with pediatric liver transplants. If the liver transplant involves a living donor, the donor's health status is also a concern. Families of pediatric patients experience significant anxiety and worry about complications such as rejection and infection. These fears and concerns negatively impact the family and affect the caregiving burden.

A literature review revealed that there is only one study aimed at determining the caregiving burden of individuals caring for liver transplant patients.[7] Due to the lack of such studies in pediatric liver transplant patients, we designed current study.

In our study, consistent with the literature, the majority (72.7%) of caregivers were women. It is reported reported that 50.5% of caregivers were women.[22] According to the American Caregivers Association data, 75% of caregivers are women.[23] It is noted that, as in our country, most caregivers in foreign countries are also women.[23]

Table 2. The characteristics of pediatric liver transplant recipients.

Demographic characteristics	n	%	Burden of Care (Mean±SD)	Depression (Mean±SD)
Age				
0-3 years	2	6.1	45.00±2.82	8.00±2.82
4-6 years	9	27.3	38.88±11.48	7.11±6.58
7-12 years	8	24.2	42.37±8.17	14.75±10.76
13-18 years	14	42.4	36.00±10.80	11.35±8.61
		F: .916, p: 0 .446	F: 1.212, p: 0.323	
Gender				
Male	13	39.4	35.00±12.44	10.69±11.78
Female	20	60.6	41.40±7.79	10.90±6.20
		t: -1.655, p: 0.115	t: -.058, p: 0.954	
Post-transplant duration				
0-6 Months	10	30.3	45.00±10.11	18.00±8.76
7-12 Months	2	6.1	48.50±2.12	11.00±7.07
13-24 Months	6	18.2	38.16±6.73	7.66±6.12
25 months and longer	15	45.5	33.80±9.39	7.26±7.09
		F: 3.845, p: 0.020*	F: 4.523, p: 0.010*	
Complications				
Yes	18	54.5	38.61±11.52	10.77±10.30
No	15	45.5	39.20±8.77	10.86±6.51
		t: -.167, p: 0.869	t: -.030, p: 0.976	
Biliary Complications gelişme				
Yes	8	24.2	40.87±5.11	11.25±7.49
No	25	75.8	38.24±11.38	10.68±9.13
		t: .629, p: 0.534	t: .177, p: 0.862	
Rejection				
Yes	5	15.2	37.40±14.53	8.80±4.76
No	28	84.8	39.14±9.58	11.17±9.19
		t: -.258, p: 0.807	t: -.865 , p: 0.407	
Infection				
Yes	2	6.1	37.00±1.41	14.5±7.78
No	31	93.9	39.00±10.53	10.58±8.77
		t: -.935, p: 0.365	t: .685, p: 0.604	

*p<0.05.

Table 3. Correlation analyses between the severity of depression and the burden of care

	(Mean±SD) (The minimum and maximum scores of the scale)	Burden of Care	Depression
Burden of Care	38.87±10.21 (0-88)	1	r: .602 p: .000
Depression	10.81±8.65 (0-63)	r: .602 p: .000	1

The average Zarit Burden Interview (ZBI) score of caregivers was found to be 38.87±10. Türe and colleagues[24] found the average ZBI score to be 47.64±15.31 in caregivers of children with chronic illnesses. Taşçıoğlu and colleagues[25] found the average ZBI score to be 45.74±1.03 in parents of hospitalized children. Similarly, another study reported the average ZBI score to be 30.58±13.09 in parents of children with chronic illnesses.[26] Bayır and colleagues[7] determined the average ZBI score to be 33.77±12.37 in caregivers of liver transplant patients.

Table 4. The regression analysis of the depression scale versus the burden of care

Dependent variable	Independent Variable	B	Std. Error	ß	t	p	R	R^2	F	Model p
Burden of Care	Constant	31.193	2.329		13.391	0.000	.602	.363	17.649	0.000
	Depression	0.710	.169	.602	4.201	0.000				

In our study, it was found that 81.8% of caregivers reported that their daily lives were affected. The caregiving burden of those whose daily lives were affected was found to be severe. The impact of caregiving burden on the daily lives of caregivers was statistically significant. Similarly, in a study by Karaaslan et al.[14] investigating the effect of caregiving burden on daytime sleepiness in caregivers of liver transplant patients, the caregiving burden score was found to be severe in individuals whose daily lives were affected.

According to the results obtained regarding the interval from the transplant and the caregiving burden scores of caregivers, it was found that the caregiving burden of caregivers decreased over time, and this decrease was statistically significant. It is thought that in the early post-transplant period, the presence of families in the hospital environment, the stress of new situations encountered in the postoperative period related to their children's illnesses, and similar factors increased the caregiving burden. As families became accustomed to living with liver transplantation in the post-transplant period, the caregiving burden was lower.

In our study, although there was no statistically significant difference, it was observed that depression scores decreased as the education level increased. In the literature, Çiftçi et al.[27] similarly found no significant difference in depression scores according to education level. The literature indicates that as education levels increase, depression scores decrease because individuals use more effective coping mechanisms and have better decision-making processes.[28]

When depression scores were examined according to income levels in our study, no statistically significant difference was found. However, when looking at the average depression scores according to income levels, it was observed that those with an income above the minimum wage had an average depression score of 7.35±9.55, while those with an income at or below the minimum wage had an average depression score of 13.36±7.15; but this difference did not reach statistical significance. The literature indicates that low household income is correlated to the severity of depression.[29] Based on this information, it can be said that our research findings support the literature.

When comparing the depression scores of caregivers with the transplant duration, the results were found to be significant. Similar to the comparison of caregiving burden with transplant duration, it is thought that the difficulties brought by the early post-transplant period increased depression levels, while as the post-transplant period extended, families' ability to cope with problems improved, and depression levels decreased.

It was found that the caregiving burden level was severe at 38.87±10.21, and the depression level was mild at 10.81±8.65. According to these results, a moderate positive relationship was observed between caregiving burden and depression level.

A simple linear regression analysis was conducted to determine the effect of caregivers' depression levels on caregiving burden, and the model was found to be significant. The R^2 value, which expresses the explanatory power of the model, was determined to be 0.363. This value indicates that 36.3% of the caregiving burden variable is explained by the independent variable depression in the model. Accordingly, depression level has a significant effect on the caregiving burden of caregivers. As the depression level increases, the caregiving burden score also increases.

In the literature, Karaaslan et al.[30] found a positive relationship between caregiving burden and depression in their study evaluating the psychological conditions and caregiving burden of parents with mentally disabled children. Similarly, Budak et al.[31] concluded that as the caregiving burden of mothers of children with chronic illnesses increases, their levels of anxiety and depression also increase.

Our study has various limitations. We did not evaluate the burden of caregivers and the level of depression in the relatives of the non-transplanted individuals. Furthermore, the sample consists only of patients hospitalized at Inonu University Liver Transplant Institute.

Conclusion

Our results showed that the majority of the caregivers are the mothers of the child. The burden of care has a major impact on the social status of the caregivers. There is a positive correlation between the burden of care and depression in caregivers. As the duration of the posttransplant period prolongs the burden and the severity of depression of the caregivers are reduced. For these reasons, we believe psychosocial support is required in the early postoperative period. This will increase the quality of care. Also, the burden of care should be shared with other members of the family.

Disclosures

Ethics Committee Approval: This study was apporved by the Inonu University Scietific Research Ethics Committee (Date: 12.04.2022, Approval Number: 2022/1072).

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