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Retrospective Study

Differences in parents of pediatric liver transplantation and chronic liver disease patients

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Abstract

BACKGROUND

With advancements in the treatment of chronic liver disease (CLD), including liver transplantation (LT), quality of life and satisfaction after LT have become an important issue for pediatric patients and their parents. More evidence-based information is needed to describe and assess the impact of pediatric CLD on parents and the satisfaction of parents with treatment to better understand their needs.

AIM

To assess the satisfaction of parents of pediatric LT patients and that of parents of pediatric CLD patients

METHODS

During this survey, data were collected from parents of pediatric patients who underwent LT between January 2010 and April 2017 (LT group; $n = 91$) and parents of pediatric patients with chronic liver disease (CLD group; $n = 94$). Group comparisons were made based on the pediatric health-related quality of

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life (PedsQL) health care parent satisfaction scale, impact on family scale (IFS) and demographic characteristics. The PedsQL was administered to parents during a phone interview and the results were used to assess the health care-related satisfaction of parents. The IFS was used to assess the impact of the child's CLD status on the family. Demographic variables such as education level (elementary *vs* middle *vs* high *vs* university), monthly income (low *vs* middle *vs* high), and place of residence (village *vs* town *vs* city) were compared between CLD and LT parent groups. Finally, PedsQL and IFS results were also analyzed according to demographic variables.

RESULTS

A total of 185 parents aged 19 to 65 years were included. There were statistically significant differences between the LT and CLD groups in terms of career ($P < 0.001$), monthly income ($P = 0.016$), and education level ($P = 0.041$). According to the PedsQL results, family inclusion, communication, technical skills, emotional needs, and overall satisfaction were significantly different between the groups; the LT group had consistently higher scores ($P < 0.001$). Additionally, scores for the IFS parameters of financial impact, familial-social impact, personal strain, and total impact were consistently higher for the LT group ($P < 0.001$). There were statistically significant relationships between education level, monthly income, and place of residence according to the IFS results but not the PedsQL results. There were inverse relationships between the difficulties that parents experience because of their child's health and education levels, monthly income, and place of residence. However, no relationship was found between education level, monthly income, or place of residence and satisfaction with health care services provided in the hospital according to the PedsQL results.

CONCLUSION

Parents of children who underwent LT were very satisfied with the health care services provided to their children. However, they had more difficulties than parents of children with CLD.

Key words: Liver transplantation; Pediatric liver transplantation; Chronic liver disease; Parent satisfaction; Health-related quality of life health care parent satisfaction scale; Impact on family scale

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Core tip: The status and satisfaction of parents of pediatric liver transplantation (LT) patients and that of parents of pediatric chronic liver disease (CLD) patients were compared using the pediatric health-related quality of life health care parent satisfaction scale and the impact on family scale, respectively. Parents of LT patients have more difficulties than parents of CLD patients due to their child's health status. The satisfaction of the parents based on the pediatric health-related quality of life results in the LT group was significantly higher when compared to parents in the CLD group. No relationship was found between education level, monthly income, or place of residence and satisfaction with the health care services.

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INTRODUCTION

Since the first successful liver transplantation (LT) was performed by Starzl and colleagues in 1967, LT has become the gold standard treatment for both pediatric and adult patients with chronic liver disease (CLD). With advances in surgical techniques, effective antimicrobial prophylaxis, and improvements in potent immunosuppressive

treatment options, 1-year and 10-year survival rates after pediatric LT have reached 95% and 80%, respectively^[1]. With the prolongation of overall survival, quality of life and satisfaction after LT have become important issues for patients and their parents. In addition to studies comparing the quality of life before and after LT, many studies have compared the quality of life of LT patients and healthy individuals^[1-3]. The primary aim of this study was to compare the satisfaction of parents of pediatric LT patients and that of parents of pediatric patients with CLD using the pediatric health-related quality of life (PedsQL) health care parent satisfaction scale and the impact on family scale (IFS). In addition, the study evaluated the relationships between education level, monthly income, and place of residence according to the PedsQL and IFS results.

MATERIALS AND METHODS

Study design

During this survey-based study, parents of children who underwent pediatric LT between January 2010 and April 2017 at Inonu University Liver Transplant Institute were consecutively selected and included in the LT group. During the same period, the parents of children with CLD who underwent regular followed-up at the pediatric hepatology outpatient clinic of the same site were consecutively selected and included in the CLD group because their child's LT indication was not yet established or they were on the LT waiting list.

Parents of 130 pediatric patients who underwent LT and survived were contacted by phone and details of the survey were shared with them. Although 105 of the parents accepted the invitation to participate, 14 were not included in the study because they were foreign nationals. As a result, 91 parents were eligible for inclusion in the LT group. Parents of 130 pediatric patients with CLD undergoing routine follow-up were informed about the survey, but 26 stated that they did not want to participate. Ten additional parents were excluded because they were foreign nationals. As a result, 94 parents were eligible for inclusion in the CLD group.

The survey was conducted by two researchers with previous experience performing survey studies. Ten parents were randomly selected from both groups to determine their comprehension of the questions. Both groups were compared in terms of number of children (one, two, three, or four or more), career (employed, unemployed, retired), education level (elementary school, middle school, high school, university), monthly income (< 1000 TL, 1000-3000 TL, > 3000 TL), place of residence (village, town, city), house where parents live (rent or own), and social assurance (yes or no). Both groups were also compared in terms of parameters of the PedsQL health care parent satisfaction scale and IFS scale.

The secondary aim of this study was to establish whether education level, monthly income, and place of residence were related to the IFS and PedsQL results. Therefore, information about education level (elementary school, middle school, high school, university), monthly income [low (< 1000 TL), middle (1000-3000 TL), high (> 3000 TL)], and the place of residence (village, town, or city) were compared according to the IFS scores and PedsQL scores. After approval was received from the Inonu University institutional review board for non-interventional studies (Approval No: 2017/11-5), parents were contacted and the survey was conducted. Verbal consent was obtained to participate in the study.

Impact on family scale

According to the Turkish version of this scale, the reported internal consistency coefficient was 0.81 (Cronbach's alpha), the total correlation coefficient of the subparameters was 0.87-0.98, and the test-retest invariance coefficient was 0.79^[4]. The IFS scale was used to assess the influence of the child's health status on parents and consisted of four main subheadings: Financial impact (4 items); familial/social impact (9 items); personal strain (6 items); and mastery (5 items). Financial burden refers to economic consequences for the family. Familial/social impact refers to the disruption of social interaction. Personal strain refers to the psychological burden experienced by the primary caretaker. Mastery refers to the coping strategies used by the family^[5]. The total impact score was calculated using the total scores obtained from the first three main subheadings (excluding the mastery score). After a few items were removed from the Turkish version, parents were asked to answer the remaining 24 Likert-type questions (strongly agree = 1, agree = 2, disagree = 3, strongly disagree = 4). Parents' responses to items were reverse-coded to calculate scores (1 = 4 points, 2 = 3 points, 3 = 2 points, 4 = 1 point). The total score was obtained by summing the points of the 24 items and varied between 24 and 96 points; a lower score indicated

lower impact and a higher score indicated higher impact^[4].

PedsQL health care parents satisfaction scale

According to the Turkish version of this scale, the reported internal consistency coefficient was 0.93 (Cronbach's alpha), total correlation coefficient of the subparameters was 0.39-0.72, and the test-retest invariance coefficient was 0.98^[6]. The PedsQL was used to assess the satisfaction of parents regarding the health care provided to their child by health care workers. This scale consisted of six main subheadings: Information (5 items); family inclusion (4 items); communication (5 items); technical skills (4 items); emotional needs (4 items); and overall satisfaction (3 items). Parents were asked to answer the 25 Likert-type questions (never satisfied = 0; sometimes satisfied = 1; often satisfied = 2; almost always satisfied = 3; always satisfied = 4; not applicable = NA). The options marked by parents were converted to scores as described in the literature (0 = 0 points, 1 = 25 points, 2 = 50 points, 3 = 75 points, 4 = 100 points)^[6].

Statistical analysis

Statistical analyses were performed using SPSS Statistics v25.0 (IBM Corp., Armonk, NY, United States). The continuous variables were expressed as median, interquartile range, and minimum-maximum. The categorical variables were reported as number and percentage. The Kolmogorov-Smirnov test was used to determine whether the quantitative variables showed normal distribution. The Mann Whitney *U* test was used to compare the two groups in terms of quantitative variables. Pearson's χ^2 and Fisher's exact test were used to compare the categorical variables. Kruskal-Wallis one-way analysis of variance pairwise comparison and χ^2 tests were used to compare more than two independent groups. A *P* value < 0.05 was considered statistically significant.

RESULTS

Demographic and social features

A total of 185 parents 19 to 65 years of age were included in this survey-based study. Of the 91 parents in the LT group, 57 were males and 34 were females. Of the 94 parents in the CLD group, 51 were male and 43 were female. Statistical significance differences were found between groups in terms of career ($P < 0.001$), monthly income ($P = 0.016$), and education level ($P = 0.041$); however, statistically significant differences were not found in terms of sex, number of children, place of residence, house where parents live, or social assurance (Table 1). In total, 75.8% of the parents in the LT group were unemployed and 44.7% of the parents in the CLD group were unemployed. Although the monthly income of 70.3% of the parents in the LT group ranged from 1000-3000 TL, the monthly income of 56.4% of the parents in the CLD group ranged from 1000-3000 TL. In total, 63.7% of the parents in the LT group and 47.9% of the parents in the CLD group finished elementary school.

PedsQL and IFS comparison

Both parent groups were compared according to the IFS and PedsQL scores (Table 2). Statistically significant differences were found between the groups in terms of financial impact ($P < 0.001$), familial-social impact ($P < 0.001$), personal strain ($P < 0.001$), and total impact ($P < 0.001$); the LT group parents had higher scores for each of these categories. Statistically significant differences were found between the parent groups in terms of PedsQL scores regarding information ($P < 0.001$), family inclusion ($P < 0.001$), communication ($P < 0.001$), technical skills ($P < 0.001$), emotional needs ($P < 0.001$), and overall satisfaction ($P < 0.001$); the LT group parents had higher scores for each PedsQL domain.

Education, monthly income, and place of residence

Statistically significant differences were found between the education level subgroups in terms of the IFS domains of financial impact ($P = 0.003$), familial-social impact ($P = 0.008$), personal strain ($P < 0.001$), and total impact ($P < 0.001$). However, these differences were not found in terms of the IFS domain of mastery ($P = 0.404$) or the PedsQL domains of family inclusion, communication, technical skills, emotional needs, and overall satisfaction (Table 3).

Statistically significant differences were found between the monthly income level subgroups in terms of the IFS domains of financial impact ($P < 0.001$), familial-social impact ($P < 0.001$), personal strain ($P = 0.001$), and total impact ($P < 0.001$). However, these differences were not found in terms of IFS mastery ($P = 0.828$) or the PedsQL domains of family inclusion, communication, technical skills, emotional needs, and

Table 1 Comparison of liver transplantation and chronic liver disease groups in terms of demographic and social parameters, n (%)

Parameters	LT group	CLD group	Total	P value
Gender				0.248 ¹
Male	57 (62.6)	51 (54.3)	108 (58.4)	
Female	34 (37.4)	43 (45.7)	77 (41.6)	
Children				0.083 ¹
One	7 (7.8)	13 (13.8)	20 (10.9)	
Two	23 (25.6)	23 (24.5)	46 (25.0)	
Three	18 (20.0)	29 (30.9)	47 (25.5)	
Four or More	42 (46.7)	29 (30.9)	71 (38.6)	
Career				< 0.001 ²
Employed	20 (22.0)	50 (53.2)	70 (37.8)	
Unemployed	69 (75.8)	42 (44.7)	111 (60.0)	
Retired	2 (2.2)	2 (2.1)	4 (2.2)	
Monthly income				0.016 ¹
Low (< 1000)	23 (25.3)	25 (26.6)	48 (25.9)	
Middle (1000-3000)	64 (70.3)	53 (56.4)	117 (63.2)	
High (> 3000)	4 (4.4)	16 (17.0)	20 (10.8)	
Residence place				0.670 ¹
Village	21 (23.1)	21 (22.3)	42 (22.7)	
Town	26 (28.6)	22 (23.4)	48 (25.9)	
City center	44 (48.4)	51 (54.3)	95 (51.4)	
Educational level				0.041 ¹
Elementary school	58 (63.7)	45 (47.9)	103 (55.7)	
Middle school	10 (11.0)	20 (21.3)	30 (16.2)	
High school	17 (18.7)	15 (16.0)	32 (17.3)	
University	6 (6.6)	14 (14.9)	20 (10.8)	
House where parents live				0.555 ¹
Rental	59 (64.8)	57 (60.6)	116 (62.7)	
Owner	32 (35.2)	37 (39.4)	69 (37.3)	
Social assurance				0.920 ¹
Yes	75 (82.4)	78 (83.0)	153 (82.7)	
No	16 (17.6)	16 (17.0)	32 (17.3)	

¹Pearson χ^2 .²Fisher's Exact. LT group: Pediatric liver transplant patients; CLD group: Pediatric chronic liver disease patients.

overall satisfaction (Table 4).

Statistically significant differences were found between the place of residence subgroups in terms of IFS domains of personal strain ($P = 0.023$) and total impact ($P = 0.027$). However, these differences were not found for other IFS parameters or any of the PedsQL domains (Table 5). The results showed that there were inverse relationships between the education level, monthly income, and place of residence and difficulties that parents experience because of their children's health status. However, no relationship was found between education level, monthly income, and place of residence and satisfaction with the health care services provided in the hospital.

DISCUSSION

The burden of liver disease continues to grow worldwide^[7,8]. Pediatric CLD affects not only the quality of life and health care satisfaction of the patient but also those of the patient's family; in addition, illness in a family member may result in a heavy financial burden for the family^[9]. Of course, parents feel it is their responsibility to give their children a happy life, and they often feel guilty when first facing the

Table 2 Comparison of liver transplant and chronic liver disease groups in terms of pediatric health-related quality of life and impact on family scale results

Parameters	Groups	Median	IQR	Min	Max	P value
IFS financial impact	LT group	10	3	4	12	< 0.001
	CLD group	8	2.5	3	12	
IFS familial-social impact	LT group	25	6	15	36	< 0.001
	CLD group	21	7.5	12	33	
IFS personal strain	LT group	30	6	18	40	< 0.001
	CLD group	26	7	13	38	
IFS mastery	LT group	7	2	4	10	0.203
	CLD group	8	3	4	16	
IFS total impact	LT group	56	10	34	76	< 0.001
	CLD group	49	15	28	73	
PEDsQL information	LT group	475	100	100	500	< 0.001
	CLD group	325	125	100	500	
PEDsQL family inclusion	LT group	375	75	100	400	< 0.001
	CLD group	275	125	75	400	
PEDsQL communication	LT group	475	118	125	500	< 0.001
	CLD group	375	168	75	500	
PEDsQL technical skills	LT group	375	100	100	400	< 0.001
	CLD group	250	100	25	400	
PEDsQL emotional needs	LT group	350	150	25	400	< 0.001
	CLD group	225	125	25	400	
PEDsQL overall satisfaction	LT group	300	50	75	300	< 0.001
	CLD group	225	143	75	300	

LT group: Pediatric liver transplant patients. CLD group: Pediatric chronic liver disease patients; PEDsQL: Pediatric health-related quality of life; IFS: Impact on family scale.

diagnosis of a chronic illness in their child^[10]. Parents need a collaborative relationship with health care providers as a key component of family-centered care because the role of the family is critical to promoting successful outcomes and adaptation to chronic illness^[11].

Pediatric LT has become a gold standard therapeutic modality for children with end-stage liver disease. It offers hope for children and families when the child is diagnosed with CLD. After successful LT, the life of the recipient is saved and the quality of life is substantially improved. However, pediatric LT patients are medically fragile and present with complex care issues requiring high-level management in the home. Pediatric LT leads to chronic medical conditions and has been identified as a disease with a high number of readmissions^[12]. However, the outcomes of LT for the pediatric population have improved significantly over the past two decades. Unfortunately, as long-term survival improves, potential complications related to immunosuppression, delayed growth and development, and metabolic issues are seen more commonly in long-term survivors. Because children who undergo LT need lifelong medication with immunosuppressants to prevent potential graft rejection, they are more vulnerable to infection and adverse drug reactions. Furthermore, it has been shown that children with LT have mean intellectual and mathematical skills scores that are significantly lower than the normative mean and are at higher risk for developing learning difficulties in terms of mathematics than the general population. This further adds to the functional, psychological, and financial difficulties of the parent who caring for and supporting a child with CLD^[13].

As long-term survival of children following LT improves, it is important to examine the quality of life for these children and their families, as well as their personal experiences and satisfaction related to their health care. Although LT is life-saving and presumably enhances the quality of life, the child remains affected by a chronic condition that includes morbidities, such as long-term management of biliary complications, renal dysfunction, risk of de novo malignancies, and a life-long need for immunosuppression. These challenges pose a potential burden with varying impacts on patients and their families. Pediatric LT patients have significantly lower health-related quality of life relative to healthy children, especially due to absence

Table 3 Comparison of pediatric health-related quality of life and impact on family scale results in terms of educational level subgroups

Parameters	Educational level	Median	IQR	Min	Max	P value
IFS financial impact	Elementary school	9 ^{ab}	3	4	12	0.003
	Middle school	8	3	5	12	
	High school	8 ^b	4.5	3	12	
	University	8 ^a	3	3	11	
IFS familial-social impact	Elementary school	24 ^c	5	15	36	0.008
	Middle school	24	9	13	34	
	High school	22	8	12	31	
	University	20 ^c	7	13	26	
IFS personal strain	Elementary school	28 ^e	6	18	40	< 0.001
	Middle school	28 ^d	8.5	17	37	
	High school	27	7.5	17	39	
	University	24 ^{de}	6.5	13	33	
IFS mastery	Elementary school	7	2	4	12	0.404
	Middle school	8	5	4	10	
	High school	8	3	4	16	
	University	8	2.7	4	11	
IFS total impact	Elementary school	55 ^e	12	34	76	< 0.001
	Middle school	54 ^f	17	30	70	
	High school	50	14	29	73	
	University	47 ^{ef}	15	28	58	
PEDsQL information	Elementary school	425	175	100	500	0.829
	Middle school	387	193	100	500	
	High school	375	200	150	500	
	University	425	175	150	500	
PEDsQL family inclusion	Elementary school	350	150	75	400	0.735
	Middle school	312	112	75	400	
	High school	325	150	100	400	
	University	337	75	100	400	
PEDsQL communication	Elementary school	412	150	75	500	0.589
	Middle school	375	150	100	500	
	High school	387	156	175	500	
	University	425	162	125	500	
PEDsQL technical skills	Elementary school	325	125	25	400	0.465
	Middle school	325	150	100	400	
	High school	300	131	100	400	
	University	350	106	100	400	
PEDsQL emotional needs	Elementary school	275	150	25	400	0.723
	Middle school	300	150	175	400	
	High school	287	168	100	400	
	University	300	75	100	400	
PEDsQL overall satisfaction	Elementary school	275	100	75	300	0.213
	Middle school	250	143	75	300	
	High school	225	125	75	300	
	University	300	75	100	300	

^aP = 0.016.^bP = 0.042.^cP = 0.009.^dP = 0.015.^eP < 0.001.^fP = 0.024. IQR: Interquartile range; PEDsQL: Pediatric health-related quality of life; IFS: Impact on family scale.

Table 4 Comparison of pediatric health-related quality of life and impact on family scale results in terms of monthly income subgroups

Parameters	Monthly Income	Median	IQR	Min	Max	P value
IFS financial impact	Low	10 ^a	3	5	12	< 0.001
	Middle	9 ^b	2,7	3	12	
	High	7 ^{ab}	2.7	3	10	
IFS familial-social impact	Low	26 ^{ad}	7	13	36	< 0.001
	Middle	23 ^{cd}	5	12	33	
	High	19 ^{ac}	7.7	13	29	
IFS personal strain	Low	29 ^a	7	20	40	0.001
	Middle	28 ^d	7	13	39	
	High	24 ^{ad}	6	14	33	
IFS mastery	Low	7	3.5	4	10	0.828
	Middle	7	2	4	16	
	High	8	3.7	4	10	
IFS total impact	Low	57 ^{af}	13.5	35	76	< 0.001
	Middle	53 ^{ef}	11.7	28	73	
	High	43 ^{ae}	13.7	31	62	
PEDsQL information	Low	400	175	150	500	0.799
	Middle	400	200	100	500	
	High	400	181	200	500	
PEDsQL family inclusion	Low	300	150	75	400	0.170
	Middle	350	143	75	400	
	High	312	68	250	400	
PEDsQL communication	Low	375	231	75	500	0.313
	Middle	425	150	100	500	
	High	425	125	200	500	
PEDsQL technical skills	Low	325	150	100	400	0.730
	Middle	325	150	25	400	
	High	325	150	175	400	
PEDsQL emotional needs	Low	225	175	25	400	0.075
	Middle	300	125	25	400	
	High	275	143	125	400	
PEDsQL overall satisfaction	Low	275	150	75	300	0.273
	Middle	250	100	75	300	
	High	300	75	125	300	

^a*P* < 0.001.^b*P* = 0.007.^c*P* = 0.027.^d*P* = 0.023.^e*P* = 0.011.^f*P* = 0.031. IQR: Interquartile range; PEDsQL: Pediatric health-related quality of life; IFS: Impact on family scale.

from school, whereas LT patient scores for social and school functioning were comparable to those of cancer patients^[14].

In addition to the emotional, physical, and financial impacts of LT on parents, research of family psychosocial needs following LT has indicated that parents of children who have undergone transplantation experience symptoms of emotional trauma^[15]. A multi-center analysis of health-related quality of life and family function indicated that parents reported significant levels of family stress, and that parents of older transplant recipients reported higher levels of stress^[2].

This study showed that parents of LT patients have more difficulties due to their children's health status, which affects many areas of their lives, than parents of CLD patients. Furthermore, the IFS scores of the LT group correlated significantly with education and income levels; scores were higher for those with lower incomes and lower education levels. This may be due to the increased pressure experienced by

Table 5 Comparison of pediatric health-related quality of life and impact on family scale results in terms of residences place subgroups

Parameters	Residence	Median	IQR	Min	Max	P value
IFS financial impact	Village	9	2.2	5	12	0.288
	Town	9	4	4	12	
	City center	9	3	3	12	
IFS familial-social impact	Village	24	4.5	13	33	0.137
	Town	25	6	14	34	
	City center	23	7.2	12	36	
IFS personal strain	Village	28	5.2	18	37	0.023
	Town	29 ^a	6.5	17	38	
	City center	27 ^a	8	13	40	
IFS mastery	Village	7	2	4	10	0.250
	Town	7	2.75	4	11	
	City center	7	3	4	16	
IFS total impact	Village	55	11.2	35	67	0.027
	Town	55	14.5	29	73	
	City center	50	17	28	76	
PEDsQL information	Village	400	187	100	500	0.683
	Town	425	175	125	500	
	City center	375	175	100	500	
PEDsQL family inclusion	Village	300	156	75	400	0.638
	Town	350	150	75	400	
	City center	325	150	75	400	
PEDsQL communication	Village	375	200	75	500	0.971
	Town	412	137	100	500	
	City center	400	150	125	500	
PEDsQL technical skills	Village	300	150	125	400	0.375
	Town	350	137	25	400	
	City center	325	150	50	400	
PEDsQL emotional needs	Village	300	168	25	400	0.938
	Town	300	150	50	400	
	City center	275	150	50	400	
PEDsQL overall satisfaction	Village	250	100	100	300	0.888
	Town	262	75	75	300	
	City center	250	100	75	300	

^aP = 0.05. IQR: Interquartile range; PEDsQL: Pediatric health-related quality of life; IFS: Impact on family scale.

low-income families when children with CLD undergo LT. For example, additional travel to the transplant center for frequent follow-up appointments, expensive medications, and frequent hospitalizations are all part of the LT process. LT imposes tremendous long-term financial and emotional constraints on parents.

Although the IFS scores were higher for the LT group than for the CLD group, the satisfaction scores of parents in the LT group regarding their child's health care were higher than those of parents in the CLD group. The feeling that they have done everything possible to save their child might contribute to this satisfaction reported by the LT group. Moreover, the level of care at the transplant center in terms of comfort and the advanced comprehensive facility offered at this center compared to the general pediatric hepatology clinics might also contribute to the improved satisfaction scores. The satisfaction scores were not significantly affected by the education and income levels of the parents.

Coping styles not only affect the health of the parents but also influence the child^[16]. For example, a qualitative study performed in China to examine the parental coping strategies of parents whose children underwent LT found that most parents had a proactive approach to coping with the diagnosis, treatment, and care of the illness^[10]. Therefore, it is important to understand what stressors might affect the parents so that

appropriate interventions can be designed to help alleviate them.

In conclusion, chronic illness is a major source of stress for pediatric patients and their families. Although children with end-stage liver diseases are saved by LT, their health-related quality of life is impaired compared to that of healthy controls. Parents of pediatric LT patients have more difficulties due to their child's health status, but they have better health care-related satisfaction levels. It is recommended that, in addition to medical follow-up after LT, psychological and financial support should be offered to the patients and their parents throughout the follow-up process.

ARTICLE HIGHLIGHTS

Research background

Parents of children with chronic liver disease (CLD) and those who undergo liver transplantation (LT) have severe emotional, physical, and financial difficulties which affect their quality of life. While LT save treat CLD, pediatric LT patients remain medically fragile and present a complex care issues requiring high-level management in the home. In this study we aim to assess the impact of pediatric LT on parent's quality of life and to study their satisfaction with treatment to better understand their needs.

Research motivation

Parents feel it is their responsibility to give their children a happy life and cure them from diseases, however in the case of pediatric LT; children remain affected by a chronic condition that includes morbidities, repeated hospitalizations and a life-long need for immunosuppression. Parents have more difficulties due to their children's health status, which affects many areas of their lives. We aim to study the impact of LT on the life of pediatric patients after transplantation to highlight areas where intervention and assistance might be needed to help parents cope with the requirements of complex of the complex management of their children.

Research objectives

The main objective of this study is to assess the satisfaction of parents of pediatric LT patients and that of parents of pediatric CLD patients. Data from this study would help us to evaluate if this pediatric LT is associated with better parents satisfaction and better quality of life, and to highlight areas where intervention and assistance might be needed by these parents.

Research methods

During this survey, data were collected from parents of 91 pediatric patients who underwent LT and parents of 94 pediatric patients with CLD. Group comparisons were made based on the pediatric health-related quality of life (PedsQL) health care parent satisfaction scale, Impact on Family Scale (IFS) and demographic characteristics. Demographic variables such as education level, monthly income, and place of residence were compared between CLD and LT parent groups. Finally, PedsQL and IFS results were also analyzed according to demographic variables.

Research results

A total of 185 parents aged 19 to 65 years were included. According to the PedsQL results, family inclusion, communication, technical skills, emotional needs, and overall satisfaction were significantly different between the groups; the LT group had consistently higher scores. Additionally, scores for the IFS parameters of financial impact, familial-social impact, personal strain, and total impact were consistently higher for the LT group.

Research conclusions

While children with CLD are saved by LT, their health-related quality of life is impaired compared to that of healthy controls. Parents of children who underwent LT were very satisfied with the health care services provided to their children. However, they had more difficulties than parents of children with CLD. These data further stress the importance providing continuous social and financial support to families of pediatric LT patients to help them with the psychological, financial and health care difficulties they have.

Research perspectives

Quality of life and satisfaction after LT have become an important issue for pediatric patients and their parents. Parents feel satisfied with the medical management when their children have LT and offered their chance of cure by advanced medical procedures, however they pass into severe difficulties after LT as their child health remain fragile and require complex long-term management for the associated morbidities including repeated hospitalization. More evidence-based information is needed to describe and assess the impact of pediatric LT on parents and to better understand their needs.

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