

Original Article



Pediatric Liver Transplantation: Caregivers' Quality of Life

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ABSTRACT

Purpose: The survival rate of pediatric patients undergoing liver transplantation has increased considerably. Despite this, the period after transplantation is still complex and poses several challenges to the recipient's family, which is responsible for care management. Recently, more attention has been paid to the impact of this complex procedure on the quality of life of caregivers. Hence, this study is aimed at assessing the quality of life of caregivers of patients who have undergone liver transplantation and the aspects that influence it.

Methods: This was an observational and cross-sectional study. From November 2020 to January 2021, short-form-36 questionnaires and additional questions were given to the main caregivers of children and adolescents who underwent pediatric liver transplantation.

Results: Thirty-eight questionnaires were completed and the results revealed a lower quality of life in comparison to Brazilian standards, primarily in the mental domains (41.8±14.1 vs. 51.1±2.8; $p<0.001$). It did not show a significant association with socioeconomic or transplant-related factors, but it did show a negative impact on parents' perception of the child's health. Parents who reported worse health status for their children had a lower mental quality of life (44.1±13.8 vs. 33.3±12.6; $p<0.05$).

Conclusion: The caregivers of transplanted children have a lower quality of life than those of the local population. Psychological assistance should be routinely provided to parents for long-term follow-up to mitigate potential negative effects on the transplanted child's care.

Keywords: Liver transplantation; Liver; Pediatrics; Quality of life; Caregivers

INTRODUCTION

The first pediatric liver transplant was performed by Starzl in 1963, but it was only after 1985 that this procedure had good results, coinciding with the beginning of immunosuppression [1]. Currently, the survival of patients undergoing liver transplantation has increased considerably owing to the evolution of immunosuppression, surgical techniques, organ preservation, and the treatment of complications [2,3]. In a series from 1968 to 2009 with multicenter data from the European Liver Transplant Registry, survival for the pediatric population was 81% in five years [2].

Conflict of Interest

The authors have no financial conflicts of interest.

Approximately one-third of pediatric liver transplants are performed on patients under one year of age, and half of the recipients are less than two years old. This is mostly because of cholestatic diseases that have multiple causes, with biliary atresia being the most common (responsible for 38.5% of transplant indications) [4,5].

Clinically, transplant patients may experience medical complications in both the short and long term [3]. Post-liver transplant complications involving the graft include acute rejection, hepatic artery thrombosis (which affects 7% of liver grafts), portal vein thrombosis (a rare complication), and biliary complications [3]. Long-term complications include post-transplant lymphoproliferative disease (PTLD), infection, nephrotoxicity with eventual renal failure, and failure to adhere to the treatment [3,6,7]. The period after liver transplantation is therefore complex, and the patient's long-term survival depends on their adherence to appropriate therapy, maintaining immunosuppression effectively, controlling the side effects, and monitoring of graft function [7,8]. The quality of life (QoL) of caregivers is affected greatly by pediatric organ transplantation, but more findings on this matter are yet to be established [8].

In addition to offering daily care, parents and family members of pediatric transplant recipients provide medical care that includes giving medication, going on hospital visits, and chaperoning diagnostic and routine tests while worrying about medical complications, disease progression, and financial burdens [6]. Thus, a child's transplant has a significant influence on the family's daily life. Therefore, the QoL of parents of pediatric recipients and the functioning of the family should be considered as part of the assessment at a child's follow-up [9].

The objective of this study was to evaluate the QoL of caregivers of children and adolescents undergoing liver transplantation monitored at a pediatric hepatology reference center in Brasília, highlighting the aspects that influence it.

MATERIALS AND METHODS

This is an observational, cross-sectional, analytical study in which the QoL of the main caregiver of children and adolescents who underwent pediatric liver transplantation was followed up at the pediatric hepatology outpatient clinic of a tertiary hospital in Brasilia, from November 2020 to January 2021. All pediatric recipients who had at least two consultations in 2020 at the outpatient clinic and completed the questionnaire were included. Patients who missed follow-up, those referred to other centers for adult health care, and those who did not send the completed questionnaire were excluded. For comparison, the Brazilian historical series of the population and published studies were used as the control group.

Health status was assessed with the 36-item short form survey (SF-36) questionnaire in the Portuguese version [10], which contains 36 items that, when scored, yield eight domains [11]. "Physical functioning" assesses limitations in physical activities, such as walking and climbing stairs [11]. The domains "role limitations-physical" and "role limitations-emotional" measure problems with work or other daily activities as a result of physical health or emotional problems [11]. The "bodily pain" domain assesses limitations due to pain, and "vitality" measures energy and tiredness [11]. The "social functioning" domain examines the effect of physical

and emotional health on normal social activities, and the “mental health” domain assesses happiness, nervousness, and depression [11]. The “general health status” domain evaluates personal health and the expectation of changes in health [11]. All domains were scored on a scale from 0 to 100, with 100 representing the best possible health state [11]. Summary scores can also be derived for physical components, such as physical functioning and role, bodily pain, and general health perceptions, and mental components, such as vitality, social functioning, mental health, and emotional role [12]. In addition, specific questions related to socioeconomic status and QoL were not addressed in the standard questionnaire. Also, data was collected through physical and electronic medical records regarding liver transplantation, its complications, the date of the procedure, and its indications.

Data was tabulated in an Excel 4.0 spreadsheet for statistical analysis and analyzed using IBM SPSS Statistics for Windows, version 27.0 (IBM Co., Armonk, NY, USA) for descriptive statistical analysis. Non-parametric statistics were performed using the Kruskal-Wallis test for samples with more than two groups and the Mann-Whitney U-test for samples with two groups. The level of significance used was 5% ($p < 0.05$); however, the results were described at a level of significance less than 0.1% ($p < 0.001$).

RESULTS

Of the 54 families that were followed up on the service, the link to the questionnaire was sent to 49 families, as we did not obtain contact with five families (via phone or email). A total of 38 complete responses were obtained, equivalent to 77.6% participation. Caregivers' characteristics are presented in **Table 1**. Most caregivers were female (86.8%), most of whom were mothers of patients, with an average age of 37.3 ± 8.0 years, 55.3% were mixed race, 50.0% belonged to the Catholic religion, 57.9% were currently inactive in the labor market, and 52.6% had a family income below two minimum wages. In terms of education, there was variability in the group, with 42.1% having a higher education degree and 31.6% without secondary education.

The complete profiles of the children and adolescents monitored at the service who underwent liver transplantation are detailed in **Table 2**. This group included 63.2% males, with an average age of 9.5 ± 5.5 years, and 81.6% were of mixed race. In terms of age at transplant, 71.1% were transplanted before the age of two, and 57.9% before the age of one, with an average age of 32.7 ± 49.3 months (or 2.7 ± 4.1 years). The main indication for transplantation was biliary atresia (68.4%), followed by autoimmune hepatitis (7.9%) and tyrosinemia (7.9%). Among the transplanted patients with biliary atresia, 30.8% underwent Kasai surgery between 60 and 90 days of life, and 26.9% did not have the possibility of performing the procedure due to their late age at diagnosis. Among the analyzed patients, 50.0% ($n=19$) had surgical complications in the postoperative period, 26.3% ($n=10$) in the biliary tract, and 23.7% ($n=9$) in vessels (arterial and venous). Among those who were younger than two years of age ($n=27$), 48.1% had postoperative surgical complications, and among those who were older than two years of age ($n=11$), 54.5% had surgical complications. Among the children who underwent transplantation due to biliary atresia, 46.2% had complications, 19.2% had biliary tract complications, and 23.1% had vessel complications. Three out of the four patients in this group who had a transplant after one year of life had surgical complications.

Table 1. Sociodemographic characteristics of caregivers (n=38)

Characteristics	Caregivers
Age (yr)	37.3±8.0
<30	8 (21.1)
30–40	14 (36.8)
40–50	14 (36.8)
>50	2 (5.3)
Sex	
Female	33 (86.8)
Male	5 (13.2)
Ethnicity	
White	13 (34.2)
Mixed	21 (55.3)
Black	4 (10.5)
Religion	
Catholic	19 (50.0)
Evangelical	13 (34.2)
Spiritism	3 (7.9)
No religion	3 (7.9)
Education status	
Incomplete middle school	5 (13.2)
Complete middle school	1 (2.6)
Incomplete high school	6 (15.8)
Complete high school	6 (15.8)
Incomplete higher education	4 (10.5)
Complete higher education	8 (21.1)
Graduate	8 (21.1)
Income	
Up to 2 minimum wages (up to \$390)	20 (52.6)
From 2 to 5 minimum wages (from \$390 to \$970)	8 (21.1)
From 5 to 10 minimum wages (from \$970 to \$1,940)	6 (15.8)
More than 10 minimum wages (more than \$1,940)	4 (10.5)
Situation in the labor market	
Inactive	22 (57.9)
Active	16 (42.1)
Relationship with patient	
Mother	33 (86.8)
Father	5 (13.2)

Values are presented as mean±standard deviation or number (%).

In **Table 3**, the mean score is represented with its respective standard deviation for each dimension of the SF-36 of the 38 caregivers of children and adolescents evaluated in this study. Of the eight dimensions, only three proved to be above the limit value of 70: “physical functioning” (86.1±15.2), “role limitations-physical” (86.8±25.2), and “social functioning” (71.7±24.9). The other dimensions, “bodily pain” (67.3±21.0), “general health status” (50.7±13.6), “vitality” (55.1±24.0), “role limitations-emotional” (62.3±41.1) and “mental health” (61.1±24.4) were compromised.

When compared with data from the Brazilian population [13], the scores of caregivers in the domains “physical functioning” (86.1±15.2 vs. 75.5±31.3; $p<0.05$) and “role limitations-physical” (86.8±25.2 vs. 77.8±5.7; $p<0.05$) were higher than the Brazilian average, respectively. The scores for “bodily pain” (67.3±21.0 vs. 76.7±25.6; $p<0.001$), “general health status” (50.7±13.6 vs. 70.2±22.7; $p<0.05$), “vitality” (55.1±24.0 vs. 71.9±22.7; $p<0.001$), “social functioning” (71.7±24.9 vs. 83.9±22.7; $p<0.001$), “role limitations-emotional” (62.3±41.1 vs. 81.7±28.4; $p<0.001$) and “mental health” (61.1±24.4 vs. 74.5±19.9; $p<0.001$) were below the national average, as shown in **Table 3**. The “physical components” domain had no significant

Table 2. Sociodemographic characteristics of liver-transplanted children and adolescents (n=38)

Characteristics	Liver transplanted children and adolescents
Age (yr)	9.5±5.5 yr
<2	3 (7.9)
2–10	19 (50.0)
10–17	11 (28.9)
>18	5 (13.2)
Sex	
Female	14 (36.8)
Male	24 (63.2)
Ethnicity	
White	7 (18.4)
Mixed	31 (81.6)
Black	0 (0.0)
Etiology	
Biliary atresia	26 (68.4)
Sclerosing cholangitis	1 (2.6)
Autoimmune hepatitis	3 (7.9)
Alagille syndrome	1 (2.6)
Tyrosinemia	3 (7.9)
Acute liver failure	2 (5.3)
Others	2 (5.3)
Age at transplantation (yr)	32.7±49.3 mo
<2	27 (71.1)
2–10	8 (21.1)
10–17	3 (7.9)
Time elapsed since transplant (yr)	81.1±67.5 mo
<1	6 (15.8)
1–5	13 (34.2)
5–10	11 (28.9)
>10	8 (21.1)
Donor	
Mother	13 (34.2)
Father	12 (31.6)
Family	8 (21.1)
Unrelated	3 (7.9)
Deceased donor	2 (5.3)
Complications	
Yes	36 (94.7)
Surgical complications (vessels or biliary tract)	19 (50.0)
PTLD	5 (13.2)
EBV infection	12 (31.6)
CMV infection	11 (28.9)
Rejection	16 (42.1)
No	2 (5.3)
Biliary atresia	
Without Kasai	7 (26.9)
Kasai (<60 d)	5 (19.2)
Kasai (60–90 d)	8 (30.8)
Kasai (90–120 d)	4 (15.4)
Kasai (>120 d)	2 (7.7)

Values are presented as mean±standard deviation or number (%).

PTLD: post-transplant lymphoproliferative disease, EBV: Epstein-Barr virus, CMV: cytomegalovirus.

difference (49.9±5.5 vs. 49.3±0.9; $p=0.908$), but the “mental components” domain was lower than the Brazilian average (41.8±14.1 vs. 51.1±2.8; $p<0.001$).

When analyzing the socioeconomic aspects of the caregivers and the scores in the different domains of the SF-36, there were no statistical differences between any of the domains with age, ethnicity, religion, education, or income, except for the domain “social functioning”

Table 3. Comparison between the mean score of the SF-36 domains of caregivers of liver transplanted children and adolescents and the Brazilian population

Domains	Caregivers	Brazil	<i>p</i> -value
Physical functioning	86.1±15.2	75.5±31.3	<0.05
Role limitation-physical	86.8±25.2	77.8±5.7	<0.05
Bodily pain	67.3±21.0	76.7±25.6	<0.001
General health status	50.7±13.6	70.2±22.7	<0.05
Vitality	55.1±24.0	71.9±22.7	<0.001
Social functioning	71.7±24.9	83.9±22.7	<0.001
Role limitation-emotional	62.3±41.1	81.7±28.4	<0.001
Mental health	61.1±24.4	74.5±19.9	<0.001
Physical Component	49.9±5.5	49.3±0.9	0.908
Mental Component	41.8±14.1	51.1±2.8	<0.001

Values are presented as mean±standard deviation.

SF-36: 36-item short form survey.

Table 4. Comparison between caregivers' perceptions of the child's health and SF-36 scores

Domains	Perception of the Child's Health		<i>p</i> -value
	Excellent and good	Average and bad	
Physical functioning	89.3±14.6	73.8±10.6	<0.05
Role limitation-physical	86.7±22.5	87.5±35.4	0.407
Bodily pain	70.5±21.3	55.4±16.0	<0.05
General health status	53.3±11.6	41.3±17.0	<0.05
Vitality	60.3±23.0	35.6±17.6	<0.05
Social functioning	74.2±25.0	62.5±24.1	0.208
Role limitation-emotional	67.8±40.6	41.7±38.8	0.160
Mental health	65.3±23.8	45.0±20.7	<0.05
Physical components	50.4±5.6	47.8±4.8	0.221
Mental components	44.1±13.8	33.3±12.6	<0.05

Values are presented as mean±standard deviation.

SF-36: 36-item short form survey.

and religion and ethnicity. Catholic caregivers had the best values for the domain “social functioning” (82.2±21.8), followed by evangelicals (66.3±24.1) with $p<0.05$ and the mixed race had the best value (79.8±23.5) with $p<0.05$. The complete data can be accessed in **Supplementary Table 1**.

The distribution of SF-36 domains between the age at which the transplant was performed and the time since transplantation was the same. There was no statistical difference between the groups with or without postoperative complications, PTLTD, Epstein-Barr virus infection, and cytomegalovirus infection and the complete data can be accessed in **Supplementary Tables 2 and 3**. As seen in **Table 4**, when analyzing the relation between the SF-36 domains and the caregiver's opinion on the health of the transplanted child or adolescent (excellent and good or average and bad), the parents who rated it as average and bad had lower values in the domains “physical functioning” (89.3±14.6 vs. 73.8±10.6; $p<0.05$), “bodily pain” (70.5±21.3 vs. 55.4±16.0; $p<0.05$), “general health status” (53.3±11.6 vs. 41.3±17.0; $p<0.05$), “vitality” (60.3±23.0 vs. 35.6±17.6; $p<0.05$) and “mental health” (65.3±23.8 vs. 45.0±20.7; $p<0.05$). As for the components, they presented the worst “mental component” (44.1±13.8 vs. 33.3±12.6; $p<0.05$), but with no difference in the “physical component” (50.4±5.6 vs. 47.8±4.8; $p=0.221$).

Of the 38 caregivers participating in this study, 86.8% felt capable of playing the role of caregiver, 5.3% had difficulties as caregivers, and 76.3% felt valued in this role. When asked about the influence of liver transplantation on their lives, 15.8% of caregivers had separated

Table 5. Caregivers' answers to additional questions (n=38)

Answers	Value
Classification of the child's health	
Excellent	17 (44.7)
Good	13 (34.2)
Average	6 (15.8)
Bad	2 (5.3)
Relationship	
Conflicts have not increased	21 (55.3)
Conflicts have increased	11 (28.9)
Separation or Divorce	6 (15.8)
Have you stopped working?	
Yes	30 (78.9)
No	7 (18.4)
Never worked	1 (2.6)
Budget concern	
Yes	33 (86.8)
No	5 (13.2)
Do you get free time?	
Yes	30 (78.9)
No	8 (21.1)
Impaired sleep	
Yes	17 (44.7)
No	21 (55.3)
Impaired social life	
Yes	12 (31.6)
No	26 (68.4)
Changing projects for the future	
Yes	28 (73.7)
No	10 (26.3)
Difficulty in having positive feelings or thoughts	
Yes	7 (18.4)
No	31 (81.6)
Need for follow-up with psychologist or psychiatrist	
Yes	19 (50.0)
No	19 (50.0)

Values are presented as number (%).

from their partners at the time of the questionnaire, and 78.9% had to stop working at some point due to their child's disease. A total of 86.8% of caregivers reported concerns about the family budget. The targeted questions showed that most caregivers did not suffer any loss in sleep (55.3%), social life (68.4%), or free time (78.9%), but 18.4% reported difficulty in having positive thoughts or feelings and half reported needing psychological or psychiatric specialist care. The complete responses are listed in **Table 5**.

DISCUSSION

Liver transplantation is now the treatment of choice for children with end-stage liver disease and, in recent decades, long-term patient survival has been exceptionally good, reaching up to 94.2% in five years [3,5,7]. Support from the families of patients and their primary caregivers is an essential component of successful outcomes after transplantation [9]. However, caring for a transplanted child can be demanding and stressful, which can negatively affect caregivers' QoL [9]. To assess the psychosocial impact of pediatric liver transplantation on the child's primary caregiver, QoL was assessed as well as the demographic characteristics of the child and caregivers, with regard to the psychosocial

outcomes of the parents. Our results were obtained from a self-reported questionnaire completed online for a small sample of patients. So, when applying our observations to other patient groups, the possibility of sampling bias must be recognized.

The caregivers of liver-transplanted children and adolescents in the present study were young women who, for the most part, quit their jobs to work fully in care. This is common in Brazilian families, in which the primary caregiver is the mother, and due to the responsibility of caring for a child with a chronic illness, most of them are housewives. This was observed in families with children with diabetes, cerebral palsy, and cancer [14-16].

The profile of the transplanted children in this study differed from the global profile. Proportionally, almost 1.8 times more children underwent transplantation due to biliary atresia in this study than in the 2011–2018 data from the Society of Pediatric Liver Transplantation [5]. This can be explained by the age difference at the time of hepatopertoenterostomy (Kasai procedure) in Brazil and the USA. According to the Brazilian experience [17], the average age at portoenterostomy was 82.6 days, and in the US it was 63 days [18]. The earlier the procedure is performed, especially before the 60th day of life, the better the prospect of remaining with the native liver for a longer time [19,20].

In addition, when comparing data on complications, the Belgian experience with 250 transplanted children reported 10.4% of vascular complications, while the American experience reported 23.2% of vascular complications, data closer to the reality of the children in this study, at 23.7% [5,21]. However, when examining biliary complications, Americans reported 13.6%, Belgians 26%, and in this study, 26.3%, while the reported incidence of biliary tract complications ranges from 7–45% [5,21,22]. The same occurred with data regarding rejection, being present in approximately 40% of the patients in both the Belgium report and this study [5,21].

Caregivers' QoL was assessed using a self-perceived health scale used worldwide in public health surveys and research on patients and caregivers. This study showed an important impact in the domains of "social functioning," "role limitations-emotional" and "mental health," in the "general health status" and in the "vitality" of caregivers of children and adolescents with liver transplantation compared to Brazilian standards [13] and those of other countries in America [11,23-25]. However, in the domains "role limitations-physical" and "physical functioning," caregivers showed equivalence or even superiority to the population of other countries [11,13,23-26].

Among Brazilian caregivers of children with other chronic diseases, caregivers of transplanted children showed better results in the domains of "physical functioning" and "role limitations-physical" [14,16]. This can be explained by the fact that children with cerebral palsy and children with cancer have, for the most part, a dependence on carrying out activities of daily living that require physical effort from their caregivers. There was no difference in the domains "bodily pain," "vitality," "social functioning," "role limitations-emotional" and "mental health" [14,16]. In the "general health status" domain, caregivers of transplanted children were statistically inferior [14,16].

This study did not show statistical differences in the scores of the different domains of the SF-36 with the socioeconomic profiles of the caregivers. This indicates that, for this group of caregivers, social class, education, ethnicity, age, or religion are not important determinants

of QoL. And when it comes to their children, the presence of short and long-term complications is also not decisive. This may be explained by the high rate of complications, given that almost all children (94.7%) had some sort of complication such as surgical complications, infection, or rejection.

However, parents' perceptions of the general health of these children are an important factor. A systematic review on the QoL of families and parents after solid organ transplantation also showed worse QoL and family burden but was unrelated to specific transplantation factors, including surgical complications, rejection, and infection [27]. Parents' perception of their child's health has a greater impact on family stress than other factors [27]. Previous research has shown that parents' perception of their child's poorer general health was exclusively related to reports of more severe symptoms of post-traumatic stress disorder in the parents, even though objective measures of treatment and other life-threatening factors were not significant predictors [28].

Given that post-transplant severity and prognosis depend on the type of operation, complications, clinical course, and etiology, these findings indicate that the impact on caregivers' QoL may be related more to the parents' perception of risk than to the "real" threat the child faces. This is important to address in follow-up consultations, as these caregivers may not be fully aware of the child's real condition. So, all caregivers and family members must have a full understanding of the severity, prognosis, and treatment regimen after a transplant.

In addition, others have reported null relationships between illness duration and family psychosocial outcomes among children with chronic illnesses [27,29]. The literature on pediatric chronic diseases provides evidence that parents with greater responsibility for their child's treatment regimen report greater stress and burden [29]. Thus, although differences in severity and prognosis are present among all transplanted children and adolescents, the relationship between parental stress and health outcomes among pediatric transplant recipients is still not well understood.

Intervention at the parent and family level can lead to better health outcomes, so screening of all families during the follow-up of these patients is imperative.

In conclusion, this study showed that the QoL of caregivers of transplanted children is inferior to that of the Brazilian norm and other countries. It is not related to the socioeconomic profile or the characteristics and complications of transplants, but parents' perception of the child's health is a significant predictor.

Given these results, we can say that psychological assistance should be provided to parents not only in the period before and after the transplant but also routinely scheduled for long-term follow-up to improve the QoL of the whole family.

So, in future research, longitudinal investigations are necessary to better understand cause-and-effect relationships and determine the long-term impact of the QoL of parents and family on the health outcomes of the patient.

SUPPLEMENTARY MATERIALS

Supplementary Table 1

Comparison between caregivers' demographic variables and SF-36 scores

[Click here to view](#)

Supplementary Table 2

Comparison between transplant-related variables and SF-36 scores

[Click here to view](#)

Supplementary Table 3

Comparison between transplant complication variables and SF-36 scores

[Click here to view](#)

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