
Original Article

Life Satisfaction and School Performance after Liver Transplantation in Children

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ABSTRACT

Background and Aim: Liver Transplantation (LT) is a procedure that can save and prolong the life of children with end stage liver disease. These patients need prolong follow up, may develop complications and thus need recurrent hospital admissions. These can affect their psychosocial functioning. The aim of this study is to evaluate the life satisfaction and school performance of children who underwent LT.

Materials and Methods: We prospectively assessed the life satisfaction and school performance in 48 pediatric patients who underwent LT between 2004 and 2008 at Organ Transplantation Center affiliated to Shiraz University of Medical Sciences. The data was collected using a standard questionnaire filled by the patients or their parents.

Results: In this study we evaluated 48 children that consisted of 30 boys (62.5%) and 18 girls (37.5%) with a mean age of 9.3 years (range: 1-18 years old) and a mean duration of follow up of 11.8 months (range: 12-48 months). Out of 25 children who were at school age, 85% went to the school and had good school performance; 64.6% of the patients believed that they will have a normal life in future and can get married. Also 68.7% of the cases had normal playing activity with their peers in the same age group.

Conclusion: The goal of LT is not only to ensure survival, but also offer patients the sort of healthy life they enjoyed before the disease, achieving a good balance between the functional efficacy of the graft and the patient's psychological and physical integrity.

Iranian J Pediatr Soc 2010; 2(1): 26-30

Keywords: Children, Liver Transplantation, Physical, Psychological

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Received: November 2009; **Accepted:** December 2009

INTRODUCTION

Different types of liver disease can progress in children and eventually lead to end-stage liver disease (1). Acute liver disease may progress to fulminant hepatic failure, as a result of which majority of patients need liver transplantation for survival (2). LT is the best treatment for pediatric patients with end-stage liver diseases. Due to advances made in the medical field and transplant surgical experiences it is widely used (3). LT can save and prolong the life of these children (4). Survival rate is 87% in the first year after LT and 80% in the third year (5). On the other hand, LT is a major operation and puts a significant stress on the patients, their families and care givers (6,7).

These patients need long time follow up, post transplant care, clinic visits, regular laboratory tests and physical rehabilitation programs (8). They need life long immunosuppressive medications and may develop multiple complications such as infection, rejection, side effect of medication, etc. They may even need recurrent hospital admissions (9,10). These complications ultimately can affect the life satisfaction of the patients and their families (11).

The aim of this study is to evaluate the life satisfaction and school performance of children who underwent LT.

MATERIALS AND METHODS

In this cross sectional study, life satisfaction and school performance was assessed in 48 pediatric patients who underwent LT between June 2004 and June 2008 at Organ Transplantation Center affiliated to Shiraz University of Medical Sciences. The data was collected using a standard questionnaire filled by patients (if they were older than 10 years old) and their parents. The variables assessed were: age, sex, etiology of liver disease, duration of follow up, graft type, the immunosuppressive medications, school performance before and after LT, life

satisfaction in patients and parents after LT, family problems, drug consumption and drug availability after LT.

RESULTS

In this study, 48 children were evaluated. They were 30 boys (62.5%) and 18 girls (37.5%) with a mean age of 9.3 ± 4.6 year old (range: 1-18 years old), a mean duration of follow up of 11.8 ± 9.6 months (range: 12-48 months), and were alive at least one year after LT.

The most common indications for LT were biliary atresia (n=12, 25%), Wilson's disease (n=7, 14.6%), tyrosinemia (n=7, 14.6%), Progressive Familial Intrahepatic Cholestasis (PFIC) (n=6, 12.4%), and autoimmune cirrhosis (n=5, 10.4%). The indications for LT are shown in Table 1. Immunosuppressive medication consisted of tacrolimus (n=44, 91.7%), mycophenolate mofetil (n=33, 68.7%), prednisolone (n=18, 37.5%) and cyclosporine (n=4, 8.7%).

Thirty patients (62.5%) had received liver from living donor and 18 patients (37.5%) had deceased donor.

Table 1. Indications for LT in 48 pediatric patients

Underlying disease	Number of patients (%)
Biliary atresia	12 (25)
Wilson's disease	7 (14.6)
Tyrosinemia	7 (14.6)
PFIC*	6 (12.4)
Autoimmune cirrhosis	5 (10.4)
Cryptogenic cirrhosis	5 (10.4)
Crigler-Najjar syndrome	1 (2.1)
Fulminant hepatitis	1 (2.1)
Congenital hepatic fibrosis	1 (2.1)
Primary sclerosing cholangitis	1 (2.1)
Neonatal hepatitis	1 (2.1)
Hypercholesterolemia	1 (2.1)
Total	48 (100)

*PFIC: Progressive familial intrahepatic cholestasis

Also 28 patients (58.3%) were in school age. Sixteen cases (53.3%) with living donor were in the school age, 9 of whom didn't come back to school due to short time after LT. The school performance of the 7 patients that came back to school, were compared before and after LT. It showed no change; 6 patients had high school performance (average 17-20) before and after LT and one patient had moderate school performance (average 14-17) before and after LT.

Of 18 cases who received deceased donor, 12 cases (66.6%) were in school age, 5 of whom didn't come back to school (due to short time after LT). Of the patients with deceased donor who came back to school, 5 (71.4%) didn't show any change in school performance; 2 patients had high school performance (average 17-20), one patient moderate (average 14-17) and 2 patients had low school performance (average lower than 14) before and after LT. Two patients (28.6%) had educational problems. Overall, from 28 patients who were at school age 14 cases (50%) came back to school and their school performances were compared before and after LT. The results showed that 12 cases (85.7%) didn't have change in school performance and only 2 (14.3%) had failed to have a positive performance. The results of the study showed that 45 families (93.7%) believed that their children had a normal life and were very hopeful to continue their lives. Meanwhile 13 families (27%) had some family problems.

On the whole, 19 parents (39.6%) didn't have any information on "caring after LT" and this could lead to certain family problems after transplantation.

Out of 48 patients, 47 (97.9%) had good compliance in drug consumption. However 21 parents (43.7%) had problems for drug availability.

Ninety-three percent of the patients were alive one year after LT, and 68.7% of them had normal playing activity with their peers in the same age

group. Out of 28 patients who were at school age, 64.6% of patients believed that they would have a normal life in future and can get married.

DISCUSSION

According to various studies in different countries, it seems that pediatric patients with end stage liver diseases have better life satisfaction after LT in comparison to their pre-transplantation stage (4,5).

In addition when compared to normal children, children after LT have more difficulties in school performance which are in normal range (12).

Multiple problems including chronic consumption of immunosuppressive medications and their side effects, irregular consumption of medication, recurrent follow up, recurrent admission due to infection, rejection, and post operation complications, can effect their life satisfaction and school performance (8-11).

Multiple studies have confirmed that post transplant children show minimal behavioral impairment (4,5, 12).

Some earlier researchers reported that after LT children develop behavioral difficulties such as anxiety and behavior problems. For example Debolt et al (7) reported that all of the children experienced psychiatric problems such as regression or belligerence following liver transplantation.

However, other researchers have reported that pediatric liver transplant recipients are largely similar to healthy children or have only a small increased risk for behavioral problems. For example one study indicated that although children developed some social competence deficits after LT, these problems were not clinically significant (13).

Many factors can affect the behavioral functioning of a child such as: age at the time of transplant, number of years passed since trans-

plantation and whether the transplanted organ came from a living or deceased donor (14).

Some studies report that social and family functioning is better in pediatric patients after living donor transplantation as compared to those who receive an organ from a deceased donor (15).

But other researchers reported that there is no difference in social functioning among children who receive an organ from a living rather than a deceased donor (16).

Based on this study, pediatric patients with living donor had better school performance than patients with deceased donor.

None of the patients with living donor had educational problems. Six patients had high school performance and 1 had moderate school performance before and after LT. However, in 7 patients with deceased donor 2 cases had educational problems and 5 patients did not have educational problems; only 2 cases had high school performance, one case had moderate school performance and 2 cases had low school performance before and after LT.

This result could be due to longer time till LT in pediatric patients with deceased donor that can affect behavioral functioning and school performance.

Also this research showed that 93.7% of parents were hopeful that their children continue living, while 64.6% of pediatric patients at school age believed that they would have a normal life in future and can get married.

This difference in the positive attitude towards future life between parents and patients could be due to the complications of the major operation, decreasing daily activity, drug consumption and recurrent follow ups and admissions in hospital that might involve the pediatric patient and indicates that these patients need close psychological follow up.

Based on this study, 39.6% of the families didn't have any information on "caring after LT". This could lead to certain problems in the family and shows that this information should be provided to the parents (including complications of LT, behavioral dysfunction, compliance of patients, post treatment costs, and recurrent follow up).

Also 43.7% of parents had complaints on drugs availability. One of the most important causes of liver rejection is irregular consumption of immunosuppressive medications, an issue which could badly affect survival after LT.

CONCLUSION

In our country this is the first study that has evaluated life satisfaction and school performance after LT. In this study we observed the dramatic impact of transplantation on recipient's life satisfaction. The goal of LT is not only to ensure survival, but also to offer patients the sort of healthy life they enjoyed before the disease, achieving a good balance between the functional efficacy of the graft and the patient's psychological and physical integrity.

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