

Evaluation of Quality of Life in Children Six Months after Liver Transplantation

Seyed Mohsen Dehghani^{*}, Mohammad Hadi Imanieh¹, Naser Honar¹, Mohmood Haghghat¹, Behrooz Astaneh¹, Ali Bahador¹, Seyed Ali Malek-Hosseini¹

1. Gastroenterohepatology Research Center, Namazi Hospital, Shiraz University of Medical Sciences, Shiraz, Iran

ABSTRACT

BACKGROUND

Liver transplantation (LT) is now performed as a cure for numerous untreatable pediatric liver diseases. Quality of life (QoL) can be affected in pediatric patients with LT.

Many factors are responsible for lower scores of QoL. This article aims to detail QoL in liver recipients six months following LT in children.

METHODS

We assessed QoL with the following questionnaires: Child Health Quality-Parent Form 50 (CHQ-PF 50) for parents and Child Health Quality-Child Form 87 (CHQ-CF 87) for children ≥ 10 years of age in 50 children with LT and their parents.

RESULTS

According to the CHQ-PF 50 questionnaire, QoL was found to be significantly lower in LT children compared with healthy children. According to the CHQ-CF 87 questionnaire, QoL was similar in pediatric liver recipients and the normal population.

CONCLUSION

According to parents' judgments, childhood liver recipients have impaired QoL. This may be due to multiple factors that include concern about the long term outcome of LT, comparing their child with other children, and complications of LT. On the other hand, older children and adolescents believe their QoL is similar to healthy children. It seems that by decreasing risk factors, we can reduce stress on families and improve QoL.

KEYWORDS

Liver transplantation; Quality of life; Children

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* Corresponding Author:

Seyed Mohsen Dehghani, MD
Associate Professor, Gastroenterohepatology Research Center, Namazi Hospital, Shiraz University of Medical Sciences, Shiraz, Iran
Tel: +98 711 626 1775
Fax: +98 711 647 42 98
Email: dehghanism@sums.ac.ir
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INTRODUCTION

Liver transplantation (LT) is standard treatment for end stage liver disease in children.^{1,2} According to different studies, over 95% of children survive one year following LT, whereas the ten year survival after LT is more than 80%.³ Due to improvements in survival, evaluation of health-related quality of life (HRQoL) has become more important

and multiple studies have been undertaken to assess this entity. Some patients have lower quality of life (QoL) scores in comparison with the general population which can be attributed to liver diseases and their complications, in addition to life-long immunosuppressive medications.⁴⁻⁶ According to some studies, such as the research by DeBolt et al., pediatric liver recipients have certain psychiatric disorders after LT.⁷ However according to the majority of research, patients have improved QoL after LT.^{8,9}

Other studies showed that patients ten or more years after LT generally have good QoL, although physical functioning is reduced; addressing issues such as recurrent disease and post-LT problems such as osteoporosis may help to improve long-term QoL.⁸

HRQoL has not been systematically studied in Iran and the current research is the first study in our country. The aim of this study is to determine the QoL in pediatric patients after LT by using validated measures. Generally, the vast majority of complications (graft rejections, bacterial and viral infections) occur during the first months following LT, after which the patient becomes more stable. For this reason we have evaluated QoL six months post-LT.

MATERIALS AND METHODS

We conducted a single-center cross-sectional study in 75 consecutive pediatric LT recipients from the Organ Transplant Center affiliated with Shiraz University of Medical Sciences. Of these, 50 cases and their families participated in our study (response rate, 66.7%).

The patients were between 1 and 18 years of age. The time since transplantation was at least six months to a maximum of eight years. Patients who expired during the six months after LT were excluded from this study because the majority of post-LT complications occur during this period. It was our intent to include patients who were relatively stable medically. Thus we compared the HRQoL views of parents and pediatric patients after LT.

For this study, we used the Child Health Quality-Parent Form 50 (CHQ-PF 50) and Child Health Quality-Child Form 87 (CHQ-CF 87) validated versions [Quality Metric Incorporated, Office of Grants and Scholarly Research (OGSR), USA].

After translation of these questionnaires, their reliability and validity were approved. The CHQ-PF50 questionnaire was completed by 15 parents and CHQ-CF 87 by 15 children older than 10 years of age. After two weeks, parents and patients completed the questionnaires again. Next, these questionnaires were checked by the Cronbach's alpha test with over 70% reliability. After assessment for reliability, questionnaires were completed by all parents (CHQ-PF 50) and children ≥ 10 years of age (CHQ-CF 87). The questionnaires were discussed and completed by a pediatric hepatologist in face-to-face interviews.

The CHQ-PF 50 determines 15 health concept profiles including the following: global health (GGH), physical functioning (PF), role/social limitations-physical (RP), bodily pain/discomfort (BP), general health (GH) and change in health (CH), role/social limitations-emotional/behavioral (REB), behavior (BE), global behavior item (GBE), mental health (MH), self-esteem (SE), and family functioning determining parental impact emotional (PE), parental impact time (PT), family activities (FA) and family cohesion (FC).

The CHQ-CF 87 determines a 14 health concept profile that includes (GGH), (PF), (RP), (BP), (GH) and (CH), role/social limitations-behavioral (RB), role/social limitations-emotional (RE), (BE), (GBE), (MH), (SE), family functioning determining (FA) and (FC).

We compared pediatric LT recipients with their peers, who were healthy children with no chronic diseases; in Western countries, such healthy children have been considered as normal controls.

Values were expressed as means and standard deviation. Scoring was done by CHQ, a user's manual from the same office. In this study, all analyses were performed using the t-test with SPSS version 15. *P* values less than 0.05 were considered significant. This study was approved by Shiraz University of Medical Sciences Institutional Review Board.

RESULTS

Patients consisted of 32 (64%) boys and 18 (36%) girls with a mean age of 10.6 ± 4.6 years (range: 1-18 years). Time since transplant was 6-96 months. According to CHQ-PF 50 the physical health subscales that included GGH ($p < 0.0001$),

PF ($p<0.0001$), RP ($p=0.003$), BP ($p=0.03$), GH ($p<0.0001$) and CH ($p<0.0001$) were significantly lower than normal children. The psychological health subscales of REB ($p=0.003$), MH ($p=0.01$), and SE ($p=0.04$) were significantly lower than normal children. BE and GBE were not different significantly in comparison with healthy children (Table 1). To summarize, all subscales of the CHQ-PF 50, with the exception of BE and GBE significantly differed from healthy children. Parents of LT recipients thought LT recipients were less satisfied with school, athletic activities, appearance and life. Only the BE and GBE subscales that included paying attention and concentration were not different from normal children.

However, according to CHQ-CF 87 regarding the measures of physical health, only RP was significantly lower than the normal population ($p=0.003$). In terms of the answers of CHQ-CF 87, patients showed limitations in the RP subscale which included limitations in school-related activities and activities with friends. There were no significant differences in all psychological subscales (RB, RE, BE, GBE, MH, and SE) and family functioning (FA and FC) between LT recipients and the normal population (Table 2).

DISCUSSION

LT is the standard of care for children with end stage liver disease.^{1,2} It is obvious that the success of pediatric LT is more than just a good patient or graft survival rate. Although life-saving, LT is not curative; instead, this fatal disease has been replaced by a chronic condition with its own associated morbidities. The ensuing post-LT course often creates new stresses for children and their parents. This consideration highlights the fact that the outcomes of LT in children must include not only the quantity but also the QoL of years survived. Over the past decade, there has been an increasing realization that the benefits of LT are not fully reflected by morbidity and mortality and the outcome of children after LT relate not only to quantity but also to QoL.³

The results of the current study revealed that according to parents' opinions (CHQ-PF 50), children six or more months after undergoing LT showed

decreased QoL in comparison with normal children. In this study, the CHQ-PF 50 questionnaire showed that children had decreased subscales in all areas except BE. Parents reported that children had decreased physical, social and emotional functioning compared with healthy children. Parents of LT recipients thought there was less satisfaction with school, athletic activities, appearance and life overall. Only in terms of BE and GBE subscales that included paying attention and concentration were LT recipients the same as normal children.

The reasons for decreased QoL based on the CHQ-PF 50 questionnaire are not clear, although it may be due to multiple factors. Our center is the most active LT center in Iran and patients and their families travel long distances to this center in Shiraz for pre-operative evaluations, transplantation, post-LT follow up and, if indicated, admission due to multiple complications (surgical, transplant rejection, infections and other complications). Also, the cost of post-transplant work up and immunosuppressive medications, in addition to the occasional shortage of these medications may affect parental QoL. Parents may also compare their children to other healthy children. These factors can induce parental stress and decrease QoL.

Several studies that assessed QoL after LT have shown gratifying results with improvement in QoL compared to before transplantation. One study has shown that transplant recipients had mild social and scholastic deficits and on many measures had equivalent levels of function to the comparison groups.⁷ The results of one study has revealed that patients ten or more years after LT generally have an good overall QoL but display a reduction in their ability to carry out physical functioning in comparison with the general population.⁸ In these studies, pediatric patients mainly have mild limitations in physical functioning after LT.^{10,11}

Alonso et al. in a multi-center study has shown that pediatric patients over the age of five have mild decreases in physical health.¹¹ Also Desai et al. in the UK showed that patients had good HRQoL 30 years following LT.⁸

To summarize, according to multiple studies that

Table 1: QoL according to the CHQ-PF 50 questionnaire.

Scales	Liver transplant (LT) children (mean±SD)	Healthy children (mean± SD)	T-value	p-value
Global health (GGH)	75.6±27.5	95±15	8.7	<0.0001
Physical functioning (PF)	76.4±20.9	96±14	8.7	<0.0001
Role, social limitation emotional, behavioral (REB)	83.52±24.6	92.5±18.6	2.9	0.003
Role, social limitation physical (RP)	77.7±29.6	93.6±18.6	2.9	0.003
Bodily pain/discomfort (BP)	75.1±27.54	81.7±19	2.2	0.03
Behavior (BE)	73.2±19.3	75.6±16.7	0.93	NA*
Global behavior item (GBE)	74.3±18.2	74.5±16.5	0.95	NA
Mental health (MH)	73.3±18.5	78.5±13.2	2.5	0.01
Self-esteem (SE)	74.1±16.6	79.8±17.5	2.1	0.04
General health (GH)	49.18±19.62	73±17.3	8.9	<0.0001
Change in health (CH)	48.2±19.5	75.5±19.5	8.8	<0.0001
Parent impact-time (PT)	69.8±25.55	87.8±19.9	5.6	<0.0001
Parent impact-emotional (PE)	46±31.33	80.3±17.3	11.5	<0.0001
Family activities (FA)	68.9±25.5	88.7±19.5	5.6	<0.0001
Family cohesion (FC)	67.8±20.2	82.3±18.4	4.3	<0.0001

*NA: Non-significant

used CHQ-PF 50, parents of LT children reported mild decreased HRQoL compared with healthy children, mainly in the area of physical functioning.

Our study showed that LT children had decreases in all of the physical, social and emotional functioning subscales with the exception of BE, compared with healthy children. However, according to the CHQ-CF 87 questionnaire, patients did not have significant differences with healthy children. There were limitations in school-related activities and playing with friends; only the RP subscale was lower than normal children.

This study had one important limitation as we did not establish the QoL in normal healthy Iranian children, but rather compared our results with normal Western children in which their QoL may differ from Iranian children.

Our study implies that rehabilitation programs

may consequently result in improved HRQoL in all areas of physical, social and emotional functioning. However, this should be confirmed in future randomized trials regarding the effects of such rehabilitation programs for LT recipients.

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CONFLICT OF INTEREST

The authors declare no conflict of interest related to this work.

Table 2: QoL according to the CHQ-CF 87 questionnaire.

Scales	Liver transplant (LT) children (mean±SD)	Healthy children (mean±SD)	T-value	p-value
Global health (GGH)	88.65±13.5	88.5±14	0.43	NA*
Physical functioning (PF)	89.75±12.7	88.8±14	0.364	NA
Role, social limitation emotional (RE)	79.26±23.82	86±21	1.57	NA
Role, social limitation behavioral (RB)	81.84±22.84	86.5±21.5	1.1	NA
Role, social limitation physical (RP)	75.5±28.9	88.3±21	2.97	0.003
Bodily pain/discomfort (BP)	79.6±23.17	74.4±23	1.1	NA
Behavior (BE)	17±19.70	76.6±14.6	1.87	NA
Global behavior (GBE)	75.6±18.8	76.5±14.3	1.7	NA
Mental health (MH)	69.5±19.87	72.7±16	0.96	NA
Self-esteem (SE)	79.66±14.65	81.8±15.8	1.6	NA
General health (GH)	61.16±19.16	66.4±14.6	1.7	NA
Change in health (CH)	76.5±13.75	77.3±19.6	1.1	NA
Family activities (FA)	81.25±23.75	85±19.5	1.67	NA
Family cohesion (FC)	79.77±21.82	83.5±17.4	1.5	NA

* NA: Non-significant

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