

Determination of Variables Influencing the Quality of Life in Children with Liver Transplantation

✉ Nurşen Altuğ¹, ✉ Çiğdem Ömür Ecevit², ✉ Miray Karakoyun³, ✉ Ezgi Kıran Taşçı³, ✉ Bahire Boluşık⁴, ✉ Sema Aydoğdu³

¹Ege University Faculty of Medicine, Organ Transplantation and Research Center, İzmir, Turkey

²Dr. Behçet Uz Children's Disease and Surgery Training and Research Hospital, Department of Pediatric Gastroenterology, Hepatology and Nutrition, İzmir, Turkey

³Ege University Faculty of Medicine, Department of Pediatric Gastroenterology, Hepatology and Nutrition, İzmir, Turkey

⁴Ege University Faculty of Nursing, Department of Pediatric Nursing, İzmir, Turkey

ABSTRACT

Aim: This clinical study examined various dimensions of quality of life in children who underwent liver transplantation.

Materials and Methods: The patient group (n=50) of the study consisted of children and their families where the child had received a liver transplant (possibly from their mother) in Ege University Organ Transplant Research Center. The control group (n=50) consisted of children and their families who did not undergo any organ transplants, did not have any health issues, and were of similar age, gender and socio-economic status with the members of the study group. The children in the study were examined with the quality of life questionnaire named KINDer Lebensqualitätsfragebogen (Children's Quality of Life Questionnaire, KINDL).

Results: The overall quality of life and the quality of life in the physical, emotional, self-esteem, family, friend, and school sub-categories as reported by the children themselves in the study group, in the 8-12- and 13-16 year age groups were determined to be higher ($p<0.05$) when compared to the children in the control group. Similarly, the quality of life for the children in the study group, as reported by their families were determined to be higher ($p<0.05$) when compared to the control group.

Conclusion: Liver transplantation has effects on the quality of life of both the children and their families.

Keywords: Liver Transplantation, Quality of Life, Children, KINDL

Introduction

Solid organ transplantation is one of the methods used for the treatment of end-stage organ failures (1). However, the greatest barrier for organ transplantation is insufficiency of cadaver-derived organs both in our country and abroad. This is why patients in the waiting list for transplantation and their families are under psychological stress and a great fear for losing. Especially, if the patient is a child, this situation causes great changes in the family and the imaginary world of the child since he/ she cannot comprehend the events properly.

The term "quality of life" was first used in United States in 1950s, and later it was widely used to measure sense of

well being both in health and society (2). Health- Related Quality of Life (HRQOL) is a versatile notion including physical, emotional and social well being of the patient, and is defined as patient's perception for the influences of the disease and its treatment (3,4). There are a few generic quality of life instruments developed for children and adolescents. Children's Quality of Life Questionnaire (KINDL) measure is used in children with various chronic diseases and developmental problems, in order to determine which dimension of their lives is affected due to these diseases or their therapy (5, 6). KINDL is a quality of life measure for children developed in German by Ravens-Sieberer et al. in 1998 (7). It is a validated and highly reliable generic Quality of Life (QOL) measure used for the assessment of physical,

Address for Correspondence

Miray Karakoyun MD, Ege University Faculty of Medicine, Department of Pediatric Gastroenterology, Hepatology and Nutrition, İzmir, Turkey
Phone: +90 505 869 96 91 E-mail: miray.karakoyun35@gmail.com ORCID ID: orcid.org/0000-0002-6533-6256

Received: 14.10.2018 Accepted: 28.12.2018

mental and social conditions. KINDL was lately validated in a number of languages (8, 9, 10). Eser et al. validated its Turkish version in 2004, and it was shown to be valid and reliable in Turkish language (9).

The aim of this study was multidimensional assessment of the quality of life in children with liver transplantation, and to determine the factors that affect the quality of life of these children.

Materials and Methods

The study group consisted of the families and 50 children between the ages of 7 – 16 years who underwent liver transplantation in our center more than 1 year ago, and admitted to our Organ Transplantation Polyclinic for the routine follow up. All children and their families agreed to participate in the study. The control group consisted of healthy age-, sex-, and socioeconomic status- matched controls and their families (n=50) who agreed to participate in the study.

A pediatric gastroenterologist examined the files of the children in the study group. The participants in control group were randomly chosen from different neighboring provinces and localities of İzmir. The age and gender of the participating child, as well as the age, educational status etc. of the participating parent were recorded in the sociodemographic data form in the control group, and all participants filled in the same forms used in the study group.

The Ethical Committee of our center approved the study; all patients and their families were informed about the study. Patient Data Form was used to record the data regarding the illness and the social status of the child and the families. The transplanted children completed KINDL.

Children's Quality of Life Questionnaire (KINDL):

The tests are applied according to the age groups of the children by dividing them into three age groups: 4 – 7 years age group, 8 – 12 years age group and 13 – 16 years age group. This scale consists a total of 30 items. Six subscales, respectively, examine the functionality in physical well being (4 items), emotional well being (4 items), self-esteem (4 items), family (4 items), friends (4 items), school (4 items) and chronic disease (6 items) subgroups. The degree of the problem specified in the item answered was asked to the

parents and children. The scale is graded on a 5- point Likert scale. Including the parents forms, all forms consist of the same items, and they differ only for the items regarding the developmental stage of the child and the sentences including third person pronouns to make the child's understanding easier. The higher score was shown that the better quality of life.

Statistical Analysis

All data were transferred into the computer using Statistical Package for Social Sciences (SPSS) version 10.0 (SPSS Inc. Chicago IL, USA). Frequency and Chi-square tests were used for the analysis of demographic data, and Mann-Whitney U and Wilcoxon tests were used to analyze the quality of life, the effects of the variables on the quality of life. The concordance between the points of the children and their parents was analyzed using Pearson's correlation analysis.

Results

The most common reason for the liver transplantation was biliary atresia (n=12, 24%). Other causes were progressive familial intrahepatic cholestasis (PFIC) 16% (n=8), tyrosinemia 10% (n=5), fulminant hepatitis 14% (n=7), glycogen storage disease 8% (n=4), autoimmune hepatitis 6% (n=3), Wilson's disease 4% (n=2), cryptogenic cirrhosis 6% (n=3) and miscellaneous 12% (n=6). The distribution of the patients (study and control groups) is shown in Table 1. The ages of the children were similar in the study and the control groups (p>0.05).

Study group in 8 – 12 years age had higher scores in physical well being, family and school subgroups compared to the control group (p<0.05). KINDL evaluation in 8-12 years age group was shown in Table 2.

The gender's effect on sum score was significant in 13 – 16 years age group control and study groups (p<0.05). 13 – 16 years age boys in study group had self-esteem, friends, chronic disease subgroups and sum score higher compared to girl. The girls in this age were had higher score at physical and emotional well being subgroups than boy. There was no significant difference in the sum score between 13 and 16 years in both groups (p> 0.05). However, its impacts on physical well being and friend subgroups were found

Table I. The distribution of the study and control groups

Variable	Study group		Control group		p value
	n	%	n	%	
Age					
8-12 year age group	32	64.00	29	58.00	0.380
13-16 year age group	18	36.00	21	42.00	
Gender	Male 52% (n=24) Female 48%(n=24)		Male %60 (n=30) Female %40 (n= 30)		

significant ($p < 0.05$). KINDL evaluation in 13-16 years age group was shown in Table 3.

Rejection of the transplant was shown to affect sum score in both age groups ($p < 0.05$). In order to determine which dependent variable caused the basic effect of the variable, a further analysis was carried out and details were shown in Table 4 and 5. The variable of being educated had a significant effect on sum score in both age groups ($p < 0.05$).

In the study, further analysis was done to determine the difference between parent - reported physical well being, emotional well being, social and school subgroups between the study and the control groups. The group effect was not found significant on sum score ($p > 0.05$). The analysis of the emotional well being, self-esteem and school subgroups were significantly higher in the study group compared to the control group ($p < 0.05$). KINDL evaluation for the family was shown in Table 6.

Table II. KINDL* evaluation in 8-12 year age group

KINDL	The mean scores of the study group	The mean scores of the control group	p value
Sum score	74.88±13.85	66.47±10.97	0.018
Physical well being	75.07±22.84	65.75±19.01	0.013
Emotional well being	73.66±19.93	65.00±20.96	0.130
Self-esteem	74.18±18.72	68.25±20.56	0.277
Family	74.56±19.61	61.08±19.01	0.014
Friends	78.26±15.84	78.26±15.84	0.108
School	73.28±18.58	66.25±17.02	0.015
Chronic disease	63.91±15.36	00+00	-

*KINDL: Children's Quality of Life Questionnaire

Table III. KINDL* evaluation in 13-16 year age group

KINDL	The mean scores of the study group	The mean scores of the control group	p value
Sum score	64.71±19.74	64.47±10.78	1.000
Physical well being	71.88±22.40	61.31±23.52	0.013
Emotional well being	63.54± 26.88	64.88±20.20	0.966
Self esteem	65.19± 26.04	67.26±19.45	0.813
Family	57.63±26.73	59.72±19.50	0.909
Friends	66.66±17.67	74.40±12.00	0.046
School	57.29±22.30	58.63±15.62	0.820
Chronic disease	68.51± 14.91	00+00	-

*KINDL: Children's Quality of Life Questionnaire

Table IV. KINDL evaluation according to postoperative education status of the study group (8-12 years age group)

8-12 years age groupchildren KINDL	Educated	Not educated	p value
Sum score	79.09±8.75	70.76±9.20	0.027
Physical well being	76.62±18.46	58.98±22.47	0.008
Emotional well being	73.75±19.96	74.27±15.54	0.977
Self esteem	86.25±12.80	74.53±16.79	0.213
Family	73.75±6.84	78.24±15.63	0.414
Friends	86.25±2.79	78.55±17.29	0.221
School	81.54±13.76	62.87±13.71	0.003
Chronic disease	69.99±10.37	57.90±11.99	0.023

KINDL: Children's Quality of Life Questionnaire

Table V. KINDL evaluation according to postoperative education status of the study group (13-16 years age group)

13-16 years age group children KINDL Domains	Educated	Not educated	p value
Sum score	78.63±20.90	63.20±19.94	0.029
Physical well being	79.00±31.74	74.52±18.65	0.036
Emotional well being	60.00±32.05	64.90±25.96	0.582
Self esteem	74.16±10.68	61.45±29.89	0.038
Family	67.50±33.48	53.84±24.14	0.027
Friends	72.50±15.05	64.42±18.64	0.290
School	72.50±8.38	51.44±23.40	0.010
Chronic disease	70.41±18.88	67.78±13.93	0.046

KINDL: Children's Quality of Life Questionnaire

Table VI. KINDL evaluation of parents

KINDL Domains	The mean scores of the study group	The mean scores of the control group	p value
Sum score	72.88±13.85	68.47±17.97	0.618
Physical well being	70.07±12.84	66.75±16.01	0.113
Emotional well being	70.66±10.93	77.00±10.94	0.017
Self esteem	72.28±26.12	68.95±6.46	0.027
Family	64.56±19.61	69.08±17.01	0.319
Friends	68.26±11.54	68.26±15.84	0.408
School	63.28±28.98	56.25±17.02	0.031
Chronic disease	63.36±16.36	00 + 00	-

KINDL: Children's Quality of Life Questionnaire

Discussion

The quality of life significantly improves in liver- transplant children. This improvement is more prominent in patients with inherited metabolic diseases under 5 years of age (11, 12). Avutzur et al. reported high quality of life in 32 liver- transplant pediatric patients 10 years after the transplantation despite chronic extrahepatic morbidity (13). In our study, children who had a critical operation such as liver transplantation had high quality of life perception similarly previous reports. Even in some subgroups, higher than their healthy control group. Perception of high physical well being in study group may be related to their previous disease experiences. Those children, who competed with serious health problems before, can tolerate milder diseases in this period of their lives. In a similar study performed by Tarter et al., the liver transplant patients were first evaluated when they were in the waiting list, and then 2 years after transplantation, and it was found that their total quality of life score were better than the control group after transplantation, however their psychological scores were lower (14). In our study, 32 children at 8 - 12 year age of study group were reported that total quality of life scores higher than control group. However, 18 children at 13 -16 year age study group were detected that

sum scores of quality of life were similar to control group. The scores for physical well being was higher and the friend scores were lower than the control group. If in the friend subgroup the expressions such as "I felt myself different from other children" are taken into consideration, although generalization is difficult, we can talk about the effect of the social environment on this age group. In a similar study, the statement of one child without any health problem as "the worst years of my life are my years in school, because the teachers say do what you can, even if you can't, this is not important" is the best example for this (15). As Bucuvalas et al. was reported long-term results of liver transplant children, one of the most important problems in this patients is long term and regular use of drugs (16). Attending the school and school trips complicate regular use of drugs. Informing teachers and other school workers on this issue is very important. In our study, the parents realized this condition, and most of the families reported that they informed school management and the teachers verbally.

Balaska et al. were determined that increasing general health, physical function and emotional function one year after the transplantation (17). A number of other studies were reported that, as the duration after transplantation increases, the functional status scores also increase (16, 18). In our study,

we determined that as the years passed by after transplantation, the quality of life increased in a number of subgroups.

The most important problem for the transplant children is rejection of the organ. Despite all new developments, the risk of organ rejection persists all life long in transplant patients, and every new rejection attack traumatizes the child and the family. In this study, we determined that lower sum scores in children who experienced rejection attacks.

The importance of education before and after transplantation is known both for the patient and parents in the transplantation process. In Sweden, a study performed on 18 children aged between 4 - 18 year was noted that education of the families / children for their new lives after transplantation was important for quality of life (15). In our study, the patients' and parents' sum scores were higher in both age groups in the educated group. It was seen that the basic effect of education was particularly due to physical well being and its effect.

In children, most of the studies refer to the evaluations of the family, teacher or the hospital staff. In fact, these evaluations are considered if the child is unable to answer to the questions because of his/her illness or he / she is too young. The correlation among the scores is affected by the factors such as age, gender and the disease. In addition, it has been reported that a higher concordance is seen in the domains in which behaviors can be observed such as physical functionality when compared to emotional or social functionality (19). The studies performed in different disease groups showed different concordances in different subgroups (20, 21). Varni et al. found that the scores obtained in the sick children group were higher than the parent- reported scores in all subgroups (22). In our study, we used a scale in which enabled parent evaluation, and compared the patient and the parent scores, and found the highest concordance between the parent and the child evaluations in the school subgroup in the transplant group.

In conclusion, regular education programs must be constituted for transplant children and their families before and after transplantation. They must follow a preformed template and at the same time answer the determined needs of the patients / families. In this way, the quality of life of the recipients will be better and their post-transplantation course will be more comfortable.

References

1. Lim KB, Schiano TD. Long-term outcome after liver transplantation. *Mt Sinai J Med* 2012; 79: 169 -189.
2. Burra P, De Bona M. Quality of life following organ transplantation. *Transplant International* 2007; 20: 397- 409.
3. WHOQOL Group. The World Health Organization Quality of Life Assessment (WHOQOL): Position paper from the World Health Organization. *Social Science and Medicine* 1995; 41: 1403 -1409.
4. Ravens-Sieberer U, Erhart M, Wille N, Wetzel R, Nickel J, Bullinger M. Generic health-related quality-of-life assessment in children and adolescents: methodological considerations. *Pharmacoeconomics* 2006; 24: 1199 - 1220.
5. Ravens-Sieberer U, Erhart M, Wille N, Wetzel R, Nickel J, Bullinger M. Generic health-related quality-of-life assessment in children and adolescents: methodological considerations. *Pharmacoeconomics* 2006; 24: 1199 - 1220.
6. KINDL questionnaire. (<http://www.kindl.org>).
7. Ravens-Sieberer U, Bullinger M. Assessing health-related quality of life in chronically ill children with the German KINDL: first psychometric and content analytical results. *Qual Life Res* 1998; 7: 399 - 407.
8. Rajmil L, Serra-Sutton V, Fernandez-Lopez JA, Berra S, Aymerich M, Cieza A, et al. The Spanish version of the German health-related quality of life questionnaire for children and adolescents: the Kindl. *An Pediatr (Barc)* 2004; 60: 514 - 521.
9. Eser E, Yüksel H, Baydur H, Erhart M, Saatli G, Cengiz Ozyurt B, et al. The psychometric properties of the new Turkish generic health-related quality of life questionnaire for children (Kid-KINDL)]. *Turkish Journal of Psychiatry* 2008; 19: 409 - 417.
10. Wee HL, Lee WW, Ravens-Sieberer U, Erhart M, Li SC. Validation of the English version of the KINDL generic children's health-related quality of life instrument for an Asian population--results from a pilot test. *Qual Life Res* 2005; 14: 1193 - 1200.
11. Kayler LK, Merion RM, Lee S, Sung RS, Punch JD, Rudich SM, et al. Long-term survival after liver transplantation in children with metabolic disorders. *Pediatr Transplant* 2002; 6: 295 - 300.
12. Cole CR, Bucuvalas JC, Hornung RW, Krug S, Ryckman FC, Atherton H, et al. Impact of liver transplantation on HRQOL in children less than 5 years old. *Pediatr Transplant* 2004; 8: 222 - 227.
13. Avitzur Y, De Luca E, Cantos M, Jimenez-Rivera C, Jones N, Fecteau A, et al. Health status ten years after pediatric liver transplantation--looking beyond the graft. *Transplantation* 2004; 78: 566 - 573.
14. Tarter RE, Switala J, Arria A, Plail J, Van Thiel D. Quality of life before and after orthotopic hepatic transplantation. *Arch Intern Med* 1991; 151:1521-1526.
15. Olausson B, Utbult Y, Hansson S, Krantz M, Brydolf M, Lindström B, et al. Transplanted children's experiences of daily living: children's narratives about their lives following transplantation. *Pediatr Transplant* 2006; 10: 575 - 585.
16. Bucuvalas JC, Ryckman FC. Long term outcome after liver transplantation in children. *Pediatr Transplant* 2002; 6: 30 - 36.
17. Balaska A, Moustafellos P, Gourgiotis S, Pistolas D, Hadjiyannakis E, Vougas V , et al. Changes in health-related quality of life in Greek adult patients 1 year after successful renal transplantation. *Exp Clin Transplant* 2006; 2: 521- 524.
18. Kong IL, Molassiotis A. Quality of life, coping and concerns in Chinese patients after renal transplantation. *Int J Nurs Stud* 1999; 36: 313 - 322.
19. Eiser C, Morse R. Quality-of-life measures in chronic diseases of childhood. *Health Technol Assess* 2001; 5: 1-15.
20. Czyzewski DI, Mariotto MJ, Bartholomew LK, Le Compte SH, Sockrider MM. Measurement of quality of well being in a child and adolescent cystic fibrosis population. *Medical Care* 1994; 32: 965-972.
21. Eiser C, Havermans T, Craft A, Kernahan J. Development of a measure to assess the perceived illness experience after treatment for cancer. *Arch Dis Child* 1995; 72: 302 - 307.
22. Varni JW, Burwinkle TM, Katz ER, Meeske K, Dickinson P. The PedsQL in pediatric cancer reliability and validity of the pediatric quality of life inventory generic core scales, multidimensional fatigue scale, and cancer module. *Cancer* 2002; 94: 2090 - 2106.