



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

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ABSTRACT

Aim: This clinical study examined various dimensions of the Quality of Life (QoL) in children who had undergone 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 a QoL questionnaire named KINDer Lebensqualitätsfragebogen (Children's Quality of Life Questionnaire).

Results: The overall QoL and the QoL in the physical, emotional, self-esteem, family, friend, and school sub-categories as reported by the children themselves in the study group, in both the 8-12 and 13-16 year age groups were determined to be higher ($p<0.05$) when compared to those children in the control group. Similarly, the QoL 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 QoL 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 on the waiting list for transplantation and their families are under psychological stress facing great fear of loss of life. 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 (QoL)" was first used in United States in 1950s, and later it was widely used to measure a sense of well-being both in health and society (2). Health-Related QoL is a versatile notion including the physical, emotional and social well-being of the patient, and is

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defined as the patient's perception of the influences of the disease and its treatment (3,4). There are a few generic QoL instruments developed for children and adolescents. The 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 are affected due to these diseases or their therapies (5,6). KINDL is a QoL measure for children developed in Germany by Ravens-Sieberer and Bullinger (7) in 1998. It is a validated and highly reliable generic QoL measure used for the assessment of physical, mental and social conditions. KINDL was lately validated in a number of languages (8-10). Eser et al. (8) validated its Turkish version in 2004, and it was shown to be valid and reliable in the Turkish language.

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

Materials and Methods

The study group consisted of 50 children between the ages of 7-16 years who had undergone liver transplantation in our center more than 1 year previously, and were admitted to our Organ Transplantation Polyclinic for routine follow up and their families. All children and their families agreed to participate in the study. The control group consisted of healthy age-, sex-, and socio-economic 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 the 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 socio-demographic data form in the control group, and all participants filled in the same forms used by the study group.

Ege University Nursing Faculty Ethics Committee (approval number: 2008-55). Informed parental consent was obtained for all infants. A Patient Data Form was used to record data regarding the illness and the social status of the child and their family. The children who had received transplants completed KINDL.

Children's Quality of Life Questionnaire

The tests were 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 of 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 the score reported, the better the QoL experienced.

Statistical Analysis

All data were transferred into the computer using (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 test and Wilcoxon tests were used to analyze the QoL and the effects of the variables on the QoL. 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 (n=8, 16%), tyrosinemia (n=5, 10%), fulminant hepatitis (n=7, 14%), glycogen storage disease (n=4, 8%), autoimmune hepatitis (n=3, 6%), Wilson's disease (n=2, 4%), cryptogenic cirrhosis (n=3, 6%) and miscellaneous (n=6, 12%). The distribution of the patients (study and control groups) is shown in Table I. The ages of the children were similar in the study and the control groups ($p>0.05$).

Study group in 8-12 years of 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 is shown in Table II.

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

($p < 0.05$). KINDL evaluation in the 13-16 years age group is shown in Table III.

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

In this study, further analysis was done to determine the difference between parent-reported physical well-being, emotional well-being, social and school subgroups for the study and the control groups. The group effect was not found significant on the 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 is shown in Table VI.

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)	-	60% (n=30)	-	-
Female	48% (n=24)	-	40% (n=30)	-	-

Table II. Children's Quality of Life Questionnaire* 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

Discussion

The QoL significantly improves in liver-transplant children. This improvement is more prominent in patients with inherited metabolic diseases under 5 years of age (11,12). Avitzur et al. (12) reported high QoL in 32 liver-transplant pediatric patients 10 years after the transplantation despite chronic extrahepatic morbidity. In our study, children who had a critical operation such as a liver transplantation had a high QoL perception similar to previous reports, even in some subgroups, transplant patients had higher scores than the healthy control group. Perception of high physical well-being in the study group may be related to their previous disease experiences. Those children, who endured serious health problems before, could now tolerate milder diseases in this period of their lives. In a similar study performed

Table III. Children's Quality of Life Questionnaire* 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. Children's Quality of Life Questionnaire evaluation according to postoperative education status of the study group (8-12 years age group)

8-12 years age group children 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

by Tarter et al. (13), the liver transplant patients were first evaluated when they were on the waiting list, and then 2 years after transplantation, and it was found that their total QoL scores after transplantation were better than the control group, however their psychological scores were lower (14). In our study, 32 children in the 8-12 years of age study group reported that their total QoL scores were higher than the control group. However, 18 children in the 13-16 years of age study group had sum scores of QoL similar to control group. The scores for physical well-being were higher and the friend scores were lower than the control group. In the friend subgroup, if expressions such as "I felt different from other children" are taken into consideration, although a 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 and Ryckman (15) reported on the long-term results of liver transplant children, one of the most important problems for these patients is the long term and regular use of drugs. Attending school and school trips complicate the regular use of drugs. Informing teachers and other school workers on this issue is very important. In our study, the parents were aware of this situation and most of the families reported that they had informed the school management and teachers verbally.

Balaska et al. (16) determined that there was increasing general health, physical function and emotional function one year after the transplantation. A number of other studies 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 QoL increased in a number of subgroups.

The most important problem for children who have had a transplant is the 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 lower sum scores in children who had experienced rejection attacks.

The importance of education before and after transplantation both for the patient and parents in the transplantation process is known. In Sweden, a study performed on 18 children aged between 4-18 years noted that education of the families/children for their new lives after transplantation was important for their QoL (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 linked to physical well-being and its effect.

For children, most 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 the questions because of his/her illness or that he/she is too young. The correlation among the scores is affected by 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

Table V. Children's Quality of Life Questionnaire 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. Children's Quality of Life Questionnaire 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

disease groups showed different concordances in different subgroups (20,21). Varni et al. (21) found that the scores obtained in the sick children group were higher than the parent-reported scores in all subgroups. In our study, we used a scale 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.

Conclusion

Regular education programs must be constituted for children who have undergone transplants and their families before and after transplantation. They must follow a prepared template and at the same time answer the determined needs of the patients/families. In this way, the QoL of the recipients will be better and their post-transplantation course will be more comfortable.

Ethics

Ethics Committee Approval: Ege University Nursing Faculty Ethics Committee (approval number: 2008-55).

Informed Consent: Informed parental consent was obtained for all infants.

Peer-review: Externally peer-reviewed.

Authorship Contributions

Surgical and Medical Practices: N.A., S.A., B.B., Concept: S.A., M.K., Ç.O.E., Design: B.B., Data Collection or Processing: N.A., M.K., E.K.T., Analysis or Interpretation: Ç.O.E., S.A., B.B., Literature Search: S.A., N.A., M.K., E.K.T. Writing: N.A., C.E., M.K., E.K.T.

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References

1. Lim KB, Schiano TD. Long-term outcome after liver transplantation. *Mt Sinai J Med* 2012;79:169-89.
2. Burra P, De Bona M. Quality of life following organ transplantation. *Transplant Int* 2007;20:397-409.
3. No authors listed. The World Health Organization Quality of Life Assessment (WHOQOL): Position paper from the World Health Organization. *Soc Sci Med* 1995;41:1403-9.
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;24:1199-220.
5. KINDL questionnaire. (<http://www.kindl.org>).
6. 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.
7. Rajmil L, Serra-Sutton V, Fernandez-Lopez JA, et al. The Spanish version of the German health-related quality of life questionnaire for children and adolescents: The Kindl. *An Pediatr (Barc)* 2004;60:514-21.
8. Eser E, Yüksel H, Baydur H, et al. The psychometric properties of the new Turkish generic health-related quality of life questionnaire for children (Kid-KINDL). *Turk J Psikiyatri Derg* 2008;19:409-17.
9. 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;14:1193-200.
10. Kayler LK, Merion RM, Lee S, et al. Long-term survival after liver transplantation in children with metabolic disorders. *Pediatr Transplant* 2002;6:295-300.
11. Cole CR, Bucuvalas JC, Hornung RW, et al. Impact of liver transplantation on HRQOL in children less than 5 years old. *Pediatr Transplant* 2004;8:222-7.
12. Avitzur Y, De Luca E, Cantos M, et al. Health status ten years after pediatric liver transplantation-looking beyond the graft. *Transplantation* 2004;78:566-73.
13. Tarter RE, Switala J, Arria A, Plail J, Van Thiel D. Quality of life before and after orthotopic hepatic transplantation. *Arch Intern Med* 1991;151:1521-6.
14. Olausson B, Utbult Y, Hansson S, et al. Transplanted children's experiences of daily living: Children's narratives about their lives following transplantation. *Pediatr Transplant* 2006;10:575-85.
15. Bucuvalas JC, Ryckman FC. Long term outcome after liver transplantation in children. *Pediatr Transplant* 2002;6:30-6.
16. Balaska A, Moustaffellos P, Gourgiotis S, et al. Changes in health-related quality of life in Greek adult patients 1 year after successful renal transplantation. *Exp Clin Transplant* 2006;2:521-4.
17. Kong IL, Molassiotis A. Quality of life, coping and concerns in Chinese patients after renal transplantation. *Int J Nurs Stud* 1999;36:313-22.
18. Eiser C, Morse R. Quality-of-life measures in chronic diseases of childhood. *Health Technol Assess* 2001;5:1-157.
19. Czyzewski DI, Mariotto MJ, Bartholomew LK, LeCompte SH, Sockrider MM. Measurement of quality of well being in a child and adolescent cystic fibrosis population. *Med Care* 1994;32:965-72.
20. 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;72:302-7.
21. 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;94:2090-106.