

# The association of family functions in families of children who undergo organ transplantation: the quality of life of the children and their families.

Mehmet Emin DÜKEN<sup>1\*)</sup>, Emriye Hilal YAYAN<sup>2</sup>

Published online: 07 June 2023.

## Abstract

**Aim:** Family functioning and quality of life are related. This study was to examine the association of family functioning in families of children/adolescents who had undergone organ transplantation and the quality of life of these children/adolescents and their parents. **Methods:** This descriptive cross-sectional study collected research data using the following tools: Child Information Form, Parent Information Form, Pediatric Quality of Life Questionnaire, Parent Quality of Life Assessment Scale, and Family Assessment Device. **Results:** This study found that the quality of life mean scores of children and parents were low. There was a positive relationship between the general quality of life of children who underwent organ transplantation and their psychosocial quality of life and the quality of life of their parents. This study also found a negative relationship between the psychosocial quality of life of children who had undergone organ transplantation and the subdimensions of roles, affective responsiveness, behavioral control, and general family functioning. **Conclusion:** This study showed that the quality of life levels of children who have undergone organ transplantation and of their parents may be low and may be associated to each other, which may lead family functioning to be negative.

**Keywords:** children, family functions, organ transplantation, parents, quality of life

## INTRODUCTION

Organ transplantation is a medical procedure that is performed on a decision about the lack of function in certain organs which can only be solved by a medical treatment. Currently, there is no treatment option other than organ transplantation for chronic solid organ failure including heart, lung, kidney and pancreas; therefore, organ donation and transplantation continue to be relevant (Kaçmaz & Barlas, 2014). Solid organ transplantation is a lifesaving treatment for end-stage organ failure in children (Kikuchi & Kamibeppu, 2015).

In recent years, the development of technology and surgical procedures has increased the survival rate of children who have undergone organ transplantation (Kikuchi & Kamibeppu, 2015). Despite these higher survival rates subsequent to the transplant, there are still many children who live their entire lives with a chronic disease requiring lifelong immunosuppressive drug use; there are also restrictions on social and physical behaviors, and these children need to visit the hospital regularly for their disease-related care (Cousino, Rea, Schumacher, Magee, & Fredericks, 2017). Today, the gradual increase in chronic diseases and prolonged life expectancy have called attention to the concept of the quality of life (Durualp, Kara, Yılmaz, & Alaybeyoğlu, 2010). Children with chronic diseases not only try to cope with the symptoms of disease, but they also experience social, psychological, developmental and environmental problems in relation to a number of factors and the course of the disease (Er, 2006). Physical and mental limitations and disabilities caused by chronic diseases reduce the independence of individuals result in the requirement of long-term care, and restrict their social activities (Durualp et al., 2010).

Family, as the smallest coherent unit of society, plays an important role in human life in various ways. Having life satisfaction, fulfilling family necessities, and being a part of society are initially provided within the family context (Tütüncüoğlu & Balkan, 2013). When any family member

<sup>1\*)</sup> Harran University, Şanlıurfa, Turkey

<sup>2</sup> University and Country: İnönü University, Malatya, Turkey

*\*) corresponding author*

Mehmet Emin DÜKEN

Harran University, Şanlıurfa, Turkey-63000  
Faculty and Department: Health Sciences of Faculty-  
Department of Child Health and Diseases Nursing  
Telephone: + (90)535 0832643  
Fax: + (90) 422 3410219  
E-mail: emin.duken@inonu.edu.tr  
E-mail: eminduken@gmail.com

suffers from a disease or there is uncertainty about the health and well-being of a family member, all family members will experience a variety of changes in their lives (Fazlıoğlu, Hocaoğlu, & Sönmez, 2010). The symptoms of chronic diseases in children may create several burdens on families due to the need for treatment management, the course of the disease, daily activity limitation, and long-term disease experience (Özdemir & Taşçı, 2013). Also, the diagnosis of chronic disease in a child can lead to psychological and psychosocial risks for parents and other family members in the long term (Fazlıoğlu et al., 2010). Chronic illnesses bring financial, social, emotional, behavioral, and cognitive changes to family life (Blackman, Gurka, Gurka, & Oliver, 2011). A previous study found that the daily routines and activities and adaptation of parents with children with a chronic disease were disrupted, and their family functions became impaired (Mishra et al., 2015). On the other hand, a study on the comparison of the children with a chronic disease with healthy children and their parents reported that the trait and state anxiety and depression levels of children with a chronic disease and their parents were higher. Moreover, it was found that there was a deterioration in the fulfillment of roles, affective responsiveness, affective involvement, and behavioral control in the family functions of parents having children with chronic diseases (Çakaloz & Kurul, 2005).

Transplantation can be regarded as a chronic disease that requires medical care for those who undergo it. The quality of life of parents is shaped by many changes and new responsibilities: hospital visits to their children, the necessity to provide daily care, fear of organ rejection, side effects of immunosuppressive agents, and risk of infection through treatment with immunosuppressive drugs (VickyLee Ng & Otle, 2008). Further considerations include the burden of medical financial expenses, specialized nutrition, medical care, the inability to spend time with and provide care and emotional support for other children, having limited leisure time, quitting a job, and lack of psychosocial support from family environment (Alonso et al., 2008; Kikuchi et al., 2015; Kikuchi & Kamibepu, 2015; Zhang et al., 2014).

These children fear academic failure, social isolation, can have a low sense of self, and experience absenteeism, grade repetition, psychiatric disorders, learning disorders, a failure to thrive, and insufficient social support (Karayurt, Ordin, Ünek, & Astarçioğlu, 2015). Rosenow et al. found that young patients reported a high level of anxiety, depression, physical, emotional, and family problems after transplantation (Rosenow & Silverman, 2014). Evans et al. reported that growth retardation was common in pediatric liver transplant recipients (Evans et al., 2005). Posfay-Barbe et al. concluded that children show developmental deficits and motor skills impairment following the liver transplantation (Posfay-Barbe, Barbe, Wetterwald, Belli, & McLin, 2013). Other researchers found that after undergoing liver transplantation, pediatric patients suffered from anxiety, anxiousness, nervousness, obesity, and impaired concentration compared with their healthy peers; however, their academic performance changed despite showing no significant difference in their mean depression scores, and displaying a high adaptation to immunosuppressive therapy (Karayurt et al., 2015). Sanchez et al. found that compared with the general population, pediatric liver transplant recipients had lower quality of life scores for general health perceptions, and in the physical and psychosocial domains (Sanchez, Eymann, De Cunto, & D'Agostino, 2010). A study conducted by Denny (2012) found a direct relationship between the quality of life of parents of pediatric liver transplant recipients and their family functioning. Pediatric

transplantation may reduce parents' quality of life by disrupting family routines and family roles (Denny et al., 2012). A study conducted by Taylor in 2009 suggested that health-related quality of life decreases in children and adolescents after liver transplantation compared to the general population, but like those with other chronic illnesses (Taylor, Franck, Gibson, Donaldson, & Dhawan, 2009). Because the number of pediatric organ transplant recipients is low, there is insufficient evidence to evaluate statistically the success of medical interventions, improvements clinical decision making, assess the changes health-related quality of life, satisfy population needs, and to evaluate health outcomes.

**Purpose of the Study:** This study was to examine the association of family functioning in families of children/adolescents who had undergone organ transplantation and the quality of life of these children/adolescents and their parents.

## MATERIALS AND METHODS

### Study Design and Sample

This study was planned as a descriptive, cross-sectional research. It was conducted in the polyclinics of Inonu University Liver Transplantation Institute between June 1, 2017 and January 24, 2018. The universe of the study consisted of all children whose ages were between 8 and 18 years. No sampling method was used, and the entire universe was included in the study. The inclusion criteria were as follows: children who underwent transplantation surgery one year prior to the study, did not have any chronic disease, did not have any complications during the study, and who did not have any psychiatric problems. A total of 77 children met the inclusion criteria of the study, and of them, 74 children agreed to participate in this study and constituted the study sample.

### Data Collection

After the clinic and ethics committee approvals were obtained for the study, a suitable environment was designated in the outpatient clinic for children and their parents who agreed to participate in the study. After the participants were informed about the scales, the data were collected from children using the Pediatric Quality of Life Questionnaire-PedsQL. Afterwards, the data were collected from the parents using the Family Assessment Device and EUROHIS (WHOQOL-8) Scale, which took 35 minutes.

### Data Collection Tools

Child Information Form, Parent Information Form, Pediatric Quality of Life Questionnaire, Family Assessment Device, and EUROHIS (WHOQOL-8) Scale were used to collect research data.

### Child Information Form

This form was created by the researchers based on the relevant literature. This form consists of 13 questions about age, sex, education, and other relevant socioeconomic details (Fredericks, Lopez, Magee, Shieck, & Opipari-Arrigan, 2007; Limbers et al., 2011; Vicky Ng et al., 2012).

### Parent Information Form

This form was created by researchers based on the relevant literature. This form consists of 11 questions about age, sex, education, profession, and other relevant socioeconomic details (Fredericks et al., 2007; Limbers et al., 2011; Vicky Ng et al., 2012).

### Pediatric Quality of Life Questionnaire (PedsQL)

PedsQL is a scale which was created by Varni et al. to assess the quality of life in children and adolescents who are aged between 2 and 18 years (Varni, Seid, & Kurtin, 2001; Varni, Seid, & Rode, 1999). The validity and reliability study of PedsQL for the age range of 8 to 18 was conducted by Çakın Memik et al. The Cronbach's alpha coefficients obtained were found to vary between 0.80 and 0.88. This study found that the Cronbach's alpha coefficients varied between 0.82 and 0.87. The pediatric quality of life questionnaire was assessed in four domains: physical functioning, emotional functioning, social functioning, and school functioning. Scoring was done in three parts: (1) total scale score (TSS), (2) physical well-being total score (PhWTS), and (3) the psychosocial well-being total score (PsWTS) were calculated through the item scores of emotional, social, and school functioning. Each item was scored between 0 and 100. The scale has five Likert response options: 'never', 'almost never', 'sometimes', 'often' and 'almost always' (corresponding to scores of 100, 75, 50, 25 and 0, respectively). Higher scores indicate better health-related quality of life (Memik, Ağaoğlu, Coşkun, & Karakay, 2008; Memik, Ağaoğlu, Coşkun, Üneri, & Karakaya, 2007).

### Family Assessment Device

The Family Assessment Device (FAD) was designed to assess several dimensions of family functioning. The FAD consists of seven scales: six scales assess the six dimensions of the McMaster Model of Family Functioning, and the seventh scale measures general family functioning. The FAD includes the subdimensions of problem solving, communication, roles, affective responsiveness, affective involvement, behavioral control, and general family functioning. The measure includes 60 statements. The FAD utilizes a 4-point Likert scale with options "strongly agree," "agree," "disagree," and "strongly disagree" (Bulut I., 1990).

### EUROHIS (WHOQOL-8) Scale

The World Health Organization Quality of Life Assessment Scale WHOQOL-Tr 8 (WHOQOL-Tr 8) is an index measure produced by selecting 8 items from the core WHOQOL-Brief and WHOQOL-100 scales (Eser et al., 2010).

### Data Analysis

The study data were analyzed using IBM SPSS Statistics version 22.0 software. Correlations, the Kruskal-Wallis test, and Student's *t*-test were used for statistical analysis.

## RESULTS AND DISCUSSION

The mean ages of the parents and children participated in this study were 37.55±7.20 years and 12.62±2.87 years, respectively.

The mean of the total quality of life scale for the children was 47.28±12.18. Among the subscales of Pediatric Quality of Life Questionnaire, the mean PhWTS was 48.52±16.47, the mean PsWTS was 38.21±13.42. The mean score of the parent quality of life questionnaire was 33.01±18.23. The problem solving, communication, and roles subscale mean scores of Family Assessment Device were 3.14±0.70, 2.84±0.50, and 2.80±0.42, respectively. In addition, the mean scores of affective responsiveness, affective involvement, behavioral control, and general family functioning subscales were 2.86±0.58, 2.54±0.30, 2.84±0.35, and 2.74±0.53, respectively; all these qualities were above the cut-off point of 2, the "risky" value.

No significant differences were found between the mean scores of the pediatric quality of life questionnaire and its subdimensions in terms of sex of the children who underwent organ transplantation and the transplantation type. A significant difference was found between the mean PsWTS scores of child age groups ( $p<0.001$ ). This study found that the quality of life of the pediatric recipients of cadaveric donor transplants were high, and there was a significant difference between the mean scores of quality of life TSS and PhWTS ( $p<0.005$ ). This study also found that the mean score of quality of life of the pediatric organ transplant recipients who attended the school after transplantation was higher compared to that of the recipients who did not attend the school. A significant difference was found between the mean scores of quality of life TSS and PsWTS for the school attendance after the transplantation ( $p<0.005$ ) (Table 1).

This study found that eight- to 12-year-old male pediatric recipients of cadaveric donor transplants who continued to attend school and whose parents were high school graduates had higher quality of life scores. The quality of life scores of male children were higher than those of female children. Also, the quality of life of children aged eight to 12 was higher than that of the 13-18 age group. The children who received cadaveric donor transplants and those with continuing post-transplant school life had higher quality of life scores. In general, children's quality of life scores were lower when their parents have low education levels. It was concluded that the sex and age group of pediatric recipients of organ transplant, transplantation type, and parent's educational level did not play a determinant role in the mean score of quality of life of the parents. A significant difference was found between the quality of life of the parents in terms of school attendance after the transplantation, quality of life of the parents whose children regularly attended the school had higher mean scores for quality of life ( $p<0.005$ ) (Table 2).

No significant difference was found between the mean scores of the family assessment device and its subdimensions in terms of the sex and age group of pediatric recipients of organ transplant, transplantation type, and their school attendance after the transplantation. Significant differences were found between parent's educational level and the mean scores of the subdimensions of family assessment device such as problem solving, communication, affective responsiveness, and general family functioning ( $p<0.005$ ). The mean scores of the subdimensions of the family assessment device were higher than the risky cut-off point of 2 (Table 3).

The relationships between the pediatric quality of life questionnaire, parent quality of life questionnaire, and family assessment device were examined. This study found a positive relationship between the TSS ( $r:0.392$   $p:0.004$ ) and PsWTS ( $r:0.345$   $p:0.011$ ) subdimensions of the Pediatric Quality of Life Questionnaire and the EUROHIS (WHOQOL-8) Scale. A negative relationship was found between PsWTS

subdimension of the Pediatric Quality of Life Questionnaire and the roles ( $r:-0.297$ ,  $p:0.031$ ), affective responsiveness ( $r:-0.281$ ,  $p:0.042$ ), behavioral control ( $r:-0.320$ ,  $p:0.020$ ) and general family functioning ( $r:-0.340$ ,  $p:0.013$ ) subdimensions of family assessment scale, which shows that lower QOL levels in children are associated with lower levels of family functioning. This study also found a negative relationship between the quality of life of parents and the

roles ( $r:-0.297$ ,  $p:0.031$ ), affective responsiveness ( $r:-0.277$ ,  $p:0.045$ ), behavioral control ( $r:-0.291$ ,  $p:0.035$ ) and general family functioning ( $r:-0.284$ ,  $p:0.039$ ) subdimensions of the family assessment scale; and as the quality of life of the parents increases, the family functions will improve. The mean scores higher than 2 in the family assessment scale indicated that the family functions were poor (Table 4).

**Table 1.**  
**The Comparison of Some Demographic Characteristics of Children and the Mean Scores of Pediatric Quality of Life Questionnaire and its Sub-Dimensions**

Descriptive Characteristics		TTS	PhWTS	PsWTS
<b>Sex</b>	Male (42)	47.22±11.65	48.14±16.40	36.61±11.87
	Female (32)	47.34±12.95	48.91±16.86	39.86±14.92
	Test value	0.035	0.169	0.880
	P value	0.972	0.867	0.383
<b>Age group</b>	8-12 (34 )	48.64±10.96	50.65±13.38	47.56±11.53
	13-18 ( 39)	46.15±13.19	46.76±18.70	30.46±9.39
	Test Value	0.736	0.852	5.951
	P Value	0.465	0.398	<b>0.000</b>
<b>Type of Transplantation</b>	Living donor (61)	44.50±10.60	37.30±11.73	45.65±16.97
	Cadaveric donor (13)	53.15±13.51	40.13±16.69	54.59±13.93
	Test value	191.500	201.500	286.000
	P value	<b>0.029</b>	<b>0.046</b>	0.703
<b>School attendance after transplantation</b>	Always (17)	54.18±9.25	53.67±8.57	45.33±12.34
	Often (27)	46.14±11.98	47.50±14.74	35.90±14.43
	Never (30)	41.37±12.19	44.33±23.16	33.52±10.50
	Test value	5.506	1.409	4.097
	P value	<b>0.007</b>	0.254	<b>0.023</b>

**Table 2.**  
**The Comparison of Mean Scores of Some Demographic Characteristics of Children and Parent Quality of Life Questionnaire**

Descriptive Characteristics	Parent Quality of Life Questionnaire	
<b>Sex</b>	Male	33.13±17.66
	Female	32.87±19.09
	Test value	0.072
	P value	0.943
<b>Age group</b>	8-12	37.37±20.71
	13-18	35.82±18.07
	Test value	1.377
	P value	0.254
<b>Type of transplantation</b>	Living donor	33.59±19.37
	Cadaveric donor	42.83±17.73
	Test value	219.000
	P value	0.097
<b>School attendance after transplantation</b>	Always	44.48±15.52
	Often	31.71±18.31
	Never	30.44±17.94
	Test value	4.302
	P value	<b>0.016</b>
<b>Parent' s educational status</b>	Literate	34.28±15.94
	Primary school	30.02±19.11
	Secondary school	33.89±14.70
	High school	39.84±23.76
	Test value	1.040
	P value	0.378

**Table 3: The Comparison of Mean Scores of Some Demographic Characteristics of Children and the Family Assessment Device**

	Problem-solving	Communication	Roles	Affective responsiveness	Affective involvement	Behavioral control	General family functioning	
Sex	Male	3.24±0.68	2.88±0.50	2.85±0.43	2.93±0.52	2.52±0.27	2.88±0.37	2.80±0.53
	Female	3.02±0.71	2.79±0.49	2.74±0.41	2.78±0.64	2.57±0.33	2.79±0.33	2.66±0.54
	Test value	1.557	0.947	1.367	1.314	0.931	1.251	1.315
	P value	0.123	0.346	0.175	0.192	0.354	0.214	0.191
Age group	8-12	3.04±0.69	2.77±0.48	2.76±0.39	2.75±0.55	2.65±0.32	2.77±0.36	2.67±0.53
	13-18	3.36±0.60	2.95±0.43	2.82±0.36	2.99±0.45	2.47±0.27	2.93±0.35	2.84±0.48
	Test value	1.331	0.617	0.133	0.769	1.576	0.907	0.581
	P value	0.269	0.605	0.940	0.514	0.200	0.441	0.629
Type of Transplantation	Living donor	3.31±0.60	2.93±0.44	2.82±0.36	2.94±0.51	2.55±0.28	2.87±0.36	2.84±0.45
	Deceased donor	3.00±0.74	2.73±0.48	2.72±0.39	2.74±0.50	2.57±0.36	2.83±0.36	2.58±0.57
	Test value	229.000	230.500	259.000	233.500	305.500	287.500	214.000
	P value	0.138	0.147	0.365	0.158	0.992	0.722	0.078
School attendance after transplantation	Always	2.95±0.73	2.68±0.51	2.65±0.49	2.70±0.51	2.49±0.33	2.75±0.35	2.53±0.54
	Sometimes	3.18±0.59	2.85±0.42	2.75±0.26	2.82±0.43	2.52±0.18	2.86±0.32	2.69±0.42
	Never	3.18±0.74	2.88±0.52	2.86±0.45	2.93±0.64	2.57±0.33	2.85±0.37	2.81±0.57
	Test value	0.755	1.080	1.956	1.170	0.516	0.649	1.983
Parent's education status	P value	0.473	0.343	0.147	0.314	0.599	0.525	0.143
	Literate	3.28±0.70	2.96±0.48	2.87±0.39	3.03±0.52	2.54±0.32	2.89±0.36	2.85±0.51
	Primary school	3.25±0.63	2.90±0.43	2.86±0.36	2.91±0.52	2.56±0.27	2.85±0.34	2.81±0.49
	Secondary school	2.75±0.60	2.61±0.39	2.61±0.43	2.50±0.48	2.58±0.32	2.64±0.31	2.42±0.37
Parent's education status	High school	2.76±0.86	2.52±0.69	2.59±0.60	2.59±0.80	2.45±0.34	2.82±0.41	2.47±0.72
	Test value	3.460	3.673	2.489	4.030	0.497	1.737	3.624
	P value	<b>0.019</b>	<b>0.015</b>	0.065	<b>0.009</b>	0.685	0.164	<b>0.016</b>

**Table 4: The Relations Between PedsQL, Parent Quality of Life Scale, and Family Assessment Device**

		TSS	PhWTS	PsWTS	PQoL
PQoL	r	<b>0.392**</b>	0.192	<b>0.345*</b>	
	p	<b>0.004</b>	0.169	<b>0.011</b>	
FAD					
Problem solving	r	-0.080	0.014	-0.269	-0.245
	p	0.570	0.922	0.051	0.077
Communication	r	-0.082	0.057	-0.257	-0.213
	p	0.559	0.687	0.063	0.126
Roles	r	-0.212	-0.025	<b>-0.297*</b>	<b>-0.297*</b>
	p	0.127	0.860	<b>0.031</b>	<b>0.031</b>
Affective responsiveness	r	-0.081	0.074	<b>-0.281*</b>	<b>-0.277*</b>
	p	0.566	0.596	<b>0.042</b>	<b>0.045</b>
Affective involvement	r	-0.019	0.156	0.082	-0.082
	p	0.892	0.265	0.559	0.561
Behavioral control	r	-0.205	-0.114	<b>-0.320*</b>	<b>-0.291*</b>
	p	0.142	0.415	<b>0.020</b>	<b>0.035</b>
General family functioning	r	-0.180	0.016	<b>-0.340*</b>	<b>-0.284*</b>
	p	0.197	0.912	<b>0.013</b>	<b>0.039</b>

\*\* Correlation is significant at the 0.01 level (2- tailed)

\*Correlation is significant at the 0.05 level (2- tailed)

## DISCUSSIONS OF FINDINGS

Organ transplantation is the only treatment option for children with acute or end-stage chronic organ failure (Baştürk et al., 2017). After organ transplantation, the lifelong necessity of receiving immunosuppressive drug therapy, side effects of drugs, and regular hospital visits lower the child's quality of life. Being always with their

child, caring for them, and lacking social support may reduce parents' quality of life and contribute to lower levels of family functioning. (Özşaker, 2014). The present study found that the quality of life of children who have organ transplantation and their parents are low, and there is a positive relationship between quality of life and family functions.

This study found that the mean health-related quality of life scores were lower in children and parents. Studies on quality of life which assessed children after 5 or 10 years had passed after organ transplantation surgery reported that the pediatric quality of life was only at a moderate level (Fredericks et al., 2007; Limbers et al., 2011). A study conducted by Vicky et al. (2012) in the US and Canada in 2012 to assess the health-related quality of life of children alive 10 years after pediatric liver transplantation found lower patient self-reported total scale scores for 10-year survivors compared with matched healthy children (Vicky Ng et al., 2012). Studies in the literature usually compared the mean scores of health-related quality of life of pediatric organ transplant recipients and their parents with the mean scores of the children with chronic diseases, and it was found that the mean scores of health-related quality of life showed similarities (Fredericks et al., 2007; Limbers et al., 2011). A study conducted by Bucuvalas found that the health-related quality of life in pediatric liver transplant recipients was lower than the one reported for healthy children although the mean scores of health-related quality of life in pediatric liver transplant recipients were high (Bucuvalas, 2003). In the present study, the mean quality of life scores of children and parents were lower than those reported in the literature. The present study was conducted within the earlier period after transplantation, which might have shaped the results. The findings of the present study showed that the early quality of life of children who have organ transplantation and their parents are low and their levels of quality of life are associated with each other.

The present study found that family functions scores of the pediatric organ transplant recipients were poor. Studies conducted to examine family functions of the pediatric organ transplant recipients found deterioration in the family roles, affective responsiveness, affective involvement, and behavioral control (Altuğ, 2011). However, the present study found that the participants obtained poor scores in all subdimensions of family functions. A study conducted with other pediatric organ transplant recipients reported that deterioration found in family function was related to lower education status of the parents, their full-time employment, and biliary complications of children (Alonso et al., 2008). The present study found that the educational status of parents is an important factor of their family functions, and as the educational levels of parents increase, there may be deteriorations in their family functions.

The present study found that gender is not related to the quality of life of children and parents and their family functions. Similarly, studies in the literature showed that gender of the child does not play any role in quality of life of the children and parents and their family functions (Alonso et al., 2008; Altuğ, 2011; Bucuvalas, 2003).

The present study found that the children between 8 and 12 years of age had higher quality of life than the adolescents between 13 and 18 years of age; there was a significant difference among these groups in the psychosocial well-being domain. A qualitative study conducted by Fujita (2016) to assess the daily lives of preadolescents and adolescents who had organ transplantations showed that the preadolescents had fewer restrictions in their daily activities such as going to school, making friends, and participating in physical and social activities, compared to the adolescents (Fujita, 2016). In contrast with the present study, Haavisto found that adolescent organ transplant recipients had a better quality of life than pre-adolescents (Haavisto et al., 2013). The present study found that the children who were between 8 and 12 years old had better quality of life scores regarding

social life, school and affective terms than those who were between 13 and 18 years old. Therefore, the present study showed the need for examining the quality of life of children aged between 13 and 18 years.

Studies found that the quality of life of the pediatric recipients of cadaveric donor transplants was higher, and there was a significant difference between the mean scores of TTS and PhWTS for children. A study conducted by Taylor et al. (2009) with adolescents who had liver transplantation reported that the type of donors may be a factor within the physical and psychosocial health status of adolescents (Taylor et al., 2009). On the other hand, another study conducted by He et al. with children who had liver transplantation reported that the type of transplantation from living donors was significantly correlated to the quality of life of children (He et al., 2015). Another study conducted by Schulz et al. with the children who had undergone organ transplantation and their parents found that the pediatric recipients of cadaveric donor transplants and their parents had a better quality of life than the pediatric recipients of living donor transplants (Schulz et al., 2001). The present study found that the quality of life of the pediatric recipients of cadaveric donor transplants were better. This may be due to the fact that the living donors were family members.

The present study found that parents' educational status did not play any role in the quality life of children and their parents. A study conducted by Bucuvalas reported that parents' educational status was not associated with the physical well-being domain of their children, but it determined their psychosocial well-being domain (Bucuvalas, 2003). On the other hand, another study showed that the quality of life of children and parents increases with an increase in parents' education status (Posfay-Barbe et al., 2013). The finding of the present study revealed that as the educational levels of parents increase, their quality of life levels can increase, is important.

The present study found that children who always attended school after transplantation had higher quality of life scores and that there was a significant difference in their total scale scores and scores on psychosocial well-being. Parents whose children had always attended school had a higher quality of life at a statistically significant level. Studies in the literature conducted with pediatric organ transplant recipients indicated that children could not attend school after transplantation (Alonso et al., 2010; Gilmour, Sorensen, Anand, Yin, & Alonso, 2010; Haavisto et al., 2013; Karayurt, Ordin, Ünek, & Astarçioğlu, 2015; Ng et al., 2012; Ngo et al., 2011). However, it was not stated whether this situation was noteworthy regarding the level of the quality of life. The present study found that children who continue to attend school were had higher quality of life levels. This finding is important for children who had organ transplantation, and it indicated the importance of going to school.

The present study found significant negative correlations between parents' education status and problem solving, communication, affective responsiveness, and general family functioning. A study conducted by Alonso et al. with children who had organ transplantation and their parents found that as the educational levels of parents decreased, the roles subdimension of family functions deteriorated (Alonso et al., 2008). Another study conducted by Coşkun and Çelebioğlu with parents of children who had a chronic disease showed that parent's educational level was related only with the general family functioning which is included in the family functions (Coşkun & Çelebioğlu, 2013). On the other hand, a study

conducted by Karaman et al. on children with chronic disease and their parents found that the educational levels of parents were not associated with the family functions (Karaman, Durukan, & Kara, 2012). The present study found that the educational levels of parents is not necessarily related to the family functions and that the deteriorations in family functions decrease as the educational level increases.

The examination of the table regarding the relationship between the Pediatric Quality of Life Questionnaire-PedsQL, EUROHIS (WHOQOL-8) Scale and family assessment device scales showed that there was a positive relationship between the quality of life and psychosocial health domain of children and the quality of life of their parents. A negative relationship was found between the psychosocial health domain of children and the quality of life of parents and the roles, affective responsiveness, behavioral control and general family functioning subdimensions of family functions (Table 4). A study conducted to examine the quality of life of children with chronic disease and their parents found that there was a positive relationship between the quality of life of children and their parents (Üneri, Turgut, Öner, Bodur, & Rezaki, 2010). However, another study found a negative relationship between the quality of life of children with chronic disease and the family functions (Firat & Tuncay, 2014). The present study found that there is a relationship between the quality of life levels of children and their parents, which might involve family functions.

### Limitations

The study had some limitations. The most significant limitation of this cross-sectional study was that it could not be used to explain the relationship between the quality of life and family functions in terms of causality. Another limitation was that the center where the data were collected was a regional hospital to which children and parents who had different cultural characteristics were transferred. Cultural characteristics had a significant effect on the quality of life and family functions (Alonso et al., 2010a; Fredericks et al., 2007). The cultural characteristics of the children and their parents who agreed to participate in this study were not considered, and this was a significant limitation of this study.

### CONCLUSIONS AND RECOMMENDATIONS

This study found that the quality of life levels of children who have undergone organ transplantation and their parents may be low, which can cause several deteriorations in family functions. It was found that sex, age group, type of transplantation, and parent's education status were not associated with measures of the quality of life. This study also found that there was a relationship between family functions and the educational status of parents, and as the educational levels increase, the deteriorations in family functions may decrease. It was also found that as the quality of life and psychosocial well-being levels of children who have undergone organ transplantation increase, the quality of life of their parents may increase. This study showed that the roles, affective responsiveness, behavioral control, and general family functioning subdimensions of the family functions may improve as the psychosocial well-being levels of children with organ transplant experience and the quality of life levels of parents increase. The findings of this study showed that there is a relationship between the

quality of life and family functioning. It is suggested that future studies should be reviewed based on the causality between the quality of life and family functioning.

### Acknowledgment

There is no conflict of interest between authors in this research. No financial support was received from any company or institution in the survey.

### Ethical Principles of the Study

Official approval for the study was obtained from the Non-Invasive Clinical Research Ethics Committee of Inonu University Institute of Health Sciences. The aim of the study was explained to the children and their parents, and informed verbal and written consent was obtained from those who agreed to participate.

- \* Data collecting-Mehmet Emin DÜKEN
- \* Analyzing-Emriye Hilal YAYAN
- \* Abstract and Keyword- Mehmet Emin DÜKEN, Emriye Hilal YAYAN
- \* Introduction- Mehmet Emin DÜKEN, Emriye Hilal YAYAN
- \* Material and Methods- Mehmet Emin DÜKEN, Emriye Hilal YAYAN
- \* Results- Mehmet Emin DÜKEN, Emriye Hilal YAYAN
- \* Discussion & Conclusions- Mehmet Emin DÜKEN, Emriye Hilal YAYAN

### How Might This Information Affect Nursing Practice

This study found that the children's quality of life was clinically associated to that of their parents. The quality of life of the transferred children and their parents was also associated to their family functions. When pediatric nurses closely monitor the values, aims and health status of families give care to the children, they also support the family by individualizing care. Pediatric nurses ensure that families are assessed using an integrated approach by fusing the different components of care (Alonso et al., 2008; Cousino et al., 2017). The results of this study show that pediatric nurses should be aware that the quality of life and family functions of the transferred children and their parents are related and support families with these issues in clinics. In addition, nurses who work in pediatric clinics should consider sociodemographic characteristics when they plan caregiving. This study found that some sociodemographic characteristics of the children and their parents affected their quality of life and family functions.

### REFERENCES

- Alonso, E., Limbers, C. A., Neighbors, K., Martz, K., Bucuvalas, J. C., Webb, T., & Varni, J. W. (2010a). Cross-Sectional Analysis of Health-Related Quality of Life in Pediatric Liver Transplant Recipients. *The Journal of Pediatrics*, *156*(2), 270–276.e1. <http://doi.org/10.1016/j.jpeds.2009.08.048>
- Alonso, E., Neighbors, K., Barton, F. B., McDiarmid, S. V., Dunn, S. P., Mazariegos, G. V., ... Bucuvalas, J. C. (2008). Health-related quality of life and family function following

- pediatric liver transplantation. *Liver Transplantation*, 14(4), 460–468. <http://doi.org/10.1002/lt.21352>
- Altuğ, N. (2011). *Karaciğer Nakilli Çocukların ve Ailelerinin Yaşam Kalitesi/Yaşam Kalitesini Etkileyen Değişkenlerin Belirlenmesi*. Ege Üniversitesi, Hemşirelik Anabilim Dalı.
- Basturk, A., Yılmaz, A., Sayar, E., Dinchan, A., Aliosmanoglu, I., Erbis, H., ... Artan, R. (2017). Pediatric Liver Transplantation: Our Experiences. *The Eurasian Journal of Medicine*, 48(3), 209–212. <http://doi.org/10.5152/eurasianjmed.2016.0147>
- Blackman, J. A., Gurka, M. J., Gurka, K. K., & Oliver, M. N. (2011). Emotional, developmental and behavioural comorbidities of children with chronic health conditions. *Journal of Paediatrics and Child Health*, 47(10), 742–747. <http://doi.org/10.1111/j.1440-1754.2011.02044.x>
- Bucuvalas, J. (2003). Health-related quality of life in pediatric liver transplant recipients: A single-center study. *Liver Transplantation*, 9(1), 62–71. <http://doi.org/10.1053/jlts.2003.50012>
- Bulut I. (1990). *Aile Değerlendirme Ölçeği El Kitabı. Özgüzelik Matbaası*. Ankara.
- Çakaloğlu, B., & Kurul, S. (2005). Duchenne Muskuler Distrofili Çocukların Aile İşlevlerinin ve Annelerinde Depresyon ve Kaygı Düzeylerinin Araştırılması. *Klinik Psikiyatri*, 8, 24–30.
- Coşkun, D., & Çelebioğlu, A. (2013). *Fiziksel engelli çocuğu olan ebeveynlerde bakım yükünün ve aile işlevlerinin değerlendirilmesi*. Atatürk Üniversitesi.
- Cousino, M. K., Rea, K. E., Schumacher, K. R., Magee, J. C., & Fredericks, E. M. (2017). A systematic review of parent and family functioning in pediatric solid organ transplant populations. *Pediatric Transplantation*, 21(3), e12900. <http://doi.org/10.1111/petr.12900>
- Denny, B., Beyerle, K., Kienhuis, M., Cora, A., Gavidia-Payne, S., & Hardikar, W. (2012). New insights into family functioning and quality of life after pediatric liver transplantation. *Pediatric Transplantation*, 16(7), 711–715. <http://doi.org/10.1111/j.1399-3046.2012.01738.x>
- Durualp, E., Kara, F. N., Yılmaz, V., & Alaybeyoğlu, K. (2010). Kronik Hastalığı Olan ve Olmayan Çocukların ve Ebeveynlerinin Görüşlerine Göre Yaşam Kalitelerinin Karşılaştırılması. *Ankara Üniversitesi Tıp Fakültesi Mecmuası*, 63(2), 55–63.
- Er, M. (2006). Çocuk, hastalık, anne-babalar ve kardeşler. *Çocuk Sağlığı ve Hastalıkları Dergisi*, 49, 155–168.
- Eser, E., Lağarlı, T., Baydur, H., Akkurt, V., Akkuş, H., Arslan, E., ... Vural, O. (2010). EUROHIS (WHOQOL-8. Tr) Türkçe Sürümünün Türk Toplumundaki Psikometrik Özellikleri. *Türkiye Halk Sağlığı Dergisi*, 8(3), 135–152. <http://doi.org/10.5421/tjph.v8i3.19>
- Evans, I. V. R., Belle, S. H., Wei, Y., Penovich, C., Ruppert, K., & Detre, K. M. (2005). Post-transplantation growth among pediatric recipients of liver transplantation. *Pediatric Transplantation*, 9(4), 480–485. <http://doi.org/10.1111/j.1399-3046.2005.00326.x>
- Fazlıoğlu, K., Hocaoğlu, Ç., & Sönmez, F. M. (2010). Çocukluk Çağı Epilepsisinin Aileye Etkisi. *Psikiyatride Güncel Yaklaşımlar*, 2(2), 190–205.
- Fırat, E., & Tuncay, T. (2014). *13-16 Yaş tip 1 diyabetli çocukların yaşam kalitesini etkileyen etmenlerin araştırılması*. Hacettepe Üniversitesi.
- Fredericks, E. M., Lopez, M. J., Magee, J. C., Shieck, V., & Opiari-Arrigan, L. (2007). Psychological Functioning, Nonadherence and Health Outcomes After Pediatric Liver Transplantation. *American Journal of Transplantation*, 7(8), 1974–1983. <http://doi.org/10.1111/j.1600-6143.2007.01878.x>
- Fujita, A. (2016). Daily lives of pre-adolescents/adolescents and their parents after liver transplant. *Japan Journal of Nursing Science*, 13(1), 10–19. <http://doi.org/10.1111/jjns.12078>
- Gilmour, S. M., Sorensen, L. G., Anand, R., Yin, W., & Alonso, E. M. (2010). School outcomes in children registered in the studies for pediatric liver transplant (SPLIT) consortium. *Liver Transplantation*, 16(9), 1041–1048. <http://doi.org/10.1002/lt.22120>
- Haavisto, A., Korkman, M., Sintonen, H., Holmberg, C., Jalanko, H., Lipsanen, J., & Qvist, E. (2013). Risk factors for impaired quality of life and psychosocial adjustment after pediatric heart, kidney, and liver transplantation. *Pediatric Transplantation*, 17(3), 256–265. <http://doi.org/10.1111/petr.12054>
- He, K., Shen, C., Chen, X., Han, L., Xi, Z., Zhou, T., ... Xia, Q. (2015). Health-related quality of life and sleep among Chinese children after living donor liver transplantation. *Pediatric Transplantation*, 19(5), 547–554. <http://doi.org/10.1111/petr.12532>
- Kacmaz, N., & Barlas, G. U. (2014). The Psychosocial Status Of Liver Transplant Patient And Their Relatives On The Effect Of Quality Of Life. *Journal of Psychiatric Nursing*, 5(1), 1–8. <http://doi.org/10.5505/phd.2014.98598>
- Karaman, D., Durukan, İ., & Kara, K. (2012). Dikkat Eksikliği Hiperaktivite Bozukluğu Olan Çocukların Aile İşlevleri ile Annelerinin Depresyon ve Anksiyete Belirti Düzeyleri. *TAF Preventive Medicine Bulletin*, 11(6), 741–748.
- Karayurt, Ö., Ordin, S., Ünek, T., & Astaroğlu, İ. (2015). No Title. *Experimental and Clinical Transplantation*, 13(3), 247–255. <http://doi.org/10.6002/ect.2014.0150>
- Kikuchi, R., & Kamibeppu, K. (2015). Parents' Quality of Life and Family Functioning in Pediatric Organ Transplantation. *Journal of Pediatric Nursing*, 30(3), 463–477. <http://doi.org/10.1016/j.pedn.2014.12.013>
- Kikuchi, R., Ono, M., Kinugawa, K., Endo, M., Mizuta, K., Urahashi, T., ... Kamibeppu, K. (2015). Health-related quality of life in parents of pediatric solid organ transplant recipients in Japan. *Pediatric Transplantation*, 19(3), 332–341. <http://doi.org/10.1111/petr.12435>
- Limbers, C. A., Neighbors, K., Martz, K., Bucuvalas, J. C., Webb, T., Varni, J. W., & Alonso, E. M. (2011). Health-related quality of life in pediatric liver transplant recipients compared with other chronic disease groups. *Pediatric*

- Transplantation*, 15(3), 245–253. <http://doi.org/10.1111/j.1399-3046.2010.01453.x>
- Memik, N. Ç., Ağaoğlu, B., Coşkun, A., & Karakay, I. (2008). Çocuklar için yaşam kalitesi ölçeğinin 8–12 yaş çocuk formunun geçerlik ve güvenilirliği. *Çocuk ve Ergen Ruh Sağlığı Dergisi*, 15, 87–98.
- Memik, N. Ç., Ağaoğlu, B., Coşkun, A., Üneri, Ö. Ş., & Karakaya, I. (2007). Çocuklar için Yaşam Kalitesi Ölçeğinin 13-18 Yaş Ergen Formunun Geçerlik ve Güvenilirliği. *Türk Psikiyatri Dergisi*, 18(4), 353–363.
- Mishra, K., Ramachandran, S., Firdaus, S., & Rath, B. (2015). The impact of pediatric nephrotic syndrome on parents' health-related quality of life and family functioning: An assessment made by the PedsQL 4.0 family impact module. *Saudi Journal of Kidney Diseases and Transplantation*, 26(2), 285. <http://doi.org/10.4103/1319-2442.152420>
- Ng, V., Alonso, E. M., Bucuvalas, J. C., Cohen, G., Limbers, C. A., Varni, J. W., ... Anand, R. (2012). Health Status of Children Alive 10 Years after Pediatric Liver Transplantation Performed in the US and Canada: Report of the Studies of Pediatric Liver Transplantation Experience. *The Journal of Pediatrics*, 160(5), 820–826.e3. <http://doi.org/10.1016/j.jpeds.2011.10.038>
- Ng, V., & Otley, A. R. (2008). Understanding quality of life for children after liver transplantation: A work in progress. *Liver Transplantation*, 14(4), 415–417. <http://doi.org/10.1002/lt.21430>
- Ngo, K. D., Farmer, D. G., McDiarmid, S. V., Artavia, K., Ament, M. E., Vargas, J., ... Venick, R. S. (2011). Pediatric health-related quality of life after intestinal transplantation. *Pediatric Transplantation*, 15(8), 849–854. <http://doi.org/10.1111/j.1399-3046.2011.01590.x>
- Özdemir, Ü., & Taşcı, S. (2013). Kronik hastalıklarda psikososyal sorunlar ve bakım. *Erciyes Üniversitesi Sağlık Bilimleri Fakültesi Dergisi*, 1(1), 57–72.
- Özşaker, E. (2014). Transplantation and Quality of Life. *Balkesir Health Sciences Journal*, 3(3), 166–173. <http://doi.org/10.5505/bsbd.2014.98598>
- Posfay-Barbe, K. M., Barbe, R. P., Wetterwald, R., Belli, D. C., & McLin, V. A. (2013). Parental functioning improves the developmental quotient of pediatric liver transplant recipients. *Pediatric Transplantation*, 17(4), 355–361. <http://doi.org/10.1111/petr.12080>
- Rosenow, S. C., & Silverman, M. J. (2014). Effects of single session music therapy on hospitalized patients recovering from a bone marrow transplant: Two studies. *The Arts in Psychotherapy*, 41(1), 65–70. <http://doi.org/10.1016/j.aip.2013.11.003>
- Sanchez, C., Eymann, A., De Cunto, C., & D'Agostino, D. (2010). Quality of life in pediatric liver transplantation in a single-center in South America. *Pediatric Transplantation*, 14(3), 332–336. <http://doi.org/10.1111/j.1399-3046.2009.01225.x>
- Schulz, K.-H., Hofmann, C., Sander, K., Edsen, S., Burdelski, M., & Rogiers, X. (2001). Comparison of quality of life and family stress in families of children with living-related liver transplants versus families of children who received a cadaveric liver. *Transplantation Proceedings*, 33(1–2), 1496–1497. [http://doi.org/10.1016/S0041-1345\(00\)02567-7](http://doi.org/10.1016/S0041-1345(00)02567-7)
- Taylor, R. M., Franck, L. S., Gibson, F., Donaldson, N., & Dhawan, A. (2009). Study of the Factors Affecting Health-Related Quality of Life in Adolescents After Liver Transplantation. *American Journal of Transplantation*, 9(5), 1179–1188. <http://doi.org/10.1111/j.1600-6143.2009.02604.x>
- Tütüncüoğlu, C., & Balkan, i. K. (2013). Diyabetli Çocuğu Olan Annelerin Aile İşlevlerinin ve Durumluk - Sürekli Kaygı Düzeylerinin incelenmesi. *Psikoloji Çalışmaları / Studies in Psychology*, 3(1), 17–39.
- Üneri, Ö. Ş., Turgut, S., Öner, P., Bodur, Ş., & Rezaki, B. (2010). Dikkat eksikliği hiperaktivite bozukluğu olan 8-12 yaş grubu çocuklarda yaşam kalitesi değerlendirilmesi. *Çocuk ve Gençlik Ruh Sağlığı Dergisi*, 17(1), 27–31.
- Varni, J. W., Seid, M., & Kurtin, P. S. (2001). PedsQL™ 4.0: Reliability and Validity of the Pediatric Quality of Life Inventory™ Version 4.0 Generic Core Scales in Healthy and Patient Populations. *Medical Care*, 39(8), 800–812.
- Varni, J. W., Seid, M., & Rode, C. A. (1999). The PedsQL™: Measurement Model for the Pediatric Quality of Life Inventory. *Medical Care*, 37(2), 126–139.
- Zhang, W. X., Wei, H., Shen, Z., Peng, X., Chen, X. G., Li, W., ... Niu, Y. J. (2014). Concerns Of and Coping Strategies by Parents Of Pediatric Liver Transplant Recipients: A Qualitative Study From China. *International Journal of Clinical and Experimental Medicine*, 7(12), 5723–5729

