

Health Related Quality of Life of Children Post Liver Transplantation versus Healthy Children

Magda M. Mohsen¹, Neanaa M. Fayed², Islam Ayoub³, Reda Elfeshawy⁴, Amany Gomaa⁵

Abstract:

Background: Health-related quality of life in pediatric organ transplant recipients has progressively become an area of concern as patient survival and graft survival rates continue to expand.

The aim of the present study was designed to assess the post liver-transplant health related quality of life versus healthy children.

Methodology: Design: A descriptive, cross sectional design was used.

Setting: The study was conducted in the pediatrics out-patient of National Liver Institute, Menoufia University-Egypt.

Sample: A purposive sample of forty child post liver transplantation was selected from the above mentioned setting. Also, a simple random sample of 40 healthy child from primary and secondary schools of Shebin El-Kom city were recruited.

Tools/ Instruments: a. structured interview questionnaire was utilized to collect biosocial characteristics of children and their parents and medical condition of children.

B. Child Health Questionnaire–Child Self-Report form CHQ-CF87 to assess health related quality of life (HRQoL).

Results: The mean age of liver transplanted Children were 10.77+₋ 4.73 years compared to 10.09 +- 3.54 years in the control group, 47.5% of children did liver transplantation due to biliary atresia. Also, there was a highly statistically. significant difference between study and control groups concerning health related quality of life total mean score.

Conclusion: Health related quality of life in a sample of pediatric liver transplant recipients were decreased compared with that of general population.

Recommendations: Strategies to improve the coordination of nursing assessment/monitoring and perioperative care for liver transplant` children may improve outcome for children and institute the efficacy of a health education program on decreasing post liver transplantation complications.

Keywords: Pediatric, Liver Transplantation, Health Related Quality of Life.

¹ Community Health Nursing, Menoufia University, Faculty of Nursing, Egypt

² Pediatric Nursing, Menoufia University, Faculty of Nursing, Egypt

³ Hepato-pancreatico-biliary surgery HPB, National Liver Institute, Faculty of Nursing, Egypt

⁴ Pediatric Nursing, Menoufia University, Faculty of Nursing, Egypt

⁵ Community Health Nursing Department, Fayoum University, Faculty of Nursing, Egypt

I. Introduction

Transplantation is one of the most complex areas of present therapies especially in children for the reason that their size, immune system, and the use of immunosuppressive strategies. That approaches improving the care of pediatric patients and graft survival rates significantly, but the long-term hazards of these therapeutic interventions stay poorly documented mainly because of deficiency of randomized clinical trials in pediatric patients [1].

Liver transplantation has the stock of care for the past three decades and been very effective in end – stage liver disease treatment in children that increase the opportunity for a long patient's survival. During this period of time, liver transplant pediatric recipients have aided from significant innovations in surgical procedures, organ procurement, pre- and postoperative medical management, and immunosuppression [2]. There are nearly 500 candidates on liver transplantations waitlist [3]. Children aged 1-5 years and 11 years or older made up the principal age groups, 30% each and followed by ages earlier than 1 year, 22.4% and 6-10 years, 14.6% [4]. Liver transplantation has improved survival rate and managing pathological disorders resistant to therapeutic interpolations with end-stage liver failure in pediatric population. In addition, it is considered as a treatment of choice [5,1]. Liver transplantation is commonly utilized as a treatment choice for children who have major complications related to end-stage chronic liver disease. Liver transplant can also be a treatment preference in rare condition of sudden liver failure [6].

The number of pediatric liver transplantation per year has remained stable in the last 10 years, averaging around 600 annually. Nearly 12,000 pediatric liver transplants have been implemented in the United States [7]. Live donor transplants have also decreased from a peak of 79 in 2015 to 62 in 2016 mostly from donors closely related to the recipients. Recipients earlier than 6 years old received 14% of liver from living donor [8]. Survival rates have been described to be improved from 70% at 1 year to 87% with 5 years survival rates of 67 to 80% after transplantation for acute liver failure [9]. Long-term survival rates described between 85% and 90% at this period [10].

The success of organ transplantation can be assessed not only in relation to allograft and survival rates but also by the capability of transplantation to return an optimal quality of life [1]. Longitudinal growth offers a main influence to child's quality of life, as it is identified that growth failure, pubertal delay and short stature have extensive impact on self – esteem and psychosocial development [11].

Evaluations of Health Related Quality of Life (HRQoL) post liver transplantation in pediatrics are one of the key attentions of numerous studies. It is imperious to note that children who have transplantation facing a set of conditions; a threatening liver illness, the transplant operation and the post-transplant support; as a result, children and families facing a long-standing stressful procedures that may impact quality of their life [5]. Independent of the capability to return to normal social life, growing, and living with the memory of a life – threatening disease remains inspiring. Most of researches on HRQoL after pediatric liver transplantation have been compared samples of pediatric liver transplantation to healthy children rather than to harmonized controls chronically ill pediatric patients. It has been proposed that pediatric liver transplantation recipients report a poorer HRQoL compared to healthy [12].

Health Related Quality of Life (HRQoL) is a multidimensional construct including a patient's physical, social, and emotional well-being assessed generally and specifically as impacted by a specific chronic illness or condition[13].Health Related Quality of Life (HRQoL) involves assessments of physical , psychosocial and functional dimensions but many researchers report only the incidence of surgical complications or the immediate effects of liver transplantation on HRQoL [14].

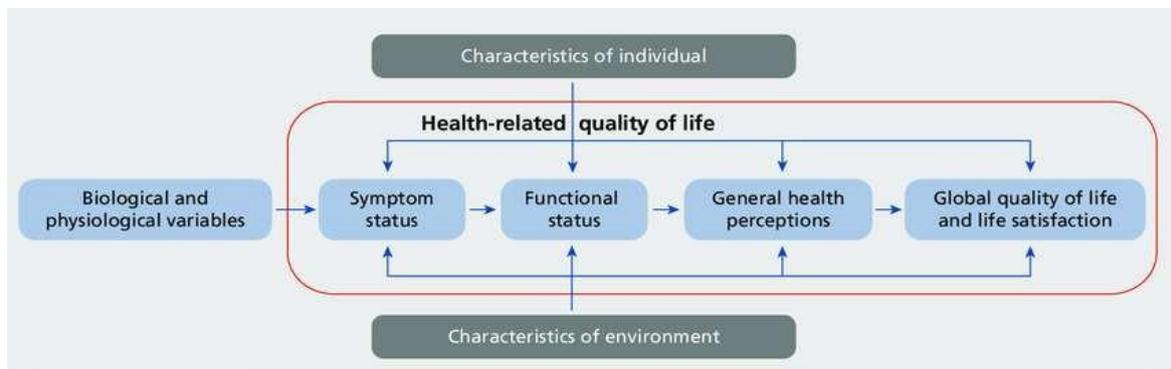


Figure (1):Conceptual model for health-related quality of life

Adapted from: Wilson IB, Cleary PD. Linking clinical variables with health-related quality of life, a conceptual model of patient outcomes.,*JAMA*. 1995; 273:59-65. [15].

The comparison between pediatric liver transplantation patients and healthy population may be valuable to understand effects of transplant process on HRQoL.Itcanpermit us to offer more clear expectations for the consequences after liver transplantation to pediatric patients, families, health care specialists and policy makers. Little is known about the effects of liver transplantation on HRQoL of children in Egypt[14].

Aim of the study

The present study was designed to assess post liver -transplant health related quality of life versus healthy children.

Research questions:

- 1- What is the quality of life of children post liver-transplantation?
- 2- What is the health related quality of life of normal/healthy children in the same age group?
- 3- Does children compliance with follow-up care affect their quality of life?

II. Subjects and Method:

Design:A descriptive, cross sectional design was used.

Setting: The study was done in the pediatrics out-patient of National Liver Institute, Menoufia University- Egypt.

Sample:two types of sample;

A) A purposive sample of forty child post liver transplantation was selected from the above mentioned setting.

Inclusion criteria:

- 1- Children aged 4-18 years.
- 2- At least 12 months following liver transplantation.
- 3- Children are conscious.

Exclusion criteria: Absence of other chronic diseases.

B) Simple random sample of 40 healthy children in the same age group were recruited for this study from primary and secondary schools of Shebin El-Kom.

Instrument of the study:

1: A structured interview questionnaire,it consists of three parts:

Part 1: It was developed by the researchers to gather data about social characteristics of children and their parents such as child's age, gender, academic year, parents' age, education, employment and their socioeconomic status.

Part 2: It included data about medical condition of children such as diagnosis, type of transplantation, period of disease, post transplantation period, any medication taken, associated problems and follow-up care.

Part 3 :Child Health Questionnaire-Child Self-report form CHQ-CF87:-

It was utilized to measure health-related quality of life (HRQOL) in children and adolescents aged 5–18 years. It was developed by [16] and adapted by the researchers. It based on WHO definition of health. This questionnaire contains child report (aged 10–18 years) and 2 versions of parent-proxy report of the child's HRQOL. It may be used with healthy children and children with acute or chronic health conditions. Child health questionnaire-child self-report form CHQ-CF87 is a valid instrument to assess post liver transplanted children health related quality of life in the previous studies [17].

Scoring system:

The items within the questionnaire domains contained three point Likert like scale.

Scale domains	Responses	Score	Levels
1-Health	-False	0	Poor: less than 50%
	-Don't know	1	Moderate :50%-65%
	-True	2	Good : more than 65%
2-Physical activities	-Verydifficult	0	Poor: less than 50%
	-Little difficult	1	Moderate :50%-65%
	-Not difficult	2	Good : more than 65%
3-Every day activities	-Verydifficult	0	Poor: less than 50%
	-Little difficult	1	Moderate :50%-65%

	-Not difficult	2	Good : more than 65%
4-Pain	-Severe	0	Poor: less than 50%
	-Moderate	1	Moderate :50%-65%
	-None	2	Good : more than 65%
5-Getting alone or behavior	-Very often	0	Poor: less than 50%
	-Sometimes	1	Moderate :50%-65%
	-Never	2	Good : more than 65%
6-General well-being	-Most of time	0	Poor: less than 50%
	-Some of time	1	Moderate :50%-65%
	-Little of time	2	Good : more than 65%
7-Self esteem	-Badly	0	Poor: less than 50%
	-Neither good or bad	1	Moderate :50%-65%
		2	Good : more than 65%
Total score of scale		0	Poor: less than 50%
		1	Moderate :50%-65%
		2	Good : more than 65%

It was modified to be suitable for study purpose. It contains seven domains which are health, physical activities, bodily pain, getting along/ behavior, general well-being and self-esteem. The completion of the CHQ is based on four week recall and takes 30-40 minutes to complete.

Procedure for Data collection:

- Data was gathered over a period of twelve months starting from October 2017 to October 2018.
- **Witten permission:**

An official permission to carry out the study was attained from the Dean of the Faculty of Nursing, El-Menoufia University clarifying the purpose of the study to the Director of the National Liver Institute of Menoufia Governorate.

- **Protection of human rights:**

The parents and their children were informed about the privacy of their data and it will be used for scientific research only, the study was voluntary, harmless, and nameless and confidentiality of answers should be respected. Parents and their children had the full right to refuse to participate in the study at any time. A formal consent was attained.

- **Validity assurance purpose:** Face validity is performed by five experts, in pediatric nursing and community health nursing.

- **Reliability of the instrument:** was done by applying the questionnaire to 8 children of the sample using Pearson Coefficient factor was 90.8 %. The instrument was applied to children and retested after two weeks.

- **A pilot study:** It was carried out on 8 children (10%) of the sample in the studied groups to test the clarity, practicability, simplicity of the study instrument and time required for data collection. No modifications were done as discovered from the pilot study. Children of the pilot study were not involved in the total sample to assure the constancy of the results.

- Children and their parents were separately interviewed by the researchers and the purpose of the study was clarified.

- Data collection was implemented four days a week during children and their parent's presence in the hospital for follow-up care. The two questionnaire used for data collection took about 30-40 minutes.

- Healthy children were individually interviewed in the schools at the end of the day or according to the appropriate time for children using a structured interview questionnaire and took about 30-40 minutes.

Limitation of study:

This descriptive study concerned a limited number of pediatric patients therefore; it would be of importance to approve these preliminary findings with a large multi-center prospective study.

III. Statistical Analysis:-

Data was organized and statistically analyzed by an IBM compatible personal computer with SPSS statistical package version 20. Number and percent were considered for qualitative data, mean (\bar{x}), standard deviation (SD) and range for quantitative data. Student's t- test was a test used for comparison between groups having quantitative variables. Mann-Whitney test (non-parametric test) is a test of significance used for comparison between two groups not normally distributed. P-value of (≤ 0.05) and (≤ 0.001) were considered statistically significant.

IV. Results

Table (1) revealed that there were no statistically significant differences between study and control groups as regarding mean age of children (10.77 ± 4.73) years versus 10.09 ± 3.54 years, respectively, where (student's t test = 0.73; $p=0.46$), sex ($\chi^2=0.21$; $p=0.64$), father's education ($\chi^2=4.13$; $p=0.38$).

Table (2) revealed that, 47.5% of children in the study group did liver transplantation due to biliary atresia and their time of transplantation ranged between 1 to 5 years, 42.5% of them had early postoperative complications and 55% of them received insufficient follow up visits

Figure (2): This figure illustrated that 47.5% of children in the study group has poor level of QOL total score while the minority (17.5 %) has good level of QOL total score

Table (3) revealed that there were statistically significant differences between health, physical activities, every day activities, pain, getting along, general well-being, self-esteem in the study and control groups ($p < 0.01$) respectively.

Figure (3): Distribution of studied groups regarding QOL domains and QOL Levels

It showed that 30% and 47.5 % of children have moderate level of health domain in the study and control groups respectively. Moreover , this figure illustrated that 10% and 32.5% of children have good level of physical activities in the study and control groups respectively.

Figure (4): Distribution of studied groups regarding self-esteem items and QOL Levels

This figure clarified that as regard to general well-being domain,47.5% and 87.5 % of children have good level in the study and control groups respectively.Also , this figure illustrated that 35% and 7.5% of children have poor level of self-esteem in the study and control groups respectively.

Figure (5): Levels of self-esteem between the study and control groups

This figure showed that the majority of children in the study group has moderate level of self-esteem while the minority of them has high level.

Table (4) revealed that there were highly statistically significant differences between study and control groups concerning levels of HRQoL ($p < 0.01$). Also, this table showed that there was highly statistically significant difference between study and control groups concerning HRQoL total mean score ($p < 0.01$).

Table (5)revealed that there were no statistically significant differences between children age, sex and their HRQoL total mean score ($p > 0.05$) in the study group. Also, the same table showed that there were statistically significant differences between mothers and father’s education, time of transplantation, post-operative complications, follow-up visits and children HRQoL ($p > 0.05$) in the study group.

Table (1): Demographic Characteristics of the Studied Groups

Demographic characteristics	Studied groups				test of significance	P value
	Study group (N=40)		Control group (N=40)			
	No.	%	No.	%		
Age (years):					Student’s t test =0.73	0.46 NS
Mean ±SD	10.77±4.73		10.09±3.54			
Range	3.00–16.00		3.00–18.00			
Sex:					χ^2 = 0.21	0.64 NS
Male	23	57.5	25	62.5		
Female	17	42.5	15	37.5		
Father's education:					χ^2 = 4.13	0.38 NS
Illiterate	4	10.0	3	7.5		
Primary	7	17.5	4	10.0		
Diploma	15	37.5	17	42.5		
Institute	3	7.5	6	15.0		
Bachelors	11	27.5	10	25.0		

Mother's education:						
Illiterate	6	15.0	5	12.5	χ^2 = 2.27	0.68 NS
Primary	7	17.5	3	7.5		
Diploma	12	30.0	13	32.5		
Institute	7	17.5	8	20.0		
Bachelors	8	20.0	11	27.5		

χ^2 = Chi square test t-test=Student's t test

Table (2): Distributions of Past and Present History of the Study group

Past and Present History	Study group (N=40)	
	No.	%
Indications of transplantation:		
Biliary atresia	19	47.5
Liver cirrhosis	10	25.0
Crigler Najjar type 1	4	10.0
PFICI (Byler's disease)	5	12.5
Budd chiari syndrome	2	5.0
Time of transplantation:		
less than one year	9	22.5
1 year to 5 years	19	47.5
More than 5 years	12	30.0
Postoperative complications:		
No	16	40.0
Early	17	42.5
Late	7	17.5
Follow up visits:		
Sufficient	18	45.0

Insufficient	22	55.0
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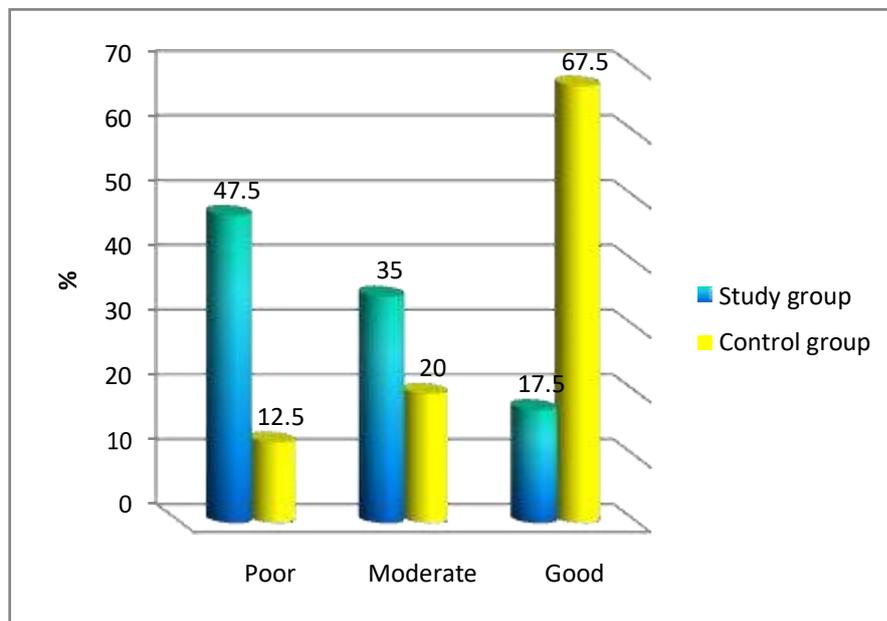


Figure (2): Distribution of QOL levels among the study and control groups

Table (3): Distribution of QOL' Domains among Study and Control Groups

QOL' Domains	Studied groups		t-test	P value
	Study group (N=40)	Control group (N=40)		
	Mean ±SD	Mean ±SD		
Health	4.20±1.43	6.42±1.75	6.21	<0.001 HS
Physical activities	4.45±1.07	6.10±1.44	3.06	0.003 S
Every day activities	3.05±1.01	4.45±1.41	3.74	<0.001 HS
Pain	3.30±0.97	2.15±1.38	U=4.30	<0.001 HS
Getting along	14.77±1.46	12.05±3.88	4.15	<0.001 HS
General well-being	9.75±2.81	10.92±1.79	2.18	0.02 S
Self- esteem	13.87±3.03	15.77±1.04	3.74	<0.001 HS

QOL Total Score:	51.70±10.65	59.12±5.76	3.87	<0.001
Range	31.00–66.00	42.00–68.00		HS

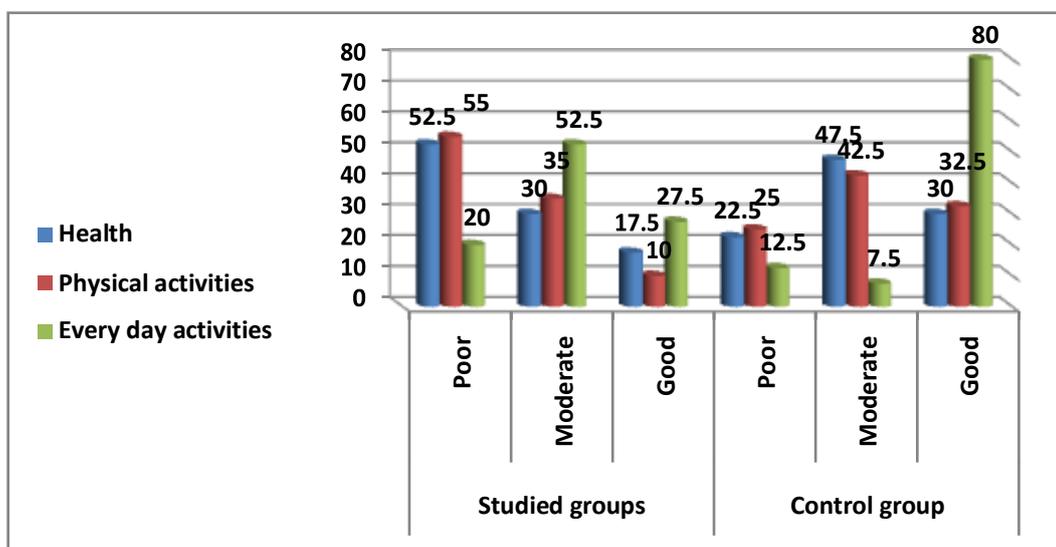


Figure (3): Distribution of Studied groups regarding QOL domains and QOL Levels

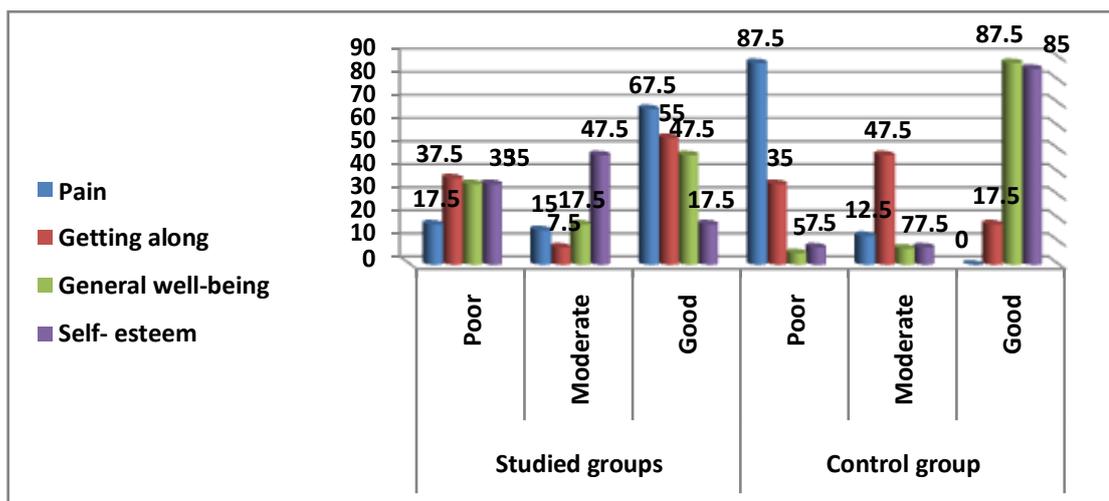


Figure (4): Distribution of Studied groups regarding self-esteem items and QOL Levels

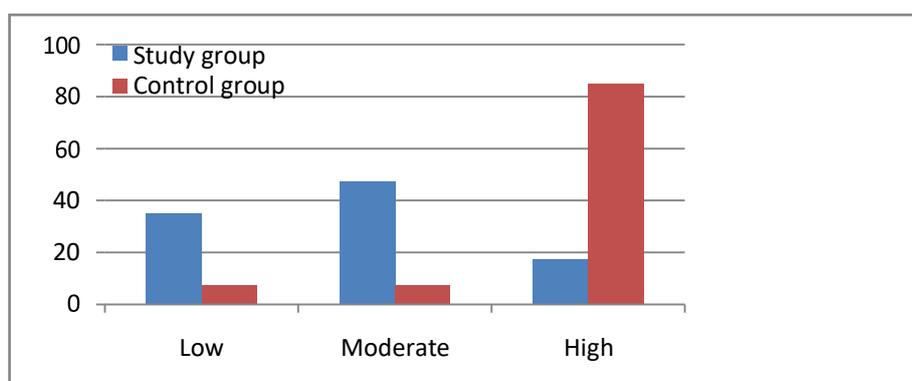


Figure (5): Levels of self-esteem between the study and control groups

Table (4): QOL Level and QOL Total Mean Score among the Studied Groups

QOL	Studied groups				χ^2 test	P value
	Study group (N=40)		Control group (N=40)			
	No.	%	No.	%		
<u>Levels of QOL:</u>						
Poor	19	47.5	5	12.5	21.57	<0.001 HS
Moderate	14	35.0	8	20.0		
Good	7	17.5	27	67.5		
<u>QOL Total Score:</u>						
Mean± SD	51.70±10.65		59.12±5.76		t=3.87	<0.001
Range	31.00–66.00		42.00–68.00			HS

Table (5): Relationship between demographic characteristics of study group and QOL total mean score

Demographic characteristics	Total Score (N=40)	Test of significance	P value
	Mean ±SD		
Age	r= 0.22	Spearman's rho	0.19 NS
Sex:			0.18
Male	53.44±8.89	t=1.34	NS
Female	48.80±12.89		
Father's education :			
Illiterate	47.73±7.82	F test= 4.51	0.02 S
Primary	49.73±10.71		
Diploma	50.82±11.09		
Institute	53.82±7.22		
Bachelors	58.91±11.91		

Mother's education :			
Illiterate	47.40±6.76	F test= 3.16	0.03 S
Primary	47.66±12.18		
Diploma	49.89±9.80		
Institute	55.90±10.18		
Bachelors	56.33±2.30		
Time of transplantation:			
less than one year	47.77±11.68	K test= 3.14	0.04 S
1 year to 5 years	49.81±10.57		
More than 5 years	58.02±9.22		
Postoperative complications:			
No	57.74±8.77	K test= 3.55	0.03 S
Early	50.84±10.93		
Late	47.08±9.16		
Follow up visits:			
Sufficient	54.92±11.19	t= 2.10	0.04 S
Insufficient	47.95±9.81		

F= Anova test

K: Kruskal Wallis test

V. Discussion

Liver transplantation is arecognized therapy for irreversible acute and chronic liver disease. It has dramatically improved the prognosis of children with liver failure. Health Related Quality of Life (HRQOL) evaluation has been combinedwith the liver transplantation results[18].Disease-specific health-related quality of life in pediatric transplant recipients using the PedsQL was assessed by [4].The aim of the current study was designed to assess the post liver-transplant health related quality of life versus healthy children.

The current study results clarified that almost half of the studied children did liver transplantation due to biliary atresia and their time of transplantation ranged between1year to 5 years, had early postoperative complications and insufficient follow up visits(**Table 2**). These findings were in agreement with the study of [19].who stated that, Biliary Atresia (BA) is commonly fatal if untreated and is the particularthe commonest cause of liver disease leading to LT in children. These findings were in line of agreement with the study of[20].they reported that, smaller recipients with biliary atresia (BA) may have better-quality outcomes with deceased donor partial liver or living donor allograft. This finding is congruent with the study of [21].Who reported that liver transplantation (LT) is an proven lifesaving therapy for children with a range of causes including biliary atresia. These discrepancies between the results may be attributed to the different reasons for conducting LTin pediatric population.

Answer the research question number1

What is the quality of life of children post liver- transplantation?

This study results clarified that there were statistically significant differences between study and control groups as regard to relationship between some of Quality of life's domains "health physical activities, every day activities, pain, getting along, general well-being, self- esteem" and their QOL total mean score ($p < 0.01$)(**Figure3**). This study finding was constant with[22].who mentioned that significant group by time interaction in the general health scale and mental health scale of the SF-36 for the study group, without significant improvement in the vitality and social functioning scales and significant group by time interaction in exercise capacity, age-predicted peak, and decreased percent of fat calories for the study group. This result constant with[23].who statedthat, transplant recipients had mild social and scholastic deficits and on several measures had equivalent function levels to the comparison group. These findings were in accordance with the study of[24].who mentioned that those LT children had decreased in all physical, social and emotional functioning, compared with healthy children. This finding was disagreed with the result of[25].who found that, the mean score of the respondents was found to be low. These study findings were supported by[22].who reported that most recipients were satisfied with life without emotional constraintsThis finding was supported bythe similar study of[26, 27]. Theystated thathealth-related fears, hinge onthe patients' self-reports subjectively and their sincerity,most patients did not experience health-related fears concerning graft rejection, recurrence or secondary illnesses. All those discrepancy between the current study results and the later results may be attributed to the differences in socioeconomic and environmental circumstances.

The current study revealed that there were high statistical significant differences between study and control groups as regard to relationship between their self- esteem andQuality of life total mean score (**Figure 4**). This study finding was supported by[28]. Who revealed that recipients experienced improved self-esteem and increased ability to handle physical, emotional and social stress. These study findings were similar to [29]. who stated that unfavorable effects were also reported, including feelings of shame and a flimsy body image. The current study was contradicting with the results of[18].who stated that emotional distress in recipients were linked to feeling of guilt. The current finding was in accordance with [30]. whostatedthat, most recipients had moderate to complete satisfactionin peer relationships. These findings were in accordance with the study of[31]. who revealed that conversations and leisureliness activities with peers often assisted to overcome emotional problems and to maintain social relations. This may be interpreted as younger pediatric patients might be less involved in the decision-making and less aware of the impending psychosocial consequences.

Answer the research question number2

What is the health related quality of life of healthy children in the same age group?

The current study revealed that there were highly statistically significant differences regarding the QOL levels and QOL total mean score among the studied groups (**Figure 2 and Table 4**). The study findings were supported by [32]. who concluded thatquality of life for transplant patients is an important component. Not just good health, but physical activity is one of the ways of maintaining a better quality of life. Physical activity has been shown to be important not only in the measurement of fitness levelsbut may also be important in the longterm healing phase following major surgery. This finding was in-line with[33]. who reported that the new

problems faced by liver recipients in recovering and preserving full function and quality of life (QOL) extend its implications vary from molecular and physical event impacts to personal perspective, resilience, and relationship.

The current study also illustrated that **Self-esteem levels was very high among healthy children compared to very low self-esteem among Post Transplant children (study group) (Table 4)**. This finding was agreed with the result of [34]. who found that, adolescents after liver transplantation experienced low HRQoL. It was associated with poor adherence of both young children and youth to the prescribed medication, non-adoptees have mothers with lower education level. Also the current study was consistent with [31]. who studied Health-related quality of life in Egyptian patients post liver transplantation. They reported that HRQOL improved significantly after LT as assessed by LDQOL questionnaire. Besides, combined questionnaires can offer correct information about the possible weakened HRQOL post-LT due to pre-transplant disease severity and post-operative complications.

The current results revealed that there were no significant differences between study and control groups as regard to relationship between age, sex and their QOL total mean score ($p > 0.05$). While current results revealed that there were significant differences between study and control groups as regard to relationship between father's education, mother's education and their QOL total mean score ($p < 0.05$) (Table 5). These findings were in accordance with the study of [35]. who stated that older children described more physical symptoms, and the sum of these symptoms was associated worse HRQoL related to physical pain, and behavior. A similar to [36]. who mentioned that, lower maternal education and HRQoL was noted in studies of children after liver transplantation. These findings were in agreement with the study of [37]. who report increased sadness and depression in the older age group and 5 of the children conveyed medication for these conditions.

Answer the research question number 3

Does children compliance with follow-up care affect their quality of life?

The current results revealed that there were significant differences between study and control groups as regard to time of transplantation, postoperative complications, follow up visits and their QOL total mean score ($p < 0.05$) (Table 5). This result was in-line with [38]. Who studies "Health-Related Quality of Life in Pediatric Liver Transplant Recipients". They revealed from the parents' report that, lower HRQoL was related to opportunistic viral infection ($P = .004$) and linked to a larger number of immunosuppressive agents ($p = -0.346$, $P = .014$). However, none of these factors were significant according to the child self-report.

VI. Conclusion:

Health-related quality of life (HRQoL) was reduced in a sample of pediatric liver transplanted recipients' compared with a sample of healthy children. Moreover, there were no statistically significant differences were found between HRQoL and recipients' age or sex. Also, Liver transplanted children compliance with follow-up care improved their quality of life.

Recommendations:

- 1- Strategies to improve the organization of nursing assessment/monitoring and perioperative care for

liver transplant` children may improve outcomes for children and family coping.

2- Future research is required for the development of intervention strategies to improve HRQoL and establish the efficiency of a health education program on decreasing post liver transplantation complications e.g. teaching self-efficacy, improving self-esteem and empowering children so they have an internal locus of control.

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