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DOI:
10.4103/jehp.jehp_855_20

Evaluation of nutritional adjustment program on quality of life in children with chronic liver disease

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Received: 18-07-2020

Accepted: 07-10-2020

Publisher: 20-05-2021

Abstract:

BACKGROUND: Chronic liver disease is associated with decreased quality of life. The quality of life of children with chronic liver disease is related to their quality of life. Malnutrition is associated with death from cirrhosis, development of complications, and health-related quality of life in people with liver disease. Therefore, this study was conducted to determine the effect of nutritional adjustment program on quality of life in children with chronic liver disease.

MATERIALS AND METHODS: This clinical trial study was performed on children with chronic liver disease referred to the nutrition clinic of Ghaem Educational-Research Center in Mashhad in 2015. In this study, 77 children with chronic liver disease were randomly divided into two groups. Before and after the intervention, patients' quality of life was assessed with the PedsQL™ 4.0 generic core scale questionnaire. Data analysis was performed using SPSS16 software.

RESULTS: In the postintervention stage, the mean total score of quality of life in the experimental group was 1965.0 ± 270.9 and in the control group was 1522.5 ± 321.3 ($P < 0.001$). The difference in quality of life score of physical, social, and school performance in the two groups was significant.

CONCLUSION: According to the results of this study, it seems that interventions that can improve the quality of life of children with chronic liver disease can be an important step in advancing these people toward a healthy and quality life. As a result, it is possible to take steps to improve the quality of life of patients by encouraging children with liver disease and providing information about diet.

Keywords:

Child, chronic liver disease, nutrition, quality of life

Introduction

“Quality of life is people’s perception of their position in life in terms of the cultural content and military values in which they live and in relation to their goals, standards, and concerns.” This concept has a wide range that affects a person’s physical health, mental health, independence, social relationships, and personal beliefs.^[1] In fact, quality of life is the distance between a person’s actual situation and an ideal situation.^[2] Currently, quality of life is one of the major concerns of

health professionals.^[3] Researchers believe that the study of quality of life and efforts to improve it plays an important role in the health and personal and social life of individuals.^[4-6] Health-related quality of life is the level of expectations of a person about physical, mental, and social well-being that are affected by medical or therapeutic conditions.^[7] Researchers cite the three basic characteristics of multidimensionality, dynamism, and subjectivity for quality of life as a health concept. Multidimensionality refers to the dimensions of physical, mental, and social health that are closely related to each other, and each of these dimensions is

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How to cite this article: Jafari SA, Rezaeian A, Namjou Z, Ghayour-Mobarhan M, ghaneifar Z. Evaluation of nutritional adjustment program on quality of life in children with chronic liver disease. J Edu Health Promot 2021;10:141.

divided into subcategories. In the last decade, with the advancement of science and technology and changes in lifestyle, the image of health has changed in terms of the cause of illness and death. In this regard, infectious and contagious diseases have been controlled and replaced by chronic and metabolic diseases.^[8] Over the last 20 years, the interest in evaluating and improving the daily functioning and quality of life of patients with chronic disease has become a goal. The term chronic, unlike the term acute, which refers to a relatively short period of illness, is usually used for a long period of illness and a condition that is sometimes incurable. The long duration of the disease makes it very difficult for patients to follow up and treat, and it affects their performance. In some cases, the patient has to endure this disease for a long period of his life or until the end of his life and adapt himself to its difficult and unfortunate conditions.^[9] Life satisfaction and feeling good in chronic illness is the main goal of care and treatment.^[10] Having chronic diseases affects patients' interactions with the physical and social environment in which they live, while preventive measures can prevent up to 70% of these problems. One of the controlling ways is educating patients with chronic diseases.^[11] According to data from the American National Research Association (Research Institute American National), 15%–18% of children and adolescents have a chronic illness, which has almost doubled in the last two decades.^[12] One of these chronic diseases that threaten the health of children is chronic liver disease. Chronic liver disease is an abnormal activity of the liver with inflammation and necrosis (at least 6 months) caused by a range of disorders with varying causes and severity. Chronic liver disease covers a wide range of diseases, from nonprogressive to severe forms.^[13] Studies show that chronic liver disease generally reduces the quality of life, regardless of the type of disease.^[9,14] Complications of cirrhosis such as encephalopathy, ascites, spontaneous bacterial peritonitis, and recurrent bleeding from varicose veins can have many negative effects on patient well-being.^[9] This disease is one of the health problems of the country, and due to the chronic and irreversible nature of the disease, it needs care and treatment education programs.^[15] Gulati *et al.* in a study entitled "Health-Related Quality of Life in Children with Autoimmune Liver Disease" showed that the average score in the physical dimensions and school dimensions was lower than in healthy individuals.^[16] On the other hand, the liver plays a central role in food metabolism and energy. Liver disease leads to complex pathophysiological damage that affects the digestion, absorption, distribution, storage, and use of food. However, the quality of a child's food intake can affect the progression of liver disease and the occurrence of complications and quality of life. High energy intake and avoidance of fatty foods affect the quality of life.^[17,18] Proper nutrition affects not only life expectancy

but also the quality of life.^[18] Studies have shown that malnutrition is associated with cirrhosis-related mortality, development of complications, reduced survival, and health-related quality of life in patients with liver disease.^[19] Past studies have confirmed the need for such studies.^[20] It is also important to pay attention to the effect of chronic liver disease on quality of life, the interaction of chronic liver disease and nutritional status, and the importance of quality of life as a clinical outcome. On the other hand, there is very little evidence about the effect of proper nutrition on quality of life in these patients; therefore, the present study was conducted to determine the effect of nutritional adjustment program on quality of life in children with chronic liver disease.

Materials and Methods

This clinical trial study (clinical trial code IRCT2015091424019N1) was conducted to evaluate the nutritional adjustment program on the quality of life of children with chronic liver disease. The study population was all children with chronic liver disease who referred to the clinic or hospitalized in the gastrointestinal ward of Ghaem Hospital in Mashhad in 2015 who met the inclusion criteria. The sample size was obtained using the formula "Comparison of the mean of two communities" and based on the findings of the pilot study and taking into account the 95% confidence level and 80% test power, equivalent to 44 people in each group. Sampling was done by available method and through archive files available in the gastrointestinal clinic as well as the hospital HIS system. Finally, 77 children with inclusion criteria were found who were divided into two groups of intervention and control by simple random method (using a table of random numbers). Forty-five patients were assigned to the intervention group and 32 patients to the control group. Finally, data analysis was performed on 45 patients in the intervention group and 30 patients in the control group. Two patients in the control group were excluded from the study due to the severity of the disease and hospitalization. Inclusion criteria were as follows: age 2–18 years, liver disease at least 6 months after the disease, Iranian citizenship, willingness to participate in the study, lack of physical and mental illness other than chronic liver disease, and under the care and support of the family. Exclusion criteria related to the child were as follows: unwillingness to continue cooperation and the child's need to be fed with a tube. Inclusion criteria related to the caregiver were as follows: willingness to participate in the study, having at least a third grade of middle school, and the possibility of making a phone call. Exclusion criteria related to the caregiver were as follows: unwillingness to continue cooperation and nonparticipation in workshops (at least 2 workshops). Nutritional adjustment guide was developed by studying authoritative scientific articles and sources by integrative

review method. This guide shows how to calculate the required calories and how to divide them among the main nutrition groups for the population of children with chronic liver disease. Macronutrient and micronutrient requirements were also disaggregated. Finally, foods that were banned or restricted in the population with chronic liver disease were also isolated. The amount of calories, macronutrients, and micronutrients of common foods was calculated using Dietplan 6 software (Forestfield Software Ltd., UK). and the end of the guide was attached. After the final summary of the manual, its scientific and formal validity was evaluated by professors of pediatric gastroenterology, pediatric nursing, research method, and nutrition by content validity method. Then, training slides were prepared based on the instruction for training in the workshop and the educational content of the workshops separately for the sessions. After obtaining permission from the Ethics Committee of Mashhad University of Medical Sciences (code 922144) and presenting it to the research site, sampling began. In the first visit of the research units to the nutrition and diet therapy clinic of Ghaem Hospital, the researcher introduced himself and the purpose of the research to the competent caregiver, and after obtaining their consent to participate in the research, the demographic information questionnaire and quality of life questionnaire were completed. All participants in the study completed their written consent to participate in the study. At this meeting, they were visited by a nutritionist and asked to record the amount and type of food the child received in the past 24 h in 24-h reminder forms. At the end of this session, the researcher invited the intervention group to attend the sessions of nutrition adjustment workshops on a specific date. The workshops were held for 6 sessions over 2 weeks. The control group was asked to return to the clinic 12 weeks after the first visit. Nutritional adjustment guide was developed by studying the articles and valid scientific sources by integrative method in both specialized and general levels by Delphi method. After finalizing the guidelines, their validity was re-evaluated by experienced professors of pediatric gastroenterology, pediatric nursing, research method, and nutrition by content validity method. As mentioned, nutritional adjustment guides were designed at the level of a specialized guide for researcher use, which can be used by specialist physicians, assistants, postgraduate nursing, and nutrition students, and a general guide was designed for patient and caregiver use. Then, training slides based on the guideline for training in the workshop and the educational content of the workshops were prepared separately for the sessions. An educational brochure on chronic liver disease was developed for patient use.

After holding the workshops, the follow-up phase of the units began for 12 weeks.^[15] During this period, the patient caregiver was expected to apply to the

patient what he/she had learned during the workshop sessions. After a 12-week follow-up, a re-evaluation was performed and a quality of life questionnaire was completed. In order to comply with the ethical principles, after the end of the study, 6 training workshops were held for the control group and a nutrition adjustment guideline was provided to the child caregiver. Demographic information questionnaire and PedsQL™ 4.0 generic core scale questionnaire were used to collect data. The quality of life questionnaire was completed by the primary caregiver (parent). The quality of life questionnaire consisted of 23 separate items and examined the child's performance in 4 separate areas. The areas of quality of life questionnaire were as follows: physical performance area (8 items), emotional performance area (5 items), social performance area (5 items), and academic performance area (5 items). The questionnaire was designed in such a way that each item examined the existence of a specific problem in the past month and the answer was based on a 5-point Likert scoring system. The reliability of the quality of life questionnaire for healthy children was confirmed in previous studies.^[21] In this study, its reliability was recalculated through Cronbach's alpha with a reliability of 0.87.

Finally, the data were analyzed using SPSS16 software (IBM, SPSS Inc., Chicago, Illinois, USA). Descriptive statistics and analysis methods were used.

Results

Of 77 participants, 40% were female and 60% were male. After 12 weeks, 45 patients in the intervention group (27 boys, 18 girls) and 30 patients (18 boys, 12 girls) in the control group were studied. There was no statistically significant difference between the two groups in terms of sex distribution, mean age, and other demographic indicators [Table 1].

The quality score of the quality of life instrument is between 0 and 2300. Mann-Whitney test showed that there was no statistically significant difference between the two groups in terms of quality of life score before the intervention ($P = 0.246$). However, after the intervention, the difference between the means between the two groups was statistically significant ($P = 0.001$). The results of Wilcoxon statistical test also showed that the mean score of quality of life in the postintervention stage was significantly higher than before the intervention in the intervention group ($P = 0.002$). In the control group, it is significantly lower ($P = 0.020$). Quality of life has four dimensions: "physical," "social," "emotional," and "school performance." Mann-Whitney test showed that there was no statistically significant difference between the mean scores of different dimensions of quality of life

Table 1: Demographic indicators of children with chronic liver disease in the intervention and control groups

Variable	Group, SD±mean n		Statistical test results
	Intervention	Control	
Age (years)	7.0±3.6	8.6±3.7	0.073*
Height (cm)	122.5±23.1	135.2±29.3	0.64*
Weight (kg)	26.0±13.9	28.3±18.5	0.103*
Body mass index (kg/m ²)	15.9±2.6	16.0±3.4	0.081*
Mother's age	32.6±0.8	36.4±8.0	0.18**
Father's age	36.0±7.2	39.8±7.9	0.19**
Mother's education level, n (%)			
Illiterate	3 (6.7)	-	0.12***
Secondary	39 (86.6)	31 (96.9)	
University	6 (6.7)	1 (3.1)	
Father's level of education, n (%)			
Illiterate	-	-	0.09***
Secondary	42 (93.3)	31 (96.9)	
University	3 (6.7)	1 (3.1)	
Mother's job, n (%)			
Homemaker	42 (93.3)	29 (90.6)	0.99***
Employed	6 (6.7)	3 (9.4)	
Father's job, n (%)			
Employee		2 (6.25)	0.27***
Manual worker	6 (13.3)	4 (12.5)	
Self-employed	39 (86.7)	81.28	

*Mann-Whitney test, **Paired t-test, ***Chi-square test. SD=Standard deviation

before the intervention between the two groups except the first dimension (first dimension [$P = 0.008$], second dimension [$P = 0.238$], third dimension [$P = 0.660$], and fourth dimension [$P = 0.465$]).

The two groups were homogeneous in terms of second dimension, third dimension, and fourth dimension but were not homogeneous in terms of first dimension. After the intervention, the difference between the means in the first dimension ($P = 0.009$), second dimension, third dimension ($P < 0.001$), and fourth dimension ($P = 0.005$) between the two groups was statistically significant [Table 2].

The score of quality of life instrument is between 0 and 2300. In order to better compare the changes in the mean score of quality of life after the intervention than before the intervention, the total score is divided into three categories: poor, moderate, and good – score 766-0 = poor quality of life, score 1533-767 = average quality of life, and score 2300-1534 = good quality of life [Table 3].

Discussion

The results of the study confirm the hypothesis of the study entitled “The quality of life of children with chronic

liver disease who use a dietary adjustment program improves compared to the control group.” The quality of life score in children in the intervention group was significantly higher than before the intervention and compared to the control group. In order to confirm the above and strengthen the relationship between improving the quality of life and the training provided in the field of adjusting the nutritional status of the child, quantitative analyzes of how the child received in the pre- and postintervention stage were performed.

The above analyses showed that along with improving the quality of life score, quality and quantity of nutrition in the field of energy and macronutrients in the intervention group compared to before the intervention and compared to the control group had a significant improvement. With this finding, it can be concluded with more confidence that improving the quality of life of the child can be the result of a change in his nutritional status.

What has already been confirmed is that liver disease significantly reduces the quality of life of affected children in various dimensions.^[22] In the population of the northeastern region of Iran, previous studies have shown a decrease in the quality of life score of children with the disease.^[23] Although the relationship between the nutritional status of affected children and their quality of life scores has not been previously measured, the severity of malnutrition reflects the severity of liver disease, and even malnourished children have higher complications in the postoperative liver transplant operation. Furthermore, certain nutritional deficiencies such as deficiency of fat-soluble vitamins and deficiency of essential fatty acids can have serious side effects.^[24] On the other hand, the severity of disease progression can negatively affect the quality of life.^[25] Thus, the relationship between the severity of malnutrition, the severity of liver disease, and reduced quality of life in children with chronic liver disease is an inextricable relationship.^[25,26] Therefore, nutritional monitoring and support of affected children should be considered from the beginning of the diagnosis.^[26] The results of the present study showed that the use of nutritional support can lead to practical results in the field of nutritional improvement and ultimately improve the quality of life of children. Zandi *et al.* in a study entitled “Evaluation of the effect of self-care program on quality of life in patients with liver cirrhosis” in which the intervention group followed a self-care program including proper diet showed that the dimensions of quality of life increased after the intervention in the experimental group.^[27] Furthermore, the results of the study of Campbell *et al.* entitled “Study of the effect of nutritional interventions on the quality of life of pre-dialysis patients” showed that there is a direct relationship between good nutrition and quality of life.^[28] Aghakhani *et al.* in a study entitled “The

Table 2: Comparison of different dimensions of quality of life in the intervention and control groups before and after the intervention

Quality of life	Group				Mann-Whitney intergroup test
	Control		Intervention		
	SD±mean	n	SD±mean	n	
Physical dimension					
Before intervention	585.5±92.2	30	640.0±118.6	45	P=0.008, Z=2.6
After intervention	530.7±86.4	30	675.0±128.8	45	P=0.009, Z=2.6
Wilcoxon intragroup test	P=0.006, Z=2.7		P=0.024, Z=2.2		
Social dimension					
Before intervention	407.1±135.3	30	415.0±82.8	45	P=0.238, Z=1.1
After intervention	360.7±153.0	30	460.0±47.9	45	P<0.001, Z=3.5
Wilcoxon intragroup test	P=0.001, Z=3.4		P=0/006, Z=2/7		
Emotional dimension					
Before intervention	385.7±86.4	30	385.0±70.5	45	P=0.660, Z=0.4
After intervention	407.1±135.3	30	445.0±59.9	45	P<0.001, Z=3.6
Wilcoxon intragroup test	P=0.880, Z=1.7		P<0.001, Z=4.3		
School performance dimension					
Before intervention	360.7±153.0	30	330.0±100.0	45	P=0.465, Z=0.7
After intervention	292.8±132.7	30	355.0±119.5	45	P=0.005, Z=2.8
Wilcoxon intragroup test	P=0.003, Z=0.3		P=0.0857, Z=0.1		
Total score					
Before intervention	1614.2±239.4	30	1770.0±328.7	45	P=0.246, Z=1.1
After intervention	1553.5±238.5	30	1935.0±307.0	45	P=0.001, Z=3.1
Wilcoxon intragroup test	P=0.020, Z=2.3		P=0.002, Z=3.1		

SD=Standard deviation

Table 3: Frequency distribution of children with chronic liver disease in terms of quality of life in the intervention and control groups

Quality of life	Before intervention		After intervention	
	Intervention group, n (%)	Control group, n (%)	Intervention group, n (%)	Control group, n (%)
Weak	0 (0)	0 (0)	0 (0)	3 (10)
Medium	16 (13.3)	12 (40)	3 (6.7)	9 (30)
Good	39 (86.7)	18 (60)	42 (93.3)	18 (60)
Test result	$\chi^2=7.01, P=0.008, Df=1$		Fisher's exact test=12.32 P=0.001	

effect of nutrition education on quality of life in patients undergoing hemodialysis” showed that people receiving nutrition education have better results in quality of life than people who did not have this education.^[29] Nguyen *et al.* also found in their study that nutrition counseling, including increasing the number of meals per day and focusing on high-energy, high-protein foods, improves the nutritional status and quality of life of patients with COPD. The results of this study are consistent with the results of our study.^[30] In their study, Comprá *et al.* stated that preventing weight loss or weight correction through nutritional support could improve the functional status and quality of life of cancer patients. This finding is consistent with our study that the quality of life of children with chronic liver disease has increased with an appropriate nutritional pattern.^[31]

In their correlation study, Lindqvist *et al.* examined nutrition-related manifestations, anorexia, and health-related quality of life in 133 patients with chronic liver failure. Their results showed that in patients with

chronic liver failure, nutrition-related manifestations and health-related quality of life were negatively correlated. They concluded that in chronic liver disease, nutrition-related manifestations are common and negatively affect the quality of life. They also suggested that future studies should consider whether intervention studies to improve nutritional status may affect people’s quality of life or no.^[32] As it was observed, the results of the present study have answered this question in such a way that performing effective nutritional interventions has been able to improve the quality of life of these patients. In this regard, Nel and Terblanche add that in children with chronic liver disease, anorexia, malnutrition, and metabolic disorders lead to malnutrition. Nutritional support should begin at an early stage of the disease to improve the quality of life and reduce posttransplant mortality.^[24] As mentioned above, many studies have been done on eating habits and quality of life in various cases such as pregnancy and chronic diseases such as diabetes.^[33-35] For this purpose, considering the results of the present studies and studies, it seems that diet affects

the quality of life in different stages of life and different conditions, including chronic diseases.

Children in the intervention group experienced less problems in physical, social, emotional, and school performance than the control group after the implementation of the nutrition adjustment program. Due to the low quality of life of children with chronic liver disease, nutrition education and encouraging these patients to follow a diet are one of the factors in feeling healthy and thus improving the quality of life and preventing its deterioration.

The use of a practical nutrition guide in children with chronic liver disease can be recommended to the treatment team to be used in children with malnutrition to improve nutrition, prevent malnutrition, and improve liver status. It is also recommended to parents by health teams in health centers and followed up like other health care. Knowledge of the results of this study increases the level of knowledge of nurses and treatment team to improve nutrition. In addition, the book designed in this project can be presented in workshops and seminars and be a comprehensive guide to nutrition in children with chronic liver disease. The results of this study can be used in various fields of medicine and nursing. In clinical nursing, especially pediatric gastroenterology, nurses can take steps to improve patients' quality of life by encouraging patients and providing information about diet. The results of this study can also be used as a reference in subsequent nursing research in the field of chronic diseases. It is recommended that other studies be performed to examine a variety of quality-related issues, such as exercise, or that other studies examine and compare a variety of lifestyle modifications, such as exercise and diet modification, to determine the effectiveness of different cases.

Conclusion

The results of this study showed that the quality of life score in the postintervention stage was significantly higher than the control group. As a result, diet-based interventions in children with chronic liver disease can improve and enhance the quality of life of these children. Given that nursing managers are one of the main actors in nursing practices, with the cooperation of the Ministry of Health, they can have proper planning to familiarize the medical team, especially pediatric gastrointestinal nurses, with the nutrition of children with liver disease through classes, seminars, and workshops.

Acknowledgment

This study is part of the master's thesis in pediatrics entitled "Study of nutritional adjustment program on quality of life and specific findings of the liver in children

with chronic liver disease," approved by Mashhad University of Medical Sciences in 2014 with the code 922144. We hereby thank and appreciate the sincere cooperation of gastroenterologists and nutritionists who cooperated in the validation of the educational booklet and the hospital officials and all the esteemed participants and the financial support of Mashhad University of Medical Sciences. This study was registered in the Iranian Registry of clinical trials (IRCT) with the code IRCT2015091424019N1.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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