The Effect of Care Program on the Quality of Life of Patients Awaiting Liver Transplantation

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Abstract- Quality of life of patients in need of liver transplantation is impaired due to many reasons, and this affects the pre and post outcomes and complications of transplantation. Therefore, the aim of this study was to evaluate the effect of a care program on the quality of life of patients awaiting liver transplantation. This quasi-experimental study was conducted in 2017 on 117 patients awaiting liver transplantation in Imam Khomeini Hospital of Tehran. Based on entry criteria, the samples were selected purposefully, and their quality of life was evaluated. Then, a care program in 6 one-hour-long sessions for 2 months was implemented for them. This program was according to patients' needs, including disease and transplant process education with using multiple educational methods. The data collection tool was a quality of life questionnaire (1999), which was completed before and six weeks after the intervention. The results showed that the overall quality of life and its entire aspects improved after the implementation of care program in patients waiting for liver transplantation, and the most change was related to the aspect of systemic ($P<0.01$). Also, the demographic variables had no significant relationship with the aspects of quality of life. The results of this study indicated a positive effect of the care program on improving the quality of life of patients awaiting liver transplantation. Eliminating the problems of these patients requires the attention and support of planners and the cooperation of managers in order to develop care programs that can be used by healthcare professionals, especially nurses.

Introduction

Today, chronic liver disease and hepatitis are on the rise and are considered as one of the causes of mortality in patients (1). The statistics show that each year, more than 15,000 cases of liver failure and 5000 liver-related deaths are being recorded in Iran. In 2017 in Iran, around 5,400 people died due to chronic liver disease and liver failure (2).

Liver transplantation is the only effective treatment for patients with end-stage liver failure and is considered a very successful method (3). Patients requiring liver transplantation are on a long waiting list since organ donation is low (4). Waiting time before surgery is a complex phenomenon with unpleasant experiences (5). Also, the complications and problems associated with the disease affect the quality of life of patients. The health-related quality of life is one of the important criteria for measuring the effects of chronic liver disease, and as an intervention guide, it helps to improve the well-being of patients (6).

Quality of life is a sense of well-being and satisfaction/dissatisfaction with the important aspects of life and is a multidimensional structure that serves as a tool for evaluating the health conditions in different areas such as mental and physical health (7). Studies have shown that long-term waiting for an organ transplant is associated with low quality of life and negative emotional reactions such as increased anxiety (8). Patients awaiting liver transplantation have many concerns about their quality of life, such as social isolation, depression, anxiety, pain, sexual dysfunction,

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fatigue, and gastrointestinal symptoms that disrupt their daily function. Although the progression of the disease in these patients disrupts their quality of life, low quality of life, as a defective cycle, affects the treatment outcomes, as nutritional problems, malnutrition, dependence, and anxiety affect the disease outcomes and complications before and after the transplantation (9).

Literature shows that patients who follow the suggestions of the transplant team experience fewer problems and overcome the constraints of their disease sooner, while they do not have much information on prevention and compliance with a medication regimen, *etc.,* (10). Results of a qualitative study that was conducted in Iran in 2018 on patients waiting for liver transplant showed that they were suffering from a number of problems, including lack of knowledge about their illness and their treatment plan (11). As it is known, patients awaiting liver transplant and their families need to have sufficient knowledge and information about the factors associated with non-compliance with the treatment regimen and related care methods in order to improve their quality of life. The results of several studies show the low quality of life of these patients and the need for intervention in this regard (12,13). Therefore, providing care programs and interventions to improve the quality of life of patients before transplantation is a necessity.

The goal of the transplant team is helping patients to make the best choices, guiding them during the care process, creating an appropriate environment for communication, encouraging proper behaviors, reducing unhealthy behaviors, and helping the patient to resume normal life (14). In this regard, nurses are one of the most effective members of the transplant team, who play an important role in caring for these patients. Therefore, this study was conducted to examine the effect of a care program on the quality of life of patients awaiting liver transplantation.

Materials and Methods

This semi-experimental and pre and post interventional study were conducted in 2017. In order to determine the sample size, similar related studies, and the sample size formula $n = \frac{(Z\alpha + Z\beta)^2}{(E/S(\Delta))}$ with a 95% confidence range, and 90% test power was used. Thus, 117 patients waiting for liver transplant in the transplant clinic of Imam Khomeini Hospital affiliated to Tehran University of Medical Sciences were selected by convenience method. The criteria for entering the study were; being 18-year-old or older, having confirmation of

the need for liver transplant by a specialist physician, being able to understand and speak Farsi, and being interested in participating in the research.

The data gathering tool was a two-part questionnaire including demographic characteristics such as age, gender, education level, marital status, occupation, place of residence, income, and health insurance status, as well as the quality of life of chronic liver patients (CLDQ) including 6 aspects of systemic, abdominal signs, worry, emotion, fatigue, and activity. The questionnaire was on a Likert scale from always to never with the score ranging from 1 to 5, respectively. The highest score indicated a better quality of life. It should be noted that the validity and reliability of this questionnaire (coefficient of 0.95) have already been confirmed in the study of Zandi *et al.*, (15). In order to determine the face and content validity, the tool was given to 10 experts and their views were applied to the final tool. The initial version of the quality of life questionnaire had 29 questions, which was reduced to 26 questions, as the questions 17, 18, and 20 were somehow the same and had the same meaning in Persian translation. To determine the reliability, the questionnaire was given to 20 patients waiting for liver transplantation, and the Cronbach's alpha coefficient of 0.97 was obtained.

In the first stage of the intervention, patients' need assessment was performed by in-depth individual interviews (11), so that a care program could be developed based on its result. Then, the content of the care program was developed by reviewing the latest articles and books and performing a search on internet websites, in accordance with the patients' needs and level of education. The program included an introduction to the underlying disease, symptoms, and complications of the disease, the ways of controlling the disease, treatment and follow-up care, methods of controlling anxiety and depression, education on diet and drug regimen as well as physical activity, introduction to the transplantation process and prevention of organ rejection and ultimately, preparation for the surgery. At first, the questionnaire was completed by the researcher in the pre-test, and then the care program was implemented in 6 one-hour-long sessions for 2 months, with the assistance of the head of the liver transplant center. The education in each session, which was delivered in the form of interacting lectures, dialogue, and questions and answers. Images and posters related to the different aspects of the disease were also used to facilitate the learning. At the end of each session, booklet, pamphlet (a total of 5 pamphlets

and 2 booklets), and CD were given to patients and their companions to be used by them, which included all the points made during the sessions. The care program, in the form of a CD (using Cometzia's software), was distributed among patients as needed. For this purpose, with the collaboration of the virtual school of Tehran University of Medical Sciences, the educational content, slides, and photos were prepared by the researcher and were audio recorded at the studio of a virtual school. Also, the content of the program was uploaded on the patient education website of the deputy of treatment of Tehran University of Medical Sciences. The educational content was also reviewed by the participants through a telegram channel. To support and ensure the implementation of the care program, all patients were followed-up by the researcher by phone call, and their questions were answered.

The researcher tried to use the assistance of clinical instructors and postgraduate students of the medical-surgical department in order to implement the care program for patients. Also, establishing an internship field for postgraduate students in the liver transplantation clinic helped to achieve this goal.

In order to control the mental and emotional symptoms, the patients awaiting liver transplant were examined by an expert psychologist, and then, they were referred to the psychiatric nursing group. The psychiatric nursing group tried to resolve the problems of patients by organizing two sessions of stress management counseling, anxiety control, and relaxation methods.

To support patients with economic problems, they were introduced to a charity that supports patients with liver disease so that their follow-up, including testing, receiving medications, and visiting a doctor, would be free of charge.

Since the care program should be in accordance with the patients' level of understanding, the researcher tried to avoid using medical terminology, which was hard for the patients to understand. So the content validity of the educational materials was reviewed by several medical and nursing professors, and after applying their suggestions and comments, they were ready for use. Also, for the face validity of the texts in terms of simplicity and understanding of the patients, 5 participants were asked to review the texts and confirm them in terms of the above validity.

After preparing the care program, it was implemented for the patients for 6 weeks, and after the follow-up, the quality of life questionnaire was completed for patients during the post-test with the assistance of the researcher. The quality of life of patients was measured after the implementation of the care program and was compared with the pre-test period. The collected data were analyzed by SPSS software version 18 using statistical tests, including paired t-test, independent t-test, ANOVA, and Pearson and Spearman's correlation coefficients. The descriptive statistics, including frequency, percentage, mean and standard deviation, were also used.

It should be noted that the above study is a part of an action research project (No. 31538, Ethics code: 9221199005) was approved by the Tehran University of Medical Sciences. Also, informed written consent was obtained from the patients, and information about the purpose and objectives of the study were given to them. Patients were also assured about the confidentiality of their information, and they were told that participation in the study is voluntary, and they can leave the study at any time for any reason. However, no one left the study.

Results

The results revealed that most patients (40%) had a monthly income of one million Toman. Also, 30% of them had supplementary insurance. About 32% of patients had one child, and 42% of them were ill between 1-5 years. Other demographic and patient-related characteristics are listed in Table 1.

Table 2 shows the frequency and percent level of quality of life in patients awaiting liver transplantation before and after the intervention. The findings showed that the overall mean score of quality of life in patients was 83.72 ± 19.6 before the intervention and 94.90 ± 16.8 after the intervention. Based on the statistical tests, the quality of life of patients waiting for liver transplantation was improved after the intervention ($P<0.01$) compared to before.

In Table 3, the different aspects of quality of life in patients awaiting liver transplantation have been compared before and after the intervention, which shows a statistically significant difference. Also, the result of the paired t-test showed that all aspects of quality of life were improved after the intervention compared to before, and this change was significant ($P<0.01$).

Table 4 compares the relationship between different aspects of quality of life and demographic characteristics of patients waiting for a liver transplant. There was no significant relationship between any of the demographic variables and aspects of quality of life. Also, no significant difference was found between age and abdominal symptoms ($P=0.23$), activity ($P=0.47$), worry

(P=0.13), systemic (P=0.15), fatigue (P=0.49) and emotion (P=0.42).

Table 1. Demographic characteristics of patients awaiting liver transplantation

Variable	Groups	Frequency	Percent
Sex	Male	75	64
	Female	42	36
Marital status	Single	22	19
	Married	89	76
	Divorced	6	5
Education	Illiterate	8	6/8
	Elementary	24	20/5
	Secondary	18	15/5
	High school	50	42/7
	Academic	17	14/5
Occupation	Employee	9	7/7
	Laborer	6	5
	Free	37	31/6
	Retired	11	9/4
	Unemployed	21	18
	Housekeeper	33	28/3
Residence	City	104	89
	Rural	13	11
Insurance	Yes	114	97/5
	No	3	2/5

Table 2. Frequency and percent level of quality of life in patients awaiting liver transplantation before and after the intervention

Group/	Before		After	
Quality of Life	Percent	Frequency	Percent	Frequency
Very weak (<47)	4	3/4	2	1/7
Weak (48-67)	20	17/1	7	6
Moderate (68-89)	51	43/6	27	23/1
Good (90-110)	29	24/8	65	55/6
Excellent (111-130)	13	11/1	16	13/7
Total	100	117	100	117

Table 3. Aspects of quality of life in patients awaiting liver transplantation before and after the intervention

Group/	Before	After	Statistics
Aspects of Life Quality	M±SD	M±SD	
Abdominal	6/24±2/37	6/86±2/37	t=-3/66, df=116, p<.001
Fatigue	8/68±2/96	10/41±2/85	t=-7/09, df=116, p<.001
Activity	9/85±3/19	11/18±2/44	t=-5/49, df=116, p<.001
Worry	15/72±6/19	17/68±4/44	t=-1/08, df=116, p<.001
Systemic	16/85±4/27	19/37±3/92	t=-7/27, df=116, p<.001

Table 4. Relationship between different aspects of quality of life and demographic characteristics of patients waiting for a liver transplant

Aspects of Life Quality/ Variables	Systemic	Worry	Emotional	Activity	Fatigue	Abdominal
Sex	F=3/56, df=115, p=0/06	F=0, df=115, p=0/95	F=3/21, df=115, p=0/07	F=0/35, df=115, p=0/55	F=0/85, df=115, p=0/35	F=0/03, df=115, p=0/84
Marital status	F=1/90, df=(2,114), p=0/15	F=1/32, df=(2,114), p=0/27	F=0/62, df=(2,114), p=0/53	F=1/55, df=(2,114), p=0/21	F=0/68, df=(2,114), p=0/51	F=0/92, df=(2,114), p=0/39
Education	F=0/41, df=(4,112), p=0/79	F=1/68, df=(4,112), p=0/15	F=1/14, df=(4,112), p=0/33	F=1/92, df=(4,112), p=0/11	F=0/27, df=(4,112), p=0/89	F=1/24, df=(4,112), p=0/29
Occupation	F=1/28, df=(6,110), p=0/27	F=0/11, df=(6,110), p=0/99	F=0/93, df=(6,110), p=0/47	F=1/64, df=(6,110), p=0/14	F=0/60, df=(6,110), p=0/72	F=0/51, df=(6,110), p=0/79
Residence	F=0/80, df=115, p=0/37	F=0/09, df=115, p=0/76	F=2/09, df=115, p=0/15	F=0, df=115, p=0/96	F=2/09, df=115, p=0/15	F=0, df=115, p=0/98
Insurance	F=1/69, df=115, p=0/19	F=0, df=115, p=0/94	F=1/89, df=115, p=0/17	F=0/03, df=115, p=0/85	F=1/29, df=115, p=0/25	F=0/36, df=115, p=0/54

Discussion

The results of the present study showed that the care program had a positive effect on the quality of life of patients awaiting liver transplantation, and their condition improved compared to them before the intervention. As shown in previous studies, the quality of life of these patients is lower than healthy people (12,15). The results of a study in Singapore showed that people with advanced chronic disease have a lower quality of life than healthy people (16). Another study found that a longer waiting time in the transplant list is associated with lower quality of life, more negative emotional responses, and increased anxiety levels (8). Results of qualitative research that was conducted in Iran in 2017 on patients who were waiting for liver transplant showed that patients waiting for liver transplant suffer from a lack of knowledge about their illness and problems in their care and treatment (17). Other studies suggest that education affects the outcomes of treatment and promotes the quality of life (18). Several studies conducted in Iran showed that intervening and providing education eliminates the lack of compliance with the treatment regimen and increase the quality of life in patients with cirrhosis, which is caused by insufficient knowledge and information in this field (11).

In our study, after the implementation of the care program, the overall score of quality of life changed from 83 before the intervention to 94 after the intervention, which also improved the health-related quality of life of patients awaiting liver transplantation. Various studies confirm the above findings. For example, the results of Zandi *et al.*, a study that examined the effect of a self-care program on the quality of life of patients with hepatic cirrhosis in Tehran's Hepatitis Center showed that the implementation of education and provision of care programs in these patients improved all aspects of quality of life in them (15). Also, in another study, the use of educational programs was shown to improve the quality of life of hepatitis patients (19). The results of a study on chronic hepatic patients after the educational-psychological intervention showed an increase in all aspects of quality of life (20). Another study also showed the positive effects of counseling and education on the quality of life of patients with chronic hepatitis (21). Therefore, if care programs are designed in a standard way according to the need and level of understanding of patients, and have the ability to be fully implemented and get patients,

families and transplant team fully involved in the treatment process, they will achieve positive results in improving the quality of life of patients.

Our study showed the effect of a care program on the quality of life of patients awaiting liver transplantation in all aspects, including abdominal symptoms, activity, worry, systemic, fatigue, and emotion. However, the results of a study in this field showed that the quality of life of patients in the intervention group increased only in three aspects of abdominal symptoms, worry, and emotion (19). Perhaps the reason for this difference is that, in the above study, the validity and reliability of educational content had not been ensured for patients, but in our study, we had simplified the educational texts for patients. Also, in our study, we tried to use multiple training methods to implement the intervention. Another study found that, in the group of patients, the worst condition was related to the role limitation (12), which could be related to the aspect of the activity. Perhaps, as patients were in the bad physical condition and had frequent complications and hospital admission, these might have affected the physical function of patients and, consequently, the aspect of the activity.

The results of the present study showed that the implementation of a care program helped to improve the quality of life of patients awaiting liver transplantation. By improving the quality of life of patients, we can prevent their treatment cessation and make them more positive and hopeful towards the treatment. The results of the present study can be used in clinical nursing to provide care and education for patients. They can also be used in education by adding this program in the nursing curriculum in order to prevent complications and improve the quality of life of patients. Patient family education is one of the recommended methods of the patient support.

Among the limitations of this study were a different knowledge, previous experience, motivation and interest of patients, and their individual differences and mental states when answering the questions, which could have affected the implementation of the program and were uncontrollable.

Acknowledgments

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