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Research Article

Effectiveness of the Educational-Supportive Program to Improve the Quality of Life Among Patients with Hepatitis C virus (HCV): A Quasi-Experimental Study

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Abstract

Background: Hepatitis C virus (HCV) infection reduces its victims' quality of life (QoL). Generally, hepatitis-C patients seem to face decreased social, family, and friends support and a social phobia that lowers their QoL and emotional state. There is a need to pay special attention to hepatitis-C patients' emotional and social needs.

Objectives: This study aimed to investigate the impact of social support, family, and education on the quality of life of hepatitis drug users.

Methods: This quasi-experimental study was conducted on 144 male drug users (72 people in each intervention and control group) with hepatitis C referring to two Drop-in Centers covered by the Welfare Organization in Isfahan, Iran, in 2017 - 2018. Convenience sampling was used in this study, and the sample size was determined to be 72 subjects in both groups, and through tossing a coin, drop-in-center no. 1 was selected as the intervention group and the drop-in-center no. 2 as the control group. Those in the intervention group were divided into six 12-person groups and were invited to participate in a supportive-educational program with a family member. A self-administered questionnaire measuring demographic characteristics, high-risk behaviors, the status of hepatitis C, and SF-36 for determining the QoL was completed by participants in both intervention and control groups before and after the intervention.

Results: The mean QoL score and changes in this score during the three times of measurements were significantly different between the two groups. However, after the intervention, the mean total QoL score in the intervention group (71.32 (16.15)) was significantly higher than the control group (48.22 (25.81)) ($P < 0.05$).

Conclusions: Educational programs with a strong emphasis on family support and companionship can improve some dimensions of the QoL in patients with HCV.

Keywords: Hepatitis C, Quality of Life, Education, Social Support, Family Support

1. Background

Chronic hepatitis C is an important public health problem, with an estimated 71 million people in 2015 were living with the hepatitis C virus (HCV) worldwide (1). In Iran, the prevalence of HCV infection in the general population differs significantly in various areas of the country, which can be attributed to differences in the quality of public health services, lifestyles, habits, and rates of high-risk behaviors in different geographic areas (2). With an overall anti-HCV prevalence of less than 1% in the general population, Iran is considered a country with low-frequency HCV infection (3). However, it seems that the prevalence of HCV is slightly rising in the country (4). Presently, injection drug use is the main route of HCV transmission (5). Injecting drug users (IDUs) are the leading cause of HCV infection in Iran and the reason for the large proportion of current HCV transmission in society (3).

A number of different studies have shown a clear reduction in the quality of life (QoL) of HCV-related liver disease patients (6). Like most infectious diseases, especially chronic ones, hepatitis C has physical, social, and economic consequences, particularly concerning health status, and significantly reduces the QoL of its victims (7). HCV infection is associated with increased fatigue and decreased functional ability, either at work, home, or school.

The sufferer does not have confidence in his/her health and is worried about future health consequences of the disease (8). The disease awareness affects reversely patient's QoL (9). Physical and psychological problems will eventually lead to frustration and reduced social functioning and social communication in these patients, translating into declined QoL (10). Also, signs and symptoms of the disease, such as fatigue, anxiety, depression, irritability, insomnia, memory impairment, impotence, decreased concentration, anemia, rash, itching, joint pain, fever, as well as labeling effects of the diagnosis of infection, affect the QoL of patients (9). Health-related to the quality of life is widely used as a tool to assess patients' social relationships, physiological, psychiatric, and physical functioning in chronic diseases with a high chance of survival (6). Many ambiguities about HCV have been corrected in recent years, but the effect of this modification on QoL is still unclear; therefore, more research should be done on QoL and the health status of patients with hepatitis C (10).

As evidenced by several studies, providing the interventions needed by HCV patients can improve their QoL. These interventions can be at the individual, family, and social levels or be related to healthcare services. And in every case where there is talk of the need to change human health-related behaviors, the issue of health education is raised (11). However, one of the reasons for the failure of health education programs is that they are directed at people, and the influence of other people on the attitude and beliefs of the individual is neglected. Abstract software are based on the fact that people are influenced by different people in society, including spouse, religious leaders, family, health workers, and so on, and such influences or pressures affect their behaviors (12). But what is certain is that the role of family and parents in the lifestyle and health behaviors of the individual is the most prominent (13), and this is while HCV patients are rejected by the community and sometimes even by their families (14, 15). Studies also report on the association between lack of social support and depressive symptoms (16, 17). For this reason, in addition to patients, the knowledge and understanding of their families regarding factors that contribute to their QoL should also be enhanced (18). It is believed that social resources can strengthen emotional self-esteem and self-confidence by providing emotional support (19). In view of the above, since the prevalence of hepatitis C in Iran in vulnerable groups, such as drug addicts, has an upward growth (20), and as the chronic and irreversible nature of the disease requires supportive training programs to independence and feel useful and to induce well-being for the patient (21). And since the negative effects of HCV on the QoL of an addict are notable, so comprehensive prevention programs, including education (22) and the ability to maintain contact with friends, spouses, and children, can help improve the quality of their lives (23).

2. Objectives

Also, since QoL means that everyone understands his/her place of life in the culture and environment in which they live, this quasi-experiment provided an opportunity to investigate the impact of social support, family, and education on the QoL of hepatitis drug users.

3. Methods

3.1. Setting and Participants

Following a quasi-experimental design, this study was conducted on 144 male drug users diagnosed with hepatitis C referring to two Drop-in Centers covered by the Welfare Organization in Isfahan, Iran, in 2017 - 2018. By tossing a coin, drop-in-center no. 1 was selected as the intervention group and the Drop-in Center no. 2 as the control group. At least 72 people in each group (test and control) were obtained. The sample size was determined as 72 subjects in each drop-in-center using the following formula.

$$
\begin{aligned}
n &= \frac{2\sigma^2\left(Z_{1-\frac{\alpha}{2}} + Z_{1-\beta}\right)^2}{d^2} \\
&= \frac{2(1.5)^2(1.96+0.84)^2}{0.7^2} \\
&= 72
\end{aligned}
$$

Where Z1 (confidence interval) was considered as 95%, ie, 1.96, Z2, test power was 80%, ie, 0.84, S, an estimate of the standard deviation of the variable score (quality of life) in the two groups, was 1.5, and d, the minimum difference between the mean variable score (quality of life) between the two groups, which shows a significant difference, was 0.7 (24). Inclusion criteria were being treated with methadone and a positive test of PCR, HCV-AB; biological symptoms of chronic hepatitis; absence of liver cirrhosis or impaired liver enzymes; aged between 18 and 49; minimum of primary education; ability to answer questions and discuss in educational sessions; living with family (married or single), and willingness to participate in the research. Exclusion criteria were missing more than one training session, the presence of any other physical or mental illness that interfered with the training process or completion of the questionnaire, and unwillingness to continue attending the study.

3.2. Instruments

Data were collected using a two-part questionnaire. The first part was about demographic characteristics, high-risk behaviors, and the status of hepatitis C. The second part was an SF-36 standard questionnaire, which was intended to determine the QoL (25). The scores are calculated such that, first, the highest score of each domain is calculated and, then, based on the conducted studies, a score higher than 60% is considered to be desirable, and a score lower than 60% is undesirable.

3.3. Procedure

After obtaining permission from the Ethics Committee in Research and written consent and stating the research objectives, a PCR test was performed for 213 participants who had a positive HCV-AB test during the last six months. A total of 144 participants whose PCR test was positive filled the questionnaire if they had the inclusion criteria. Then, using coin toss, drop-in-center no. 1 was selected as the intervention group and drop-in center no. 2 as the control group. Next, the participants of both groups were visited by an infectious disease specialist, and a medical record was formed for them, and personal characteristics, high-risk behaviors, test results, liver ultrasound, and disease symptoms were recorded. All participants (intervention and control groups) were referred to a specific laboratory for PCR testing and liver ultrasound (at the discretion of an internal medicine physician). Noteworthy, all costs were paid by a charity for vulnerable people, and laboratory discounts were also obtained. Based on their disease condition, participants of both groups were referred for receiving hepatitis C treatment free of charge. Afterward, those in the intervention group were divided into six 12-person groups and were invited to participate in a supportive-educational program with a family member.

The educational intervention was performed in several stages based on the family center-empowerment model (26, 27): Stage 1 (perceived threat): at this stage, using an educational session and through lectures and question and answers, the disease process, the severity of the complications and risks, the current situation of the disease, and the process of self-care and treatment were explained to the participants of each group in a simple language. The second stage (promotion of self-efficacy or problem-solving): In these sessions, the patients discussed the disease-related problems (such as symptoms, their needs to follow-up their treatment, the costs of treatment, the impact of the disease on their daily lives, and their relationships with others, especially family members) under the supervision of the researcher and mentioned some objective examples of their situation. The third stage (self-esteem): At this stage, the patients were asked to participate in educating an active member of their family about hepatitis C-related problems and to encourage them to help them. The material discussed in the previous sessions was transferred to the active member of the family through the patient in the form of an educational CD.

In fact, as the health interface, the patients took the role of educating other family members and by increasing their self-esteem, they could talk with their family about the problems and receive family support in the process of the disease treatment and follow-up. The fourth stage (assessment): assessment was performed in all stages of the intervention; so that the educational materials of the previous session were assessed (questions and answers) in the next session (Figure 1). After the last stage of filling the questionnaire, a 2-hour educational session was held for those in the control group and their families. The quality-of-life questionnaire has been standardized in more than 50 countries, including Iran (28, 29). Moreover, the internal validity of different subscales of the questionnaire has been assessed in Iran in 2004, yielding a Cronbach's alpha of 0.77 to 0.90 (30). Thus, the validity and reliability of the questionnaire had been approved for the present study. Collected data were analyzed by SPSS version 19 using the independent *t*-test, Chi-square, Mann-Whitney, and ANOVA Bonferroni post hoc test. In all the tests, $P < 0.05$ was considered significant.

4. Results

A total of 144 drug users with hepatitis C entered the study. The mean (SD) age of participants was 35.25 ± 2.86 years in the intervention group and 37.00 ± 2.33 years in the control group (Table 1). The mean score of eight dimensions of QoL was not statistically significant at the very beginning of the study so that in both groups, the highest and lowest QoL scores belonged to physical function and vitality, respectively. After providing the educational-supportive intervention, the highest QoL score in the control and intervention groups belonged to the dimensions of physical role and social function, respectively (Table 2).

Based on the results of the repeated measures ANOVA, the effect of the intervention was significant at the level of 5% error. Therefore, the assumption that the mean score of QoL is the same in the two groups is rejected ($P < 0.05$). Moreover, the effect of follow-up and the effect of change at different levels of time were found to be significant between the two groups ($P < 0.001$). Therefore, the mean score of QoL and changes in this score during the three times of measurement were significantly different between the two groups (Table 3). Based on the Bonferroni post-hoc test, the overall QoL score of the participants of

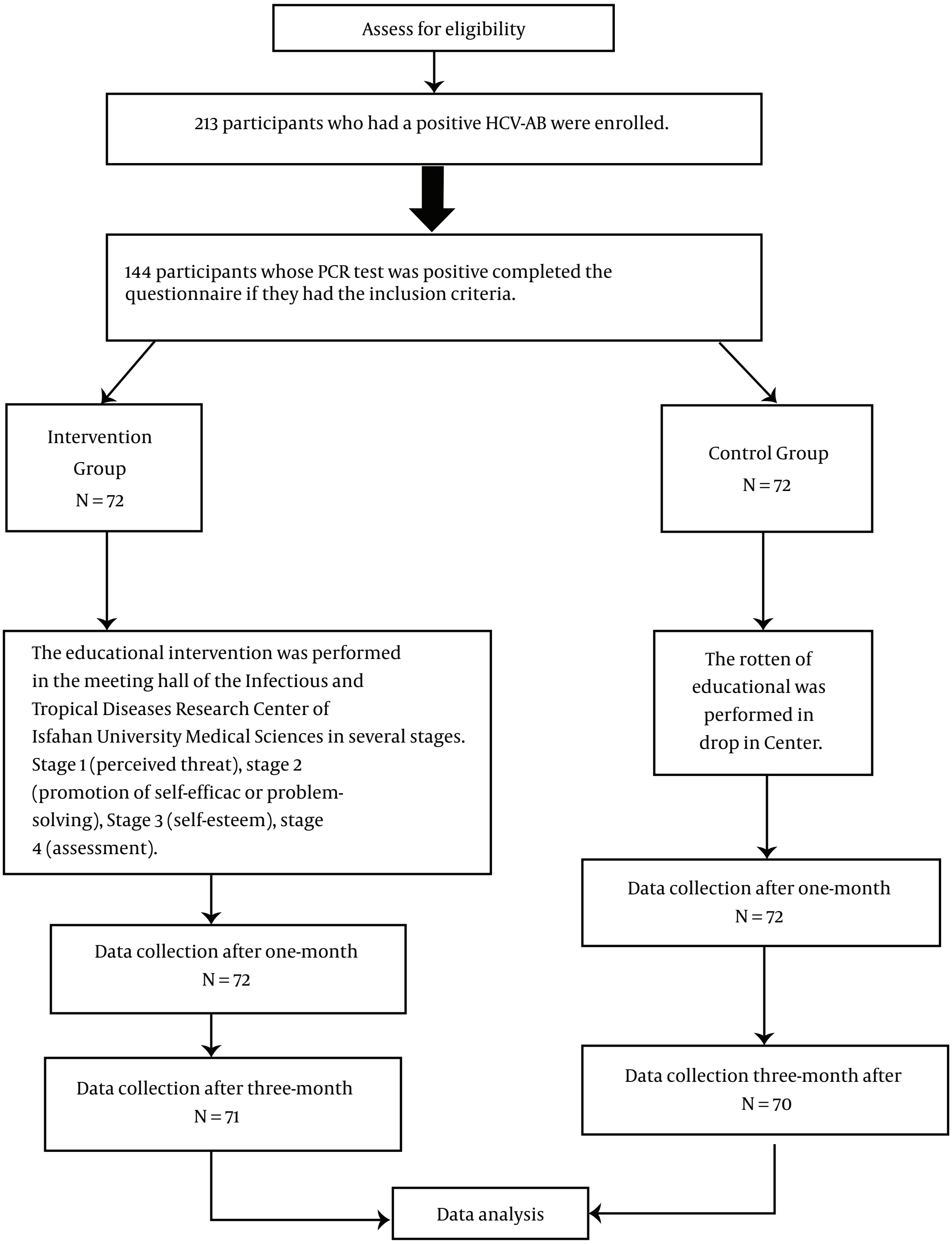

Figure 1. Research procedure diagram

Table 1. Frequency Distribution of Demographic Characteristics, High-risk Behaviors, and Disease Status in the Intervention and Control Groups [a]

Variables	Intervention Group	Control Group	P-Value
Marital status			0.09
Single	24	34	
Married	31	21	
Divorce	0	2	
Living together without marriage	17	15	
Level of education			0.15
Illiterate	3	0	
Elementary	13	14	
High school	31	24	
Diploma	24	31	
Above diploma	1	3	
Occupation			0.09
Government's employee	2	1	
Self-employment			
37	41		
Unemployed	32	30	
Sex other than spouse			0.58
Yes	18	16	
No	52	54	
Use a shared syringe			0.56
Yes	31	28	
No	40	42	
Having clinical symptoms			0.52
Yes	57	53	
No	15	19	
Duration of illness (y)			0.68
Less than 5	13	12	
5 - 10	39	44	
More than 10	20	16	

[a] Values are expressed as No. (%).

both groups was not significantly different before the test, and it was low in the participants of both groups. However, one and three months after the intervention, the mean total score of QoL in the intervention group was significantly higher than the control group ($P < 0.05$).

5. Discussion

Based on the findings, there was no significant difference between the eight dimensions of quality of life (QoL) at the beginning of the study. So that the highest QoL score in both groups belonged to the physical function, while the lowest score was for vitality. A study that intended to evaluate the QoL of people living with HIV/AIDS and its contributing factors reported a mean QoL score of 64.5. Also, the mean scores of physical and psychosocial dimensions were 66.8 and 62.2, respectively (31). Another study on HCV patients reported significantly lower scores for physical efficiency, physical role, emotional role, vitality, mental health, social health, physical pain, and general health, which was evaluated using SF-36 (32, 33). The results of these studies are consistent with the present study, as both studies indicated a lower QoL score for the psychosocial dimension. Chronic hepatitis has a severe effect on physical, mental, and family life of the patients and threatens their overall integrity to the extent that they face many challenges (34, 35). Diagnosis of hepatitis causes depression and anxiety, leading to frustration and despair in patients. These patients have difficulty in finding a job, are not able to work and care for their families, and are rejected by society and sometimes even by their families (36).

The results of the study also showed that the total mean score of QoL in the intervention group was significantly higher than the control group after receiving the intervention. A study showed that educational interventions presented a significant effect on patients' knowledge, correction of behaviors, including tests related to the diagnosis and vaccination, willingness to start and adhere to treatment, self-efficacy score, and vitality/energy in patients with hepatitis B and hepatitis C (37, 38). Providing education is necessary for patients suffering from chronic hepatitis, particularly those receiving antiviral therapy and patients with poor health-related quality of life. Also, the study showed that increasing social support for people living with HIV/AIDS improves their QoL. The low QoL of HCV patients in psychological dimension indicates the need for more psychological interventions (39). In other words, providing interventions intended to address patients' psychological problems, along with biological treatment, can have a significant impact on their QoL.

Maintaining a cheerful spirit in these patients is as important as taking care of their bodies. In this regard, the support of society, service providers, and families is of particular importance. To address the problems of people with hepatitis C, there must be a change in the health and social services system as well as the services for educating and informing the public (40). In the present study, the participants tried to educate their families and gain their support. The education of the participants in the intervention group and their families was accompanied by their participation in the Hepatitis C campaign for the public. Thus, the overall QoL was improved after providing the in-

Table 2. Determining and Comparing the Mean Total Score of Quality of Life of the Participants Before and After the Intervention in the Intervention and Control Groups [a]

Domain	Before Intervention			After Intervention		
	Intervention Group	Control Group	P-Value	Intervention Group	Control Group	P-Value
Role- physical	58.7 ± 17.30	61.04 ± 3.15	0.521	71.2 ± 15.3	50.2 ± 46.3	0.002 >
Physical function	56.42 ± 18.8	54.6 ± 16.5	0.090	72.11 ± 27.2	61.3 ± 72.1	0.001 >
Pain	59.9 ± 16.7	60.6 ± 20.7	0.620	75.10 ± 10.6	59.3 ± 74.24	0.05
General health	43.5 ± 12.3	41.6 ± 13.3	0.513	69.22 ± 10.8	39.32 ± 62.18	0.003 >
Vitality	38.1 ± 11.60	35/75 ± 12.7	0.304	70.12 ± 9.7	40.52 ± 2.7	0.001 >
Social function	45.9 ± 17.20	46.7 ± 13.5	0.224	87.1 ± 7.8	57.02 ± 91.2	0.001 >
Role- mental	43.5 ± 12.7	41.5 ± 14.3	0.232	66.8 ± 13.2	39.45 ± 57.2	0.001 >
Mental health	45 ± 34.24	43.28 ± 14.8	0.422	75.90 ± 19.2	47.34 ± 14.16	0.001 >

[a] Values are expressed as mean ± SD.

Table 3. Comparing the Mean Quality of Life Score of Participants in the Intervention and Control Groups Before, One, and Three Months After the Intervention

Time	Intervention Group	Control Group	Effect of Group	Effect of Time	Time and Group Interaction
Before the intervention	43.32 ± 21.41	40.34 ± 26.50	< 0.002	< 0.001	< 0.001
One month after the intervention	59.51 ± 20.22	48.30 ± 25.91			
Three months after the intervention	71.32 ± 16.15	48.22 ± 25.81			

[a] Values are expressed as mean ± SD.

tervention.

According to previous studies, the participation of patients in education and learning programs can enhance their self-care and awareness. Based on the results of a study, planning for short and simple educational programs has a significant effect on patients' control over the disease and its side effects; in addition, it can improve QoL, life satisfaction, and mechanisms of coping with treatment in patients with viral hepatitis. The purpose of self-care in patients is not only to increase their awareness and hope but also to promote their participation in the treatment and care process assiduously (41). Given that, in this study, these conditions were provided for the intervention group, improved status of the psychosocial dimension of the QoL seems to be reasonable.

It is necessary to mention some limitations of our study. Participants do not represent the characteristics of the general population of addicts or patients with hepatitis C in Iran. Another limitation of the study was the low motivation of the research participants to participate in educational sessions, which was overcome by encouraging them to participate in the sessions. The authors recommend further studies with more extended periods while emphasizing more follow-up sessions to stabilize health behaviors in patients. Despite the limitations of this study, the study also has strengths. For instance, provision of medicine and tests for all participants, regardless of their group, by a charity, participation of normal and non-vulnerable cases in the community to support people using drugs, and investigating a chronic disease such as hepatitis C. Also, the presence of participants in the intervention group in training sessions with a family member was a significant measure, and the research team stayed in contact with participants and their families for a long time after the sampling. This was due to the support and sincere relationship of the research team with the participants. Moreover, the fact that a family member trusted the consumer and participated in training sessions and neighborhood campaigns were among the strengths of this study.

5.1. Conclusions

This study demonstrated that educational and social support affect the QoL of patients with hepatitis C. Therefore, designing appropriate intervention programs can be effective and useful in this regard. Therefore, we recommend performing educational programs for these patients to improve the QoL of hepatitis C patients. Moreover, the general health and QoL of hepatitis C patients should be emphasized while enhancing the role of health centers. As hepatitis C is a chronic disease and families can also participate in the care process of these patients, we recommend providing specific education to family members of hepatitis C patients in future studies.

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Footnotes

Authors' Contribution: Study concept and design, Z.BO. And F.K.; Analysis and interpretation of data, B.A., Drafting of the manuscript: Z.BO. And Z.BA; Critical revision of the manuscript for important intellectual content: Z.BA. And B.A.; Statistical analysis: F.K.

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Data Reproducibility: The authors did not declare it.

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