

## The Impact of Self-Care Instructional program on Quality of Life of Patients with Liver cirrhosis at El-Kasr EL Ainy Cairo University Hospital

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**Abstract:** Liver Cirrhosis is a serious and irreversible disease. It is a consequence of chronic liver disease characterized by replacement of liver tissue by fibrotic scar tissue as well as regenerative nodules, leading to progressive loss of liver function. Patients with chronic liver disease experience a variety of symptoms with profound negative impact on their HRQL. Working with patients with chronic liver disease requires not just dealing with the medical aspects of their disorder, but also working with the whole person-physically, emotionally and socially. The aim of this study was to determine the impact of a self care program on quality of life of cirrhotic patients. A quasi experimental research design was utilized in the current study. A convenient sample of 60 male and female patients in the hepatology units in ELkasr El Ainy hospital was selected as a study sample. Data pertinent to the study variables were collected from the study sample through structured interviews, utilizing two questionnaires designed by the researcher and chronic liver disease questionnaire (CLDQ) used to measure QOL in chronic liver disease patients. In addition to self care instructional program. Study findings revealed that the majority of the study sample felt bad impact of the disease on their family and worried about the disease progression most of time. The patients' knowledge about the prevention and care of cirrhotic patients is improved after the educational program. All of patients knew the complications of cirrhosis, allowed and prohibited food and drugs after the program. The total knowledge score is improved after the educational program. Based on the findings of the present study, continuous education and follow up of chronic hepatitis patients is needed to prevent the complications of cirrhosis and education of nurses regarding patients responses and perception of stress related to have chronic liver disease needs to be addressed.

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### 1. Introduction

Chronic disease is a form of handicap that one has to live with. It is not an entity in itself but an umbrella term that encompasses long- lasting diseases, which often are associated with some degree of disability. Chronic illness may threaten a person's basic emotional stability, and the whole situation may be unbearable to others. The length of illness, periodic hospitalizations and increased financial, emotional, and social burdens are stressors that threaten the family's integrity (Monahan *et al.*,2007).

Chronic disease is a global issue that affects both rich and poor nations. Chronic conditions have become the major cause of health related problems in developed countries as well as in developing countries which are also trying to cope with new and emerging infectious diseases. (Smeltzer *et al.*,2010).

Patient and family teaching is an important nursing role that may make the difference in the ability of the patient and family to adapt to chronic conditions .Well-informed ,educated patients are more likely than uninformed patients to be concerned about their health and to do what is necessary to

maintain it. They are also more likely to manage symptoms, recognize the onset of complications and seek health care early. Knowledge is the key to making informed choices and decisions during all phases of the chronic illness trajectory.(Kocaman *et al.*,2007)

Quality of life(QOL) is a concept that incorporates many aspects of an individual 's experience, general well-being, satisfaction, social and physical function. By definition QOL is subjective and multi-dimension. It can be influenced by socioeconomic factors, age, gender, presence of disease and treatment. QOL examines how patients experience and perceive. Its results provide a basis for holistic view of the patient and complements the organic outcomes ( Glise &Wilklund, 2002).

Liver cirrhosis is the term applied to chronic disease of the liver characterized by diffuse inflammation and fibrosis resulting in drastic structural changes and significant loss of liver function. The basic changes with cirrhosis are liver cell death and replacement of normal tissue by scar tissue that results in nodules of normal liver parenchyma surrounded by fibrous tissue and fat

(Starr & Hand, 2002). Cirrhosis of the liver is the third leading cause of death in people between the ages of 25 and 65 years, exceeded only by cardiovascular disease and cancer.

Hepatitis C is a lethal virus which can cause liver cirrhosis and cancer. In Egypt over one half million people get infected by the hepatitis C virus (HCV) each year, for more than any other country in the world, according to a new study published in the proceeding of the national Academy of Sciences. The epidemic has raged in the country for several decades now and shows no signs of abating. Nearly seven out of every 1,000 of Egypt 77 million people get infected each year. Around 10% of Egyptians are chronically infected and infectious, creating a large reservoir that supplies the spread of the disease, mainly through hospitals and clinics. (El-zanaty & Way, 2009 IRIN, 2010 and Miller, 2010).

A variety of signs and symptoms can be seen in persons with cirrhosis, they reflect the diminishing capacity of the liver to function normally. The patient may exhibit any or all of the signs and symptoms. Most manifestations can be directly related to the pathophysiologic changes as nausea, vomiting, anorexia, indigestion, flatulence, constipation, weight loss masked by water retention, malnutrition, abdominal pain, and late signs occurring gradually as ascites, jaundice, edema, anemia and bleeding (Smeltzer *et al.*, 2010).

Complications such as encephalopathy, ascites, bacterial peritonitis, and frequent bleeding from variceal veins dramatically alter the well being of cirrhotic patients as well as their quality of life. Studies have shown the negative effects of the disease on the patients' activities. (Porth & Matfin, 2009).

#### **Significance of the study**

More than 170 million people world wide are chronically infected with the hepatitis C virus (HCV). Chronic infection with HCV may have serious consequences, 15-20% of those with chronic infection will develop cirrhosis after 20 years and of these, 5-10% will develop hepatocellular carcinoma. (Fischer *et al.*, (2004).

Cirrhosis of the liver is the third leading cause of death in people between the ages of 25 and 65 years, exceeded only by cardiovascular disease and cancer. Cirrhosis and chronic liver diseases accounted for more than 25,000 deaths and 373,000 hospital discharges annually in the adult in the united states. The cost of cirrhosis in terms of human suffering, financial burden, and loss of productive life is devastating. (Zandi *et al.*, 2005).

The world health organization estimated 2011 that Egypt comes first world wide in hepatitis C (HCV) prevalence with more than 22 percent

suffering from the disease and shocking yearly number of infections exceeding 165,000.

#### **Aim of the study**

The aim of the study is to determine the impact of a self care instructional program on quality of life of cirrhotic patients.

#### **Research Hypotheses**

H1- Patients who will participate in the self-care instructional program will have better knowledge scores than prior participation.

H2- Patients who will participate in the self-care instructional program will demonstrate an improvement in their quality of life scores as compared to prior participation.

H3- There will be statistically significant positive correlation score between knowledge score and quality of life score among the studied subjects post participation in the instructional program.

## **2. Subjects and Methods**

### **Research design**

The study conducted using a quasi-experimental research design.

### **Setting**

The study conducted in the patients' hepatology units in El Kasr El-Aini Hospital.

### **Subjects**

A sample of convenience of (60) male and female adult patients with confirmed diagnosis of liver cirrhosis were included in the present study.

Inclusion criteria:

- 1- Adult patients up to 60 years old
- 2- Fully conscious with no mental disorders
- 3- Patients admitted to hepatology units with confirmed diagnosis of liver cirrhosis
- 4- Length of hospital stay not less than one week
- 5- Willingness to participate in the study.

### **Ethical Consideration:**

Ethical approval obtained from the relevant research ethical committee in the faculty of nursing, Cairo university, to approve the research. An official permission obtained from the directors of hepatology units in Elkasr Elainy hospital. A written consent obtained from the patients after explaining the aim of the study, its benefits and risks, duration of the study and the data collection tools. Patients assured that they can withdraw at any time from research without any effect on the treatment. Patients assured about confidentiality of all data.

### **Data collection tools:**

Data pertinent to the study variables were collected through structured interviews, utilizing two questionnaires designed by the researcher and chronic liver disease questionnaire (CLDQ) used to measure QOL in chronic liver disease patients developed by (Younossi *et al.*, 1999) and modified by

the researcher after pilot study. In addition to self care instructional program.

(1) A socio demographic and medical back ground data sheet used to elicit patient's age, sex, level of education, marital status, number of children, occupation, residence, frequency of previous hospitalization, cause of hospitalization, the duration, severity of the disease and other co morbidity.

(2) Pre/post Knowledge Assessment Questionnaire : consists of questions related to the common problems such as fatigue, itching, dry mouth, muscular cramps, and also common problems related to dietary regimen and drug therapy. The patient respond to the questionnaire as "yes" or "no".

(3) Chronic liver disease questionnaire (CLDQ) used to measure QOL in chronic liver disease patients developed by (Younnosi *et al.*, 1999). The CLDQ include 29 items in the following six domains: abdominal symptoms, fatigue, systemic symptoms, activity, emotional function and worry. It has 7 likert scale and modified by the researcher to 5 likert scale after pilot study, type of answers ranging from all of the time to none of the time. Possible range 29-145 from worst to best QOL).

(4) Self Care Instructional program was designed to clarify liver function, diagnostic tests, liver cirrhosis causes, signs & symptoms & complications, preventive measures of the disease, care & other regimen. This program translated to Arabic language, its content based on patients needs & literature review.

#### **Tool Validity and reliability:**

Extensive literature review and pilot study established content and face validity of the study tools. Structured interviews were conducted using the developed questionnaire sheets which consists of a series of questions to elicit subject's knowledge regarding the liver cirrhosis as a chronic disease. The self care instructional program was examined by five experts in the field of nursing education for correctness, relevance, feasibility & clarity. Chronic liver disease questionnaire (CLDQ) was translated into Arabic & revised by 5 experts in the field of nursing.

#### **Data collection Procedure**

Permission to conduct the proposed study was obtained from relevant authorities and agreement of the patients who participated in the study. Once permission was granted to proceed with the proposed study, a pilot study was conducted on 10 patients to test the feasibility of conducting the study, and the ability of the tools to elicit the desired information. Tools were also tested for appropriateness, content, wording and order. According to the result obtained from the pilot study, required changes in the tools were accommodated.

Patients who met the criteria for study inclusion were selected. Each patient was provided written consent before participation. The tools for data collection & self care instructional program were designed by the researcher. The self care instructional program was examined by five experts in the field of nursing education for correctness, relevance, feasibility & clarity. Chronic liver disease questionnaire (CLDQ) was translated into Arabic & revised by 5 experts in the field of nursing.

All patients were divided into eight small groups of 7-8 patients (relatives are permitted to attend). With regard to their levels of education and their free time. The content of educational program was similar in all groups except for its simplicity (based on subjects educational level). Four educational sessions were held for each group.

Each session was last from 30 to 45 minutes. Each subject was met by the researcher to collect socio demographic & medical back ground data using the designed socio demographic & medical back ground data sheet. Pre/Post knowledge assessment sheet was done for each patient individually to assess their base line knowledge score prior participation in the self care instructional program. Patients were allowed to ask questions and relevant guidance was provided by the researcher. Each patient was exposed to self instructional program using the instructional booklet.

Knowledge level of patients was assessed again using the Pre/ post Knowledge assessment questionnaire, scoring was done by the researcher for all subjects. The data collection phase took nine months from April to December 2011.

#### **Statistical analysis**

Data was analyzed using SPSS statistical system, each questionnaire sheet was coded and participant's answers were calculated. data were summarized using the relevant statistical tests. Numerical Data were expressed as mean and standard deviation as appropriate. Qualitative data were expressed as frequency and percentage.

### **3. Results**

The Current Study included 60 adult male and female patients. The study results indicated that, 65% of the study sample was males and 35 % of them were females. Their age ranged from less than 40 years to more than 60 years. 18.3% of the study sample was less than 40 years, 15% of them were between 40 and 50 years, 35% were between 50 and 60 years, and 31.7 of them were more than 60 years of age. The mean of age of the study sample was  $53.95 \pm 15.52$ . In relation to the marital status 8.3% of the study sample was single and 91.7 of them were married. Additionally, 45% of the study sample were illiterate, 25% of them could read and write, 25% had

middle education, 5% had university education. Regarding the occupation, 50% of the study sample had no regular work, whereas 41.7% were employees in professional work and 8.3% were employees in written work.

Table (1) showed the patients' cause of entering the hospital. 23.3% of the study sample entered the hospital by hematemesis, 35% of them entered hospital by lower limb edema, while 31.7% entered hospital by ascites, 5% of them entered hospital by hypertension, and 5% of the study sample entered hospital by difficulty of breathing. In relation to the hospital stay, 11.7% of them stayed in hospital for one week, 31.7% stayed in hospital for two weeks, and 56.7% stayed in hospital for more than three weeks.

Regarding to the domain of abdominal symptoms table (2) illustrated that 31.7% of patients felt all time by abdominal distension during the last two weeks, 60% of them felt it most of time and 8.3% of them felt it little of time. The mean of it was  $1.766 \pm .592$ . In relation to feeling abdominal pain, 25% of them felt it all time, 58.3% of them felt it most of time, 15% of them felt it little of time, while 1.7% of them rarely felt abdominal pain during last two weeks. The mean of it was  $1.933 \pm .685$ . As regards to feeling abdominal disorder during last two weeks, 30% of them felt it all time, 51.7% of them felt it most of time, while 18.3% of them felt it little of time. The mean of it was  $1.883 \pm .691$ .

As regards to the domain of fatigue table (3) revealed that 66.7% of the study sample felt tired all time during last two weeks, 28.3% of them felt it most of time, while 5% of them felt it little of time. The mean of it was  $1.38 \pm .58$ . In relation to feeling sleep, 16.7% of the study sample feeling sleep all time during the last two weeks, 43.3% of them felt it most of time, 35% of them felt it little of time. The mean of it was  $2.28 \pm .80$ . As regards to feeling weakness, 31.7% of the study sample felt it all time, 58.3% felt it most of time. The mean of it was  $1.86 \pm .83$ . In relation to feeling low energy during last two weeks, 6.7% of the study sample felt it all time, 88.3% of them felt it most of time. The mean of it was  $1.98 \pm .34$ . As regards to feeling dizzy, 20% of the study sample felt it all time, 28.3% of them felt it most of time, 40% of them felt it little of time, The mean of it was  $2.46 \pm 1.01$ .

In relation to systemic symptoms domain table (4) illustrated that 46.7% of the study sample felt bodily pain all time during the last two weeks, 41.7% of them felt it most of time, 10% of them felt it little of time. The mean of it was  $1.66 \pm .72$ . In relation to feeling by shortness of breath, 8.3% of the study sample felt it all time during last two weeks, 28.3% of them felt it most of time, 58.3% of them felt it

little of time. The mean of it was  $2.61 \pm .76$ . As regards to muscle contraction, 5% of the study sample felt it all time during last two weeks, 38.3% felt it most of time, 38.3% felt it little of time. The mean of it was  $2.80 \pm 1.02$ . In relation to feeling by mouth dryness, 31.7% of the study sample felt it all time during last two weeks, 35% of them felt it most of time, 18.3% of them felt it little of time. The mean of it was  $2.21 \pm 1.15$ . As regards to feeling by body itching, 13.3% of the study sample felt it all time, 45% of them felt it most of time, 33.3% of them felt it little of time. The mean of it was  $2.40 \pm .90$ .

Regarding to activity domain table (5) showed that 16.7% of the study sample felt all time that they not able to eat as before in the last two weeks, 68.3% of them felt it most of time and 10% of them felt it little of time. The mean of it was  $2.050 \pm .746$ . In relation to ability to lifting loads, 40% of the study sample felt that they could not lift loads all time less than before, 20% of them felt it most of time and 33.3% of them felt it little of time. The mean of it was  $2.083 \pm 1.046$ . As regards to feeling bothered to limited meal during the last two weeks, 26.7% of the study sample felt it all time, 53.3% of them felt it most of time and 10% of them felt it little of time. The mean of it was  $2.083 \pm 1.013$ .

As regards the emotional function domain table (6) showed that 21.7% of the study sample felt annoyed during the last two weeks all time, 60% of them felt it most of time and 15% of them felt it little of time. The mean of it was  $2.01 \pm .77$ . In relation to feeling unhappy, 28.3% of the study sample felt it all time, 40% of them felt it most of time and 26.7% of them felt it little of time. The mean of it was  $2.08 \pm .86$ . As regards to feeling by restlessness 36.7% of the study sample felt it all time and 53.3% of them felt it most of time during the last two weeks. The mean of it was  $1.80 \pm .83$ . In relation to insomnia at night, 15% of the study sample felt it all time, 48.3% of them felt it most of time and 31.7% of them felt it little of time. The mean of it was  $2.26 \pm .77$ . In relation to feeling by mood swings, 25% of the study sample felt it all time, 48.3% of them felt it most of time, 18.3% of them felt it little of time during the last two weeks. The mean of it was  $2.11 \pm .92$ . Regarding to inability to sleep at night, 15% of the study sample felt it all time, 45% of them felt it most of time and 36.7% of them felt it little of time. The mean of it was  $2.28 \pm .76$ . As regards to feeling by depression, 16.7% of the study sample felt it most of time, 51.7% of them felt it little of time, 16.7% of them rarely felt it, and 15% of them did not feel it during the last two weeks. The mean of it was  $3.30 \pm .92$ . In relation to feeling by less concentration, 18.3% of the study sample felt it all time, 36.7% of them felt it most of time and 26.7% of

them felt it little of time during the last two weeks. The mean of it was  $2.51 \pm 1.12$ .

In relation to worry table(7) illustrated that 38.3% of the study sample felt all time that their disease had bad impact on their family, while 61.7% of them felt it most of time during the last two weeks. The mean of it was  $1.61 \pm .49$ . In relation to feeling worry about disease symptoms, 8.3% of the study sample felt it all time, 73.3% of them felt it most of time and 10% of them felt it little of time during the last two weeks. the mean of it was  $2.25 \pm .89$ . As regards to feeling by possible deterioration, 3.3% of the study sample felt it all time, 73.3% of them felt it most of time and 15% of them felt it little of time during the last two weeks. The mean of it was  $2.30 \pm .72$ .

In relation to feeling by lack of improvement, 31.7% of the study sample felt it all time, 53.3% of them felt it most of time and 10% of them felt it little of time. The mean of it was  $1.88 \pm .78$ . As regards to the possibility of liver transplantation if needed, 10% of them cared about it all time, 31.7% of them cared about it most of time, 18.3% of them cared about it little of time, 25% of them rarely cared about it, and 15% of them did not care about it during the last two weeks. The mean of it was  $3.03 \pm 1.26$ .

Clearly table (8) illustrated that each one of the six domains of CLDQ has highly significant correlation with each other one of them and with the total QOL score.

It is evident from table (9) that, total knowledge after the program has highly significant correlation with the total score of QOL.

**Table (1): Frequency and percentage distribution of patients' cause of entering the hospital (n=60)**

Variables	No	%
Hematemesis	14	23.3
Lower limb edema	21	35
Ascites	15	31.7
Hypertension	3	5
Difficulty of breathing	3	5
Duration of hospital stay		
One week	7	11.7
Two weeks	19	31.7
More than 3 weeks	34	56.7

**Table (2): Frequency and percentage distribution of patients responses to CLDQ related to abdominal symptoms (AS) items 1,5,17 (n=60)**

Response	score	Abdominal. Distension		Abdominal Pain		Abdominal disorder	
		No	%	No	%	No	%
All time	1	19	31.7	15	25	18	30
Most of time	2	36	60	35	58.3	31	51.7
Little of time	3	5	8.3	9	15	11	18.3
Rarely	4	-	-	1	1.7	-	-
$\bar{X} \pm SD$		1.766± .592		1.933± .685		1.883± .691	

**Table (3): Frequency and percentage distribution of patients responses CLDQ related to fatigue (FA) domain items 2,4,8,11,13 (n=60).**

Response	Tired		Sleep		Weakness		low energy		Dizziness	
	No	%	No	%	No	%	No	%	No	%
All time 1	40	66.7	10	16.7	19	31.7	4	6.7	12	20
Most of time 2	17	28.3	26	43.3	35	58.3	53	88.3	17	28.3
Little of time 3	3	5	21	35	2	3.3	3	5	24	40
Rarely 4	-	-	3	5	3	5	-	-	5	8.3
Don't feel 5	-	-	-	-	1	1.7	-	-	2	3.3
$\bar{X} \pm SD$	1.38±.58		2.28± .80		1.86±.83		1.98±.34		2.46±1.01	



**Table (4): Frequency and percentage distribution of patients' responses to CLDQ related to systemic symptoms (SS) domain items 3,6, 21, 23,27(n=60).**

Response	Pain		Shortness of breath		Muscle contraction		Mouth dryness		Body itching	
	No	%	No	%	No	%	No	%	No	%
All time 1	28	46.7	5	8.3	3	5	19	31.7	8	13.3
Most of time 2	25	41.7	17	28.3	23	38.3	21	35	27	45
Little of time 3	6	10	35	58.3	23	38.3	11	18.3	20	33.3
Rarely 4	1	1.7	2	3.3	5	8.3	6	10	3	5
Don't feel 5	-	-	1	1.7	6	10	3	5	2	3.3
$\bar{X} \pm SD$	1.66±.72		2.61±.76		2.80±.1.02		2.21±1.15		2.40±.90	

**Table (5): Frequency and percentage distribution of patients' responses to CLDQ related to activity(Ac) domain items 7,9,14 (n=60).**

Response	score	Inability to eat		Lifting loads		Bothered to limited meal	
		No	%	No	%	No	%
All time	1	10	16.7	24	40	16	26.7
Most of time	2	41	68.3	12	20	32	53.3
Little of time	3	6	10	20	33.3	6	10
Rarely	4	2	3.3	3	5	3	5
Do not feel	5	1	1.7	1	1.7	3	5
$\bar{X} \pm SD$		2.050±.746		2.083± 1.046		2.083± 1.013	

**Table (6): Frequency and percentage distribution of patients' responses to CLDQ related to Emotional function(EF) domain items 10,12,15,16,19,20,24,26 (n=60):**

Response	Annoyed		Unhappiness		Restlessness		Insomnia	
	No	%	No	%	No	%	No	%
All time 1	13	21.7	17	28.3	22	36.7	9	15
Most of time 2	36	60	24	40	32	53.3	29	48.3
Little of time 3	9	15	16	26.7	4	6.7	19	31.7
Rarely 4	1	1.7	3	5	-	-	3	5
Don't feel 5	1	1.7	-	-	2	3.3	-	-
$\bar{X} \pm SD$	2.01±.77		2.08±.86		1.80±.83		2.26±.77	

**Table (6) Cont 'd**

Response	Mood swings		Inability to sleep		Depression		Less concentration	
	No	%	No	%	No	%	No	%
All time 1	15	25	9	15	0	0	11	18.3
Most of time 2	29	48.3	27	45	10	16.7	22	36.7
Little of time 3	11	18.3	22	36.7	31	51.7	16	26.7
Rarely 4	4	6.7	2	3.3	10	16.7	7	11.7
Don't feel 5	1	1.7	-	-	9	15	4	6.7
$\bar{X} \pm SD$	2.11±.92		2.28±.76		3.30±.92		2.51± 1.12	

**Table (7): Frequency and percentage distribution of patients' responses to CLDQ related to worry(WO) domain items 18,22,25,28,29 (n=60).**

Response	Bad impact on family		Worry about disease symptoms		Deterioration		Lack of improvement		Liver transplant	
	No	%	No	%	No	%	No	%	No	%
All time	23	38.3	5	8.3	2	3.3	19	31.7	6	10
Most of time	37	61.7	44	73.3	44	73.7	32	53.3	19	31.7
Little of time	-	-	6	10	9	15	6	10	11	18.3
Rarely	-	-	1	1.7	4	6.7	3	5	15	25
Don't feel	-	-	4	6.7	1	1.7	-	-	9	15
$\bar{X} \pm SD$	1.61±.49		2.25±.89		2.30±.72		1.88±.78		3.03± 1.26	

**Table (8): Correlations between the total scores of the six domains of CLDQ & Total QOL score(n=60):**

Total Domain	Total Abdominal symptoms QOL	Total Fatigue QOL	Total Systemic symptoms	Total Activity
Total Abdominal symptoms	1.000	.466**	.230	.448**
Total Fatigue	.466**	1.000	.497**	.644**
Total Systemic symptoms	.230	.497**	1.000	.433**
Total Activity	.448**	.644**	.433**	1.000
Total emotional symptoms	.510**	.488**	.612**	.526*8
Total Worry	.289*	.388**	.618**	.409**
QOL Total score	.574**	.730**	.782**	.717**

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

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

**Table (8) cont'd:**

Total Domain	Total emotional symptoms QOL	Total Worry QOL	QOL Total score
Total Abdominal symptoms	.510**	.289*	.574**
Total Fatigue	.488**	.388**	.730**
Total Systemic symptoms	.612**	.618**	.782**
Total Activity	.526**	.409**	.717**
Total emotional symptoms	1.000	.688**	.880**
Total Worry	.688**	1.000	.796**
QOL Total score	.880**	.796**	1.000

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

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

**Table(9): Correlations between total knowledge pre and post the educational program and total QOL score(n=60):**

	Total Knowledge pre	Total Knowledge post	QOL total score	t	df
Total Knowledge Pre $\bar{X} \pm SD$ 12.25 $\pm$ 2.64	1.000	.111	.165	-13.54	59
Total Knowledge Post $\bar{X} \pm SD$ 16.85 $\pm$ 3.60	.111	1.000	.323*		
QOL total score	.165	.323*	1.000		
Total Knowledge pre - Total Knowledge Post $\bar{X} \pm SD$ 4.60 $\pm$ 2.63					

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

#### 4. Discussion

Results from data collected in this study showed that the majority of the patients included were males, the present study revealed that most of the study subjects were in the fifties, while the minority were in the forties. The mean age of patients in the study sample was below sixty. In relation to the marital status, the majority of the study sample were married and the minority of them were single.

As regards to level of education, about half of the sample were illiterate, while one fourth of patients in the study sample either can read and write or had middle education, While the minority of the study sample had university education. In relation to occupation, half of the sample were not work, the

minority of them were official employees. In relation to monthly income, more than half of the study sample asserted that their income is enough, and the others shown it not enough for their responsibilities. As regards to the place of residence, more than half of the study sample were residents in rural areas, while the others were residents in urban areas.

Sobhonslidsuk *et al.* (2006), asserted that old age had a negative impact on HRQL, the elderly is associated with less favorable appraisal of personal health due to their health concerns, pessimistic health appraisal, social isolation and unemployment. In stead of females have more health concerns and are more treatment seeker than male, the study found that female gender yielded negative influence on physical

functioning, and they found marital status did not affect HRQL, this may be explained in Thai society by that CLD patients could get psychological support from other family members even when they are single or divorced. Law socioeconomic status also was shown to be important factor affecting HRQL in normal population. In general level of education also can help people cope their own problems. Low educated people are prone to have psychological problems and have false beliefs. People with lower socioeconomic status have more stress, more depression, and interfamilial relationship problems in their life.

Symptoms of HCV can include fatigue, weakness, general malaise, mild abdominal pain, chronic pain and loss of appetite, although some patients may not experience any identifiable symptoms. Although research has demonstrated that HCV is associated with the development of advanced liver disease, cirrhosis, and hepato-cellular carcinoma (HCC), and is a leading indication for liver transplantation. (Jessop, 2004).

When patients were asked about the cause of entering the hospital more than one third of the study sample entered the hospital by lower limb edema, less than one third entered the hospital by hematemesis or ascites, while the others entered it because of hypertension or difficulty in breathing. As regards to the duration of hospital stay, the majority of them stayed in the hospital for more than three weeks, about one third of them stayed in the hospital for two weeks, while the minority of them stayed in the hospital for one week. Sangiovanni *et al.* (2003) mentioned that most patients develop cirrhosis will remain well compensated for the remainder of their lives. Decompensation, manifested by development of ascites, encephalopathy, jaundice and hematemesis. At least one third of deaths in patients with cirrhosis occurs as a consequence of these complications. Decompensation is of great prognostic importance even if the decompensation event is transient or easily managed. Mahta & Rothstein (2009), also mentioned that cirrhosis is the end result of chronic liver damage caused by chronic liver disease, it is caused by irreversible scarring of the liver, once cirrhosis develops, it is not possible to heal the liver or return its function to normal. It is a serious condition that can lead to many complications as ascites, portal hypertension, hematemesis and hepatocellular carcinoma or hepatic encephalopathy.

In relation to the domain of abdominal symptoms, the majority of the patients in the study sample felt abdominal distension, pain and discomfort most of time during the last two weeks in the time of data collection, more than one third of them felt abdominal pain and discomfort all time, while the

minority of them felt it little of time, This coincides with the available literature which shows that symptoms of cirrhosis may develop gradually, when symptoms do occurs they can include abdominal bloating, abdominal indigestion or pain, nausea and vomiting, swelling or fluid build up of the legs, and in the abdomen (ascites), vomiting blood, or blood in stool, weakness and weight loss(Garcia, 2009).

When patients were asked about their feeling of fatigue, tiredness, sleep disturbances, weakness, low energy and dizziness, the majority of them felt tired all time, the majority of them also felt weak, sleepy, and had low energy most of time, more than one third of them felt dizzy little of time, and the minority of them rarely or never felt it. About quarter of them felt dizzy all time or most of time. Dienstag & Isselbacher (2005), asserted that the client with cirrhosis often experiences severe fatigue, leading to activity intolerance related to bed rest, fatigue, lack of energy and altered respiratory function secondary to ascites.

Clinicians often prescribe rest for clients with cirrhosis, but how much rest is necessary is debated. During periods of acute malfunction, rest reduces metabolic demands on the liver and increases circulation. Long term planning should include counseling the client to rest frequently and to avoid unnecessary fatigue. Smeltzer & Bare (2010).

When patients were asked about systemic symptoms as pain, shortness of breathing, muscle contraction, mouth dryness and body itching, about half of them responded that they felt pain all time, and more than one third of them felt pain , muscle contraction, mouth dryness and body itching most of time, more than half of them felt shortness of breathing little of time, and the minority of them felt all these systemic symptoms rarely or never felt it. This goes in agreement with Chung & Podolsky (2005), they stated that ascites leads to many other problems as shortness of breathing related to increased intra- abdominal pressure on the diaphragm , in clients with ascites severe edema as well as other problems may develop as impaired skin integrity, abdominal pain, pruritus(itching) , due to immobility, edema, and pressure from abdomen, restriction of fluid also causes mouth dryness and muscle contraction due to electrolyte imbalance.

Petta *et al.* (2010), mentioned that muscle cramps are common in patients with cirrhosis, especially once fluid retention develops. Many patients have muscle cramps despite normokalemia due to pressure induced by ascites. It can improve with control of fluid over load and does not warrant specific treatment other wise. Mayo (2007), supported that leg cramps are very common in patients with cirrhosis. They are frequently due to decreased amounts of minerals in the body such as



calcium, magnesium, and zinc. So it is preferable for patients take these kinds of minerals supplements to avoid cramps.

In relation to activity, the majority of the study sample were unable to eat as much as they like in the last two weeks most of time, the majority of them also were bothered to limitation of their meal in the last two weeks most of time, one third of them had trouble lifting or carrying heavy objects little of time, while more than one third of them had this trouble all time, in the last two weeks of data collection time.

As reported by Blei (2007), patients with cirrhosis had imbalanced nutrition related to impaired utilization and storage of nutrients, increased pressure on stomach and intestines, feeling full, anorexia, nausea, loss of nutrients from vomiting. They also had activity intolerance related to anemia from poor nutrition and bleeding, ascites, dyspnea from pressure of ascites on diaphragm and muscle wasting. (Abraides & Bosch, 2007).

Nair (2010) mentioned that when patient pears down and does valsalva maneuver to pick up something heavy, he/she can dramatically increase the pressure in esophageal varices, can suddenly bleed. So the patients with esophageal varices were advised to limit the weight that they left to 40 pounds (18 kilograms).

In relation to the domain of emotional function, the majority of the study sample felt anxious and unhappy most of time during the last two weeks of data collection, while more than half of them felt irritable and had insomnia most of time,. As regards to mood swings and inability to sleep at night, about half of them felt it most of time, while more than half of them felt depressed little of time, more than one third of them had problems concentrating most of time in the last two weeks, This coincides with Stein, Maksad & Clarke, (2001) who emphasized that a patients who learns that he or she has contracted CLD or HCV may exhibit a range of emotional responses, including worry, fear, hopelessness, depression, and anger.

In relation to the domain of worry, more than one third of the study sample felt worried about the bad impact of their liver disease on their family all time, and they also felt worried about lack of improvement, more than half of the study sample felt all time by bad impact of their disease on their family, worried about disease symptoms, and felt by deterioration of their condition. About one third of them concerned most of time about the availability of a liver if they need liver transplantation. Sheikh *et al.* (2004), asserted that the neurologic changes occur with gastrointestinal bleeding, hepatic encephalopathy, and accumulation of ammonia impairs memory, attention, concentration and rate of

response. Sleep pattern reversal often occurs, with the client awake at night and sleepy during the day. Hand writing and speech shows significant changes as intellectual deterioration occurs. As the syndrome progresses, the client's level of consciousness slowly diminished and confusion becomes more severe and coma may eventually ensue. A liver transplant may be performed in cases of fulminant liver failure.

The CLDQ scores in patients with cirrhosis deteriorated as severity of chronic liver disease increased, more than half of the study sample had moderate scoring range of total abdominal symptoms, fatigue, activity symptoms, systemic symptoms, emotional symptoms and worry. Which means more worst QOL than the higher score which considered the best QOL. Half of the study sample had worse total score of QOL than others who had high score of QOL. This coincides with Bianchi *et al.* (2003), Cordoba, (2005), they stated that chronic liver disease (CLD) had negative effect on QOL and QOL worsened as the severity of disease increased.

According to Runyon (2011), many people who have cirrhosis remain undiagnosed. Careful attention to risk factors for liver disease and clues to the presence of cirrhosis on history, physical examination, laboratory testing, and imaging can rule in the presence of cirrhosis and help avoid harmful treatments. The risks versus benefits of medication and each procedure must be carefully weighed. Do no harm is the relevant dictum.

According to Orem, self care is a learned behavior, which can satisfy many needs of patients, provide growth, and development, and prevent deviation from health. For patients with chronic conditions, health related quality of life can improve significantly when they are trained in self management techniques and empowered with education. (Zandi *et al.*, 2005).

As regards to patients' knowledge about symptoms of liver cirrhosis, the majority of the study sample were knew the cirrhosis symptoms, but the majority of them gave unsatisfied answer and approximately all of them knew how liver cirrhosis is diagnosed before giving the program. After applying it, all of the study sample knew the cirrhosis symptoms and diagnosis measures and they gave a satisfied answer. Bonis & Chopra (2011), supported that people with cirrhosis may or may not have symptoms early in the course of the disease, they have weakened immune system and are at increased risk of infections and malnutrition. They mentioned also that many people with advanced cirrhosis have jaundice, fatigue, itching, and are at increased risk of developing liver cancer. Naghabi *et al.* (2010), asserted that providing information to the patients' about their disease course, treatment and side effects

will increase their tolerance, compliance and adherence to disease therapy.

Rosselli, Zuckermann (2011), emphasized that cirrhosis diagnosis is testing performed to confirm the diagnosis of cirrhosis, determine the underlying cause, determine the severity of cirrhosis, and monitor of complications. Diagnosis includes liver biopsy, which still the reference method to assess the grade of inflammation and the stage of fibrosis, imaging tests such as ultrasound and blood tests. Craxi, *et al.* (2011), asserted that assiduous monitoring and management of side effects especially those linked to portal hypertension and hyper splenism is required and patients with cirrhosis should undergo regular surveillance of HCC. testing usually require an ultrasound examination of the liver every six months.

Runyon (2009), asserted that patients with cirrhosis are susceptible to infections, and bleeding, both of which can be life threatening. The cirrhotic patients must contact the doctor if any of the following symptoms occurs, fever, confusion, vomiting more than once/day, rectal bleeding, vomiting of blood, diarrhea, abdominal or chest pain, shortness of breathing, abdominal swelling and jaundice. The previous findings imply that knowledge of the patients improved after application of the educational program and all the study sample ranged in moderate total scoring range and moderate quality of life.

## 5. Conclusion

Based on the results of the present study, it can be concluded that, patients with cirrhosis deteriorated as disease becomes more severe as measured by CLDQ, abdominal symptoms, fatigue, worry, decreased energy, and activity were major problems and symptoms of cirrhotic patients that impaired the quality of life of those patients. It was evident from the findings that there was a beneficial effects of educational and self-care program on the health related quality of life of cirrhotic patients and there was an improvement in patients quality of life after self care and educational program.

## Recommendations

**Based on the findings of the present study, it was recommended that:**

-A comprehensive plan is needed to prevent and control hepatitis C in Egypt. This plan should address increasing community awareness and education. Preventing HCV infection in health care settings, ensuring safe blood supply, establishing surveillance and monitoring to track the effectiveness of control programs, and providing care and treatment.

- Education of nurses regarding patients responses and perception of stress related to have chronic liver disease and uncertainty toward future needs to be addressed.

- Continuous education and follow up in chronic hepatitis B&C patients to decrease the side effects, ultimately resulting in a better quality of life.

- Replication of the study on a large sample and in different hospital settings is recommended for generalization of results.

- Studies should be done to correlate responses and socio-demographic data of cirrhotic patients.

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