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RESEARCH ARTICLE

EFFECT OF AN EDUCATIONAL PROGRAM ON HEPATITIS C PATIENTS TREATED WITH INTERFERON AND THEIR FAMILY CAREGIVERS

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ABSTRACT

Hepatitis C virus (HCV) stands as one of the most important etiologies of chronic liver disease and is an emerging infection in the world. Egypt has the largest burden of HCV infection in the world.

Aim: - To identify effect of an educational program on hepatitis C patients treated with interferon and their family caregivers.

Materials and Method: A quazi experimental study design was used in this study. This study was carried out in the outpatient clinic at Al-Mahalla educational liver hospital. Purposive number of 50 HCV patients (numbers of cases in 6 months) and 50 of their family caregivers attending the previous setting were included in the study. Three tools were used in this study interview sheet, health profile sheet and SF36 HRQoL.

Results: the result of this study showed that before implementation of the program the studied patients and their family caregivers' had low scores of knowledge and practices furthermore, the studied patients also had poor life style behaviors and poor quality of life. After implementation of the program there was a significant improvement in the total knowledge and total practices score of the studied patients and their family caregiver's pre, immediate, and three months post program intervention. P (<0.001). There was a significant improvement in the dietary habits practices, activity of daily living and quality of life of the studied HCV patients.

Conclusion: it can be concluded that the education program was effective and improved the level of HCV patients and their family care givers knowledge and practices toward management of HCV. And improve patient quality of life. Recommendation this study recommended that, an educational program should be planned and offered at regular basis to all patients and their caregivers to improve their knowledge, practices and quality of life.

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INTRODUCTION

Hepatitis C virus (HCV) infection is a common global public health problem (Alavian and Fallahian, 2009 and Alavian *et al.*, 2011). Approximately 200 million individuals are infected with HCV worldwide (Alavian *et al.*, 2009). Although the prevalence of HCV infections has reduced in developed countries because of effective prevention plan, it still high in developing countries (Alter, 2007 and Alavian and Fallahian, 2008). HCV is considered as the main cause of liver diseases in both developed and developing countries and contributes to the increasing risk of liver failure and hepatocellular carcinoma (HCC) (Alavian *et al.*, 2009; Alter, 2007; Alavian, 2010 and Alavian *et al.*, 2005). In addition, HCV is responsible for 20% of all acute hepatitis cases, 70% of all

Chronic hepatitis cases, 40% of all liver cirrhosis cases, 60% of HCCs, and 30% of infections in liver transplants in Europe (Ahmadipour *et al.*, 2005 and Alavian *et al.*, 2010). Moreover, most of the recently admitted HCC patients had viral hepatitis C (Ohishi *et al.*, 2011). Egypt has the highest prevalence of HCV in the world. Recently the Egyptian Demographic Health Survey [EDHS] (2008), reported a representative sample of the entire country for HCV antibody (14.7%). The survey included both urban and rural populations and all governorates (El-Zanaty *et al.*, 2009). HCV is a hepato-trophic virus usually spread when blood or body discharges from patient enters a susceptible. The virus is commonly transmitted through exposure to infectious blood as blood transfusions, blood products, organ transplants; contaminated syringes, needle-stick injuries in health-care settings; injection drug use; from mother to her baby, sharing of personal equipment's and less commonly through sex (World Health Organization, 2012 and Washington State Department of Health, 2012).

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Approximately 80% of people do not exhibit symptoms. Patients who are acutely symptomatic may exhibit fever, fatigue, decreased appetite, nausea, vomiting, abdominal pain, dark urine, pale stool, joint pain, and jaundice. When a chronically-infected person develops symptoms, it may indicate advanced liver disease (World Health Organization, 2012; Washington State Department of Health, 2012; Burke *et al.*, 2011 and Talley *et al.*, 2008). Patients are usually managed at home unless symptoms are severe. Therefore, the patient and family need to be assisted to cope with the problem and to be aware of the indications to seek additional health care if the symptoms persist or worsen (Brunner and Sunddardh, 2006). According to the Family Caregiver Alliance, caregivers have a higher risk of mental and physical health problems. They experience depression, pain, loneliness, grief, and fear of unknown, death and of change. They may feel insecure about their ability to give adequate support, the risk of acquiring HCV, or of being a single parent or sole financial provider (Lucinda K. Porter, 2009).

Lankarani (2004), stated that improving compliance with therapy can be enhanced by some measures such as patient and caregiver education, close follow up, adequate treatment of side effects and dose adjustment. While lack of expertise in the proper management of these side effects as well as lack of educating patient may lead to higher rates of drug discontinuation or dose reduction with lower efficacy of treatment (Lankarani, 2004). Health education is a process by which individuals and groups of people learn to behave in a manner to the promotion, maintenance or restoration of health (Park, 2009). Strategically, health professionals find track and treat diseases before becoming a crisis. Community health nurses as members of the health team are part of the first-line of defense against disease and illness by using proven practices, strategies, and examining the overall health needs of families in the community (Public Health Nursing, 2012). Community health nurses are actively involved in identifying the risk factors for infection in population in the event of epidemic. They apply the principles of teaching and learning to promote positive health actions to facilitate behavior change. The goal to use these principles is to learn clients about healthy functioning (Clark, 2008).

MATERIALS

Study design-

A quazi experimental study design was used in this study.

Setting

This study was carried out in the outpatient clinic at Al-Mahalla educational liver hospital affiliated to ministry of health.

Subjects

A purposive number of 50 HCV patients (numbers of cases in 6 months) and 50 of their family caregivers (the family member who provide the care to the patient) attending the

previous setting were included in the study. The patients were selected according to the following criteria's:

A-Inclusive criteria

- 1- Age 18-60 year (recommended age for receiving interferon)
- 2- Both sex
- 3- First time treated with interferon/ribavirin therapy

B- Exclusive criteria

- 1- Patient with liver cirrhosis

Tools: - Two tools were developed by the researcher and sf36 scale was used in order to obtain the necessary data.

Tool 1:- An Interview sheet (pre / post-test): it was developed by the researcher After reviewing literature (Alavian, 2010; El-Zanaty *et al.*, 2009 and Talley *et al.*, 2008) in order to assess the patient and his caregiver knowledge about hepatitis C virus it was include the following 4 parts:-

Part 1:- Sociodemographic and environmental data

Sociodemographic data:- such as age, sex, marital status, education, occupation, family income, family size, kin relationship, and residence .

Environmental data:- such as the housing condition regarding number of rooms, availability of sanitary water supply, ventilation and the presence of sewage and refuse disposal system .

Part 2:- The patient and his family caregiver knowledge about

Types of hepatitis, HCV definition, incubation period, mode of transmission, signs and symptoms, treatment of and complications

Part 3:- Family caregiver knowledge and patient habits and lifestyle

The patient will be asked about: Regularity and frequency of meals, Types of food, Amount of and types of fluids, Physical activity or exercise and Smoking or drug abuse.

Part 4:- The patient and his family caregiver knowledge and practices to prevent spread of HCV

Common syringes, Disposal of contaminated blood, Personal equipment's share or disposal and Use of protective equipments

Tool II:- Health profile sheet:- (pre -test): it was developed by the researcher in order to assess the patient and his family health history. It was include the following 3 parts:-

Part 1:- Current health history Patient of :- Onset of HCV, Diagnostic methods of HCV and treatment (time of administration and type used).

Part 2:- previous medical and surgical history of patient:- Previous hospitalization, History of chronic disease., History of schistosomiasis and treatment used, History of hepatitis A or B, History of operation and blood transfusion, History of dental treatment procedures and Previous tattoo.

Part 3:- Family history:- Liver disease (HCV).and kinship

Tool III: - Health related quality of life scale (HRQOL) (pre / post –test)

Short Form 36 Questionnaire (SF36) ⁽²²⁾ was used to assess health related

Quality of life of the patients (physical and mental state) which include

Physical functioning, Role limitations due to physical health, Bodily pain, General health perceptions, Vitality (energy/fatigue), Social functioning, Role limitations due to emotional health and General mental health (psychological distress/wellbeing). All raw scores were transformed to a 0-100 score using the following formula

Transformed score = $\frac{\text{actual raw score} - \text{lowest possible raw score}}{\text{Possible raw score range}} \times 100$

Higher score indicates better Generic Health-Related Quality Of Life (HRQOL).

METHODS

Obtaining approvals

- Official permission to conduct the study was obtained from the Faculty of Nursing -Tanta University.
- Official permission to conduct the study was obtained from the Ministry of Health – The General Organization for Teaching Hospitals and Institutes to conduct the study at Al mehala educational Liver Hospital.

Developing the tools

- Study tools (tool I and II) were developed by the researcher based on literature review.
- The developed tools were distributed to a jury of 5 academic professors before conducting the study to test the face and content validity. The necessary modifications were done.

The pilot study

A pilot study was carried out on 10 HCV patients and 10 of their family caregivers to test the tool for its clarity, organization, applicability and to determine the length of time needed to collect the data. The necessary modifications were done. Those patients and their family caregivers were excluded from the study sample.

Implementation phase

- The program was totally carried out by the researcher; this is to ensure providing complete, consistent and accurate knowledge about hepatitis c virus and its management to the study participants.
- Informed consent was obtained from the study group to participate in the study.
- Implementation of the program was carried out in the outpatient clinic at Al-Mahalla educational liver hospital
- Every patient and his family caregiver were informed about the purpose and benefits of the study at the beginning of interview.
- Ethical considerations: keeping privacy and confidentiality of any information obtained from the study subjects.
- The researcher was meeting with patient and his family caregiver at outpatient clinic three days per week (Saturday, Sunday and Thursday) from six days of receiving interferon therapy from September 2012 until the middle of July 2013 about 10 months
- Hepatitis c patients and their family caregiver were present all 8 sessions of the program (480 minutes) 60 minutes for each session
- Each patient and his family care giver were met once per week according to his schedule of receiving interferon injection in the outpatient clinic.
- The program was implemented for the patients and their family caregivers together. To ensure that they were exposed to the same learning experience, they also received the same program content and used the teaching methods
- The audiovisual material used in this study included booklet, power point and real materials (e.g. syringe, cotton, safety box, gloves and cholrx).
- Lectures, group discussions and demonstration and redemonstration were used as teaching methods.
- Each session started by a summary of what was given in previous session and specific objectives of present session.
- Booklet of hepatitis c educational program was distributed to all participants to use it as future reference.

Evaluation phase

- Assessment was done to the participants in order to test their knowledge and practices about hepatitis C.
- Assessment was done to the patients in order to test the impact of hepatitis C on their quality of life before and after education. Assessment was done according to the following:-

Tool I was introduced to the study subjects three times:-

First time: - before implementation of the program,

Second time: - immediately after implementation of the program and

Third time: - three months after the implementation of the program.

Tool II was administered to the patients one time before implementation of the program

Tool III was administered to the patients two times:-

First time: - before implementation of the program and

Second time: - three months after the implementation of the program.

Data analysis

A-Statistical analysis

The collected data was organized, tabulated and statistically analyzed using SPSS software statistical computer package version 17. Using chi square test (X^2). For quantitative data the range, mean, stander deviation, paired sample t test was calculated to compare between means, the. Correlation between variables was evaluated using Pearson's correlation coefficient. Significance was adopted at $P < 0.001$ for interpretation of results of tests of significance.

Scoring system

The knowledge score of the studied HCV patients regarding hepatitis & HCV:- each of the answers to knowledge question was given a score . The total score amounted to 60 points knowledge score had been classified into three categories as follows :-

Poor knowledge: < 50 % of the total knowledge.

Average knowledge: $50 - < 65$ % of the total knowledge.

High knowledge: ≥ 65 % of the total knowledge.

The practices score of the studied HCV patients and their family caregivers regarding HCV preventive measures:- each of the answers to practice question was given a score. The total score amounted to 10 points practices score had been classified into three categories as follows:-

Poor practice: ≥ 50 % of the total practice.

Average practice: $50 - < 65$ % of the total practice.

good practice: ≥ 65 % of the total practice.

The knowledge score of the studied family caregivers regarding hepatitis & HCV:-each of the answers to knowledge question was given a score. The total score amounted to 72 points knowledge score had been classified into three categories as follows:-

Poor knowledge: < 50 % of the total knowledge.

Average knowledge: $50 - < 65$ % of the total knowledge.

Good knowledge : ≥ 65 % of the total knowledge.

The quality of life score of the studied HCV patients: - All raw scores were transformed to a 0-100 score for each domain using previous formula and each domain scored as the following

Poor < 65 % of the total domain score

Fair $65 - < 80$ % of the total domain score

Good ≥ 80 % of the total domain score

RESULTS

Table (1) represents the distribution of the studied patients according to their socio- demographic characteristics. It shows that their age ranged from 21-57 years with mean 40.62 ± 10.03 years. Slightly more than half of them were male and unemployed. About 42% of the patients were illiterate or read & write and the majority of them (86%) were married. Regarding the family income more than two thirds (70%) mentioned that their income just sufficient and only (2%) reported that it was sufficient and they can save. More than half of them (56%) have family that composed of more than or equal to 5 members with mean 4.70 ± 1.47 . In relation to residence the majority (84%) of the studied HCV patients were living in rural areas and their numbers of rooms ranged from 1-4 with mean 2.70 ± 0.74 . two thirds of them (62%) reported that they have more than or equal 3 rooms.

Table 1. Distribution of the studied patients according to their socio- demographic characteristics

Socio-demographic Characteristics	The studied patients (n=50)	
	No	%
Age		
21-	8	16
31-	16	32
41-	17	34
51-	9	18
Range	21-57	
Mean \pm SD	40.62 ± 10.03	
Sex		
Male	26	52
Female	24	48
Education		
Illiterate or Read & write	21	42
Elementary education	6	12
Secondary & technical education	18	36
University & above	5	10
Occupation		
Unemployed	26	52
Skilled workers	12	24
Farmers	8	16
Professional	4	8
Marital Status		
Married	43	86
Single	5	10
Widow & divorced	2	4
Family Income		
Just sufficient	35	70
Not sufficient	14	28
Sufficient and save	1	2
Family members		
< 5 members	22	44
≥ 5 members	28	56
Range	1-9	
Mean \pm SD	4.70 ± 1.47	
Residence		
Rural	42	84
Urban	8	16
Number of rooms		
< 3	19	38
≥ 3	31	62
Range	1-4	

Figure (1) represents the distribution of the studied HCV patients' pre, immediate, and three months post program intervention according to their total knowledge score. It shows that, there was a significant improvement in the total

knowledge score of the studied patients' pre, immediate, and three months post program intervention. $P = (<0.001)$, where the mean scores of their knowledge increased from 17.70 ± 13.09 pre- intervention to 57.56 ± 1.69 immediate post - intervention and 53.68 ± 2.73 three months post - intervention. This difference was a statistical significant $t = (24.30)$.

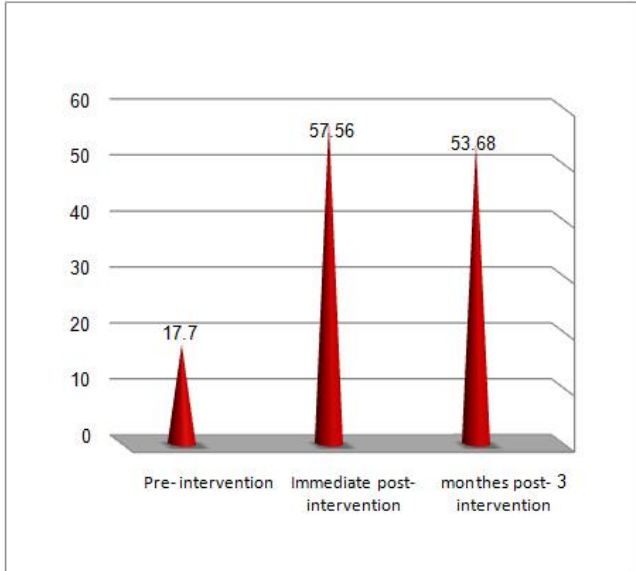


Figure 1: Mean total knowledge score of the studied HCV patients pre, immediate, and three months after program intervention

Figure (2) represents the distribution of the studied HCV patients pre, immediate, and three months post program intervention according to their total practices score. It shows that, there was a significant improvement in the total practices score of the studied patients' pre, immediate, and three months post program intervention.

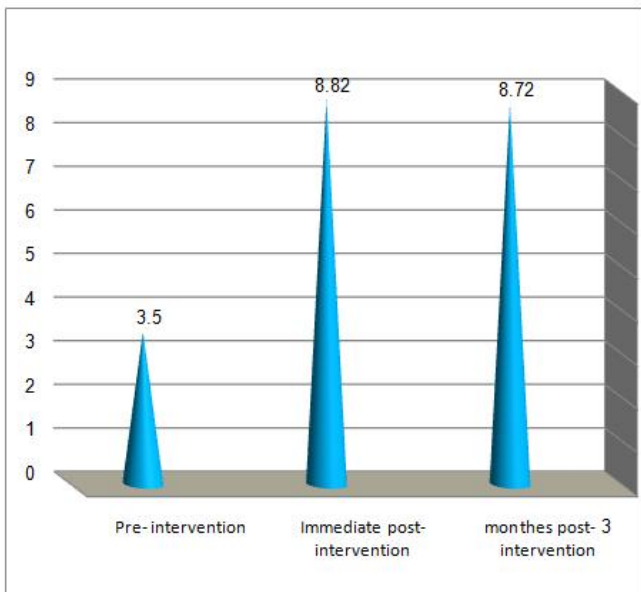


Figure 2: Mean total practices score of the studied HCV patients pre, immediate, and three months after program intervention

$P = (<0.001)$, where the mean scores of their practices increased from 3.50 ± 3.02 pre- intervention to 8.82 ± 0.91 immediate post -intervention and 8.72 ± 1.23 three months post - intervention. This difference was a statistical significant $t = (14.58)$.

Figure (3) represents the distribution of the studied family caregivers' pre, immediate, and three months post program intervention according to their total knowledge score. It shows that, there was a significant improvement in the total knowledge score of the studied family caregivers' pre, immediate, and three months post program intervention. $P(<0.001)$, where the mean scores of their knowledge increased from 24.86 ± 26.39 pre- intervention to 70.40 ± 2.13 immediate post -intervention and 65.54 ± 4.27 three months post - intervention. This difference was a statistical significant $t = (11.88)$.

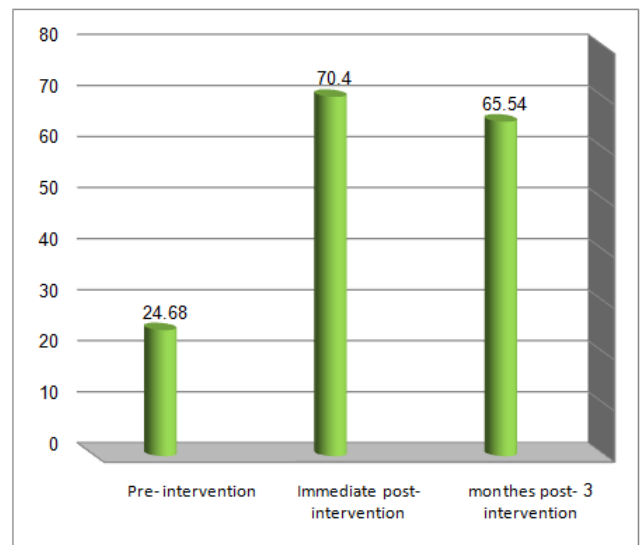


Figure 3: Mean total knowledge score of the family caregivers pre, immediate, and three months after program intervention

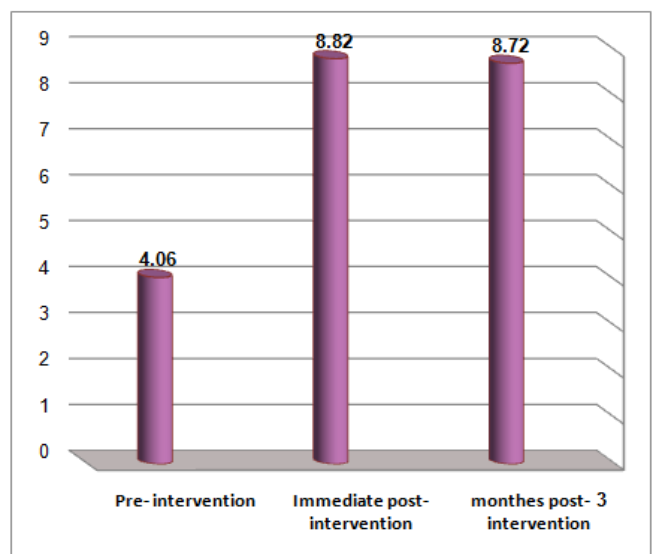


Figure 4: Represents the distribution of the studied family caregivers' pre, immediate, and three months after program intervention regarding their total reported practices score

Figure (4) represents the distribution of the studied family caregivers' pre, immediate, and three months after program intervention regarding their total reported practices score. It shows that, there was a significant improvement in the total practices score of the studied family caregivers' pre, immediate, and three months post program intervention. $P(<0.001)$, where the mean scores of their practices increased from 4.06 ± 3.40 pre- intervention to 8.82 ± 0.91 immediate post -intervention and 8.72 ± 1.23 three months post - intervention. This difference was a statistical significant $t = (9.01)$.

Table (2) represents the distribution of the studied HCV patients pre and three months post program intervention according to their SF-36 HRQOL measurement. It shows that, there was a significant improvement in the all SF-36 HRQOL domains which includes (Physical functioning, Role limitations due to physical health, Bodily pain, General health perceptions, Vitality (energy/fatigue), Social functioning, Role limitations due to emotional health, and Emotional well-being) of the studied patients three months post program intervention. $P = (<0.001)$ respectively.

Table 2. Distribution of the studied HCV patients pre, immediate, and three months after program intervention regarding their SF-36 HRQOL measurement

Quality of life items	The intervention group												t P
	Pre- intervention (n=50)						3months post- intervention (n=50)						
	Good		Fair		Poor		Good		Fair		Poor		
	N	%	N	%	N	%	N	%	N	%	N	%	
Physical functioning	9	18	9	18	32	64	20	40	30	60	0	0	7.40 0.000**
Role limitations due to physical health	7	14	16	32	27	54	25	50	25	50	0	0	6.78 0.000**
Bodily pain	11	22	13	26	26	52	20	40	25	50	5	10	8.08 0.000**
General health perceptions	0	0	13	26	37	74	15	30	23	46	12	24	7.16 0.000**
Vitality (energy/fatigue)	7	14	13	26	30	60	15	30	20	40	15	30	2.59 0.000**
Social functioning	16	32	18	36	16	32	23	46	27	54	0	0	4.49 0.000**
Role limitations due to emotional health	7	14	8	16	35	70	22	44	28	56	0	0	9.52 0.000**
Mental health	13	26	11	22	26	52	20	40	20	40	10	20	4.92 0.000**

Table (3) shows correlation between knowledge, practice, and quality of life of the studied HCV patient's pre program intervention. The table revealed that, there was a significant positive correlation between knowledge, practice, and patient quality of life $p=<0.001$ respectively.

Table 3. Correlations of patient total quality of life , total knowledge, and total practices

Variables	Quality of life	Knowledge	Practices
	r	r	r
	p	p	p
Knowledge	.970 0.000**	-	.956 0.000**
Practices	.947 0.000**	.956 0.000**	-

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

Table (4) shows correlation between patient and family caregivers knowledge and practice pre program intervention.

The table revealed that, there was a significant positive correlation between patient and family caregivers knowledge and practice $p=<0.001$ respectively.

DISCUSSION

Hepatitis C virus stands as one of the most important etiologies of chronic liver disease and is an emerging infection in the world (Hu *et al.*, 2010). Egypt has the largest burden of HCV infection in the world. The hepatitis C epidemic in Egypt began during 1960–1980, when mass campaigns were conducted to control schistosomiasis through parenteral anti schistosomal therapy (PAT) administered by health-care workers using improperly sterilized glass syringes (Strickland, 2006). HCV transmission is ongoing in Egypt, and incidence rates have been estimated at 2.4 per 1,000 person-years (165,000 new infections annually) (Strickland, 2006). In 2008, nearly 15% of the population aged 15–59 years had antibodies to HCV (anti-HCV), and 10% (approximately 5 million persons) had chronic HCV infection (El-Zanaty *et al.*, 2009). The most newly diagnosed HCV patient, common concerns included disease progression, premature death, infecting family members and side-effects of treatment (Minuk *et al.*,

Table 4. Correlations of patients and family caregivers total knowledge and practice

Variables	Patients knowledge	Patients practices	Family caregivers knowledge	Family caregivers practices
	r	R	r	r
	p	p	p	p
Patients practices	.956 0.000**	-	.922 0.000**	.965 0.000**
Family caregivers knowledge	.929 0.000**	.922 0.000**	-	.953 0.000**
Family caregivers practices	.930 0.000**	.965 0.000**	.953 0.000**	-

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

2005). This highlights the necessity for a comprehensive HCV educational program such as that implemented in this study in order to adequately address patient's concerns. Regarding

socio-demographic characteristics of the studied sample. The result of the present study revealed that slightly more than half of the studied HCV patient's were male and unemployed, their mean age are 40.62 ± 10.03 years. About 42% of the patients were illiterate or read & write and the majority of them were married (Table 1-4). The result of present study agreed with Talaat *et al.* (2010), Mostafa A(2010) and Paez Jimenez A (2009) Prevalence of chronic HCV infection in Egypt is higher among men than women (12% and 8%, respectively), increases with age (reaching >25% among persons aged >50 years), and is higher among persons residing in rural versus urban areas (12% versus 7%)⁽¹¹⁾. Primary modes of HCV transmission include unsafe injections, other inadequate infection control practices, and unsafe blood transfusions. HCV transmission also occurs among injection-drug users in Egypt (Paez Jimenez *et al.*, 2010; Mostafa *et al.*, 2010 and Mohamed *et al.*, 2009). The result of present study in contrast with (Ibrahim and Madian 2011) and Surjadi *et al.* (2011) they found that half of the subjects of the study done in Damnhore governorate and other study in California San Francisco university had high school or higher education. The researcher point of view this may be due to the residence of place in which the patient live. Because the majority of subjects of present study from rural areas and their income either just sufficient or not sufficient and this made them unable to expend money on education in additional too bad health life styles (Table 1-4).

In relation to, effect of education program on the total knowledge & total practices scores of the studied sample the result of present study showed that there was a significant improvement in the total knowledge and total practices mean score of the studied HCV patients and their family caregivers' pre, immediate, and three months post program intervention. (<0.001) respectively (Figure 1,2,3,4). The result of present study agreed with El Hoseiny (2005), who found that there was a significant improvement in the total knowledge and total practices mean score of her studied HCV patients and their family members after exposure to health education program. In the same line Ibrahim and Madiam (2011), also found after the implementation of health educational program, the experimental group showed significant improvement in their total knowledge and total practices score compared with the control group. In relation to effect of HCV on HRQoL, the result of the present study revealed that there was statistical significant difference after three months post program implementation as the post test showed that there was significant improvement of the eight domains of sf-36 HRQOL (physical function, Role limitation due to physical health, vitality, bodily pain, social function, general health, role limitation due to emotional problem, mental health compared with pretest (Table 2)

The result of present study agreed with Paola *et al.* (2007), and Myra *et al.* (2008), who found that a significant improvement of eight domains of sf-36 of HRQOL measurement of the studied sample of CHC after conduct to health education program also the result of present study agreed with Ibrahim and Madiam (2011), who found that after implementation of the health education program, the experiment group showed significant improvement in physical and mental component

summary and all domains of the SF -36 measuring HRQOL compared with the control group. The result of the present study revealed that, there was a significant positive correlation between knowledge, practice, and patient quality of life $p < 0.001$ respectively. In addition to, a significant positive correlation between patient and family caregivers knowledge and practice $p < 0.001$ respectively (Table 3, 4). The result of present study agreed with Verma *et al.* (2001) and Saleem *et al.* (2012) they reported a significant positive correlation between knowledge and HRQoL of study subject (0.3, $p < 0.001$) respectively. The reported positive correlations are explainable by the theory of Reasoned Action. A person's intention to a specific behaviour is a function of their attitude towards that behaviour. Furthermore, the attitude toward the behaviour is determined by the person's belief that a given outcome will occur if he/she will perform the behaviour (Fisher *et al.*, 1995). It is concluded that adequate knowledge can lead to a positive attitude, resulting in good practices (Haq *et al.*, 2012 and Singh and Purohit, 2010).

Conclusion

An educational program was effective and improved the studied HCV patients and their family caregivers level of knowledge and practices toward management of HCV. A significant improvement in the knowledge and practices scores of the studied subjects about HCV was observed from pre program, immediate and three months after program intervention. Furthermore, a significant improvement in the dietary habits practices, activity of daily living and quality of life of the studied subjects about HCV was observed from pre program and three months after program intervention.

- Establishing health education units in every hospitals or outpatient clinics to provide pre therapeutic education to patients and their family caregivers regarding the information they need about treatment process, medication side effects and available organization that may support them.
- Increase the utilization of mass media such as television, radio, and printed media to arouse the public awareness regarding preventive practices to prevent HCV.
- Public health sectors should emphasizing effective disease surveillance for early detection and reporting of out breaks as early case finding and prompt treatment have good prognosis.

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