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STIGMA AND QUALITY OF LIFE AS PERCEIVED BY PATIENTS WITH HEPATITS C VIRUS

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Abstract: Hepatitis C is the most pressing public health challenge in Egypt that had direct effect on HRQOL in addition to being stigmatized related to infection had negative consequences on psychological status that considered major problem in adherence behavior to treatment process The aim of this study: was to assess stigma and health related quality of life as perceived by patients with hepatitis C virus. Design: Descriptive exploratory design was utilized in this study. Setting: the study held at the Outpatient Clinics of "National Hepatology and Tropical Medicine Research Institute Cairo". Sample: A convenience of 200 HCV patients were enrolled in this study .Tools for data collection were: Socio-demographic sheet, HCV Stigma scale. Quality Of Life scale Results: Regarding HRQOL there were high level of quality of life among HCV patients in this study and the highest mean scores was found among studied subjects was in relation to general behavior, social relation, economic status, physical health and activities, On the other hand there was high level of stigma among HCV patients and the highest mean scores was found among studied subjects was in relation to public attitude, Personalized stigma and Negative self-image, Also the current study revealed that there was statistical significant differences in HRQOL and stigma among the HCV studied subjects in relation to their, occupation, level of education, history of family infection and antiviral medication use, but there was statistical insignificant differences in HRQOL and stigma among them in relation to their gender, income and residence place Conclusion: Patients with HCV often feel stigmatized and unsupported in their care, relationships, and work environments, Recommendations: Assessment the society perception towards HCV infected person , programmers to control psychiatric symptoms considered in treatment plan for HCV patients.

Keywords: HCV, HRQOL, Stigma.

1. INTRODUCTION

Hepatitis C is a disease affecting the liver via the hepatitis C virus (HCV); which is a blood borne virus; transmitted parentally leading to both acute and chronic hepatitis, ranging in severity from a mild illness lasting a few weeks to a serious, lifelong disease and is considered a major cause of hepatic carcinoma (World Health Organization, 2017). According to World Health Organization (WHO), Egypt has the highest prevalence of hepatitis C virus (HCV) in 2015, HCV is estimated that, in the 1–59-year age group, 5.3 million persons are positive for HCV antibodies In Egypt (World Health Organization, 2016)

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HCV infection is characterized by an acute or chronic course that can be complicated to chronic liver disease, cirrhosis and finally hepatocellular carcinoma (HCC). Besides its impact on the liver, Patients with HCV encounter problems in a wide variety of health areas including (HRQOL), mental and physical health (Umumararungu, Ntaganda, Kagira, & Maina, 2017).

Stigma is "a mark of disgrace linked to a specific occasion, quality or person." Perceived stigma associated with HCV infection leads to high levels of anxiety and exaggerated fear of transmission, and can be a major cause of social isolation and decreased the intimacy in relationships. More than 90% of transmission in developed countries takes place through the sharing of non-sterilized needles and syringes in the intravenous drug-using population (Modabbernia, Poustchi, & Malekzadeh, 2013)

Social relationships were usually linked to social stigma, fatigue, emotional distress and negative psychological behavior. Patients seemed most hurt by change in relationship with family members; some reported strained relationship due to their families' fear of transmission of infection, some mentioned problems with spouse due to change in intimacy and sexual relationship (Modabbernia, Poustchi, & Malekzadeh, 2013). The stigma associated with HCV may lead to high levels and fear of transmitting the virus. This fear may be the main cause for social isolation and decreased intimacy (Armstrong et al., 2016).

Health-related quality of life (HRQOL) is defined as a multidimensional construct composed of the patients' perceptions of the disease impact and treatment on his or her functioning in a variety of aspects of life, including physical, psychological and social health domains. (Samardakiewicz & Kowalczyk, 2007). Health related quality of life (HRQOL) is an important outcome of the clinical trials and the populations' health assessment. It is used interchangeably with the term QOL as it is assumed to be a specific aspect of it. HRQOL is an umbrella term which envelops all the facet of life, not necessarily, only/also acquiescent to health care services Quality of life (QOL) has been described as a subjective term and defined as a person's sense of social, emotional and physical well-being and his/her ability to function in the ordinary tasks of daily living (Chaudhry & Siddiqui, 2012)

The chronic nature and individual experience of the disease are conditioning factors on HRQOL, with clinical and social implications, due not only to the diagnostic but also to its evolution (Iriana, Curry, & Afdhal, 2017). Several studies have stated that chronic hepatitis C may lead to several complications and despite the fact that most of the patients with HCV are asymptomatic, they consistently report a significant reduction in health-related HRQOL, when compared with the general population (Adinolfi, Nevola, Rinaldi, Romano, & Giordano, 2017)

Several studies reported that HRQOL is decreased regardless of the severity of the hepatic or psychiatric diseases. Moreover, the quality of life frequently improves after completion of antiviral treatment, these observations suggest that HCV may exert a direct effect on HRQOL, although the mechanism is unknown (Spiegel, Melmed, Robbins, & Esrailian, 2008) also fatigue, malaise, depression and cognitive impairment, all neuropsychiatric disorders are among the commonest complaints of patients with chronic HCV (Blasiole, Shinkunas, LaBrecque, Arnold, & Zickmund, 2006).

Nurses practicing holistic care focus care on the whole person and not on diseases. Holism advocates the view of the whole person that goes beyond their physical or medical care. Holism defined in nursing as understanding the health and illness as involving the whole person that is body, mind and spirit. Nurses play a significant role in educating patients with chronic HCV, advocating for them and helping them to achieve a reason able state of wellbeing. Nurses also have the important role of providing partners with information and support that will assist them as caregivers (Diluzio, 2002).

Nurses can also help people living with hepatitis C to access sources of support. Individual support may come from family, friends and health care providers. Peer support is often available through meetings, support groups, telephone contacts and online chat groups. Nurses can help family and friends learn how to support someone living with hepatitis C (Ibrahim & Madian, 2011).

Significance of the study

In October 2018, the ministry of health launched a large mass screening and treatment campaign to eliminate HCV in Egypt (100 Million Health) under the directive of the Egyptian President Abdel- Fattah El-Sisi which aims to eradicate HCV across the nations as a part of the strategic plan 2020, the campaign started in October 2018 and is scheduled to end



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in April 2019, the propagation of this campaign was done through SMS messages, TV, radio & newspapers, social media (Facebook, twitter etc.), hot line, electronic web site. That revealed Total HCV Ab positive participants were 2 million and 197 thousand. So, there is an urgent need for strengthening prevention efforts as (150000) new cases per year in Egypt

With a global prevalence rate of 2.8%, equating to over 185 million infections, and more than 350000 deaths annually, hepatitis C virus (HCV) infection is undoubtedly considered a major public health problem. Globally, an estimated 3 million to 4 million new cases of HCV infection emerge every year. Furthermore, the HCV-related mortality is the most important leading cause of viral hepatitis-related mortality in the near future (Petruzziello, Marigliano, Loquercio, Cozzolino, & Cacciapuoti, 2016).

The current study results will help in understanding the unique nature of HCV stigma in Egyptian cultures, also it will provide data base for researchers about HCV stigma. On the other hand, it will help in psychiatric nursing researches in the future by providing basic information about the magnitude of the problem in Egypt. Evidence based psychiatric nursing practices will be established based on the results of this study.

Aim of the study

This study aimed to assess the stigma and health related quality of life as perceived by patients with hepatitis C virus.

Research Questions

Q1: What is the level of stigma among HCV patients?

Q2: What is level of quality of life among HCV patients?

Research Design: Descriptive exploratory design was utilized in this study

Setting

This study was conducted at Out Patient Clinic at National Hepatology and Tropical Medicine Research Institute (NHTMRI) in Cairo that considered one of the educational institutes of the (General Authority for Educational Hospitals of the Ministry of Health) which provides medical services to nearly a quarter of a million liver patients annually: Moreover, the Institute has 19 departments, most notably "endemic diseases, liver, microbiology and immunology, parasites, chemical pathology, surgery, diagnostic radiology, the Institute aims to combat endemic diseases and critical medical conditions in Egypt.

Sample

A sample of convenience of 200 HCV patients was enrolled in this study according to sample equation (Dawson & Trapp, 2004) with inclusion criteria that patient diagnosed since 6 months, patients' age range between 20–50 years, no other comorbidities, both genders, can read and write and excluded the hepatic encephalopathy patients ant those with dementia

Tools of Data Collection

Data were collected over period of time three months (April 2018 to August 2018) by using the socio-demographic and medical data sheet, HCV stigma scale and HRQOL scale

1-Personal and Medical Data Sheet

It was developed by the researcher; this sheet includes Patient code, gender, age, date of diagnosis, marital status, income, level of education, occupation, date of starting treatment protocol, the family history of HCV infection etc.,.

2. HCV stigma scale

Stigma was measured using a modified version of the HIV Stigma Scale. which developed by Barbara Berger (1996) to measure HIV stigma and modified by (Todicheeney-Mannes, 2013)to measure HCV stigma, Its four point-Likert scale ranged between Strongly disagree (SD) to Strongly Agree (SA) the scale was translated to Arabic version and back translated to English to ensure the scale validity.



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The scale consists of 40 items classified into four subscales personalized stigma, Disclosure concerns, Negative self-image, and Concern with public attitudes toward people living with HCV, the items are centered on the experiences, feelings, and opinions about how persons living with HCV feel and how they are treated, sixteen items belong to more than one subscale, reflecting the intercorrelations of the factors on which the subscales are based, the ranges of the coefficient a were between .90 and .93 for the four subscales and .96 for the 40-item instrument provided evidence of internal consistency reliability, the HCV Stigma Scale was reliable and valid with a large, diverse sample of persons living with HCV (Golden, Conroy, O'Dwyer, Golden, & Hardouin, 2006)

HCV Stigma Scale for the personalized stigma subscale, scores can range from 18 to 72. For the disclosure subscale, scores can range from 10 to 40. For the negative self-image subscale, scores can range from 14 to 56. For the public attitudes subscale, scores can range from 20 to 80 (Berger et al., 2001). According to the mean percent of participant's perception about stigma the low level of stigma (0%-40%) the middle level (40%-60%) the high level (60%-100%).

3- Quality Of Life scale

This scale was designed to measure HRQOL in all domains through 85 item, it was adopted from Phillip and Long (2010) then modified by (Mohamed, 2015), It was consisted of (8) subscales as follow: physical health and activities (13 items), social relationships and economic status (13 items), general behavior and attitude (12 items), habits (3 items), thoughts and speech (12 items), memory and attention (2 items), orientation and insight (2) items and mood (20) items. The HRQOL is scored as follows Low HRQOL = (0 - 60%), moderate HRQOL = (60% - 575%), and High HRQOL=(75-100%) the reliability of tool is measured by cronbach alpha test = 0.864 indicating a high degree of internal consistency

Ethical consideration

A primary approval was obtained from the ethical committee of scientific research at the Faculty of Nursing, Cairo University. In addition, an official permission to conduct the proposed study was obtained from National Hepatology and Tropical Medicine Research Institute Cairo. Written consent was obtained from participants and complete description of the purpose and nature of the study was explained to all subjects and they were informed that participation in the current study was voluntary, anonymity and confidentiality of each subject was protected by the allocation of a code number for each participant, they were also assured that they can withdraw at any time from the study.

Procedure

After comprehensive reading of the related literature to assure the significance of the study and attain an idea about the current researches in this field, an official permission was obtained from ethical committee and administrative department of NHTMRI to proceed with the proposed study and approval was obtained from the ethical committee of scientific research at the Faculty of Nursing, Cairo University, assessment the setting and the climate of the outpatient clinic done to select the suitable place which interviewing were done to illustrate the tools and how to fill the study tools after revision by three experts in the psychiatric field to assure the content validity of each. First interviewing done in front of HCV clinic to meet HCV Patients only, then the nature of the study and purpose was explained to them after that select the patients who met the criteria of selection, after obtaining written consent from patients who are willing to participate in the study..

Pilot Study

A pilot study was conducted in order to test the applicability and relevance of the tools, sample accessibility, estimate the time needed to complete the study and to find out any problem that might interfere with the process of data collection, A total of 20 HCV patients that equal (10%) of study sample were chosen to pilot study according to the criteria and, then if no modification was done to the tool the pilot cases will be included in the study.

2. STATISTICAL ANALYSIS

Data were collected, summarized and reported on data collection sheets. Data was re-entered into computer Microsoft Excel sheets with appropriate tabulation and graphical presentation .the threshold of significance is fixed at 5% level (p-value).



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3. RESULTS

Table (1) Frequency distribution of participants' socio-demographic characteristics (n=200).

Socio-demographic characteristics	NO	9/0
Age (yrs):	•	·
10-<20 years	19	9.5
21-<30 years	38	19
31-<40 years	90	45
41-<50 years	53	26.5
Gender		
Male	104	52
Female	96	48
Occupation		
Not working	85	42.5
Working	115	57.5
Level of education		
Cannot read or write	14	7
Read and write	57	28.5
Middle education	78	39
High education	51	25.5
Marital status		
Married	101	50.5
Single	56	28
Divorced	5	2.5
Widowed	38	19
Residence	,	
Rural	85	42.5
Urban	115	57.5

Table (1) highlighted that the near half of the studied subjects were in age group (30-40) years old and (52%) of them were male. According to education, study findings showed that, (39%) of the participants had middle education. Results showed in relation to marital status that (50.5%) were married and according to occupation (57.5%) were working.in relation to residence (57.5%) from urban

Table (2): Frequency distribution of participants' clinical data (n=200).

Clinical data	NO	%
History of family infection	·	·
Yes	55	27.5
No	145	72.5
Illness Duration		
6 months- 1 year	46	23
1-5 years	87	43.5
5-10 years	37	18.5
10-15 years	30	15
Anti-viral medication start		
Yes	136	68
No	64	32

The current study revealed that (68%) of them took antiviral medication and (27.5) had positive family history and in relation to illness duration (43.5%) of them were infected since (1-5) years



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Table 3: Mean and standard deviation of subjects' perception about HRQOL (n=200).

Dimensions	Minimum	Maximum	Mean	Std. Deviation	Mean %
Physical health and activities	12	26	20.99	3.72	80.7
Social relation& economic status	7	26	21.26	5.05	81.8
General behavior	18	24	24.73	2.17	95.1
Habits	1	6	5.32	1.13	88.7
Thinking and speaking	10	24	19.75	3.08	89.8
Memory and attention	.00	4	2.86	1.20	47.7
Orientation & foresight	2	4	3.89	.43	97.3
Mood	16	40	30.52	6.28	76.3
Total health related quality of life	88	154	129.31	16.07	84

The above table illustrated that there was a high level ((mean%=84) of health related quality of life among HCV patients

Table 4: Mean and standard deviation of subjects' perception about stigma related to HCV infection

Dimensions	Minimum	Maximum	Mean	Std. Deviation	Mean %
Personalized stigma	24	61	37.01	8.33	60.7
Disclosure stigma	16	32	21.05	3.68	65.8
Negative self-image	19	44	29.07	6.35	66
Public attitude	28	70	43	9.61	61.4
Total stigma	92	200	130.11	26.56	65

The above table illustrated that there was c high level (mean%=65) of stigma among HCV patients

Table 5: Comparison between Subjects' HRQOL and HCV Stigma in Relation to their Level of Education, occupation, and age groups (n=200).

Variables	Level of Education	Mean	SD		One way ANOVA		A
variables	Level of Education	Level of Education Weali		SD -		P	
	Cannot read or write	123.3571	24.19665	5	2.835	.0039*	
ПВООІ	Read and write	134.4314	10.02647	7			
HRQOL	Middle education	128.5897	16.64483	3			
	High education	127.1579	16.53113	3			
	Cannot read or write	95.3571	21.05892	2	5.304	.002**	
Stigma	Read and write	92.0784	21.07970)			
Stigilia	Middle education	85.7179	15.71408	3			
	High education	80.8214	12.48433				
Variables	Age groups	Mean	SD		ay ANOVA		
- v arrables		Wican	SD .	F			P
	10-<20 years	123.90	10.29				
	21-<30 years	131.31	13.36				
HRQOL	3			7.733			**000
	31-<40 years	137.42	17.49				
	41-<50 years	135.26	14.29				
Variables	Occupation	Mean	SD		Indepe	ndent t tes	t
v arrabics	Occupation	Wican	51		T		P
	Not working	128.4522	15	.74258	.872		.004*
HRQOL	Working	130.4588	16	5.53391			

The Above table indecated that there were a highly statistical significant difference in HRQOL among the studied subjects in relation to their age group at (p= 0.000**) and occupation at p (0.04) and in relation to level of education showed that there was statistical significant difference in HRQOL and stigma among the studied subjects at (p= 0.039*& p= 0.002**) respectively



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Table 6: Comparison between Subjects' HRQOL and Stigma Related to HCV in Relation to their history of family infection Income and residence (n=200).

	History of family infaction	Mean	SD	Indep	Independent t test		
Variables	History of family infection	Mean	SD	T	P		
	Yes	133.54	55 10.3	9733 2.895	.0	01**	
HRQOL	No	127.69	17.5	2194			
Stigma	Yes	82.927	3 21.1	7113 1.639	.0	24*	
	No	88.069	15.6	1049			
Variables	Income	Mean	SD	Indepe	Independent t test		
variables	meome	Wican	SD	t	P		
HRQOL	Sufficient	128.3778	16.7607	77 1.177	.236		
	Not sufficient	131.2308	14.4760)2			
Stigma	Sufficient	83.2985	16.2952	22 4.042	.514		
	Not sufficient	93.5538	17.7588	33			
Variables	Residence place	Mean	SD	Indepe	Independent t test		
variables	Residence place	Mean	SD	t	P		
YYD O OY	Rural	129.7765	15.86729	.356	.765		
HRQOL	Urban	128.9565	16.28442	2			
a :	Rural	85.9881	17.86866	.456	.442		
Stigma	Urban	87.1304	17.15232)			

The above table indicated that in relation to history of family infection there was statistical significant difference in HRQOL among the studied subjects in relation to their at (p=0.001**) and the same statistical significant difference for stigma at (p=0.024*). On the other hand there was statistical insignificant difference in HRQOL among the studied subjects in relation to their income and residence

4. DISCUSSION

The current study results indecated high score of HRQOL among the study participants and in contrast several studies have documented significant HRQOL impairment in patients with chronic hepatitis C (Younossi et al., 2014), HRQOL areas that are most affected in patients with chronic hepatitis C are those related to activity, energy, vitality and fatigue (Kallman et al., 2007), Also (El-Wahab, 2016) in his study among Egyptian HCV patients added that HRQOL is reduced in the patients with chronic viral liver disease in comparison with the healthy persons supported

But that majority of the studied subjects (93%) never had any visual or auditory problems, while more than half of them (57%) never had sleeping problem (Sleeping much more or less than usual) and that might illustrate the high score of HRQOL among the studied subjects in comparison to other researches this might be related to interrelated factors as early sustained virologic response, antiviral medication use, occupation and level of education.

Other aspects of HRQOL revealed by (Erim et al., 2010) that People with HCV infection have a higher risk for depression, anxiety, somatization, insecurity, aggression/hostility, phobic anxiety, and psychosis which parallel to the current study results as more than one quarter of the studied subjects had depressed mood most of time and another quarter of them had generalized anxiety most of times and supported that (Boscarino et al., 2015) who indecated that the prevalence of depression in HCV patients is up to 50%

But about psychosis not consistent with the current study results because (97%) never had bizarrely illogical or disorganized behavior or speech and the same percent never had bizarre false beliefs or perceptual distortions (e.g., having imaginary voices, or smells) also the current study results supported as one third reported feeling of Anger: Irritability and one quarter of them most of time has generalized anxiety: Frequent, persistent, and intense feelings of



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being nervous, tense. and this is consistent (Blasiole et al., 2006) stated that participants expressed difficulty in controlling these feelings of anger, with some describing a significant loss of impulse control

Also (Metwally et al., 2013) revealed that isolation from friends because of fatigue represented the commonest cause of isolation because fatigue is common to HCV-infected individuals and interferes with many daily activities; however, the severity of fatigue varies widely among individuals (Glacken, Coates, Kernohan, & Hegarty, 2003). And this goes parallel to the current study results as half of studied subjects sometimes had Fatigue to complete their daily life activities and near half of them had Physical pain or discomfort most of times

(Weissenborn et al., 2004) confirmed that the occurrence of significant deficits in executive function and attention in patients complaining of fatigue has been reported in HCV patients with normal liver function, also impairment in executive function, sustained attention, working memory, verbal learning and verbal recall (Monaco et al., 2015), In contrast the current study results revealed that (82.5%) of the studied subjects never confirm attention easily diverted by extraneous stimuli might be due to the new generation of anti-viral drugs with less side effect such as fatigue and restlessness so that lead to high HRQOL among the studied subjects

The current study revealed high level of stigma mean among the study participants might be related to stigma poses significant challenges to those with chronic hepatitis C, their social networks and society,d lead to depression and anxiety in patients with chronic hepatitis .also cause distress for the patient and family, life, poor self-esteem, and discrimination in medical and workplace settings (Martin, Lang and Olafsdottir 2008)

Based on the current study results which revealed that there was slightly high level (mean%=65) of stigma among HCV patients the researcher concluded that hepatitis C does carry a stigma for several issues. First, HCV is potentially infectious. Although not easily transmitted, people are fearful from those who have the disease. Fear and ignorance have cost patients their jobs, friendships and marriages even marriages have been challenge

Second important item in elevating the stigma score among the studied subjects, discriminatory reactions which also affect self-perception in those living with HCV and the way in which they express their feeling the fear of being labeled by others or to the shame of having a disabling condition. Also discrimination from poorly informed health professionals or significant others can erode patients' self-worth and lead to exaggerated fear of virus transmission and this might increase the fear of stigma level and the current study results revealed near half of participants agree that Since learning they have HCV, they worry about people discriminating against them

Third item stigma HCV is patient neglicance in social activities and this lead the patient to cognitive distortion as(catastrophic thinking about his medical condition and magnification) and that illustrated above also the concept of being bad person and nonproductive person as the current study results mentioned that more than three quarters of participants agree that having HCV makes them feel unclean this consistent with (Soltan, Salama, & Aboelmagd, 2018) who mentioned that (20.8%) of their subjects feel dirty and (43.1%) feel he/she is a bad person

Fourth item determined the high stigma level was disclosure and the person trust in people dealing with and its effect on social relationship in this study around two thirds of participants agree that telling someone they have HCV is risky also around three quarters of the studied subjects agree that they were rejected when others find out so there were strong limitation in disclosing the fact f having HCV

This consistent with (Soltan et al., 2018) who mentioned that near one quarter of HCV patients in their study are repulsive and are rejected from others, also another one quarter had been hurt by the reactions of others and not important to tell people about the fact of having HCV, that parallel with the current study results as near half of them strongly agreed that as a rule telling others that they had HCV was a mistake and more than half of them worked hard to keep their HCV a secret In addition to and another fifty percent of them agreed that they were very careful who they told about had HCV.

From the researcher point of view fear of stigma may inhibit disclosure of HCV status to others given the predominantly asymptomatic nature of the illness, might the patient trusted partner or closed family member to disclose his feeling and the fact of having HCV supported that (Hopwood and Treloar, 2003) who indecated that disclosure to family, partners and medical staff is common



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5. CONCLUSIONS

Hepatitis C Virus (HCV) has a major impact on quality of life and can put patients in significant distress. Great concern that there is no vaccine to prevent HCV infection and no post exposure prophylaxis. Therefore, prevention can only be based on increase awareness of HCV infection and change harmful behaviors aiming to reduce the risk of transmission of HCV infection to the others. So, education remains the leading way to change negative perceptions and attitudes towards HCV as infectious disease supported that (Mohsen, Fareed, El-Sheikh, & Abbas, 2011) who mentioned that nurses play critical role in providing support, education, counseling and referrals that provide the greatest opportunity for staying on treatment and receiving care

The Campaign 100 million health discover large number of HCV positive patients and this will help the HCV eradication in Egypt if they adhere to treatment, the psychological consequences must considered with this campaign in the treatment process and highlight the importance of psychiatric nurse role overall treatment process

6. RECOMMENDATION

- Assessment the society perception towards HCV and people reaction to HCV infected person
- HCV patient need programs to control their psychiatric symptoms and maintain stable mental health during treatment process

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