

Assessing Psycho-Social Stressors for Chronically Infected Hepatitis C Virus Patients in Egypt

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Abstract—People with hepatitis C are likely to experience psychological distress related to adjustment issues following diagnosis. Objective: The study was conducted to determine the psycho-social stressors accompanying Hepatitis C virus (HCV) chronic infection. The study focused on immediate and later on reactions to being diagnosed as infected HCV patients. Effect of HCV on disruption of patients' relationships in term of family relationship and friendship, employment and financial status was assessed. The magnitude and causes of the social stigma and its relation to awareness about illness, level of education were also assessed. Methods: During this study the subjective experiences of people having HCV was explored through a designed questionnaire targeted 540 cases; 359 males and 181 females from ten out of 21 National Treatment Reference Centers of National Hepatology and Tropical Medicine Research Institutes of Ministry of Health (MOH) hospitals. The study was conducted along a period of six months from September 2011 to March 2012. Results: The study revealed that the financial problems are the commonest problems faced by 75.5% of the cases. More than 70% of the cases suffered from immediate sadness versus 67.4% suffered from worry. Social stigma was reported by 13 % of HCV +patients, the majority of which were females. Conclusions: Exploring the psychosocial consequences of HCV infection can act as pressing motivators for behavior change needed for limiting HCV endemicity in Egypt.

Keywords—Egypt, HCV infection, psychosocial adjustment, stigma.

I. INTRODUCTION

HEPATITIS C often referred to as the “silent epidemic”. The World Health Organization (WHO) reports that approximately 3% of the world population, or approximately 170 million persons, are infected with the Hepatitis C Virus (HCV) with between 3 and 4 millions new infections each year [1], [2]. Africa and Asia have the highest reported prevalence rates, in contrast to the low rates of HCV in North America, Western Europe, and Australia [3]. Egypt has the highest prevalence of Hepatitis C in the world [4]. Geographically, the Hepatitis C prevalence has been shown to be higher in Lower Egypt (Nile Delta) than in Upper Egypt and lower in urban compared to rural areas [5]. HCV infection

has become the leading risk factor for hepatocellular carcinoma (HCC) in Egypt [6].

Hepatitis C (HCV) is an equal opportunity virus. It affects men and women from all ethnic backgrounds [7]. Hepatitis C infection has an uncertain disease course that varies from person to person. It is often a silent disease. Some people report no symptoms and are often surprised when they learn that they have HCV. The most common symptom of HCV is fatigue. Nausea, body ache, abdominal discomfort, irritability, memory impairment and depression are also symptoms of HCV [8]–[16].

The diagnosis of HCV can have harmful effects on psychological well being. The emotional challenge becomes great [17]. Most people experience some sort of emotional reaction after being diagnosed with chronic HCV. Fear, anger, sadness, denial and depression are common reactions. Although it is normal to have these short-term reactions, it is not healthy in the long-term. Support groups can help women and men cope with HCV, its treatment and its effect on their lives [7].

For some, disclosure is a sticky issue. HCV is stigmatized for two reasons. First, it is an infectious disease and people may react negatively out of fear of acquiring HCV. Second, injection drug use is the most common route of HCV infection [18]. The link between alcohol, intravenous drug use and liver disease frequently trigger reactions in others that the disease may well be a consequence of inappropriate behavior; thus casting the shadow of stigmatization over patients[19].

Stigma is often overlooked although of being painful component of HCV. For some, the stigma of HCV hurts more than HCV itself [20]. Stigma related to hepatitis C has been found to have negative effects on self-esteem, access to health care, employment and social support [18]. Stigma has major effects upon physical health and psychological well-being [21], [22]. It is one of the principal barriers that prevent people from coming forward for management and treatment [23].

HCV touches homes and workplace of the patients. HCV affect patients' interactions with family, friends or other important groups [24]. Relationships may be strained by worries about sufferers' uncertain health. Family and friends may withdraw out of fear of infection. Patients themselves or others may shy away from personal contact, fearing that the disease might spread. Patients may suddenly feel unclean regardless of their previous lifestyle, and find their new illness framed by shame [25]. Moreover, debilitating symptoms and

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the medications used to treat HCV may impair daily activities, social roles and work performance. Such problems cause patients to feel alone and rejected from their much-needed social support system [24].

Living with HCV often entails significant physical, cognitive and emotional adjustments as well. Social support is critical for adjustment. Healthcare professionals play a major role in providing supportive guidance for HCV-infected patients yet patients have also reported significant strains in these important relationships [26]. Self-management programs provide problem-solving and behavioral skills along with disease-specific information. They have been shown to improve chronic symptoms, increase health-supporting behaviors, and enhance overall quality of life [27]-[29] while consuming few medical care resources [30], [31] with other chronic diseases. The aim of this study was to determine the psycho-social stressors accompanying Hepatitis C virus (HCV) chronic infection. The study focused on immediate and later on reactions to being diagnosed as infected HCV patients. Effect of HCV on disruption of patients' relationships in term of family relationship and friendship, employment and financial status was assessed. The magnitude and causes of the social stigma and its relation to awareness about illness, level of education were also assessed.

II. METHODS

The current study is a cross sectional descriptive study. Data collection was carried out along a period of six months from September 2011 to March 2012. The study population included HCV patients in 21 National Treatment Reference Centers of National Hepatology and Tropical Medicine Research Institutes of MOH hospitals, from which 10 centers are selected randomly. The study group included 540 cases; 359 males and 181 females (≈ 50 patients/ Center). We calculated the sample size depending on: prevalence of HCV =15%, confidence interval = 90%, margin of error = 5%, design effect = 2, percentage of loss =10%. So sample size of 540 cases fulfilled the criteria.

The subjective experiences of people having HCV was explored through a designed questionnaire focusing on immediate and later on reactions to being diagnosed as infected HCV patients, effect of HCV on disruption of patients' relationships and causes of social stigma. Data entry and analysis were done using statistical package for the social sciences software (SPSS) program version 18. Frequency tables were used to describe qualitative data and chi-square was used as the test of statistical significance. Significant values were considered at $p < 0.05$.

III. RESULTS

TABLE I
COMMON IMMEDIATE REACTIONS (WITHIN ONE MONTH) TO BEING
DIAGNOSED AS HCV INFECTED PATIENTS ACCORDING TO SEX

Immediate reactions	Males (n= 359) No. %	Females (n=181) No. %	Total (n= 540) No. %	P value
Sadness				
Yes	239(66.5)	141(77.7)	380(70.3)	0.009
No	120(33.5)	40(22.3)	160(29.7)	
Anger				
Yes	134(37.2)	76(41.8)	210(38.7)	0.343
No	225(62.8)	105(58.2)	330(61.3)	
Shame				
Yes	109(30.5)	56(30.9)	165(30.7)	1.000
No	250(69.5)	125(69.1)	375(69.3)	
Worry				
Yes	239(66.6)	125(68.9)	364(67.4)	0.624
No	120(33.4)	56(31.1)	176(32.6)	
Dirty and dangerous				
Yes	142(39.4)	80(44.3)	222(41.1)	0.301
No	217(60.6)	101(55.7)	318(58.9)	
Accept the situation				
Yes	96(26.4)	53(29.1)	149(27.6)	0.534
No	263(73.6)	128(70.9)	391(72.4)	

As regards immediate reactions to being diagnosed as HCV infected patients more than 60% of the patients suffered from sadness and worry, while more 40% reported feeling dirty and dangerous to other people. There was significant difference between the females (77.7%) and males (65.5) as regard sadness (Table I).

As regards later on reactions of being diagnosed as infected HCV patients, less than 30% of the patients continue their suffering from sadness, feeling with dirty, shame and worry. Female patients significantly reported these later on reactions as compared to males (Table II).

As regards HCV and disruption of patient's relationship, more than 35% of the HCV patients reported family relationship problems. The highest percentage was for HCV patients reported feeling their children sympathy (44.7%). Patient withdrawal from his family because of his nervousness or his fear on them was reported by 32.6% and 24.8% respectively by HCV patients. There was no significant difference between males and females except for wife / husband alienation from his partner that was significantly reported by females (14.3%) as compared to males (5.6%) (Table III).

More than 35.0 % of the HCV patients reported friend relationship problems. Isolation from friends because of severe fatigue represented the commonest problem among females (25.4%), while Isolated from his friends because of his nervousness represented the commonest problem among males (20.4%). Losing a friend being afraid from catching the disease was significantly reported by females (12.4%) as compared to males (5.7%) (Table IV).

TABLE II
LATER ON REACTION OF BEING HCV INFECTED PATIENT ACCORDING TO SEX (ADJUSTMENT BY TIME TO THE INFECTION)

Later on reaction	Males (n= 359) No. %	Females (n=181) No. %	Total (n= 540) No. %	P value
Sadness				
Yes	65(18.0)	56(31.1)	121(22.4)	0.001
No	294(82.0)	125(68.9)	419(77.6)	
Anger				
Yes	35(9.7)	29(15.9)	64(11.8)	0.044
No	324(90.3)	152(84.1)	476(88.2)	
Shame				
Yes	51(14.2)	31(17.0)	82(15.2)	0.398
No	308 (85.5)	150(83.0)	458(84.8)	
Worry				
Yes	98(27.4)	69(38.1)	167(31.0)	0.016
No	261(72.6)	112(61.9)	373(69.0)	
Dirty and danger				
Yes	61(17.0)	45(24.7)	106(19.6)	0.046
No	298(83.0)	136(75.3)	434(80.4)	
Accept situation				
Yes	290(80.7)	143(79.2)	433(80.2)	0.727
No	69(19.3)	38(20.8)	107(19.8)	

TABLE III
EFFECT OF HCV ON FAMILY RELATIONSHIP

Effect on family relationship	Males (n= 359) No. %	Females (n=181) No. %	Total (n= 540) No. %	P value
Not affected				
Yes	222(61.8)	122(67.3)	344(63.6)	0.241
No	137(38.2)	59(32.7)	196(36.4)	
Wife / husband alienated from his partner				
Yes	20(5.6)	26(14.3)	46(8.5)	0.002
No	339(94.4)	155(85.7)	494(91.5)	
Children alienated from their diseased parent for fear from being diseased				
Yes	17(4.7)	10(5.8)	27(5.1)	0.671
No	342(95.3)	171(94.2)	513(94.9)	
Children refuse that diseased parent prepare their food				
Yes	10(2.7)	5(2.9)	15(2.8)	1.000
No	349(97.3)	176(97.1)	525(97.2)	
Children sympathy				
Yes	162(45.0)	80(44.2)	242(44.7)	0.925
No	197(55.0)	101(55.8)	298(55.3)	
Patient withdrawal from his family as he fear on them				
Yes	90(25.2)	43(23.8)	133(24.8)	0.747
No	269(74.8)	138(76.2)	407(75.2)	
Patient withdrawal from his family because of nervousness				
Yes	120(33.4)	56(30.8)	176(32.6)	0.618
No	239(66.6)	125(69.2)	364(67.4)	

TABLE IV
EFFECT OF HCV ON THE FRIENDSHIP

Effect on friendship	Males (n= 359) No. %	Females (n=181) No. %	Total (n= 540) No. %	P value
Not affected				
Yes	224(62.4)	126(69.4)	350(64.7)	0.120
No	135(37.6)	55(30.6)	190(35.3)	
Losing a friend for fear of catching the disease				
Yes	20(5.7)	22(12.4)	42(7.8)	0.014
No	339(94.3)	159(87.6)	498(92.2)	
Isolation from friends because of fear on them				
Yes	43(11.9)	15(8.2)	58(10.7)	0.229
No	316(88.1)	166(91.8)	482(89.3)	
Isolation from friends because of feel shame				
Yes	33(9.1)	16(8.9)	49(9.0)	1.000
No	326(90.9)	165(91.1)	491(91.0)	
Isolation from friends because of fatigue				
Yes	82(22.8)	46(25.4)	128(23.7)	0.510
No	277(77.2)	135(74.6)	312(76.3)	
Isolation from friends because of nervousness				
Yes	74(20.4)	35(19.4)	109(20.1)	0.817
No	285(79.6)	146(80.6)	431(79.9)	

TABLE V
EFFECT OF HCV ON THE EMPLOYMENT

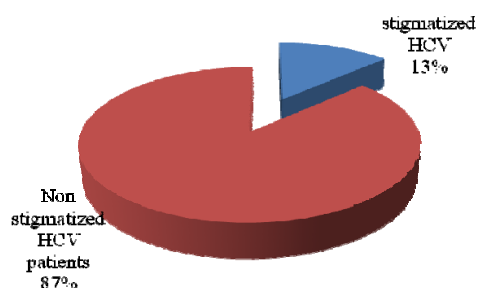
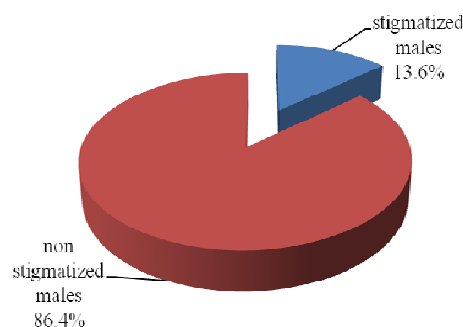
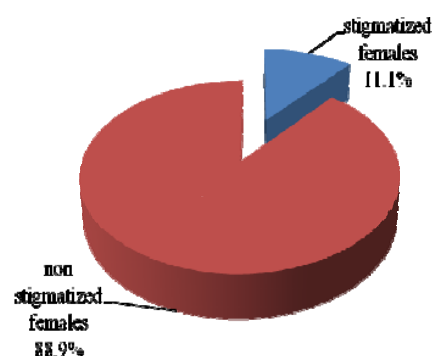
Effect on employment	Males working (n= 287) No. %	Females working (n=28) No. %	Total working (n= 315) No. %	P value
Not affected				
Yes	137(47.7)	21(73.9)	158(50.2)	0.017
No	150(52.3)	7(26.1)	157(49.8)	
Not active				
Yes	115(40.2)	7(25.0)	122(39.0)	0.172
No	172(59.8)	21(75.0)	193(61.0)	
Friends withdrawal				
Yes	25(8.5)	2(8.7)	27(8.5)	1.000
No	262(91.5)	26(91.3)	288(91.5)	
Lost job because he couldn't do it				
Yes	51(17.8)	6(21.7)	57(18.1)	0.581
No	236(82.2)	22(78.3)	258(81.9)	
Retired as people fear him				
Yes	16(5.6)	1(4.3)	17(5.5)	1.000
No	271(94.4)	27(95.7)	298(94.5)	

Employment problems were significantly reported by HCV working males (52.3%) as compared to HCV working females (26.1%). Losing activity in work was the commonest employment problem reported by HCV working males (40.2%) and HCV working females (25.0%) (Table V).

Less than one third of both males and females reported no financial problems and so more than 70% of both HCV males and HCV females reported financial problems. Mild financial problem was significantly reported by HCV males (25.4%) as compared to HCV females (14.4%). On the contrary, severe financial problems were significantly reported by HCV females (62.3) versus (49.0%) by the HCV males (Table VI).

TABLE VI
EFFECTS OF HCV ON FINANCIAL STATE

Financial state	Males (n= 359) No. %	Females (n=181) No. %	Total (n= 540) No. %	P value
Not affected	91(25.4)	41(22.6)	132(24.5)	0.515
Mildly affected	91(25.4)	26(14.4)	117(21.9)	0.004
Severely affected	177(49.2)	114(63.0)	291(53.6)	0.005

Fig. 1 HCV and stigma among HCV patients ($p>0.05$)Fig. 2 HCV and stigma among males ($p>0.05$)Fig. 3 HCV and stigma among females ($p>0.05$)

As regards stigma, 13% the HCV patients are suffering from stigma with no significant difference between males and females (Figs. 1-3).

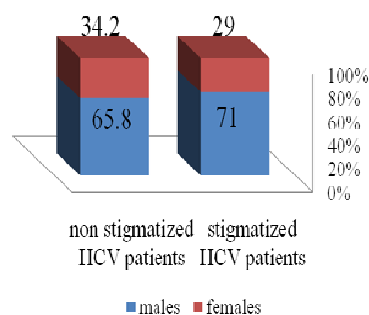
Fig. 4 Comparison between stigmatized and non stigmatized HCV patients as regard sex ($p > 0.05$)

Fig. 4 shows that 71.0% of the stigmatized HCV patients were males with no significant difference between males and females.

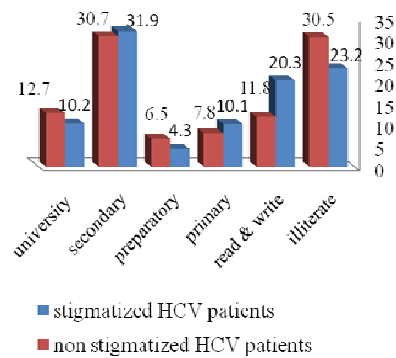


Fig. 5 Comparison between stigmatized and non stigmatized HCV patients as regard level of education ($p > 0.05$)

Fig. 5 represents no significant difference between stigmatized and non stigmatized HCV patients as regards different levels of education starting from illiteracy till university level of education.

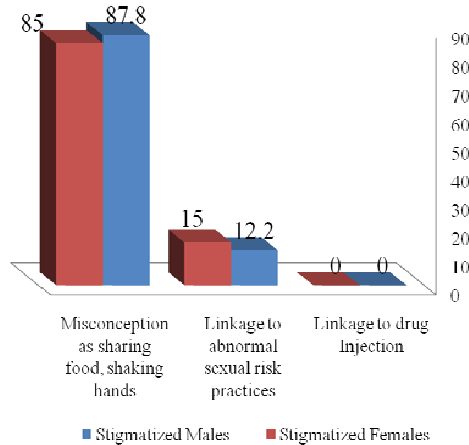


Fig. 6 Comparison between stigmatized males and females as regards causes of feeling of stigma ($p > 0.05$)

Fig. 6 represents misconception about mode of transmission of HCV (through sharing food and shaking hands) was the main cause of stigma among stigmatized males (87.8%) and females (85.0%). Linkage of HCV to abnormal sexual practice as a cause of stigma was reported only by 12.2% of the stigmatized males and 15.0% of the stigmatized females. There was no significant difference between males and females as regard causes of stigma.

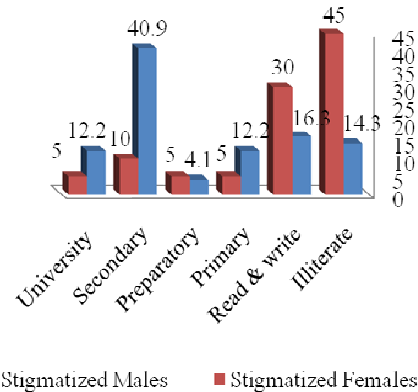


Fig. 7 Comparison between stigmatized males and females as regard level of education ($p < 0.05$)

There was significant difference between stigmatized males and females as regards education in which 45.0% of stigmatized females were illiterate versus 14.3% of males. Also 10.0% of stigmatized females had secondary o diploma degree of education versus 40.8% of stigmatized males (Fig. 7).

TABLE VII
TOPICS THAT THE MOTIVATIONAL MESSAGES SHOULD STRESS ON FOR
BEHAVIORAL CHANGES BEFORE GETTING INFECTED (PROBLEMS FACED BY
PATIENTS)

Problems faced	Cases (HCV+ve) (n= 540) No. (%)
Financial problems	408(75.5)
Family relationship problems	196(36.4)
Friendship problems	190(35.3)
Employment problems	157(29.0)
Some psychological problems (sadness, shame, worry, irritability, feeling dirty and danger).	107(19.8)
Sigma	69(13.0)
Marital problems	46(8.5)

Table VII prioritizes HCV patients' problems most likely to act as pressing motivators to be effective in promoting change in behavior. The greatest of all is the financial problems. Three quarter of the HCV patients reported financial problems (75.5 %), followed by family relationship problems (36.4%) and friendship problems (35.3%).

IV. DISCUSSION

Most people who are diagnosed with HCV infection react with some degree of shock, fear and denial [32]. The effects of hepatitis C on families, work environments, and on society as a whole, are impressive and of particular concern [33].

According to Erik et al. [34], initial reactions to the diagnosis of HCV included fear, denial, and/or shame, relief, guilt, anger, depression, hopelessness and worry about death. Similar to what was stated by Erik et al., [34], and other previous studies [18], [35], [36] we found in the current study that most participants reported a variety of negative feelings

when first diagnosed with HCV. More than 60% of the patients suffered from sadness and irritability, while more 40% reported feeling dirty and dangerous to other people. There was significant difference between the females (77.7%) and males (65.5) as regard sadness. Only 27.6% accepted the situation.

As regards later on reactions of being diagnosed as infected HCV patients, less than 30% of the patients continue their suffering from sadness, feeling with dirty, shame and worry. Female patients significantly reported these later on reactions as compared to males. Eighty percent accepted the situation later on. Another study found that 35% of HCV patients reported emotional distress [37]. Previous studies debate whether psychological symptoms related to HCV-infection can be attributed to the biological disease process or mainly result from the stress of living with a serious chronic illness [38].

Amy et al. [39] stated that a number of participants in a group focus discussion discussed experiencing intense feelings of irritability and anger. Frequently, these feelings were directed towards the people around them. A number of participants expressed difficulty in controlling these feelings of anger, with some describing a significant loss of impulse control. This is consistent with our results where 31.0% reported feeling of irritability and 11.8% reported feeling of anger as later on reaction to HCV diagnosis.

Social relationship issues emerged as an important and common theme. Patients reported difficulty with a variety of themes including telling people about their HCV, family interactions, and long-term/marital relationships. This is consistent with previous data suggesting that relationships are strained by worries about future health and fear of infection transmission and that such concerns may lead to reduced social interaction [24].

The current study displayed the frequency and characterized the nature of the relationship challenges that patients with HCV experience. More than one third of this group of HCV infected patients described a negative impact of their disease on family and friendship relationships (36.4% and 35.3% respectively). Our results are consistent with prior studies focusing on patients with HIV/AIDS or tuberculosis, who also felt rejected by relatives and friends [40], [41].

In the current study the patient feared interactions with others, because of the perceived risk that they might infect them and that is reported by 24.8% of the patients as regards family relationship and by 10.7% as regards friendship relationship. This goes parallel to the study conducted by informal web poll about stigma and viral hepatitis which revealed that 13 percent of HCV patients had been alienated from family and friends because of viral hepatitis [43].

Also, 32.6% of HCV positive patients in our study personally chose to withdraw from family contact because of their nervousness, while 20.1% withdrawn themselves from friendship relations because of nervousness. This is consistent with focus group discussion that was done by Amy [39]. He found that feelings of emotional disruptions and concern about

stigma led many HCV patients to withdraw or isolate themselves from others. In the current study twenty seven participants (5.1%) complained that his/her children withdrawn themselves from their diseased parent for fear of catching the disease. A similar breakdown occurred outside of the home, with 7.8% of the participants reporting that friends had shied away from them. Also, Julie et al. [42] reported that 12% of the HCV patients had experienced the loss of at least one friend. This is consistent with previous studies that stated that relationships are strained by fear of infection transmission and that such concerns may lead to reduced social interaction..

Isolation from friends because of fatigue represented the commonest cause of isolation (23.7%) in the current study. Fatigue is common to HCV-infected individuals and interferes with many daily activities; however, the severity of fatigue varies widely among individuals [44]. But it was often unclear how much of the fatigue was due to HCV versus normal aging or lifestyle (substance use, diet, depression) [45], [46].

The most devastating consequences were the financial burden as experienced by 75.5% of the participants that came either through a loss of work and/or through the cost of the antiviral medication. Mild financial problem was significantly reported by HCV males (25.4%) as compared to HCV females (14.4%). On the contrary, severe financial problems were significantly reported by HCV females (62.3) versus (49.0%) by the HCV males. This goes parallel to the study done by Sean [47] who found that 60% of HCV patients were concerned about financial stress and their ability to pay for prescribed medicines. Patients developed a variety of strategies to cope, including borrowing money, delaying the purchase of drugs and asking their health care provider for a cheaper substitute for an expensive drug. Some participants were uncomfortable discussing cost issues with their physician and instead sought such discussions with their pharmacist. He stated that many participants took a range of prescribed medicines to treat multiple conditions, including mental health issues, particularly anxiety and depression, higher-than-normal blood pressure, inflammation. This in addition to purchased supplements and complementary therapies, which increased their financial stress. Employment problems were significantly reported by HCV working males (52.3%) as compared to HCV working females (26.1%). Losing activity in work was the commonest employment problem reported by HCV working males (40.2%) and HCV working females (25.0%). But losing work was reported by 18.1% of HCV patients. This goes parallel to what reported by Julie et al., [42] where 25% of the HCV patients lost their work after being diseased. Also Conrad et al., [43] reported that 20 % of HCV patients had experienced job discrimination due to having hepatitis C.

As reported in prior studies, a substantial number of patients experienced frank stigmatization [48]-[50]. In the present study 13% of HCV patients reported feeling stigma with no significant difference between males and females. On the other hand, according Zickmund et al., [19] more than half of the patients had experienced stigmatization as a result of

having hepatitis C. Women were more likely to report stigmatization than men. Also Conrad et al. [43] reported that 58 percent of HCV patients faced stigma due to living with hepatitis. In the current study, misconception about mode of transmission of HCV (through sharing food and shaking hands) was the main cause of stigma among stigmatized males (87.8%) and females (85.0%). Linkage of HCV to abnormal sexual practice as a cause of stigma was reported only by 12.2% of the stigmatized males and 15.0% of the stigmatized females. There was no significant difference between males and females. According to Zickmund et al., [19] the three most common perceived reasons for stigma were society's association of hepatitis C virus with HIV/AIDS, the attribution of promiscuity, and the assumption that the person with hepatitis C was an injecting drug user.

Lack of knowledge and awareness about Hepatitis C in the community often leads to misinformation, missing of opportunities for prevention and treatment, and stigmatization of infected populations. The consequences for members of at-risk communities are important in that missing opportunities for prevention can lead to infection of additional people with HCV. Once infected, they frequently are unaware of their infection and so run the risk of unknowingly infecting others and of not receiving appropriate medical management [51], [52]. Our results suggest that participants still have misconceptions about HCV. More education appears needed. Participant conceptions about "using clean needles," transmission of the virus, the benefit of lifestyle changes, and antiviral treatment can also be addressed through a recently developed self-management program that provides interactive skills training in addition to basic information on HCV.

Hepatitis C Virus (HCV) has a major impact on quality of life and can cause patients significant distress. From a public health perspective, it is of 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.

V. CONCLUSION

Patients with hepatitis C often face financial insecurity, employment problems, internalized shame and significant social and psychological problems. The majority of HCV subjects have limited insight about the risk factors for its spread. Exploring the associated psychosocial consequences of HCV infection can act as pressing motivators for behavior change needed for limiting HCV endemicity in Egypt.

VI. RECOMMENDATIONS

Ministry of Health (MOH) activities, Hospitals and specialized centers activities and educational campaigns have to increase awareness of population at risk and general

population about HCV. These activities should have the priority to combat misconceptions about HCV that leads to stigmatization of infected populations for not missing the opportunities for prevention and treatment and limiting the endemicity of HCV.

Media should disseminate messages that motivate adopting risk-reduction behaviors for hepatitis with special emphasis on expressing the associated psychosocial consequences of HCV infection to encourage people to take a more active role in preventing exposure to HCV and/or modifying their behavior that permit transmission of HCV.

HCV individuals have to be counseled and encouraged to participate in educational programs at the time of diagnosis to reduce unnecessary behavioral changes and stigmatization perceptions to improve quality of life.

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