

INTRODUCTION

Hepatitis C is 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. Africa and Asia have the highest reported prevalence rates, in contrast to the low rates of HCV in North America, Western Europe, and Australia (*Xia and Luo, 2008*).

Egypt has the highest prevalence of Hepatitis C in the world. Overall, estimates of the HCV rate in the general population have range between 10 and 20 percent. 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. HCV infection has become the leading risk factor for hepatocellular carcinoma (HCC) in Egypt (antibodies present in as many as 75–90% of HCC cases) (*Ibrahim and Madian, 2011*).

Also *Eassa et al. (2007)* reported that HCV infection is generally acquired through parenteral exposure (e.g. blood and blood product transfusion in the past not currently, parenteral drug abuse, tattooing, blood piercing,

accidental needle stick, hemodialysis, donated organs or semen from an HCV carrier), snoring of drugs such as cocaine (causing damage to nasal mucosa and transmitted by sharing of straws), rarely by sexual and maternal-fetal transmission, and also by other mechanisms not fully defined (perhaps the sharing of razors and toothbrushes, nicks by straight razors in the barber shop).

HCV leads to cirrhosis in up to 20% of those chronically infected and is the primary indication for liver transplantation worldwide. This economic burden is multiplied by the dramatic impact of HCV on health related quality of life (HRQOL) resulting from complications of advanced liver disease such as encephalopathy, variceal hemorrhage, ascites, and liver transplantation. However, these end-stage complications are relatively rare compared with the vast majority of patients with HCV in the absence of clinically significant liver disease. Despite the previous consensus that this majority of patients has asymptomatic seropositivity, evolving data now indicate that HCV itself may diminish HRQOL in the absence of advanced liver disease (**Brennan et al., 2005**).

In addition **Groessl et al. (2011)** reported that most HCV-infected individuals experience a variety of physical and psychological symptoms, functional limitations and impaired health quality of life as a result of having HCV and co-existing chronic health problems.

Treatment recommendations for HCV-infected patients often include attending regular follow-up visits, obtaining additional laboratory tests, undergoing psychiatric evaluation, abstention from alcohol, avoiding transmission of the virus, avoiding certain foods or medications, exercise/losing weight and making decisions concerning antiviral treatment. Yet, many patients may not have the information or skills required to adhere to these recommendations successfully (*Fried and Hadziyannis, 2004*).

Also, *Bodenheimer (2002)* added that. Self-management education for patients with chronic illness means assisting patients to improve their clinical outcomes and enjoy the best possible quality of life. Self-management education includes traditional patient education but also involves helping patients to set achievable goals and learn techniques of problem-solving that will improve their outcomes and quality of life.

There are social, behavioural, and cognitive skills that patients can use to participate more effectively in the management of their HCV. These self-management strategies can help patients manage their symptoms, increase their functionality, make more informed decisions about treatment and potentially help prevent them from spreading the virus to others. Despite the need for such

approaches, little or no research on self-management for hepatitis C has been undertaken (*RWJF, 2001*).

Significance of the study:

Chronic hepatitis C is the second-commonest cause of death in Egypt, after heart disease. Deaths from liver disease were peak in 2010-2012: The burden of HCC is further demonstrative of the burden of disease linked to hepatitis C in Egypt. HCC is one of the three most commonly diagnosed cancers in Egypt, and it is estimated that 51.5% of cases can be attributed to HCV infection (*Sylvie et al., 2006*).

For HCV, treatment is not indicated in all cases. This is due to several factors, including the very high cost of treatment (upwards of 25,000 LE for HCV), its long duration up to a year for HCV patients and its significant and unpleasant side effects (*Wahid et al., 2010*).

Several specificities of the Egyptian epidemic are to be noted. First, nearly all Egyptian HCV infections (upwards of 95%) are genotype 4. While HCV genotype has no impact on the course of the disease, different genotypes do react differently to treatment; genotype 4 has an intermediate resistance to treatment. For this reason, Egyptian patients must undergo longer courses of treatment: 48 weeks instead of the 24 weeks recommended

for patients infected with genotypes 2 and 3. Egyptian patients may also be co-infected with Schistosomiasis, a pathogen that also harms the liver and accelerates the course of liver disease (*Wahid et al., 2010*).

In addition *Groessl et al. (2011)* asked that there is a need for programmes that can help patients improve HRQOL. Also Chronic disease self-management interventions have also impacted other outcomes such as reduced health care utilization and increased health behaviours. Despite the need for such approaches, there has been little or no research conducted with self-management programmes for patients with hepatitis C.

It is hoped that, data generated from this study could help in intervention of self management program for all patients with chronic HCV. It is also hoped that findings will generate attention and motivation for further investigations into these topics as well as the lack of local researches concerned with such a problem necessitate the conduction of this study.

AIM OF THE STUDY

This study aims to:

To study effect of self management program on health related quality of life for patients with chronic hepatitis C through the following:

1. Assess needs of patients with chronic hepatitis C.
2. Measure health related quality of life for patients with chronic hepatitis C.
3. Develop and implement self management program for patients with chronic hepatitis C based on needs assessment identified.
4. Evaluate the effect of program on HRQOL for patients with chronic hepatitis C.

Research Hypothesis:

Is a self - management program will has a positively change on HRQOL for patients with chronic hepatitis C.

REVIEW OF LITERATURE

Introduction:

Hepatitis C virus (HCV), first identified in 1989, is strictly a blood-borne ribonucleic acid (RNA) viral infection in the family Flaviviridae. Humans are the only reservoir for this viral infection. HCV infection most often leads to an asymptomatic chronic state, which can later progress to active liver disease, liver failure, or primary hepatocellular carcinoma. Treatment of HCV is costly, beyond the reach of most patients in less-developed countries, requires 48 or more weeks to complete, and has serious adverse effects and low efficiency. HCV in a family member can be socially and economically detrimental. There is no vaccine for HCV (*Miller and Abu-Raddad, 2010*).

The hepatitis C virus (HCV) is a major public health problem and a leading cause of chronic liver disease. The World Health Organization has declare Hepatitis C a global health problem, with approximately 3% of the world's population (roughly 170-200 million people) infected with HCV and 3–4 million persons are newly infected each year. Hepatitis C is the principal cause of death from liver disease and the leading indication for liver transplantation. Some calculations suggest that mortality related to HCV

infection (death from liver failure or hepatocellular carcinoma) will continue to increase over the next two decades (*Hassan et al., 2012 and Coppola et al., 2007*).

HCV is an RNA virus of the Flaviviridae family. Genetically, there is great variability in its structure. There are six main types of HCV, known as genotypes. These are identified by number, for example genotype 1, genotype 2, and genotype 3 etc. Each genotype has further subtypes, of which there are over 100 in total: genotype 1a, genotype 3b etc. Genotype does not determine the severity of disease, but some genotypes respond better to treatment than others (*Forns and Sanchez-Tapias, 2005*).

HCV is a blood-borne infection. Globally, modes of transmission vary. In the developed world, the most common route of HCV transmission is injecting drug use. In England, the Health Protection Agency identified injecting drug use as the risk factor for HCV infection in 92% of reported infections between 1996 and 2005. The prevalence of HCV infection in the UK is low; the prevalence amongst the current injecting drug user population is estimated to be around 45% (*HPA, 2006*).

In Egypt, the major route of exposure appears to be due to injection therapy and inadequate infection control practices.

In addition to blood transfusions prior to 1994, the major risk factor associated with HCV infection is a history of antischistosomal injection treatment before 1986. Also transmission of hepatitis C through other non medical routes has become more significant. For example, tattooing, circumcision or other medical procedures performed by non-medical personnel are more frequent routes of infection in Egypt than elsewhere. In addition, household transmission, vertical transmission and sexual transmission are routes that are also under investigation (*Mohamed, 2006*).

Pathology of HCV

Hepatitis C is a single-stranded ribonucleic acid (RNA) virus belonging to the family Flaviviridae. A distinctive feature, of HCV is the diversity of its RNA sequence. When RNA sequences differ by greater than 30% between samples, a different genotype is said to exist; currently there are six identified HCV genotypes within genotypes, a 10 to 30% variation in RNA Sequencing is identified as a subtype (*Fowler, 2007*).

In the United States, genotype 1a comprises fifty-seven percent of the cases of hepatitis C; genotype 1b accounts for seventeen percent. Genotype 2a accounts for four percent; genotype 2b accounts for an additional eleven percent. Genotype 3 accounts for seven percent, and

genotypes 4, 5, and 6 account for the remaining four percent. Clinically, the identification of HCV genotype is important in determining likelihood of response to treatment, Overview of the Egyptian viral hepatitis epidemic. With genotypes 1 and 4 more likely to be resistant (**Hoofnagle & Heller, 2003**).

HCV replication occurs primarily in the liver after binding to a cell-surface receptor followed by entry of the virus into the hepatocytes and uncoating of the viral genome. Liver histology of chronic HCV is characterized by hepatocellular injury, necrosis, portal and parenchymal inflammation, and variable degrees of fibrosis. Approximately thirty percent of patients with chronic hepatitis C will have persistently normal liver enzymes (**Lee & Harrison, 2005**). Patients with normal enzymes and no symptoms may have significant inflammation, and patients with normal physical findings and hepatic synthetic function may have considerable fibrosis (**Shehab et al., 2003**).

A liver biopsy can be useful in determining the likelihood of progression of liver injury in chronic hepatitis C. Liver biopsies are not, however, without risk. A liver biopsy is associated with pain in 30% of patients, severe complications in 0.3%, and death in 0.03% (**Garcia & Keeffe, 2001**). Liver biopsy results are reported as a “grade” and a “stage.” “Grading” refers to the assessment

of the activity of the liver disease and the amount of hepatocellular injury and inflammation. “Staging” refers to assessment of the degree of fibrosis or permanent architectural liver damage (*Hoofnagle & Heller, 2003*).

The histological hallmark of chronic hepatitis C is an infiltration of lymphoid cells in the portal tracts that disrupts the limiting plate, invading the surrounding parenchyma and leading to periportal or “piecemeal” necrosis (*Apolinario et al., 2002*). Chronic HCV progresses to the development of fibrosis, and fibrosis leads to the irreversible scarring and nodule formation that characterizes cirrhosis. Moderate or severe inflammation and fibrosis have been associated with a more rapid progression to cirrhosis (*Garcia & Keefe, 2001*).

Cirrhosis caused by hepatitis C occurs more frequently in men, in those infected after age 50, in those individuals with a high hepatic iron content, and in patients who consume more than six ounces per day of alcohol. HCV genotype also plays a role in the development of cirrhosis. The height of serum aminotransferase levels, duration of known infection, history of acute hepatitis, source of infection, and body weight generally do not correlate with the stage of fibrosis (*Hoofnagle & Heller, 2003*).

Approximately 15%–25% of persons clear the virus from their bodies without treatment and do not develop chronic infection; the reasons for this are not well known. Superinfection is possible if risk behaviors (e.g., injection drug use) for HCV infection continue, but it is believed to be very uncommon (*CDC, 2011*).

Overview of the Egyptian viral hepatitis epidemic

Approximately 15% of 59 million Egyptians in 1996 were estimated to have positive test results for anti-hepatitis C virus (HCV) antibody, and based on 60% viremia, more than five million Egyptians are chronically infected with HCV (*Millera and Abu-Raddadb, 2010 and Siegel, 2002*).

While *Yahia (2011)* added that Egypt is a hepatitis C anomaly. Globally, roughly one person in 50 is infected with the hepatitis C virus (HCV). In Egypt, a recent study found that about one person in seven of Egypt's 83 million populations tested positive for antibodies against HCV, indicating that these individuals have been infected with the virus at some point. However, nearly one person in ten carries its viral RNA and is therefore chronically infected.

The treatment of chronic hepatitis C (CHC) patients is considered a public health priority in Egypt to reduce

both the burden of liver disease and the transmission of HCV. However, dramatic health care budget constraints limit access to the costly treatment recommended in Western countries. Decision to treat should depend on the expected benefits from treatment of CHC patients, who are mostly infected with the genotype 1, living in the Nile Delta rural areas, and generally unaware of their HCV serological status in the absence of systematic screening (*Schwarzingher et al., 2004*).

a. Origins of the Epidemic

Egypt has among the world's highest prevalence rates of HCV estimated nationally at 14.7%. An estimated 9.8% are chronically infected. Numerous studies have confirmed that Egypt's viral hepatitis epidemic, particularly with regards to HCV, originated in the 1960s and 1970s during a mass campaign of parenteral antischistosomal therapy (PAT) using improperly sterilized glass syringes. Schistosomiasis, also known as bilharzia, is a parasitic infestation carried by snails living in The connection between antischistosomal therapy and HCV has been proven by studies demonstrating the positive correlation between exposure to PAT and risk of HCV infection, the overlapping geographic distribution of HCV and Schistosomiasis infection in the country²¹, and genotype tracing of HCV in Egypt (*Tanaka et al., 2004*).

Incidence is estimated at 2-6/1,000 per year in rural Egypt, depending on the community prevalence of HCV viremia. It is estimated that 70,000-140,000 new infections occur annually, most of them in rural areas. As there is currently no surveillance mechanism in place for HCV, it is impossible to monitor trends in prevalence rates (*Wahid et al., 2010*).

The current and future burden of disease caused by viral hepatitis in Egypt is significant: it is not an exaggeration to say that viral hepatitis (particularly HCV) is currently and will remain for some time Egypt's most pressing public health issue. There is like wise a large occult reservoir of HCV caused chronic liver disease. Liver disease is thus the second-commonest cause of death in Egypt, after heart disease. Deaths from liver disease are predicted to peak in 2010-2012: one model predicts 700,000 cases of cirrhosis and 140,000 cases of hepatocellular carcinoma within the next 20-30 years (*Mohamed, 2006*).

The burden of hepatocellular carcinoma (HCC) is further demonstrative of the burden of disease linked to viral hepatitis in Egypt. HCC is one of the three most commonly diagnosed cancers in Egypt, and it is estimated that 51.5% of cases can be attributed to HCV infection. Moreover, HCC rates appear to be on the rise, according to national and local cancer registries, as well as statistical

models of the epidemic (one paper predicts a 2.4-fold increase of HCC over the next 20 years) (*El-Zayadi et al., 2001*).

Several specificities of the Egyptian epidemic are to be noted. First, nearly all Egyptian HCV infections (upwards of 95%) are genotype 4. While HCV genotype has no impact on the course of the disease, different genotypes do react differently to treatment; genotype 4 has an intermediate resistance to treatment. For this reason, Egyptian patients must undergo longer courses of treatment: 48 weeks instead of the 24 weeks recommended for patients infected with genotypes 2 and (*Mostafa et al., 2006*).

Egyptian patients may also be co-infected with Schistosomiasis, a pathogen that also harms the liver and accelerates the course of liver disease. On the other hand, some aspects of the Egyptian situation tend to mitigate the potential impact of viral hepatitis from an epidemiological and medical standpoint. Prevalence rates of HIV are extremely low (estimated at <1%), which favorably affects the prognosis of individual patients (HIV can accelerate liver damage via the action of the virus itself). Finally, Egypt's Islamic culture means that rates of alcoholism and average per capita alcohol consumption are much lower than in the West, which may result in lower morbidity from