THE EXTENT OF PREVAILING STIGMA AMONG HEPATITIS C PATIENTS IN PESHAWAR KHYBER PUKHTUNKHWA PAKISTAN

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Abstract

Purpose of the study: This study was conducted with the sole aim to assess the prevalence of stigma in patients with Hepatitis C and to assess the association between them through the quantitative measure, i.e. chi-square test.

Methodology: A cross-sectional-based study was designed from 361 sampled respondents (Hepatitis C patients) in 3 teaching hospitals in Peshawar-Pakistan. Data was collected on a three-level Likert Scale interview schedule covering both the study variables. A conceptual framework comprised of the dependent variable *health-related quality of life among HCV patients* was cross-tabulated and indexed with the independent variable *social stigma disease carry* through the application of chi-square test statistics.

Principal Findings: The association of Health-Related Quality of Life was found significant with perceiving shaking hands with HCV patients as a cause of the disease ($P=0.018$), people hesitate in embracing HCV patients ($P=0.000$), people were uncomfortable while sitting beside HCV patients ($P=0.001$), family members are reluctant in carrying out HCV test for other family members ($P=0.028$), patients were given due attention at family (0.007), patients shared their problem with others without any fear ($P=0.014$), patients telling people about their disease ($P=0.000$), patients blamed themselves for disease ($p=0.009$) and patients participated in social activities ($P=0.000$).

Applications of this study: Raising awareness, through reliable sources, among masses, especially with relation to symptoms and causes of HCV, to reduce the reluctance of people in contacting HCV patients and training families of HCV patients to adopt the allowable social interaction with HCV patients were some of the recommendations in light of the study.

Novelty/Originality of this study: This cross-sectional study is designed to assess the prevalence of stigma in patients with Hepatitis C and to assess the association between them through the quantitative measure, i.e. chi-square test. This research has come under the domain of medical sociology, social psychology, along with diagnosing the hidden dilemma, which exists since its existence.

Keywords: *Health-Related Quality of Life, Hepatitis C, Social Stigma, Peshawar.*

INTRODUCTION

Hepatitis C (HCV) is a viral infection and blood-borne disease which causes damage to the normal functioning of the liver. It is now one of the major health issues worldwide. It reduces the quality of sound health and significantly contributes to mortality and morbidity as well. The virus is responsible for transfusion-associated non-A non-B Hepatitis was identified and later named with Hepatitis C (HCV) in 1989 ([Fokuo et al. 2020](#)).

A normal liver performs around 500 functions and contributes 2% of the total weight to the average human being. It is of crucial importance, i.e. it processes breath, converts substances into energy, builds immune response against disease, stores vitamins and sugars for later use, removes poison that reacts harmfully to health, etc. Hepatitis C virus damages liver cells which then no more remain capable of execution of such vital functions. The immune response also is paralyzed to defend and create building blocks against the virus ([Wait et al. 2017](#)).

HCV infection is slow and progressive. The virus of hepatitis C (HCV) attacks cells in the liver, causes liver inflammation, liver cirrhosis (replacement of liver cells by the scared cells), and hepatocellular carcinoma (liver cancer) which is one of the most well-familiar cancer and fifth worldwide route leading to mortality. Once a person has cirrhosis, their liver is usually incapable of being cured by itself ([Marinho & Barreira 2013](#)).

HCV, in most cases, is caused by drinking contaminated water, use of already used syringes/needles, direct blood-to-blood contact, and children born to mothers infected with HCV, which is commonly known as Mother to Child Transmission (MTCT). Sharing one's items, i.e. razors, toothbrushes are less likely in causing HCV. Likewise, exposure to sexual behaviour is also rarely considered a contributor to HCV. Those who suffer from HCV (usually with acute Hepatitis C) experience quite strange symptoms, including mild flu, fatigue, fever, night sweats, abdominal pain, loss of appetite, diarrhoea, jaundice, vomiting, muscular or joint pain, indigestion, and headache, etc. Patient of Chronic Hepatitis C (CHC) also experiences the same symptoms like acute HCV, but it has some different symptoms including, depression, brain-fag, mood swings, etc. ([Holton et al. 2015](#)). Chronic Hepatitis C shows nonspecific symptoms, which

make clinical diagnosis difficult to identify (Wait et al. 2017). Chu et al., (2016) added that complications due to hepatitis increase when the patients are unaware of their disease or its associated symptoms.

The complex web of diseases, its cost of treatment, complexities, and social stigma combine to affect the Quality of Life (QoL) of patients. The concept of QoL firstly came into sight in medical science in the 1970s. It is a well-known and most commonly used term that encompasses overall well-being, i.e. aspect of happiness, fully satisfied from life and tension-free. In short, it can also be expressed as the physical, psychological, and social well-being of a person. Health is the major determinant of QoL with varying meanings across the globe. Good health ensures high life quality, whereas, poor health due to severe diseases, like HCV, may lead to poor Quality of Life (Ali et al., 2020). Economists and Statisticians see QoL in term of material prosperity, good and services one need to live happily, whereas, Sociologists and Psychologists very distinctively determine QoL as the level of satisfaction of individuals about their social network or social organization (Turan et al., 2019). Health-Related Quality of Life (HRQoL) pertains not merely to the absence of disease or level of its severity or infirmity. A complete condition of one's physical, psychological, social well-being and also a contended state of being happy, healthy, and prosperous (Wait et al. 2017).

One of the social repercussions of chronic diseases like HCV is a social stigma associated with to disease. Social stigma, a mark of infamy or label of deviance, is being attached to a different illness like diabetes, HIV, and notably with HCV. Stigma is a treating agent to a patient's psychological well-being and affecting the hope of recovery from HCV. The societal speculations and misperceptions restrain healthy people's contact with an infected person and exclude the patient from the social sphere where he or she is not supposed to get together with others in social activities. Social stigma is the core factor that further degrades a patient's social status. In extreme cases, the patient victimized by social stigma starts blaming himself or herself for the cause of the disease rather than the reality (Madden et al. 2018). Social stigma poses a tough challenge to those with HCV, their families; social networks (colleagues, co-workers), communities, and society, as they also face severe torment of social stigma. Stigma is primarily based on speculations and perceived threats attached to illness significantly affect and get down the morale of patients to fight disease (Taft and Keefer, 2016).

HCV patients pose adverse effects to their self-image due to social stigma. The patient faces considerable challenges in interaction with others in society who are being marked, as usual, i.e. those perceived as having no such attributes as those stigmatized. Although the virus of hepatitis C is not easily transmitted as it has been historically perceived. Yet HCV does carry a societal attached stigma, which is potentially life-threatening. People deliberately stay away and shun those who are infected with HCV. Members of their family separate utensils, i.e. plates, glass, etc., and do not eat with them. This is what the exaggerated fear and their ignorance which overwhelms reality and leads to a reduction in HRQoL (Gross et al. 2020).

Cinar et al., (2015) reported patients hurt by perceived stigma, colligated with HCV, is extremely dangerous for their well-being. Social stigma creates supernumerary anxiety with HCV in a result infected population do not prefer to expose their infected status to their family member or colleagues. However, without any delay, they lose social support and become confined to their circle, usually isolated from the social sphere of interaction. Not only medical treatment is necessary for curing such diseases, but social support highly pervades medical treatment in the healing of a disease. Non-disclosure by adapting the way to conceal their HCV positive status leads to mental impairment as well, that is still perceived stigma rather than actual overwhelm over reality (Hill et al. 2014).

Finally, fear of stigmatization may cause one to avoid being tested, and those whose laboratory tests are declared positive with HCV/CHC may also refrain from treatment, attention, and care. Similarly, it has also been seen that their families give significantly little due heeds to them even do not carry diagnostic tests for them (Herek et al. 2003). Complexities of actual disease and perceived stigma create problems to patient's mental health and HRQoL. The patients, most often, show neuropsychiatric symptoms like depression, cognitive disorder, anxiety, and fatigue meantime they present zero progress to fight HCV (Kostic et al., 2016).

The rationale of the study and objective

The development of a nation depends on the productive involvement of its members in the development endeavour. Such constructive participation on the part of members is unequal as it varies from person to person and uneven as it varies on the physical, social and psychological state of individuals during their life. State of poor health in terms of chronic disease drastically affects human efficiency and their productive involvement. The situation is further worsened when a poor health state is poor, ill-informed, maltreated, and stigmatized. **This research study, therefore, is devised to find out the association between social stigma attached to HCV and Health-related quality of life (HRQoL) of HCV patients.**

METHODOLOGY

The study was carried out in three teaching hospitals, namely Lady Reading Hospital, Khyber Teaching Hospital, and Hayatabad Medical Complex located in Peshawar City, Khyber Pakhtunkhwa, Pakistan. A pilot survey was conducted to estimate the number of HCV patients admitted/visited these hospitals every month. The total population of potential respondents infected with HCV came out to be 5580. For a population size of 5580, a sample size of 361 suffices as per

the criterion devised by [Sekaran \(2003\)](#). The respondents were selected by using a systematic sampling technique, where the first respondent was randomly selected, and the following were chosen by a skip interval of 16.

Table 1: Conceptual framework

Independent variable	Dependent variable
Social Stigma	Health-Related Quality of Life among Hepatitis C Patients

A conceptual framework was devised comprising of two study variables, i.e. Health-related quality of life (HRQoL) (Dependent Variable) and social stigma (Independent Variable) (see Table 1). For the measurement of study variables, the attitudinal statement was pooled from the existing literature, and three Level Likert Scales were constituted for each study variable (15 attitudinal statements including statements for physical, psychological, economic, and social well-being, for measurement of HRQoL and 11 attitudinal statements indicative of social stigma).

The respondents were interviewed by the researcher himself, keeping in view APA standard of ethics. The dependent variable (Health-Related Quality of Life among Hepatitis C Patients) was indexed to get summarise results for HRQoL for each patient. A patient was ranked as having a good quality of life if he/she responded positive attitude on more than ten attitudinal statements on HRQoL. Those that reacted positively on 6-10 attitudinal statements related to HRQoL were ranked as fair on the scale, and the rest were having poor quality of life as they responded negatively on more than ten attitudinal statements on HRQoL.

The indexed dependent variable (Health-Related Quality of Life among Hepatitis C Patients) was cross-tabulated with the independent variable (Social Stigma) to measure the association among study variables. Chi-Square (χ^2) Statistics was used a 95% confidence interval to test the association of variables at the Bi-Variate Level. The Statistical procedure outlined by [Tai \(1978\)](#) was adopted to calculate the value of Chi-Square (χ^2) Statistics through the formula as below;

$$\chi^2 = \sum_{i=1}^r \sum_{j=1}^c \frac{(O_{ij} - e_{ij})^2}{e_{ij}}$$

RESULTS AND DISCUSSIONS

Frequency and percentage distribution of respondents' regarding their feelings of social stigma associated with HCV

The results indicate that the majority 69.5%, of the respondents, agreed that people often hesitate in shaking hands with them, while 30.5% disagreed that people were reluctant to meet with them. Furthermore, 77.6% of respondents admitted that people do not assume or hug them, and 22.4% reported that people embrace them happily without showing a sign of hesitation. Similarly, the majority of the respondents, i.e. 93.1%, viewed that people were not comfortable while sitting beside them, and 96.9% opined that people were comfortable while sitting beside them. Hepatitis C virus is non-transmittable due to regular body connections like shaking hands, sitting beside, or embracing patients. Avoiding such contact with HCV patients makes them feel stigmatized with strong psychological solids. These findings are supported by the inferences of Weiss & Ramakrishna suggested those who suffer from HCV carry social stigma and this stigma is not attached to the disease naturally while it has been intentionally or unintentionally created by society. It has been advised that not to shake or hug those who suffer from a specific disease, and do not let them sit with you ([Madden et al. 2018](#)).

Similarly, 93.1% of the respondents believed not their family members and friends do not share their meals with them because of positive HCV, whereas, 6.9% replied that members of their families and their friends shared their dinner with them without any fear. HCV is a fatal illness. It is a general perception that HCV is transmitted if a healthy person shares his meal with an HCV patient; therefore, the majority of people avoids taking a meal with such patients. These findings are supported by observations made by [Zack \(2006\)](#), both of them agreed upon that their family members and friends of HCV patients usually do not share their meal and utensils, i.e. plates and glass, etc. with patients. The utensils are being separated for them as a preventive to avoid the risk of getting a disease.

Furthermore, 74.2% of the respondents perceived that their family members are not reluctant in carrying HCV tests and 25.8% were reluctant in doing so. In addition, the majority of the respondents, 84.2%, were given due attention to family while 15.8% were not given due attention in their family. Poverty, poor access to medical facilities, and a casual attitude towards health are the major causes of adversities in diseases. The findings of the study are immensely supported by [Wait et al. \(2016\)](#) they viewed that family members of the patients pay low heed to their patient's health, the diagnosis was delayed, and patients were provided delayed treatment that leads to severe condition of disease, i.e. chronic hepatitis C (CHC). Furthermore, 60.9% of the respondents revealed that they did not share their problems with their families, while 39.1% shared their issues with family and friends. In addition, the majority, 84.2%, said that they usually did not tell people about their disease, while, 15.8% told people about their condition. The findings of [Faye & Irurita \(2003\)](#) supported these results that because of the fear of social stigma, patients do not disclose their positive status and keep secret their current HCV status from family members and close friends.

Moreover, 92.5% of respondents said that the behaviour of respondents has changed due to social stigma attached to the disease and people do not behave with them as generally as they were behaving before the disease; only 7.5% negated the statement. Similarly, 70.9% of the respondents blamed themselves for the disease they are suffering from, and 29.1% did not blame themselves as a primary cause for the conditions. Patients, severe diseases like HCV blame themselves out of despair. Such despairs are also a result of social stigma. [Madden et al. \(2018\)](#) stated that because of social stigma with disease patients blame themselves for the cause of disease instead than to trace the real cause of illness; this is how the fear of social stigma affects their behaviour. The results indicate that 87%, of respondents, were unable to participate in daily social activities. A combination of physical disabilities and social stigma compel for low social participation of patients with a fatal disease, while 13% were able to participate in social activities. These findings agree with the inferences draw by [Al-Kanaani \(2011\)](#). He reveals that disease made man paralyzed to play his/her assigned role and participate in social occasions, i.e. Eid festival, etc.

It is concluded that social stigma remained associated with HCV prevailed and it seriously affected the regular social interaction of HCV patients. The patients were avoided for normal physical and social contact. They feared to disclose their disease identity and received low attention from family and friends. The result was heavy psychological stress due to the stigma attached to the disease that reduced normal physical and social activities on the part of patients.

Table 2: Frequency and percentage distribution of respondents' regarding their feelings of Social stigma associated with HCV

Attributes	Yes(%)	No(%)	Uncertain(%)
People don't hesitate in shaking hands with you	110(30.5)	251(69.5)	0(0)
People don't hesitate when they embrace you	81(22.4)	280(77.6)	0(0)
People are comfortable while sitting beside you	25(6.9)	336(93.1)	0(0)
Your family/friends share their meal with you	25(6.9)	336(93.1)	0(0)
Your family members are not reluctant in carrying out the HCV test	268(74.2)	93(25.8)	0(0)
You are given due attention at your family	304(84.2)	57(15.8)	0(0)
You share your problems with family without any fear	141(39.1)	220(60.9)	0(0)
You tell people about your disease	57(15.8)	304(84.2)	0(0)
Behaviour of people is as usually it was before disease	27(7.5)	334(92.5)	0(0)
You blame yourself for this disease	105(29.1)	256(70.9)	0(0)
You participate in daily social activities, as usual, you were before disease.	47(13.0)	314(87.0)	0(0)

*Values in the table present frequency while values in the parenthesis represent the percentages proportion of the respondents.

Association between social stigma and Health-Related Quality of Life (HRQoL)

A significant relationship ($P=0.018$) was found between HRQoL and people don't hesitate in shaking hands with HCV patients. Similarly, a very highly significant association ($P=0.000$) was found between HRQoL and people don't hesitate when they embrace a person who is making medically unsound. A significant association ($P=0.001$) was found between HRQoL and people who are comfortable while sitting beside patients. The frequency distribution of these results makes it evident that those patients that feel that people are reluctant in shaking hands, embracing and sitting beside HCV patients are more prone to have a poor quality of life. HCV is transmitted from a patient to a healthy person only through the blood to blood contact. The general misunderstanding of not touching patients with HCV creates a sense of stigma among patients it may lead to the worse psychological immune response to fight disease and reduced quality of life in them. [Madden et al. \(2018\)](#) claim that because of societal solid stigmatization of a particular illness; people often restrain themselves from an infected person. The perception of transmission of disease, this apparent behaviour of controlling from a person suffering from a disease may create a feeling of stigma, and hopelessness in an already ailing person.

A considerable association ($P=0.028$) was confirmed between HRQoL and family members are not reluctant in carrying out HCV test for other family members. Similarly, a significant association ($P=0.007$) was found between Health-Related Quality of Life and giving due attention to family. Those that were given proper attention at a family level were more likely to have a good quality of life, similarly, those HCV patients who carried out timely diagnostic tests were more likely to have a better quality of life. Quality of life, therefore, is a firm associate with proper care of patients and early diagnosis of disease. This strengthens the patient psychologically, reduces his worries, and reduces the feeling of social stigma associated with the disease. These findings of the study are supported by [Hill et al. \(2015\)](#), that patient having poor quality of life has a history of family members that pay no due heeds toward their patients' health and even they are in a poor precautionary position to carry out diagnostic tests for them in advance. When the signs and symptoms of HCV are observed by the patient the motion is denied by the family and he is ignored for carrying out diagnostic tests

for him. Furthermore, a significant association ($P=0.014$) was found between Health-Related Quality of Life and patients share their problems with family without any fear. A highly significant association ($P=0.000$) was found between HRQoL and telling people about the disease. Patients that don't share their disease-related problems with family members and are reluctant to disclose their disease to others are more prone to have a poor quality of life. The social stigma associated with the condition may compel the patient to hide facts that are the cause of their poor life quality. [Faye & Irurita \(2003\)](#) also elaborated that patients hide facts due to social stigma and try to overcome the psychological effects of the disease. This, however, is self-damaging to patients and have adverse physical and psychological effects.

Similarly, a highly significant association ($P=0.000$) was found between HRQoL and behaviour of people is as it was before the disease. In addition, considerable association ($P=0.009$) is shown between Health-Related Quality of Life and blaming oneself for the illness. It is evident from the results that those who feel that people's behaviour has been changed with them and those that don't participate in routine social activities are more prone to have a poor quality of life. However, those patients that don't blame themselves for the disease are more likely to have a good quality of life. [Smith et al. \(2012\)](#) reveal that the behaviour of people changes and turns strange with a person to whom they were close before he or she was not stigmatized as a patient. In such cases, the patient seems to feel like a cause of disease. The social stigma, therefore, worsens the patients quality of life. Furthermore, a highly significant association ($P=0.000$) was found between HRQoL and participation in daily social activities. This statement is supported by [Krzeczkowska et al. \(2011\)](#) claim that while fighting disease a patient is unable of participating in all those social activities in which he or she was participating while healthy.

Non-significant association ($P=0.618$) was found between HRQoL and sharing of meals and utensils of family members with the patient. The frequency distribution of these results indicates that when patients were diagnosed with HCV, family members were less inclined to share a meal and as well as utensils with a patient which may lead to poor quality of life. [Krzeczkowska et al. \(2011\)](#) & [Rei et al. \(2017\)](#) reveal patient's family members and friends usually do not share their meals and utensils, i.e. plates and glass, etc. This could only happen when there is a strong association of social stigma with the patient's ailing status, and such situations in which the patient is strongly isolated in the family reduce his quality of life. Poor knowledge and understanding of causes and vectors of a fatal disease, like HCV, creates a sense of hesitation and reluctance among masses, especially the friends and family members of patients, to take the patient usually. They abstain from regular social interaction with the patients. The feeling of social stigma attached to the disease is also reflected in family and patients behaviour. The family members are not prompt in taking proper care of patients, and the patients are reluctant in disclosing their ailment identity to others. The stigma, besides physical stresses, constrains the patients to participate in regular social activities. The combination of all these effects stigmatizes the patients' identity and has the worst effects on patients' quality of life.

Table 3 Association between the social stigma and Health-Related Quality of Life (HRQoL) N= 361

The social stigma attached to HCV	Feeling	HRQoL among HCV Patients			Total	Chi-Square (P-Value)
		Good	Fair	Poor		
People don't hesitate in shaking hands with you	Yes	16(35.6)	17(50.0)	77(27.3)	110(30.5)	$\chi^2=8.004$ (0.018)
	No	29(64.4)	17(50.0)	205(72.7)	251(69.5)	
People don't hesitate when they embrace you	Yes	14(31.1)	16(47.1)	51(18.1)	81(22.4)	$\chi^2=16.858$ (0.000)
	No	31(68.9)	18(52.9)	231(81.9)	280(77.6)	
People are comfortable while sitting beside you	Yes	9(20.0)	0(00.0)	16(5.7)	25(6.9)	$\chi^2=15.150$ (0.001)
	No	36(80.0)	34(100.0)	266(94.3)	336(93.1)	
Your family/friends share their meal with you	Yes	3(6.7)	1(2.9)	21(7.4)	25(6.9)	$\chi^2=0.961$ (0.618)
	No	42(93.3)	33(97.1)	261(92.6)	336(93.1)	
Your family members are not reluctant in carrying out the HCV test	Yes	36(80.0)	31(91.2)	201(71.3)	268(74.2)	$\chi^2=7.175$ (0.028)
	No	9(20.0)	3(8.8)	81(28.7)	93(25.8)	
You are given due attention at your family	Yes	41(91.1)	34(100.0)	229(81.2)	304(84.20)	$\chi^2=9.902$ (0.007)
	No	4(8.9)	0(00.0)	53(18.8)	54(15.8)	
You share your problems with family without any fear	Yes	26(57.8)	15(44.1)	100(35.5)	141(39.1)	$\chi^2=8.524$ (0.014)
	No	19(42.2)	19(55.9)	182(64.5)	220(60.9)	
You tell people about your disease	Yes	10(22.2)	14(41.2)	33(11.7)	57(15.8)	$\chi^2=21.424$ (0.000)
	No	35(77.8)	20(58.8)	249(83.3)	304(84.2)	
Behavior of people is, as usual, it was	Yes	13(28.9)	4(11.8)	10(3.5)	27(7.5)	$\chi^2=37.015$

before the disease	No	32(71.1)	30(88.2)	272(96.5)	334(92.5)	(0.000)
You blame yourself for this disease	Yes	7(15.6)	5(14.7)	93(33.0)	105(29.1)	$\chi^2=9.475$
	No	38(84.4)	29(85.3)	189(67.0)	256(70.9)	(0.009)
You participate in daily social activities as usual, you were before the disease	Yes	13(28.9)	0(00.0)	34(12.1)	47(13.0)	$\chi^2=15.327$
	No	32(71.1)	34(100.0)	248(87.9)	314(87.0)	(0.000)

CONCLUSIONS AND RECOMMENADTIONS

It is concluded from the study that there was a common misperception about HCV disease and modes of its spread that prevented family members to have normal social contact with patients. The HCV patients, therefore, felt stigmatized in the prevailing social setup. These feelings compelled the patients to hide the truth even in front of doctors and resulted in poor quality of life. Furthermore, due to strong feelings of stigma, patients were reluctant to expose their positive status of HCV to their families in the initial stage of the disease. The disease, therefore, remained unnoticed during the initial stages and was only diagnosed when reached the more chronic and fatal stage.

It is strongly recommended to train families of HCV patients to adopt the allowable social interaction with HCV patients and remove their sense of stigma attached to the disease and adopt necessary precautions to safeguard family members from getting infected with diseases. The HCV patients also need thorough counselling to overcome being stigmatized and secure a better life quality.

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AUTHORS CONTRIBUTION

Quadrat Ullah is the Principal author of this research paper, which gives the main idea and conceptualise it in a better manner. Dr Asad Ullah was responsible for the supervision and designing the statistical application in the whole process. Younas Khan was responsible for article writing, proofreading and play a crucial role in being the corresponding author of this esteemed journal. Farooq Ahmad Khan assisted the whole process of the data collection process.

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