

# HEPATITIS-C (HCV)-RELATED SOCIAL STIGMA; DEVELOPMENT OF A SCALE

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## ABSTRACT

**In the past two decades, there has been a substantial research on disease related stigma especially the HIV stigma. However, only a few studies address the issue of HCV related social stigma. Through this study a scale was developed to measure HCV related social stigma. The scale was developed using literature review and interview with 26 individuals divided in five different groups. The nineteen item scale developed after this activity was distributed among 221 respondents. Results indicate that the scale shows robust psychometric properties with good alpha value having a four factor solution. The results are discussed with theoretical and practical implications that how this scale will facilitate measurement of HCV related social stigma in future studies.**

## INTRODUCTION

Globally, Hepatitis C (HCV) is ranked among the three most widespread chronic viral infections (McCarron, Main, & Thomas, 1997; Soriano, Barreiro, & Nunez, 2006; Alavian, Adibi, & Zali, 2005) and HCV carriers are ten times higher than people carrying HIV (Global AIDS Epidemics, 2006), which makes HCV a major health problem worldwide (Brown Jr & Gaglio, 2003). Apart from the medical complications associated with the disease like chronic liver cancer, it is also a source of psychological problems which include depression, anxiety (Alter & Seeff, 2000; Golden et al., 2005) discrimination, social separation and stigma (Golden et al., 2006; Brener et al., 2007).

Stigma is an outcome of social process (Weiss et al., 2006) that disgraces individual within a social context (Goffman, 1963) and symbolizes degradation (Pearsall, 1999). Recent years witnessed increased attention of researchers towards HIV stigma (e.g. Fife & Wright, 2000; Fontana & Kronfol, 2004) and its social outcomes (Herek et al., 2002) including devaluation and discrimination by society (Bashir, 2011). Still, limited studies focus HCV related stigma (Paterson et al., 2007), though it is a noteworthy issue that requires attention (Hopwood & Southgate, 2003; Zacks et al., 2006). There is also a dearth of knowledge on HCV stigma in those contexts (e.g. Pakistan), where it has emerged as a biggest threat. Butt (2008) suggested that being a complex social phenomenon, studies must address

the socio cultural factors associated with HCV stigma. Occurrence of HCV is high in several Asian countries (Thanachartwet et al., 2007; Wang et al., 2008), and in majority of underdeveloped countries HCV stigma is not properly understood (Van Rie et al., 2008). If we specifically take the example of Pakistan, Kuo et al., (2006) suggests that very limited studies addressed the issue in this particular context, where prevalence of HCV is alarmingly high.

Another omission in HCV stigma literature is non availability of an instrument that can measure stigma in different social environment with robust psychometric properties across cultures (Van Brakel, 2003), as causes of stigma vary across cultures (Clair et al., 2005). To the best of our knowledge, no standardized instrument is available to measure social stigma associated with HCV. The probable reason for omissions can be attributed to the fact that HCV is probably not a big threat to many developed countries, and in underdeveloped countries like Pakistan, where millions of people have lost their lives because of complications associated with HCV; studies have paid limited attention towards HCV stigma and its measurement through a validated scale. Thus, an important contribution of the present study is its address to this gap under researched area.

## HCV related Social Stigma

An individual can be socially stigmatized on the

basis of some visible or non visible source (Tsui & Gutek, 1999). The visible sources include age, color and race, while non visible sources are religion, occupation and illness (Williams & O'Reilly, 1998). The invisibility of illness creates confusion resulting in social isolation of patients (Cox, 1993). The fear that the disease may transmit to others within a social group (Sandelowski, Lambe, & Barroso, 2004) makes individuals socially worthless (Reidpath, Chan, Gifford, & Allotey, 2005) causing deterioration in their physical and psychological well-being (Major & O'Brien, 2005).

HCV carriers are considered socially irresponsible (Paterson et al., 2007) and they encounter stressful social interactions and isolation (Crocker & Major, 1989). Studies also reveal that social stigma associated with disease also enhances medical complications (Riaz, Ahmad, & Khanam, 2011), as fear of isolation and stigma forces the HCV carriers not to pursue the treatment properly (Madden & Cavalieri, 2007). This fear can be a major reason for wide spread of disease as people avoid the tests of infectious diseases (Kalichman et al. 2005) due to fear of stigmatization (Hopwood, Treloar, & Bryant, 2006). Awareness among masses about transmission of disease can reduce sufferings of patients (Butt, 2008), and they can have support from others regarding better treatment (Jones et al., 2012), which can help in reduction in spread of disease (Corrigan & Penn, 1999).

### **The study context: HCV in Pakistan**

A considerable geographical difference has been noticed in prevalence of HCV globally (Sood et al., 2012). In South America, North America, Europe and Asia, there is considerable unpredictability in HBV and HCV occurrence (Pereira & Levey, 1997; Sulowicz, Radziszewski & Chowanec, 2007). According to Aceijas and Rhodes (2007), HCV occurrence estimation by area varies as follows: 2–100% in Latin America, 8–90% in North America, 25–88% in Australia and New Zealand, and 2–93% in Western Europe, 10–96% in Eastern Europe & Central Asia, 10–100% in South and South–East Asia, 34–93% in East-Asia and Pacific, 5–60% in North Africa and Middle-East.

Prevalence of HCV in Pakistan is alarmingly high, and studies suggest that there are around 10 million HCV patients in Pakistan (Hamid et al., 2004). Similarly, studies on random samples (e.g. Idrees, Lal, Naseem, & Khalid, 2008) confirm that the disease is spreading across country at a threatening rate. HCV has become a problem for every house hold. The mother of one colleague lost her life after struggling for two years against chronic liver cirrhosis caused by

HCV, and so is the case with almost every family in Pakistan. Being a collectivist society (Hosftede, 1980), the disease has a number of social implications along with psychological problems (Qureshi, Khokhar, & Shafqat, 2012). However, the social stigma associated with HCV in specific context of Pakistan has never been studied.

## **RESEARCH METHODOLOGY**

### **Scale Development**

The measurement of stigma has also remained an area of interest in the extant literature. Berger, Ferrans, and Lashley (2001)'s 40 item scale is considered to be the most reliable scale to measure stigma associated with HIV. Similarly, the scales to measure stigma associated with other diseases include perceived stigma for substance abuse (Link, 1987), onchocerciasis (Brieger, Oshiname, & Ososanya, 1998), mental illness (Ritsher, Otilingam, & Grajales 2003), leprosy (Tsutsumi et al., 2004) and epilepsy (Westbrook, Bauman, & Shinnar, 1992; Austin, MacLeod, Dunn, Shen, & Perkins, 2004; Austin & Huberty 1993; Jacoby, Baker, Smith, Dewey, & Chadwick, 1993; Cramer et al., 1999; Tekle-Haimanot et al., 1992; Aziz, Akhtar, & Hasan, 1997).

Van Brakel (2006) suggested that most of these instruments were developed focusing American context except few which focused the regional contexts. Kalichman et al. (2005) developed the multi item scale of HIV/AIDS stigma in South Africa. Moriya, Gir and Hayashida (1994) developed the stigma scale for Brazil, while Nyblade et al. (2005) developed it for Tanzania. However, limited studies attempted to develop a scale stigma associated with HCV (Habib & Adorjany, 2003). These factors signify the need to develop a specific scale to measure social stigma associated with HCV, which seems missing in literature.

For present study, HCV related social stigma was identified through literature review. As per Goffman (1963)'s findings, there are three aspects of stigma, and the items identified mainly relate to these three dimensions of social stigma. Later these items were extensively discussed by five focus groups comprising of twenty six individuals. These individuals included medical doctors treating the HCV carriers, and also with individuals who had an interaction with HCV patient. Based on this discussion, a total of 19 items were included in the scale which were adopted from various sources (e.g. Link, Cullen, Frank, & Wozniak, 1987; Visser, Kershaw, Makin, & Forsyth, 2008; Genberg et al., 2009; Kalichman et al., 2005). The items responses were taken using a 5 point likert scale

with 1 representing strongly disagree and 5 representing strongly agree.

### Sample

The main criterion for recruitment of sample was that respondents must have some sort of social interaction with HCV patient either as a family member, friend a class fellow or coworker. For this purpose, four universities were visited, along with six banks, three public sector organizations and two hospitals in the cities of Rawalpindi and Islamabad. It was noticed with concern that almost all the people working in these organizations had some sort of social interaction with HCV patients. Most of them also told stories of their dear ones who lost their lives in battle against HCV. This explains the extent to which this disease has spread in Pakistan. However, the questionnaires were distributed only to those respondents who confirmed that they had a routine interaction with HCV patients.

The questionnaires were distributed with the help of HR department in these organizations. The objectives of this study were explained to respondents in detail. Some respondents were unable to comprehend the questionnaire due to low literacy level; hence questions were read aloud in front of them and responses were asked. The data was collected from December 2012 to April 2013. This required frequent visits to these organizations during this time period.

A total of 343 questionnaires were distributed in these organizations, and 233 were received, of which 11 were incomplete; hence, 221 were used for final analysis making response rate as 64% which seemed adequate. The composition of this sample included 59% male and 41% female respondents. As for educational qualification, 30% of respondents had less than school certificate level education, 22% had bachelor degree, while 48% held masters degree. The age composition of respondents indicated that 40 % respondents were between the age of 20 to 30 years; 26 % between 31 to 40 years; 22% between 41 to 50 years and 22% were above 50 years of age.

### RESULTS

For pilot testing initially, the questionnaires were distributed among 63 respondents and a satisfactory alpha reliability value of 0.886 was observed. Data was collected from 221 respondents. The values of corrected items, total correlation and cronbach alpha are shown in Table I, while Table II indicates the items mean and standard deviation values.

**TABLE 1**  
**HCV related stigma scale corrected item - total correlation and cronbach alpha coefficients if items deleted item (n=221)**

Items#	r <sub>It</sub>	α1
1	.539	.881
2	.619	.880
3	.647	.877
4	.863	.870
5	.833	.871
6	.670	.879
7	.301	.903
8	.581	.879
9	.384	.905
10	.361	.894
11	.386	.889
12	.539	.881
13	.619	.880
14	.647	.877
15	.863	.870
16	.833	.871
17	.696	.876
18	.714	.873
19	.842	.873

The results of factor analysis with varimax orthogonal rotation are shown in Table 2. A total of 19 items were analyzed showing the four factor solution.

### DISCUSSION

The basic objective of the present study was to firstly introduce the concept of HCV related social stigma, and then to develop a robust instrument to measure it. There are important insights which this study has added to the extant literature on HCV related social stigma. Since HCV carriers are stigmatized by 'others' around them, it is important to analyze the feelings and perceptions of these individuals to correctly address the issue. Parker and Aggelton (2003), while discussing HIV stigma concluded, that stigma is an important issue and the uninfected individuals have to live and accommodate people with HIV. On the same analogy, this study suggests that through awareness and tolerance to live with HCV carriers and not to discernment them socially, the psychological miseries of HCV carriers can be reduced to some extent, if not totally eradicated.

The scale developed to analyze the social stigma associated with HCV is found to have robust reliability. The four dimensions identified as a result of factor analysis are in line with stigma theory presented through his seminal work by (Goffman, 1963), which is social isolation, negative social perception, fear of contagion and pity attitude. These dimensions indicate the types of social stigma the HCV carriers face on day-to-day basis.

**TABLE 2**  
**HCV related stigma scale five factors, factor loadings and items**

Factor		Loading	Item	
1.Social Isolation	9 items, $\alpha=0.821$ , Eigen value=7.33, 32.22%	0.863	1	HCV carriers should not be trusted
		0.876	2	Although HCV patients may seem all right it is dangerous to forget for a moment that they are HCV carriers.
		0.878	3	I would not like to sit next to someone with HCV in public transport.
		0.594	6	I would not like to have friendship with someone having HCV.
		0.831	7	It is safe for a person with HCV to look after somebody else's children.
		0.876	12	People living with HCV in this community face rejection from their peers.
		0.878	13	People living with HCV in this community face neglect from their family members.
		0.893	15	People with HCV should be allowed to fully participate in social events in this community (R).
		0.842	16	I feel comfortable being seen in public with HCV carrier (R)
2. Negative social Perception	3 items, $\alpha=0.713$ , Eigen value=2.13, 7.33%	0.841	9	I would not employ someone with HCV.
		0.851	5	I think less of someone because they have HCV.
		0.851	11	I feel uncomfortable around people with HCV.
3: Fear of Contagion	3 items, $\alpha=0.761$ , Eigen value=1.13, 3.22%	0.833	19	A person with HCV must have done something wrong and deserves to be punished.
		0.939	8	I feel afraid to be around people with HCV.
		0.604	14	Most people would not buy edibles from a shopkeeper or food seller that they knew had HCV.
4: Pity attitude	3 items, $\alpha=0.87$ , Eigen value=2.12, 5.42%	0.939	17	I am afraid of catching the HCV from an affected person.
		0.632	4	Having HCV is just a matter of bad luck.
		0.844	10	People with HCV deserve as much respect as anyone else.
		0.809	18	I feel sorry for a person with HCV.

Almost each and every Pakistani observes people dying of HCV in their surroundings. Thus, fear associated with this disease is alarmingly high, which itself is a major source of social stigma. People avoid HCV carriers with the unknown fear that they might catch the disease. Lack of awareness plays an important role in this regard as most of the people don't know the exact cause of disease, and this ambiguity results in negative

perception about the disease. In an Asian context, the problem becomes more serious regarding HIV. Bhattacharya (2004) suggested that Aids is considered a dirty disease in South Asia; we observed similar opinion among masses about HCV. People tend to isolate HCV carriers socially, and do not prefer social interaction with them. Earlier studies suggest that lack of awareness and illiteracy further intensify the issue manifold. During

interviews, majority of respondents indicated that they do not prefer to eat with HCV carriers or to interact with them. They considered that HCV spreads using same utensils or normal social interaction like hand shaking and hugging. Some families indicated that they have separated the utensils etc, of patients, although HCV does not spread through this mode.

People generally think it is because of sins or intentional wrong doing by the HCV carrier, and thus he/she deserved this punishment in the form of this disease. Hence, a person who deserves sympathy is subjected to negative perception in social context, making his/her life more miserable. Some people take it as anyone having this disease is not a normal person, and thus they deserve sympathy or which we call petty attitude. This attitude also causes a sort of discrimination with the HCV carriers. People try to show sympathy to them which may hurt their ego. In social gatherings or normal day-to-day life, the HCV carriers are discussed as being unfortunate ones, who deserve special sympathy and consideration; thus, indirectly, the petty attitude can be considered a source of social stigma.

Another important issue which the HCV carriers may face is stigma at workplace. Studies indicate that HIV is a source of workplace stigma in various contexts including Pakistan (Bashir, 2011). Similarly, HCV carriers are less likely to be offered jobs, or at jobs they are less likely to have equal opportunities parallel to a normal employee. So, the social stigma associated with HCV can be seen at homes, at shopping malls, at social gatherings and at workplace.

This study made an important contribution to literature and theory of stigma by developing a scale to measure social stigma associated with HCV. There are not many scales available to comprehensively measure HCV related social stigma with good psychometric properties. It is evident from the initial testing that this scale will help the researchers to correctly assess and measure the stigma. On practical side, studies using this scale will help to identify the miseries being faced by HCV patients, and to propose the remedial measures so that the HCV carriers can lead a normal life like other people. It will help to raise awareness among masses that HCV carriers are normal human beings; the disease is cure able and does not spread with normal social interaction.

In the end, we must acknowledge the limitations of the study. Since the major objective was to develop a test, the test-retest reliability was not explored; this aspect must be addressed by future researchers. Another limitation was sample, HCV is a disease spread across Pakistan, but due to limited resources available, the data could not be collected from many areas of Pakistan. The future studies should try to use a more comprehensive sample to conform psychometric properties of this scale.

## ANNEXURE

### HCV Social Stigma Scale

- 1 HCV carriers should not be trusted
- 2 Although HCV patients may seem all right it is dangerous to forget for a moment that they are HCV carriers.
- 3 I would not like to sit next to someone with HCV in public transport.
- 4 Having HCV is just a matter of bad luck.
- 5 I think less of someone because they have HCV.
- 6 I would not like to have friendship with someone having HCV.
- 7 It is safe for a person with HCV to look after somebody else's children(R).
- 8 I feel afraid to be around people with HCV.
- 9 I would not employ someone with HCV.
- 10 People with HCV deserve as much respect as anyone else.
- 11 I feel uncomfortable around people with HCV.
- 12 People living with HCV in this community face rejection from their peers.
- 13 People living with HCV in this community face neglect from their family members.
- 14 Most people would not buy edibles from a shopkeeper or food seller that they knew had HCV.
- 15 People with HCV should be allowed to fully participate in social events in this community (R).
- 16 I feel comfortable being seen in public with HCV carrier (R).
- 17 I am afraid of catching the HCV from an affected person.
- 18 I feel sorry for a person with HCV.
- 19 A person with HCV must have done something wrong and deserves to be punished.

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