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## Association of Awareness about Hepatitis C Infection with Patterns of Health Seeking Behavior among Hepatitis C Patients in Karachi, Pakistan

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### ABSTRACT

**Background:** Hepatitis C infection is one of the significant causes of morbidity and mortality throughout the world. In Pakistan, hepatitis C infection rate is 4.8%, which is the second highest prevalence rate among all developing countries. This study aimed to identify the association between awareness about hepatitis C infection and pattern of health seeking behavior among patients living with hepatitis C in Karachi, Pakistan.

**Methods:** A descriptive, cross-sectional study was conducted among 250 hepatitis C patients who were recruited from the Aga Khan University Hospital and the Civil Hospital Karachi, Pakistan between March and May 2013. Data were collected through a modified questionnaire on 'awareness about hepatitis C and patterns of health seeking behavior among hepatitis C patients'.

**Results:** We did not find any association between participants' awareness of hepatitis C infection and their primary contact with a health care provider. However, this study found that only half of the study participants (52%) had correct knowledge of hepatitis C. The patterns of health seeking behavior showed that a majority of the study participants approached a medical doctor (n=368), followed by spiritual healers (n=206), and a few participants approached traditional healers (n=39) and homeopaths (n=11).

**Conclusions:** The study did not find any association between the patients' level of awareness about hepatitis C infection and their primary contact with health care providers. However, it has been found that patterns of health seeking behavior are strongly related to the patients' cultural practices and beliefs, which affect their choice of health care providers. This study has provided a basis for planning interventional studies aimed at improving patients' level of awareness about hepatitis C and their health seeking behavior.

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## INTRODUCTION

Globally, 170 million people are infected with hepatitis C virus (HCV) [1] and each year around 3-4 million people are newly infected with the virus [2]. Worldwide, HCV causes more than 350,000 deaths per year [3]. HCV has become a major health problem in the developing countries [4]. The prevalence of hepatitis C infection in the Asian countries ranges from 3.2% to 22% [1]. In Pakistan, the HCV infection rate is 4.8% which is the second highest prevalence rate among all the developing countries [1]. HCV infection is one of the significant causes of morbidity and mortality throughout the world. Statistically, 80% patients with hepatitis C infection develop chronic hepatitis, 25% to 30% develop liver cirrhosis, and up to 25% end up with hepatocellular carcinoma [5].

According to the WHO [1], 80% of patients at the initial infection stage of HCV do not exhibit any symptoms. As a result, undiagnosed patients can unknowingly continue to spread the virus to others. Various studies have been conducted globally to assess awareness of hepatitis C infection [6-9], and found that patients lack knowledge of the risk factors [6,7], preventive measures [6,7], complications [8], and treatment [6]. It has been emphasized by Merck [10] that to win the battle against hepatitis C, improved public awareness and education is required.

The desired health care seeking behavior is that an individual responds to an illness by seeking, first and foremost, help from a trained allopathic doctor, in a formally recognized health care setting [11]. Studies found that patients with hepatitis C also visit non-medical professionals such as homeopaths, *hakims*, faith healers [9,12] or prefer alternative treatments like herbal medicine, acupuncture, Ayurveda and folk healing [13]. Literature highlights several reasons on why HCV patients access non-medical approaches or alternative treatments. A few of such reasons include adverse side effects of medical treatment, financial issues, parental advice, cultural practices, lack of knowledge about hepatitis C, beliefs and perceived benefits of alternative treatments [12,14-20]. However, literature also reveals that none of the alternative treatments has proven to be effective for treating

hepatitis C infection [21,22].

In Pakistan, the general health seeking behavior of patients is sporadic. Patients' cultural beliefs and practices often lead to home remedies and consultation with traditional healers, which result in delays in treatment seeking from modern healthcare services [23]. Also, the advice of elderly women in the family is also considered very instrumental and cannot be ignored in the community [23]. Globally, health promotion programs have been based on the notion that providing knowledge about the disease and the choices available for treatment would bring a change in individual behavior towards more beneficial health seeking behavior.

Previous studies have focused on awareness about hepatitis C, and barriers to optimum health seeking behaviors as separate concepts; however, the present study focused on identifying the level of awareness about hepatitis C infection, patterns of health seeking behavior and the association between patients' awareness about hepatitis C and their primary contact with health care providers (a measure of their health seeking behavior) in Karachi, Pakistan. To our knowledge, this is the first study of its kind to be conducted in a Pakistani setting. The identified associations will help in determining whether patients' awareness about the disease affects their choice of health care provider, or strong cultural beliefs and practices override awareness, amongst the study population. The information generated through this study provide insights to health educators so as to develop and implement pertinent strategies for promoting health awareness among patients and their families, which may in turn influence their choice of health care provider.

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## MATERIALS AND METHODS

### Study Design and Setting

A quantitative descriptive cross-sectional study design was used to answer the identified research question. A total of 250 hepatitis C patients were recruited through purposive sampling. The eligibility criteria for participation in the study included: (a) male or female, 18 years of age or above; (b) visited gastrointestinal

(GI)/hepatitis clinic during the data collection period; (c) diagnosed with hepatitis C infection on the basis of presence of antibodies against HCV (anti-HCV) and/or HCV RNA testing within the last three years; and (d) absence of co-morbidities. The study settings were the GI clinic of Aga Khan University Hospital (AKUH) and the hepatitis clinic of the Civil Hospital Karachi, Pakistan. The AKUH and Civil Hospital, Karachi were selected because these are amongst the two largest and most accessed tertiary care hospitals in Karachi in private and public sectors, respectively. The rationale for selecting one private and one government hospital was to capture patients from diverse socio-economic backgrounds and geographical locations. The Civil Hospital is approached by patients from the entire provinces of Sindh and Baluchistan.

### **Sample Size Calculation**

The sample size was calculated by Open Epi software. First, the sample size was calculated to assess awareness about hepatitis C and seeking care, primarily from the medical professionals. In this we assumed that the frequency of awareness about hepatitis C and seeking care was in the range of 10% to 20% [24]. Using these parameters with 95% confidence interval, the resulting sample size was in the range of 27 to 128 hepatitis C patients. Next, the sample size calculation was carried out to assess the association of awareness of hepatitis C with health seeking behavior. This sample size was computed by taking the ratio of aware and unaware as 1:1 [6]. Further, it was assumed that a minimum of 10% patients having awareness about hepatitis C infection would approach non-medical professionals [25]; using 95% confidence interval, power of 80%, and odd ratio of 3 [6]. Hence, a sample size of 224 was calculated. A refusal rate of 10% was also estimated, which led to an increase in the sample size from 224 to 247.

### **Data Collection**

The data were collected between March and May 2013 through a modified questionnaire on 'awareness about hepatitis C and patterns of health seeking behavior among patients living with hepatitis C.' We first determined the eligibility of the patients for their inclusion in the

study. The eligible patients were then given information about the study purpose, risks, benefits, and their rights as participants. Patients who were interested and willing to participate were provided with the written consent form. After that, researcher completed the questionnaire based on the participants' responses. The process of data collection took about 20-30 minutes.

### **Validity and Reliability of the Tool**

The validity and reliability of the tool was assessed before the data collection. The study questionnaire was originally in the English language which was then translated into Urdu by an expert in the language. The translated questionnaire was then back translated into English by an expert who had good command over both the languages. No major changes were found in the questionnaire after back translation. For the content validity of the questionnaire, the content validity index (CVI) of the Urdu translated questionnaire was calculated after taking input from a committee of experts including gastroenterologists. The procedure for calculating the CVI was followed as illustrated by Polit and Beck [26]. The CVI of the tool was then calculated based on the experts' rating, which came out to be 0.95 for 'relevancy' and 0.90 for 'linguistic clarity'. Before the actual data collection process, the translated tool was pilot tested on 13 participants (5% of the total sample size of 250). Pilot testing of the instrument was done to ensure its face validity and to identify any issues that the participants might face in the interpretation of the questions.

### **Ethical Considerations**

Ethical approval was obtained from the Ethical Review Committee of the Aga Khan University Hospital. Permission for data collection was sought from heads of the study settings. A written informed consent was obtained from each patient at the beginning of the interview. The principles of autonomy, confidentiality, and anonymity of the participants were followed throughout the study.

### **Statistical Analyses**

The association between patients' awareness of hepatitis C and their primary contact with health

care providers was determined by univariate logistic regression, where a p-value of 0.05 was regarded as statistically significant. The association was established for each health care provider such as doctors, homeopaths, traditional healers and spiritual healers with the participants' awareness of hepatitis C. The participants who scored  $\geq 52$  percentile were considered as aware (having correct knowledge) about hepatitis C whereas those who scored  $< 52$  percentile were considered as unaware (having incorrect knowledge) about hepatitis C. For the analysis of patterns of health seeking behavior, frequencies and percentages were computed for those participants who approached doctors, homeopaths, traditional healers (*hakims*) and spiritual healers (*dum*) as their first, second, third, and fourth visit options.

## RESULTS

### Socio-demographic Characteristics of the Participants

Table 1 shows the participants' demographic characteristics. About 56.4% of the participants were males. The age ranged from 18 to 72 years with a mean of 38 years (SD  $\pm 10.8$  years). Most of the participants (42.4%) were unemployed, worked as religious teachers or were studying. A majority of the participants (54.4%) had a household income of less than Rs. 10,000 per month. The study participants had representation from all of the 18 towns of Karachi; however, the majority of participants lived in Baldia town (14%), outside Karachi (13%), and in Kemari town (10.8%).

### Participants' Awareness of Hepatitis C Infection

Of the total 250, only 130 participants (52%) had correct knowledge about hepatitis C infection. Table 2 shows the number of participants having correct and incorrect knowledge of hepatitis C infection with regard to each item of the awareness tool. The participants' knowledge about risk factors and transmission of hepatitis C infection revealed that more than half of the study participants (64%) were aware that the main mode of transmission of HCV was through blood. However, only 26.4% of participants were

aware about the cause of their own HCV infection. In addition, more than half of the study participants had incorrect knowledge about the

**Table 1. Socio-demographic Characteristics of the Participants (n=250)**

Characteristics	n	%
<b>Gender</b>		
Male	141	56.4
Female	109	43.6
<b>Age (years)</b>		
$\leq 29$	58	23.2
30-39	71	28.4
$\geq 40$	121	48.4
<b>Occupational category</b>		
Laborer	90	36.0
Service	43	17.2
Business	11	4.4
Others / Unemployed	106	42.4
<b>Educational level</b>		
Primary	46	18.4
Middle	17	6.8
Matric	44	17.6
Intermediate	17	6.8
Higher / Others	20	8.0
<b>Ethnicity</b>		
Sindhi	45	18
Punjabi / Saraiki	44	17.6
Urdu / Gujrati / Memon / Kachhi	66	26.4
Balochi	13	5.2
Khyber Pakhtunkhwa / Gilgit Baltistan	75	30.0
Others	7	2.8
<b>Income (PRs/month)</b>		
$\leq 10,000$	136	54.4
$> 10,000$	114	45.6

**Table 1 (cont). Socio-demographic Characteristics of the Participants (n=250)**

<b>Number of children</b>		
≤4	153	61.2
>4	97	38.8
Not sure	6 (11.5)	12 (18.8)
<b>Diagnosed of HCV infection (months)</b>		
1-3	59	23.6
4-6	70	28.0
7-12	58	23.2
>12	63	25.2
<b>Number of sexual partners</b>		
1	188	75.2
>1	2	0.8
No partners	60	24.0
<b>Use of sexual protection</b>		
Yes	98	39.2
No	152	60.8

transmission of HCV infection. With regard to the knowledge about the diagnosis and treatment of HCV infection, 75% of the participants had correct knowledge that HCV is a curable disease; however, around 91% of the participants had incorrect knowledge that preventable vaccine is available for hepatitis C infection.

### **Patterns of Health Seeking Behavior of Hepatitis C Patients**

As shown in Table 3, four types of health care providers were found to be commonly approached by the study participants for the treatment of hepatitis C infection: doctors, homeopaths, traditional healers (*hakims*), and spiritual healers (*dum*). In their three visits, the majority of the participants had approached doctors (n = 359), followed by spiritual healers (n = 103), with a few approaching traditional healers (n = 38) and homeopaths (n = 11). In addition, the participants were taking treatment from more than one health care provider at the same time.

### **Association between Participants' Awareness of Hepatitis C Infection and their Primary Contact with a Health Care Provider**

The highest numbers of participants who had correct knowledge about hepatitis C were those who visited traditional healers as their second contact (53%), followed by participants who approached doctors as their second contact (52.9%). On the other hand, the highest numbers of participants who had incorrect knowledge about hepatitis C were those who visited homeopaths as their second visit (49%). This was followed by participants who also approached homeopaths as their first visit (48.4%). However, the univariate analysis showed that there was no significant association between participants' awareness of hepatitis C and their primary contact with a health care provider as illustrated in Table 4.

## **DISCUSSION**

Our study did not show any association between awareness of hepatitis C infection and the participants' primary contact with health care providers. This could be due to the fact that cultural beliefs are stronger in shaping their practices as compared to awareness about the disease. This finding is similar to the study conducted on tuberculosis (TB) patients in Ethiopia, which found that health care seeking behavior was not affected by the participants' knowledge about TB [26]. However, other studies conducted in Kenya and Vietnam found that health seeking behavior was affected by the knowledge of the disease [27,28]. This variation might be because of the participants' socio-demographic profile such as the education level, income, residential area, and so on.

Our study showed that the highest numbers of participants who had correct knowledge about hepatitis C were those who visited traditional healers as their second contact. The reason for having correct knowledge among these participants might be because these participants had already approached a doctor in their first visit and became aware about the disease from them. However, when they became dissatisfied with the doctors, they approached the traditional

**Table 2. Study Participants' Awareness of Hepatitis C Infection**

Questionnaire Items	Correct n (%)	Incorrect n (%)
<b>I. General information about hepatitis C virus infection:</b>		
1. Hepatitis C is common in our society	207 (82.8)	43 (17.2)
2. Hepatitis C can affect any age group	189 (75.6)	61 (24.4)
3. Hepatitis C is related to HIV/AIDS	15 (6.0)	235 (94.0)
<b>II. Knowledge of risk factors/ transmission of HCV infection:</b>		
4. Hepatitis C is a viral infection	86 (34.4)	164 (65.6)
5. The mode of transmission of HCV infection is blood	160 (64)	90 (36)
6. Do you know how you acquired hepatitis C infection? If yes, please specify	68 (27.2)	182(72.8)
7. Risk factors for the transmission of hepatitis C virus include:		
a) Unsterilized needles and surgical instruments	180 (72)	70 (28)
b) Un-screened blood transfusion	186 (74.4)	64 (25.6)
c) Sexual intercourse with an infected person	114 (45.6)	136 (54.4)
d) Tattooing	84 (33.6)	166 (66.4)
e) Ear and nose piercing	116 (46.4)	134 (53.6)
f) Mother to child transfer during child birth	132 (52.8)	118 (47.2)
g) Sharing tooth brush with infected person	179 (71.6)	71 (28.4)
h) Sharing eating utensils with infected person	116 (46.4)	134 (53.6)
i) Sharing towels/clothes with infected person	58 (23.2)	192 (76.8)
j) Hair cut or shaving at the barber's shop	185 (74)	65 (26)
k) Hand shaking with infected person	140 (56)	110 (44)
l) Talking with infected person	150 (60)	100 (40)
m) Kissing the infected person	85 (34)	165 (66)
n) Coughing	62(24.8)	188 (75.2)
o) Using nail cutter of infected person	122 (48.8)	128 (51.2)
<b>III. Knowledge of symptoms and complications of hepatitis C virus infection:</b>		
8. Most of the people with hepatitis C remain asymptomatic	128 (51.2)	122 (48.8)
9. Hepatitis C primarily affects the liver	214 (85.6)	36 (14.4)
10. People can die because of HCV infection	226 (90.4)	24 (9.6)
11. People with HCV can be infected for life	191(76.4)	59 (23.6)
12. Hepatitis C can cause liver cancer	184 (73.6)	66 (26.4)
<b>IV. Knowledge of diagnosis and treatment of hepatitis C virus infection:</b>		
13. HCV infection is curable	188 (75.2)	62 (24.8)
14. Is there any preventable vaccine available for hepatitis C infection?	23 (9.2)	227 (90.8)
15. Can hepatitis C treatment cause flu like symptoms?	86 (34.4)	164 (65.6)
16. Do you think you need to go for lab test for diagnosis of HCV?	232 (92.8)	18 (7.2)
17. The medicines used in hepatitis C treatment are interferon and ribavirin	218 (87.2)	32 (12.8)



<b>Table 3. Patterns of Health Seeking Behavior of Hepatitis C Patients</b>				
	<b>Medical Doctors (n = 359)</b>	<b>Homeopaths (n = 11)</b>	<b>Traditional Healers (n = 38)</b>	<b>Spiritual Healers (n = 103)</b>
	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>
<b>First visit</b>	179 (71.6)	6 (2.4)	17 (6.8)	61 (24.4)
<b>Second visit</b>	129 (51.6)	5 (2.0)	16 (6.4)	29 (11.6)
<b>Third visit</b>	51 (20.4)	0	5 (2.0)	13 (5.2)

<b>Table 4. Association between Participants' Awareness of Hepatitis C Infection and their Primary Contact with a Health Care Provider</b>				
<b>Health Care Providers</b>	<b>Visit Status</b>	<b>Knowledge Status n (%)</b>		<b>Odds Ratio (95% Confidence Intervals)</b>
		<b>Correct</b>	<b>Incorrect</b>	
Medical Doctors	First	41(51.9)	38 (48.1)	1.01 (0.59, 1.72)
	Second	64 (52.9)	57 (47.1)	0.93 (0.57, 1.53)
Homeopaths	First	126 (51.6)	118 (48.4)	1.87 (0.34, 10.42)
	Second	125 (51.0)	120 (49.0)	-
Traditional Healers	First	122 (52.4)	111 (47.6)	0.81 (0.30, 2.17)
	Second	124 (53.0)	110 (47.0)	0.53 (0.19, 1.51)
Spiritual Healers	First	99 (52.4)	90 (47.6)	0.94 (0.53, 1.67)
	Second	115 (52.0)	106 (48.0)	-

healers. Another reason could be that these participants might be taking treatment from doctors in concordance with traditional healers. However, this shows that patients, who were aware about the disease process, complications, and medical treatment, were still giving priority to non-medical approaches. There are several important reasons why the participants might have approached non-medical professionals for the treatment of hepatitis C. Firstly, half of the study participants reported that they contracted HCV infection from the medical staff; so, they might have thought that they should refrain from going back to the medical staff to avoid getting

further infections. This is similar to the findings of other national studies [27,28], which indicated the level of ignorance and the poor practices of health care professionals in Pakistan.

Another reason might be the unprofessional attitude and the poor communication skills of health care professionals, which hinder patients from accessing medical treatment. This is consistent with the findings of Jiwani [29] and Zickmund [30], who found that the communication skills of the health care professionals was one of the decisive factors in patients choosing allopathic versus homeopathic



or traditional (*hakim*) treatments. Finally, dependence on traditional healers and faith healers for the treatment of disease is a common practice among people in Pakistan. A study in Pakistan found that the main reason for consulting *hakims*, homeopaths and spiritual healers was the participants' belief that '*they are effective health care providers*' [31]. Additionally, the advice of elderly women in the family is also considered very influential and cannot be ignored in Pakistani community [23]. Thus, it is not only the lack of awareness about the disease which prevents people from accessing appropriate health care providers, it is also the practices of health care professionals and families' strong faith in non-medical approaches that affects patients' choice of health care providers.

On the other hand, however, the present study also found that the highest number of participants who had incorrect knowledge about hepatitis C were those who visited homeopaths on their first and second visit. This is similar to the findings of recent studies conducted in Australia [17] and USA [15], which found that lack of knowledge about hepatitis C was one of the major barriers in seeking care from appropriate health care providers.

There were various limitations of the present study. Firstly, we used a cross-sectional design, which does not establish the causal relationship between variables. Therefore, data collected at one point in time in cross-sectional studies, cannot determine which variable led to the other. Thus, we were not sure whether knowledge came first or the health seeking behavior. Secondly, there was a risk of recall bias. This recall bias was associated with the patients' recall of their exact patterns of health seeking behavior. In order to limit the effects of recall bias, those patients were recruited who had been diagnosed with hepatitis C during the past three years; however, it is assumed that, even then, this might have influenced the study findings. Thirdly, a very important limitation of this study was the recruitment of participants from hospital settings, so the proportion of patients consulting medical professionals was high as compared to others. Therefore, the patterns of health seeking behavior were biased in favor of medical professionals. Finally, there was a chance of response bias - there is a

possibility that the participants did not give factual information in order to hide the truth from the researcher or to please the researcher.

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## CONCLUSIONS

We did not identify any association between the patients' level of awareness about HCV and their primary contact with a health care provider. However, it has been found that patterns of health seeking behavior are strongly related to the patients' cultural practices and beliefs, which affect their choice of health care providers. Moreover, this study also identified misconceptions regarding HCV transmission and the risk factors among HCV patients, which reflect a dire need for public awareness.

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## AUTHORS' CONTRIBUTIONS

The project was conceptualized by all authors. FWI and SSP collected the data, SP performed the literature search, and TSA and SA performed statistical analyses. The manuscript was prepared by SSP. All authors have read and approved the final manuscript.

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## CONFLICT OF INTEREST

Authors have declared that no competing interests exist.

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