

ORIGINAL ARTICLE

Knowledge, Awareness and Health Seeking Behaviour among Hepatitis patients attending a Tertiary Care Hospital in Delhi

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ABSTRACT

Introduction: People living with Chronic Viral Hepatitis in India often lack awareness about risk factors and prevention. **Objective:** Objective of this article is to assess the health seeking behaviour of viral hepatitis infected patients attending super specialty hospital in Delhi. **Methods:** Total 389 patients attending a super specialty hospital in Delhi were interviewed. **Results:** The first point of contact for the treatment of hepatitis was a private practitioner (71%). Before coming to ILBS, 77.4% visited a private practitioner, followed by (42.7%) Govt. facilities (PHC/CHC/DH/Medical College), 12% visited a AYUSH doctor, about 10% visited either a *Vaidya* or a *Hakim*. About 40% believed that HBV is curable and 36.2% respondents thought that HCV is curable. Our findings show that 7.2% respondents have been vaccinated for HBV infection in the past, 20.8% respondents have screened their families for Hepatitis B infections. **Conclusion:** Need to create awareness about myths, further screening of HBV and HCV infection, early diagnosis and treatment.

Key words: Awareness, Knowledge, Viral Hepatitis, Myths, Health Seeking Behavior

Introduction

The viral hepatitis is responsible for an estimated 1.4 million deaths per year from acute infection and hepatitis-related liver cancer and cirrhosis. Out of those deaths, approximately 47% are attributable to hepatitis B virus, 48% to hepatitis-C virus and the remainder to hepatitis A virus and hepatitis E virus¹. Globally, an estimated 1.4 million cases of Hepatitis A virus (HAV) infection occur annually². Most acute liver failures diagnosed in India are attributable to HEV, which is also the most common cause of hepatitis during pregnancy. Both HAV and HEV are transmitted through the fecal-oral route, due to ingestion of contaminated water-sewage and inadequately-treated water³. HDV infection is not very common in India and is observed in 10% to 20% of HBV positive patients. HDV transmits through both iatrogenic and sexual routes.

The chronic hepatitis-B can lead to serious health issues, like cirrhosis or liver cancer. At least 15-25% of chronically HBV infected people will die due to liver disease caused by HBV and this constitutes nearly one million people each year⁴. The best way to prevent Hepatitis-B is by getting vaccinated⁵. In addition, implementation of blood safety strategies, including quality-assured screening of all donated blood and blood components used for transfusion, safe injection practices, safer sex practices can prevent transmission of HBV⁶. Treatment of Chronic Hepatitis B infection can slow the progression of cirrhosis, reduce incidence of liver cancer and improve long term survival.⁶

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The Hepatitis C is a blood-borne virus and most people become infected by sharing needles or other equipment to inject drugs.⁷ The best way to prevent Hepatitis C is by avoiding behaviors that can spread the disease, especially injecting drugs.⁷ Population prevalence of chronic HCV infection in India is around 1 per cent. Prevalence of hepatitis C has been observed to be relatively higher in Punjab, Haryana, Andhra Pradesh, Puducherry, Arunachal Pradesh and Mizoram compared to other states.^{8,9,10,11,12}

Chronic infection with HCV is usually clinically silent, and is only very rarely associated with life-threatening disease. Spontaneous clearance of acute HCV infection occurs within six months of infection in 15–45% of infected individuals in the absence of treatment.^{13,14} Of those with chronic HCV infection, the risk of cirrhosis of the liver is 15–30% within 20 years. The therapy with direct antiviral agents (DAAs) can cure most persons with HCV infection and treatment is shorter (usually 12 weeks) and safer¹⁵.

The study of health seeking behavior enables the physicians to optimize their care and promote regular disease surveillance. In Singapore asymptomatic Hepatitis Virus (HBV) carriers are often followed up at primary and secondary care centers. The study found that there was evidence of doctor hopping among the HBV carriers in seeking the follow-up of their disease. Compliance to follow-up seemed to be sub-optimal, arising from apathy, denial, perceived inconvenience and cost of review.¹⁶

There are lack of studies on health seeking behavior of HBV/HCS patients in India, therefore a study to assess the knowledge, awareness, health seeking behavior, among HBV/HCV carrier patients was conducted in a Government Tertiary Care Hospital in Delhi.

Materials and Methods

The present study was conducted at an apex tertiary care government hospital in Delhi during Oct 2016- Jan 2017. Ethical approval was taken from Institutional Ethics Committee of NIHFV as well as Institutional Review Board of the hospital. The inclusion criteria for the study was those patients diagnosed with HBV or HCV infections for more than six months, and age ≥ 18 yrs to 75 yrs. Patients with acute viral hepatitis, Hepatitis B/C with cancer or in coma were excluded from the study. Data was collected from 422 patients in the hospital. However, after scrutinizing for accuracy and completeness of data, total 389 (350 out-patients and 39 in-patients) interview schedules were analyzed using the SPSS Version 23.0. The Chi-square test was employed to find out association with background variables like gender, education and place of residence.

Results

Profile of Respondents: Out of 389 patients, 299 (76.8%) were male and 90 (23.2%) were female patients. 78% came from urban area and 22% from rural area. Minimum age was 18 and maximum was 75 years with the mean age 41.8 years. In the sample, 62.5% were graduate and above, 20.6% were secondary or a senior secondary, merely 7% were primary or a below primary level. Most of the patients had a government or a private job (50%), followed by business (18%). The median household yearly income is Rs.3,60,000/- per year. About 4% respondents had BPL card. Out of 389 patients 334 (86%) were HBV positive, 49 (12%) were HCV positive and 6 (2%) were both HBV and HCV positive. Around 13.9% respondents had history of receiving blood.

Knowledge about Transmission of HBV and HCV: The correct knowledge about spread, prevention and treatment may promote appropriate health seeking behavior. Therefore, attempts were made in our study to assess the knowledge about modes of transmission of HBV and HCV among patients.

Table-1: Knowledge of respondents about modes of transmission of HBV/HCV (N=389)

HBV/HCV can be spread through	No.	%
Sexual contact with a person infected with HBV/HCV	353	90.7
Transfusion of infected blood	367	94.3
From mother to child	350	90.0
Using a razor, pierced ear ring, needle and syringe used by infected person	365	93.8

*Multiple responses

Table 1 describes that more than 90% of patients were aware about routes of transmission and highest percentage (94%) responded that it can be transmitted by transfusion of infected blood. The high percentage maybe as patients were already educated by the hospital staff.

Myths about Transmission of HBV/HCV: Myths and misconceptions always poses barrier in health seeking behavior.

The table 2 shows that over 40% respondents had one or the other misconceptions about the transmission.

Table-2: Myths about modes of transmission of HBV/HCV (N=389)

HBV/HCV can be spread by *	No.	%
Contaminated water	166	42.7
Contaminated food	55	14.1
Sharing towels used by infected person	64	16.5
Sharing the same tableware with an infected person	21	5.4
Sharing utensils with infected person	33	8.5
Eating together with an infected person	75	19.3
Shaking hands with infected person	11	2.8
If by slightly kiss of a person infected	170	43.7

*Multiple responses

There was higher percentage among male patients had myths compared to females. Though such myths were not much different among male/female patients but some myths like (i) 'it can be spread using towels used by infected persons' was more in females (15.1% males, 21.1% females), (ii) 'it can be transmitted by sharing the same tableware' (5.0% males, 6.7% females) was more among females and may result in discrimination in family., About one fifth (21.4% males, 12.2% females) believed it can be transmitted by eating together.

Different myths like 'HBV/HCV can spread through contaminated water, contaminated food, HBV/HCV can be transmitted by eating together, HBV/HCV can be transmitted by sharing the same table ware were consistently higher among less literate patients ($p < 0.05$). On contrary, facts like HBV/HCV spread through sharing towels, HBV/HCV can be transmitted by shaking hands with an infected person, HBV/HCV can be transmitted even with slight kiss with an infected person, HBV/HCV can be transmitted by sharing utensils were found similar among different education categories ($p > 0.05$).

Regarding the misconception that HBV/HCV can be transmitted by contaminated water, 39.9 % of those from Urban area and 52.3% of those from Rural area said Yes. When asked ‘Whether HBV/HCV can be spread through sharing towels?’, 19% of those who residing in Urban area and 7 % of those who residing in Rural area said, Yes. When enquired ‘Whether HBV/HCV can be spread by using the same table ware?’, 6.9% of those who lived in urban area said Yes. Statistically significant difference exists in urban and rural area regarding above misconceptions. ($p < 0.05$). However, some misconceptions that HBV/HCV can be transmitted from contaminated food, HBV/HCV be transmitted by eating together, by sharing utensils, by shaking hands, and by slightly kiss with an infected person, not much difference was found with respect to urban and rural areas ($p > 0.05$).

Awareness about Consequences, Treatment and Vaccination of HBV/HCV Infection: The table 3 indicates that high percentage of patients (75-90%) were aware about various facts. In spite of visiting super specialty hospital, less than 10% believed that there is vaccine for prevention of HCV infection. About 30-40% believed that HBV & HCV are curable and not much difference exists between male and female. Even 20 % respondents said that liver cirrhosis is curable. Almost one third (33.7%) informed that they were aware of a friend or a relative suffering from either Hepatitis B or Hepatitis C infection. We found that on some aspects like HBV/HCV infection can cause liver cancer and even without any signs and symptoms, one may continue to be infected with HBV/HCV, awareness was very high ($> 80\%$) and also increased with level of education.

Table-3: Awareness among respondents on consequences of viral hepatitis (N=389)

Consequences of viral hepatitis	No.	%
Believed that even though the liver function test is normal one can continue to be infected with HBV/HCV infection.	331	85.1
Believed that even though there is no special signs and symptoms, one may continue to be infected with HBV/HCV infection.	354	91
Believed that HBV/HCV infection can cause liver cancers in 90% respondents in long run	323	83
Believed that by treating HBV/HCV infection adequately, one may able to completely cure or delay the advancement of cirrhosis or cancer	331	85.1
Aware about vaccination for HBV infection	348	89.5
Believed that there may be a vaccination for HCV infection	36	9.3
Believed that HBV is curable	154	39.6
Believed that HCV is curable	141	36.2
Believed that liver cirrhosis is curable	78	20.1
Aware about friend/relatives suffering from Viral Hepatitis	131	33.7

Fact like ‘even though the liver function test is normal one may continue to be infected with the HBV/HCV?’ and ‘By treating HBV/HCV adequately one may able to completely cure or delay the advancement of cirrhosis/cancer’, awareness ranged from 60-88%. When enquired about knowledge regarding availability of vaccine to prevent HBV infection, 60-90% in different educational level were aware and awareness consistently increased with level of education ($p < 0.05$). However, awareness was low on some facts like regarding curability of HBV/HCV. We found 20-40% of patients in different educational categories were familiar with the fact. But the variation with increase in education was not consistent. Education does not have an association with all the above outcome variables discussed in this paragraph ($p > 0.05$). Awareness about the fact that HBV & HCV are curable, not much difference exist between rural and urban areas ($p > 0.05$).

Preventive Practices among Respondents against Viral Hepatitis: Our findings show that 7.2% respondents have been vaccinated for HBV infection in the past, 20.8% respondents have screened their families for hepatitis-B infections and 77.9% respondents have received antiviral medications (table 4).

Table-4: Practices of respondents for tackling Viral Hepatitis (N=389)

Variables to study practices for tackling Viral Hepatitis	No.	%
Respondents who has a prior h/o vaccination for preventing HBV infection before being diagnosed with Chronic HBV/HCV	28	7.2
Respondents who got screened their family for HBV infection	81	20.8
Respondents who had taken antiviral treatment	303	77.9

Our findings show not much gender-wise difference (7.4% males, 6.7% females) among patients getting vaccinated for HBV infection in the past. Higher female percentage (19.4% males, 25.6% females) respondents had screened their families for Hepatitis B infections and have received antiviral medications (76.3% males and 83.3% females).

Health Seeking Behavior: Table 5 describes that initially when the respondent had symptoms or had been diagnosed to be HBV/HCV positive, the first contact person was a private practitioner (71%) followed by Government Dispensary or a PHC (13.6%), and even 13% took self-medications. When enquired about how many health facilities they visited before coming to this hospital, 82.5% visited 1 to 3 health facilities

Table-5: Health Seeking Behavior of the respondents (N=389)

Health seeking behavior		No.	%
First contact person of the respondent	Self-medication	51	13.1
	Vaidya	2	0.5
	Pharmacist	1	0.3
	Dispensary/PHC	53	13.6
	Private Doctor/Hospital	276	71
	AYUSH Doctor	2	0.5
Number of health facilities visited by the respondent before coming to ILBS	Others	4	1
	0	30	7.7
	1	72	18.5
	2	126	32.4
	3	123	31.6
	4	23	5.9
Type of medical facilities visited before coming to ILBS*	5	8	2.1
	6	7	1.8
	Vaidya	7	1.8
	Hakim	3	0.8
	Private Clinic / Hospital	301	77.4
Person who referred the respondent to ILBS	Govt. Facilities (PHC/ CHC/ DH/Medical College)	166	42.7
	AYUSH Doctor	47	12.1
	Private Doctor/Hospital	124	31.9
	Govt. Hospital	66	17
	Friend or Relative	112	28.8
	Self	68	17.5
	Internet	19	4.9

*Multiple response

Type of Health Facilities Visited Earlier by background characteristics: When we further enquired, which were the medical facilities they visited before coming to this hospital, about 77.4% said it was a private practitioner, followed by Govt. Facilities (42.7%), 12% visited a AYUSH doctor and some (10 patients) even visited either a *Vaidya* or a *Hakim*. Majority (31.9%) of respondents were referred by a private practitioner and 17% by Government hospital. More than 50% came were through informal channels

The gender-wise analysis informs that higher percentage of females visited informal service provider as first point of contact but more males visited formal service providers. Gender had significant association ($p < 0.05$) with type of facility as first point of contact.

From urban vs. rural perspectives, we found that 66.3% of those living in urban area and 87.2% of those respondents living in rural area said they consulted a private practitioner. This shows poor utilization of government health facilities (9.3%) by the people living in rural areas compared to those living in urban areas (14.9%). Only rural patients (2.3%) first visited *Vaidya*. Higher percentage (16.5%) of patients from urban area and 1.2% of those living in rural area took self-medication, probably due to easy availability of medical stores. The place of stay has a significant association with the person/health facilities contacted first for their problems ($p < 0.05$).

It was also found that less educated patients (20.0% of illiterate/ can just read and write, 5.0% of those who attended a primary/High school, 15.0% of those who attended a secondary/Senior secondary school) visited Govt. Dispensary/ PHC compared to higher educated patients. Thus, private practitioners were first point of contact in majority of cases. Our analysis shows that the education is significantly associated with 'first point of contact' ($p < 0.05$). We also found that highly educated patients (Graduate and above) going to private doctor in comparison the illiterate/less educated patients who visits to the Govt. Dispensary. This may be due to higher capacity to pay for private services for consultation, investigations and medicines.

Number of facilities Visited before coming to ILBS by Background Characteristics: It is found that more males (33.3%) compared to females (25.6%) visited higher number of health facilities (3) before coming to the ILBS super specialty hospital. The gender of the respondents is found to be significantly associated with number of health facilities visited before coming to ILBS ($p < 0.05$).

'Regarding urban vs rural pattern, we found that about 34% of those living in urban area and 28% of those respondents living in rural area said '2' visits. Followed by 31.7% of those living in urban area and 31.4% of those respondents living in rural area said '3' visits. Thus, place of stay does not have an influence on number of health facilities visited before coming to ILBS ($p > 0.05$).

Referral Practices to Super Specialty Hospital: Our data describes that about highest percentage of patients (one third) were referred to the hospital by a private practitioner (33.1% males, 27.8% females), followed by one fourth of the patients by friends/relatives (26.4% males, 36.7% females). Less than one fifth (16.7% males, 17.8% females) were referred by a Government hospital, less than one fifth (18.1% males, 15.6% females) came by self and around five percent (5.7% males, 2.2% females) referred an internet and came to this hospital. Higher percentages of female patients were referred by friends/relatives.

Role of private practitioners in referring rural patients (41.9%) was more compared to urban patients (29%), followed by friend or relative (41.9% in rural area and 29.7% in urban area, respectively). About 15% of those living in urban area and 23.3% of those living in rural area said it was Government Hospital which referred them to the hospital. However, in case of visits made to *Vaidya / Hakim* place of stay has a significant association as merely 0.7% of those

living in urban area but 5.8% of those living in rural area visited Vaidya and only 3.5% of those living in Rural area visited a Hakim ($p < 0.05$). It was found that the place of stay is significantly associated with those who referred the respondents to the hospital ($P < 0.05$).

Sources of Information about Viral Hepatitis: Table 6 informs that majority (89.2%) of respondents received the knowledge about viral hepatitis through the Doctors, followed by friend or relatives (29.8%), Only 9.5% respondents received knowledge through health staff,

Table-6: Sources of information about Viral Hepatitis (N=389)		
Sources of Information*	No.	%
Health Staff	37	9.5
Doctor	347	89.2
TV	9	2.3
Radio	3	0.8
Poster	2	0.5
Friend/Relative	116	29.8
Internet	107	27.5

*Multiple responses

Regarding adequacy of information, two fifths of (40.5% males, 37.8% females) respondents told that they got information adequately, 59.% respondents (58.2% males, 62.2% females) told that they got only 'some information' and very few of them (1.3% males) told that they did not get any information about their condition or the treatment. Analyzing this by educational background, receiving 'Adequate Information' was reported by 35% of those who attended a primary to secondary school and 42% of those attended a senior secondary school to college. 'Somewhat information' was reported by 100% of those who were illiterate/ just read and write, 65% of those who attended a primary to secondary school and 56.7% of those attended a senior secondary school to college said they got some information about the disease.

Discussion

The health seeking behavior is one of the important determinants of early diagnosis and getting effective treatment. Similar to our findings, another study found that awareness, distance, economic capacity and referral are important factors determining health seeking behavior. A significant proportion of the carriers had tried alternate therapy. Most carriers had adopted healthier lifestyle after their diagnosis with regular exercise, smoking cessation and alcohol abstinence. Many HBV carriers' inadequate understanding of the disease resulted in indifferent or inappropriate health-seeking behavior towards their disease management¹⁶ A cross-sectional study conducted in Pakistan found significant positive linear correlations between knowledge attitude ($r = 0.466$, $p < 0.01$) knowledge-practice ($r = 0.221$, $p < 0.01$) and attitude-practice ($r = 0.224$, $p < 0.01$)¹⁷

In a study conducted by Tamayu et al titled "Correlates of disease-specific knowledge among patients with chronic hepatitis B or hepatitis C infection in India", assessed the association for patient's knowledge with chronic viral hepatitis. Untreated patients chronically infected with HBV ($n = 500$) or HCV ($n = 500$) were enrolled at 19 centers across India. The association of IHKI with disease underscores the need to understand connections between hepatitis

knowledge and progression and may guide efforts to address patient education and awareness of chronic viral hepatitis in India”¹⁸.

In our study quite high percentage (80%) of patients knew about various aspects of HBV/HCV infection. There is hardly any difference in the knowledge among gender. However, higher percentages of males (92.3%) than females (82.2%) knew that the infection can be transmitted from mother to child during pregnancy. Looking into the association of education with knowledge of transmission of HBV/HCV findings revealed that education has a significant relationship with the knowledge of transmission of the disease.

Lack of awareness and misconception is also reported from many other studies. A community-based study conducted by Victoria M et.al at Seattle among Vietnamese men and women was done on Hepatitis B awareness and knowledge. A majority of the participants knew that HBV can be transmitted during sexual intercourse (71% of men, 68% of women), by sharing toothbrushes (67% of men, 77% of women), and by sharing razors (59% of men, 67% of women). Less than one-half knew that hepatitis B is not spread by eating food prepared by an infected person (46% of men, 27% of women), nor by coughing (39% of men, 25% of women)¹⁹.

A study was conducted in United States looking into the correlates of hepatitis B knowledge and health behavior framework, among four Asian-American migrants groups-Vietnamese, Hmong, Korean and Cambodian. The study found that hepatitis B awareness varied across the four groups and ranged from 45% within the Hmong to 79% among Korean Americans. While most respondents in all four groups correctly identified that hepatitis B could be transmitted through sharing needles and in childbirth, large proportions of all groups incorrectly believed it could be transmitted by coughing, and sharing food, drink and eating utensils. Thirty-eight percent of Vietnamese respondents believed that people with hepatitis B were face avoidance compared to 70% of Cambodian respondents, indicating variable levels of stigma across communities. The researchers did not find a relationship between increased knowledge about hepatitis B and perceived susceptibility, perceived severity, awareness of stigma and a belief in the efficacy of testing across the four groups.²⁰

Stigma can significantly affect the patients’ lives causing a lower quality of life. Our study reported fear of transmitting infection to others by sharing things such as utensils, cups, glasses and towels was expressed by respondents, indicating poor knowledge about transmission of HBV/HCV. Our study found that males were more worried of transmitting their infection to others than females and also only males said they quit smoking and drinking^{21,22}. A study conducted by Rafique et al at Rawalpindi, Pakistan, found males were more affected than females in term of changes in lifestyle, fear of disease transmission and changes in relationship with the spouse. In contrast, more females than males reported feeling of loneliness and isolation. Changes in lifestyle also happen either due to weakness (fatigue) or emotional disturbances (mood swings, anxiety, irritability, depression, etc.)^{23,24}. Change in patients’ daily life has been attributed to worries and uncertainties associated with hepatitis due to its slow and silent nature as well as a lack of proper information about its transmission, prognosis and treatment²⁵.

Early detection and treatment helps both the respondents and physicians keep the disease under control. In our study, 39.6% respondents believed that HBV seems to be curable and 36.2% believed that HCV is curable. In this new era of directly acting agents to cure HCV were 90% of cases with HCV can be cured with recently invented potent medicines, the awareness that HCV can be cured seems to be low.

Our study found very high percentage of patients (75-90%) had knowledge about various aspects of infection and treatment. Health care professionals working in community health settings such as private and public health clinics, school health programs, college student health clinics, and home visit programs all can play an important role in educating clients and families on prevention, transmission, and progression of hepatitis B infection.²⁶

Hepatitis B vaccination is the mainstay of Hepatitis B prevention. In our study, higher percentage of females got screened their families may be because of ANC care. In a community-based study conducted by Victoria during 2002, it was found that 67% reported HBV testing (66% of men, 68% of women). One-third of respondents did not recall being tested for HBV)¹⁶⁰. The low vaccination is matter of concern in many countries. Major barrier identified is the perceived high cost of the vaccine.²⁷

Stigma from service providers also reported by many studies. Almost 50% of patients responded that doctors did not provide information about the disease. A diagnosis of hepatitis B and C is an opportunity for health-care providers to create awareness about the disease and to encourage patients in their commitment to treatment and self-care. Stigma among health-care providers is reported by few other studies, also.^{28, 29}

Conclusion

The National Hepatitis Control Programme may arrange training to ASHA, ANM, Medical Officers working in Primary Health Care Centers to identify people having symptoms of viral hepatitis, screen them and refer them to appropriate centers to seek early diagnosis and treatment. Frequent screening of high risk population is also suggested. Nursing and other para-medical staff can be assigned responsibility to educate the patients about the disease management, vaccination and screening. The health professional should be oriented not to stigmatize patients with viral hepatitis.

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