

Original Research Article

Stigmatisation in chronic hepatitis B and C infections-time to debunk the myth!

Sabreena Qadri¹, Aadil Ashraf², Javid Ahmed Khan^{3*}, Altaf Shah⁴, Arshad Hussain⁵

¹Department of Psychiatry, AIG Hospitals, Hyderabad, India

²Department of Gastroenterology, AIG, Hyderabad, India

³Department of Medicine, GMC Srinagar, Jammu and Kashmir, India

⁴Department of Gastroenterology, SKIMS, Soura, Jammu and Kashmir, India

⁵Department of Psychiatry, GMC Srinagar, Jammu and Kashmir, India

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*Correspondence:

Dr. Javid Ahmed Khan,

E-mail: khanjaved69@yahoo.com

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ABSTRACT

Background: Hepatitis B and C are chronic diseases with mental and social impacts which can result in poor quality of life. The routes of transmission and lack of education among the masses may cause stigmatisation of the affected patients. The aim of the study was to document the stigmatisation among chronic hepatitis B and C positive patients.

Methods: The 242 patients suffering from hepatitis B and C were included in the study. Stigma experienced from relatives, friends, spouse and health care providers was assessed using a semi structured questionnaire.

Results: Majority of the patients were males 174 (72%). The 162 (67%) were hepatitis B infected and 76 (32%) were Hepatitis C infected and 4 were dual infected. Male patients were significantly more affected than females in term of changes in lifestyle (86% versus 61%) and changes in relationship with the spouse (89% versus 16%). Significantly more females than males reported feelings of loneliness and isolation (64% versus 30%). Stigma was marked in terms of disease transmission, with 170 (70%) of patients fearing that they could transmit the infection to others. Marital relationships were affected for 52% of married patients. Around 80% unmarried patients were experiencing delay in getting married.

Conclusions: Patients comments showed a sense of family and societal discrimination resulting in feelings of disappointment which could be changed by educational interventions, effective patient and family centric awareness and scientific models of approach.

Keywords: Hepatitis B, Hepatitis C, Stigmatisation

INTRODUCTION

Hepatitis B and C are main causes of chronic liver disease leading to chronic liver disease and its fraught complications.¹ These infections spread through blood and other body fluids, including sexual routes, as such patients may be considered dirty, immoral and hence a likelihood of being stigmatised from family or society.² Stigma has previously been defined as -a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from

experience, perception or reasonable anticipation of an adverse social judgement about a person or group.³

Scambler et al further add that this judgment is “medically unwarranted.” Stigma can be further categorized as social (also known as public or enacted) stigma, internalized (self/felt) stigma and structural (institutional) stigma.³

There are several stigmas related to hepatitis B and C infection which include isolation from society, problems

with inter-personal relationships, failure to get employment, loss of employment, fear of transmitting the disease, lifestyle and emotional difficulties and problems within the provider-patient relationship.⁴ The stigma fixed towards people living with HBV emanates from several origins. These include preconceptions that a person may use drugs or may be sexually promiscuous as well as an irrational fear of contagion, often fuelled by a lack of knowledge and understanding of transmission routes for HBV which limits patients with HBV their social contacts, which adds to their loneliness and gloom. Moreover, feelings of shame and worry and reluctance in discussing health issues with life partners creates hurdles in looking for health care and adopting the essential preventive measures to avoid disease transmission.⁵

METHODS

This study was conducted in outpatient departments and inpatient medical wards of Sher I Kashmir institute of medical sciences (SKIMS) Soura, the largest tertiary care centre in Kashmir Valley from September 2018 to August 2021. A total of 242 patients with confirmed HBV and/or HCV infection who were aged over 18 years and had been diagnosed for more than 6 months were enrolled. Patients with acute hepatitis, hepatitis B or C with cancer, or coma were excluded. Patients coming to outpatient departments who met the inclusion criteria were informed about the objectives of the study and, after they had given written informed consent, were interviewed in a separate room by trained researchers. After written informed consent had been taken, questionnaire was used to assess, which was conducted in the local language by trained interviewers. The semi structured questionnaire comprised 6 sections: collected patients' background data (i.e., age, sex, marital status, occupation, social class and type of hepatitis) and how they thought they had acquired the disease. Comprised personal stigma experienced by patients (i.e., how they had found out about the disease, feelings about being HBV/HCV positive, fear of transmitting the disease, general behaviour of people around them, feelings of loneliness and isolation). Concerned stigma from the patients' close family members (brothers, sisters, parents), other relatives (cousins) and friends (i.e., had they informed family members and friends, had family/friends started ignoring/avoiding them, refusing to share personal belongings and avoiding eating, shaking hands or sitting with them). Concerned stigma from the spouse (i.e., had they had informed spouse, what was spouse's reaction, how had it affected the marital relationship, fear of transmitting the disease to a child). Concerned patients' experiences of medical treatment and healthcare providers (i.e., were they receiving treatment for the disease, satisfaction with treatment, had they been given information and what was the healthcare providers' attitude/behaviour towards them). Concerned patients' financial and job issues (i.e., were they working and if so, had they informed work colleagues, had colleagues' behaviour towards them changed).

A patient was defined as stigmatized if he/she experienced at least one of the following: loneliness and isolation, fear of transmission of virus, changes in the marital relationship or changes in colleagues' attitudes at work. Lifestyle change was defined as when a person experienced a change in routine activities due to weakness and behavioural changes with family, relatives and friends. Worry was defined as when a patient was anxious and troubled due to hepatitis. A stigmatizing attitude/behaviour of physicians was when patients felt that the physician was taking extra precautions or avoiding them rather than behaving as normal.

Data analysis

The data were entered and analysed using SPSS, version 22. Responses to open-ended questions during interviews were noted by the primary investigators. Transcripts were manually analysed by researchers, and texts with similar meanings were grouped into categories and subcategories after reaching a consensus.

RESULTS

A total of 242 patients were included in the study. The demographic characteristics of the 140 study participants are shown in Table 1. A majority of respondents were males 174 (72%), aged > 40 years 174(72%) and of lower socioeconomic status 170 (70%). The great majority of patients were positive for HCV 162 (67%) or HBV alone 76 (32%) ; 4 patients (1.6%) reported having dual infection.

Questionnaire data

Attitude towards the illness

The personal assessment of patients about their disease showed that 213 patients (88%) said they were worried when they found out they had hepatitis. A total of 191 patients (79%) agreed that hepatitis had affected their lifestyle (Table 2). Of these, 91 (48%) said that their routine activities were disturbed while 60 (31%) felt depressed and avoided social activities and gatherings.

The 170 (70%) were afraid of transmitting the virus to others and 96(37%) felt lonely and isolated (24% sometimes and 13% always). Among the 170 respondents who believed in viral transmission, 113 (67%) thought that the virus could be transmitted through sharing things (towels, utensils, etc.) and 39 thought it was transmitted via blood donations, 8 by sexual intercourse and 3 from other sources. However, 7 patients reported that this could be transmitted through both sharing things and blood donations.

Personal experiences of stigma

A total of 199 (82%) patients reported experiencing at least one kind of stigma. There were no significant

differences in age, sex/other demographic characteristics of the stigma. There were also no differences by inpatient/outpatient status or duration of illness.

Relationship with relatives, friends and spouse

The great majority of patients said they had informed their close family members 232 (96%), other relatives 200 (83%) and friends 195 (81%) about their disease.

When respondents were asked about the impact of the disease on their relationships, 10% reported that family members, 24% that other relative and 9% that friends had started ignoring or avoiding them after finding out about their disease status, although the friends and relatives of around 22% of patients became sympathetic. The 157 patients (64%) reported that family members felt worried and 26% that they had asked for treatment. However, 71% of patients felt that there was no change in the attitude and response of friends and of other relatives. Although some patients reported that their family members were always (7%) or sometimes (12%) hesitant in sharing towels, soap, eating utensils, glasses and cups, 81% of patients did not notice any changes. Patients also reported noticing that family and friends were hesitant about eating, shaking hands or sitting with them.

A total of 181 /202 married patients (90%) had told their spouse about their disease status (Table 2). 105 (52%) patients reported that this had affected their marital relations; 86 patients (42%) said that their spouse avoided intercourse altogether and 38 (19%) had started using condoms. When asked to rate how much the disease affected their marital relations, 48 (24%) reported that it was very affected and 36(18%) that it was only a little affected, while the remainder felt that they were not affected.

Financial and job issues

Of the 98 employed patients, 63 were already employed while 33 had found a job after getting the diagnosis and 2 reported problems in getting a job. A majority 77 (79%) had informed their colleagues and 58 of them felt that there had been changes in the attitude of their colleagues. However, 21 patients did not share their disease status due to fear of bad reactions.

Treatment and relationship with healthcare providers

A total of 201 patients (83%) were receiving treatment for the disease and 184 of them (92%) were satisfied with their treatment, although 112 (56%) said that doctors did not provide additional information about the disease. When asked about the attitude/behaviour of doctors, 87% reported that it was as normal (Table 2), while 7% said that doctors took extra precautions with them, 3% felt that doctors were avoiding them and the remainder did not respond.

Comparison of experiences of male and female patients

Male patients were significantly more affected than females were in term of changes in lifestyle (86% versus 42%) and changes in relationship with the spouse (89% versus 16%). They were also more likely to report receiving treatment (90% vs 63%) and that the attitude of doctors towards them was as normal (92% versus 73%). Significantly more females than males reported feelings of loneliness and isolation (64% versus 52%) (Table 2).

Generally, comments of patients showed bitter trajectory of their life after hepatitis. The emotional disturbances due to changes in behaviour of family members, relatives and friends were more commonly reported.

Table 1: Characteristics of studied population.

Patient characteristics	Total, n=242 (%)		Experienced stigma, n=199 (%)		P value
	N	%	N	%	
Sex					
Male	174	72	142	81	0.68
Female	68	28	57	84	
Age (Years)					
18-40	68	28	53	78	1.19
>40	174	72	146	84	
Socioeconomic status					
Upper	22	9	19	86	0.49
Middle	50	20	42	84	
Lower	170	71	138	81	
Marital status					
Married	202	83	164	81	0.34
Unmarried	40	17	35	87	
Hepatitis status					
Hepatitis B	162	67	132	81	0.22
Hepatitis C	76	31	64	84	
Dual infection	4	2	2	50	

Table 2: Stigmata in studied population.

Stigma	Total		Male		Female		P value
	N	%	N	%	N	%	
Spouse							
Informed spouse	181	89	135	93	46	80	0.10
Change in relationship	105	52	89	61	16	23	0.0002
Personal							
Lifestyle affected	191	79	149	86	42	61	0.0003
Feeling lonely	96	37	52	30	44	64	0.0001
Fear of transmission	170	70	116	67	54	79	0.06
Health care providers							
Getting Rx	201	83	158	90	43	63	0.0001
Satisfied with Rx	184	92	154	97	30	66	0.0001
Staff provided information	135	56	104	60	31	45	0.04
Normal behaviour of staff	210	87	160	92	50	73	0.001

DISCUSSION

This study shows that HBV and HCV positive patients have to face difficulties in their routine life and that there are various types of stigmas that are attached to them. Marital relationships were strongly affected by the disease and in the present study; nearly half of married patients (52%) reported deviations in their spousal relationship including consensual sexual relationships. A study describing social stigma in HCV positive women established that women were concerned about sexual transmission, pregnancy and child care affecting their close relationships and their likely gender role.⁶ In another study, negative symptoms such as shame, avoidance, and putting others in danger were felt by 70-90% of HBV patients. Around 60% of HBV patients in this study felt that hepatitis B could be transmitted by sharing utensils thinking that saliva is the mode of transmission. The knowledge about transmission of HBV by sexual intercourse, intravenous drug use, and mother to child was present in 88%, 75%, and 52% of HBV patients and 32%, 38%, and 40% of healthy individuals, respectively.⁷ There is a need to increase the level of awareness among the people about modes of transmission, specifically for hepatitis positive couples, as this may reduce their fears and help avoid difficulties in marital relationships. Changes in lifestyle were reported by majority of participants in the current study. This was either due to fatigue mood swings, anxiety, irritability, depression, etc.^{8,9} Change in patients' daily life has been attributed to worries and uncertainties associated with hepatitis due to lack of proper information about its transmission, prognosis and treatment.¹⁰ Similarly, a fear of transmitting infection to others by sharing things due to poor knowledge about transmission of HBV/HCV was reported by 68% of our cases, which was similar to findings were reported in other studies.¹¹

Stigma from healthcare providers was reported by few patients in the present study, which contrast with the findings of some other studies.¹² On the other hand, almost half of patients thought that doctors did not provide information about the disease. A diagnosis of the

hepatitis B and C is an opportunity for healthcare providers to create awareness about the disease and to encourage patients in their commitment to treatment and selfcare. Stigma related to hepatitis occurs in both sexes; however, female patients have been reported as more concerned with family and social relations, sexual transmission and pregnancy and child care as compared with males and this concern affects their relationships and ability to fulfil their gender roles.⁶ When the experiences of male and female patients were compared in our study, 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 feelings of loneliness and isolation. The findings of the open-ended questions revealed that a majority of patients had bitter experiences in their routine life. Stress in relationships with spouses or fiancés were noted in this study and were also reported in a study from the United States.¹³ Similarly, the financial burden was also huge, either to humble attitudes of employers and colleagues or to physical helplessness to complete tasks appropriately. It was noted that some patients reported being severely affected by knowledge of their disease, unemployment and restriction to travel. This needs to be amended and, if someone is found to be positive during screening, there should be proper counselling and mechanisms to guide them. The overall assessment showed that experiences of stigma varied depending on the patient's situation. However, these findings indicate that HBC/HCV patients face discrimination in every walk of life, including breakage in inter and intra-familial relations, financial constraints due to loss of job or problems in getting a new job. Limitation of the study was that this was a hospital based study conducted on patients presenting at one centre, and therefore these findings could not be generalized.

CONCLUSIONS

Hepatitis B and C patients experience emotional disturbances due to knowledge about their disease status and its associated stigma leading to changes in their lifestyles. The stigmatization is mostly due to ignorance and lack of awareness about the mode of disease

transmission among patients and their family members. These issues can be changed by educational interventions, effective patient and family centric awareness and scientific models of approach.

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