

Social challenges experienced by Hepatitis B patients: A mixed method study

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ABSTRACT

Background: Hepatitis B has a wide range of effects on patients' lives due to its chronic nature. Living with Hepatitis B has been associated with various social challenges such as stigma, disclosure, and discrimination. **Aim:** To assess the social challenges experienced by Hepatitis B-positive patients seeking treatment at a super specialty liver hospital of the country. **Methods and Results:** A mixed-method research design was used to explore various social challenges experienced by Hepatitis B-positive patients. Descriptive research design was used in the first phase and thematic analysis was done in the second phase of the study. Data were collected using a modified Hepatitis B stigma assessment tool and semi-structured interview guide. Total 180 Hepatitis B-positive patients were recruited for the first phase. Face to face interviews were recorded for the 9 patients facing high stigma in the second phase of the study. Mean age of the patients was 45 ± 13.1 years and 80% of the patients were male. Mean overall stigma score was found to be 74.34 ± 10.13 . Of all, 5.1% patients experienced high stigma, 2.1% moderate stigma, and 92% patients experienced low stigma. Thematic analysis method uncovered various attributing factors to social challenges broadly classified into reaction on getting diagnosed with Hepatitis B, psychological issues, stigmatization in families, stigmatization at workplace, and stigmatization in healthcare settings. **Conclusion:** Patients with Hepatitis B experience social challenges in aspect of lack of awareness, psychological issues, and stigmatization by healthcare providers, family members, and by the colleagues at their workplace. A better understanding and awareness regarding Hepatitis B is needed to eliminate stigma and discrimination among these patients. Hence, a holistic approach is must to treat patients with Hepatitis B.

Keywords: Disclosure, discrimination, Hepatitis B, social challenges, stigma, mixed-method study

Introduction

Hepatitis B has a wide range of effects on patients' lives due to its chronic nature. Global evidence indicates that living with Hepatitis B is associated with social and psychological afflictions such as stigma, discrimination, anxiety, depression, and low quality of life.^[1] Hepatitis B virus (HBV)-related stigmatization may occur at family, community, or institutional level and may be perceived or expressed visibly or invisibly.^[2] Stigma has a negative

impact on seeking help, screening, and disclosing the disease and is a major impediment to the successful implementation of HBV prevention, diagnosis, and treatment. Feelings of social isolation among hepatitis patients create a fear of disclosing their disease to anyone and hence poses a risk to the family and society due to nondisclosure.^[3]

There is a long history of social discrimination against patients with infectious diseases such as Hepatitis B and there are ample examples of persons with hepatitis being evicted from their homes, their jobs, and rejected by their families, friends, and neighbors.^[4] Stigma, depression, social marginalization, and financial problems are some of the challenges in these patients which occur due to the complications of the disease and

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unknown fear in the patients and families.^[5] Globally, stigma has been identified as a significant barrier for screening, diagnosis, and treatment of Hepatitis B.

Although many studies are conducted on stigma,^[6] disclosure,^[7] and discrimination^[8] among Hepatitis B patients worldwide, the researchers could not find many studies conducted in India on social challenges experienced by Hepatitis B patients. Of the studies which were available, most of them were on knowledge, attitude, or practice^[9-13] and few descriptive studies^[14-16] were also found which lack the exploration of the construct, that is, social challenges. Hence, the researchers took this study with a mixed (Quantitative + Qualitative) approach to understand the social challenges experienced by Hepatitis B patients.

The primary objective of the study was to assess, explore, and understand the social challenges experienced by patients with Hepatitis B seeking treatment at a super specialty liver hospital of the country.

Social challenges were described as problems experienced by Hepatitis B patients in interacting with people in the society and consisted of overall stigma, personalized stigma, disclosure concern, negative self-image, and public attitude. Levine's conservation model as proposed by Myra Estrin Levine was used as foundation to prepare the conceptual framework of the study.^[17]

Health-related information and care is primarily delivered by healthcare workers in India, who have also being reported to be major sources of stigma in chronic infections such as HIV or Hepatitis B. Previous studies have reported negative attitude of healthcare workers toward patients affected by such diseases. The findings of present study would be helpful to understand in detail about the perspectives of patients regarding healthcare workers attitude about them and their disease.^[18]

Materials and Methods

STUDY DESIGN AND SETTING: A mixed-method study using exploratory sequential research approach was carried out among Hepatitis B patients seeking treatment at a Super Specialty Liver Hospital of the country. As the study used mixed method, a descriptive research design was selected for quantitative part (Phase I) and thematic analysis method was selected for qualitative part (Phase II) of the study.

SAMPLE SIZE AND SAMPLING TECHNIQUE: Sample size calculation for this study was done after considering the expected prevalence of Hepatitis B (47.4%) as reported by Al-Essa M *et al.*,^[19] with an acceptable margin of an error of 5% with alpha 5%. Total 180 patients were calculated to be enrolled into the study. Convenient sampling technique was used to select 180 patients with Hepatitis B for Phase I. The score was analyzed simultaneously and patients with high score (108-132) were purposively selected for Phase II of the

study. A qualitative in-depth interview was conducted on nine Hepatitis B–positive patients who were facing high stigma identified from patients who filled the questionnaire for the quantitative study.

Inclusion Criteria

Hepatitis B patients who were:

- Diagnosed to have Hepatitis B for at least three months and seeking treatment at a selected hospital.
- 18-70 years of age.
- Conscious, oriented to person, place, and time.
- Able to understand Hindi and English.
- Willing to participate.

Exclusion Criteria

Patients with Hepatitis B who were:

- Hemodynamically unstable.
- Concomitant infection with Hepatitis C.
- Suffering with mental illness.

OUTCOME VARIABLE: To explore the social challenges experienced by Hepatitis B–positive patients.

Study questionnaire

Subject datasheet was used to collect the sociodemographic and clinical information which included personal characteristics such as age, gender, residence, occupation education, monthly income, and marital status and clinical information such as duration of Hepatitis B diagnosis, specific treatment for the hepatitis B (at present), any side effect during treatment, comorbidity, treatment setting, history of hospitalization in past one year, support system, source of support system, and accompanying person. Social challenges were assessed by a standardized modified Hepatitis B stigma assessment scale^[20] and a semi-structured interview guide. Modified Hepatitis B stigma assessment scale consists 33 items including four domains, that is, personalized stigma, negative self-image stigma, disclosure stigma, and public attitude stigma. Depending on the scores, stigma is classified as Minimal Stigma (33-57), Low Stigma (58-82), Moderate Stigma (83-107), and High Stigma (108-132). Established content validity and reliability of the modified Hepatitis B stigma assessment scale is 0.89 and 0.95, respectively. Interview guide mainly included a set of questions in a semi-structured form. An additional set of questions were included during the interview of Hepatitis B patients. Trustworthiness was established by using Guba and Lincoln method. The thematic analysis of experiences of Hepatitis B patients took place after each interview was completed and transcribed by using Colaizzi method (1978).^[21] The questionnaire was pretested on 15 Hepatitis B patients who were selected conveniently seeking treatment at a super specialized liver hospital. Necessary modifications were done in the questionnaires after piloting before initiation of the data collection.

Ethical approval

Ethical permission was obtained from Scientific Review Committee and Ethics Committee of the institute.

DATA COLLECTION PROCEDURE: The final data for the present study were conducted in the month of November, 2021 at OPD and General Wards of the selected hospital. After a formal administrative approval, the patients were approached on individual basis and the informed written consent was obtained from them. Sociodemographic data and clinical data were taken using structured questionnaire and the patients were asked to fill the standardized questionnaire on assessment of social challenges. As the patients filled the questionnaire, scoring was done at the same time and the patients who were having high stigma level (score of more than 108) were approached for the second phase of the study, that is, thematic analysis method. The informed written consent was again obtained from patients before conducting an interview as well. The researcher briefed about the interview and confidentiality. Hepatitis B patients were interviewed in a separate interview room. All patients were interviewed two times as per their availability. Beginning with a grand tour question: “How did you find out you had Hepatitis B?,” additional probing questions were included. All the important information or events were explored in depth related to the disease condition experienced by patients during the period of illness. Scheduling 45 to 60 minutes for this semi-structured interview allowed patients to determine the length of time; however, each patient took the full hour to complete the interview. The interviews were audio-recorded and recordings were transcribed within one week of the interview by the researcher. Credibility, member checking, transferability, dependability, and confirmability was done at the end of each interview. Interviews were validated by the recommended experts.

Statistical analysis

The data for quantitative analysis were entered into SPSS version 22 and analyzed using descriptive and inferential statistics. Frequencies and means were generated from patients’ responses and the results were presented in tables and figures.

The qualitative data were analyzed through a rapid review of the notes identifying major pattern and preliminary themes. The qualitative analysis was based on Colaizzi method and thematic analysis was used to understand and explore the social challenges experienced by the patients. The in-depth interviews were transcribed with transcripts edited for accuracy.

Results

Phase I (Quantitative part)

The mean (standard deviation, SD) age of the patients was 45.14 (\pm 13.1) years. Majority (80%) of the patients were male and married (87.2%). About half of the patients (45%) had monthly family income of less than ₹20,000, whereas 18.3% had monthly family income more than 61,000. It was found

that 41.1% patients were diagnosed to have Hepatitis B since 4-6 years, while 5.1% patients had Hepatitis B for more than 10 years [Table 1].

Mean overall stigma score was found to be 74.3 (\pm 10.13) [Table 2]. Ninety two percent patients experienced low stigma, whereas 5.1% patients experienced high stigma [Figure 1]. Item-wise analysis of modified Hepatitis B stigma assessment scale is given in Table 3.

Finding represented graphically in Figure 1.

Association of overall stigma with selected demographic variables and clinical variables depicted a significant association of stigma with monthly income and reason of hospitalization in the past one year. It was found that patients having monthly income less than 20,000 experienced more stigma as compared to patients with high monthly income ($P = 0.018$). Also, patients with a history of ascites as a reason of hospitalization had more stigma as compared to patients with the reason of hospitalization was fever, jaundice, and pruritus ($P = 0.001$).

Findings of Phase II (Qualitative Phase)

In-depth interviews findings

Patients who experienced high stigma were considered for the phase II of the study. The thematic analysis of experiences of Hepatitis B patients took place after each interview. It was found that social challenges have a significant effect on the patients in such a way that they have to experience various challenges in their life related to the family support, work place discrimination, and social issues [Figure 2].

Table 4 shows the themes and subthemes as emerged from qualitative data analysis.

These themes and subthemes are described below:

1. Getting diagnosed with Hepatitis B

The phase in which a person gets to know about a fact that was unknown is really crucial. It has been seen that the patients got to know about their Hepatitis B–positive status during general medical tests, predonation blood tests, pre-employment tests, and antenatal visit.

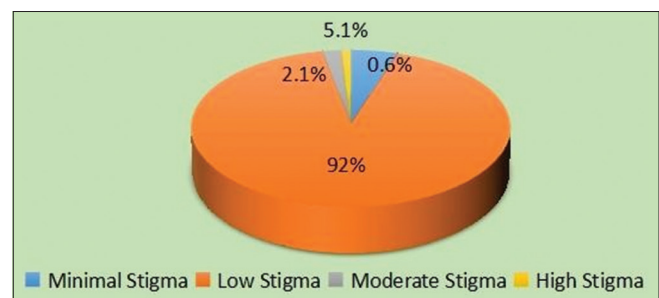


Figure 1: Pie chart presenting of different levels of stigma experienced by Hepatitis B patients

Table 1: Frequency and percentage distribution of patients with Hepatitis B according to their sociodemographic variables and clinical variables (n=180)

Sociodemographic/Clinical Variables	Frequency (f)	Percentage
Age (in years)		
18-35	45	25.3
36-50	78	43.3
>51	57	31.3
Education		
Non- Literate	7	3.9
Primary	35	19.4
High School	39	21.6
Intermediate	57	31.7
Graduates or Above	42	23.3
Monthly Income (₹)		
< 20,000	81	45
20,000-40,000	34	18.9
41,000-60,000	32	17.8
> 61,000	33	18.3
Duration of Hepatitis B diagnosis (in yrs.)		
1-3	59	32.9
4-6	74	41.1
7-9	37	20.6
10-13	09	5.1
Comorbidity		
Present	146	81.1
Not Present	34	18.9
History of hospitalization in past 1 year		
Yes	32	17.8
No	148	82.2
If yes, then specify the reason (n=32)		
Fever	08	4.4
Ascites	07	3.9
Jaundice	08	4.4
Other*	09	05

Other=Itching and Abdominal pain

Table 2: Frequency and percentage distribution of Hepatitis B patients in terms of level of stigma and overall stigma experienced (n=180)

	Frequency (f)	Percentage	Range
Level of stigma			
Minimal stigma	01	0.6	33-56
Low Stigma	165	92	58-82
Moderate Stigma	05	2.1	83-107
High stigma	09	5.1	108-132
Overall Stigma (Mean±SD)		74.34±10.13	

Minimum=55, Maximum=114

"I was very stressed and extremely concerned about this situation. I believed that everyone who had a close relationship with me can get infected from me" (P6, 37 yrs, male).

"My first reaction was. why me ?" (P3, 31 yrs, male).

"I was unaware about hepatitis when first time I got to know about it. but when I shared with one of my friend. he told me that it is same as HIV and this disturbed me a lot... I even lost my job because I

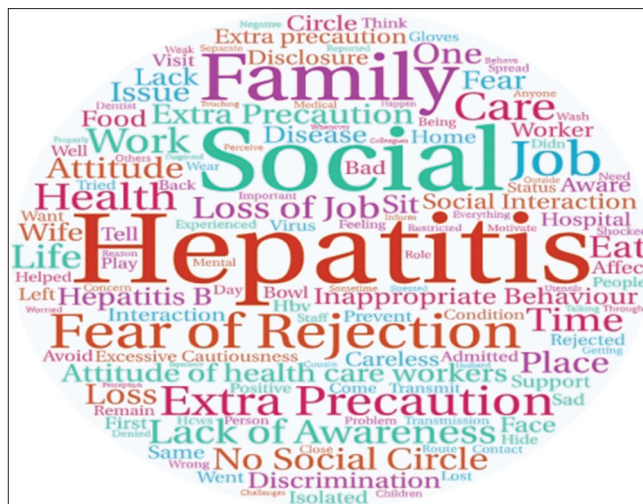


Figure 2: Word cloud of collected verbatim from Hepatitis B patients

lost interest in doing things and started to remain at home only" (P1, 48 yrs, male).

"When I found out that I had hepatitis, I was worriedI cried frequently and didn't know how to inform my husband about my status. I had a fear that he may perceive this in a wrong way" (P7, 29 yrs, female).

It was found that patients with Hepatitis B had feeling of sadness, shocked, and were depressed when they got to know about their disease condition first time.

2. Psychosocial Issues

Patients with Hepatitis B have been experiencing psychosocial issues in their daily life. It has been seen that patients started to remain at home and restricted social interaction after being diagnosed with Hepatitis B.

"I spend time while watching TV and avoid to go out because whenever I go outside and play with my friends...they laugh at me saying..you are weak and can't play with us..." (P2, 22 yrs, male).

"One of my cousin was afraid of getting infected and asked me not to come in her children's contact. That day I felt really bad and tried not to go outside" (P6, 37 yrs, male).

"As people perceive Hepatitis B same as HIV and behave inappropriately, I prefer to stay at home and avoid going out" (P3, 31 yrs, male).

"I informed about my disease to those who were close to me and with whom I used to share food I didn't want to get them infected.... Now when we have meals together, they serve me food to prevent me from touching the food" (P4, 31 yrs, male).

It was found that psychological and social challenges that persons with hepatitis B experienced right from the time of diagnosis throughout their life.

Table 3: Item wise analysis of social challenges experienced by Hepatitis B patients (n=180)

Item	Strongly disagree f(%)	Disagree f(%)	Agree f(%)	Strongly agree f(%)
People's attitudes about hepatitis B make me feel worse about myself	07 (3.9)	145 (80.6)	21 (11.7)	07 (3.9)
Telling someone I have hepatitis B is risky	06 (3.3)	125 (69.4)	05 (2.5)	04 (2.2)
People with hepatitis B lose their jobs when their employers find out	10 (5.6)	150 (83.3)	04 (5)	11 (6.1)
I work hard to keep my hepatitis B a secret	13 (7.2)	141 (78.3)	08 (4.4)	18 (10)
I feel I am not as good a person as others because I have hepatitis B	-22 (12.2)	146 (81.1)	12 (6.7)	00
People with hepatitis B are treated like outcasts	08 (4.4)	81 (45)	65 (36.1)	26 (14.4)
Most people believe that a person who has hepatitis B is dirty	08 (4.4)	136 (75.6)	27 (15)	09 (5)
It is easier to avoid new friendships than worry about telling someone that I have hepatitis B	13 (7.2)	121 (67.2)	35 (19.4)	11 (6.1)
Since learning I have hepatitis B, I feel set apart and isolated from the rest of the world	11 (6.1)	135 (75)	15 (8.3)	19 (10.6)
Most people think that a person with hepatitis B is disgusting	09 (5)	133 (73.9)	29 (16.1)	09 (5)
Having hepatitis B makes me feel that I'm a bad person	12 (6.7)	150 (83.3)	18 (10)	00
Most people with hepatitis B are rejected when others find out	06 (3.3)	115 (63)	50 (27.8)	09 (5)
I am very careful who I tell that I have hepatitis B	05 (2.8)	64 (35.6)	95 (52.8)	16 (8.9)
Some people who know I have hepatitis B have grown more distant	11 (6.1)	100 (55.6)	36 (20)	33 (18.3)
Since learning I have Hepatitis B, I worry about people discriminating against me.	22 (12.2)	77 (42.8)	74 (41.1)	07 (3.9)
Most people are uncomfortable around someone with hepatitis B	09 (5)	131 (72.8)	38 (21.1)	02 (1.1)
Having hepatitis B in my body is disgusting to me	15 (8.3)	101 (56.1)	49 (27.2)	15 (8.3)
I have been hurt by how people reacted to learning I have hepatitis B	24 (13.3)	81 (45)	44 (24.4)	31 (17.2)
I worry that people who know I have hepatitis B will tell others	09 (5)	135 (75)	17 (9.4)	19 (10.6)
I regret having told some people that I have hepatitis B	04 (2.2)	139 (77.2)	35 (19.4)	02 (1.1)
As a rule, telling others that I have hepatitis B has been a mistake	37 (20.6)	133 (73.9)	06 (3.3)	04 (2.1)
Some people avoid touching me once they know I have hepatitis B	20 (11.1)	133 (73.9)	12 (6.7)	15 (8.3)
People I care about stopped calling after learning I have hepatitis B	05 (2.8)	163 (90.6)	12 (6.7)	00
People have told me that getting hepatitis B is what I deserve for how I lived my life	12 (6.7)	129 (71.7)	19 (10.6)	20 (11.1)
Some people close to me are afraid others will reject them if it becomes known that I have hepatitis B.	2 (1.1)	81 (45)	89 (49.4)	08 (4.4)
People don't want me around their children once they know I have hepatitis B	12 (6.7)	115 (63.9)	43 (23.9)	10 (5.6)
People have physically backed away from me when they learn I have hepatitis B	04 (2.2)	148 (82.2)	19 (10.6)	09 (5)
I have stopped socializing with some people because of their reactions to my having hepatitis B	07 (3.9)	112 (62.2)	52 (28.9)	09 (5)
I have told people close to me to keep the fact that I have hepatitis B a secret	07 (3.9)	142 (78)	24 (13.3)	07 (3.9)
People who know I have hepatitis B tend to ignore my good points	16 (8.9)	124 (68.9)	28 (15.6)	12 (6.7)
People seem afraid of me once they learn I have hepatitis B	14 (7.8)	137 (76.1)	29 (16.1)	00
When people learn you have hepatitis B, they look for flaws in your character	7 (3.9)	101 (56.1)	63 (35)	09 (5)

f = Frequency, % = Percentage

Table 4: Summary of themes and subthemes emerged

Themes	Sub themes
Getting diagnosed with Hepatitis B	a) Reaction on diagnosis b) Lack of Awareness
Psychosocial Issues	a) Social alienation b) Nondisclosure c) Felt Discrimination
Stigmatization in Families	a) Unaccommodating nature of family members.
Stigmatization at Workplace	b) Family support a) Repulsive behaviour by colleagues b) Issues in getting employed
Stigmatization in Health care setting	a) Attitude of healthcare workers b) Excessive cautiousness c) Procedure postponement and Avoidance

"My wife had been avoiding me since diagnosis of this disease. She even tried to keep my children away from me. I don't want to live anymore" (P5, 33 yrs, male).

"My grandson and granddaughter do not sit with me as my son has told them not to come in my contact, otherwise it will spread to them also. I even eat food in separate bowl and then wash my utensils to prevent the spread of the disease" (P1, 48 yrs, male).

Even discrimination was seen at healthcare setting also. One of the patient faced inappropriate behaviour of healthcare workers after getting to know about his disease condition.

3. Stigmatization in Families

Family is the most important support system in this crucial period when a person got to know about a disease condition. It has been seen that patients got supported by their family member in their hard time. Some patients felt that their family members have grown distant as they got to know about their Hepatitis B-positive status.

"My family members behave inappropriately...in my family there is my elder brother and my cousins...no one comes to meet me or visits me in the hospital" (P9, 42 yrs, male).

"My son left us alone. ...he does not come to my home and if we (me and my wife) visit him at his house we sit at door on a chair.... We (my wife and me) are not even allowed to go inside the house" (P4, 55 yrs, male).

"There is no problem with family infact they are supporting me since the beginning" (P3, 31yrs, male).

"I am so blessed that I have a family that helped and motivated me alot in my hard time to deal with the illness" (P2, 22 yrs, male).

Most of the patients stated that they were supported by their family members. It was found that patients were happy about the fact that they were not left aloof in their hard time. They got courage to fight against illness due to the support given by their family members.

4. Stigmatization at workplace

Patients with Hepatitis B got stigmatized at their work place also. Patients faced unusual behaviour of their colleagues or even their friends at their work place. It was found that people at their workplace started making stories by their own without knowing the actual cause of disease condition.

"I applied for a job in a bank. During the medical examination only I got to know that I was hepatitis B positive. They refused to take me, and when I asked the reason the staff said, 'You cannot join even as a security gaurd' because of this disease. This is our bank policy" (P3, 31 yrs, male).

"I was an autorickshaw driver, but due to hepatitis B, I became so ill and weak that I could not work properly. To meet the treatment cost I had to sell my rickshaw. Nobody helped me in my hard time" (P5,33 yrs, male).

It was found that patients got stigmatized at workplace as well. Some of the patients lost as their company or the colleagues got to know about their disease condition.

5. Stigmatization in Healthcare setting

Healthcare service has a major role in resolving problems and making people aware about the disease condition. It has been seen that patients expressed a profound disconnect between the expectations for Hepatitis B treatments and their healthcare experiences.

"I had history of stones in my gall bladder for which I got admitted in hospital...the health care personnels were really good. If I had any concern, then they were always there with solutions and really motivated me a lot. As a carrier of hepatitis B virus I was really anxious about surgery and the procedures. They helped me a lot in my hard time" (P7, 29 yrs, female).

"When recently I admitted to the hospital I have seen some healthcare personnel to wear extra gloves like 3 or 4 pairs of gloves when they come to

give oral medication or even just for bed making. I was surprised to see all these things" (P6, 37 yrs, male).

"When I was admitted in hospital due to fever and ascites, they hanged a board at my bed side with the instruction UNIVERSAL PRECAUTION. All the patients and their attendants were looking at me with weired expression and talking behind me. I was not ok with it" (P9, 42 yrs, male).

Being infected with Hepatitis B can lead to social challenges among patients. Social challenges have a significant effect on the patients in such a way that they have to experience various challenges in their life related to the family support, work place discrimination, and social issues.

Discussion

Being infected with Hepatitis B can lead to social challenges among patients. Social challenges consisted of personalised stigma, disclosure stigma, negative self-image stigma, and public attitude stigma. It was found that 92% Hepatitis B–positive patients had a low level of stigma, whereas 5.1% of Hepatitis B patients had a high level of stigma. Hepatitis B was diagnosed unexpectedly among patients. There were patients who were found to have Hepatitis B while undergoing general medical tests, predonation blood tests, febrile illness, pre-employment tests, and during antenatal visit. Similarly in a study by Olusegun Adekanle *et al.* (2019),^[22] respondents got to know about their disease condition during medical tests for febrile illness, antenatal visit, visa application, general medical tests, pre-employment tests, predonation blood tests, staff screening exercise, and the mandatory national youth service medical tests. This emphasizes the need of a routine medical examination for general population.

In the present study, patients having monthly income less than 20,000 had experienced more social challenges. This pattern is similar to a study by Chiao-Wen Cheng *et al.* (2019),^[23] when they found that individuals with lower socioeconomic status are more likely to be exposed to diseases like HBV due to their environmental and social conditions.

Patients were found to have incorrect information regarding mode of transmission of disease. Patients reported that shaking hands, touching, and sharing utensils may transmit the infection to others. This pattern is similar to a study by Adjei CA *et al.* (2019),^[1] which showed that perceived contagiousness were beliefs that Hepatitis B can be transmitted through casual contact such as handshaking, touching, and the sharing of eating utensils with patient living with Hepatitis B and a focus on body fluids, such as sweat, as a source of infection. Another study by Leila Valizadeh *et al.* (2017)^[24] also revealed the same that separating personal items such as patients' spoon, glass, and serving dishes and avoiding close contact with patients caused evasive behaviors among the patients' families and relatives. Also one more study by Ibrar Rafique *et al.* (2015)^[25] found that

among the 92 respondents, 63 (68%) thought that the virus could be transmitted through sharing things such as towels and utensils with others.

In this study, it was found that some patients withdrew from their social networks and became reluctant in making new friends due to fear of stigmatization or rejection. Moreover, experiencing social distancing and isolation made some participants perceived themselves as contagious and consequently developed a pervasive fear of transmitting the infection to others. Previous studies conducted on patients with Hepatitis B such as Haeok Lee *et al.* (2016)^[2] supports the current finding where it was reported that social withdrawal because of concerns of infecting others and experiencing social isolation is common among Hepatitis B-positive patients. It has been revealed by some of the patients that they started to remain at home and restricted social interaction after being diagnosed with Hepatitis B. Patients faced difficulty disclosing their disease condition and isolated themselves from their peers in an effort to prevent possible transmission of the virus to others. Some of the patients were treated as outcasts and had social restrictions. This pattern is similar to a study by Leila Valizadeh *et al.* (2017)^[24] where it was found that sense of loneliness and social isolation is caused by the patients' thoughts and fear of transmitting the disease to family members and close contacts.

Some patients had bad experience and some patients felt discriminated during the hospital visits. Some patients experienced careless behavior toward them and some reported that healthcare workers become overprotective and over cautious. In a study by Adjei CA *et al.* (2019),^[1] similar findings were found that stigmatization took form as excessive cautiousness, procedure postponement or avoidance, task-shifting, and breaches of confidentiality. Perhaps inadequate knowledge and fear of acquisition of HBV among the healthcare personnel led to the excessive cautiousness and fear.

The findings of this study showed that some of the patients with HBV infection had difficulties in receiving medical services and were subjected to disrespect and inattentiveness. In a study by Leila Valizadeh *et al.* (2017),^[24] it was seen that the high proportion of patients (63%) had expressed not receiving equitable healthcare services from some physicians and nurses and 60% of the patients stated that they were treated with a lack of respect and consideration.

Strengths of the study

The present study is a mixed-method study in which the assessment and gaining in-depth understanding of the social challenges of Hepatitis B patients takes place simultaneously. The use of standardized questionnaire to assess the social challenges among Hepatitis B patients also adds in the strength. Counseling was provided to those patients who experienced high stigma to overcome their difficulties and in coping with their disease condition.

Limitations of the study

A single-centric study done on small sample size limits the generalizability of the study.

Conclusion

Based on the findings, it can be concluded that being infected with Hepatitis B can lead to social challenges among patients. It was found that 92% of Hepatitis B-positive patients had a low level of stigma, whereas 5.1% of Hepatitis B patients had a high level of stigma. Patients who had less monthly income and who had a history of hospitalization in past one year due to ascites had faced significantly more social challenges. Patients with Hepatitis B experience social challenges in aspect of a lack of awareness and understanding about disease condition, lack of support from friends and family, challenges at work place, and negative attitude of healthcare providers. A better understanding and awareness regarding Hepatitis B is needed to eliminate stigma and discrimination among these patients. Hence, a holistic approach is must to treat patients with Hepatitis B.

Recommendation

A multicentric study can be conducted on large sample size for better generalisation of the findings. Interventional studies may be undertaken to manage the social challenges among Hepatitis B patients. Awareness campaigns may be organized to disseminate the correct information about Hepatitis B to general population.

Key points

- There is a lack of awareness among patients about their own disease. Hence, improved public awareness on transmission routes, screening, and follow-up is clearly needed.
- Experiences of social challenges varied depending on the patient's situation. However, Hepatitis B-positive patients face discrimination in every walk of life, including breakage in interfamilial and intrafamilial relations, financial constraints due to loss of job or problems in getting a new job.
- Stigma in the healthcare settings has been seen and continuing professional development program for healthcare professionals on Hepatitis B is needed to enhance HCPs knowledge in parallel to public awareness campaigns.

Take home message

The root cause of stigma among Hepatitis B patients is ignorance and a lack of information. People need to know how the disease is transmitted and be assured that they will not be at risk during casual contacts. The healthcare workers have a significant role in educating the patients and the community at large regarding Hepatitis B-related transmission routes, screening, and follow-up. There is an urgent need of treating a patient holistically not just the physical symptoms.

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Conflicts of interest

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