



Stigma, Discrimination, and Living with Hepatitis B in Turkey

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Abstract

Background: Hepatitis B is an older and more common infection worldwide than hepatitis C virus (HCV) and human immunodeficiency virus (HIV). Nonetheless, there is a dearth of studies on hepatitis B-related stigma and discrimination compared to HCV and HIV.

Objectives: It aimed to evaluate stigma and discrimination by classifying them as social environment, work environment, and while receiving health care. It was planned to examine the relationship of these data with hiding behaviors and anxiety levels.

Methods: In this study, a questionnaire prepared for chronic hepatitis B patients was applied using the face-to-face interview technique. The questionnaire used included a total of 43 items, the first 10 of which were descriptive data, and the others were aimed at determining stigma and discrimination.

Results: A total of 505 patients were interviewed. The mean age of the patients was 41 years, and 56% were male. Moreover, 47.1% of patients asserted that they hid their illness from those around them, 47% feared stigma, and 36% feared exclusion. In addition, 20 (4%) cases stated that they broke up with their spouse or lover due to their illness, and 47 (11.7%) subjects indicated that they did not plan to marry due to their illness. It was determined that 73.8% of participants were afraid of transmitting the disease to others. Moreover, 21.6% of patients revealed that they experienced stigma while receiving health services. The rate of exposure to any stigma and discrimination in the workplace was 12.3% (n=43). Furthermore, 21 (5.8%) participants asserted that they lost their job due to their illness. There was a significant difference between those who hid their disease and those who did not, in terms of age, education level, marital status, place of residence, worrying about the course of the disease, fear of infecting others, and exposure to any stigma. It was observed that the individuals shared their hepatitis positivity with fewer people, with a gradual increase in their level of education (P=0.002).

Conclusion: The results of this study demonstrated that hepatitis B virus (HBV) positive people in Turkey accept this situation as a reason for stigmatization and discrimination. Participants pointed out that they often avoid disclosing their illness out of fear of being stigmatized and excluded.

Keywords: Anxiety, Concealment, Discrimination, Hepatitis B, Stigma

1. Background

Stigma has been defined as a deep sense of worthlessness and lack of social acceptance (1). It has been reported in previous studies that people with Human Immunodeficiency Virus (HIV)/Acquired Immune Deficiency Syndrome (AIDS) and mental illness experience stigma and discrimination in different aspects of life. This stigma in people with hepatitis creates an atmosphere of secrecy and denial, discouraging people from seeking screening and treatment (2); therefore, they tend to hide their disease (3).

HIV and hepatitis C are more common among homosexual and bisexual men; moreover, intravenous (IV) drug users are strongly associated with sexual and drug use behaviors. Therefore, stigmatization and discrimination against these patients are more common (4) and well-defined in the literature. Nonetheless, hepatitis B is an older and more common infection worldwide than hepatitis C virus (HCV) and HIV. Studies on stigma and discrimination attached to hepatitis B have been mainly performed on Asian people (5-7). Studies have demonstrated that patients are reluctant to be

screened and treated for stigma and therefore tend to hide their disease (2, 5, 6). It has also been reported that stigma and cultural barriers make it difficult to treat and manage these patients (8). In addition, upon detection of positive hepatitis B, the patients may be abandoned by their partners or lose their jobs (9).

2. Objectives

In Turkey, there is no study investigating disease concealment behavior and its relationship with stigma and discrimination. In light of the aforementioned issues, the present study aimed to determine the rates of stigma and discrimination in people with hepatitis B in our region and present data from Turkey to the international literature.

3. Methods

3.1. Study design and participants

This prospectively planned clinical study was conducted on individuals with positive hepatitis B surface antigen (HBs Ag) who were referred to Samsun Training and Research Hospital Infectious

Diseases and Clinical Microbiology outpatient clinic and Çarşamba State Hospital Infectious Diseases outpatient clinic. This study was performed on all volunteers who were referred to our clinic between January 1st and December 31st, 2015. This study was carried out based on an observational cohort design at the specified time interval. Data were obtained through a face-to-face interview by an infectious diseases and clinical microbiology specialist. The content of the research was explained to the participants before the interview, and their consent was obtained.

3.2. Questionnaire and outcome measurement

A questionnaire (Appendix A) prepared for chronic hepatitis B patients was applied in this study. The inclusion criteria were: (a) to be HBsAg positive for at least six months and (b) an age range of above 18 years. There were no exclusion criteria. Volunteer participants were asked about their demographic characteristics, social and economic status, whether they concealed their hepatitis B infection, their effects on their relationships with their social environment, as well as their experiences of stigmatization and discrimination in the family, work, and social life. The patients were informed that they could refuse any question they wanted.

3.3. Ethical issue

Approval for the study was obtained from the Ethics Committee Chairmanship of Health Sciences University Samsun Training and Research Hospital (EPK 2013/11).

3.4. Statistical analysis

In this study, data were analyzed in SPSS (Statistical Program for Social Sciences), IBM SPSS V23, and IBM SPSS AMOS V24. The Chi-square test was used to analyze categorical data. The Kruskal-Wallis test was applied to analyze the quantitative data. The causal relationship of consciousness, concealment, and anxiety dimensions was examined by structural equation modeling. Categorical data were presented as frequency and percentage, while quantitative data were illustrated as mean±SD. A p-value less than 0.05 was considered statistically significant.

4. Results

The mean age of patients was 41.2±17.6 years, and 56% of the total 505 participants were male. The mean disease duration was 7.5±4.6 years. Other demographic characteristics are displayed in [Table 1](#).

Table 1. Demographics of Participants Interviewed (n=505)

Characteristic	number	%
Gender		
Female	222	44
Male	283	56
Stage of diseases		
Chronic active hepatitis	181	35.8
Inactive carriers	303	60
Remission after treatment	11	2.2
Cirrhosis /another	10	2.0
Education		
Illiterate	44	8.7
Primary school	285	56.4
High school	95	18.8
University	81	16
Settlement		
City centre	173	34.3
District	184	36.4
Village	148	29.3
Smoking	153	30.3
Alcohol	37	7.3
Substance use	2	0.003
Marital status		
Never married	81	16
Single	28	5.6
Married	396	78.4
Having a family member with hepatitis		
Yes	316	62.6
No	189	37.4
Knowledge about HBV		
Very sufficient	41	8.1
Quite sufficient	123	24.4
Somewhat sufficient	205	40.6
Insufficient	136	26.9
	Mean	Range
Age (years)	Mean	SD
Time since infection (years)	41.2	17.6

Table 2. Patients' reasons for hiding their hepatitis positivity

Answer	n	%
Since the result is negative when announced before marriage.	2	1
I don't want them to pity me.	2	1
I am afraid of being judged because it is a sexually transmitted disease, and I am ashamed.	7	3.3
Fear of being excluded - I am afraid that people will avoid me.	75	36.1
I'm afraid of being fired.	7	3.3
I'm afraid of being stigmatized as sick.	6	3
I don't want to make people worry.	9	4.3
I am afraid of prejudices because society is unconscious of this issue.	47	23
I am afraid of any adverse reaction.	26	13
I don't want my privacy known.	19	9
I'm afraid of being mocked and teased.	3	1
I do not care about the disease.	5	2
Total	208	100

A number of 101 (20%) participants asserted that they felt ashamed of their hepatitis B, 238 (47.1%) cases stated that they hid their illness from those around them, and 185 (36.6%) subjects only shared it with their close friends. The patients were asked about their reasons for hiding their diseases, and the answers provided by 208 cases are illustrated in Table 2. In this regard, 97 (47%) and 75 (36%) subjects were afraid of being stigmatized and excluded, respectively.

It was determined that the majority of participants (73.8% n=373) were afraid of transmitting hepatitis B at different intensities. In this connection, 99 (19.6%) cases stated that they were always careful and anxious about this issue, and 36.9% of them declared a moderate level of anxiety. On the other hand, 88 (17.5%) subjects reported that they were conscious of this issue and aware that it can not be transmitted through routine social relationships. The rates of stigma and discrimination faced by patients in various social situations are presented in Table 3. The obtained data denoted that hepatitis B positivity also affected participants' marital status (Table 3).

The patients were assigned to three groups: those who never conceal their hepatitis B positivity, those who only share it with their relatives, and those who do not share it with anyone. There were significant differences between the groups in terms of age, education level, marital status, place of residence, worrying about the course of the disease, fear of infecting others, and exposure to any stigma (Table

4). As the level of education increased gradually, it was observed that the individuals shared their disease with fewer people (P=0.002). It was determined that those who had never been married and those living in towns and villages were more inclined to hide their hepatitis positivity (P=0.020 and P=0.011, respectively).

It was observed that the hiding behavior increased with an elevation in participants' anxiety about the course of the disease and their fear of infecting others (P=0.004 and P=0.009). It was detected that those who concealed their hepatitis were significantly less exposed to stigma and discrimination compared to other groups (P<0.001). It was found that those who hide their hepatitis B positivity from everyone experience more difficulties receiving health care (P=0.004). Moreover, their relationships with spouses, children, close neighbors and friends, and social relations were negatively affected by their increased hiding behavior. It was determined that the neighbors and other social acquaintances of those living in districts and villages were significantly affected (Table 4).

The effect of hiding behavior, level of consciousness, and anxiety level on the relationship was examined using the structural equation model. It was determined that only anxiety had a significant effect on the relationship, while concealment and consciousness did not have a significant effect (Figure 1). Table 5 depicts the path coefficients related to the latent variables that affect the relationship and the goodness of fit criteria of the model.

Table 3. Rates of experiencing stigma and discrimination in patients with chronic hepatitis B

Variable	N	%
Exposure to Stigmatization in health care services	87	21.6
Feeling that the healthcare worker is abstaining	46	11.4
Exposure to stigmatization in the workplace	43	12.3
Dismissal from work due to hepatitis B	21	5.8
Separation from fiance /lover/spouse	20	4
Deterioration in relations with partner	47	11.1
Deterioration in relations with children	30	7.7
Deterioration in relations with neighbors	27	6.8
Deterioration in relations with friends	39	9.1
Stigma from the social environment	55	11
Judged by their social environment	53	10.6
Punished by the social environment	28	5.6

Table 4. Evaluation of concealment situations and influencing factors

	Never hide n (%)	Share with only relatives n (%)	Always keep n (%)	p
Gender				
Male	145 (54.3)	107 (57.8)	31 (58.5)	0.706
Female	122 (45.7)	78 (42.2)	22 (41.5)	
Age mean (min-max) year	42 (20-80)	36 (17-70)	38 (18-70)	0.006
Year of illness	6 (1-55)	6 (1-35)	5 (1-36)	0.554
Having a family member with Hepatitis				
Yes	173 (59.7)	118 (62.4)	34 (59.6)	0.820
No	117 (40.3)	71 (37.6)	23 (40.4)	
Disease stage				
Inactive carrier	150 (57.3)	117 (64.6)	36 (67.9)	0.323
Chronic active hepatitis	103 (35.9)	62 (34.3)	16 (30.2)	
Post-treatment remission	8 (3.1)	2 (1.1)	1 (1.9)	
Educational status				
Illiterate	26 (9.7)	13 (7)	5 (9.4)	0.002
Literate	20 (7.5)	8 (4.3)	8 (15.1)	
Primary education	145 (54.3)	79 (42.7)	25 (47.2)	
High school	45 (16.9)	45 (24.4)	5 (9.4)	
Collage	31 (11.6)	40 (21.6)	10 (18.9)	
Marital status				
Married	221 (82.8)	136 (73.5)	39 (73.6)	0.020
Never married	29 (10.8)	40 (21.6)	12 (22.6)	
Widow-divorced	17 (6.4)	9 (4.9)	2 (3.8)	
Living place				
Village	88 (33)	43 (23.3)	17 (32.1)	0.011
District	80 (30)	80 (43.2)	24 (45.3)	
Province	99 (37)	62 (33.5)	12 (22.6)	
What is your anxiety level about the course of your disease?				
none	140 (52.4)	66 (35.7)	24 (45.3)	0.004
mild	48 (18)	42 (22.7)	8 (15.1)	
moderate	60 (22.5)	57 (30.8)	11 (20.8)	
severe	19 (7.1)	20 (10.8)	10 (18.8)	
Do you have a fear of Infecting Others?				
none	82 (30.7)	33 (17.8)	17 (32.1)	0.009
mild	35 (13.1)	43 (23.3)	10 (18.9)	
moderate	96 (35.9)	76 (41.1)	14 (26.4)	
severe	54 (20.2)	33 (17.8)	12 (22.6)	
Have you ever been stigmatized or discriminated?				
Yes	14 (22.7)	31 (16.8)	13 (24.5)	0.001
No	253 (56.8)	154 (83.2)	40 (75.5)	
Total	267 (100)	185 (100)	53 (100)	

Table 5. Path coefficients of latent variables affecting the relationship and goodness of fit of the model

Latent Variable	Coefficient	P-value	Root mean square error of approximation (RMSEA)
Hiding	1.503	0.536	0.075
Anxiety	0.517	0.002	
Consciousness	0.003	0.844	

RMSEA is the value showing the model fit, and a value between 0.05 and 0.08 indicates an acceptable fit of the model

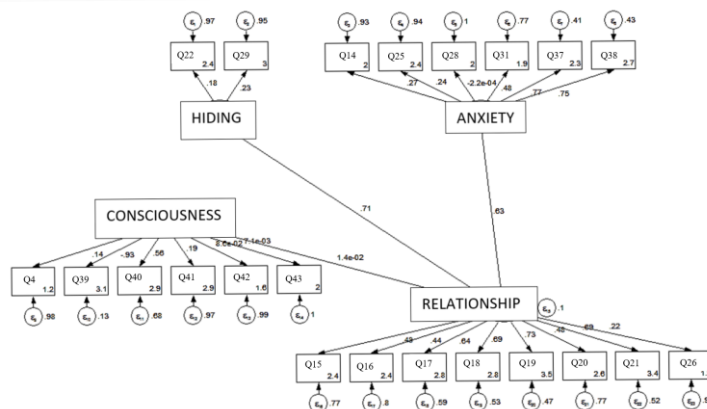


Figure 1. Effect of concealment, consciousness, and anxiety level on the relationship with the structural equation model

5. Discussion

As evidenced by the results of this study, hepatitis B patients were exposed to stigma and discrimination. In this regard, patients were exposed to stigma and discrimination during health care (21.6%), at work (12.3%), and in their social environment (11%). In addition, it was found that 47% of them tended to hide the presence of hepatitis B mainly out of fear of being exposed to stigma and discrimination. Furthermore, it was reported that the presence of anxiety resulted in the deterioration of social relationships.

Psychiatrists state that disease concealment may confront patients with an internal conflict that may negatively affect their mental, emotional and physical health (3). Social withdrawal and isolation can be observed in people due to stigma. Studies have pointed out that people with hepatitis perceive stigma from family members and even healthcare professionals; therefore, they tend to hide their disease (10). The patients in the current study also reported similar problems.

It has been reported that healthcare professionals are also hesitant and reluctant toward patients with hepatitis B, although not as much as patients with HIV (11) (12). In this study, 11.4% of healthcare professionals were reluctant to treat patients with hepatitis B. This low discrimination rate compared to HIV or Hepatitis C can be attributed to healthcare workers' vaccination against hepatitis B. It was determined that 53 (10%) patients did not share their hepatitis B positivity with anyone, and 185 (36.6%) cases only shared it with their family members. In a study conducted on 483 hepatitis B patients in Malaysia, it was reported that 33.5% of patients were reluctant to disclose their illness, and 93.6% only informed their families (13). It has also been shown that there is less exclusion and discrimination within the family (14); moreover, discrimination and stigmatization are very low if the person with hepatitis is within the family (15).

It was determined that patients' relationships with their spouses were severely affected by hepatitis B, and the unmarried ones were afraid of getting married. In a study conducted in Pakistan, 35% of participants disclosed that their relationship with their spouse deteriorated (16). In our study, this rate was 11.1%, suggesting the low rates of premarital diagnostic tests and vaccination in our country. In a study carried out in China, 33% of subjects believed that people with hepatitis B are not good candidates for marriage (14). In this study, 11.7% of patients decided not to marry due to hepatitis B.

This study indicated that the neighbors and other social acquaintances of the people living in districts and villages were significantly affected by hepatitis B since neighborly and kinship relations are more close-knit in rural areas. Furthermore, since the

education level is lower in rural areas, the transmission routes are not well-known or taboo. In a study conducted in rural areas of China, it was shown that women are most exposed to discrimination (17). In a study carried out in Pakistan, it was reported that women felt more lonely and isolated (16). In our study, no significant difference was found between genders in terms of exposure to stigmatization and discrimination, as well as disease concealment.

Hepatitis B is perceived as an incurable and contagious disease; moreover, it is thought to be like HCV, HIV, or other sexually transmitted diseases. Most people (52%) still believe that the virus can be transmitted by sharing food or close contact (18). Since poor Chinese immigrants live together in small rooms, discrimination exerts a more profound effect on them, causing patients to avoid testing since being stigmatized as a hepatitis B carrier affects different aspects of their lives, such as renting a room, finding a job, and making friends. In a Canadian study on HBV-infected Chinese immigrants, it was reported that 31% of patients were ashamed of their HBV positivity, and 53% of them did not want to talk to their family members or friends about it (18). In this study, the participants stated that they felt excluded from the social environment and judged by their social environment.

In a study, 19% of patients with hepatitis B reported that they experienced discrimination by employers or employees, and 15% of them stated they lost their job (14). These rates were found to be lower in the present research (12.3% and 5%, respectively). In a study conducted on Chinese and Vietnamese immigrants living in Australia, it was shown that the Chinese avoided disclosing their illnesses for fear of stigma and discrimination (19). It has been demonstrated that stigma has a negative effect on disease screening and vaccination rates (2). Numerous economic, ethnic, and cultural reasons for living as an immigrant lead to stigma and discrimination. In addition, the presence of a contagious disease can be regarded as a mechanism that triggers stigma and discrimination. In this study, the existence of health-related stigmatization and discrimination was investigated independently of any cultural, social, or ethnic discrimination.

In a study conducted on university students in Taiwan, it was determined that 70% of participants were afraid of contracting the disease from their friends who were hepatitis B carriers (5). In a study conducted in our country, 60% of participants were aware of the transmission routes after being HBV positive, and it was shown that 66% of the 60% of participants had their family members vaccinated (20). In this study, knowledge of the disease and transmission routes was found to be quite low; accordingly, it can be concluded that society should be informed about the horizontal transmission of HBV.

In a study performed on Chinese students, it was illustrated that stigma and discrimination are lower in those who have family members, friends, or acquaintances with chronic HBV carriers than those who do not. In the current study, 64% of patients had hepatitis in their families, and there was no difference in the concealment behaviors between people with and without a family member with hepatitis. Multiple studies have demonstrated that stigma and discrimination in people with hepatitis B are predominantly due to a poor understanding of transmission rather than the demoralization of hepatitis C and HIV (4, 21). In a study performed on healthy adults in Russia, the fear of contracting chronic hepatitis B and C was associated with insufficient knowledge of the transmission factors and routes of these diseases (15).

It was observed that the patients concealed their disease out of fear of isolation and prejudice. William Hazlitt's quote: "prejudice is the child of ignorance." underlines the need to eliminate ignorance in order to end prejudices. It was determined that participants' knowledge of hepatitis B was low before they were HBV positive since it is generally perceived as a sexually transmitted disease and a less talked about issue in society. It is necessary to talk more about hepatitis B so that stigma can be reduced in society and people can cope with stigma. This is necessary in order to educate community, not just families.

Among the notable limitations of this study, we can refer to the fact that it was conducted in Samsun; therefore, the obtained results can not be generalized to people in other parts of the country. Secondly, there is no standardized questionnaire on stigma and discrimination for this patient group. The questionnaires used in the studies are cross-sectional tools in which a single immigrant or settled population is evaluated. These questionnaires need to be validated over time in many different groups and languages. Therefore, researcher-made questionnaires were used in this study. In our country, there is a need for criteria that have been validated and prepared in accordance with our own norms and multicenter studies to be conducted with them. The questionnaire is presented in Appendix A.

6. Conclusion

The results of this study demonstrated that hepatitis B virus (HBV) positive people in Turkey accept this situation as a reason for stigmatization and discrimination. Participants pointed out that they often avoid disclosing their illness out of fear of being stigmatized and excluded. Despite the misperceptions of society, patients share their HBV positivity with their families and close circles, hoping for their support to cope with the disease. Therefore, in order to prevent the stigma against hepatitis B, it is

necessary to increase the level of knowledge and awareness regarding disease transmission.

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Footnotes

Conflicts of Interest: The authors declare that they have no conflict of interest.

Author's Contributions: Based on the ICMJE guidelines for authorship criteria, all authors were involved in the conceptualization and methodology of the article, data collection, data analysis and interpretation, design of the article, review, and final approval manuscript.

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Appendix A

Stigma, Discrimination, and Living With Hepatitis B/C patients Questionnaire

1. Age:
2. Your Gender: a. male / b. female
3. Your disease
 - a. Hepatitis B
 - b. Hepatitis C
4. How many years have you known about your disease?
5. Stage of the disease (to be filled by the doctor)
 - a. chronic active hepatitis
 - b. inactive carrier
 - c. Cirrhosis
 - d. Post-treatment remission
 - e. Other
6. What is your education status?
 - a. Illiterate
 - b. Literate
 - c. Primary education
 - d. High school
 - e. High education
7. What is your job?
8. Where do you live?
 - a. City center
 - b. District
 - c. Village
9. Your marital status
10. Is your marital status directly related to your illness? a. Yes/ b. No
11. Do you use cigarettes, alcohol and/or drugs?
 - a. cigarettes, b. Alcohol c. drug d. No
12. Who is aware of your illness? (You can mark more than one item)
 - a. Mom/dad
 - b. Spouse
 - c. children
 - d. Relative
 - e. Neighbor
 - f. Colleague
 - g. Social friend
13. Did these people learn about your illness at your request? Yes/No
14. How would you describe your level of anxiety about your illness?
 - a. never b. mild c. moderate d. Severe

15. Has your illness negatively affected your relationship with your parents?
a. never b. mild c. moderate d. Severe
16. Has your illness negatively affected your relationship with your spouse?
a. never b. mild c. moderate d. Severe
17. Has your illness negatively affected your relationship with your child?
a. never b. mild c. moderate d. Severe
18. Has your illness negatively affected your relationships with your relatives?
a. never b. mild c. moderate d. Severe
19. Has your illness negatively affected your relations with your neighbors?
a. never b. mild c. moderate d. Severe
20. Has your illness negatively affected your relationships with your co-workers?
a. never b. mild c. moderate d. Severe
21. Has your illness negatively affected your relationships with your social-friends
a. never b. mild c. moderate d. Severe
22. Do you feel the need to hide your illness?
a. I do not hide
b. Sometimes I hide
c. I always keep
23. Why do you want to hide your illness?
24. Do you experience shame because of your illness?
a. never b. mild c. moderate d. Severe
25. Do you have a fear of infecting others with your disease?
a. never b. mild c. moderate d. Severe
26. Has your illness negatively affected your sexual life?
a. never b. mild c. moderate d. Severe
27. Have you separated from your spouse/fiancé/lover because of your illness? Yes/No
28. Have you considered not getting married because of your illness? Yes/No
29. Do you report your illness while receiving health care (dental treatment, injection, etc.)? Yes/No
30. Has the doctor or healthcare worker ever refused to care for you or acted timidly when you reported it? Yes/No
31. Do you experience shyness (distress) due to your illness while receiving health care (dental treatment, injection, etc.)?
a. never b. mild c. moderate d. Severe
32. Have you been laid off due to your illness? Yes/No
33. Have you experienced any restriction / breach of confidentiality (referral, report, status change, etc.) at your workplace due to your illness? Yes/No
34. Has your illness adversely affected your working life?
a. never b. mild c. moderate d. Severe
35. Has your illness adversely affected your economic conditions?
a. never b. mild c. moderate d. Severe
36. Do you think that you are excluded from your social environment because of your illness?
a. never b. mild c. moderate d. Severe
37. Do you think you are being judged by your social circle because of your illness?
a. never b. mild c. moderate d. Severe
38. Do you think you are punished because of your illness?
a. never b. mild c. moderate d. Severe
39. Do you think you have enough information about your disease (Hepatitis B / C)?
a. very sufficient b. enough c. a little d. Insufficient
40. Do you think you need training? Yes/No
41. Does anyone in your family have hepatitis B/C? Yes/No
42. Would you try to stay away from hepatitis patients in your family or social circle before you got sick?
a. never b. mild c. moderate d. Severe
43. Did you know about the disease before learning about your disease?
a. I didn't know
b. I've heard of the disease
c. I knew it was a blood-borne disease
d. I knew it was a sexually transmitted disease
e. other