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Survey of hepatitis B knowledge and stigma among chronically infected patients and uninfected persons in Beijing, China

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Abstract

Background & Aims: Hepatitis B virus (HBV) infection carries substantial stigma in China. We surveyed HBV knowledge and stigma among chronic hepatitis B (CHB) patients and persons without HBV infection in Beijing, China. *Methods:* Four hundred and thirty five CHB patients and 801 controls at Peking University People's Hospital were surveyed. *Results:* Chronic hepatitis B patients were older (mean 46 vs. 39 years) and more often men (71 vs. 48%) than controls. Mean knowledge score was 11.9/15 for CHB and 9.3/15 for control patients ($P < 0.001$). Average stigma score was 22.1/39 for CHB and 19.2/30 for control patients. Controls expressed discomfort with close contact (45%) or sharing meals with CHB patients (39%) and believed CHB patients should not be allowed to work in restaurants (58%) or childcare (44%). Chronic hepatitis B patients felt that they were undesirable as spouses (33 vs. 17%) and brought trouble to their families (58 vs. 34%) more often than controls. Despite legal prohibitions, 40% of CHB patients were required to undergo pre-employment HBV testing, and 29% of these individuals thought that they lost job opportunities because of their disease status. 16% of CHB patients regretted disclosing their HBV status and disclosure was inversely associated with stigma. Higher stigma was associated with older age, lower education and lower knowledge score among controls; and with lower education, younger age, having undergone pre-employment HBV testing and regret disclosing their HBV status among CHB patients. *Conclusion:* Despite high prevalence of CHB in China, our study shows knowledge is limited and there is significant societal and internalized stigma associated with HBV infection.

Keywords
chronic hepatitis B – discrimination – hepatitis B virus – infection – transmission

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The prevalence of chronic hepatitis B virus (HBV) infection is disproportionately high in China, with recent estimates of almost 75 million HBV carriers, affecting 5.49% of China's population of 1.36 billion people (1–3). The financial costs related to its prevention, care, and research amount to an estimated $110 billion in government investment per year, but the social burden is often overlooked (4, 5). Despite recent national laws prohibiting discrimination towards HBV carriers from employers and schools and additional regulations put forth in February 2010, acts of discrimination are still commonly reported

Abbreviations
CHB, chronic hepatitis B; HBV, hepatitis B virus; HIV/AIDS, human immunodeficiency virus/acquired immunodeficiency syndrome; PUHSC, Peking University Health Sciences Center.

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Key points

- Our study compared chronic hepatitis B (CHB) patients and non-infected controls knowledge and stigma about hepatitis B in China.
- We found stigma in all four domains: interpersonal relationship, physical contact, employment and perception; with average stigma score of 22.1/39 for CHB and 19.2/30 for control patients.
- Higher stigma was associated with older age, lower education and lower knowledge score among controls; and with lower education, younger age, having undergone pre-employment HBV testing, and regret disclosing their HBV status among CHB patients.
- Chronic hepatitis B patients in China blame themselves for being a burden to their family and face employment-based discrimination.

(6–8). A recent study of 1607 postings from a major online chronic hepatitis B (CHB) support group (The Hepatitis B Camp Network of China) reported numerous anecdotes of institutional discrimination, relationship difficulties, limited health care access and financial constraints (9). Stigma for CHB patients remains a national problem in China.

Health-related stigma is a social process characterized by the devaluation of a person on the basis of disease or health identity (10, 11). Research into health-related stigma has been dominated by studies on HIV/AIDS, leprosy and mental illness, with few examining stigma associated with CHB (12). A 2012 study of 343 subjects enrolled from a general practice clinic and an English as a second language class at a Chinese community center in Toronto showed stigma was common, and low stigma and high knowledge scores were independent predictors of prior HBV screening (13). Another study of 201 Chinese patients seen in an internal medicine clinic in Chicago's Chinatown found stigma was greatest in the fear of contagion domain and that familiarity with HBV was inversely related to stigma (14). Although both studies included mostly Chinese immigrants, their findings may not reflect stigma associated with HBV in mainland China. Indeed, a study conducted on 6538 adults in rural communities in China in 2015 found a high level of discrimination against CHB patients: fear of transmission of infection and low level of education were major contributors to discrimination (15). None of these studies compared the perspectives of infected persons and uninfected controls.

Our study seeks to build on the literature by assessing levels of HBV knowledge and stigma in CHB patients and uninfected controls living in China. By offering a detailed survey of transmission routes and stigma domains from the perspective of both the stigmatized and that of their community, we aimed to identify areas for improvement that will reduce stigma, both real and perceived, faced by CHB patients.

Methods

Study design

We conducted a survey study of CHB patients and controls attending outpatient clinics at the People's Hospital, Peking University Health Science Center (PUHSC) in Beijing, China between June 8 and July 21, 2015. The Peking University People's Hospital is a large tertiary care hospital with 2.8 million outpatient visits in 2015, of which 90 000 were visits to the hepatology clinic. Chronic hepatitis B patients were enrolled from the hepatology clinic and control patients with no known diagnosis of HBV were enrolled from a health check-up clinic and a gastroenterology clinic. The surveys were completed by patients or administered verbally to patients who were unable to read the surveys by one of three medical students from the University of Michigan.

This study was conducted as a global health project by medical students from the University of Michigan in collaboration with the Peking University People's Hospital. The supervising faculty from both teams had been collaborating on similar student projects as well as other research projects since 2011. The three medical students were selected based on their fluency in Mandarin Chinese and underwent training in human subjects research and survey implementation at the University of Michigan followed by orientation at the hepatology clinic at the Peking University People's Hospital. The students were instructed to read the questions and options for responses verbatim and not to interpret the questions or influence the responses when administering the surveys. We obtained approval from the Institutional Review Board of the University of Michigan and the Institutional Review Board of Peking University for this study. All participation was voluntary and patients provided verbal consent.

Survey

The survey included demographic information and questions concerning knowledge about HBV, and stigma and discrimination related to HBV. The stigma and knowledge questions were adapted from studies by Li *et al.* in Canada and Cotler *et al.* in the United States (13, 14). Separate surveys with corresponding questions were administered to the CHB and control groups. The surveys were initially developed in English, translated into Chinese and then back-translated to verify accuracy in translation. We conducted pilot testing on seven CHB and 13 control patients at PUHSC and revisions were made based on feedback from these patients. A copy of the surveys is included in the supplementary material.

HBV Knowledge

The knowledge component of the survey consists of 15 yes/no/don't know questions with eight questions

on modes of transmission of HBV and seven questions on the progression of HBV and disease management. A correct answer was given one point and an incorrect/do not know response was given zero points.

HBV stigma

The stigma section included 13 questions for CHB patients and 10 questions for control patients. The questions were organized across four domains: interpersonal relationships, personal contact, employment and perception. Seven questions probing the same issues were administered to both CHB and control patients with parallel phrasing to assess how CHB patients perceived themselves and how uninfected persons perceived HBV carriers. For each statement, patients indicated whether they agreed, disagreed or were neutral. A response indicating a high degree of stigma was given three points, a neutral response was given two points, and a response indicating no stigma was given one point. The maximum stigma score was 39 points for CHB patients and 30 points for control patients with higher scores indicating higher degree of stigma. Chronic hepatitis B patients were also asked if they disclosed their HBV status to others, whether they regretted doing so, whether they had been required to undergo HBV testing prior to employment and whether they had been fired because of their HBV status.

Data analyses

Data were analysed with the IBM SPSS Statistics (SPSS) version 23 (Armonk, NY, USA). Comparisons between groups were conducted using *t*-tests for continuous data and chi-squared tests for categorical data. Multiple linear regression analysis was performed to determine the factors that predict HBV knowledge and stigma.

Results

A total of 435 CHB and 801 control patients (365 from the health check-up clinic and 436 from the gastroenterology clinic) were enrolled in the study. Of the CHB patients approached for this study, 77% participated and there were no differences in demographics between those who did and those who did not participate in the study. The demographic characteristics of the patients are summarized in Table 1. Chronic hepatitis B patients were older, more likely male, and had less education than control patients. Among control patients, those recruited from the gastroenterology clinic were older, more likely female, and had less education than those at the health check-up clinic. Control patients enrolled at the gastroenterology clinic were more similar to CHB patients in terms of age and education level, though they were still more likely to be female. The majority (69%) of CHB patients had been diagnosed more than 10 years ago while 16% had been diagnosed within the last 5 years. Three-quarters of CHB patients were receiving HBV treatment. Roughly half (54%) of CHB and 11% of control patients had family members diagnosed with HBV. In the control group, 52% had been tested for HBV and 60% had been vaccinated.

The majority of the surveys were self-administered by patients (79% of CHB and 80% of controls). In both groups, subjects who self-administered the survey were significantly younger (mean age 42.4 vs. 60.4 years for CHB, $P < 0.001$; and 35.9 vs. 52.5 years for controls, $P < 0.001$), and more likely to have university education than those who had surveys verbally administered by a researcher (56 vs. 24% of CHB, $P < 0.001$; and 68 vs. 41% of controls, $P < 0.001$). While there was no significant difference in mean total knowledge score (11.9 vs. 11.8 for CHB and 9.4 vs. 9.2 for controls), mean stigma score was higher in patients who self-administered the

Table 1. Characteristics of CHB and control patients

	CHB $n = 435$	Control $n = 801$	Health check-up $n = 365$	Gastroenterology $n = 436$
Age, Mean ± SD*†	46.2 ± 15.5	39.2 ± 17.6	26.3 ± 7.7	49.9 ± 16.4
Gender (%)*†				
Male	71	48	56	40
Female	29	52	44	60
Education (%)*†				
High school or less	51	37	24	48
College or postgraduate	49	63	76	52
Marital status (%)*†				
Single	12	42	78	13
Married	82	54	19	82
Other	6	4	3	5
Family members with CHB (%)*	54	11	9	14

*$P < 0.001$ between CHB and control.

†$P < 0.001$ between controls enrolled in health check-up and gastroenterology clinics.

surveys than those who had the surveys administered by a researcher (22.4 vs. 21.0 for CHB, $P = 0.023$; and 20.3 vs. 18.9 for controls, $P < 0.001$).

HBV Knowledge

Knowledge scores (maximum 15) were significantly higher for CHB patients than controls. The average total knowledge score was 11.9 ± 2.3 for CHB patients and 9.3 ± 2.9 for controls ($P < 0.001$). The average transmission knowledge score (maximum 8) was 5.8 ± 1.6 for CHB patients and 4.4 ± 1.8 for controls ($P < 0.001$) while the average outcome and disease management knowledge score (maximum 7) was 6.0 ± 1.2 for CHB patients and 4.9 ± 1.7 for controls ($P < 0.001$). Having a family member with HBV was significantly associated with a higher total knowledge score and higher transmission knowledge score for the control group ($P < 0.001$ for both) but not the CHB group.

Transmission

A higher percentage of CHB patients responded correctly to each question on HBV transmission than controls (Fig. 1). Although most CHB and control patients correctly recognized HBV can be transmitted from mother-to-child (85% CHB vs. 72% controls, $P < 0.001$), roughly half of CHB patients and controls also thought HBV is an inherited disease (57% CHB vs. 52% controls, $P = 0.028$). Most (71%) CHB patients, but only 47% controls, knew HBV can be transmitted sexually ($P < 0.001$). The biggest discrepancy in knowledge between the two groups pertains to HBV transmission via sharing food or utensils, with 70% of CHB patients but only 27% of controls correctly identifying that sharing food or utensils does not spread HBV ($P < 0.001$).

Outcome and disease management

Chronic hepatitis B patients had significantly greater knowledge regarding HBV progression than controls. A higher percentage of CHB patients compared to control patients recognized that HBV can progress to cirrhosis (78% CHB vs. 67% controls, $P < 0.001$), liver cancer (91% CHB vs. 59% controls, $P < 0.001$), and lifelong infection (75% CHB vs. 55% controls, $P < 0.001$). Additionally, a higher percentage of CHB patients than controls knew that HBV can be treated with medications (91% CHB vs. 79% controls, $P < 0.001$) and prevented by vaccination (92% CHB vs. 86% controls, $P < 0.001$).

Sources of knowledge

The vast majority of CHB patients, regardless of age, regarded their liver doctor as the most important source of information on HBV. Almost a quarter of younger CHB patients (age <55) stated the Internet was their most important source of information compared to only 4% of older CHB patients. In the control group, television and public advertisements were the most important source of information on HBV across all age groups. Other sources of information included family or friends and self-reading for older controls, and the Internet for younger controls.

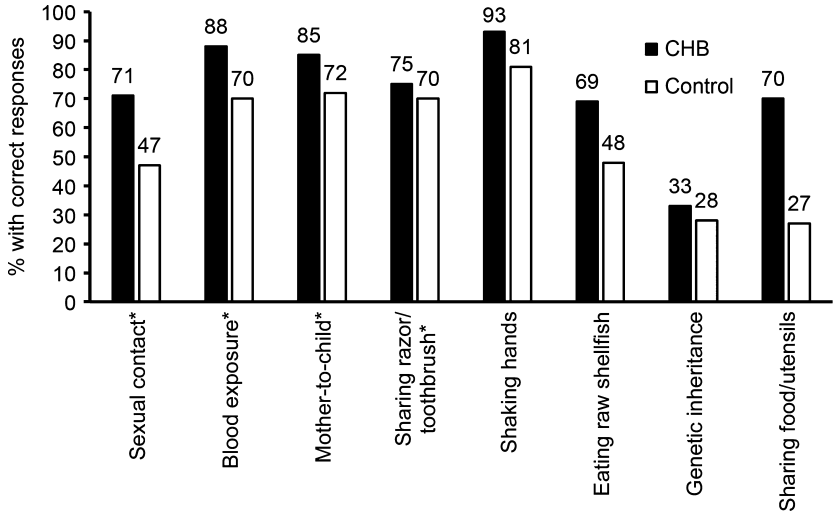

Fig. 1. Knowledge about modes of transmission of HBV. Subjects were asked to identify valid and invalid modes of transmission of HBV by responding 'true/false/don't know.' Valid modes of transmission are denoted by an asterisk. The figure depicts the % of correct responses to each question within the CHB and control groups. For each transmission question, a significantly higher percentage of CHB patients responded correctly compared to controls. Significance values are listed from left to right: $P < 0.001$, $P < 0.001$, $P < 0.001$, $P = 0.023$, $P < 0.001$, $P < 0.001$, $P = 0.028$, $P < 0.001$.

Multiple linear regression analysis

Multiple regression analyses to predict total knowledge and transmission knowledge scores were performed using age, gender and education. Higher education, older age and female gender predicted higher total knowledge score for controls ($P < 0.001$, $P < 0.001$, $P = 0.014$, respectively) but only higher education was a significant predictor for the CHB group ($P < 0.001$). For transmission knowledge score, only higher education was a significant predictor of higher scores for both control ($P < 0.001$) and CHB groups ($P < 0.001$).

HBV stigma

The average stigma score for CHB patients was 22.1 ± 5.2 (maximum 39) and for controls 19.2 ± 3.8 (maximum 30). Among controls, having a family member with CHB or having been tested for HBV or vaccinated against HBV did not significantly impact stigma scores. Responses to each item are shown in Table 2 and responses to the seven items common to both CHB patients and controls are shown in Figure 2.

Interpersonal relationship domain

In the interpersonal relationship domain, CHB patients responded with higher levels of stigma than controls. More than half (58%) of CHB patients feel they have brought trouble to their families and 33% feel they would not be desirable as spouses. In contrast, fewer controls believe CHB patients bring trouble to families (34%) or are less desirable spouses (17%). These strong responses stand in contrast with the actual discrimination felt by CHB patients: only 5% reported discrimination from their families and only 13% from their friends.

Physical contact domain

In the physical contact domain, controls responded with higher levels of stigma: 45% indicated HBV carriers should avoid close contact with others and 39% indicated HBV carriers should avoid sharing meals with others compared to 36 and 20% of CHB patients respectively. Both CHB patients and controls who thought HBV can be spread by sharing food and eating utensils were more likely to indicate CHB patients should avoid sharing food with others (37 vs. 15% of CHB, $P < 0.001$; 50 vs. 15% of controls, $P < 0.001$) (Table 3).

Employment domain

In the employment domain, only 11% of controls responded that HBV carriers were not desirable as employees yet 58% felt HBV carriers should not be allowed to work in restaurants and 44% felt they should not be allowed to work with children. Among CHB patients, 40% reported having to undergo pre-employment HBV screening, 19% felt discriminated by coworkers or employers and 15% reported having lost job opportunities because of their HBV status. Chronic hepatitis B patients who had to undergo pre-employment HBV screening were more likely to report being

Table 2. Responses of CHB patients and controls to questions on stigma

	CHB, *n* = 435			Control, *n* = 801		
	Agree	Neutral	Disagree	Agree	Neutral	Disagree
Domain 1. Interpersonal relationships						
Bring trouble to family	58	21	21	34	31	35
Not as desirable as a spouse	33	20	47	17	39	44
Should not be isolated by friends/ family	71	12	17	n/a	n/a	n/a
Discriminated by family	5	12	83	n/a	n/a	n/a
Discriminated by friends	13	28	59	n/a	n/a	n/a
Domain 2. Physical contact						
Should avoid close contact with others	36	22	42	45	25	30
Should avoid sharing meals with others	20	20	60	39	27	34
Domain 3. Employment						
Discriminated by coworkers	19	30	51	n/a	n/a	n/a
Discriminated by employers	19	33	48	n/a	n/a	n/a
Been denied jobs/fired from jobs	15	19	66	n/a	n/a	n/a
Should be allowed to work in restaurants	n/a	n/a	n/a	20	22	58
Should be allowed to work with children	n/a	n/a	n/a	26	30	44
Not as desirable as an employee	n/a	n/a	n/a	11	30	59
Domain 4. Perception						
Should be blamed for having HBV	17	30	53	3	10	87
Can be trusted not to bring harm to others	72	20	8	54	32	14
Put others at risk for HBV	52	18	30	57	30	13

Results expressed as percent of CHB patients or controls.

denied employment (29 vs. 6%, $P < 0.001$) compared to those not required to undergo testing (Table 3).

Perception domain

Responses in the perception domain were mixed, 17% of CHB patients believed they should be blamed for having HBV and 72% felt they could be trusted not to bring harm to others. In contrast, only 3% of controls felt HBV carriers should be blamed for having HBV and 54% felt HBV carriers could be trusted not to bring harm to others.

Multiple linear regression analysis

Multiple regression analyses to predict stigma score in the control group were performed using education, age, gender and total knowledge score. Lower education, older age and lower total knowledge score were significant predictors of higher stigma score (Table 4). Analysis in the CHB group included two additional factors: requirement of pre-employment testing and regret of disclosure of HBV status. Lower education, younger age, being required to undergo pre-employment testing and regret towards disclosure of HBV status were significant predictors of higher stigma score. Similar findings were observed when total knowledge score was replaced by transmission knowledge score; and transmission knowledge score was a stronger predictor of stigma than total knowledge score in the control group (Table 4).

Disclosure of HBV status

Most CHB patients indicated that they disclosed their HBV status to their spouse/significant other (88%), parents (80%) and siblings (81%) but fewer disclosed their status to their children (57%), close friends (47%), coworkers (31%), employers (26%) or doctors/dentists (49%). Chronic hepatitis B patients who agreed with the statement 'CHB patients bring trouble to their family' were less likely to disclose their HBV status to their significant others or children (Table 3). Overall, 16% of CHB patients regretted disclosing their status to others.

Discussion

In this study of 435 CHB patients and 801 controls conducted in Beijing, China, we found a high degree of perceived and self-imposed stigma among CHB patients. We also identified a high degree of stigma towards CHB patients from uninfected persons. Our data demonstrate that HBV-related stigma affects multiple aspects of a patient's life, including interpersonal relationships, physical contact, employment opportunities and perception.

Stigma towards an infectious disease may be a result of ignorance, especially in regards to routes of transmission. While a study of Chinese immigrants in Chicago found that better knowledge about HBV transmission was associated with lower stigma, a survey of a rural population in China found no association between knowledge of HBV transmission and discrimination (14, 15). Our study found lower total knowledge score

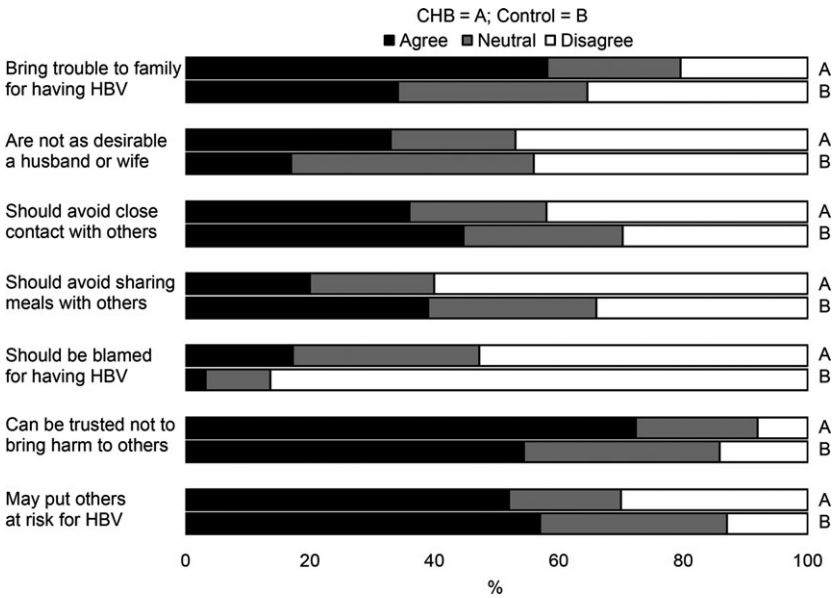

Fig. 2. Response of CHB patients and controls to overlapping questions on stigma. Both CHB and control patients were asked to respond 'agree/neutral/disagree' to these seven statements used to assess stigma.

Table 3. Correlations between hepatitis B virus (HBV) knowledge, stigma, and disclosure

	Chronic hepatitis B	Control
HBV patients bring trouble to family		
Disclosure of HBV status to significant other	87% (220/253)	n/a
Disclosure of HBV status to children	54%[a] (135/251)	n/a
HBV patients *do not* bring trouble to family		
Disclosure of HBV status to significant other	94% (83/88)	n/a
Disclosure of HBV status to children	69%[a] (61/88)	n/a
HBV can be transmitted via sharing food/utensils		
HBV patients should avoid sharing meals with others	37%[b] (38/103)	50%[c] (259/517)
HBV patients should not work in restaurants	n/a	65%[d] (336/517)
HBV *is not* transmitted via sharing food/utensils		
HBV patients should avoid sharing meals with others	15%[b] (44/300)	15%[c] (34/220)
HBV patients should not work in restaurants	n/a	45%[d] (99/220)
Having to undergo HBV testing prior to employment		
Being fired or lost a job	29%[e] (50/172)	n/a
Not having to undergo HBV testing prior to employment		
Being fired or lost a job	6%[e] (16/261)	n/a

[a]$P < 0.05$, [bcde]$P < 0.001$.

in controls was significantly associated with higher stigma and lower transmission knowledge score was an even stronger predictor of stigma. In CHB patients, neither total knowledge nor transmission-based knowledge correlated with stigma score but this may be related to high knowledge score in this group. In accordance with prior studies, there is a common misconception that HBV can be spread by sharing food or eating utensils (14, 16). We found that those with this misconception were more likely to believe CHB patients should avoid sharing food with others and should be barred from working in a restaurant. Our findings suggest that education programs to improve understanding of HBV transmission in the general public may decrease stigma towards HBV carriers.

Similar to other studies on stigma, we found that higher education level correlated with lower stigma in both CHB patients and controls (14, 15, 17). Age had contrasting effects on stigma in the control and CHB groups; whereas older controls had higher stigma scores, older CHB patients had lower stigma scores. Perhaps, this is reflective of how those living with the disease for a longer period have developed ways to cope with the stigma over time. Surprisingly, and contrary with the study by Cotler *et al.* (14), we found that having a family member with CHB had no impact on stigma scores in the controls.

Stigma can also arise from moral judgment. A study conducted in Hong Kong demonstrated that diseases like HIV, which are associated with perceived immoral action related to injection drug use or sexual contact, had a higher degree of stigma than diseases like tuberculosis or SARS, which are transmitted through air droplets (18). Vaughn-Sandler *et al.* (19) surveyed patients with cirrhosis and found that 82% felt stigmatized because of the perceived association between cirrhosis and alcoholism. In our study, the vast majority of our CHB patients and controls knew HBV can be transmitted from infected mothers to their infants, a mode of transmission less associated with immorality, yet only half of the controls realized HBV can be transmitted sexually. Thus, perceived immoral action is unlikely to be a major contributor to stigma associated with HBV infection in China.

We found an alarmingly high degree of internalized stigma among CHB patients. While Cotler *et al.* (14) found that 36% of HBV carriers believed they bring trouble to their families, that number was even higher in our study, with 58% of CHB patients responding along those lines. Furthermore, a third (both men and women) felt their disease status made them less desirable as a spouse. The financial burden (e.g. cost of medical care and loss of job opportunities) and physical impact (e.g. symptoms from HBV, risk of cirrhosis and liver cancer and reduced life expectancy) may cultivate guilt and lead patients to self-imposed blame. This trend has previously been noted in mainland China. Kleinman *et al.* documented instances of this behaviour in mainland China in the context of HIV, and Wu *et al.*, in a study of Chinese Canadians with CHB in Toronto, showed that 31% of CHB patients were ashamed of their illness and recent immigrants were most likely to express this sentiment (16, 20). Internalized stigma may be unwarranted, as controls in our study were less likely to indicate that CHB patients bring trouble to their families than CHB patients themselves. Our findings suggest that healthcare workers should encourage open dialogue between patients and families and educate patients on how to manage their disease and prevent transmission.

Our study confirms reports that CHB patients in China face barriers outside the home. The non-governmental organization Beijing Yirenping Center provides free legal assistance to HBV patients who have faced discrimination. A survey by this group in 2007 found many employers, including state-owned enterprises, are non-compliant with Chinese law and pre-employment HBV testing and employment discrimination remain widespread (6, 9, 20). An updated report in 2012 suggests almost half of CHB patients have suffered from employment related discrimination (21). In our study, 40% of

Table 4. Regression analysis predicting stigma in CHB and control patients

	CHB			Control		
Predictors	B	95% CI	*P*-value	B	95% CI	*P*-value
Higher education	−1.40	(−2.39, −0.40)	0.006	−0.91	(−1.47, −0.35)	0.002
Age (years)	−0.05	(−0.08, −0.02)	0.004	0.04	(0.02, 0.05)	<0.001
Female gender	0.70	(−0.32, 1.73)	0.178	0.22	(−0.31, 0.74)	0.417
Total knowledge score	0.001	(−0.20, 0.20)	0.991	−0.10	(−0.20, −0.01)	0.030
Pre-employment test	2.63	(1.67, 3.59)	<0.001			
Regret of disclosure	2.78	('1.50, 4.05)	<0.001			
R^2	0.16			0.07		
Higher education	−1.48	(−2.47, −0.49)	0.003	−0.86	(−1.42, −0.30)	0.003
Age (years)	−0.05	(−0.08, −0.01)	0.004	0.04	(0.02, 0.05)	<0.001
Female gender	0.72	(−0.31, 1.74)	0.171	0.20	(−0.32, 0.73)	0.443
Transmission knowledge score	0.10	(−0.19, 0.40)	0.489	−0.23	(−0.37, −0.09)	0.002
Pre-employment test	2.63	(1.67, 3.59)	<0.001			
Regret of disclosure	2.75	(1.48, 4.02)	<0.001			
R^2	0.17			0.07		

Multiple regression was conducted using the variables of education, age, gender and knowledge score to predict stigma score in controls. A similar model with two additional predictors (having undergone pre-employment testing and expression of regret of disclosure) was created to predict stigma score in CHB patients. The unstandardized B coefficient shows the effect of each predictor on the dependent variable of stigma.

CHB patients reported they were required to undergo pre-employment testing for HBV and there was a significant correlation between requirement for pre-employment testing and being denied job opportunities. While legal prohibition of employment discrimination towards HBV patients in China is in place, enforcement remains lax.

Many other studies involving HBV, hepatitis C and HIV/AIDS have shown stigma negatively impacts healthy behaviours such as screening, likelihood of disclosure, prevention of transmission and adherence to medications (13, 14, 22, 23). In our study, CHB patients who disclosed their status to their family had significantly lower stigma scores, which perhaps reflects that patients who experience lower stigma are more comfortable about disclosing their status (24). Chronic hepatitis B patients were less likely to disclose their HBV status to acquaintances outside of their immediate family, with low rates of disclosure even to physicians and dentists. To improve health outcomes of CHB patients, combating stigma needs to be a priority among health care workers.

Our study is unique in that it is the first systematic study on HBV stigma in China that includes both infected and non-infected persons, though some limitations exist. As our study was confined to one hospital in Beijing, it is possible stigma associated with HBV infection is worse elsewhere in China. Chronic hepatitis B patients differed from controls in terms of demographic profile and this limits our comparison of responses between the two groups but not analysis of responses within the groups. Most of our CHB patients had been diagnosed more than 10 years ago, giving them ample time to understand and cope with their disease and thus the stigma they perceive may differ from that of more recently diagnosed patients. The large majority of surveys were self-administered by CHB patients and controls but some required verbal administration by researchers, which could have affected the stigma scores. Finally, our survey was limited in scope and there may be other areas of stigma that were not addressed.

In summary, we have shown that living with HBV in China has consequences beyond the clinical course of the disease. Employment discrimination continues despite legal prohibition, and self-guilt of CHB patients is alarmingly common. We also found a high degree of stigma towards CHB patients among uninfected persons and fear of transmission might be a major contributor to the negative attitudes. By quantifying stigma in multiple dimensions in both the affected and unaffected populations, our study provided insights into the degree of stigma associated with HBV infection and potential interventions to reduce this burden.

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