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Patient Knowledge, Beliefs and Barriers to Hepatitis B Care: Results of a Multi-center, Multi-ethnic Patient Survey

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Abstract

Background—A greater understanding of the determinants of health behavior among those with and at-risk for chronic hepatitis B virus (HBV) infection is needed for effective design and implementation of public health initiatives.

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Aims—To determine factors associated with (1) willingness to accept HBV antiviral treatment and (2) satisfaction with provider communication regarding HBV care in a diverse cohort of HBV-infected patients.

Methods—Using a multi-faceted model of health behavior, the Health Behavior Framework, we conducted a comprehensive assessment of knowledge, attitudes, beliefs, and barriers to HBV care.

Results—We enrolled 510 patients, with mean age 46 years; 53.1% men; and 71.6% Asian or Hawaiian/Pacific Islander. Patients were knowledgeable about HBV infection, but one-fifth did not think that HBV was a treatable disease; over a quarter felt it was so common among family and friends that it did not concern them; and less than half of patients believed they were likely to have liver problems or transmit HBV to others during their lifetime. Perceived susceptibility to disease risk was the only independent predictor of willingness to accept HBV treatment (β = 0.23, p= 0.0005), and contrary to expectations, having a doctor that speaks the same language was predictive of lower patient satisfaction with provider communication about their HBV care (β = -0.65, p<0.0001).

Conclusions—Patients with greater perceived susceptibility to the health consequences of HBV infection are more likely to accept treatment, and patient-provider language concordance impacts patient satisfaction with communication regarding HBV care in an unexpected direction.

Keywords

Health behavior framework; HBV epidemiology; HBV prevention; HBV treatment; HBV education

Introduction

Chronic hepatitis B virus (HBV) infection confers an increased lifetime risk for the development of cirrhosis, liver failure, and hepatocellular carcinoma (HCC) and represents a significant cause of morbidity and mortality worldwide.[1] In the United States and Canada, prevalence of chronic HBV infection among adults remained largely unchanged over the last two decades despite the implementation of national vaccination programs, primarily due to immigration of HBV-infected persons from countries of high HBV endemicity.[2] Conservative estimates suggest that up to 1.4 million Americans are infected with HBV, but the actual number of persons chronically infected is predicted to be more than 2 million when foreign-born persons are taken into account.[3] Despite the availability of safe and effective antiviral therapy, rates of screening for and treatment of HBV infection remain suboptimal. Given the enormous global burden of disease and its associated health and economic implications, increased efforts to identify and treat HBV-infected persons are needed. Integral to the development of HBV-related public health initiatives is a thorough understanding of patients' perceptions and beliefs regarding HBV infection and treatment that can help shape clinical management.

Chronic HBV infection represents a major health disparity that disproportionately affects vulnerable populations, including low-income, low education level and immigrant populations, and studies suggest that the majority of HBV-infected individuals are either unaware of their infection or not receiving appropriate care.[4, 5] The reasons for the

adequate health insurance.[10]

suboptimal management of HBV patients are likely multifactorial. Limited studies have explored these factors among Asian immigrants living in North America, a population disproportionately affected by HBV. Provider-related factors shown to be associated with HBV screening and vaccination include providers' attitudes towards HBV prevention and knowledge or familiarity with established management guidelines.[6–9] Patient-related factors include knowledge of HBV, perceived risk of infection and liver cancer, trust in western medicine, and language barriers. Socio-cultural factors that influence HBV management include concerns about stigma associated with HBV infection and access to

Theoretical models in the area of health behavior change provide useful tools for guiding the exploration of the complex interplay of factors that may help shape HBV disease understanding and management. The Health Behavior Framework (HBF) represents a synthesis of various models of health behavior change that have been successfully used to evaluate and improve HBV screening practices across various Asian American populations using culturally-appropriate interventions.[11, 12] The HBF assumes that individual, support system, and community cues influence health behavior. This relationship is dependent on a complex interplay of an individual's perceptions about facilitators and barriers of behavior change. In this study, we used established HBF constructs to conduct a comprehensive assessment of patients' knowledge, attitudes, beliefs and perceived barriers to HBV care as predictors of willingness to accept HBV antiviral treatment if recommended and patient satisfaction with provider communication regarding HBV care.

Methods

Patients were recruited from hepatology clinics at six academic medical centers in the United States and Canada, including the University of California, San Francisco, University of Michigan, University of Minnesota, University of North Carolina, Washington University in St. Louis, and the University of Toronto. Informed consent was obtained from adults 18 years old with chronic HBV infection (defined as hepatitis B surface antigen positivity for at least 6 months). New and established clinic patients were enrolled. Exclusion criteria included: history of HCC; hepatic decompensation; organ or bone marrow transplantation; ongoing HBV therapy; HIV infection; other concomitant liver disease; significant comorbidities that would interfere with study completion; and non-English and non-Chinese speaking. Demographic and clinical data were collected, including age, sex, race/ethnicity, country of birth, duration of residence in the U.S. or Canada, socioeconomic status (education and income level), insurance status, family history of HBV or liver disease, and history of HBV therapy. Laboratory data (ALT, HBV viral load, HBV E-antigen status, hepatitis C or D coinfection) and clinical data (presence of cirrhosis, prior HBV therapy, duration of HBV infection) were extracted from patient medical records. This study was approved by the Institutional Review Boards (Research Ethics Board in the case of the Toronto site) of all participating centers.

Survey Design and Measures

The survey instrument was developed using the HBF with input from expert hepatologists and behavioral scientists experienced in health behavior change research. The vast majority of questions used in the current study were previously validated in Asian American populations being screened for HBV.[13] The rigorous survey development process included engagement with Asian American community advisory boards, qualitative interviews, examination of existing instruments, pilot testing survey items with advisory board input, and backward and forward translation in three Asian languages, thereby demonstrating strong content validity for use in HBV patient populations.[13] A few additional items were taken from previously validated questionnaires related to medical mistrust (of providers and medical research) and disparities of care. [14, 15] These items were either used verbatim or modified for use in the HBV-infected population. The final survey items were then organized into five domains: (1) HBV knowledge; (2) beliefs about HBV infection (with sub-domains of perceived severity, stigma, treatment efficacy, self-efficacy to discuss hepatitis B, and perceived susceptibility to disease risk); (3) barriers to HBV care; (4) cues to action (i.e., internal or external stimuli that might trigger the decision to seek HBV care); and (5) medical mistrust (Supplemental Table 1). The survey instrument was developed in English and translated to traditional Chinese, the most common foreign language identified in the study populations.

Data Analyses

Patient characteristics were summarized using mean (\pm SD), median (range), and frequency. Survey responses were summarized using frequencies and percentages. Composite scores for each of the domains and sub-domains were calculated from responses to questions designed to assess these factors as follows: 1) "knowledge" score was computed as the number of correct responses to 5 questions (1 for correct, 0 for incorrect; max score 5); 2) scores for each "beliefs" subdomain were determined by summing the numerical codes (1 or 0) assigned to the responses for corresponding questions [perceived severity (max score 6), stigma (max score 1), treatment efficacy (max score 1), self-efficacy to discuss hepatitis B (max score 1), and perceived susceptibility to disease risk(max score 2)]; 3) "barriers to HBV care" score was determined by summing the numerical codes for responses to 8 questions (1 for "agree or yes", 0.5 for "moderately agree or unsure", and 0 for "disagree or no"; max score 8); 4) "cues to action" score was determined by summing the numerical codes assigned to responses to 5 questions (1 for "yes", 0 for "no"; max score 5); and 5) "medical mistrust" score was determined by summing the numerical codes (1 or 0) assigned to responses to 2 questions (max score 2).

Frequencies and proportions between subgroups (Asians vs. non-Asians, Chinese vs English-speaking, and males vs. females) were examined using Chi-square tests. Univariable and multivariable linear regression modeling was used to assess factors associated with two outcomes: (1) willingness to accept HBV treatment if recommended by provider (using a Likert scale from 1–5, with 1 representing "not likely" and 5 representing "extremely likely" to accept HBV treatment) and (2) satisfaction with provider communication about HBV care (composite score of two survey items using a Likert scale 1–5, with 1 representing "not satisfied" and 5 representing "extremely satisfied" with provider communication). Predictors

used in the multivariable models included those identified as important *a priori* (patient age, gender, race/ethnicity, HBV knowledge, and barriers to HBV care) and those variables with a p-value <0.1 (two-sided) on univariable analysis. All analyses were performed using SAS 9.2.[16]

Results

A total of 510 patients were enrolled between January 2013 and January 2014. The median number of patients enrolled at each site was 55 (range 32–197). Mean age of the patients was 46 years (range: 18–77 years) and 53.1% were men (Table 1). The majority of patients (71.6%) identified as Asian or Hawaiian/Pacific Islander (API), 12.6% identified as White and 12.0% as Black. Most patients (86.5%) were foreign immigrants to the U.S. or Canada with a mean duration of stay of 18 years. More than half of the patients (57.3%) had college/ technical/vocational training or advanced degree education and 72.0% were employed, but 48.8% had a household income of less than \$50,000. Nearly half of patients (51.8%) relied on publicly funded health insurance. Limited English fluency was reported by 42.8% of patients, 44.9% of patients were seen by a doctor who speaks the same language, and 39.2% relied on the use of a translator. Patients had been aware of their HBV infection for a mean duration of 18 years, 18.0% reported prior treatment for HBV, and 44.9% had a family history of HBV or liver disease.

Survey Responses

Overall, patients were knowledgeable about HBV infection, with a mean knowledge score of 3.9 ± 1.1 out of a max score of 5 (Supplemental Table 1). However, 30.6% of patients thought that HBV could be spread by sharing food, drinks, or eating utensils. While a majority of patients (87.7%) felt that treatment for HBV was efficacious and could prevent their liver disease from getting worse, 20.8% did not think that HBV was a treatable disease, and 28.2% felt that it was so common among family and friends that they were not worried about it.

Over half of patients (55.9%) ascribed stigma to HBV infection, believing that some persons avoid HBV-infected individuals. Perceived susceptibility to disease risk was variable, with less than half of patients (47.7%) believing they were quite or extremely likely to have liver problems during their lifetime and 23.6% believing they were quite or extremely likely to give HBV to others during their lifetime. One-fourth to one-third of patients identified concerns about having a liver biopsy, side effects of treatment, burden of treatment on their family, and the cost of hepatitis B care as major barriers to HBV care. The majority of patients sought HBV care because they were referred by their primary care provider (88.6%) or due to concerns for their health (87.1%). Medical mistrust was generally low among survey participants, with the majority of patients (97.1%) trusting their doctor's judgments concerning their medical care.

In comparison to non-Asian patients, Asians were more likely to be immigrants to North America (94.8% vs 65.3%), have family history of HBV or liver disease (62.9% vs 29.0%), limited English fluency (46.9% vs 16.8%), a doctor who speaks the same language (56.0% vs 41.9%), low household income (64.2% vs 51.7%), and publicly-funded health insurance

(60.6% vs 43.2%) (Table 2). Asian patients had lower knowledge (3.8 vs 4.2), but higher perceived susceptibility to disease risk (0.8 vs 0.5), barriers (3.3 vs 2.3), and cues to action (3.0 vs 2.8) scores compared to non-Asian patients. The comparison of Chinese- to English-speaking patients (based on language of questionnaire administered) largely mirrored those observed in comparing Asian to non-Asian patients (Supplemental Table 2), with the additional findings that a lower proportion of Chinese-speaking patients graduated high school or beyond (64.9% vs 88.7%), and Chinese-speaking patients had lower perceived severity (3.3 vs 3.8) and self-efficacy to discuss HBV infection (0.6 vs 0.8) scores compared to English-speaking patients.

Compared to males, females were more likely to have a family history of hepatitis B or liver disease (64.6% vs 42.5%), be unemployed (32.4% vs 23.4%), and have higher perceived barriers to HBV care scores (3.2 vs 2.8) (Supplemental Table 3).

Factors Associated with Willingness to Accept HBV Treatment

On univariable analysis, having a doctor that speaks the same language (β = -0.14, p= 0.088), low household income (β = -0.20, p= 0.021), and publicly-funded health insurance (β = -0.18, p= 0.024) were negatively associated with willingness to accept HBV treatment. Higher patient knowledge (β = 0.085, p= 0.013), stigma (β = 0.14, p= 0.070), perceived treatment efficacy (β = 0.21, p= 0.064), and perceived susceptibility to disease risk (β = 0.20, p<0.0001) were positively associated with acceptance of HBV treatment. The multivariable analysis found that perceived susceptibility to disease risk was the only independent predictor of willingness to accept HBV treatment (β = 0.23, p= 0.0005) (Table 3).

Factors Associated with Satisfaction with Provider Communication about HBV Care

The univariable analysis found that older patient age (β = -0.089, p= 0.077), API race/ ethnicity (β = -0.48, p= 0.014), recent immigration to North America (β = -0.31, p= 0.016), limited English fluency (β = -0.53, p<0.0001), having a doctor that speaks the same language (β = -0.62, p<0.0001), low household income (β = -0.48, p= 0.0004), publiclyfunded health insurance (β = -0.37, p= 0.0061), and greater barriers to HBV care (β = -0.060, p= 0.039) were negatively associated with satisfaction with provider communication about HBV care. In addition to cirrhosis (β = 0.52, p= 0.090), higher patient knowledge (β = 0.10, p= 0.080), perceived severity of disease (β = 0.17, p= 0.0075), and self-efficacy to discuss HBV infection (β = 0.41, p= 0.0067) were positively associated with satisfaction with provider communication. The multivariable analysis found that having a doctor that speaks the same language was the only independent predictor of lower satisfaction with provider communication about HBV care (β = -0.65, p<0.0001) (Table 3).

Discussion

In order to design effective public health interventions, greater efforts are needed to understand determinants of health behaviors among patients with and those at-risk for HBV infection. To our knowledge, this is the first study utilizing a theoretical framework of health behavior to examine patients' perceptions related to uptake of HBV treatment and satisfaction with medical provider communication regarding HBV care in a large, multi-

ethnic, North American cohort of HBV-infected patients. In addition to an ethnically diverse API population, the non-Asian patients were comprised of similar numbers of Whites and Blacks. In this study, greater perceived susceptibility to disease risk emerged as the only independent predictor of willingness to accept HBV treatment recommendation. Contrary to expectations, having a doctor that speaks the same language was predictive of lower patient satisfaction with provider communication about their HBV care. Thus, the findings of this study highlight the complex interplay of psychosocial factors that shape HBV-related health behaviors.

Risk perception represents a major component of health behavior models that refers to an individual's perceived susceptibility to a threat and is thought to be a major determinant of patient intentions and behaviors.[17] In this cohort, perceived susceptibility to disease risk was relatively low, with less than half of patients believing they were likely to have liver problems during their lifetime and less than a quarter believing they might transmit the infection to others. The reasons for the relatively low perceived susceptibility in this cohort are unclear, particularly given that patients were highly knowledgeable. However, those patients with higher perceived susceptibility scores were much more willing to accept HBV treatment if recommended by their provider. This finding lends support for the notion that patients with greater perceived susceptibility to the negative consequences of a health condition will take appropriate measures to mitigate this risk. In addition, it highlights the need for further public health interventions aimed at reinforcing the negative health consequences of HBV infection and the benefits of antiviral treatment in preventing liver disease progression.

An unexpected finding of this study is the inverse relationship between patient-provider language concordance and satisfaction with provider communication about HBV care. Some prior studies have suggested that patient English fluency and matching with a provider who speaks the same language promotes increased HBV screening,[18, 19] while others have shown that patient or provider language were not major determinants of HBV prevention and management.[6, 7] Indeed, several studies showed that communication-centered interventions had no impact on patient health outcomes.[20, 21] This discrepancy in the literature challenges the notion that shared identity is equivalent to providing culturally competent care for all patients.[22] Additional unmeasured factors, such as provider language skills, patient perception of level of expertise among physicians not trained in North America or patient interactions with clinical support staff, may have played a role in our findings.

HBV-related stigma has been shown to negatively affect health and health behaviors among API populations.[23] In this cohort, there were high rates of stigma ascribed to HBV infection (55.9% of patients) that did not differ significantly between the racial/ethnic groups, but stigma was not shown to impact acceptance of HBV treatment or satisfaction with HBV-related communication by the patient's care team. Similarly, a large proportion of patients (76.3%) demonstrated self-efficacy to discuss HBV with family and friends, but this was also not found to be a major determinant of HBV treatment uptake or satisfaction with communication regarding HBV care, a finding that adds to conflicting data regarding the significance of this psychosocial factor in shaping health behaviors.[24] Notably, despite

higher rates of family history of HBV or liver disease, HBV-infected women had higher rates of perceived barriers to HBV care compared to men, perhaps in part related to higher rates of unemployment. Although female sex and barriers to HBV care did not emerge as independent predictors of acceptance of HBV treatment or satisfaction with communication regarding HBV care, these findings highlight the need for a closer examination of gender differences in HBV-related health behaviors.

Strengths of this study include the comprehensive assessment of knowledge, attitudes, beliefs, and barriers in a large number of HBV-infected patients, and the diversity of the patient cohort with respect to both race/ethnicity and geographic distribution across North America add to the generalizability of the findings. Limitations of the study include those inherent to survey studies, including self-report and recall bias and that the study population was already engaged in HBV specialty care. In addition, we were unable to pilot test our questionnaire prior to initiating the current study; however, the majority of survey items used in this study were developed and piloted with stakeholder input for prior studies in Asian American communities at risk for chronic hepatitis B, demonstrating strong content validity for the target population. This study focuses on Chinese- and English-speaking patients, so the findings cannot be extrapolated to patients that speak other languages. Similarly, the majority of our patients were API, but HBV infection affects APIs disproportionately and the racial/ethnic mix of our study population mimics that of the HBV-infected population in North America. Nevertheless, identification of gaps in patient knowledge and high levels of stigma despite receipt of specialty care indicates potential targets for interventions within specialty clinics and supports the need to explore these findings in community settings.

In summary, our findings suggest that perceived susceptibility to disease risk is critical to willingness to take HBV therapy, and patient-provider language concordance has a negative influence on satisfaction with communication regarding HBV care. While race/ethnicity did not emerge as an independent predictor of HBV-related health behaviors or outcomes, there were significant differences between Asian and non-Asian populations that warrant further exploration. This study builds upon the limited literature exploring the determinants of health behaviors among HBV-infected individuals using theoretical constructs that are needed to help shape effective public health interventions.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Patient Characteristics.

Chanastanistia	All Patients	
Characteristic	(N=510)	
Age (mean ± SD), years	45.5 ± 12.8	
Male sex (N, (%))	271 (53.1)	
Race/ethnicity (N, (%))		
White/Caucasian	64 (12.6)	
Black/African American	61 (12.0)	
Asian or Hawaiian/Pacific Islander	365 (71.6)	
Native American/Alaska Native/Other or Missing	19 (3.7)	
Latino/Hispanic ethnicity (N, (%))	6 (1.2)	
Born in U.S. or Canada (N, (%))	69 (13.5)	
Duration of stay in U.S. (mean \pm SD), years	17.5 ± 11.2	
Fluent in English (N, (%))	291 (57.1)	
Duration of HBV infection (mean \pm SD), years	17.6 ± 13.4	
ALT (mean ± SD), units/L	46.3 ± 74.9	
HBV DNA (mean ± SD), log ₁₀ IU/mL	4.0 ± 2.0	
HBeAg negative (N, (%))	396 (77.7)	
HCV Ab positive (N, (%))	11 (2.2)	
HDV Ab positive (N, (%))	8 (1.6)	
Diagnosis of cirrhosis (N, (%))	23 (4.5)	
Prior history of HBV therapy (N, (%))	92 (18.0)	
Family history of hepatitis B or liver disease (N, (%))	229 (44.9)	
Highest Level of Education (N, (%))		
College/vocational/technical school or advanced degree	292 (57.3)	
Graduated high school or GED	123 (24.1)	
Some high school or less	94 (18.4)	
Currently employed	367 (72.0)	
Household income less than \$50K	249 (48.82)	
Public insurance (Medicaid/Medicare/Gov, N, (%))	264 (51.8)	

Table 2.

Comparison of Asian vs. non-Asian patients with chronic hepatitis B*.

Characteristic	Non-Asian N=144	Asian N=365	P-value
Age, years (mean ± SD)	43.3 ± 12.0	46.3 ± 13.0	0.015
Male sex (N(%))	84 (58.3)	186 (51.0)	0.13
Birth Place and Length of Immigration (N(%))			<0.0001
Born in U.S. or Canada	50 (34.7)	19 (5.2)	
Foreign-born and immigrated >20 years ago	24 (16.7)	113 (31.0)	
Foreign born and immigrated 20 years ago	57 (39.6)	189 (51.8)	
Foreign-born and immigration date unknown	13 (9.0)	44 (12.1)	
ALT (log2) (mean ± SD)	5.1 ± 0.9	5.1 ± 0.9	0.69
HBV DNA (log10) (mean ± SD)	6.5 ± 7.1	6.6 ± 7.1	0.28
HBeAg negative (N(%))	120 (87.0)	275 (76.2)	0.0080
HCV Ab positive (N(%))	9 (6.3)	2 (0.6)	<0.0001
Known cirrhosis (N(%))	10 (6.9)	13 (3.6)	0.099
Prior history of HBV therapy (N(%))	24 (16.7)	68 (18.6)	0.60
Family history of hepatitis B or liver disease (N(%))	36 (29.0)	193 (62.9)	<0.0001
Patient has limited English fluency (N(%))	24 (16.8)	152 (46.9)	<0.0001
Patient speaks mostly native language with friends (N(%))	30 (20.8)	177 (48.5)	<0.0001
Doctor speaks same language as patient (N(%))	52 (41.9)	200 (56.0)	0.0068
Other member of medical team translates for patient or speaks same language $(N(\%))$	100 (80.0)	181 (50.8)	<0.0001
Graduated high school/GED or above (N(%))	124 (86.1)	290 (79.7)	0.092
Currently unemployed (N(%))	45 (31.5)	95 (26.2)	0.23
Household income <\$50K (N(%))	60 (51.7)	188 (64.2)	0.020
Public insurance (N(%))	57 (43.2)	206 (60.6)	0.0006
Domain 1: Knowledge (mean ± SD)	4.2 ± 0.9	3.8 ± 1.2	0.0013
Domain 2: Beliefs about HBV Infection (mean ± SD)			
a. Perceived severity	3.7 ± 0.9	3.6 ± 1.1	0.11
b. Stigma	0.5 ± 0.5	0.6 ± 0.5	0.51
c. Treatment efficacy	0.8 ± 0.4	0.9 ± 0.3	0.21
d. Self-efficacy to discuss HBV infection	0.8 ± 0.4	0.7 ± 0.4	0.057
e. Perceived susceptibility to disease risk	0.5 ± 0.7	0.8 ± 0.8	0.0020
Domain 3: Barriers to HBV Care (mean ± SD)	2.3 ± 2.1	3.3 ± 2.2	<0.0001
Domain 4: Cues to Action (mean ± SD)	2.8 ± 1.2	3.0 ± 1.2	0.042
Domain 5: Medical Mistrust (mean ± SD)	0.08 ± 0.3	0.06 ± 0.2	0.29

Race data was missing for one patient.

Table 3.

Multivariable linear regression models of factors associated with acceptance of HBV treatment and satisfaction with HBV care team communication.

Variable	Acceptance of HBV Treatment		Satisfaction with HBV Care Team Communication	
	Beta	P-value	Beta	P-value
Age (per decade)	-0.0029	0.94	0.018	0.77
Male sex (vs female)	0.10	0.26	0.077	0.61
Race (vs Caucasian)				
Black	0.19	0.36	0.24	0.49
Asian/HPI	-0.11	0.48	0.21	0.38
Other	-0.17	0.52	0.18	0.67
Recent Immigrant (vs Born in North America or Immigrated >20y ago)			0.030	0.85
HBV DNA (log10)			-0.041	0.44
HBeAg negative (vs positive)			-0.38	0.17
Known cirrhosis			0.073	0.84
Patient has limited English fluency (vs fluent)			0.13	0.47
Doctor speaks same language as patient	-0.097	0.32	-0.65	<0.0001
Household income <\$50K (vs \$50K)	0.15	0.18	-0.35	0.057
Public insurance (vs Private)	-0.14	0.18	-0.12	0.48
Domain 1: Knowledge	0.011	0.80	-0.019	0.81
Domain 2: Beliefs about HBV Infection				
a. Perceived severity			-0.0017	0.98
b. Stigma	0.073	0.45		
c. Treatment efficacy	0.14	0.35		
d. Self-efficacy to discuss HBV infection			0.25	0.21
e. Perceived susceptibility to disease risk	0.23	0.0005		
Domain 3: Barriers to HBV Care	0.030	0.20	-0.063	0.074