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Survey of Asian patients with Hepatitis B infection: limited knowledge of transmission and screening of family members

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Abstract

Background—Asian American families are disproportionately affected by Hepatitis B (HBV) infection. We aimed to assess the extent of screening family members of Asian patients with known HBV infection as well as patients' knowledge of HBV disease.

Methods—A cross-sectional survey of established Asian patients with HBV-infection was performed at a university liver clinic. Outcome measures included the percentage of family members whose HBV serostatus was unknown and the percentage of patients who were able to correctly identify modes of transmission.

Results—A total of 803 US-based family members were identified by 58 patients. Patients did not know the HBV serostatus of 50% of their family members and 28% of their immediate family members. Fifty percent of participants did not know how they had acquired HBV or stated unlikely transmission modes.

Conclusion—Though nationwide vaccination campaigns target this underrepresented population, screening family members of Asian patients with HBV remains a challenge.

Keywords

HBV; screening; knowledge; family testing; HCC

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INTRODUCTION

An estimated 800,000 people live with chronic Hepatitis B (HBV) infection in the United States (1) and given the underrepresentation of Asians in national data, some models suggest that the actual numbers approach 1.4 million (2, 3). Indeed, the burden of HBV infection in the Asian community is disproportionately elevated. Community-based data suggest that the prevalence of Hepatitis B surface antigen (HBsAg) in Asians ranges from 6–14% (4–6). Of vertically infected individuals with chronic HBV, approximately 25% will succumb to complications associated with chronic liver disease or develop hepatocellular carcinoma (HCC) during their lifetimes (7–9).

Most public health interventions have focused on targeting individuals of Asian descent through community efforts. In 2006, a California State resolution (10) was passed mandating universal HBV screening and vaccination be made available to all residents of San Francisco county through the “Hep B Free” campaign. This campaign utilizes advertisements in Asian newspapers, radio, and television to promote screening and vaccination. So far, approximately 6.5% of individuals screened have been found to be HBsAg-positive in this campaign (11).

To our knowledge, there are no specific public health efforts directed towards the family members of individuals with known HBV infection. Given that HBV is mostly vertically transmitted in the Asian population, the “family member” is a unique target for a screening intervention. However, little is known of the communication of HBV from the HBV-infected patient to his/her family members and barriers to screening these family members (12). In addition, many individuals with undiagnosed HBV are often young and healthy and do not present for clinical care for other reasons. Therefore, the HBV-infected patient represents an important, and perhaps the only, opportunity for medical providers to reach out to family members to encourage early screening. We aimed to determine the extent of screening efforts within the families of Asian patients with known HBV-infection as well as patients’ knowledge about HBV transmission.

METHODS

Participants

This was a cross-sectional survey of individuals with known HBV infection at a tertiary Hepatology clinic. From May-December 2009, consecutive adult individuals of Asian descent with known HBV infection, who were returning patients of a university Hepatology Clinic, were approached to participate in the study.

Data collection

Prior to enrollment, at other visits to the clinic, all patients received written and verbal information, via an interpreter as needed, about the variable progression of HBV disease, modes of transmission and need to screen and vaccinate family members. After enrollment in the study, patients completed detailed, confidential questionnaires about their medical and family histories using interpreters if needed. Basic demographic information was recorded for each patient, including age, sex, country of birth, and language primarily spoken at

home. Patients were asked specifically about knowledge of their HBV disease, including time and manner of diagnosis, when they were referred to a hepatologist and mode of acquisition of HBV. They were asked to document the number of immediate and extended family members currently living in the United States as well as each family member's HBV status and any diagnosis of hepatocellular carcinoma (HCC) associated with Hepatitis B. At the completion of the questionnaire, patients were offered coupons to give to family members who then could be screened for HBV without cost through the University of California San Francisco Hep B Free clinic. Patients of Chinese descent, the largest ethnic group, were given a second questionnaire one year later, reassessing their knowledge of HBV infection. The second questionnaire was administered in English or Chinese (Cantonese or Mandarin).

Measures

The primary outcome measure was the absolute number of immediate and extended family members per patient whose HBV serostatus was unknown. Secondary outcome measures included the percentage of patients who were able to identify correct modes of HBV transmission and convey an understanding of the natural history of HBV infection, specifically with respect to HCC as well as the percentage of distributed coupons used by family members.

Analysis

Statistical analysis was performed using T-test, Chi-squared, Fisher exact analyses and logistic regression as appropriate using Excel (Microsoft Corporation) and Stata v 11.1 (Statacorp LP, College Station, TX). This study was approved by the UCSF Committee for Human Research.

RESULTS

Characteristics of patients

Of 68 individuals approached, 58 patients consented to complete detailed confidential questionnaires about their medical and family histories. Those who refused cited perceived loss of confidentiality, no family in United States or unwillingness to engage in research activities. Fifty-five percent of the patients were male and 89% of the patients were born outside the US (Table 1). The majority (55.2%) was of Chinese descent, including those from Taiwan. The median time from diagnosis to liver referral was 108 months (IQR 12, 228). Eighty percent carried private insurance; 17% had Medicare benefits and 3% had Medicaid benefits.

Characteristics and knowledge of serostatus of family network

A total of 803 family members living in United States were identified by patients. Of these, 325 were immediate family members, including 112 parents, 92 siblings, 46 spouses, and 75 children (Table 2). The median number of immediate family members reported as having unknown serostatus per index case was 1 (IQR 0, 2). The distributions of these reported values are depicted in figure 1. A total of 401/803 (49.9%) relatives were identified as having unknown HBV serostatus, of which 91 (22.7%) were first-degree relatives or spouses

(immediate family members). One individual reported 44 extended family members whose serostatus s/he did not know. Among the immediate family members identified as having unknown serostatus, 49.5% were parents; 33% siblings; 13.2% children; and 4.4% were spouses of patients (Table 2). Patients were more likely to know the serostatus of their spouses (91%) and children (84%) than parents (60%) and siblings (67%) ($p < .0001$).

Nine HBV patients reported 12 family members with hepatocellular carcinoma (HCC). Even among those families with a history of HCC, patients reported unknown serostatus in 152 relatives. Two patients, who reported at least one parent with HCC, did not know the HBV serostatus of their five children.

When stratified by country of descent/ethnicity, individuals of Chinese ethnicity were more likely than those of other ethnicities to know the serostatus of their children (93.9% vs. 76.2%, $p = 0.04$) and their parents (67.8% vs. 50.9%, $p = 0.05$). When stratified by language, more English speakers than non-English speakers knew the serostatus of their parents (74.5% vs. 49.5%, $p = 0.006$), their children (94.4% vs. 80.7%, $p = 0.13$) and first-degree relatives or spouses (81.7% vs. 65.8%, $p = 0.001$).

Patients' knowledge of HBV disease acquisition

Most individuals did not know why they had been tested for HBV in the first place (table 3). While nearly half (48%) of patients identified their parents as the source of their infection, 50% stated they either did not know how they acquired the disease or stated reasons other than sexual intercourse, vertical or parenteral transmission (table 3). These other reasons included drinking dirty water, sharing food with mother or babysitter, or eating food purchased from street vendors. There were no statistically significant differences in knowledge of acquisition of HBV between those of Chinese and non-Chinese descents, nor between English speakers and non-English speakers. However, when 19 of the original 34 patients of Chinese descent responded to a second questionnaire one year later, 84% reported familial transmission of HBV compared to 47% on the prior questionnaire. Twelve of 14 non-English speakers and all 5 English speakers stated there was a familial risk of HCC. All 19 individuals stated that families should be told about HBV and liver cancer. The majority of these Chinese patients (80%) knew there was a vaccine for HBV.

There was no significant association between time to referral (to a hepatologist) and knowledge of HBV acquisition (logistic regression, $p > .05$).

Family member notification by patients

Eighty-nine percent of patients stated that they had notified their family members of their HBV serostatus. Among those that had not notified family members, reasons for not disclosing included shame, privacy, and fear of being shunned by the community. One individual stated that « [others] consider it like AIDS. » Another reported that « it is a disgrace and [people] would not sit with me at church or share their food...[if they knew]. » One individual stated that s/he didn't « see a need to [disclose] as [s/he] was not sharing needles or having sex. » One patient who reported that both parents had HCC had not disclosed his serostatus to family members. When stratified by ethnicity or language, there was no difference in notification rates. Forty-seven patients (81%) requested coupons. Of

162 coupons given to patients, only two family members came to the Hep B Free clinic for testing. Both family members were HBsAg negative and one required vaccination.

DISCUSSION

In this study, patients with chronic HBV infection evaluated at a tertiary liver clinic did not know the HBV status of nearly 50% of their family members. This knowledge gap existed despite extensive counseling regarding family testing at every clinic visit. In addition, patients, including those with a known family history of HCC who have a higher risk of developing HCC, did not know the serostatus of over a quarter (91/325) of first-degree relatives or spouses. Furthermore, our study suggests that language barriers may play an important role, even with the availability of interpreters, as non-English speakers were less likely to know their family members' serostatus than English speakers. It is possible that the language barrier is also a proxy for acculturation; that is, the less English a patient speaks, the less likely that patient may feel comfortable with the specific cultural practices expected in our healthcare system.

Of note, access to care was not a major issue in our population. Eighty percent of our study population carried private insurance, and the remainder had government insurance. We did not capture specific socioeconomic data such as income or education, but the majority of our patient population has at least one employed member in their immediate families. It is likely, therefore, that our findings understate the lack of screening efforts in Asian families, particularly those who may be more impoverished and have less access to care (12, 13).

Universal perinatal screening and vaccination of newborns in the United States was proposed in 1982 (14). In spite of this, patients in our study did not know the serostatus of 16% of their children. This is most likely due to the fact that 80% of our sampled population is foreign born, and many of their children may have been born outside of the US or before universal vaccination efforts. However, even with improvements in the care for pregnant women in the United States, it is likely that current estimates of perinatal transmission are underreported by as much as 20-fold (15, 16).

The apparent discrepancy between individuals of Chinese descent and others may be due to the large size of the Chinese community in the San Francisco Bay Area. Additionally, the discrepancy may be due to specific efforts that the San Francisco Hep B Free campaign has made in reaching out to the Chinese-speaking community through local Chinese media, although other ethnic media have also been targeted. Interestingly, the re-administered survey to Chinese patients demonstrated an awareness of the need for testing and vaccination that was not previously noted. It is unclear what factors may have contributed to this improvement, but it is possible that written instruments that highlight relevant information may be as important as verbal explanations from the doctor at the time of the visit even though we had initially assumed verbal explanation would be a much more personable way of imparting the information, particularly with the help of interpreters if needed.

There were several limitations to our study. First, the sample size of patients was small, but nonetheless, we were able to identify a large sample of family members. Secondly, our population was selective as patients came from an academic tertiary care hospital and therefore not generalizable to all Asian patients living in the United States. However, because we chose this particular setting, we were able to assess the depth of screening in an Asian population that theoretically had little or no barriers to access to care. Thirdly, we did not offer incentives to patients or their contacts and relied on altruism, personal initiative and self-efficacy. Prior studies on using patients' social network to increase case finding have benefited from incentivizing patients and members of their social network (17). Finally, we did not test family members but relied on patient report, which may be unreliable. Patients may have underreported or overestimated the number of family members whose status they knew or did not know and this results in information bias. Family members may not have shared their serostatus for cultural reasons or because of stigma. However, developing an understanding of one's family history is a critical component of disease prevention (18). Our results highlight the need to determine better ways to educate patients about transmission of Hepatitis B and the importance of testing family members. Furthermore, stigma remains a central problem in our ability to screen family members of patients with Hepatitis B and though media campaigns through the SF Hep B Free campaign have helped mitigate this to some extent, it is clear that additional measures need to be explored.

Screening individuals of Asian descent for Hepatitis B has been shown to be cost-effective, especially when a ring vaccination program (whereby contacts are also screened and vaccinated) is included in the screening process (19). Cost-saving estimates are over \$39,000 per quality-adjusted life-year (19). Despite this, only an estimated 5% of individuals with chronic Hepatitis B infection are screened, enter into a health care system, and obtain treatment (20). Asians in the United States in particular greatly underutilize health care resources and several studies have delineated barriers to accessing care within this population. These include: 1) provider-related barriers, as some providers are not familiar with basic screening and/or management of chronic hepatitis B infection; 2) patient-related barriers, such as lack of knowledge, language and communication as well as stigma and denial of disease; and finally 3) resource-related barriers, whereby socioeconomic status and immigration status preclude individuals from having insurance to access care (3, 12, 21, 22). Our study supports the second of these prevailing theories, with a particular emphasis on the influence of stigma.

While community-based screening efforts are important, targeting family members of Asian individuals with HBV infection may provide an effective way to control the epidemic in this marginalized population if done correctly. Vaccination of susceptible familial contacts is important in reducing transmission of HBV (3) and furthermore early initiation of antiviral treatment may be indicated in many individuals with chronic HBV who have not been screened (23). The HBV-infected patient represents an important opportunity for medical providers to reach out to these family members and encourage early screening. An effective, robust, culturally competent approach to do this is essential. Rigorous qualitative research using targeted focus groups or semi-structured interviews with individuals from the Asian

community, including Asian health care professionals, may assist in determining appropriate approaches.

Nationwide vaccination campaigns are beginning to target this underrepresented foreign-born population on a community-level. Focusing efforts on screening family members of individuals with HBV infection will likely increase case finding exponentially and furthermore, improve the efficiency of public health endeavors. The means to achieve this goal, however, remain to be determined.

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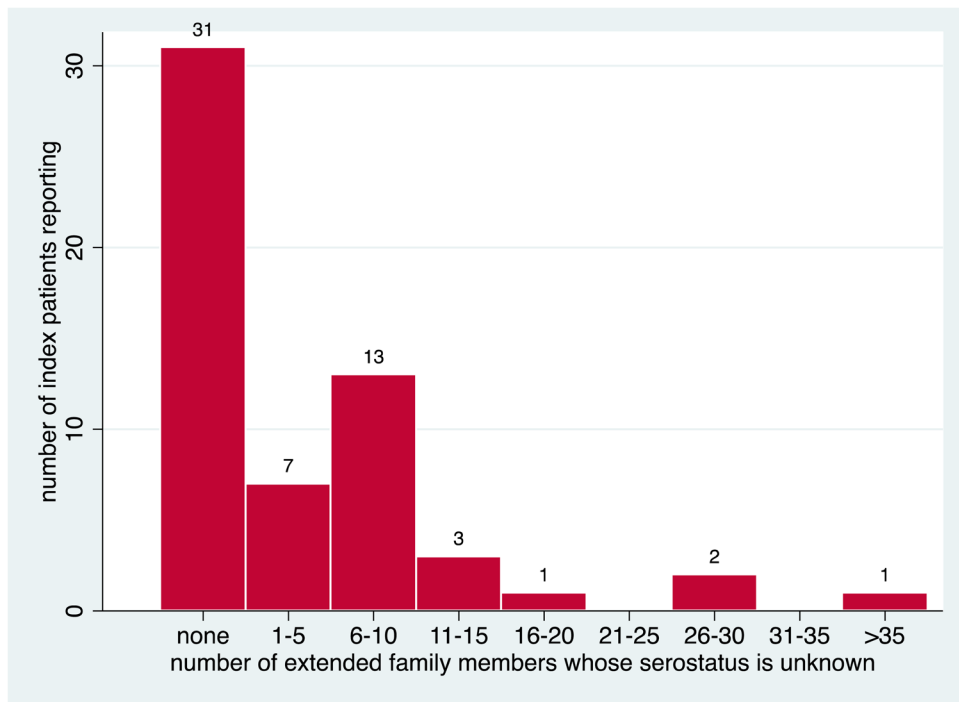
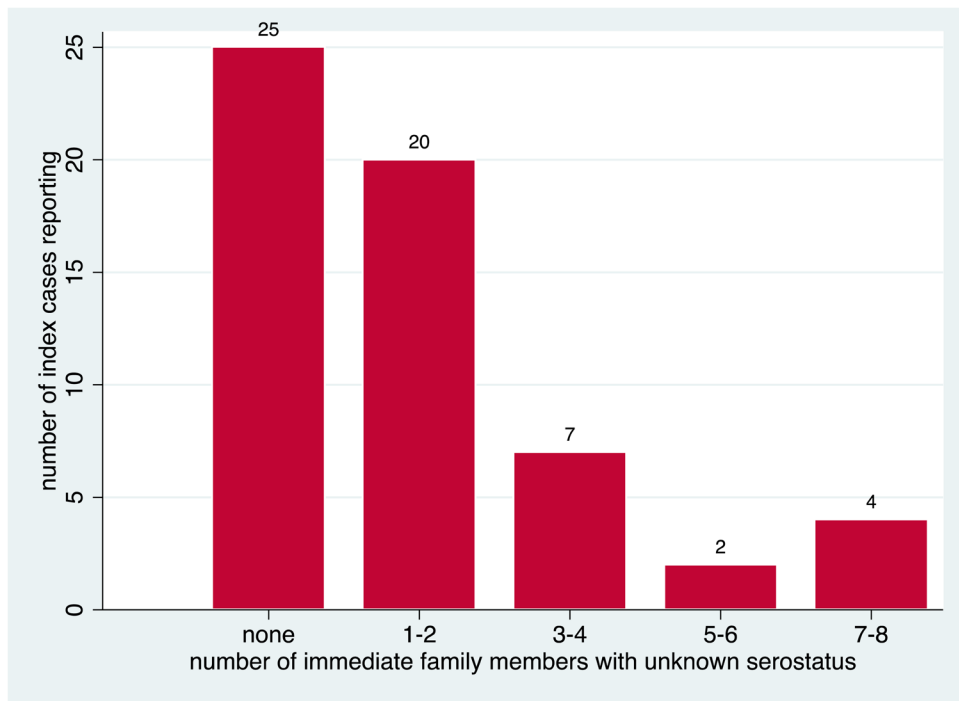


Figure 1. Figure 1a and 1b. The number of immediate family members whose serostatus was unknown by the index cases is shown in Figure 1a. The number of extended family members whose serostatus was unknown by the index cases is shown in Figure 1b.

Table 1

Characteristics of Asian Patients with Hepatitis B (HBV) Infection

Total number of patients	58
Mean Age, y (range)	46 (22–87)
Gender, male (%)	55%
Single, %	20.7%
English as primary language, %	50%
Born outside of US, %	89%
Ethnicity, %	
Chinese	55.2%
Filipino	12.1%
Vietnamese	12.1%
Korean	8.6%
Japanese	5.2%
Thai	1.7%
Cambodian	1.7%
South Asian	1.7%
Other	1.7%

Table 2

Number and percentage of family members whose Hepatitis B (HBV) serostatus is positive, negative and unknown, as reported by patients

	N	Believed to be HBV positive (%)	Believed to be HBV negative (%)	Unknown Serostatus (%)
Spouses	46	4%	87%	9%
Children	75	7%	77%	16%
Siblings	92	34%	34%	33%
Parents	112	27%	33%	40%
Subtotal	325	21%	51%	28%
Aunts/Uncles	157	16%	26%	58%
Cousins	210	6%	20%	75%
Other	111	2%	42%	56%
TOTAL	803	13%	37%	50%

Table 3

Patient report: Reasons for having been tested, how they were diagnosed and their knowledge of Hepatitis B transmission methods

Questions	frequency of patient responses (%)
Why were you tested for Hepatitis B?	
Doctor requested	13 (22.4%)
Family member got sick	5 (8.6%)
Family member was tested	2 (3.5%)
I was sick	5 (8.6%)
Other/Unknown	33 (56.9%)
Who diagnosed you with Hepatitis B?	
Family doctor	33 (56.9%)
Hep B Free Clinic	1 (1.7%)
Obstetrician	1 (1.7%)
Other/unknown	23 (39.7%)
How did you get Hepatitis B?	
Don't know	22 (37.9%)
From Parent	28 (48.3%)
From Partner/Spouse	0 (0%)
From Needles	1 (1.7%)
From a Blood Transfusion	0 (0%)
From Other	7 (12.1%)