



## Original research

## Existing knowledge, myths, and perceptions about hepatitis B and liver cancer within highly impacted immigrant communities



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## ABSTRACT

**Background:** Immigrant groups from Southeast Asia, the Pacific Islands, sub-Saharan Africa, and the Caribbean bear the heaviest burden of chronic hepatitis B and primary liver cancer in the United States. Educational campaigns to increase knowledge about these diseases and their connection are necessary to promote protective health behaviors within these communities, to ultimately reduce the burden of disease, lessen stigma, and eliminate health disparities.

**Objectives:** This project sought to engage groups within highly impacted communities to identify existing gaps in hepatitis B- and liver cancer-related knowledge, in order to inform future health education programming that will aim to reduce stigma and promote liver cancer prevention and early detection behaviors within and across groups.

**Methods:** Fifteen focus groups and two key informant interviews were conducted virtually with participants from Micronesian, Chinese, Hmong, Nigerian, Ghanaian, Vietnamese, Korean, Somali, Ethiopian, Filipino, Haitian, and Francophone West African communities. Qualitative data were analyzed using thematic coding.

**Results:** There are large gaps in knowledge and awareness of hepatitis B and liver cancer, and the link between these two diseases among Asian, Pacific Islander, African and Haitian immigrant communities. This limited knowledge and misinformation, exacerbated by stigma, hinder these groups' utilization of hepatitis B and liver cancer diagnostic and preventative healthcare services.

**Conclusion:** To reduce hepatitis B and liver cancer health disparities within heavily burdened groups, health education needs to be community-informed, culturally sensitive, and actionable. Study results can guide the development of culturally and linguistically appropriate education programs that focus on the link between hepatitis B and liver cancer and the need for vaccination and routine screening, and that are responsive to the knowledge gaps and misperceptions of diverse communities. The results also provide valuable insights for healthcare providers to improve the knowledge gaps of the diverse patient populations that they serve.

## 1. Introduction

Worldwide, the hepatitis B virus (HBV) is the leading risk factor for hepatocellular carcinoma (HCC), or primary liver cancer, making it a significant global health threat.<sup>1,2</sup> About 15 %–25 % of individuals living with unmanaged chronic hepatitis B (CHB) die prematurely from cirrhosis or liver cancer.<sup>3</sup>

In the U.S., up to 2.4 million people are living with CHB,<sup>4</sup> with immigrant groups from endemic countries disproportionately

affected.<sup>5–7</sup> The prevalence of CHB among immigrant people living in the U.S. is approximately 3.1 %, with prevalence rates ranging from 4.5 % among people from Oceania, to 5.9 % among people from Asia and 8.6 % among people from Africa.<sup>4</sup> Furthermore, immigrant communities have increased risk of progression to HCC,<sup>8–12</sup> and increased rates of premature mortality attributed to CHB-related HCC compared to the non-Hispanic white population in the U.S.<sup>13,14</sup> Despite the negative health impacts of CHB and HCC within immigrant groups in the U.S., screening and vaccination rates remain suboptimal,<sup>15–18</sup> and fewer than

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30 % of individuals who are living with CHB are aware of their status.<sup>5</sup>

Limited knowledge of CHB and the risks it poses, including HCC, is a primary driver of low screening rates within many communities.<sup>18–20</sup> Across communities, increased HBV-related knowledge can reduce associated stigma,<sup>21,22</sup> and promote the uptake of protective health behaviors.<sup>23</sup> In the absence of accurate and robust disease-related knowledge, the deeply entrenched HBV-related stigma found in many communities can increase, typically due to the intersection of cultural mores about sexual behavior and perceptions about disease transmission, thus increasing fear of disclosing disease status,<sup>19,24</sup> and impeding the practice of protective health behaviors.<sup>21,22</sup> Thus, effective, culturally sensitive health education is necessary to increase awareness and knowledge of HBV and HCC and address misperceptions to reduce disease-related stigma,<sup>20,21,25</sup> and can improve vaccination and screening rates.<sup>14</sup>

Existing studies have explored the individual-level factors that contribute to HBV- and HCC-related health disparities, yet there is insufficient literature documenting community knowledge about the link between the two conditions and the differences in knowledge among different immigrant communities disproportionately impacted by HBV.<sup>26,27</sup>

In the present study, researchers partnered with Asian and Pacific Islander (API), African, and Caribbean community leaders and members to assess current levels of knowledge and awareness of HBV and its association with HCC within these groups. The results shed light on the myths and misperceptions surrounding the two diseases, providing a nuanced perspective on the reasons for low vaccination and screening rates, late detection of HCC, and heightened health disparities. The findings from this study will inform future public health communication efforts that aim to improve the health of these communities and improve long-term health outcomes.

## 2. Methods and materials

### 2.1. Data collection

Fifteen focus groups and two key informant interviews were conducted virtually, over Zoom, from April to September 2021. Inclusion criteria for participation included identifying as API, Caribbean, or African, and being older than 18 years of age.

At the start of the project, an advisory committee was assembled with members from the API, African and Caribbean communities. The committee included public health professionals, healthcare providers, people with lived experience of HBV, and representatives of community-

based organizations.

The committee contributed to the research process by identifying community members to facilitate and participate in focus groups. A purposive sampling strategy was used to ensure that each community was adequately represented. To ensure cultural relevance, the committee co-created the focus group guide, which was translated into different languages by a certified translation company and reviewed by bi-lingual community researchers before use. The guides helped to ensure consistent data collection, allowing for accurate comparisons during analysis.

Participants included API, Haitian, and African immigrant communities residing in 12 cities around the U.S. Sociodemographic information, including age, nativity and type of residential location, was collected prior to the focus group discussion. Further demographic details are provided in Table 1. Focus groups were held with members of the advisory committee, as well as Micronesian, Chinese (Mandarin- and Cantonese-speaking), Hmong, Nigerian, Ghanaian, Vietnamese, Korean, Somali, Ethiopian, Filipino, Haitian, and Francophone West African communities. Two additional key informant interviews were conducted with committee members, who could not attend the main focus group. Focus groups consisted of between seven and 12 participants.

All focus groups were 60–90 min in length and upon completion, participants were compensated with a gift card. The sessions were recorded and conducted by trained facilitators in either English or another preferred language, determined by the focus group leader. Other languages included Cantonese, Haitian Creole, Yoruba, French, Amharic, Vietnamese, Marshallese, and Korean. Audio recordings were transcribed and if needed, translated into English.

**Method for Protecting Confidentiality:** All focus groups were conducted anonymously, and no identifying information was collected. Verbal consent and authorization to record the focus group and analyze data was collected from all participants. The voluntary nature of participating in and contributing to any portion of the discussion was made explicit at the beginning of each session. IRB approval was obtained before the initiation of this study (Heartland IRB Project No. 329–062421).

### 2.2. Data analysis

NVivo 20 software was used for thematic coding and qualitative data analysis. The research team developed a codebook *a priori* that was revised during the coding process as new themes emerged (Appendix 1). Each transcript was independently coded by a primary and secondary coder. To ensure inter-coder reliability, primary and secondary coders

**Table 1**  
Demographic characteristics of focus group participants, 2021.

Community Group	Overall N (%)	Mean age <sup>a</sup> (years)	Residence N (%)		Born in U.S. N (%)		Mean length of Time in U.S. (years)
			Urban	Suburban	No	Yes	
	101 (100)	52	84 (83.3)	16 (16.7)	92 (91.3)	8 (8.7)	25.3
Chinese (Cantonese)	6	66.5	6 (100)	–	6 (100)	–	38.5
Chinese (Mandarin)	6	37	3 (50)	3 (50)	5 (83)	1 (17)	22
Filipinx	8	65	8 (100)	–	8 (100)	–	39.5
Hmong	6	36	3 (50)	3 (50)	1 (17)	5 (83)	23
Korean	9	55	9 (100)	–	9 (100)	–	19
Micronesian	5	45	5 (100)	–	5 (100)	–	24
Vietnamese	10	58	10 (100)	–	10 (100)	–	26
Ethiopian	6	54	3 (50)	3 (50)	6 (100)	–	32
Nigerian	9	62.5	9 (100)	–	9 (100)	–	35
Nigerian and Ghanaian	6	53	2 (33)	4 (67)	6 (100)	–	18
West African	13	49	13 (100)	–	13 (100)	–	12
Somali	8	41.5	8 (100)	–	7 (87.5)	1 (12.5)	20
Haitian	9	58	9 (100)	–	9 (100)	–	20

<sup>a</sup> Participant age was not asked directly in any focus group. Instead, age was determined by accounting for age upon arrival in the United States and length of time spent in the United States.

discussed each transcript to resolve discrepancies. The final kappa coefficient was 0.78, indicating high inter-coder reliability.

### 3. Results

#### 3.1. Participant characteristics

In total, 101 people participated in the focus groups (Table 1). Most participants (91.3 %) were foreign-born and spent an average of 25.31 years in the U.S. Table 2 presents the average perceived severity of HBV and HCC among participants.

Table 1. Table 1 presents the demographic makeup of study participants.

Table 2. The average perceived severity of hepatitis B and liver cancer, based on a Likert scale with 1 being not at all severe, and 5 being extremely severe, across the focus group communities was 4.15 and 4.81, respectively.

#### 3.2. Qualitative findings: Existing knowledge, myths and perceptions

##### 3.2.1. Regarding hepatitis B

3.2.1.1. Limited knowledge of the different types of hepatitis. Many participants demonstrated a general understanding that hepatitis is a disease that affects the liver, but some were unaware of the multiple strains of hepatitis virus. One Haitian participant said, “I only knew there was hepatitis, but I didn’t know about the different types that can affect my liver.”

3.2.1.2. Incomplete understanding of how HBV is transmitted. Most participants were aware that HBV is a bloodborne pathogen, and risk of transmission increases with sexual activity, intravenous drug use, and vertical transmission during childbirth. However, several participants held different cultural beliefs about how HBV is transmitted. For example, one person from the Ethiopian community stated:

*[Hepatitis B] used to be referred to as bird’s disease. So, there [are] a lot of myths around it. People used to say it was the bat that causes it and that it can be healed with traditional medicine.*

Some participants confused hepatitis B with hepatitis A, citing consumption of unsanitary food and water as primary transmission routes. A Korean participant shared, “I have heard that Koreans are at a much higher risk of contracting hepatitis because they share a one-dish food such as soup.” Many Chinese-Mandarin participants believed HBV can be spread through saliva and thus limited the sharing of utensils. One person posited, “I always thought that we get transmitted by being dirty, using the same utensils.”

**Table 2**  
Perceived severity of hepatitis B and hepatocellular carcinoma among study participants, 2021.

Community Group	Average Perception of HBV Severity (SD)	Average Perception of Liver Cancer Severity (SD)
Chinese (Mandarin)	4 (1)	5 (0)
Nigerian and Ghanaian (D.C.)	4 (1.1)	5 (0)
Filipinx	5 (0.5)	5 (0.35)
Chinese (Cantonese)	5 (0.5)	5 (0)
Micronesian	4 (0.5)	5 (0)
Hmong	3 (1.3)	5 (0)
Korean	4 (0.66)	5 (0.44)
Nigerian (Chicago)	5 (1.33)	5 (1.33)
West African	4 (1.3)	4 (1.5)
Ethiopian	4 (0.5)	5 (0.4)
Somali	5 (0.38)	4.5 (0.38)
Vietnamese	3 (1.2)	4 (1.3)
Haitian	4 (1.1)	5 (0.33)
<b>Total</b>	<b>4.15 (0.688)</b>	<b>4.81 (0.38)</b>

3.2.1.3. Stigma and shame associated with HBV diagnosis. Focus group discussions in many communities confirmed that the perceived association between HBV and poor hygiene, alcoholism, and sexual promiscuity can exacerbate stigma and shame surrounding an HBV diagnosis. A Haitian participant commented that sexually transmitted diseases are often hidden in their culture given possible stigmatization: “Well, most of the time when someone has a disease, the only reason that I can think of as to why they hide it is because they say that it is sexually transmitted. It is shameful for them.” A Nigerian participant revealed that an HBV diagnosis may lead to fear and physical abuse within a family unit:

*People who have [hepatitis B] are scared others may keep away because they think the disease will keep them just by interacting with someone who has it. I knew a husband abusing his wife when he found out she is a disease carrier just because he knew about [the associated stigma].*

A Micronesian participant described her perception of disease-related shame:

*I think it is because of a lack of understanding of the diseases. When we heard about HIV or hepatitis, these diseases are easily transmitted through bodily fluid. It often discourages people from telling others they have it. Our community is so small, and we all know each other, so it is shameful for someone to disclose their health issues because it is not that common.*

##### 3.2.2. Regarding liver cancer

3.2.2.1. Relationship between liver cancer and alcohol. When HCC was discussed in focus groups, many participants associated this disease with excessive alcohol consumption. Participants in the Ethiopian, Cantonese-speaking, and Korean groups cited that alcohol use can lead to liver disease complications, specifically cancer. Furthermore, several participants discussed stories from close friends and family about how alcohol and liver disease can cause death. One Filipino community member recalled:

*A friend of mine recently died of liver cancer about two months ago. The wife told me he had a history of drinking and was an [alcoholic] for many years. The doctor told him that because of his history of drinking, liver cancer is possible, and that his liver would be damaged slowly.*

Interestingly, an African advisory committee member discussed how religious beliefs surrounding alcohol often reduce perceived susceptibility to liver cancer: “I’ve had a few patients who are devout Muslims, and they tell me they can never get liver cancer because they do not drink. Their understanding is that the disease is mainly or only caused by drinking alcohol.”

3.2.2.2. Partial understanding of symptoms. Overall, participants were able to cite symptoms of liver cancer but had an incomplete understanding of how it physically presents. Those who had some understanding of symptomatology typically had first or second-hand experience with the disease. One West African participant stated:

*Liver cancer is very bad, I got to know a little bit about it over time. If your liver starts acting up and you do not treat it, you can develop cirrhosis which are lumps or bumps that grow on your liver. A person with liver problems tends to have yellowish skin or yellowish eyes.*

Some recognized that both HBV and HCC may often be asymptomatic, making timely detection difficult. A Haitian participant mentioned:

*When [hepatitis B] turns into cancer, someone might be asymptomatic. They may have [had] the disease for years and not be aware of it. When they go to do a screening test it might be too late because it has turned into cirrhosis or cancer.*

3.2.2.3. *Poor prognosis of liver cancer.* Those who had personal experiences with HCC noted how challenging the disease was. A Cantonese-speaking participant commented on the suffering at the end stage of liver disease:

*Liver cancer makes your life really tough. I have two family members who passed away with liver cancer. When you eat, you puke it out. No matter what you eat, you cannot swallow it. But if you do not eat, you do not have enough nutrients. You are hungry but cannot eat. It can be painful and uncomfortable, especially at an advanced stage.*

A Chinese-Mandarin participant explained that although she did not know all the medical details, her “*first impression of liver cancer is that there is no cure, or it is very hard to cure.*” Another Cantonese-speaking participant summarized her sentiments: “*Liver cancer is a death sentence.*”

### 3.2.3. Regarding the link between hepatitis B and liver cancer

3.2.3.1. *Varied understanding of link between HBV and liver cancer.* Overall, there was varied knowledge regarding the causal relationship between HBV and HCC. Some participants who worked as healthcare professionals knew the detailed progression of disease. For example, one Micronesian participant said:

*For those who were unfortunate enough to not have prevented hepatitis B from taking hold in their body, they can go on to develop liver cancer. I learned all of that through medical school, so I think I have an advantage here.*

Many discovered the association through personal experience. For example, a Hmong participant had recently learned about the connection through her mother’s diagnosis, recalling, “*I learned about it for the first time when my mom was diagnosed with liver cancer. I knew that hepatitis B affected the liver, but I did not realize it could cause cirrhosis and liver cancer if not treated.*” Interestingly, another Micronesian participant learned about the connection by participating in this study:

*I learned about it today that hepatitis B can lead to liver cancer. My first thought was that the two were the same, but today I learned that the two are totally different illnesses that someone can have.*

## 4. Discussion

Study results identified critical knowledge gaps and common misperceptions about HBV and HCC, and transmission-related stigma. Additionally, this study adds to existing literature by documenting the subtle but important differences among highly impacted communities’ understanding of the link between HBV and HCC.

### 4.1. Limited existing knowledge of HBV and HCC connection

In this study, there was varied understanding regarding HBV, HCC, and their connection, within and across the different groups. Specifically, the link between HBV and HCC remains incompletely understood. While some participants from the Vietnamese, Korean, Micronesian and Hmong communities had pre-existing knowledge from their academic background or personal experience with the diseases, the Cantonese-speaking, Haitian, Somali, Marshallese and other community participants had limited knowledge of HBV’s connection to HCC. This knowledge gap leads to groups placing less weight on HBV as a cause of liver cancer, and reflexively thinking liver cancer is a death sentence. This finding is similar to other studies that described a generally low awareness and understanding of the course of HBV infection and its relationship to HCC among West African and Haitian immigrant groups.<sup>13,19,21</sup>

Many study participants, including those in the West African,

Ethiopian, Haitian and Korean communities reported some awareness of the signs of liver failure, specifically jaundice, but most were unaware of the lack of symptomology of both HBV and HCC, which aligns with previous research.<sup>24</sup> This can play a role in people not seeking care until they exhibit symptoms, which often means liver failure has already begun.<sup>17</sup>

### 4.2. Stigma and shame

HBV and HCC diagnoses are often stigmatized, which discourages open communication and expedient health-seeking behaviors. One of the reasons for this is the limited knowledge of transmission pathways, which has been identified as a barrier to healthcare utilization in this study and previously.<sup>13,17,19</sup> In this study, the Somali and Nigerian groups were aware of sexual transmission pathways, corroborating prior study findings.<sup>17,19</sup> However, participants in the Korean, Micronesian, Filipino, Chinese-Mandarin and Cantonese-speaking groups held misperceptions that HBV could be acquired through saliva, sharing utensils, or practicing unhygienic behaviors. These misperceptions have been identified in a previous study within similar populations.<sup>21</sup>

In the present study, there was some existing knowledge about the association between alcohol use and liver cancer among the Ethiopian, Cantonese-speaking, Korean, and Filipino groups, which has also been reported previously.<sup>24,28</sup> The stigma surrounding alcohol use often becomes most apparent in HCC and has been shown to reduce uptake of screening and health maintenance behaviors.<sup>23</sup> These findings demonstrate that incorporating cultural and, where appropriate, religious beliefs into educational initiatives is a necessary endeavor, to improve knowledge of the diseases and overcome prevailing attitudes that may reduce utilization of healthcare services, such as routine liver cancer screening.

As mentioned by participants from the Nigerian and Micronesian communities, people often avoid disclosing their hepatitis status out of fear of the associated stigma, and subsequent perceived consequences of social isolation and ostracization, reinforcing previous research findings.<sup>9,13</sup> When people do not want to share their diagnosis, they are less likely to seek care for their HBV, which ultimately increases their risk of progressing to HCC. This finding is corroborated by existing literature, which finds that fear of social exclusion after disease disclosure is often associated with reduced engagement in health-seeking behaviors.<sup>13,23</sup>

In light of this, it is important to emphasize that unmanaged HBV is an independent risk factor for HCC and to educate communities on the preventive behaviors that can reduce the risk of progression to HCC. Underscoring that casual contact is not a transmission route for HBV, that hepatitis B is primarily transmitted perinatally, and that acquisition of HBV and HCC can occur in the absence of any alcohol use is crucial. Improved understanding of transmission routes may reverse stigma and misperceptions about these diseases.<sup>24</sup>

### 4.3. Education to increase utilization of screening and vaccination services

Given that HBV is preventable through a highly efficacious vaccine,<sup>14</sup> providing education on its availability and its role in preventing liver cancer may promote vaccine-seeking behavior within impacted communities. HBV is also manageable through antiviral therapies,<sup>14,29,30</sup> and if managed properly, people with HBV can have a significantly reduced risk of progression to HCC.<sup>19</sup> Moreover, with routine surveillance, HCC can be detected early when it is still highly treatable<sup>30</sup> either surgically or medically.<sup>31</sup> It is therefore essential to increase awareness and understanding of the connection between HBV and HCC; the importance of HBV vaccination and screening for the prevention and early diagnosis of liver cancer; the need for ongoing care and surveillance; and the positive impact these behaviors can have on health outcomes.

Given that both conditions are preventable and manageable, it is the



role of healthcare professionals to bridge the knowledge gaps within heavily impacted communities, and in doing so, reduce barriers to and delays in care. Evidence shows that improving knowledge regarding HBV, HCC, and the benefits of prevention and management behaviors can increase uptake of screening.<sup>28</sup> To do this, culturally appropriate education and community-specific resources are essential to promote HBV vaccination and screening, and routine HCC monitoring, which can lead to increased rates of early detection. Educational campaigns could promote liver cancer screening for those already living with HBV, and earlier HBV screenings for those who have never been screened. Future programs guided by this study can facilitate improvements in knowledge and awareness, which can reduce stigma through the normalization of conversations regarding HBV and HCC.

## 5. Lessons and limitations

This study has several limitations. The findings from this study may not be generalizable to the broader foreign-born populations given the homogeneity of each focus group. Selection bias may also impact this study, as participants were recruited through local community leaders. Despite a purposive sampling strategy, each community may not be equally represented.

Additionally, social desirability bias may impact the validity of the study results. Focus groups were conducted in a group setting, and thus may have prompted bias in responses. Several groups also included healthcare professionals with high medical literacy who may have skewed the overall perception of knowledge and awareness of HBV and HCC. Conversely, those with low medical literacy may have contributed less to the conversation and the interview guide lacked a mechanism to ensure each participant contributed equally.

Given the many languages represented in this study, translating findings back to English may have caused inaccuracies or misrepresentations.

## 6. Conclusion

This study adds to current research impacted by these conditions. There are critical gaps in knowledge and awareness of HBV, HCC, and the link between the two among Asian, Pacific Islander, African and Haitian immigrant communities. The two diseases are highly stigmatized, and misperceptions and lack of knowledge contribute to these groups' low utilization of both preventative and maintenance healthcare services.

To reduce HBV and HCC health disparities, health education needs to be informed by communities of focus, culturally sensitive, and actionable. Educational efforts should not solely focus on reducing the fear surrounding liver cancer but look upstream and highlight the benefits of diagnosing and managing HBV with routine screening and treatment. These study results can guide the development of culturally appropriate educational programs that focus on the link between HBV and HCC, address HBV- and HCC-related stigma, and highlight the need for vaccination and routine screening and monitoring.

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## CRediT authorship contribution statement

**Thomas Chen:** Data curation, Formal analysis, Investigation, Writing – original draft, Writing – review & editing. **Fiona Borondy-**

**Jenkins:** Writing – original draft, Writing – review & editing. **Beatrice Zovich:** Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Writing – review & editing. **Suzanne J. Block:** Data curation, Formal analysis, Investigation, Writing – review & editing. **Kate Moraras:** Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Writing – review & editing. **Alice Chan:** Investigation, Writing – review & editing. **Chari Cohen:** Conceptualization, Funding acquisition, Project administration, Supervision, Writing – review & editing.

## Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

The Hepatitis B Foundation receives public health program and research grants from BMS, GSK, Gilead Sciences and VBI Vaccines.

Chari Cohen serves on a patient/advocacy advisory committee for GSK and Gilead Sciences, with funds being distributed to the Hepatitis B Foundation.

Beatrice Zovich has also served on an advisory committee for Gilead for which she was financially compensated.

## Data availability

Data will be made available on request.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.jve.2024.100379>.

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