

Understanding Disparities in Hepatitis B & Liver Cancer Knowledge & Screening Rates Among Highly Impacted Communities Around the United States

23RD MARCH 2022



Participating in the Webinar



Audio: Attendees on mute



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Background and Project Objectives

- Up to 2.4 million people in the US live with chronic hepatitis B infection.
 - Communities born outside the US are most impacted.
 - Unmanaged hepatitis B carries a 15-30% lifetime risk of premature death from cirrhosis or liver cancer.
 - Low awareness, cultural norms, and misperceptions play a role in low screening and care rates in highly impacted communities.
 - Primary objective: To better understand knowledge and misperceptions about hepatitis B and its relationship to liver cancer in high-risk communities and to use the findings to develop and employ effective communication strategies that raise awareness and dispel myths.
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Study Methods

- 15 focus groups and two key informant interviews with community members, community leaders, and public health experts from around the US were conducted
 - Communities included Vietnamese, Chinese (Mandarin and Cantonese speakers), Haitian, three different West African communities (with members from Senegal, Cote d'Ivoire, Mali, Burkina Faso, Guinea, Nigeria, Ghana, and Niger), Hmong, Somali, Ethiopian, Filipino, Korean, and Micronesian
 - Advisory committee comprised of 14 community and public health leaders
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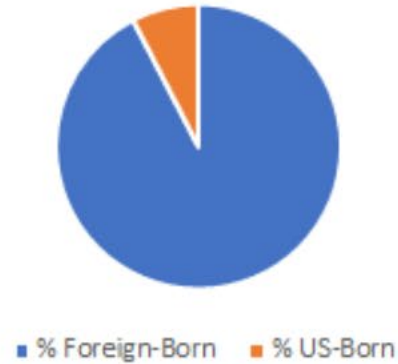
Demographics of Focus Group Participants

- Average Length of Time in US: 25.75 years
- Average Age: 52 years
- Average Comfort Level with Arranging a Doctor's Appointment: 4.3
- Average Perceived Severity of Hepatitis B: 4.2
- Average Perceived Severity of Liver Cancer: 4.8

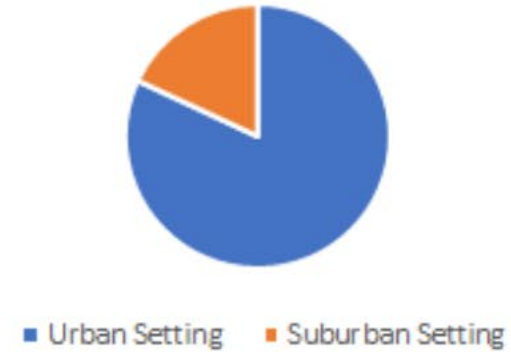


Demographics of Focus Group Participants

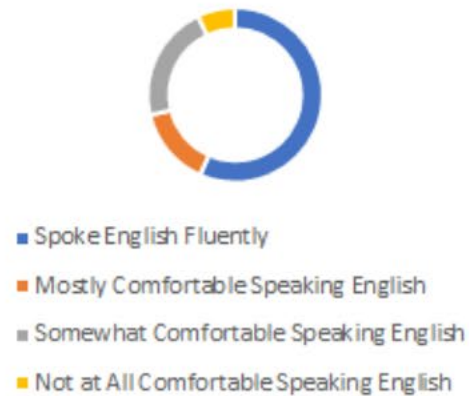
Foreign- vs. US-Born



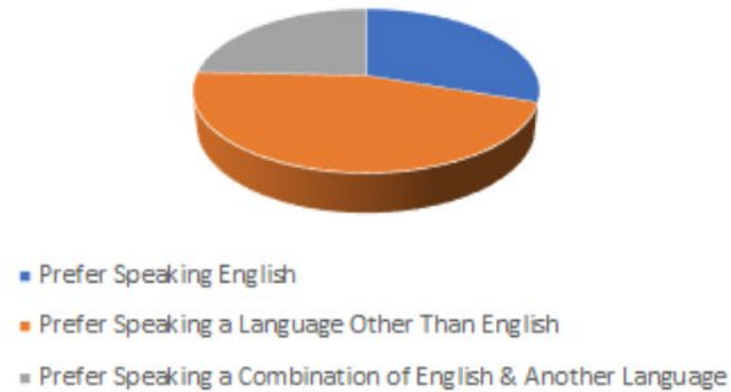
Type of Residential Setting in US



Comfort Level Speaking English



Spoken Language Preferences



PRELIMINARY RESULTS



ACQUISITION OF KNOWLEDGE

- A lot of knowledge came from personal connections.
- Some came from the need to get vaccines for immigration or for children's school.
- Googling and research prior to focus groups



Desire for Knowledge of Diagnoses



- "I think I would love to know if I do have it or what can I do to prevent them from spreading...it's easier to treat it when it's early than waiting for it to get worse. So if I have it, I would love to know, and get treated before it gets difficult and have to deal with all those other symptoms, that is harder to bear." "And I remember being afraid to find out my status, and the reason was because I already knew what hepatitis B was and what it can cause and I was afraid to know my status, and then if it was positive, how would that change my life, I didn't understand what the future hold for me, if I was hepatitis B positive." "God is punishing them because they don't go to church, that's a big deal, that's a big deal among the people of our community and that's probably why they don't want to know the truth if they're sick." - Micronesian Community Focus Group Participants
- "Based on my personal experience with Hepatitis B as a man and the opinions of people around me, I feel burdened to put down everything I was doing when I found out that I had Hepatitis B. So I think the inspection rate is low because I don't think it's good to know that Hepatitis B is caught. This is because once you know the disease, you have no choice but to pay attention and feel pressured to quit what you are doing." "When the person is made aware, when the person is educated about a certain number of things, he or she will become aware, and will want to get tested." - Korean Community Focus Group Participants
- "Okay I would like to know if I have hepatitis and liver cancer also. Because when I know, I would be more cautious and know what I can eat and what I cannot eat and take care of myself. So I would like to know." - Haitian Community Focus Group Participant


STIGMA AND SHAME

- The lack of awareness leads to fear, which leads to stigma.
- Associated with poor hygiene, sexual promiscuity, and alcoholism
- Common belief that stigma can be overcome with more information



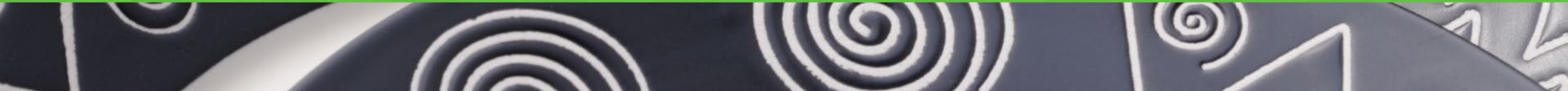


Feelings of Control Over Diagnoses

- "As for me, if I know for a fact that I do not have hepatitis, then I think it is controllable. I can stop myself from getting liver cancer. Even if you have hepatitis, you still need to stop it from turning into cancer." - Cantonese Community Focus Group Participant
 - "Okay, so when I think of faith, I think of the plan of God, right? So, I think - of course, whatever is destined for us will come. However, I do feel like we do have a level of control of whether or not we get the virus." - Somali Community Focus Group Participant
 - "To be honest, I think that getting hepatitis cannot be completely prevented no matter how much we control it in our daily life, and it is our destiny. However, I believe that some miracle can be created with the power of faith. If I pray diligently, I believe that God will protect me and have a positive mind, and I think this will definitely help cure diseases." - Korean Community Focus Group Participant
 - "I think to answer that question, my answer is a yes and no. For us who are born here in America, I feel there is more of control because there's more of an infrastructure here, and our quality of life here is much better. But I do believe that fate does play a role too, because we don't get to choose where, when we want to be born. And so, for our parents and our grandparents who have come from a third world country where there's no running water, there's no such thing as sanitation, I do believe that it is fate, because back then, they don't know what Hepatitis B is or liver cancer. Even a doctor was out of the question, like seeing a doctor." - Hmong Community Focus Group Participant
 - "...if you're living with anybody that has it, if you know or you don't know, or if they tell you or they don't tell you, if you're, I mean, sharing everything with them, like spoon whatever, I think you can have it if you don't have it before. So that's the only thing and I don't think anybody have control." - Nigerian Community Focus Group Participant
 - "But certain illnesses and diseases, seemed harder to control, and seems more like fate bound. It's like when you find out, you find out, and hopefully, it's not too late." - Mandarin Community Focus Group Participant
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Culturally Appropriate Presentation of a Communication Campaign

- Important to highlight differences in age-specific messaging: "As I am getting older, I am more aware of the risk of developing a chronic condition. There is an obstacle that young people don't pay attention on this. They don't even visit doctor once a year. They are not scared at all; they don't care because they never being sick. The older you get the more fear you will have; young people have no fear at all." - Vietnamese Community Focus Group Participant
 - No real differences in messaging based on gender, but perhaps differences in presentation
 - Differing opinions on proverbs - could be generational and depend on familiarity with language
 - In most cases, avoid religious messaging, this is not helpful. However, faith leaders are often very important.
 - "Okay. So, it is one thing that in our culture, they gather, whatever happens to you is predetermined by God, and be conscious about that even when you're talking about preventative health care. You mentioned whatever happens, God determines happens but still Islam talks about prevention on how being healthy is better than being sick, and using that aspect while talking about balancing religious values and education of the community on preventative health care." - Somali Community Focus Group Participant
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Delivery Methods for a Communication Campaign

- Power of personal testimonials and stories: "If we can add a little bit story. People who get exposed and how they did, people who they have a family member, they had hepatitis B and it led to - and liver cancer like, a little story. People they want to hear the stories, so they might relate to them and sometimes they can be learning something from that." - Somali Community Focus Group Participant
- "Typically, nowadays programs like this, they like to include heroes, where these are survivors or people who are currently having the disease, so people who have hepatitis B can show an example of how to live life with hepatitis B and be successful at it, so messages from heroes are really helpful." - Micronesian Community Focus Group Participant



#justB

Introduction to Panelists

- Dr. Patricia Jones, Hepatologist and Researcher, University of Miami
- Dr. Moon Chen, Professor and Associate Director of Community Outreach and Engagement, UC Davis Comprehensive Cancer Center
- Kenson Alik, Director, Micronesian Education for Liver Wellness Program, Honolulu, HI
- Janet Afoakwah, MPH, Executive Director, United States Coalition on African Immigrant Health



LIMITATIONS

- Sometimes leading questions were asked.
- Might consider doing a hep B 101 session with each group next time.
- A few groups included healthcare professionals who had pre-existing knowledge.



LESSONS LEARNED

- Many challenges to increasing screening for hep B and liver cancer persist in highly impacted communities.
- Community engagement is essential to overcoming these challenges.
- Awareness and misperceptions differ by community, as do culturally-specific beliefs and communication strategies needed to improve uptake of screening and care.
- Community members must be part of the design and implementation for communications to be effective.



NEXT STEPS

- Work toward design of communication campaign
- Year 2 of project includes pilot testing, adjustment, and dissemination of campaign



THANK YOU! QUESTIONS?





- A recording of this webinar and slide presentation will be emailed to all participants.
- Please complete the evaluation form for this webinar. Your feedback is valuable!
- Please visit our website at www.hepb.org and our Liver Cancer Connect program at <https://www.hepb.org/research-and-programs/liver/>
- Email beatrice.zovich@hepb.org
- Thank you!