Lack of Knowledge About Hepatitis B Disadvantages Black Communities

Culturally mindful educational programs may help Black people seek help earlier and throttle hep B incidence rates in these communities.

October 29, 2020 By Sukanya Charuchandra

Hepatitis B is known to affect Black people to a greater extent than whites in the United States. Only Asians have a higher rate. Both African American and Haitian Black communities have poor knowledge about the disease, which might limit prevention, diagnosis and treatment, researchers reported in a study published in Cancer Causes & Control.

These findings highlight the need for community-level, culture-specific programs that include Black communities and guide them toward earlier screening and treatment for hep B.

Over years or decades, chronic hepatitis B virus (HBV) infection can lead to serious complications, including cirrhosis and hepatocellular carcinoma, the most common type of liver cancer. Hep B is known to increase the odds of developing hepatocellular carcinoma by almost 22 times, and it is a leading cause of liver cancer worldwide.

“Essentially, if you don’t know that you have HBV, you cannot seek treatment for it, and if you develop cancer, you will likely present when the cancer is advanced and there are fewer options for treatment,” Patricia Jones, MD, of the University of Miami’s Sylvester Comprehensive Cancer Center, said in a press release. “We want to interrupt that cycle by better understanding the perspectives of the populations most affected and creating programs that address those specific needs.”

Of the estimated 1.4 million people with chronic hep B in the United States, only 26% are aware they carry the virus. In an earlier study, the researchers had found that despite being heavily affected by hep B, Blacks were likely to be unaware of their infection until they were diagnosed with hepatocellular carcinoma. Further, when diagnosed, African Americans were younger and further along in their disease progression than their white, Latino and Asian counterparts.

“When we studied patients with liver cancer in South Florida, we found that 8% of white liver cancer patients had long-term HBV infections, compared to 21% of African-American Black and 30% of Haitian liver cancer patients,” Jones said.

In South Florida, Jones and her colleagues recruited Black participants through email, social media, local radio, word of mouth or a hepatology clinic. Between February 2017 and February 2018, they conducted focus groups in Haitian Creole or English to determine these communities' understanding of hep B, hepatocellular carcinoma and availability of screening.

They included Black men and women born in the United States or Haiti and excluded any individuals who had been diagnosed with hepatitis C or who already had cirrhosis or liver cancer. Of the 55 participants, 15 (27%) had chronic HBV infection.

Among the Haitian Blacks, only 42% knew about hep B. Comparatively, 78% of African Americans knew about the virus. People with chronic hep B were more knowledgeable about the virus than individuals without hep B.

There was little knowledge about liver cancer within the African-American community, with most believing it to be uncommon. On the other hand, cirrhosis was reported as being common, with most participants having some understanding of its causes and symptoms.

All participants in this group knew of at least one individual with cirrhosis and considered it to be related to heavy alcohol and drug use. This group was less aware of hep B, including its transmission route, and hepatocellular carcinoma. Many participants were under the impression that hep B was somehow related to HIV.

In comparison to African Americans, Haitian Blacks were better informed about cirrhosis and hep B. They knew about its symptoms and preventive vaccines. But many individuals were unaware of its transmission route and connection to hepatocellular carcinoma. Participants from this group also talked about "supernatural" causes leading to sickness—even though most acknowledged their disbelief in these long-held and firmly rooted beliefs in the community. While this group knew that hep B and HIV were different, stigma was associated with both. Those living with hep B were unlikely to reveal the information to anybody else.

"In two communities disproportionately affected by HBV, misconceptions about disease transmission, stigma, low health literacy and decreased access to care may limit detection for HBV," wrote the researchers.

Both communities were of the opinion that distrust of medical facilities, stigma and fear might prevent members from accessing health care. Economic disadvantage and lack of education were held responsible for the higher likelihood of late-stage diagnosis of hepatocellular carcinoma among Black individuals.

Overall, both groups believed that a lack of access to opportunities and health care was a result of the low economic status of their communities. Moreover, these communities concurred that they are less likely to have access to the care afforded white people. Census data reaffirmed that white people are more likely to be insured in comparison with Latinos and Blacks.

Further, people who had been diagnosed with hep B reported having to educate themselves about the viral infection because information from their providers was lacking.“It’s critical that we, as physicians, ask how much patients understand and that we assess their understanding,” Jones said.

Through the focus group, it became apparent that more awareness of hepatitis and cirrhosis is needed across Black communities. Public service announcements via social media or more traditional institutions, educational town hall meetings and even Haitian radio would be suitable routes for hep B education. Getting community leaders involved in the dissemination of this information would help engage the community. Home-based screening or using a confidential mobile testing service would also aid in increasing access.

“The key is to understand how to work best with communities and get people to engage in education, screenings, medical care and research,” Jones said.

In conclusion, the reseachers wrote, “Culturally relevant community-based interventions are needed to increase HBV detection.”

Click here to read the study abstract in Cancer Causes & Control.

Click here to learn more about hepatitis B.
