2025

Examining sociocultural factors influencing disparities in chronic liver diseases within Afro-Caribbean diaspora communit

https://hdl.handle.net/2144/52298

BOSTON UNIVERSITY

ARAM V. CHOBANIAN & EDWARD AVEDISIAN SCHOOL OF MEDICINE

Thesis

EXAMINING SOCIOCULTURAL FACTORS INFLUENCING DISPARITIES IN CHRONIC LIVER DISEASES WITHIN AFRO-CARIBBEAN DIASPORA COMMUNITIES

by

TYHANNA A. HIBBERT

B.S., Florida State University, 2019

Submitted in partial fulfillment of the
requirements for the degree of
Master of Science
2025

Approved by

First Reader

Ekaterina Kintsurashvili, Ph.D.
Research Assistant Professor, Pharmacology, Physiology and Biophysics

Second Reader

Patricia D. Jones, M.D., M.S.C.R.
Associate Professor of Clinical Medicine
University of Miami, Department of Medicine
Division of Digestive Health and Liver Diseases

ACKNOWLEDGMENTS

I’d like to express my sincere gratitude to my research mentor, Dr. Patricia D. Jones, for the time taken and the dedicated manner in which she offered her exceptional guidance over the past year. As a student outside of her medical school institution, I greatly appreciate her willingness to accept and train me in the fields of clinical research and hepatology. I extend this gratitude towards the project manager of the Jones Lab, Stephanie Garces, for always being an attentive and accessible point of contact whenever I had questions or needed help. I would also like to thank my thesis advisor, Dr. Ekaterina Kintsurashvili, for her insightful and detailed feedback on my thesis project and her general supportiveness of my endeavors since the beginning of my MAMS journey. Finally, my family and friends, especially Mom, Dad, Sheldon, and Stephen, deserve special thanks for their encouragement and unwavering demonstrations of support throughout this difficult journey. I could not have accomplished shaping this thesis without their individual and collective contributions toward my success.

EXAMINING SOCIOCULTURAL FACTORS INFLUENCING DISPARITIES IN CHRONIC LIVER DISEASES WITHIN AFRO-CARIBBEAN DIASPORA COMMUNITIES

TYHANNA A. HIBBERT

ABSTRACT

Background: Chronic liver diseases (CLD) are a leading cause of global mortality. Several risk factors linked to the etiology of CLD, such as type 2 diabetes, obesity, and alcohol use disorder, disproportionately affect certain racial and ethnic minority groups. Evidence from related literature provides clues that structural and social determinants of health contribute to these communities having poorer health outcomes. The intersectionality of Afro-Caribbean identity means that many social and cultural factors affect this diaspora, but little is currently understood about their specific relation to CLD in this community. The present study aimed to identify these factors and examine whether notable differences existed when compared by age, country of birth, and gender.

Methods: A one-time survey was administered in English via an interview or was self-administered online to 237 eligible Afro-Caribbean adult participants. The survey assessed demographics, health history, lifestyle factors, cultural perceptions, and health-related behaviors using a combination of Likert-scale, open-ended, and multiple-choice questions. Quantitative survey data was pre-coded within REDCap and analyzed using STATA. Frequencies were converted to percentages for categorical variables, and median and interquartile range (IQR) were assessed for continuous variables. A rudimentary qualitative analysis was done to identify major themes in the qualitative data.

Results: We identified the following key factors among the participants from quantitative analysis: low awareness and disease knowledge, alcohol misuse, infrequent exercise, poor diet, and history of chronic health conditions (asthma, obesity, diabetes, and hypertension). Additionally, significant differences were identified among certain of these factors by gender and country of birth. Prevailing themes were also identified within participant responses about factors they thought were relevant to cultural perceptions and perceived barriers around CLD in their communities. These include alcohol/drug misuse, poor diet, lack of exercise, obesity, low awareness and health knowledge, social stigma, shame, medical mistrust, lack of financial resources and healthcare access, fear of diagnosis, religious/spiritual beliefs, and tendency to use alternative medicine.

Conclusion: Sociocultural factors are important targets to address disparities in CLD facing the Afro-Caribbean diaspora. Future investigation of the factors identified by this study and how they may compare within specific Afro-Caribbean culture groups are necessary to aid in elucidating the role they play and the steps that can be taken to manage them strategically.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

AIH	Autoimmune hepatitis
ALD	Alcohol-associated liver disease
CDC	Centers for Disease Control and Prevention
CLD	Chronic liver disease
ECM	Extracellular matrix
HBV	Hepatitis B virus
HCC	Hepatocellular Carcinoma
HCV	Hepatitis C virus
HIV	Human immunodeficiency virus
IQR	Interquartile Range
IRB	Institutional Review Board
LAC	Latin America and the Caribbean
MASH	Metabolic-associated steatotic hepatitis
MASLD	Metabolic-associated steatotic liver disease
NAFLD	Non-alcoholic fatty liver disease
NASH	Non-alcoholic steatotic hepatitis
PBC	Primary biliary cholangitis
PLWH	People living with HIV
SDOH	Social determinants of health
SSDOH	Structural and social determinants of health

INTRODUCTION

Background and Significance of Chronic Liver Diseases

Chronic Liver Diseases (CLD) are among the most frequent causes of death worldwide, particularly in the developing world. These diseases are responsible for one out of every twenty-five deaths worldwide, with most occurring as a result of complications from cirrhosis and a type of liver cancer called Hepatocellular Carcinoma (HCC). [1] With such high prevalence and mortality rates, CLDs require continued research attention and should also be the focus of global and public health initiatives. While cirrhosis and HCC are end-stage consequences of other chronic types of liver disease, there are multiple etiologies for developing these outcomes.

A healthy liver has many specialized organ functions within the body, including helping with digestion, purification and detoxification of blood, metabolism, and the production of some essential proteins that the body needs to function (clotting factors, carrier proteins, fat transfer proteins, etc.). The many functions of the liver serve to help maintain homeostasis and overall health. To perform these functions, the liver has a unique 3D, cellular, and molecular structure, and the integrity of this structure is fundamentally tied to successful organ function. CLD is defined as a continuous and progressive degeneration of these liver functions over a period greater than six months due to a remodeling of the liver parenchyma. [2] Some of the most common causes of CLD include chronic viral hepatitis (B and C), non-alcoholic fatty liver disease (NAFLD), now known as metabolic-associated steatotic liver disease (MASLD), and alcohol-associated liver disease (ALD). Less common CLDs include those that are linked to genetic factors, such as Wilson’s disease, alpha-antitrypsin deficiency, hereditary hemochromatosis, and autoimmune liver diseases, such as autoimmune hepatitis (AIH) and primary biliary cholangitis (PBC).

The hallmark of these diseases is inflammation, which compounds injury to the liver’s hepatocyte cells and initiates the development of fibrosis through an accumulation of inflammatory immune cells, cytokine secretion, profibrogenic macrophage production, collagen-secreting myofibroblast activation, excess extracellular matrix (ECM) production, and the formation of fibrous scar tissue. [3] The inflammation, scarring, and damage associated with fibrosis may be reversible in many cases with the elimination of the various causes that promote the inflammation. [3] However, over long periods of time, these changes can become irreversible. The result of this long-term fibrosis, whereby regenerative hepatic nodules replace the normal hepatic structural architecture, is cirrhosis. [4]

Late-stage cirrhotic impairment is linked to progression to HCC, which can cause complete liver failure, the need for a liver transplant, and/or death. HCC is a leading cause of cancer, is among the leading causes of cancer deaths, and is one of the fastest-growing causes of cancer-related death worldwide. The global burden of HCC and other liver cancers is significant. Liver cancer was within the top three and top five causes of cancer deaths in 46 and 90 countries, respectively, worldwide, and its incidence is expected to continue increasing up to the year 2040, according to current predictions. [5] Most cases of HCC are diagnosed in advanced stages, which makes them, oftentimes, impossible to treat using surgical resection. [6] The complex nature of the liver’s functional tissue makes it notoriously difficult to detect liver cancers and thus makes diagnosis a complicated feat.

Although HCC is associated with limited survival, ~20% at 5 years, hope lies in the fact that there is an understood progression in the pathway of early-stage liver injury to terminal HCC. The link between HCC and cirrhosis is clear, and a causal relationship has been established, which makes HCC one of the few cancers that are known to be potentially preventable with early intervention. Current literature establishes that approximately 80 percent of HCC cases arise from cases of cirrhosis. [7] Therefore, the most apparent way to prevent the severe morbidity and mortality associated with CLD complications is to interrupt the progression of fibrotic and cirrhotic damage to the liver's functional tissue before it reaches advanced stages. The diagram below (Fig. 1) shows a simplified flow chart of the progressive pathogenesis of HCC from healthy and chronically diseased livers.

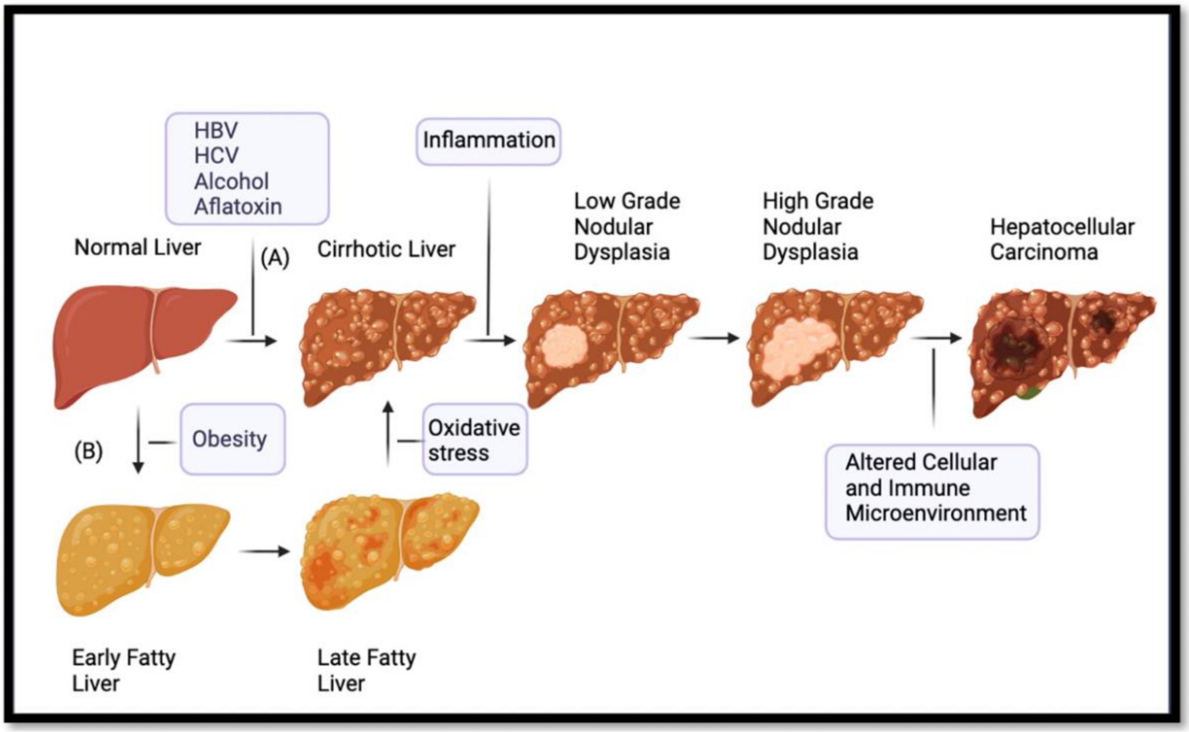


Figure 1. Hepatocellular Carcinoma Pathogenesis Pathways. Pathway (A) shows the progression of a normal liver exposed to toxins and viruses resulting in cirrhosis, which leads to the formation of dysplastic nodules and eventually, HCC. Pathway (B) shows how fatty liver-mediated oxidative stress leads to cirrhotic damage, which also results in HCC. [6]

While it is clear that early intervention is the best way to approach reducing adverse CLD outcomes, this early intervention requires early recognition. The challenge to early recognition of CLDs is that they often progress without any symptoms in their earlier stages, with symptoms typically surfacing once there are already complications. The asymptomatic phases of CLDs tend to be much longer than the symptomatic phases, and many diseases like MASLD tend to be slow in their progression from the benign to symptomatic stages that interfere with organ function. [4,8] Progression from benign stages to clinically symptomatic stages of CLD can take decades. In the case of non-alcoholic steatohepatitis (NASH, now called MASH), about fifteen to twenty percent of patients eventually develop cirrhosis over the course of three to four decades. [8] The clinical manifestations of decompensated (advanced-symptomatic) and compensated (non-symptomatic) cirrhosis vary, but the physical signs and symptoms are rarely seen outside of cases of decompensated disease. [4]

Contrary to common misconceptions, symptoms often thought to be the tell-tale signs of liver disease, such as jaundice (yellowing of the skin and eyes), abdominal swelling, skin and nail changes, and drastic weight loss, are actually better categorized as symptoms of later-stage liver disease and liver failure. Physical symptoms of CLD are mostly absent in the beginning stages, except in cases of chronic viral hepatitis B/C since they begin as acute infections. Only a small percent of hepatitis B virus (HBV) infected adults, and roughly fifty-five to eighty-five percent of hepatitis C virus (HCV) adults develop into chronic infection or liver disease. [9] On the other hand, the majority of HBV-infected children and infants develop chronic infection, which heavily contributes to the high global prevalence. [9] The most frequent symptoms of early-stage viral hepatitis B/C include fatigue, malaise, and anorexia, while less common symptoms can include right upper quadrant pain, fever, and rash [9] Though viral hepatitis cases are only some of the few instances of CLD that have a symptomatic presentation with onset, their roles as etiological risk factors for more serious CLD outcomes makes them important targets for screening and early intervention efforts.

Roughly 20% of chronic HBV cases lead to cirrhosis and hepatic decompensation, and 5% develop HCC; on the other hand, 30% of chronic HCV patients develop cirrhosis, and HCV-infected patients have a higher risk of HCC when cirrhosis is present. [9,10] Of note, cirrhosis is not required for the development of HCC in patients with HBV, and up to 20% of patients with HBV-related HCC do not have cirrhosis. Viral hepatitis is unique from other etiologies of CLD because, as a communicable disease, it can be targeted not only for screening as an early intervention method but also as prevention via vaccination. Though there is no vaccine against HCV, hepatitis vaccination is a paramount epidemiological endeavor since the most common cause of viral hepatitis is due to HBV, which has an effective vaccine. Countless new infections are documented every year, especially in poorly resourced areas that lack strict vaccination policies, despite the fact that there is a potent vaccine available. [11] This is just one of the many instances where non-medical factors such as resources can drive regional and/or demographic differences in preventative measures and screening, diagnostic, and treatment efforts among a population.

Discussion of Social and Cultural Factors and the Afro-Caribbean Diaspora

The Caribbean, as a region comprised of mostly small developing nations, is one such geographic area where social, environmental, lifestyle and infrastructural factors influence the health outcomes of its people. Many of these influences transcend physical residence in the Caribbean and follow its people beyond the region through emigration and into multigenerational communities in their respective global diaspora. Immigrants to new countries assume new social statuses and, with that, new challenges and circumstances in their new home countries. Social caste systems and systemic, structural, and institutional barriers in countries such as the United States can place immigrants from these Caribbean countries in socially and medically disadvantaged circumstances. The interactions between these factors may contribute to disparities in health outcomes in these demographic minority groups.

Many of the risk factors associated with the etiology of hepatobiliary diseases, such as type 2 diabetes mellitus, obesity, hyperlipidemia, and alcohol use disorder, disproportionally affect certain racial and ethnic minority groups. In the United States, Black people have higher rates of some risk factors than other groups due to genetics, dietary & lifestyle factors, and social determinants of health (SDOH). For example, a study on racial and ethnic disparities in alcohol-associated liver disease (ALD) showed that Black people had the highest daily consumption while Hispanics had the greatest prevalence of drinking episodes in the United States. [12] These combined influences not only affect risk but can also affect the health outcomes of individuals from this demographic. In the case of patients with metabolic-dysfunction-associated steatotic liver disease (MASLD), Black patients tend to have worse outcomes and higher mortality rates than Hispanic, White, and Asian patients, although they have a lower prevalence of MASLD; Hispanic patients have the highest prevalence of the disease. [13,14]

The comorbidities that drive the risk of developing these CLDs as well as exacerbating their progression, such as obesity, diabetes, dyslipidemia, hypertension, etc., are clear common denominators between Black and Hispanic communities. These groups share similarities in cultural foods that can be high in carbohydrates and fats, as well as trends in alcohol use, and often reside within similar socioeconomic and environmental conditions in the United States. It is evident that the various sociocultural factors associated with certain ethnic and racial minority groups are driving factors for the disparities that exist within these communities. Many macro-level social and systemic forces also make and reinforce inequities, unmet social needs, and poor health outcomes for marginalized groups through the context of structural and social determinants of health (SSDOH). [14] These include laws, social policies, and systems that regulate the distribution of resources and access to education, housing, employment, and medical/healthcare. [14] The existence of these phenomena over time has demonstrated how avoidable contributors to poor outcomes in marginalized minority groups have been upheld by various methods. This has understandably amplified other SDOH, such as medical mistrust from groups who have historically experienced systemic and institutional racism and discrimination in healthcare in the United States. Systemic biases, structural racism, and socioeconomic inequities contribute to poor outcomes for these Black patients by limiting their access to preventative medicine, early diagnosis, and treatment and also by acting as a barrier to aggressive treatment and follow-up care. [13]

Afro-Caribbean people living in the United States exist at a unique intersection of living as minorities in this country while also experiencing all of the social effects of being an immigrant population. This identity can be further complicated for Afro-Caribbean people who are also Latino. As they assimilate into the societal structure of the United States, Afro-Caribbean people often face parallel social struggles to African Americans and other minority groups and become a part of the medically underserved population of this country. In the context of CLD, Afro-Caribbean Americans have an additional predisposition since many members of the diaspora were born outside of the U.S. in Caribbean nations where HBV is prevalent and/or was endemic in the recent past.

The Centers for Disease Control and Prevention (CDC) has stated that though only 14% of the population of the U.S. is foreign-born, the non-U.S.-born population is disproportionately infected by HBV and makes up 69% of the population living with chronic HBV. [15] The prevalence of HBV in the Caribbean was estimated to be between 2-4% in 2005. The prevalence has presumably decreased due to systemic HBV vaccination, though there is not much information on the current prevalence of the region. A universal HBV immunization recommendation was passed in 1992, which resulted in a steady increase in the number of countries that included HBV vaccination as part of their national vaccination schedules. [16] One study on the regional prevalence of chronic HBV estimated the prevalence in 2010 to be 13.6%, 3.8%, 4.1%, and 1.3% in Haiti, Jamaica, the Dominican Republic, and Cuba, respectively. [16] Another study estimated the combined regional prevalence of HBV in Latin America and the Caribbean (LAC) to be 4.2 to 6.2% in 2019, though this statistic is specific to infections in people living with HIV (PLWH). [17] Many limitations related to data availability, quality, and consistency contribute to a lack of current specifics of prevalence in the Caribbean. Despite this gap in systematic viral hepatitis surveillance information in the region, we know that most Afro-Caribbean adults would have been born during times when prevalence, and thus exposure risk, was higher than it is today. This places Afro-Caribbean people at increased risk and sustains the importance of targeted screening for chronic HBV, HCV, and other related CLDs.

Despite the high viral hepatitis infection rates within the Caribbean, awareness of HBV, HCV, and other CLDs remains low in the Afro-Caribbean diaspora. A constant-comparative analysis of hepatitis B and HCC on Black ethnic communities in South Florida used focus groups to compare a sample of 55 participants comprised of African American Blacks and Haitian Blacks. [18] They found that among Haitian Blacks, only 42% knew what HBV was compared to 78% of African-American Blacks. [18] Both ethnic groups reported that some level of fear, denial, stigma, and mistrust of their healthcare providers are factors they thought might dissuade persons from seeking care. [18] The disproportionate effect of HBV on both communities is indicative of how low health literacy, limited awareness, stigma, decreased access to healthcare, and misconceptions about disease transmission act as limitations to optional HBV screening.

While the interplay between these various geographic, social, and cultural factors has proven to be very complex, we can infer that identifying the associations between these SDOH and disparities in CLD outcomes in the Afro-Caribbean diaspora is important to achieve health equity for these groups. To do so, we must pinpoint what specific SDOH are at play to understand how they might moderate factors, including inconsistent screening/surveillance, barriers to early diagnosis, and obstacles to treatment adherence. As described, relevant existing literature compares African Americans with individual Afro-Caribbean diaspora communities, including Afro-Haitian individuals. However, there is a significant gap in the literature regarding most other Afro-Caribbean communities in the diaspora within and outside of the U.S. regarding SDOH and CLDs. This study will provide data to help fill this gap in our current understanding of these associations and how they may uniquely affect the health equity of the Afro-Caribbean diaspora.

Within the Caribbean, many national and regional differences exist among the various sub-cultures and diasporas, including between Anglophone, Francophone, Spanish, and Dutch-speaking nations. Differences also exist within cultures among different geographic locations, generations, genders, education levels, etc. Recognizing that cultural experience is multi-dimensional, we expect to identify differences among some of the subgroups within our sample population.

OBJECTIVES

The purpose of this study is to identify how specific social and cultural factors are associated with chronic liver disease in the Afro-Caribbean diaspora communities. We will look to see what lifestyle factors, health history, cultural perceptions, and other social determinants of health affect our sample and their health behaviors toward liver disease. We will examine how certain factors differ by age, gender, and country of birth by exploring how they compare within our sample.

STUDY DESIGN AND METHODS

Overview

This was a community-based analytical cross-sectional survey study conducted through the University of Miami School of Medicine. In order to explore our study aims, we created and administered the Hepatology Sociocultural Factor Survey (Appendix A) to collect data from our participants. This study was approved by the University of Miami Institutional Review Board (IRB) to analyze the social and cultural factors that relate to CLD among Afro-Caribbean communities.

Study Participants

We surveyed 237 participants who met the following criteria. Individuals who were adults (18 years or older), self-identified as Black and had Caribbean heritage were eligible to participate. Participants provided verbal consent. Participants were allowed to self-identify their Afro-Caribbean heritage in order to participate. Thus, our sample includes participants who were born in the Caribbean, first-generation Afro-Caribbean Americans, individuals with only one Afro-Caribbean parent, other multi-generational Afro-Caribbean individuals, and those of mixed Afro-Caribbean ancestry. Multiracial individuals who self-identified as being Black as a part of their racial admixture were also considered to meet inclusion criteria. Caribbean heritage was defined by having national, citizenship, and/or familial ties to one of the geographically, historically, or culturally Caribbean nations. The nations that were considered as meeting the aforementioned classification as Caribbean are listed below (Table 1).

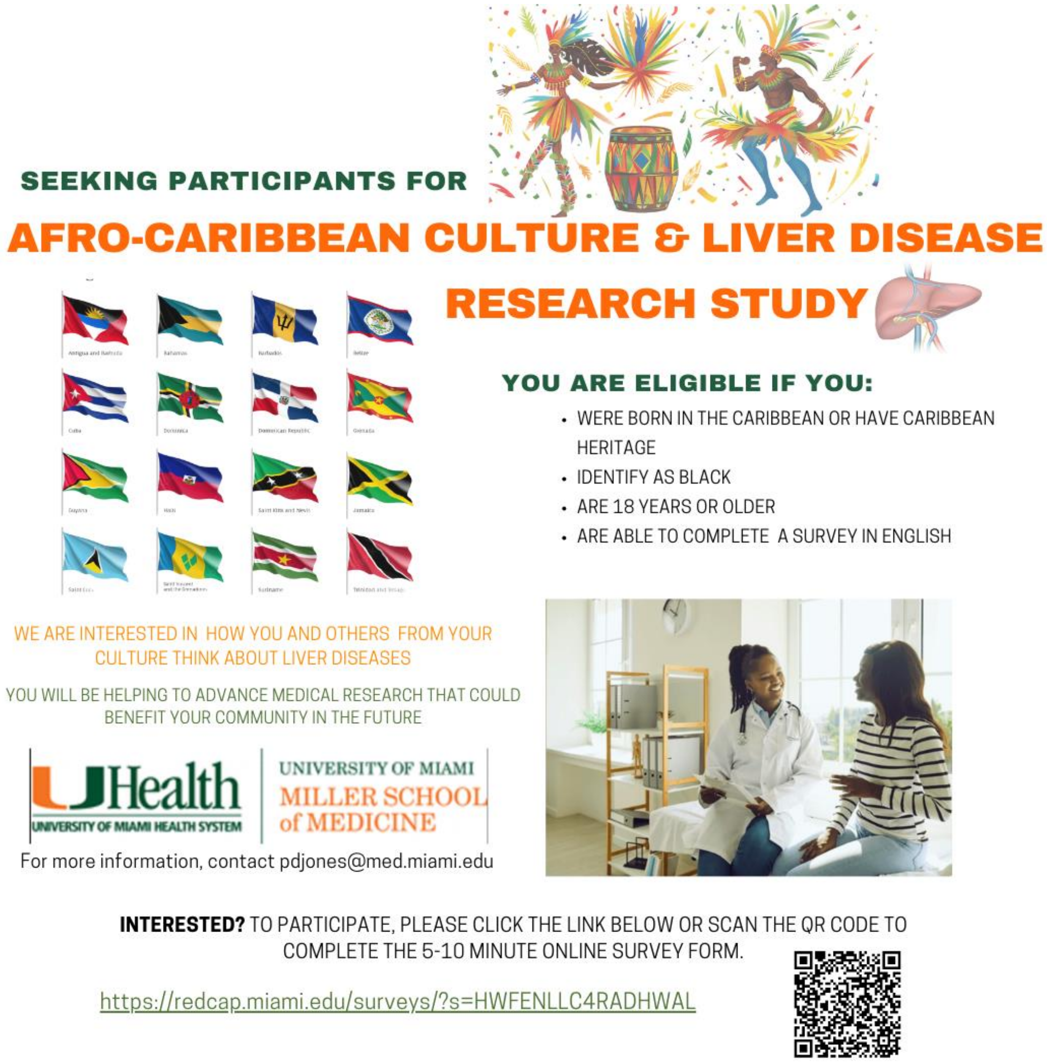
Table 1. List of Caribbean Nations that Meet Heritage Criteria.

Anguilla	Cuba	Martinique	Saint Vincent and The Grenadines
Antigua and Barbuda	Curacao	Jamaica	Sint Maarten
Aruba	Dominica	Montserrat	Suriname
Bahamas	Dominican Republic	Puerto Rico	Trinidad and Tobago
Barbados	Grenada	Saint Barthélemy	Turks and Caicos Islands
Belize	Guadeloupe	Saint Kitts and Nevis	United States Virgin Islands
British Virgin Islands	Guyana	Saint Lucia	
Cayman Islands	Haiti	Saint Martin	

Recruitment

Participants who met the inclusion criteria were invited to participate in the study by completing the Hepatology Sociocultural Factor Survey via the REDCap survey and database platform. Recruitment was done on a rolling basis following IRB approval. Two primary recruitment methods were utilized in reaching participants for this study. We aimed to recruit 125 adults from each recruitment procedure. We targeted our recruitment efforts towards convenience sampling to prioritize the maximum number of participants. The first procedure involved directly approaching participants in person at various community field sites using the recruitment plea and verbal consent script outlined in Appendix B. Local community sites in South Florida used for in-person recruitment included Caribbean restaurants, multicultural churches, ethnic supermarkets, and local community colleges/university campuses in Broward, Palm Beach, and Miami-Dade Counties. Participants who seemed agreeable upon approach had the survey administered to them in an interview style where their answers were recorded directly into the survey form by the study team member on site. Each interview lasted approximately 5-10 minutes, though completion time varied based on the speed of participant response and processing of each question. Participants who were approached in person and seemed otherwise agreeable except for being under a strict time constraint at the time of approach were offered a direct link or to scan a QR code to complete the survey independently at a later time.

The second recruitment procedure involved online recruitment utilizing digital flyers shown in Figure 2. Flyers were distributed across social media platforms, including Instagram, Facebook, and TikTok. Posted flyers introduced the study, stated the target population, and contained a direct link to the survey, which included a landing page outlining that completing the survey indicated their consent to participate in the study. In both recruitment procedures, participants were advised that they were able to terminate or discontinue their participation or interest at any time, for any reason, and that they may skip any question they did not wish to answer. In addition, Afro-Caribbean individuals known to the study team were directly invited to participate and encouraged to share the survey link with others meeting inclusion criteria, e.g., word of mouth.



SEEKING PARTICIPANTS FOR

AFRO-CARIBBEAN CULTURE & LIVER DISEASE RESEARCH STUDY

YOU ARE ELIGIBLE IF YOU:

- WERE BORN IN THE CARIBBEAN OR HAVE CARIBBEAN HERITAGE
- IDENTIFY AS BLACK
- ARE 18 YEARS OR OLDER
- ARE ABLE TO COMPLETE A SURVEY IN ENGLISH

WE ARE INTERESTED IN HOW YOU AND OTHERS FROM YOUR CULTURE THINK ABOUT LIVER DISEASES

YOU WILL BE HELPING TO ADVANCE MEDICAL RESEARCH THAT COULD BENEFIT YOUR COMMUNITY IN THE FUTURE

UHealth UNIVERSITY OF MIAMI HEALTH SYSTEM | UNIVERSITY OF MIAMI MILLER SCHOOL of MEDICINE

For more information, contact pdjones@med.miami.edu

INTERESTED? TO PARTICIPATE, PLEASE CLICK THE LINK BELOW OR SCAN THE QR CODE TO COMPLETE THE 5-10 MINUTE ONLINE SURVEY FORM.

https://redcap.miami.edu/surveys/?s=HWFENLLC4RADHWAL

Figure 2. Online Recruitment Flyer Post A copy of the IRB-approved recruitment flyer that was used for online recruitment of participants on Instagram, TikTok, and Facebook.

Study Measures

The Hepatology Sociocultural Factor Survey (Appendix A) was designed based on the stated aims of the present study. The survey administered to all participants was identical in content and structure, and all survey responses were collected through the

REDCap survey platform, regardless of recruitment method. All survey administering methods were conducted in English only and took approximately 5 -10 minutes to complete. Additionally, the in-person interviews were facilitated by the researcher, who was born and raised in Jamaica and thus is a member of the Afro-Caribbean community who is intimately familiar with the culture of the participants and the design of the study. All surveys were administered between January 2025 and February 2025. Response results from all participants were included, regardless of the degree of survey completion.

The survey questionnaire was organized into four brief sections, including basic demographic information, general health and lifestyle, cultural perceptions, and health-related behaviors. No identifying data such as name, date of birth, address, etc., were collected from participants in this study. The demographic section collected data on important categorical and continuous variables of interest such as age, gender, race, ethnicity, nationality, education level, religion, languages, and a timeline of residence in and outside of the United States. The questions in the section captured important information about the identity of our sample and allowed us to compare and contextualize the other social/cultural factors assessed by the survey. The health and lifestyle section provided a measure of the health profile of our sample, including their personal and family history of CLD, their history of other chronic health conditions, and lifestyle factors related to CLD, including exercise, alcohol consumption/abuse, and Hepatitis B vaccination status. The cultural perceptions section included 12 Likert-style questions with five responses from “Strongly Disagree” to “Strongly Agree”. This scale measured the following variables: cultural health literacy, shared cultural attitudes, social stigma, social support, feelings of shame, health privacy attitudes, medical mistrust, tendency to self-medicate, religious influences, financial satisfaction, lifestyle factors, and personal CLD awareness. This section also included free-response and multiple-choice questions about Hepatitis B transmission, perceived barriers, and perceived cultural attitudes. Altogether, this section measured each participant's personal perceptions towards CLD and what they believed to be the perceptions of others in their cultural communities. The fourth and final survey section used 8 Likert-styled questions similar to those in the previous section. This scale measured the following variables: health consciousness, health-seeking behavior, symptom dismissal, diagnostic avoidance, lifestyle changes, diet modification, treatment adherence, and preventative measures. This section evaluated each participant’s personal inclination towards certain health behaviors and decisions relating to CLD.

Data Analysis Plan

Statistical analyses on the data collected were performed using STATA 18.5 Software (College Station, TX). Most data variables collected were pre-coded within the radio button options by the researcher in the REDCap (Nashville, TN) survey form, including some categorical variables such as gender, race, ethnicity, language, etc. Responses to the Likert scale and other questions in sections 3 and 4 of the survey were also pre-coded in this way when creating the survey in REDCap. The complete data worksheet was exported from REDCap into an Excel Spreadsheet, where it was organized. Answers to the free-text questions, such as “Country of Birth” etc., were standardized in Excel from their varying input formats into one consistent entry for each distinct response. Some variables were manually re-coded in Excel for ease of analysis. Additionally, country of birth responses were categorized as US-born or foreign-born. The longer format responses to open-ended questions in the cultural perceptions section were also analyzed and organized for brevity. However, the general response style and structure of this data were preserved for the integrity of the quoted ideas.

Data that was organized, standardized, and re-coded in Excel was imported into STATA for analysis. For categorical variables, frequencies were analyzed, and proportions of the total sample size were calculated. For continuous variables such as age, the median, minimum, and maximum values, as well as the interquartile ranges (IQR), were assessed. Bivariate analyses were also conducted to compare certain variables of interest in our sample using the Chi-Squared test and Two-sample Wilcoxon rank-sum (Mann-Whitney) tests for categorical and continuous variables, respectively. P-values < 0.05 were considered statistically significant. Data from the free text/open-ended questions were evaluated and analyzed for their content to identify prevalent themes, but this data was not coded.

RESULTS

Demographics

A total of 237 participants completed the survey, and all responses were analyzed, including those that were only partially complete. Of the 237, 202 stated their ages, which range from 21 to 71 with a median age of 35 and an IQR of 28-52. The sample consisted of 57 participants who identified as male and 170 who identified as female.

Participants were asked to indicate their racial identity for inclusion purposes by selecting all that apply. 212 indicated they identify as Black, and of these 212, there were multiple racial admixtures. Of those who indicated Black race, 2 also indicated White, 2 also indicated Asian, 3 also indicated Multiracial/Mixed, and 1 also indicated “Other Race”. Of the 2 who also indicated White, 1 additionally indicated Asian. There were 2 participants who checked Multiracial but did not check Black and 10 who checked Other Race who did not check Black. All who indicated Multiracial and Other Race were prompted to specify. Descriptive data of the specified answers and other study variables are displayed in Table 2. Of the 209 participants who indicated their ethnicity, 5% indicated they identified as Hispanic/Latino, and 95% did not identify as Hispanic/Latino.

Figure 3 shows the geographic reach of our study based on the 220 participants who indicated their current residence by state. Participants’ responses indicated they were located across 19 U.S. states and 4 nations. The most concentrated locations of our participant populace were Florida, New York, Jamaica, and Saint Lucia, making up approximately 46%, 12%, 10.5%, and 7% of our sample, respectively.

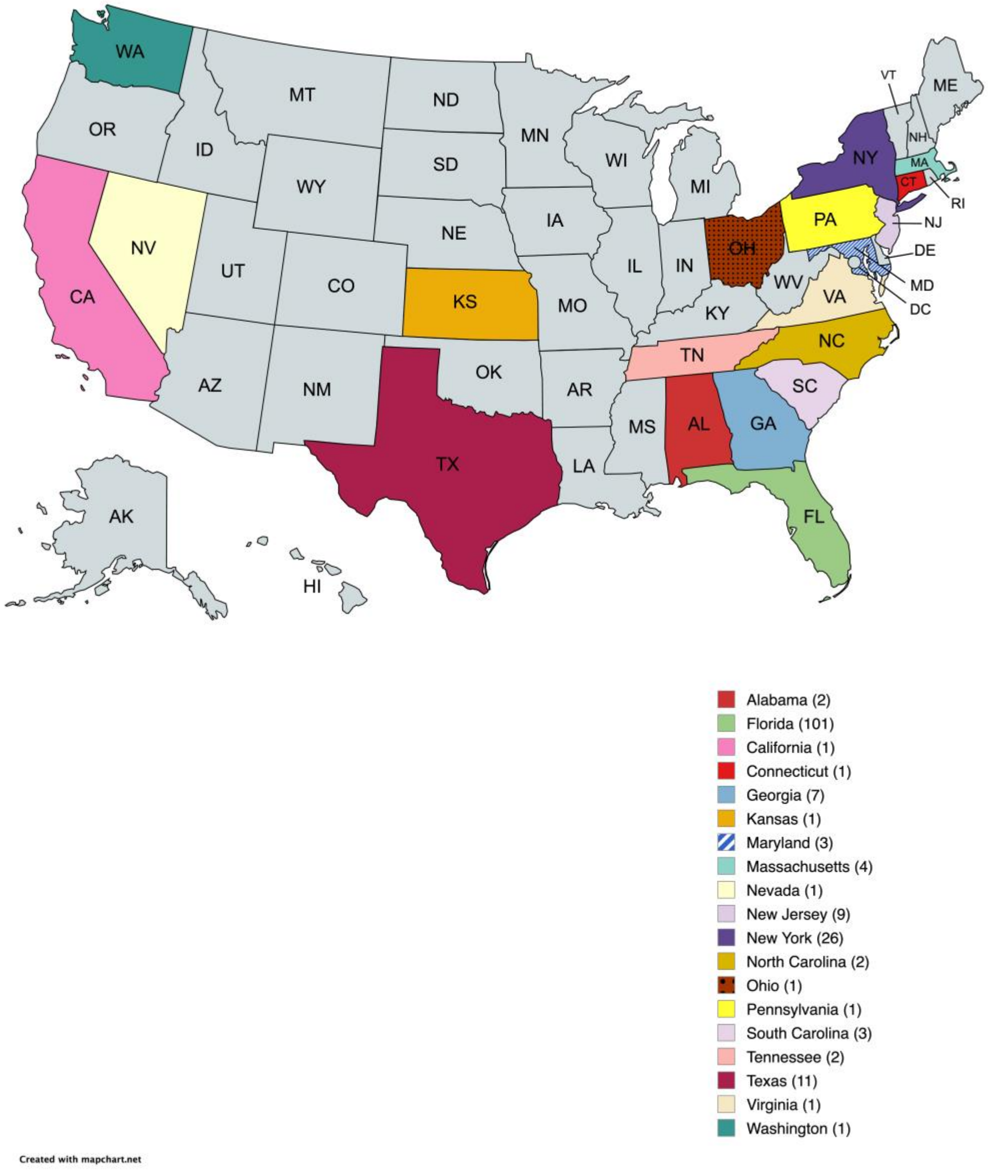


Figure 3. Study Geographic Reach Displays the states where participants of the study were located and the number of individuals from each state. Not pictured: Non-US state locations including Canada (1), Jamaica (23), Saint Lucia (15), the United Kingdom (2), and an unspecified U.S. state (1).

Among 218 individuals who indicated their country of birth, 159 (73%) were foreign-born, and 58 (27%) were US-born. One participant indicated “Virgin Islands” but did not specify whether it was U.S. or British Virgin Islands. Therefore, they were not analyzed for US-born vs foreign-born status. Participants were also asked to indicate their mother's and father's nationalities to assess their relationship with Afro-Caribbean heritage. Table 1 shows frequencies and percentages of specific nations of heritage. 180 (80%) of participants stated that they currently reside in the United States, while 46 (20%) said they live in other nations.

Participants were asked to state their first language and any other languages that they speak. Of 224 responses to first language, there were 203 English, 5 Spanish, 1 French, 13 Haitian Creole, and 2 "Other". The two that said other indicated that their first languages were Yoruba and German. 114 participants indicated that they also spoke other languages and/or dialects along with their first language. In addition to the first language options, some participants also indicated speaking a combination of the following languages: Belizean Creole, Guyanese Creole, French Creole/Patois, Jamaican Patois, Mina, Spanish Creole, Ge'ez, Amharic, Wolof, and Portuguese.

Among 225 responses in our sample, 42% of participants had a bachelor's degree or higher, 29% had some post-secondary education, 9% had a high school diploma, and 2% had completed less than high school. Out of 223 responses to religious affiliation, 16 said no religion, 187 said Christian or Catholic, 1 said Buddhist, 1 said Muslim, 5 said Rastafarian, 1 said Sikh, and 12 indicated other religions. Among the 12 that said other were 1 Baptist, 1 Greek Gods, 1 Pentecostal, 5 Seventh Day Adventists, and 2 Spiritual but not religious.

Table 2. Descriptive Statistics for Study Sample Demographic Factors The frequencies and percentages were defined for each categorical variable. For quantitative variables such as age, the median, IQR, minimum, and maximum were described. [n (%) = frequency (percentage)]

Variables	**Overall n= 237**		**Comments**
Median Age (IQR)	35(28-52) Range 21-71		n= 202
Gender n (%)			
Male	57(25.11)		n=227
Female	170(74.86)		
Race	-		Black, n=212
Ethnicity n (%)			
Hispanic/Latino	11(5.25)		n=209
Not Hispanic Latino	198(94.74)		
Location n (%)	Alabama 2 (0.91) California 1 (0.45) Canada 1 (0.45) Connecticut 1 (0.45) Florida 101 (45.91) Georgia 7 (3.18) Jamaica 23 (10.45) Kansas 1 (0.45) Maryland 3 (1.36) Massachusetts 4 (1.82) Nevada 1 (0.45) New Jersey 9 (4.09) New York 26 (11.82)	North Carolina 2 (0.91) Ohio 1 (0.45) Pennsylvania 1 (0.45) St. Lucia 15 (6.82) South Carolina 3 (1.36) Tennessee 2 (0.91) Texas 11 (5.00) United Kingdom 2 (0.91) Unspecified U.S. State 1 (0.45) Virginia 1 (0.45) Washington 1 (0.45)	n=220
Country of Birth n (%)	Bahamas 2 (0.92)	Nigeria 1 (0.46)	

	Belize 1 (0.46) Canada 1 (0.46) Cuba 3 (1.38) Dominica 2 (0.92) Grenada 2 (0.92) Guyana 3 (1.38) Haiti 12 (5.50) Jamaica 104 (47.71)	St. Kitts & Nevis 1 (0.46) St. Lucia 16 (7.34) St Vincent & the Grenadines 1 (0.46) Trinidad and Tobago 6 (2.75) United Kingdom 4 (1.83) United States 58 (26.61) Virgin Islands 1 (0.46)	n=218
Mother's Nationality n (%)	Aruba 1 (0.46) Bahamas 3 (1.38) Barbados 1 (0.46) Belize 2 (0.92) Benin 1 (0.46) Cuba 3 (1.38) Dominica 3 (1.38) Dominican Republic 3 (1.38) Grenada 2 (0.92) Guyana 5 (2.29) Haiti 23 (10.55) Jamaica 130 (59.63)	Montserrat 1 (0.46) Nigeria 1 (0.46) St. Kitts & Nevis 1 (0.46) St. Lucia 16 (7.34) St. Vincent & the Grenadines 1 (0.46) Trinidad & Tobago 6 (2.75) United Kingdom 2 (0.92) United States 12 (5.50) Virgin Islands 1 (0.46)	n=218
Father's Nationality n (%)	Bahamas 3 (1.37) Barbados 1 (0.46) Belize 2 (0.91) Colombia 1 (0.46) Cuba 3 (1.37) Dominica 2 (0.91) Dominican Republic 2 (0.91) Grenada 2 (0.91) Guyana 5 (2.28) Haiti 24 (10.96)	Jamaica 128 (58.45) Mali 1 (0.46) Nigeria 1 (0.46) St. Kitts & Nevis 1 (0.46) St. Lucia 17 (7.76) Togo 1 (0.46) Trinidad & Tobago 8 (3.65) United Kingdom 2 (0.91) United States 14 (6.39) Virgin Islands 1 (0.46)	n=219
Country of Residence n (%)			

Live in the U.S.? Yes No	180(79.65) 46(20.35)	n=226
Year Moved	Ranges from 1959-2025	n=147
Median Time in U. S (IQR) (years)	23.5(32-10)	n=156
Median Time in Birth Nation, if non-US born (IQR) (years)	25(36-16)	n=195
First Language n (%) English Spanish French Haitian Creole Other	203(90.62) 5(2.23) 1(0.45) 13(5.80) 2(0.89)	n=224 Of 2 Other, 1 specified Yoruba and 1 said German.
Other Languages	-	n=114
Education Level n (%) Less than Highschool High School Diploma Post-Secondary Certificate Some College Trade or Vocational School Associate's degree Bachelor's Degree Master's Degree Doctorate Degree	4(1.78) 21(9.33) 4(1.78) 24(10.67) 12(5.33) 26(11.56) 66(29.33) 52(23.11) 16(7.11)	n=225
Religion n (%) No religion Christian or Catholic	16(7.17) 187(83.86)	n=223

Buddhist	1(0.45)	Of 12 Other, 1 Baptist, 1 Greek Gods, 1 Pentecostal, 5 Seventh Day Adventist and 2 Spiritual.
Muslim	1(0.45)	
Rastafarian	5(2.24)	
Sikh	1(0.45)	
Other	12(5.38)	

[a] **Race** Those who chose either Multiracial or “Other Race” specified the following: Multiracial specifics-1 Afro-Caribbean, 1 Chinese, 1 Latino/Black, 1 “Mongrel”. Other Race specifics- African 1, 2 Afro Caribbean, 1 British Caribbean, 1 Caribbean American, 1 From the Caribbean, 1 Human, 1 Jamaican born, 1 Saint Lucian, 1 West Indian.

Health History and Lifestyle Factors

In our evaluation of health history and lifestyle factors, we found that most participants indicated no personal or family history of CLD. When asked whether they have ever had a CLD, 219 of the 222 participants who responded indicated no, while 2 said yes and 1 said unsure. Both individuals who said yes specified a diagnosis of Fatty Liver Disease. Out of 220 participants, 198 said no, 8 said yes, and 14 said unsure to having a family history of CLD. Regarding a history of chronic health conditions, 237 responses indicated a variety of chronic conditions, as detailed in Table 3. Participants were asked to check all that apply. The most common health conditions reported were Hypertension (19%), Asthma (15%), Diabetes (10%), and Obesity (9%).

216 participants indicated their alcohol use frequency where 20% said they never drank, 46% said they drank monthly or less, 24% said they drank 2-4 times/ month, 7% reported drinking 2-3 times/week, 1% said 4+ times/week and 1% reported daily drinking. 213 participants answered how often they consumed 5+ alcoholic drinks in one sitting in the last year (henceforth referred to as binge drinking behavior). Of these, 135 (63%) said never, 51(24%) said monthly or less, 21 (10%) said 2-4 times/month, and 2 (1%) each said 2-3 times/week, 4+ times/week, and every day, respectively.

Regarding vaccination status for HBV, 68% indicated they had been vaccinated, 17% reported they were not vaccinated, and 15% were unsure of their vaccination status. 217 individuals responded to how often they exercise, where 38 said none, 58 said less than once/week, 40 said 1-2 times/week, 61 said 3-5 times/week, and 20 said 5+ times/week.

Table 3. Summary of Health History and Lifestyle Factor Variables The frequencies and percentages [n (%)] were detailed for each variable.

Variables n (%)	**Overall n= 237**	**Comments**
Diagnosed or Treated for a CLD?		
Yes	2(0.90)	n=222
No	219(98.65)	
Unsure	1(0.45)	
CLD Diagnosis History		
Hepatitis B	0	
Hepatitis C	0	
Fatty Liver Disease	2(0.84)	
Alcoholic Liver Disease	0	
Liver Cirrhosis	0	n=237
Primary Biliary Cirrhosis	0	
Autoimmune Hepatitis	0	
Wilson's Disease	0	
Alpha-antitrypsin Deficiency	0	
Cystic Fibrosis	0	
Liver Cancer	0	
Family History of CLD?		
Yes	8(3.64)	
No	198(90.00)	n=220
Unsure	14(6.36)	
History of any Chronic Health Conditions? n checked (%)		
Asthma	36(15.19)	
Arthritis	14(5.91)	
Diabetes	23(9.70)	
Hyperlipidemia	2(0.84)	
HIV/AIDS	1(0.42)	
High Cholesterol	14(5.91)	n=237
Low Blood Pressure	2(0.84)	
Obesity	21(8.86)	
High Blood Pressure	45(18.99)	Of 9 Other: 1 said Acid Reflux, 1 Blood clots, 1 Dense Breast Tissue, 1 Fibromyalgia, 1 "Holistic body" and 1 COVID-19 -Related Lung Disease, 3 did not specify.
Heart Disease	5(2.11)	
Thyroid Diseases	5(2.11)	
Chronic Kidney Disease	2(0.84)	
Chronic Skin Conditions	1(0.42)	
Cancer	9(3.80)	
Stroke	0(0)	
Autoimmune Disorders	3(1.27)	
Psychological Disorders	3(1.27)	
Other Chronic Illness	9(3.80)	
Alcohol Use		
Never	44(20.37)	

Monthly or less	100(46.30)	n=216
Two to four times per month	52(24.07)	
Two to three times per week	15(6.94)	
Four or more times per week	2(0.93)	
Everyday	3(1.39)	
Frequency of 5+ alcoholic drinks in one sitting in last 12m?		n=213
Never	135(63.38)	
Monthly or Less	51(23.94)	
Two to four times per month	21(9.86)	
Two to three times per week	2(0.94)	
Four or more time per week	2(0.94)	
Everyday	2(0.94)	
Vaccinated for Hepatitis B?		n=219
Yes	147(67.74)	
No	37(17.05)	
Unsure	33(15.21)	
Exercise		n=217
None	38(17.51)	
Less than once a week	58(26.73)	
1 to 2 times a week	40(18.43)	
3 to 5 times a week	61(28.11)	
5 or more times a week	20(9.22)	

Perceptual Factors

When asked, “Do you personally know someone who has had a CLD?”, 44 (22%) participants said yes, and 154 (78%) said no, out of 198 responses. When asked, “Where did you first learn about liver disease?”, 85 (43%) out of 196 reported that they first heard of CLD in their home Caribbean country, and 111 (57%) first heard of CLD in the United States. When asked, “Do you know how the HBV is spread?” 198 individuals responded, with 100 (51%) saying yes and 98 (49%) saying no. Of the 98 that said yes to knowing how HBV is spread, 83 indicated how they thought the virus was transmitted. Of those 83, 79 (95%) listed one or more correct transmission methods for HBV. Four of the 83 indicated an answer that was deemed incorrect or insufficient in detail to determine accuracy. These four responses included: “Airborne”, “Direct contact”, “Various ways”, and “Contact”.

The twelve Likert-scale questions on cultural perceptions varied in number of respondents, where they each provided one of five answers indicating how they personally thought and how they believed others in their culture thought about the statements (Table 4).

Results by Question/Variable

Q1: *Cultural Health Literacy*: People from my culture are well-informed about liver diseases. 70% of respondents disagreed to some degree, 23% were neutral, and 8% agreed to some degree with this statement.

Q2: *Shared Cultural Attitudes*: People from my culture share similar ideas & attitudes about health. 29% of respondents disagreed to some degree, 26% were neutral, and 45% agreed to some degree with this statement.

Q3: *Social Stigma*: In my culture, someone with a liver disease would face isolation or be treated poorly. 61.5% of respondents disagreed to some degree, 21.5% were neutral, and 17% agreed to some degree with this statement.

Q4: *Social Support*: If I was diagnosed with a CLD, I feel I would have strong support from my family and friends during my treatment. 5% of respondents disagreed to some degree, 11% were neutral, and 84% agreed to some degree with this statement.

Q5: *Feelings of Shame*: I would feel ashamed if I was diagnosed with a CLD. 67.5% of respondents disagreed to some degree, 18% were neutral, and 14.5% agreed to some degree with this statement.

Q6: *Health Privacy Attitude*: I would tell my family if I was diagnosed with a CLD. 7% of respondents disagreed to some degree, 7% were neutral, and 86% agreed to some degree with this statement.

Q7: *Medical Mistrust*: People from my culture are trusting of their medical providers and healthcare system. 32.5% of respondents disagreed to some degree with this statement, 29.5% were neutral, and 38% agreed to some degree with this statement.

Q8: *Tendency to Self-Medicate*: People from my culture tend to use home remedies/ over-the-counter medications instead of going to the doctor when feeling sick. 9.5% of respondents disagreed to some degree, 15.5% were neutral, and 75% agreed to some degree with this statement.

Q9: *Religious Influences*: I feel that religion influences the way people in my culture think about their health. 19% of respondents disagreed to some degree, 25% were neutral, and 56% agreed to some degree with this statement.

Q10: *Financial Satisfaction*: I feel satisfied with my current financial situation. 38% of respondents disagreed to some degree, 26% were neutral, and 36% agreed to some degree with this statement.

Q11: *Lifestyle Factors (Diet)*: I feel that my cultural foods are high in fat and sugar. 19% of respondents disagreed to some degree, 17.5% were neutral, and 63.5% agreed to some degree with this statement.

Q12: *Personal CLD Awareness*: I feel I can recognize the signs and symptoms of liver diseases. 43% of respondents disagreed to some degree, 17% were neutral, and 41% agreed to some degree with this statement.

Table 4. Summary of Perceptual Factor Variables The frequencies and percentages [n (%)] were detailed for each variable. [SD=Strongly Disagree, D= Disagree, N= Neither Agree nor Disagree, A=Agree, SA= Strongly Agree]

Variables n (%)	**Overall n= 237**					
Cultural Perceptions	SD	D	N	A	SA	**n**
Q1 Cultural group well informed about CLD?	58(29.00)	82(41.00)	45(22.50)	12(6.00)	3(1.50)	n=200
Q2 Cultural group share attitudes toward health?	17(8.54)	41(20.60)	51(25.63)	79(39.70)	11(5.53)	n=199
Q3 Cultural group would treat person with CLD poorly?	51(25.50)	72(36.00)	43(21.50)	28(14.00)	6(3.00)	n=200
Q4 If CLD, strong social support system?	4(2.03)	5(2.54)	22(11.17)	78(39.59)	88(44.67)	n=197
Q5 Would feel ashamed if had CLD?	74(37.00)	61(30.50)	36(18.00)	22(11.00)	7(3.50)	n=200
Q6 Would tell family about CLD diagnosis?	8(4.02)	5(2.51)	13(6.53)	88(44.22)	85(42.71)	n=199
Q7 Cultural group trusting of medical system?	28(14.00)	37(18.50)	59(29.50)	59(29.50)	17(8.50)	n=200
Q8 Cultural tendency to use home remedies instead?	6(3.00)	13(6.50)	31(15.50)	76(38.00)	74(37.00)	n=200
Q9 Cultural group’s health ideas influenced by religion?	12(6.03)	25(12.56)	50(25.13)	83(41.71)	29(14.57)	n=199

Q10 Satisfied with finances?	26(13.07)	50(25.13)	51(25.63)	55(27.64)	17(8.54)	n=199
Q11 Food high in sugar/fat?	9(4.50)	29(14.50)	35(17.50)	88(44.00)	39(19.50)	n=200
Q12 I know the symptoms of liver disease?	32(16.08)	53(26.63)	33(16.58)	50(25.13)	31(15.58)	n=199
Know a person with a CLD?						n=198
Yes	44(22.22)					
No	154(77.78)					
What do you think causes CLD?	-					n=171
Location you first learned of CLD?						
In my home country	85(43.37)					n=196
In the United States	111(56.63)					
Perceptions of people in your culture on CLD?	-					n=151
Perceived barriers to CLD diagnosis/treatment in your culture?	-					n=160
Know how Hep B is spread?						n=198
Yes	100(50.51)					
No	98(49.49)					
Correct about Hep B Trans?						n=83
Correct	79(95.18)					
Incorrect	4(4.82)					

Basic Qualitative Assessment of Open-Ended Perceptual Questions

When asked the question “What do you think are the most common causes of liver disease?” 171 participants responded, listing their proposed causes. The overwhelming majority of answers indicated that participants thought excessive alcohol consumption/alcohol abuse was the main cause of CLD. Other common themes among answers included poor diet, unhealthy lifestyle, obesity/fatty liver, smoking, genetics, medication, and hepatitis infection. Less commonly mentioned answer themes were toxin exposure, inadequate water intake, herbal medicine ingestion, and “neglecting to excrete body waste”.

When prompted to “Briefly describe what you think people in your cultural community think about liver disease,” there were 151 responses. A wide variety of answers and themes were present. One of the prevailing themes was that liver disease is not perceived as a topic of concern for most and/or that it is not commonly discussed among participants’ cultures. Some respondents said:

“In Jamaica, I don't believe they take it seriously. I think it's more of a "when we reach that bridge, we'll cross it" type of thing there. There isn't much thought into it because the way sex and alcohol are praised there, I strongly doubt liver disease is a thought for the majority.”

“I honestly don't think it's really thought of I think in general my country is more relaxed in how they approach medical concerns and we also compared to other countries, have a more indulging society with everything alcohol, smoking and more…”

“We don't think about this much, but if we did, I would say it would be a lot of blame placed on the individual with liver disease.”

“I don't believe they think about it.”

Several comments also indicated that liver diseases are thought of as serious and were thought to be associated with death. Another remarkable response theme indicated that several participants thought that people in their culture may attribute liver disease to supernatural/spiritual elements such as witchcraft or “bad luck”. For example, comments included: “That it is bad luck,” “That it is from the devil,” and “They would say it is related to Obeah (Witchcraft)”. Other comments suggest that an individual with a liver disease may be perceived to be at fault for their illness in some cultures due to a perception that all liver diseases are alcohol-related. Related comments include, “That people who have it are alcoholics,” “They think alcoholics get it,” and “Some think that liver disease is solely due to alcohol”. Many other comments addressed the idea that their cultural communities are largely uninformed about liver diseases and may hold other misconceptions surrounding the topic. Several comments also stated that the respondents themselves were unsure about the perceptions of liver disease in their communities.

When prompted to “Briefly list what things you think might stop people from your culture from seeking diagnosis or treatment for a liver disease,” 160 respondents provided comments. The predominant themes of these perceived barriers were lack of resources (especially financial), lack of access to healthcare, mistrust of healthcare providers, fear of racism/discrimination, lack of awareness, fear of diagnosis, shame, and social stigma. Other notable themes that were prevalent were the tendency towards using alternative medicine and reliance on their faith/belief system. Some respondents provided longer answers rather than listed answers. Some expressed:

“People in my culture generally try to seek herbal alternatives rather than visit a physician.”

“Fear of finding out something is wrong”

“They don’t believe in doctors.”

“Hospitals are expensive and kind of inconvenient. In the Dominican Republic, my family is from the countryside, so they have to drive four hours to go to a good hospital.”

“Being ashamed/having too much pride, Thinking they can fix themselves when clearly that hasn't worked.”

“Stigma, Distrust in the medical system, Belief that God will heal them, Belief that herbal remedies can fit it.”

“Superstition”

“Not accepting that they are unwell”

“... Thinking its spiritual warfare unto them”

“Fear of medical professionals, Feeling that praying will cure them, Thinking that it's not a big deal”

Health-Behavioral Factors

The eight Likert-scale questions on health behaviors varied in number of respondents, where they each provided one of five answers indicating how they personally feel towards each behavior/decision statement (Table 5)

Table 5. Summary of Health-Behavior Variables. The frequencies and percentages [n (%)] were detailed for each variable. [SD=Strongly Disagree, D= Disagree, N= Neither Agree nor Disagree, A=Agree, SA= Strongly Agree]

Variables n (%)	**Overall n=237**					**Comments**
Health-Related Behaviors	SD	D	N	A	SA	**n**
Q1 I follow up with PCP every year?	7(3.68)	20(10.53)	17(8.95)	69(36.32)	77(40.53)	n=190
Q2 Would seek urgent attention for CLD symptoms?	3(1.57)	1(0.52)	10(5.24)	72(37.70)	105(54.97)	n=191
Q3 Would use cultural remedies if symptoms minor?	30(15.62)	58(30.21)	27(14.06)	61(31.77)	16(8.33)	n=192
Q4 Fear would cause me to avoid CLD tests?	83(43.92)	65(34.39)	23(12.17)	15(7.94)	3(1.59)	n=189
Q5 Would change lifestyle to treat CLD?	5(2.66)	0(0)	6(3.19)	59(31.38)	118(62.77)	n=188
Q6 Willing to avoid cultural food to treat a CLD?	3(1.59)	2(1.06)	8(4.23)	77(40.74)	99(52.38)	n=189
Q7 Stick to treatment plan for a CLD?	2(1.05)	1(0.52)	12(6.28)	81(42.41)	95(49.74)	n=191
Q8 Would vaccinate my kid for Hep B?	5(2.62)	5(2.62)	21(10.99)	59(30.89)	101(52.88)	n=191

Results by Question/Variable

Q1: Health Consciousness: I follow up with my PCP at least once a year, even if I am feeling sick. Of the 190 respondents, 14% disagreed to some degree with this statement, 9% were neutral, and 77% agreed to some degree.

Q2: Health-seeking Behavior: If I noticed symptoms of a liver disease, I would urgently seek medical attention. Of the 191 respondents, 2% disagreed to some degree, 5% were neutral, and 93% agreed to some degree with this statement.

Q3: Symptom dismissal: If I felt my symptoms were minor, I would try to use cultural or herbal remedies to help myself. Of the 192 respondents, 46% disagreed to some degree, 14% were neutral, and 40% agreed to some degree with this statement.

Q4: Diagnostic avoidance: My fear of being diagnosed with a CLD would cause me to avoid going to get tested. Of the 189 respondents, 78% disagreed to some degree, 12% were neutral, and 10% agreed to some degree with this statement.

Q5: Lifestyle Changes: I would make lifestyle changes including exercising and avoiding alcohol or smoking if necessary to treat a liver disease. Of the 188 respondents, 3% disagreed to some degree, 3% were neutral, and 94% agreed to some degree with this statement.

Q6: Diet Modification: I am willing to change my diet to a low-sugar and low-fat diet if it would help me avoid or reverse a liver disease, even if it means avoiding some of my cultural foods. Of the 189 respondents, 3% disagreed to some degree, 4% were neutral, and 93% agreed to some degree with this statement.

Q7: Treatment Adherence: If diagnosed with a liver disease, I would stick to the treatment plan given by my healthcare providers. Of the 191 respondents, 2% disagreed to some degree, 6% were neutral, and 92% agreed to some degree with this statement.

Q8: Preventative Measures: I would vaccinate my children against the Hepatitis B virus. Of the 191 respondents, 5% disagreed to some degree, 11% were neutral, and 84% agreed to some degree with this statement.

Bivariate Analyses

The variables of interest in our sample were analyzed using Chi-squared tests and two-sample Wilcoxon rank-sum tests to compare them by gender (Male vs Female) and Country of Birth (Foreign-born vs. US-born) (Table 6). Though initially intended, a comparison by age was not completed due to a very narrow range in age observed in the preliminary data analysis. We determined that age categories were not broad/varied enough to yield meaningful comparisons.

Country of Birth

We observed a significant difference in the ages of our foreign-born vs US-born groups. Our foreign-born population was older, with a median age of 40 years (IQR) (28-53) compared to 31 years (26-41) in US-born participants (p=0.001). There was a statistically significant difference observed between the foreign-born and US-born groups regarding a health history of obesity. Obesity was more common and affected 19% of U.S.-born participants (n=11), compared to 6% of foreign-born participants (n=9), p=0.003.

Significant differences were also noted among US-born and foreign-born groups regarding how often they reported consuming alcohol. Notably, more foreign-born participants said they never drank alcohol compared to US-born participants (24% vs 9%). Additionally, US-born participants more frequently reported drinking 2-4 times/month than foreign-born participants (35% vs 19%, p=0.012). Binge drinking behavior was also more commonly reported in US-born participants, where only 49% said they never drank 5+ alcoholic beverages in one sitting compared to 69% of foreign-born participants, p=0.020. Of those who report some binge drinking behavior, higher frequencies were found among US-born participants than foreign-born participants. Specifically, more of the US-born group reported binge drinking monthly or less than the foreign-born group (35% vs 19%). Finally, daily binge drinking was only reported among US-born participants, where 4% of respondents indicated drinking at this frequency.

Gender

There was a significant difference observed in the level of education between our male and female groups (p=0.011). Female participants completed more graduate-level education than males, with 36% having a master's degree or higher compared to 14% of males. Conversely, 43% of males had completed an undergraduate-level degree compared to 40% of females. 25% of male participants had completed some post-secondary (including some college, trade/vocational school, and post-secondary certificate) schooling compared to 15% of female participants. Lastly, twice as many (18%) male participants had a secondary education or less compared to 9% of female participants.

A significant difference was identified between males and females within our sample regarding binge drinking behavior (p<0.001). Binge drinking was more commonly reported among male participants, where only 38% reported that they never drank 5+ drinks in one sitting compared to 71% of female participants. 19% of women said they engaged in binge drinking monthly or less compared to 40% of males. 1% of the female sample reported binge drinking every day compared to 0% of males. The two female respondents who comprise this 1% are, interestingly, the only two individuals within our sample who reported binge drinking at this frequency, and both are also US-born.

Additionally, we noted a significant difference in exercise frequency among males and females ($p<0.001$). Notably, 20% of females compared to 10% of males reported not exercising. 30% of females reported exercising less than weekly compared to 15% of males. 25% of females reported exercising 3-5 times/week compared to 40% of males. Finally, 23% of males reported exercising 5+ times/week compared to 5% of females.

We also discovered a significant difference in knowledge of HBV transmission among genders in our sample ($p=0.018$), where 55% of female participants reported that they knew how HBV is spread compared to 36% of males.

Table 6. Bivariate Analysis of Study Sample by Gender and Country of Birth Variables compared by Gender and Country of Birth. The frequencies, column percentages, and p-values are detailed, where p<0.05 is considered statistically significant. Statistically significant values are displayed in red.

	Overall n = 237	**Male**	**Female**	**P-value**	**Foreign-Born**	**US-born**	**P-value**
Median Age (IQR) Minimum-Maximum	35 (28-52)	31(27.5-47)	38.5(28-52)	0.191	40(28-53)	31(26-41)	
	Range 21-71	21-70	21-71		23-71	21-65	0.001
Gender n (%)							
Male	57 (25.11)	-	-	-	41(25.79)	14(24.14)	0.805
Female	170 (74.86)				118(74.21)	44(75.86)	
Ethnicity n (%)							
Hispanic/Latino	11(5.25)	5(9.62)	6(3.82)	0.105	5(3.52)	6(10.53)	0.051
Not Hispanic Latino	198(94.74)	47(90.38)	151(96.18)		137(96.48)	51(89.47)	
Country of Residence n (%)							
Living in U.S.	180(79.65)	40(71.43)	140(82.35)	0.078	115(72.33)	57(98.28)	0.000
Foreign Residence	46(20.35)	16(28.57)	30(17.65)		44(27.67)	1(1.72)	
First Language n (%)							
English	203(90.62)	50(89.29)	153(91.07)		142(90.45)	52(91.23)	
Spanish	5(2.23)	2(3.57)	3(1.79)		3(1.91)	2(1.3)	0.866
French	1(0.45)	0(0)	1(0.60)	0.764	1(0.64)	0(0)	
Haitian Creole	13(5.80)	4(7.14)	9(5.36)		10(6.37)	3(5.26)	
Other	2(0.89)	0(0)	2(1.19)		1(0.64)	0(0)	
Education Level n (%)							
Less than Highschool	4(1.78)	3(5.36)	1(0.59)		4(2.53)	0(0)	
High School Diploma	21(9.33)	7(12.50)	14(8.28)		18(11.39)	3(5.26)	
Post-Secondary Certif.	4(1.78)	0(0)	4(2.37)		3(1.90)	1(1.75)	
Some College	24(10.67)	9(16.07)	15(8.88)		20(12.66)	3(5.26)	
Trade/Vocation. School	12(5.33)	5(8.93)	7(4.14)	0.011	10(6.33)	1(1.75)	0.198
Associate’s degree	26(11.56)	4(7.14)	22(13.02)		15(9.49)	10(17.54)	
Bachelor’s Degree	66(29.33)	20(35.71)	46(27.22)		45(28.48)	18(31.58)	
Master’s Degree	52(23.11)	6(10.71)	46(27.22)		32(20.25)	17(29.82)	

Doctorate Degree	16(7.11)	2(3.57)	14(8.28)		11(6.96)	4(7.02)	
Diagnosed or Treated for a CLD? n (%)							
Yes	2(0.90)	0(0)	2(1.20)		1(0.64)	0(0)	
No	219(98.65)	55(100)	164(98.20)	0.606	154(98.72)	57(100)	0.692
Unsure	1(0.45)	0(0)	1(0.60)		1(0.64)	0(0)	
Family History of CLD? n (%)							
Yes	8(3.64)	2(3.64)	6(3.64)		6(3.87)	1(1.79)	
No	198(90.00)	49(89.09)	149(90.30)	0.950	140(90.32)	50(89.29)	0.563
Unsure	14(6.36)	4(7.27)	10(6.06)		9(5.81)	5(8.93)	
History of any Chronic Health Conditions? n (%) checked							
Asthma	36(84.81)	10(17.54)	26(15.29)	0.687	25(15.72)	11(18.97)	0.570
Arthritis	14(5.91)	4(7.02)	10(5.88)	0.758	13(8.18)	1(1.72)	0.087
Diabetes	23(9.70)	5(8.77)	18(10.59)	0.694	17(10.69)	6(10.34)	0.941
Hyperlipidemia	2(0.84)	0(0)	1(0.59)	0.562	1(0.63)	0(0)	0.545
HIV/AIDS	1(0.42)	1(1.75)	0(0)	0.083	0(0)	1(1.72)	0.097
High Cholesterol	14(5.91)	2(3.51)	12(7.06)	0.335	10(6.29)	293.45)	0.418
Low Blood Pressure	2(0.84)	2(3.51)	0(0)	0.014	2(1.26)	0(0)	0.391
Obesity	21(8.86)	1(1.75)	20(11.76)	0.024	9(5.66)	11(18.97)	0.003
High Blood Pressure	45(18.99)	10(17.54)	35(20.59)	0.618	35(22.01)	10(17.24)	0.443
Heart Disease	5(2.11)	1(1.75)	4(2.35)	0.790	4(2.52)	0(0)	0.223
Thyroid Diseases	5(2.11)	1(1.75)	4(2.35)	0.790	4(2.52)	1(1.72)	0.731
Chronic Kidney Disease	2(0.84)	0(0)	1(0.59)	0.562	1(0.63)	0(0)	0.545
Chronic Skin Conditions	1(0.42)	1(1.75)	0(0)	0.083	1(0.63)	0(0)	0.545
Cancer	9(3.80)	2(3.51)	7(4.12)	0.838	6(3.77)	3(5.17)	0.647
Stroke	0(0)	0(0)	0(0)	-	0(0)	0(0)	-
Autoimmune Disorders	3(1.27)	0(0)	3(1.76)	0.313	2(1.26)	1(1.72)	0.795
Psychological Disorders	3(1.27)	0(0)	3(1.76)	0.313	2(1.26)	1(1.72)	0.795
Other Chronic Illness	9(3.80)	3(5.26)	6(3.53)	0.562	8(5.03)	1(1.72)	0.280
Alcohol Use n (%)							
Never	44(20.37)	10(19.23)	34(20.73)		36(23.84)	5(8.77)	
Monthly or less	100(46.30)	21(40.38)	79(48.17)		73(48.34)	25(43.86)	
Two to four times per month	52(24.07)	12(23.08)	40(24.39)	0.271	29(19.21)	20(35.09)	0.012

Two to three times per week	15(6.94)	6(11.54)	9(5.49)		11(7.28)	4(7.02)	
Four or more times per week	2(0.93)	1(1.92)	1(0.61)		0(0)	2(3.51)	
Everyday	3(1.39)	2(3.85)	1(0.61)		2(1.32)	1(1.75)	
Frequency of 5+ alcoholic drinks in one sitting in last 12m? n (%)							
Never	135(63.38)	20(38.46)	115(71.43)		103(68.67)	28(49.12)	
Monthly or Less	51(23.94)	21(40.38)	30(18.63)		29(19.33)	20(35.09)	
Two to four times per month	21(9.86)	8(15.38)	13(8.07)	0.000	15(10.00)	6(10.53)	
Two to three times per week	2(0.94)	2(3.85)	0(0)		2(1.33)	0(0)	0.020
Four or more time per week	2(0.94)	1(1.92)	1(0.62)		1(0.67)	1(1.75)	
Everyday	2(0.94)	0(0)	2(1.24)		0(0)	2(3.51)	
Vaccinated for Hepatitis B? n (%)							
Yes	147(67.74)	31(59.62)	116(70.30)		98(64.47)	44(77.19)	
No	37(17.05)	11(21.15)	26(15.76)	0.355	25(16.45)	9(15.79)	0.090
Unsure	33(15.21)	10(19.23)	23(13.94)		29(19.08)	4(7.02)	
Exercise n (%)							
None	38(17.51)	5(9.62)	33(20.00)		25(16.45)	11(19.30)	
Less than once a week	58(26.73)	8(15.38)	50(30.30)		42(27.63)	15(26.32)	
1 to 2 times a week	40(18.43)	6(11.54)	34(20.61)	0.000	28(18.42)	9(15.79)	
3 to 5 times a week	61(28.11)	21(40.38)	40(24.24)		43(28.29)	16(28.07)	0.977
5 or more times a week	20(9.22)	12(23.08)	8(4.85)		14(9.21)	6(10.53)	
Know a person with a CLD? n (%)							
Yes	44(22.22)	9(18.00)	35(23.65)	0.406	36(26.09)	7(13.21)	
No	154(77.78)	41(82.00)	113(76.35)		102(73.91)	46(86.79)	0.056
Know how Hep B is spread? n (%)							
Yes	100(50.51)	18(36.00)	82(55.41)	0.018	69(50.00)	25(47.17)	0.726
No	98(49.49)	32(64.00)	66(44.59)		69(50.00)	28(52.83)	

DISCUSSION

This pilot study sought to identify specific factors affecting the Afro-Caribbean diaspora that are related to CLD by examining various social-determining health factors such as lifestyle, health history, cultural perception, and behavioral tendencies. We also explored whether there were any notable differences within our sample when compared by factors such as age, country of birth, and gender. We expected to identify differences in some factors among sub-groups within the sample. There were some key findings deduced from analyzing the results of this survey.

Firstly, the survey reached a demographically diverse sample, as supported by the geographic, cultural, and linguistic variety among participants. There were participants from 19+ U.S. states and 4 foreign nations, with about 80% of our sample residing in the U.S. compared to 20% outside the U.S. The study also had a diverse variety of Afro-Caribbean culture groups, with individuals indicating ties to at least 17 distinct Caribbean nation communities (Table 2). Linguistic diversity was demonstrated by the 16+ languages and dialects spoken by survey respondents. The majority (73%) of our sample were U.S.-born Caribbean Americans compared to Caribbean-born (27%). During our analysis, we identified several social and cultural factors that are related to CLD.

Health History and Lifestyle Factors

According to the literature, most CLD are not diagnosed until the advanced stages, which often takes decades, and even then, many signs and symptoms associated with liver disease are quite nonspecific, which acts as a barrier to diagnosis. [8,19] This fact, the young age range of our sample, and the small sample size may be responsible for the seemingly low prevalence of CLD among participants and the lack of reports of family history of CLD. This suggests that the dearth of early surveillance options may contribute to this gap by limiting diagnosis to later ages. The indication of fatty liver disease as the sole CLD identified among participants despite the stated limitations is within expectations since MASLD is one of the most globally prevalent liver diseases. [20] Overall, the prevalence and family history of CLD within our sample remain unclear, and further investigation is necessary to identify the magnitude to which CLD affects the Afro-Caribbean community.

Conditions such as hypertension, diabetes, and obesity were most common among our participants. It is known that the increase in the prevalence of certain chronic conditions, such as obesity, is expected to contribute to an increase in the prevalence of NAFLD/MASLD. [20] The frequent rates of these conditions among our sample signals that they may be important risk factors among Afro-Caribbean communities, which potentially contribute to CLD. One explanation of these findings is that poor access to affordable healthy food options may increase the risk of Afro-Caribbean individuals developing obesity, diabetes, and hypertension. Significantly higher rates of obesity were found in US-born participants than in foreign-born participants. A relevant study showed that a shorter time living in the U.S. was associated with better cardiometabolic health among foreign-born Blacks. [21] The findings of this study suggested that Caribbean-born Black individuals who lived in the U.S. for shorter periods maintain better dietary practices and are more physically active, likely due to cultural practices from their home countries promoting healthier lifestyles. [21] Interestingly, most participants agreed to some degree that their cultural foods were high in fat and sugar. Together, these results suggest that factors related to migration, such as assimilation and acculturation, may play a role in worsening the health behaviors and risk factors that moderate CLD within the Afro-Caribbean diaspora living in the United States.

It was important to examine any cultural tendencies towards alcohol misuse since ALD is the most common cause of advanced hepatic disease worldwide. [22] Harmful drinking is a major risk factor for ALD and liver damage, recognized as 3+ drinks/day or 21+/week in men and 2+ drinks/day and 14+/week in women. [22] In our study, we found that over two-thirds of participants reported drinking monthly or less, and less than two-thirds also reported never drinking 5+ drinks in one sitting. We also found that male and US-born participants reported significantly higher rates of binge drinking. Gender is a potential driving factor for the aforementioned differences since more foreign-born participants were females, and our sample was majority foreign-born. Bivariate analysis also showed males within our sample had a significantly higher frequency of weekly exercise. This is consistent with results from another study, which found a higher prevalence of alcohol and other substance use among middle-aged Jamaican men compared to women. [23] A strong relationship was identified between substance use and behaviors traditionally associated with men, such as risk-taking, dominance, and emotional restraint. [23] Therefore, it is plausible that the differences between males and females in our sample are attributable to gender-specific cultural norms around lifestyle factors related to CLD among Afro-Caribbean groups.

Many challenges to immunization monitoring systems exist within Latin America and the Caribbean (LAC), which are barriers to proper data on vaccination coverage in the region. Our analysis showed that 68% of respondents believed that they were vaccinated for HBV, 17% did not think they were, and 15% were unsure of their HBV vaccination status. One study reported that the coverage of the HBV birth dose vaccine (given within 24 hours of birth) in LAC was 79% in 2018. [24] No reliable data was found on vaccine administration rates beyond the first of three doses within the series of HBV. Consequently, it is unclear whether our results are consistent with the current literature and trends. This is further complicated by the fact that our sample consists of individuals who were born in and are residing in different nations, which have different monitoring systems and vaccine availability. Additionally, the existing data, however limited, points to LAC as a region rather than just the Caribbean or Afro-Caribbean populations. With these limitations, it is not possible to ascertain whether/how HBV vaccination is a substantial factor related to CLD in the Afro-Caribbean diaspora through this study.

Perceptual Factors

Our study found a lack of awareness of CLD among Afro-Caribbean cultures, particularly among those still living in the Caribbean. Most participants agreed to some degree that individuals in their culture were not well-informed about CLD, and less than half agreed that they could identify the symptoms of CLD. Our qualitative analysis further echoed the quantitative results by revealing that many participants felt that CLD was not a topic of concern or a commonly discussed subject within their communities. Hepatitis B transmission knowledge within our sample further exemplifies that awareness around liver disease in the diaspora is limited, with almost an equal split between individuals who said whether they knew how the virus was spread (51% yes vs. 49% no). These results mirror the findings of existing literature, which showed that only 42% of Afro-Haitians knew what HBV was compared to 78% of African Americans. [18] With this in mind, public health initiatives should be developed to target improving shared cultural attitudes and awareness towards CLD in the Afro-Caribbean diaspora. An increase in awareness is likely to improve CLD surveillance efforts and prevention by addressing misconceptions around vaccination, viral hepatitis transmission, and harmful lifestyle norms that increase the risk of CLD.

Another key perceptual factor we looked for was social stigma. All forms of social stigma, including public, self-directed, and structural forms, contribute to delays or failure to seek help, inferior healthcare, and adverse health outcomes. [25] We found that when asked whether they thought someone from their culture would be treated negatively with a CLD, most participants disagreed to some extent. However, this question was probably poorly designed to evaluate for stigma because it relied on the assumption that people would discriminatively act on the stigma rather than the presence of the stigma itself. Shame, a related factor, was also seemingly unsupported since most disagreed to some degree that they would feel ashamed if they had a CLD. In contrast, results from our qualitative analysis provided evidence for both stigma and shame as key social factors that were perceived by our participants to interfere with CLD diagnosis and treatment. This highlights a need for the implementation of efforts to address negative perceptions around CLD among Afro-Caribbean communities.

Based on the existing literature, we expected to see a clear majority of participants who felt that their community was mistrusting of healthcare providers; however, only 32.5% disagreed regarding trusting healthcare providers/systems. It is unclear why this discrepancy exists because our qualitative analysis found that medical mistrust was a prevailing theme in the response of participants regarding perceived barriers to CLD treatment/diagnosis. Response biases associated with question structure may be responsible for the ambiguous results from these Likert-style questions. The historical existence of anti-black systemic racism, discrimination, and inequalities in healthcare has helped to establish a widespread mistrust among Black people in the U.S. One study suggests the implementation of universal health policies designed to benefit all citizens is insufficient to reduce Black racial health inequities. [26] In the context of Afro-Caribbean people, this illuminates a need for community-specific policies to address the current health disparities. Perhaps an increase in culturally competent healthcare can help to reduce factors such as mistrust and care avoidance in the diaspora. A reduction in these factors may influence change toward better screening and treatment adherence for CLD by increasing care-seeking behavior in the Afro-Caribbean people.

Other prevailing themes identified within qualitative results of the perceived barriers include lack of financial resources, lack of access to healthcare, fear of racism/discrimination, fear of diagnosis, religious influence, and tendency to use alternative medicine. These factors are also congruent with existing literature. [18,25,26]

Health-Related Behavioral Factors

Respondents mostly demonstrated an inclination towards health consciousness and health-seeking behaviors. Most respondents disagreed that fear of diagnosis would stop them from testing for CLD. The overwhelming majority of respondents also indicated that they are inclined to make lifestyle changes/ diet modifications if necessary to avoid/treat a CLD. Most also said they would adhere to the treatment plan given by their healthcare providers. Finally, a majority agreed that they would vaccinate their children for HBV. The collective results gathered from this health behavior analysis show that our respondents have positive attitudes toward the preservation of their health, including against CLD. However, this is not consistent with the themes identified from qualitative results as factors that they perceived as barriers to CLD diagnosis and treatment within their cultural communities. Despite detailing many potentially adverse attitudes and behaviors among their cultures, most respondents did not express a likelihood of engaging in these attitudes or behaviors themselves. This inconsistency could be attributed to response biases. The negative perceptions held by respondents regarding attitudes and behaviors towards CLD in their communities may have promoted a need to hide their true likelihood towards the behavior statements to seem more socially acceptable. The structure of most behavior questions on the Likert scale could have promoted an acquiescence bias by presenting what participants interpreted as positive behaviors, along with binary response options where they may tend to agree. [27]

Study Limitations

In addition to the aforementioned weaknesses, this study had other limitations. Firstly, the survey instrument was not validated, though it was created based on a literature review and the study aims. Thus, addressing the previously discussed biases relating to survey structure would depend on conducting a follow-up study using validated instruments to better investigate the variables of interest. The “check all that apply” format of the race question introduces a challenge in determining whether participants met the inclusion criteria due to the ability to select other or multiracial without also selecting black. This could be simplified by having a separate question that asked, “Do you identify as Afro-Caribbean?” that would prompt participants to specify their racial admixture as monoracial or multiracial black if they said yes and alerted towards discontinuing the survey if they selected no. Similarly, an additional question should have been included to identify which Afro-Caribbean communities they belonged to, along with the existing questions about their parents’ nationalities. This would further illuminate the status of participants within the diaspora by providing a point of cultural connection for people who were multigenerational Caribbean Americans. We planned to compare factors in our sample by age as done with gender and country of birth; however, during a preliminary analysis of our data, we noticed that the age range was very narrow and young. Therefore, it was decided that this range was a limitation to determining any worthwhile differences relating to age. Lesser-educated and older participants may not be technologically savvy enough to complete the survey through these mediums on their own. Older individuals may also be less engaged on social media platforms than younger individuals, which may have lessened their chances of coming across recruitment posts. Any future efforts would require targeting older participants by focusing on in-person/phone interviews to match the engagement of young participants from online recruitment. This strategy would also be effective in recruiting more individuals who are less well-educated on average than our current sample, including those who struggle with literacy. Broadening the participant age and education range would result in a sample that is more generalizable to the target population. We also hoped to have more ethnic diversity in our sample with more Hispanic/Latino Afro-Caribbean individuals. The survey only being administered in English was the main limitation to reaching this demographic since there are many people from this community who only or primarily speak Spanish. Translating the survey into Spanish would be a means of addressing this weakness. Finally, we sought to examine the potential differences between those who lived in the U.S. vs their birth nations for longer vs. shorter periods to look for any trends potentially related to assimilation. However, limiting responses to only foreign-born respondents proved to be one of a few challenges that made it difficult to measure and complicated to analyze. This can be an additional target for future efforts.

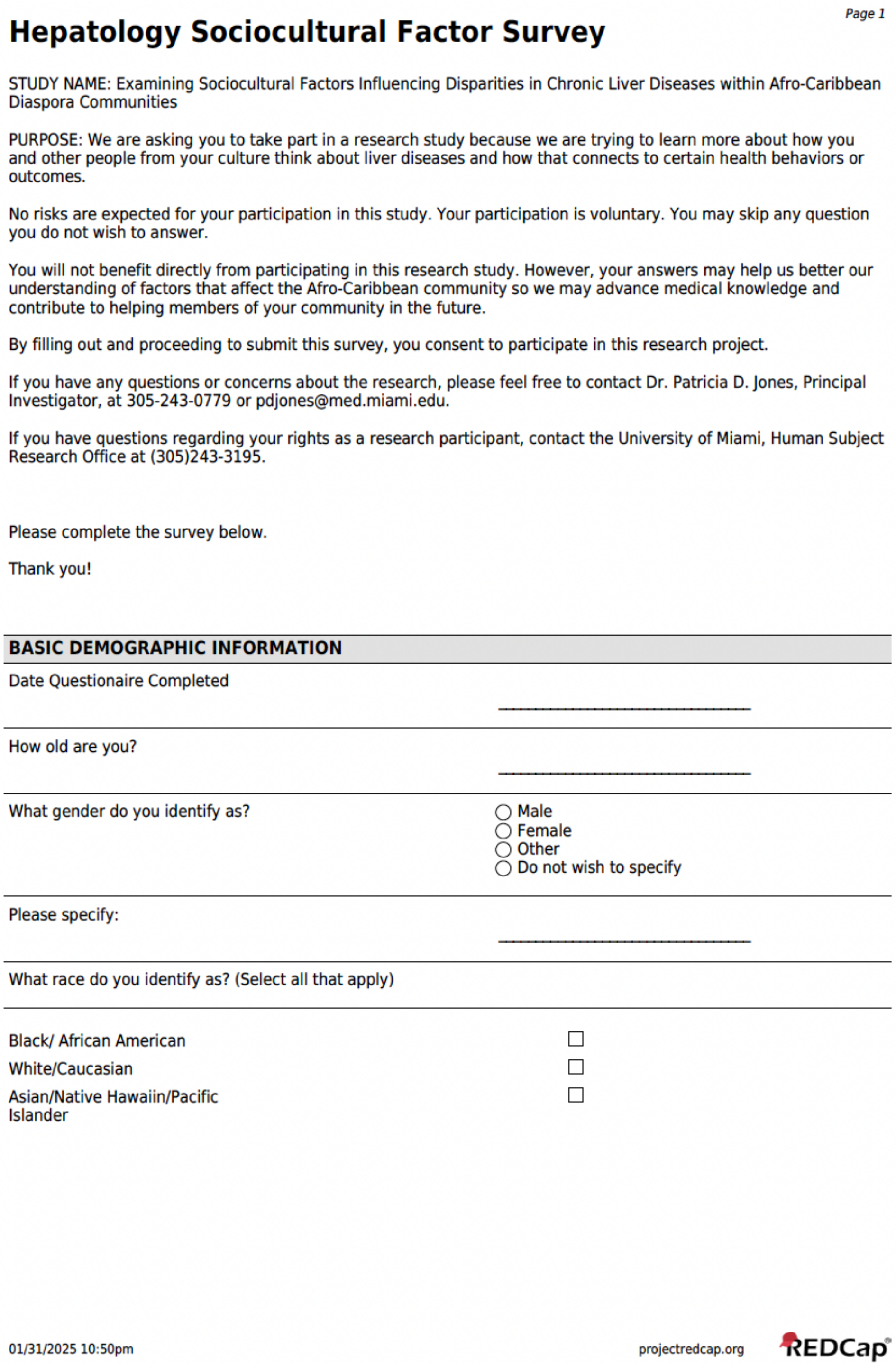
Conclusion

To this author's best knowledge, this is the first and only study to survey multiple Afro-Caribbean communities relating sociocultural factors to chronic liver disease. With the heterogeneity of demographic characteristics within the sample, it is reasonable to propose that the social and cultural factors identified apply across the Afro-Caribbean diaspora. The results of this study provided evidence of key social and cultural factors that are related to CLD within the Afro-Caribbean diaspora that were identified among our sample and based on what participants perceived to be relevant among their communities. The factors include alcohol/drug misuse, poor diet, lack of exercise, history of obesity and diabetes, lack of awareness and knowledge, low health literacy, social stigma, shame, medical mistrust, lack of financial resources and healthcare access, fear of diagnosis, religious/spiritual beliefs, and tendency to use alternative medicine. Statistically significant differences were also identified between genders and birth locations for some factors such as obesity prevalence, exercise, alcohol usage, and binge drinking.

An improved understanding of the role these factors play and how they potentially drive disparities in preventative measures, early diagnostic surveillance, and treatment outcomes are important targets for future studies. Once the roles of these principal factors are understood, we will gain the opportunity to address health inequities facing the Afro-Caribbean diaspora. Future research is also necessary to identify any differences within the specific Afro-Caribbean cultures to understand how they compare or differ from each other and other minority groups in the U.S.

APPENDIX A

THE SOCIOCULTURAL FACTOR SURVEY INSTRUMENT



Page 1

Hepatology Sociocultural Factor Survey

STUDY NAME: Examining Sociocultural Factors Influencing Disparities in Chronic Liver Diseases within Afro-Caribbean Diaspora Communities

PURPOSE: We are asking you to take part in a research study because we are trying to learn more about how you and other people from your culture think about liver diseases and how that connects to certain health behaviors or outcomes.

No risks are expected for your participation in this study. Your participation is voluntary. You may skip any question you do not wish to answer.

You will not benefit directly from participating in this research study. However, your answers may help us better our understanding of factors that affect the Afro-Caribbean community so we may advance medical knowledge and contribute to helping members of your community in the future.

By filling out and proceeding to submit this survey, you consent to participate in this research project.

If you have any questions or concerns about the research, please feel free to contact Dr. Patricia D. Jones, Principal Investigator, at 305-243-0779 or pdjones@med.miami.edu.

If you have questions regarding your rights as a research participant, contact the University of Miami, Human Subject Research Office at (305)243-3195.

Please complete the survey below.

Thank you!

BASIC DEMOGRAPHIC INFORMATION

Date Questionaire Completed ______________________________

How old are you? ______________________________

What gender do you identify as?
○ Male
○ Female
○ Other
○ Do not wish to specify

Please specify: ______________________________

What race do you identify as? (Select all that apply)

Black/ African American ☐
White/Caucasian ☐
Asian/Native Hawaiin/Pacific Islander ☐

01/31/2025 10:50pm projectredcap.org

Indigenous American/ Alaskan Native	☐
Multiracial	☐
Other	☐
Please specify:	__________________________________
Please specify:	__________________________________
What ethnicity do you identify as?	○ I am Hispanic/Latino ○ I am not Hispanic/Latino
What city do you currently live in?	__________________________________
What state do you currently live in?	__________________________________
What country were you born in?	__________________________________
What country was your mother born in?	__________________________________
What country was your father born in?	__________________________________
Do you currently live in the United States?	○ Yes ○ No
If yes, what year did you move to the U.S.?	__________________________________
If yes, how many years have you lived in the U.S. in total?	__________________________________
How many years did you live in the country you were born?	__________________________________
What is your first language?	○ English ○ Spanish ○ French ○ Haitian Creole ○ Dutch ○ Other
Please specify:	__________________________________
What other languages and/or dialects do you speak?	__________________________________

What is your highest level of education?	○ Less than High School ○ High School Diploma ○ Post-Secondary Certificate ○ Some College ○ Trade or Vocational School ○ Associate's Degree ○ Bachelor's Degree ○ Master's Degree ○ Doctorate Degree
Religion is often intertwined with and can be connected to a person's cultural identity. If applicable, please select one of the following religious affiliations:	○ No religion ○ Christian or Catholic ○ Buddhist ○ Hindu ○ Jewish ○ Muslim ○ Rastafarian ○ Sikh ○ Other
Please specify:	__________________________________

GENERAL HEALTH AND LIFESTYLE

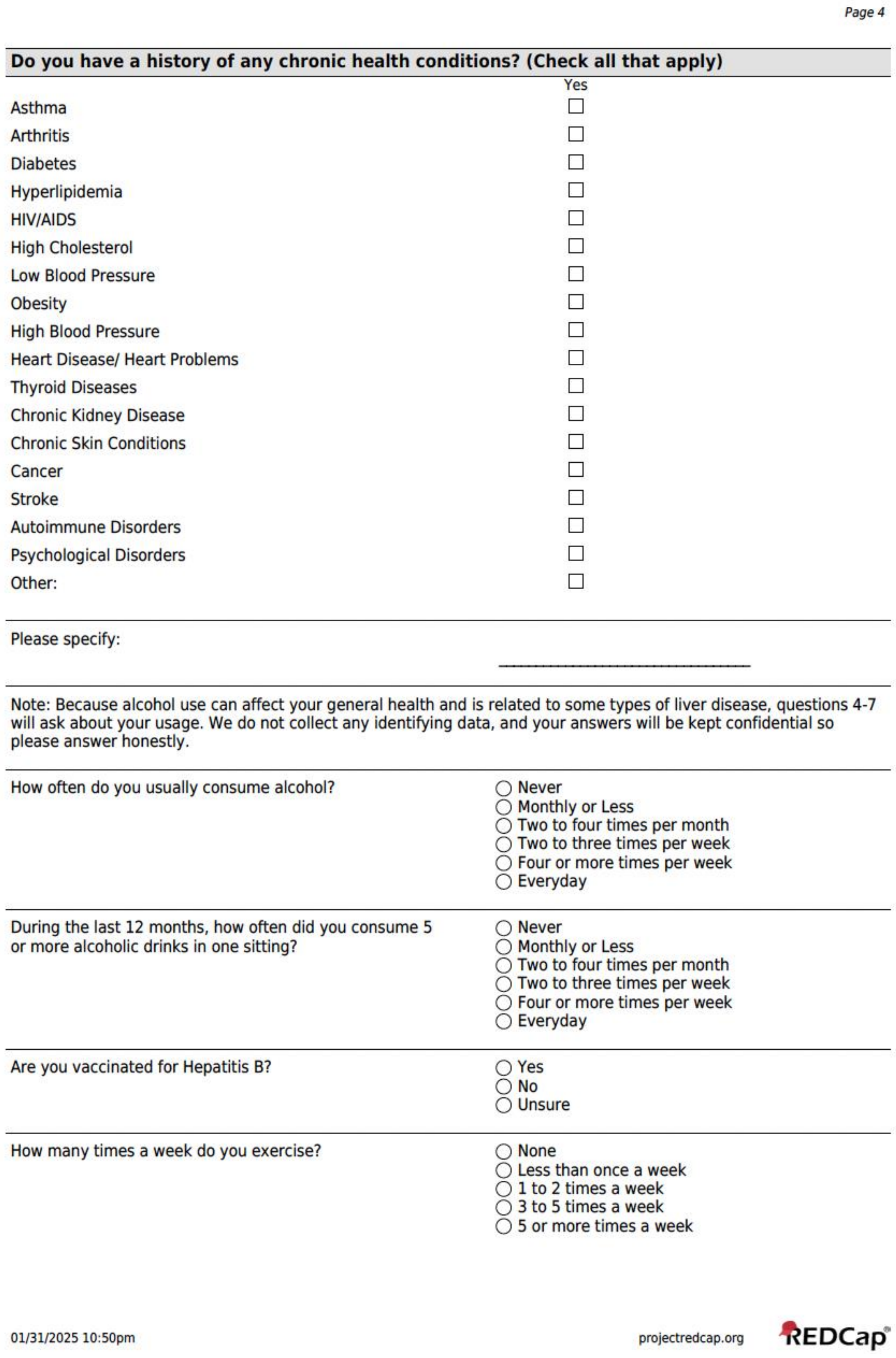
The following questions will ask about your general health background and exposure to liver diseases. Please answer to the best of your ability:

Have you ever been diagnosed with or treated for any chronic liver diseases?	○ Yes ○ No ○ Unsure

If you answered yes to having a history of chronic liver disease, check all that apply:

	Yes
Hepatitis B	☐
Hepatitis C	☐
Fatty Liver Disease	☐
Alcoholic Liver Disease	☐
Liver Cirrhosis	☐
Primary Biliary Cirrhosis	☐
Autoimmune Hepatitis	☐
Wlison's Disease	☐
Alpha-antitrypsin Deficiency	☐
Cystic Fibrosis	☐
Liver Cancer	☐

Do you have a family history of liver disease?	○ Yes ○ No ○ Unsure



Do you have a history of any chronic health conditions? (Check all that apply)

	Yes
Asthma	☐
Arthritis	☐
Diabetes	☐
Hyperlipidemia	☐
HIV/AIDS	☐
High Cholesterol	☐
Low Blood Pressure	☐
Obesity	☐
High Blood Pressure	☐
Heart Disease/ Heart Problems	☐
Thyroid Diseases	☐
Chronic Kidney Disease	☐
Chronic Skin Conditions	☐
Cancer	☐
Stroke	☐
Autoimmune Disorders	☐
Psychological Disorders	☐
Other:	☐

Please specify: ________________________________

Note: Because alcohol use can affect your general health and is related to some types of liver disease, questions 4-7 will ask about your usage. We do not collect any identifying data, and your answers will be kept confidential so please answer honestly.

How often do you usually consume alcohol?	○ Never ○ Monthly or Less ○ Two to four times per month ○ Two to three times per week ○ Four or more times per week ○ Everyday
During the last 12 months, how often did you consume 5 or more alcoholic drinks in one sitting?	○ Never ○ Monthly or Less ○ Two to four times per month ○ Two to three times per week ○ Four or more times per week ○ Everyday
Are you vaccinated for Hepatitis B?	○ Yes ○ No ○ Unsure
How many times a week do you exercise?	○ None ○ Less than once a week ○ 1 to 2 times a week ○ 3 to 5 times a week ○ 5 or more times a week

CULTURAL PERCEPTIONS

Below is a list of statements about health, lifestyle, and liver diseases that may apply to the perceptions of you and and others in your cultural community. Please indicate or mark one answer per line to represent how much you agree with each statement where
1=Strongly Disagree 2=Disagree 3=Neither Agree nor Disagree 4=Agree 5=Strongly Agree

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
People from my culture are well informed about liver diseases.	○	○	○	○	○
People from my culture share similar ideas & attitudes about health.	○	○	○	○	○
In my culture, someone with a liver disease would face isolation or be treated poorly.	○	○	○	○	○
If I was diagnosed with a chronic liver disease, I feel I would have strong support from my family and friends during my treatment.	○	○	○	○	○
I would feel ashamed if I was diagnosed with a chronic liver disease.	○	○	○	○	○
I would tell my family if I was diagnosed with a chronic liver disease.	○	○	○	○	○
People from my culture are trusting of their medical providers and healthcare system.	○	○	○	○	○
People from my culture tend to use home remedies or over-the-counter medications instead of going to the doctor when feeling sick.	○	○	○	○	○
I feel that religion influences the way people in my culture think about their health.	○	○	○	○	○
I feel satisfied with my current financial situation.	○	○	○	○	○
I feel that my cultural foods are high in fat and sugar.	○	○	○	○	○
I feel I can recognize the signs and symptoms of liver diseases.	○	○	○	○	○

The following questions will ask you about your general perception of liver disease.

Do you personally know someone who has had a chronic liver disease? ○ Yes ○ No

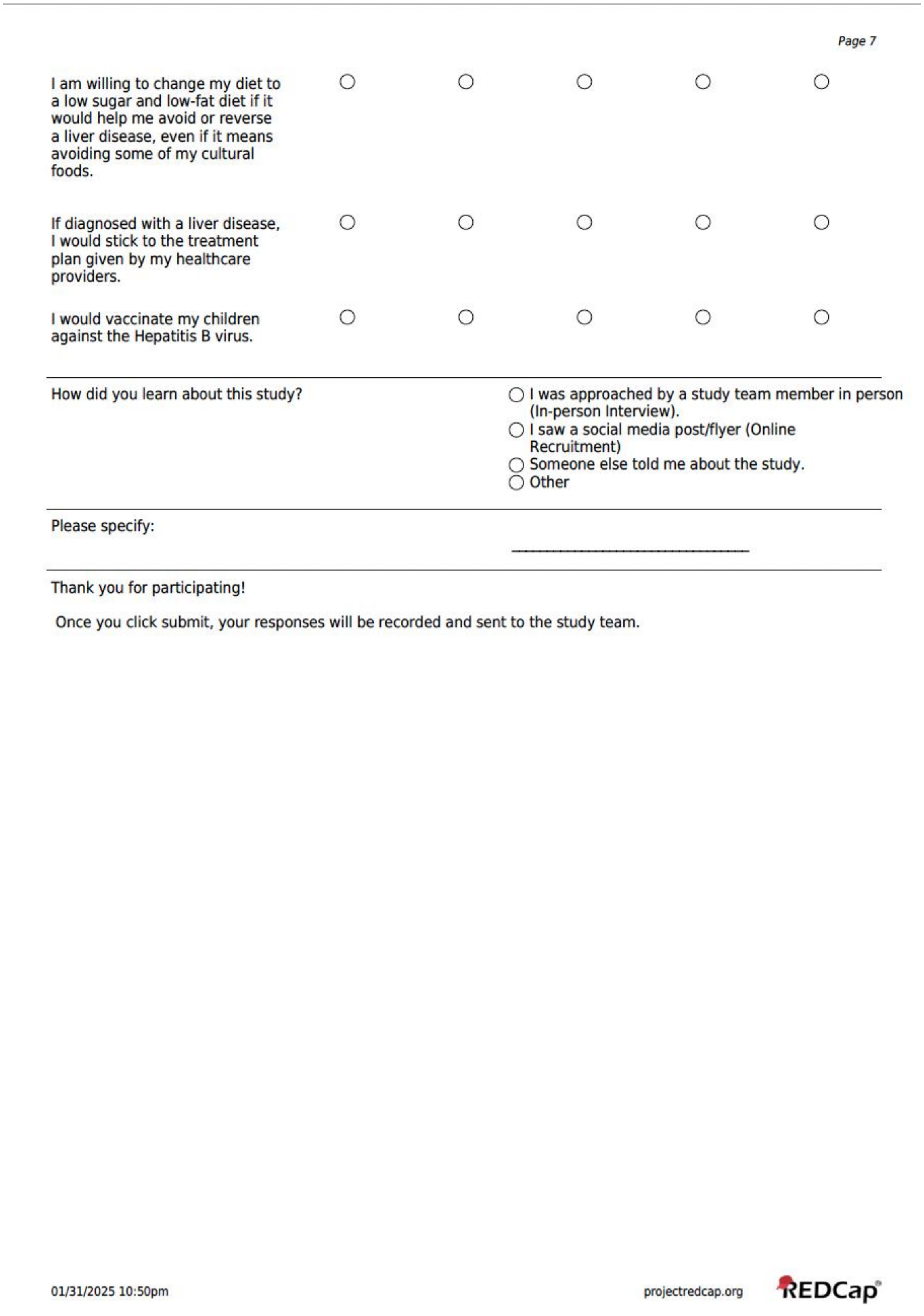
What do you think are the most common causes of liver disease?	________________________
Where did you first hear about liver disease?	○ In my home country (In the Caribbean) ○ In the United States
Briefly describe what you think people in your cultural community think about liver disease.	________________________
Briefly list what things you feel might stop people from your culture from seeking medical diagnosis or treatment for liver diseases?	________________________
Do you know how the Hepatitis B virus is spread?	○ Yes ○ No
If you answered yes, how is the Hepatitis B virus spread?	________________________

HEALTH-RELATED BEHAVIOR

Below is a list of statements about personal health behaviors and decisions that you as an individual may make to prevent or get diagnosed/treated for liver diseases. Please indicate or mark one answer per line to represent how much you agree with each statement.

1= Strongly Disagree 2=Disagree 3=Neither Agree nor Disagree 4=Agree 5=Strongly Agree

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
I routinely follow up with my primary care doctor at least once a year, even if I am feeling fine.	○	○	○	○	○
If I noticed symptoms of a liver disease, I would urgently seek medical attention.	○	○	○	○	○
If I felt my symptoms were minor, I would try to use cultural or herbal remedies to help myself.	○	○	○	○	○
My fear of being diagnosed with a chronic liver disease would cause me to avoid going to get tested.	○	○	○	○	○
I would make lifestyle changes including exercising and avoiding alcohol or smoking if necessary to treat a liver disease.	○	○	○	○	○



Page 7

I am willing to change my diet to a low sugar and low-fat diet if it would help me avoid or reverse a liver disease, even if it means avoiding some of my cultural foods.	○	○	○	○	○
If diagnosed with a liver disease, I would stick to the treatment plan given by my healthcare providers.	○	○	○	○	○
I would vaccinate my children against the Hepatitis B virus.	○	○	○	○	○

How did you learn about this study?	○ I was approached by a study team member in person (In-person Interview). ○ I saw a social media post/flyer (Online Recruitment) ○ Someone else told me about the study. ○ Other
Please specify:	__________________________________

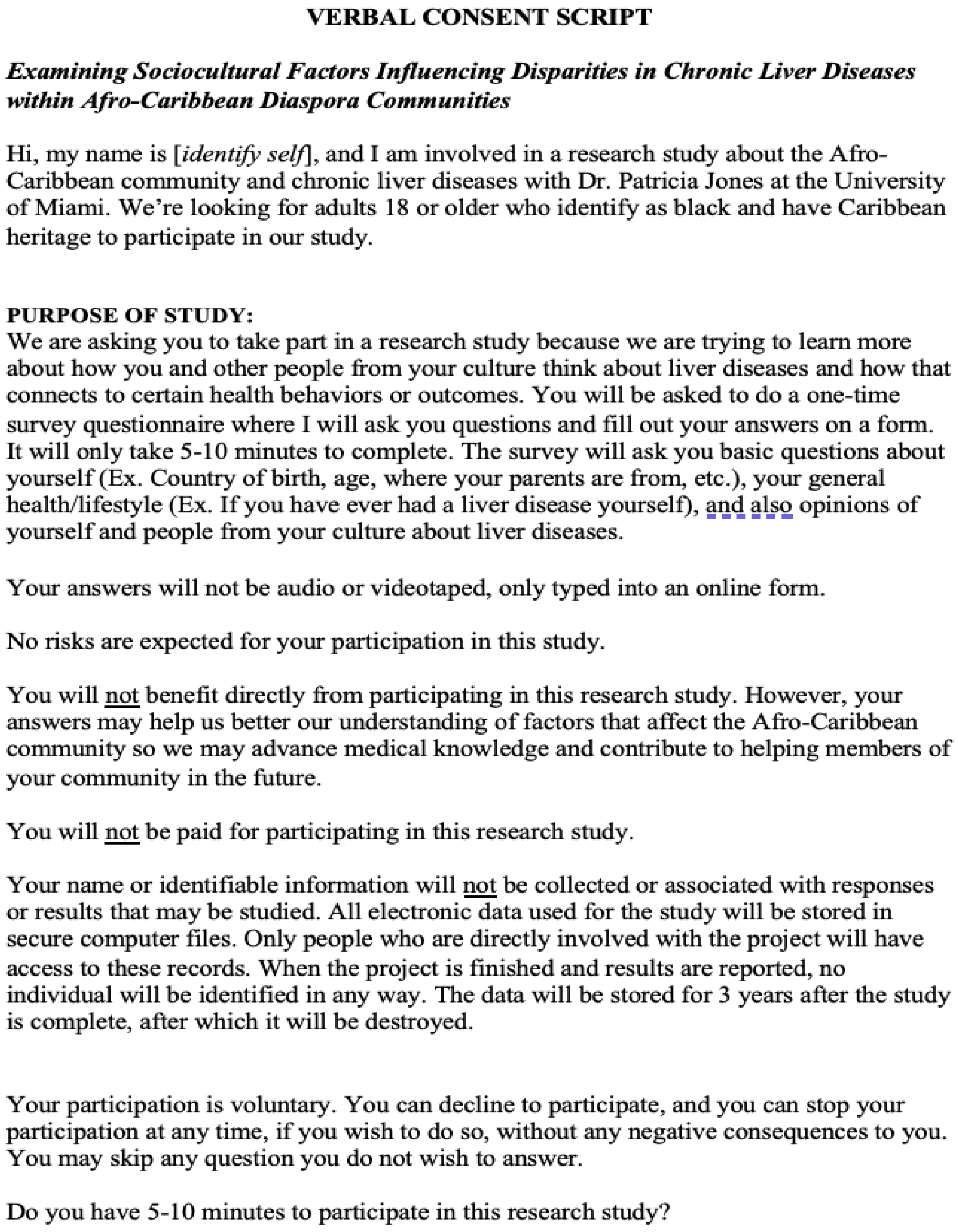
Thank you for participating!

Once you click submit, your responses will be recorded and sent to the study team.

01/31/2025 10:50pm projectredcap.org REDCap

APPENDIX B

RECRUITMENT PLEA AND VERBAL CONSENT SCRIPT



VERBAL CONSENT SCRIPT

Examining Sociocultural Factors Influencing Disparities in Chronic Liver Diseases within Afro-Caribbean Diaspora Communities

Hi, my name is [*identify self*], and I am involved in a research study about the Afro-Caribbean community and chronic liver diseases with Dr. Patricia Jones at the University of Miami. We're looking for adults 18 or older who identify as black and have Caribbean heritage to participate in our study.

PURPOSE OF STUDY:
We are asking you to take part in a research study because we are trying to learn more about how you and other people from your culture think about liver diseases and how that connects to certain health behaviors or outcomes. You will be asked to do a one-time survey questionnaire where I will ask you questions and fill out your answers on a form. It will only take 5-10 minutes to complete. The survey will ask you basic questions about yourself (Ex. Country of birth, age, where your parents are from, etc.), your general health/lifestyle (Ex. If you have ever had a liver disease yourself), and also opinions of yourself and people from your culture about liver diseases.

Your answers will not be audio or videotaped, only typed into an online form.

No risks are expected for your participation in this study.

You will not benefit directly from participating in this research study. However, your answers may help us better our understanding of factors that affect the Afro-Caribbean community so we may advance medical knowledge and contribute to helping members of your community in the future.

You will not be paid for participating in this research study.

Your name or identifiable information will not be collected or associated with responses or results that may be studied. All electronic data used for the study will be stored in secure computer files. Only people who are directly involved with the project will have access to these records. When the project is finished and results are reported, no individual will be identified in any way. The data will be stored for 3 years after the study is complete, after which it will be destroyed.

Your participation is voluntary. You can decline to participate, and you can stop your participation at any time, if you wish to do so, without any negative consequences to you. You may skip any question you do not wish to answer.

Do you have 5-10 minutes to participate in this research study?

{<u>Only if the participant seems agreeable but expresses that they do not have the time while on-site</u>} If you are interested in participating but do not have the time right now, you can scan this QR code for a link where you can complete the survey on your own at a more convenient time.

By you answering the survey/interview questions that I will ask, this means you consent to participate in this research project. Do you have any questions?

If you have any questions or concerns about the research, please feel free to contact Dr. Patricia D. Jones, Principal Investigator, at 305-243-0779 or pdjones@med.miami.edu.

If you have questions regarding your rights as a research participant, contact the University of Miami, Human Subject Research Office at (305)243-3195.

BIBLIOGRAPHY

1. Devarbhavi H, Asrani SK, Arab JP, Nartey YA, Pose E, Kamath PS. Global burden of liver disease: 2023 update. *Journal of Hepatology*. 2023;79(2):516-537. doi:10.1016/j.jhep.2023.03.017

2. Sharma A, Nagalli S. Chronic Liver Disease. In: *StatPearls*. StatPearls Publishing; 2024. Accessed October 6, 2024. http://www.ncbi.nlm.nih.gov/books/NBK554597/

3. Akkız H, Gieseler RK, Canbay A. Liver Fibrosis: From Basic Science towards Clinical Progress, Focusing on the Central Role of Hepatic Stellate Cells. *International Journal of Molecular Sciences*. 2024;25(14):7873. doi:10.3390/ijms25147873

4. Ginès P, Krag A, Abraldes JG, Solà E, Fabrellas N, Kamath PS. Liver cirrhosis. *The Lancet*. 2021;398(10308):1359-1376. doi:10.1016/S0140-6736(21)01374-X

5. Rumgay H, Arnold M, Ferlay J, et al. Global burden of primary liver cancer in 2020 and predictions to 2040. *Journal of Hepatology*. 2022;77(6):1598-1606. doi:10.1016/j.jhep.2022.08.021

6. Coffin P, He A. Hepatocellular Carcinoma: Past and Present Challenges and Progress in Molecular Classification and Precision Oncology. *International Journal of Molecular Sciences*. 2023;24(17):13274. doi:10.3390/ijms241713274

7. Gabbia D, De Martin S. Insights into Hepatocellular Carcinoma: From Pathophysiology to Novel Therapies. *International Journal of Molecular Sciences*. 2024;25(8):4188. doi:10.3390/ijms25084188

8. Parola M, Pinzani M. Liver fibrosis in NAFLD/NASH: from pathophysiology towards diagnostic and therapeutic strategies. *Molecular Aspects of Medicine*. 2024;95:101231. doi:10.1016/j.mam.2023.101231

9. Mehta P, Grant LM, Reddivari AKR. Viral Hepatitis. In: *StatPearls*. StatPearls Publishing; 2025. Accessed January 26, 2025. http://www.ncbi.nlm.nih.gov/books/NBK554549/

10. Usuda D, Kaneoka Y, Ono R, et al. Current perspectives of viral hepatitis. *World Journal of Gastroenterology*. 2024;30(18):2402-2417. doi:10.3748/wjg.v30.i18.2402

11. Asandem DA, Segbefia SP, Kusi KA, Bonney JHK. Hepatitis B Virus Infection: A Mini Review. *Viruses*. 2024;16(5):724. doi:10.3390/v16050724

12. Ayares G, Díaz LA, Fuentes-López E, et al. Racial and ethnic disparities in the natural history of alcohol-associated liver disease in the United States. *Liver International*. 2024;44(10):2822-2833. doi:10.1111/liv.16023

13. Bae JH. Racial and ethnic disparities in metabolic dysfunction-associated steatotic liver disease outcomes: A call for culturally sensitive interventions: Editorial on "Differences in liver and mortality outcomes of non-alcoholic fatty liver disease by race and ethnicity: A longitudinal real-world study." *Clinical and Molecular Hepatology*. 2024;30(4):665-668. doi:10.3350/cmh.2024.0562

14. Kardashian A, Serper M, Terrault N, Nephew LD. Health disparities in chronic liver disease. *Hepatology*. 2023;77(4):1382. doi:10.1002/hep.32743

15. Conners EE. Screening and Testing for Hepatitis B Virus Infection: CDC Recommendations — United States, 2023. *Morbidity and Mortality Weekly Report. Recommendations and Reports*. 2023;72. doi:10.15585/mmwr.rr7201a1

16. Schweitzer A, Horn J, Mikolajczyk RT, Krause G, Ott JJ. Estimations of worldwide prevalence of chronic hepatitis B virus infection: a systematic review of data published between 1965 and 2013. *The Lancet*. 2015;386(10003):1546-1555. doi:10.1016/S0140-6736(15)61412-X

17. Leumi S, Bigna JJ, Amougou MA, Ngouo A, Nyaga UF, Noubiap JJ. Global Burden of Hepatitis B Infection in People Living With Human Immunodeficiency Virus: A Systematic Review and Meta-analysis. *Clinical Infectious Diseases*. 2020;71(11):2799-2806. doi:10.1093/cid/ciz1170

18. Jones P, Soler J, Solle NS, Martin P, Kobetz E. A mixed-methods approach to understanding perceptions of hepatitis B and hepatocellular carcinoma among ethnically diverse Black communities in South Florida. *Cancer Causes Control CCC*. 2020;31(12):1079-1091. doi:10.1007/s10552-020-01345-6

19. Wilson R, Williams DM. Cirrhosis. *Medical Clinics of North America*. 2022;106(3):437-446. doi:10.1016/j.mcna.2021.12.001

20. Han SK, Baik SK, Kim MY. Non-alcoholic fatty liver disease: Definition and subtypes. *Clinical and Molecular Hepatology*. 2022;29(suppl):S5-S16. doi:10.3350/cmh.2022.0424

21. Anikpo I, Dodds L, Mesa RA, Tremblay J, Vilchez L, Elfassy T. Length of Time in the United States and Cardiometabolic Outcomes Among Foreign and US-Born Black Adults. *Journal of Racial and Ethnic Health Disparities*. 2025;12(1):640-648. doi:10.1007/s40615-023-01902-0

22. Jophlin LL, Singal AK, Bataller R, et al. ACG Clinical Guideline: Alcohol-Associated Liver Disease. *Official Journal of the American College of Gastroenterology ACG*. 2024;119(1):30. doi:10.14309/ajg.0000000000002572

23. Govia IO, Doubova SV, Younger-Coleman N, Atkinson U. Gender Differences in Prevalence and Risk Factors Associated With Substance Use in 50- to 65-Year-Old Jamaicans. *Journal of Addictions Nursing*. 2022;33(3):144. doi:10.1097/JAN.0000000000000430

24. Velandia-González M, Vilajeliu A, Contreras M, et al. Monitoring progress of maternal and neonatal immunization in Latin America and the Caribbean. *Vaccine*. 2021;39 Suppl 2:B55-B63. doi:10.1016/j.vaccine.2020.12.043

25. Schomerus G, Leonhard A, Manthey J, et al. The stigma of alcohol-related liver disease and its impact on healthcare. *Journal of Hepatology*. 2022;77(2):516-524. doi:10.1016/j.jhep.2022.04.026

26. Neighbors HW, Mattingly DT, Johnson J, Morse K. The contribution of research to racial health equity? Blame and responsibility in navigating the status quo of anti-black systemic racism. *Social Science and Medicine*. 2023;316:115209. doi:10.1016/j.socscimed.2022.115209

27. Westland JC. Information loss and bias in likert survey responses. *Public Library of Science One*. 2022;17(7):e0271949. doi:10.1371/journal.pone.0271949

CURRICULUM VITAE

[redacted]

[redacted]

[redacted]