

Why Liver Cancer Hits Home: Bridging Healthcare Disparities in the Asian American and Pacific Islander Community

Daneng Li¹, Spencer Cheng², Andrea Wilson Woods³, Allyson Luong³, Sarah Schiltz³, Ruoding Tan², Zeena Huang Chi²

¹City of Hope Comprehensive Cancer Center, Duarte, CA, USA; ²Genentech, South San Francisco, CA, USA; ³Blue Faery: The Adrienne Wilson Liver Cancer Association, Birmingham, AL, USA

Correspondence: Daneng Li, City of Hope Comprehensive Cancer Center, 1500 E. Duarte Road, Duarte, CA, 91010, USA, Email danli@coh.org

Abstract: Asian Americans and Pacific Islanders have an increased risk of developing liver cancer and higher risk of death compared to non-Hispanic White individuals. The role of individual-level risk factors, social determinants of health, and barriers navigating health systems present unique challenges in obtaining liver cancer care for these patients. Additionally, the Asian American and Pacific Islander population is a heterogeneous group originating from several different countries and speaking various languages, and they are often underrepresented in cancer clinical trial populations. This article describes the challenges faced by Asian American and Pacific Islander patients with liver cancer from the clinician, research, and patient advocacy perspectives and proposes targeted solutions to reduce healthcare disparities in this group.

Keywords: Asian American and Pacific Islander, health equity, hepatocellular carcinoma, cancer care

Introduction

In 2021, approximately 24 million Asian Americans and 1.7 million Native Hawaiian and Other Pacific Islanders were living in the United States (US). Asian American and Pacific Islanders (AAPI) currently represent the fastest-growing racial and ethnic population and are projected to exceed 40 million in the US by 2060.^{1,2} While Asian individuals in the US generally have a 40% lower overall cancer death rate than non-Hispanic White individuals, disparities still exist in certain types of cancer. In particular, Asian Americans are 40% more likely to die from liver cancer.³ Overall, cancer remains the leading cause of death for Asian Americans.^{3,4}

Liver cancer is ranked one of the top 3 most common cancer types among AAPI individuals.³ Despite comprising only 6% to 7% of the total US population, AAPI represents over 50% of individuals affected by hepatitis B, a condition associated with 50% of hepatocellular carcinoma (HCC) cases globally, which is the predominant form of liver cancer.^{1,5,6} Recent studies indicate that while the overall incidence of HCC has been increasing in the US between 2001 and 2020, there have been decreases in incidence in the AAPI population. This trend is mostly attributed to the early detection and treatment of liver conditions, including those caused by hepatitis B virus (HBV).^{3,5,6}

Along the liver cancer care cascade, from awareness and screening to specialist care and receipt of treatment, AAPI patients experience unique barriers to care. The oncology healthcare community must understand the current state of liver cancer disparities experienced by Asian Americans in order to address the hurdles that exist. This article discusses these healthcare disparities from the clinician, research, and patient advocacy perspectives. By highlighting these multifaceted issues, we can then suggest and advocate for targeted initiatives that can effectively improve outcomes in the AAPI population.

AAP: A Heterogenous Group

The AAP population is made up of individuals from over 30 countries and diverse ethnic backgrounds, collectively speaking more than 100 different languages. Despite this rich diversity, they are frequently grouped as a single racial and ethnic group in US healthcare settings, overlooking inherent differences in their cancer risk factors, clinical outcomes, communication styles, and access barriers.⁷ Specifically, differences in cultural beliefs, languages, migration history and patterns, socioeconomic status, and behavioral factors uniquely impact overall health and cancer-specific risk factors for each individual within the AAP population. As a result, liver cancer mortality varies greatly within this population. For example, a study published in 2021 found that Vietnamese Americans were three times more likely to die from liver cancer compared with non-Hispanic White individuals, but the likelihood of death was 35% less among Indian Americans compared with non-Hispanic White individuals.⁸ A 2023 study using data from the California Cancer Registry found that among AAP patients with hepatocellular carcinoma (HCC), those born in Southeast Asia have higher mortality rates compared to those born in East Asian countries.⁹

Individual-Level Liver Cancer Risk Factors

In the US population, the primary risk factor for liver cancer is cirrhosis from underlying conditions, including chronic HBV and hepatitis C virus (HCV) infections.¹⁰ However, in the AAP population distinct patterns of risk factors are closely tied to country of origin, immigration patterns, and health behaviors.

In the US, AAP individuals account for more than 50% of chronic HBV cases, with a significant portion occurring in immigrants. This disparity creates a higher burden of liver cancer due to HBV infection compared with the overall population.^{5,11,12} While many universal HBV vaccination programs in Asian countries have been associated with decreases in liver cancer incidence, the vaccination rates in the AAP population in the US remain low, and the prevalence of and mortality from HBV is more than two times that in non-Hispanic White individuals, allowing the risk of liver cancer to persist.^{13,14} The effectiveness of programs to prevent liver cancer through HBV vaccination and antiviral agent use has been limited due to disparities in healthcare access, awareness, and utilization of the most effective treatment modalities.^{14,15}

While AAP individuals in the US comprise a smaller proportion of HCV cases, notable variations exist across different ethnic groups. For example, a study published in 2022 revealed varying prevalence rates of HCV infection among different Asian communities in California. The highest prevalence was observed among Cambodian and Vietnamese populations, whereas Chinese and Korean populations exhibited the lowest rates.¹⁶ It is important to highlight that HCV transmission within AAP communities is less commonly associated with intravenous drug use but, rather, is linked to the reuse of needles in acupuncture and immunizations.¹⁷ Additionally, the incidence and mortality of liver cancer related to alcoholic fatty liver disease and metabolic dysfunction-associated fatty liver disease have increased.¹⁰

Social Determinants of Health

In addition to disease-related risk factors, specific social determinants of health and behaviors also contribute to the increased risk of liver cancer and disparities in treatment and access to care among AAP individuals. Approximately 13% of first-generation AAP patients live in poverty, and 4% are unemployed. AAP individuals constitute approximately 30% of legal immigrants who enter the US annually, and nearly two-thirds of AAP individuals in the US are foreign born.⁷ The assimilation process among immigrants can lead to sedentary and isolated lifestyles, potentially leading to increased rates of overweight and obesity. Additionally, the Native Hawaiian and Pacific Islander population has higher rates of smoking, alcohol consumption, and obesity compared with other minority populations in the US.¹⁸

The average uninsured rate for all AAP patients was approximately 7% in 2019; however, this varies greatly among subgroups, ranging from 3% for Japanese Americans, 10% for Korean Americans, and 12% for Native Hawaiian and Pacific Islanders. These statistics do not account for those who are underinsured or have difficulties navigating coverage barriers, which also greatly impact access to care and treatment options.¹⁹ A 2022 report showed that older Native

Hawaiian and Other Pacific Islander patients are less likely to be able to pay medical bills associated with cancer treatments and more likely to delay or forgo medical care compared with non-Hispanic White patients.²⁰

Clinical Trial Representation and Data Equity

Despite the growing AAPI population in the US and their increased risk of cancer-related mortality, their representation in oncology clinical trials remains disproportionately low. Historically, clinical trials examining risk factors and tumor development have predominantly included individuals with European ancestry or White individuals. A study published in 2022 found that Asian Americans comprised only 2% of US clinical trial participants across 231 studies conducted between 2015 and 2019.⁴ This lack of representation in racial and ethnic minority populations has significantly limited our knowledge of genetic predispositions that lead to increased risk, higher incidence, and greater mortality of cancer in these patients.

As highlighted above, the significant heterogeneity within racial and ethnic minority groups underscores the critical need to disaggregate the AAPI subpopulations for data collection and analyses. The grouping together of different subpopulations has resulted in assumptions that all AAPI patients have better survival compared with other racial and ethnic groups. However, it is more likely that each subpopulation experiences distinct outcomes. Two studies examining AAPI subpopulations have found disparities in diagnosis rates, receipt of treatment, and mortality risks of liver cancer among different subpopulations. Such variations can lead to misinterpretations and inflations in liver cancer outcomes data for subgroups broadly categorized as AAPI in US clinical research.^{21,22} These studies underscore the importance of disaggregating such data to help accurately reflect the true cancer burden in subpopulations and tailor strategies that can adequately address disparities in cancer care.^{4,22}

To improve the data equity and increase AAPI clinical trial inclusion, it is important that AAPI patients with liver cancer are equally informed about their clinical trial opportunities. While several institutions are beginning to use interpreters for trial materials such as questionnaires, which are typically only available in English and Spanish, there remains a lack of awareness or hesitancy among AAPI patients regarding the benefits of participating in clinical research.²³ To address this, it has been recommended to organize AAPI community outreach events during early trial recruitment phases to increase awareness and participation. Additionally, the diverse nature of the AAPI populations across the country, including cultural hesitancies and beliefs, should be taken into account when planning targeted events.

Language Barriers and Healthcare System Navigation

A survey from 2016 examining key challenges encountered by AAPI patients with lung cancer found that the most pressing needs involved patient education and understanding of treatment options.²⁴ These concerns are directly relevant to liver cancer care. From the patient perspective, concerns regarding language barriers may lead them to seek care from Asian community providers rather than disease specialists, potentially limiting access to expert-level care. In academic or specialized healthcare settings, medical personnel may be reluctant to spend more time with these patients because of the increased time commitment or inadequate resources related to telephone or in-person translators. Moreover, clinicians attempting to serve as interpreters may lack the qualification to communicate comprehensive care plans effectively.

While these constraints exist, the use of in-person translators has shown significant impacts, as they can provide extensive support to AAPI patients and families in navigating the medical system. Following a diagnosis of liver cancer, it would be beneficial to establish a seamless connection with advocacy and support groups to ensure that patients receive comprehensive education and have access to resources to help combat a new diagnosis and develop optimal care plans. The goal is to transition toward a more proactive approach, moving away from the currently reactive solutions that these patients are given. Furthermore, the increased utilization of designated patient navigators who are properly trained to address language and cultural barriers could greatly assist patients in navigating the liver cancer journey and health system.

Cultural Beliefs and Self-Stigmas

Cultural beliefs influence how AAPI patients engage with and perceive health care. In many Asian American families, children or family members of patients are often reluctant to deliver bad news due to cultural norms, especially when

caring for older patients. Additionally, Asian men diagnosed with liver cancer are particularly less likely to report symptoms or concerns about treatment, fearing it may be perceived as a sign of weakness. It is important to recognize that these behaviors may manifest differently among subpopulations (eg, Chinese vs Japanese vs Korean vs Others).

Limited healthcare literacy among AAPI individuals adds another layer of complexity to communicating a diagnosis and treatment plans, thereby impacting the liver cancer care cascade. This is particularly important in the case of selecting high-risk oral medications such as tyrosine kinase inhibitors that are not taken under the close supervision of a healthcare provider. Therefore, it is essential that medication education, monitoring, and follow-up are fully comprehended by the patient, as such factors play a significant role in multidisciplinary care.

Self-stigma among Asian Americans with cancer has also been identified as a factor that decreases quality-of-life outcomes due to self-perceived burden. Cultural beliefs regarding illness, such as bad luck or karma, misconceptions about cancer being contagious, or the perception that their illness is solely their responsibility, contribute to a reluctance among AAPI patients to share diagnoses, seek support, or visit providers unless severe symptoms are experienced. One study conducted among Chinese Americans with cancer showed that self-stigma can lead to decreased physical and emotional quality-of-life outcomes. Interventions that aim to reduce self-stigma or perceived burden in AAPI groups may reduce the reluctance to care and improve quality of life and cancer survivorship.²⁵

Empowering Community Engagement: A Call to Action for Healthcare Providers, Community Leaders, and Patient Advocacy Groups

Community engagement and outreach events have demonstrated a positive impact on the AAPI population at risk of liver cancer. For instance, one program successfully implemented a culturally and linguistically tailored HBV screening, vaccination, and linkage-to-care initiative targeting Vietnamese Americans in three Mississippi counties.²⁶ This intervention utilized community health workers as care navigators and involved a community advisory board and focus groups within the Vietnamese community to develop an implementation plan. Recruitment materials were shared through church bulletins and a Vietnamese American newspaper. As a result, approximately 500 Vietnamese individuals were screened, with over 75% of vaccine-eligible patients receiving vaccination. Furthermore, the program contributed to an increase in the number of primary care providers offering HBV treatment in the area.²⁶

Another study conducted a comparative trial to evaluate the effectiveness of a culturally tailored patient navigator-led program for monitoring and treating Asian Americans (Chinese, Vietnamese, and Korean patients) with chronic HBV in the Philadelphia and New York City metropolitan areas. Over 500 patients living with chronic HBV were included, and the patient navigator intervention group had higher rates of healthcare provider visits at 6- and 12-month follow-ups compared with controls (77% vs 46% and 91% vs 61%).²⁷ Both of these successful programs reduced barriers to care in AAPI populations through community-based participatory frameworks, cultural and linguistic adaptations, patient navigators for coordination of care, and community advisory boards for recruitment.

At the clinician level, healthcare providers have been collaborating with outreach groups targeting the AAPI community, including local chapters of the American Cancer Society that provide Asian community cancer education. These organizations often serve as support groups and play a critical role in destigmatizing discussions about cancer diagnoses and sharing the journey with the Asian community. In 2024, the Asian & Pacific Islander American Health Forum was awarded a grant to collaborate with community-based organizations and members to educate Asian American, Native Hawaiian, and Pacific Islander communities throughout California. Their efforts aim to target healthcare workers and marginalized groups within this population through culturally and linguistically adapted methods.

Patient advocacy groups also have an instrumental role in reaching specific patient populations and their families or caregivers. Blue Faery, a liver cancer patient advocacy group, provides website resources in multiple languages for AAPI (Chinese, Korean, Japanese, Vietnamese, and Thai) patients. Blue Faery also holds online events to raise liver cancer awareness in marginalized populations, including AAPI groups, in their first languages and are often led by clinicians who represent or care for their population. Other patient advocacy organizations such as the Hepatitis B Foundation and Hep B United also offer targeted interventions for AAPI patients at risk of HBV, including online questionnaires in multiple languages and local campaigns in partnership with community-based organizations, health systems, and

healthcare providers. Partnerships with patient advocacy groups and understanding how each population or community receives their health information can amplify the impact of awareness and education events. Creating tools that are patient centered and culturally appropriate as well as utilizing locally run newspapers, television channels, or radio stations with predominantly Asian audiences has shown to be effective in other disease areas given the accessibility and trust in these outlets. One example of this includes a liver cancer health fair held by a nonprofit organization, New Tang Dynasty Television, in 2024. New Tang Dynasty Television has a predominant viewership of Chinese Americans and thus was able to recruit over 400 Chinese adults in the New York area to conduct health screens and education related to liver cancer and risk factors.

Conclusion

This article discussed the significant health disparities in the AAPI population with liver cancer, and provided insights into potential approaches for addressing these barriers. By leveraging our understanding of the unique challenges faced by different Asian communities and identifying key risk factors, we can target interventions to minimize disparities and enhance outcomes in care. Our collective goal is to empower the most vulnerable segments of the AAPI population, ensuring equitable access to effective prevention, screening, and treatment strategies.

Abbreviations

AAPI, Asian American and Pacific Islanders; HBV, hepatitis B virus; HCC, hepatocellular carcinoma; HCV, hepatitis C virus; US, United States.

Acknowledgments

Nucleus Global provided manuscript editing support.

Disclosure

Dr Daneng Li reports grants, personal fees from AstraZeneca, personal fees from AbbVie, personal fees from Adagene, personal fees from Coherus, personal fees from Delcath Systems, personal fees from Eisai, personal fees from Exelixis, personal fees from Genentech, personal fees from Ipsen, personal fees from Merck, personal fees from QED, personal fees from Servier, personal fees from Sumitomo Pharma Oncology, personal fees from TerSera, personal fees from TransThera Biosciences, and personal fees from TriSalus Life Sciences, outside the submitted work. Dr Spencer Cheng reports grants from Genentech, outside the submitted work. Dr Ruoding Tan reports employment from Roche/Genentech and stocks from Roche/Genentech, outside the submitted work. The authors report no other conflicts of interest in this work.

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