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(703) 299-6640
(703) 299-6620 FAX

Address any correspondence to:
National Cancer Registrars Association
1330 Braddock Place, #520
Alexandria, VA 22314

Address all editorial correspondence to:
Nadine Walker, MS, ODS-C
Email: JRMEditor@ncra-usa.org
Telephone: (703) 299-6640 ext. 327

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Contents

Indexing

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Letter from the Editor

Dear Colleagues,

This year marks the fifth year for the annual North American Association of Central Cancer Registries (NAACCR) special edition of the National Cancer Registrars Association (NCRA)'s *Journal of Registry Management (JRM)*. This edition is an opportunity for the NAACCR community to publish cancer surveillance work, experiences, and ideas. The submission deadline for next year is Monday, September 29, 2025.

As the contents of this edition show, we are interested in research articles as well as short reports, editorials, and registry-specific experiences. This issue contains an editorial, 3 original research articles, a short report, and the 3 winning posters from the NAACCR 2024 Annual Conference held in Boise, Idaho in June 2024. As in prior years, the articles underwent a peer review process with reviewers selected from members active in at least one Research and Data Use Steering Committee workgroup or taskforce. The published posters also underwent a peer review process before being accepted at the NAACCR Annual Conference, met the criteria to be judged as part of our annual conference proceedings, and won their respective categories.

This volume contains 2 articles focused on liver cancer. The first, by Frances B. Maguire, PhD, and colleagues, examines the incidence of liver cancer in California. The second, by Margaret Gates Kuliszewski, ScD, and colleagues, describes the New York Cancer Registry's experience with linking to external data to determine hepatitis infection status for liver cancer cases. The California paper is the subject of this issues' continuing education quiz. The third research article, by Daniela Ramirez-Aguilar, MPH, and colleagues, describes the demographic profile of colorectal cancer in Arkansas. The short report by Kaitlin R. Kruger, MS, and Emily C. Bunt, MA, covers Ohio's experience and lessons learned with modified record reporting.

The winning posters were presented and judged at our annual conference in Boise, Idaho. The Research and Data Use winning poster was from the Wisconsin Cancer Registry on their approach to handling cancer concerns from the community (Lena Swander, MPH, et al). The Standards and Registry Operations winning poster is from partners at the University of California San Francisco on a cancer registrar workload and staffing study (Laurie Hailer, MA, MEd, et al). The poster awarded Honorable Mention was from the California Cancer Registry and was in the Research and Data Use category. This poster presented cancer incidence in areas of persistent poverty (Ani S. Movsisyan Vernon, et al).

The editorial by T. Patrick Hill, PhD, focuses on the 1996 Health Insurance Portability and Accountability Act (HIPAA) and sets the stage for thoughtful discussion about the interplay among the competing needs of privacy, confidentiality, and the use of cancer registry data to reduce the burden of cancer in our communities.

Please note that the opinions, findings, and conclusions in this publication are those of the authors and do not necessarily represent the views of the NAACCR, NCRA, or the *JRM*.

I am grateful to continue our collaboration with NCRA and the *JRM* on this special publication of NAACCR focused articles.

With gratitude,

Recinda Sherman, PhD, MPH, ODS-C
Guest Editor, *JRM*

Editorial

NAACCR and HIPAA: Hip, Hip, Hooray?

T. Patrick Hill, PhD

Much about the 1996 Health Insurance Portability and Accountability Act (HIPAA) is commendable. Its provisions for portability prevent, in part or entirely, insurance companies from using preexisting medical conditions to deny coverage when a person changes insurance plans. Its provisions hold covered health information entities accountable for inappropriate sharing of medical data and establishes criteria for identifying and protecting personal medical information. HIPAA rejects the questionable claim that, when collected by government agencies, personal health information becomes government property. Central to these provisions is the assumption that, in the context of medical services, there is such a thing as the common good or public health as a necessary condition of access to personal health care services. Likewise, these provisions assume the notion of health care—but not health—as a human right that would be violated by, for example, preexisting condition limitations.

In light of this, one can see how the North American Association of Central Cancer Registries (NAACCR) would welcome HIPAA as an ally even though it is not one of HIPAA's covered health information entities in regard to accountability. Why is this? Cancer surveillance, a quintessentially public health enterprise, is the stuff of which NAACCR is made. As such, its focus is different from that of HIPAA, which protects access to individual health care. This difference is critical to assessing NAACCR's exclusive reliance on HIPAA's understanding of health information privacy in its approach to sharing cancer surveillance data. Since privacy in relation to public health is distinctly different from privacy in relation to health care, the merits for claiming privacy as a prerogative will differ and should be honored accordingly. To do otherwise—as appears to be the case at present—risks compromising NAACCR's public health focus.

NAACCR must not forget that, as Geoffrey Rose has noted, the effectiveness of public health depends on a balance between the values of autonomy (of which privacy is an expression) and social justice.[1] To that end, it is critical to understand the fundamental difference between achieving the public versus individual health, so that health care's claims for privacy and public health's claims for disclosure can both be respected. At its most fundamental, again according to Rose, health care is about the determinants for individual cases of a disease.[1] Why is *this patient* affected by this disease at this time, and how can it be treated or prevented? In contrast, public health focuses on the incidence rate of disease within populations. Why is *this population* affected by this disease at this time, and how can it be mitigated or prevented altogether?

Despite their differences in focus, there is a critical interdependence between the public health and that of the individual based on the shared goal of preventing disease by eliminating any proneness to it. As Rose observed, by knowing and thus controlling the causes of disease, population and individual susceptibility cease to be an issue.[1] Consequently, the overriding goal remains discovering and controlling the causes of disease. But knowing the incidence of disease depends on acquiring sufficient individual data. The constitutional context within which NAACCR acquires its data involves semi-independent states as members of a federation. In the case of NAACCR, that federation entails reciprocal responsibilities for the public health. The states that make up the federation are equivalent to individuals who make up society, both functioning in a relationship conditioned by two forces designed to secure the frequently incompatible interests of society at large and individuals living in society. One is centripetal, by which the host entity (in this case, the federation or society) pursues its interests, which are perceived as indispensable. The other is centrifugal, by which the constituents (here, the individual states or persons) pursue their interests, similarly perceived as indispensable. Unless these forces operate with mutual respect, either force may become dominant. With the centripetal dominant, the federation or society can become totalitarian. Consider, for example, the history of state policies for tubal sterilization. If the centrifugal dominates, the state or the individual can become anarchical. Consider, for instance, the recent surge in personal opposition to vaccination. Neither outcome is acceptable since each would undermine the essential interests of both host and constituent.

NAACCR's assessment of the merits of privacy, a distinctly individual interest, has serious implications for its ability to meet its responsibilities to the public health through cancer surveillance. Since its sole focus is *health* care, HIPAA may be justified in requiring privacy to override all other relevant values. For NAACCR—whose focus is public health—to rely on HIPAA's appreciation of privacy is highly questionable. Although the word *privacy* does not appear in the US Constitution, it is understood to be a sovereignty over personal decisions that is provided protection (eg, in the Fourth Amendment).[2] But unlike HIPAA privacy, constitutional privacy is limited in certain circumstances; for instance, where privacy interferes with other values such as disease control or prevention. Acknowledging the validity of limiting privacy in NAACCR's cancer surveillance agenda demonstrates a need for NAACCR to cut

Address correspondence to T. Patrick Hill. Email: hillpatrick925@gmail.com.

itself loose from HIPAA's privacy restrictions. NAACCR urgently needs to develop its own privacy policy that embraces the interdependence between individual and public health interests while including robust provisions for controlled disclosure when securing the public health. As a human right, public health has equal standing with the right to health care, and may, therefore, legitimately override the claims to privacy when they needlessly interfere with securing the public health.

Dr. Hill is an associate professor emeritus of ethics and law at Rutgers University and the author of No Place for Ethics: Judicial Review, Legal Positivism, and the Supreme Court of The United States *(2021).*

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Original Article

An Examination of Liver Cancer Incidence in California

Frances B. Maguire, PhD, MPH[a]; Brenda M. Hofer, MA[a]; Arti Parikh-Patel, PhD, MPH[a]; Theresa H. M. Keegan, PhD, MS[a,b]

Abstract: Background and Objective: Liver cancer is composed of 2 main types, hepatocellular carcinoma (HCC) and cholangiocarcinoma (CCA). After years of increasing HCC incidence rates in the United States, declines have been noted in recent years, but CCA incidence rates have continued increasing. Given these variable trends; documented disparities by sex, age, and race/ethnicity; and shifting risk factors from viral infection (hepatitis B and C) to metabolic causes (obesity, diabetes, nonalcoholic fatty liver disease), we sought to assess the incidence rate trends for HCC and CCA in California to inform whether California trends are similar to those observed in the United States as a whole, whether these trends have continued in the most recent years for which data is available, and to identify at-risk groups that may benefit from targeted intervention. Methods: Using SEER*Stat software, we calculated age-adjusted incidence rates (AAIR) by sex, age group, and race/ethnicity for patients aged ≥40 years diagnosed with HCC and CCA from 2010 to 2021 identified in the California Cancer Registry. We assessed the annual percent change (APC) over this period for each subgroup using Joinpoint software. Results: For HCC, the AAIR significantly decreased for men (–2.68%) and women (–2.23%) since 2014. Significant decreases were observed for men among all racial/ethnic groups, but among women, decreases were only seen in Black and Asian/Pacific Islander patients. Decreases in AAIR were greatest among those aged 40 to 64 years (men, –7.01%; women, –7.79%) and increases were observed for men aged ≥75 years since 2010 (1.15%). For CCA, the AAIR significantly increased for men aged ≥75 years (2.8%) and for women in all age groups. Only White men had decreasing AAIRs. Conclusion: HCC AAIR trends have declined in California, but not for all groups. Older men and Hispanic and White women did not experience the same reductions in HCC AAIR observed in other groups. CCA AAIR trends have increased among nearly all groups for women. Future research should focus on evaluating risk factors by liver cancer subtype, and regular screening of individuals with risk factors should be considered.

Key words: *California, cancer registry, cholangiocarcinoma, hepatocellular carcinoma, liver cancer*

Introduction

Liver cancer incidence rates in the United States increased from the 1970s until approximately 2010, when rates began to decline.[1-3] The observed changes in the incidence rate trends differ by the 2 main types of liver cancer, hepatocellular carcinoma (HCC; the most common form) and cholangiocarcinoma (CCA), with HCC rates declining and CCA rates increasing over time.[3-5] Differences in liver cancer incidence rates by sex, age, and race/ethnicity have been documented. Specifically, men, Asian/Pacific Islander patients, and younger individuals (<50 years) have had prominent declines in HCC, while CCA incidence rates have been increasing among all racial/ethnic groups, across age groups, and for both men and women.[3,5]

Globally, the main risk factors for HCC and CCA include cirrhosis and viral hepatitis.[6,7] Other risk factors include fatty liver disease (alcoholic and nonalcoholic) and aflatoxin exposure for HCC and primary sclerosing cholangitis for CCA.[6,7] Better treatments for hepatitis C have resulted in cure,[8,9] lessening the impact of viral hepatitis on liver disease, while rising obesity and diabetes rates have increased nonalcoholic fatty liver disease, which is becoming the most common cause of chronic liver disease in the United States.[10-12]

Given variable trends by subtype and shifting risk factors, we sought to examine liver cancer incidence rates among adults in California by the 2 main subtypes and demographic characteristics. The purpose of this evaluation was to assess the incidence rate trends for HCC and CCA to inform whether California trends are similar to those observed in the United States and whether these trends have continued in the most recent years for which data is

[a]California Cancer Reporting and Epidemiologic Surveillance Program, University of California Davis Comprehensive Cancer Center, Sacramento, California.
[b]Center for Oncology Hematology Outcomes Research and Training (COHORT) and Division of Hematology and Oncology, University of California Davis School of Medicine, Sacramento, California.

Address correspondence to Frances B. Maguire, 1631 Alhambra Blvd Suite 200, Sacramento, CA 95816. Email: fbmaguire@ucdavis.edu. ORCID ID: 0000-0001-8490-6229.

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available. Describing disparities by sex, age group, and race/ethnicity can identify at risk groups that may benefit from targeted interventions.

Methods

Study Population

We identified patients in the California Cancer Registry (CCR) aged ≥40 years when diagnosed during 2010 to 2021 with invasive liver cancer using *International Classification of Diseases for Oncology, Third Edition (ICD-O-3)* codes of 8170–8175 for HCC and 8160 for CCA. We focused on ages ≥40 years since the median age at diagnosis for liver cancer is 67 years, and fewer than 3% of cases occur in those younger than 40 years.[13] The CCR is a population-based cancer surveillance system that collects incidence reports on more than 160,000 cases of cancer diagnosed annually in California. It has collected data on tumor characteristics, treatment, and patient demographics since 1988. CCR's regional registries are affiliated with the National Cancer Institute's (NCI) Surveillance, Epidemiology and End Results (SEER) program.

Sociodemographic and Clinical Characteristics

We obtained information on patient sociodemographic characteristics including sex, age at diagnosis, and race/ethnicity from the CCR and categorized patients by sex (male or female) and grouped them by age (40–64, 65–74, or ≥75 years). We grouped race/ethnicity into non-Hispanic White (White), non-Hispanic Black (Black), Hispanic, and Asian/Pacific Islander based on the North American Association of Central Cancer Registries' Hispanic and Asian/Pacific Islander Identification Algorithm (NHAPIIA).[14] Because of small numbers of patients, we excluded those with American Indian race/ethnicity (n = 553; 1.4%) and other/unknown race/ethnicity (n = 138; 0.4%) from the analyses.

Statistical Analysis

We calculated age-adjusted incidence rates (AAIR) by sex, age group, and race/ethnicity for each histologic type (ie, HCC and CCA) using SEER*Stat software version 8.4.4. Rates were calculated per 100,000 population and age-adjusted to the 2000 US standard population. Population data used in the denominators came from Woods and Poole/SEER population estimates.[15] We used Joinpoint software version 5.2.0 to determine cancer incidence rate trends from 2010 to 2021. Joinpoint describes trends during different time segments when the algorithm detects a change in the slope of the regression line. In the figures, we report the annual percent change (APC) for the most recent time segment detected by Joinpoint. If no joinpoint was detected, we report the APC for the entire interval. The average annual percent change (AAPC), a summary measure of a trend over a prespecified fixed interval, was calculated for the entire period by histologic type and demographic group and presented in the tables. Rates for 2020 were included in the overall rate calculations but were excluded from the trend analyses due to underreporting of cancer during the COVID-19 pandemic resulting from delays in screening and diagnostic services, as recommended by SEER.[16] All analyses were overseen by the Institutional Review Board of the University of California, Davis.

Results

For both histologic types, men had higher AAIRs than women (27.0 vs 8.2 for HCC, 5.0 vs 4.0 for CCA) (Tables 1 and 2). For HCC, the trend from 2010 to 2014 did not significantly change for men ($APC_{2010-2014}$, 1.02; 95% CI, –0.44 to 3.82) and increased among women ($APC_{2010-2014}$, 2.70; 95% CI, 0.09–10.23), but from 2014 to 2021, the APC significantly decreased for both men ($APC_{2014-2021}$, –2.68; 95% CI, –3.83 to –1.97) and women ($APC_{2014-2021}$, -2.23; 95% CI, –6.43 to -0.92) (Figure 1; Tables 1 and 2). For CCA, the trend significantly increased over the entire period for women ($APC_{2010-2021}$, 4.07; 95% CI, 3.12–5.17). For men, the trend was variable, with no significant change from 2015 to 2018 or from 2018 to 2021, but over the entire range, the AAPC significantly increased ($AAPC_{2010-2021}$, 3.61; 95% CI, 2.35–4.67).

Among men, those aged 65–74 years had the highest AAIRs (53.9) for HCC, while among women, those aged ≥75 years had the highest rates (20.0). The greatest declines in AAIRs for HCC were seen among 40- to 64-year-old patients. For men aged 40–64 years, the decline was evident since 2010, but the greatest decline occurred from 2014 to 2021 ($APC_{2014-2021}$, –7.01; 95% CI, –7.45 to –6.61), while for women aged 40–64 years, no decline was evident until 2016 to 2021 ($APC_{2016-2021}$, –7.79; 95% CI, –20.95 to –3.84). Among men aged 65–74 years, AAIRs for HCC declined from 2017 to 2021 ($APC_{2017-2021}$, –2.50; 95% CI, –6.33 to –0.21) after increasing from 2010 to 2017 (APC, 3.65; 95% CI, 2.63–6.04). Among women aged ≥65 years, there were no significant changes in HCC AAIRs over the period (Figure 2; Tables 1 and 2). Among men aged ≥75 years, AAIRs for HCC increased over the study period ($APC_{2010-2021}$, 1.15; 95% CI, 0.28–2.08).

For CCA, patients aged ≥75 years had the highest AAIRs among both men (14.6) and women (10.9). Women in all age groups experienced significant increases in AAIRs for CCA over the study period ($APC_{2010-2021}$ 40–64 years, 4.97; 95% CI, 2.77–7.06; $APC_{2010-2021}$ 65–74 years, 3.76; 95% CI, 0.53–7.23; $APC_{2010-2021}$ ≥75 years, 4.16; 95% CI, 2.26–6.39). For men, AAIRs for those aged ≥75 years increased over the period ($APC_{2010-2021}$, 2.80; 95% CI, 1.31–4.49), but for the younger age groups, the AAIRs increased until 2014 and then did not significantly change for those aged 40–64 years and remained stable for those aged 65–74 years (Figure 2; Tables 1 and 2).

For both men and women, AAIRs for HCC were highest for Asian/Pacific Islander patients at the start of the study period, but at the end, they were highest for Hispanic patients. AAIRs were lowest for White patients. AAIRs for HCC significantly decreased for all racial/ethnic groups among men, while for women, decreases were found only among Black ($APC_{2018-2021}$, –13.48; 95% CI, –27.61 to –0.84) and Asian/Pacific Islander patients ($APC_{2010-2021}$, –5.34; 95% CI, 6.72 to –3.99) (Figure 3; Tables 1 and 2). For White women, AAIRs significantly increased until 2014 ($APC_{2010-2014}$, 4.37; 95% CI, 0.30–20.1) followed by no significant changes since

Table 1. Age-Adjusted Incidence Rates (AAIR), Average Annual Percent Change (AAPC), Annual Percent Change (APC) for Hepatocellular Carcinoma (HCC) and Cholangiocarcinoma (CCA) for Men, 2010–2021, California

HCC										
Characteristic	n	AAIR	AAPC (95% CI)	Years	APC1 (95% CI)	Years	APC2 (95% CI)	Years	APC3 (95% CI)	Years
Overall	29,011	27.0	–1.35* (–1.79, –0.92)	2010–2021	1.02 (–0.44, 3.82)	2010–2014	–2.68* (–3.83, –1.97)	2014–2021		
Age group, y										
40–64	14,982	17.2	–4.87* (–5.11, –4.65)	2010–2021	–1.00* (–1.77, –0.28)	2010–2014	–7.01* (–7.45, –6.61)	2014–2021		
65–74	8,990	53.9	1.37* (0.42, 2.37)	2010–2021	3.65* (2.63, 6.04)	2010–2017	–2.50* (–6.33, –0.21)	2017–2021		
≥75	5,039	46.7	1.15* (0.28, 2.08)	2010–2021	1.15* (0.28, 2.08)	2010–2021				
Race/ethnicity[†]										
White	11,331	18.8	–1.11 (–2.28, –0.11)	2010–2021	5.82 (–0.27, 12.78)	2010–2012	–2.59* (–4.87, –1.91)	2012–2021		
Black	2,103	32.5	–3.46* (–6.36, –1.04)	2010–2021	1.35 (–2.17, 15.4)	2010–2015	–7.29* (–16.59, –4.28)	2015–2021		
Hispanic	9,300	37.6	–1.05* (–1.86, –0.22)	2010–2021	0.09 (–1.28, 5.16)	2010–2015	–1.99* (–4.91, –0.83)	2015–2021		
Asian/PI	5,771	37.3	–3.85* (–5.77, –1.96)	2010–2021	–3.85* (–5.77, –1.96)	2010–2021				
CCA										
Characteristic	n	AAIR	AAPC (95% CI)	Years	APC1 (95% CI)	Years	APC2 (95% CI)	Years	APC3 (95% CI)	Years
Overall	4,896	5.0	3.61* (2.35, 4.67)	2010–2021	7.00* (4.65, 11.79)	2010–2015	–3.07 (–5.77, 4.43)	2015–2018	4.96 (–0.40, 8.21)	2018–2021
Age group, y										
40–64	1,742	2.0	4.24* (2.25, 5.91)	2010–2021	10.76* (6.80, 19.33)	2010–2014	–3.14 (–10.17, 1.21)	2014–2018	6.02 (–2.00, 12.84)	2018–2021
65–74	1,576	9.6	3.90* (1.58, 6.91)	2010–2021	15.07* (5.69, 39.96)	2010–2013	–0.01 (–4.84, 2.03)	2013–2021		
≥75	1,578	14.6	2.80* (1.31, 4.49)	2010–2021	2.80* (1.31, 4.49)	2010–2021				
Race/ethnicity[†]										
White	2,373	4.3	2.84* (1.92, 3.95)	2010–2021	10.69* (7.40, 16.44)	2010–2014	–1.39* (–3.06, –0.02)	2014–2021		
Black	245	4.5	1.27 (–3.00, 6.43)	2010–2021	1.27 (–3.00, 6.43)	2010–2021				
Hispanic	1,279	6.0	3.39* (0.80, 6.49)	2010–2021	3.39* (0.80, 6.49)	2010–2021				
Asian/PI	954	6.5	1.50 (–1.97, 5.58)	2010–2021	1.50 (–1.97, 5.58)	2010–2021				

[†]White, non-Hispanic White; Black, non-Hispanic Black; PI, Pacific Islander

[*]Significantly different from zero at $P < .05$. A negative AAPC or APC indicates decreasing rates while a positive AAPC or APC indicates increasing rates.

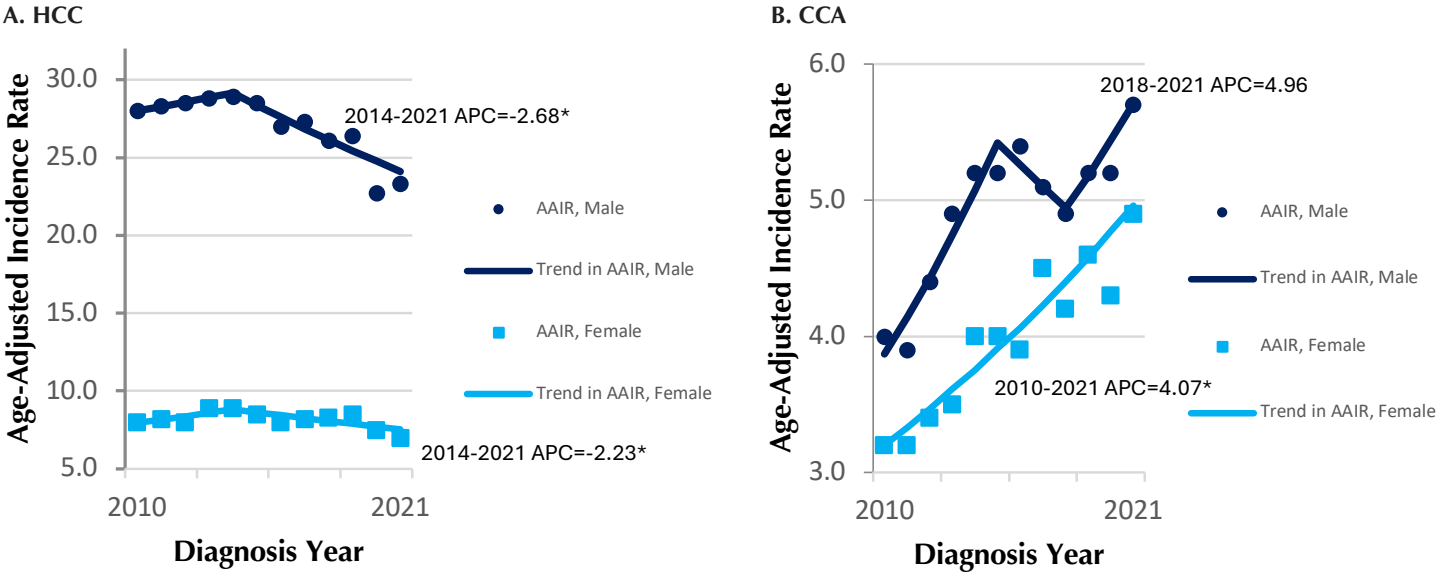
Table 2. Age-Adjusted Incidence Rates (AAIR), Average Annual Percent Change (AAPC), Annual Percent Change (APC) for Hepatocellular Carcinoma (HCC) and Cholangiocarcinoma (CCA) for Women, 2010–2021, California

HCC								
Characteristic	n	AAIR	AAPC (95% CI)	Years	APC1 (95% CI)	Years	APC2 (95% CI)	Years
Overall	9,717	8.2	–0.47 (–1.82, 0.712)	2010–2021	2.70* (0.09, 10.23)	2010–2014	–2.23* (–6.43, –0.92)	2014–2021
Age group, y								
40–64	3,444	3.8	–3.75* (–7.27, –0.66)	2010–2021	–0.25 (–2.77, 18.23)	2010–2016	–7.79* (–20.95, –3.84)	2016–2021
65–74	3,250	17.4	0.82 (–1.63, 3.54)	2010–2021	0.82 (–1.63, 3.54)	2010–2021		
75 and older	3,023	20.0	0.58 (–2.07, 3.41)	2010–2021	0.58 (–2.07, 3.41)	2010–2021		
Race/ethnicity†								
White	3,279	5.1	0.31 (–2.19, 2.53)	2010–2021	4.37* (0.30, 20.1)	2010–2014	–1.95 (–10.25, 0.44)	2014–2021
Black	684	9.3	–5.14* (–9.24, –0.77)	2010–2021	–1.81 (–9.36, 22.89)	2010–2018	–13.48* (–27.61, –0.84)	2018–2021
Hispanic	3,405	13.1	0.34 (–1.87, 2.75)	2010–2021	0.34 (–1.87, 2.75)	2010–2021		
Asian/PI	2,164	11.5	–5.34* (–6.72, –3.99)	2010–2021	–5.34* (–6.72, –3.99)	2010–2021		
CCA								
Characteristic	n	AAIR	AAPC (95% CI)	Years	APC1 (95% CI)	Years	APC2 (95% CI)	Years
Overall	4,725	4.0	4.07* (3.12, 5.17)	2010–2021	4.07* (3.12, 5.17)	2010–2021		
Age group, y								
40–64	1,597	1.8	4.97* (2.77, 7.06)	2010–2021	4.97* (2.77, 7.06)	2010–2021		
65–74	1,424	7.7	3.76* (0.53, 7.23)	2010–2021	3.76* (0.53, 7.23)	2010–2021		
75 and older	1,704	10.9	4.16* (2.26, 6.39)	2010–2021	4.16* (2.26, 6.39)	2010–2021		
Race/ethnicity†								
White	2,118	3.3	4.43* (3.37, 5.46)	2010–2021	4.43* (3.37, 5.46)	2010–2021		
Black	227	3.3	1.46 (–3.48, 7.09)	2010–2021	1.46 (–3.48, 7.09)	2010–2021		
Hispanic	1,453	5.5	3.27* (1.71, 5.05)	2010–2021	3.27* (1.71, 5.05)	2010–2021		
Asian/PI	881	4.6	3.32* (0.84, 6.43)	2010–2021	3.32* (0.84, 6.43)	2010–2021		

†White, non-Hispanic White; Black, non-Hispanic Black; PI, Pacific Islander

*Significantly different from zero at $P < .05$. A negative AAPC or APC indicates decreasing rates while a positive AAPC or APC indicates increasing rates.

Figure 1. Trends in Hepatocellular Carcinoma (HCC; Panel A) and Cholangiocarcinoma (CCA; Panel B) Among Patients Aged ≥40 Years by Sex, California, 2010–2021



AAIR, age-adjusted incidence rates; APC, annual percent change. *Significantly different from zero at $P < .05$. A negative APC indicates decreasing rates while a positive APC indicates increasing rates. The APC for the most recent time segment detected by joinpoint is shown. If no joinpoint was detected, the APC for the entire interval is shown.

then. For Hispanic women, AAIRs remained stable over the study period. Among men, the greatest declines were seen among Black patients from 2015–2021 ($APC_{2015-2021}$, –7.29; 95% CI, –16.59 to –4.28) and Asian/Pacific Islander patients over the study period ($APC_{2010-2021}$, –3.85; 95% CI, –5.77 to –1.96).

For CCA, AAIRs were highest for Asian/Pacific Islander patients (6.5) among men and Hispanic patients (5.5) among women. AAIRs for CCA significantly increased for Hispanic men over the study period ($APC_{2010-2021}$, 3.39; 95% CI, 0.80–6.49), while AAIRs did not significantly change for Black ($APC_{2010-2021}$, 1.27; 95% CI, –3.00 to 6.43) or Asian/Pacific Islander men ($APC_{2010-2021}$, 1.50; 95% CI, –1.97 to 5.58). For White men, AAIRs of CCA decreased from 2014 to 2021 ($APC_{2014-2021}$, –1.39; 95% CI, –3.06 to –0.02) after increasing from 2010 to 2014 ($APC_{2010-2014}$, 10.69; 95% CI, 7.40–16.44). Among women, AAIRs for CCA increased for White ($APC_{2010-2021}$, 4.43; 95% CI, 3.37–5.46), Hispanic ($APC_{2010-2021}$, 3.27; 95% CI, 1.71–5.05), and Asian/Pacific Islander patients ($APC_{2010-2021}$, 3.32; 95% CI, 0.84–6.43), but for Black women, rates did not significantly change ($APC_{2010-2021}$, 1.46; 95% CI, –3.48 to 7.09) (Figure 4; Tables 1 and 2).

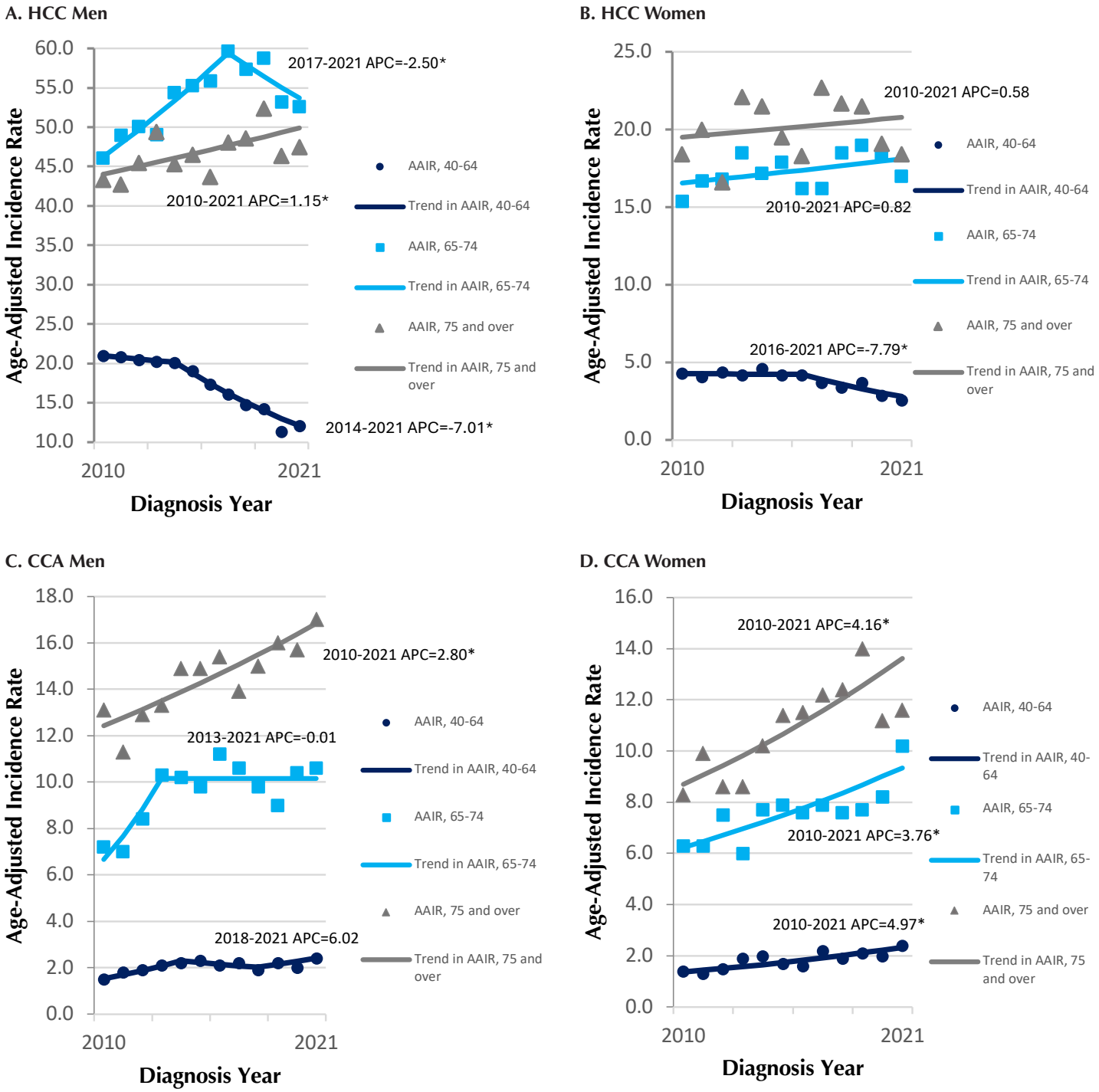
Discussion

In this population-based analysis, we found decreasing overall incidence rates of HCC and increasing overall incidence rates for CCA among both men and women with differences by sex, age, and race/ethnicity. Our findings of decreasing HCC incidence rates among middle-aged adults and increases or no change among older adults are consistent with prior research.[2,3,17] White and Hispanic women were the only racial/ethnic groups groups that did not experience decreasing incidence rates for HCC. Increases in CCA incidence rates have been reported previously,[5,18,19] and were notable among women in all the age groups; men aged ≥75 years; and Hispanic, White, Asian/Pacific Islander women in our study. Our findings highlight the need to identify risk factors underlying the incidence trends to inform targeted interventions to reduce the burden of liver cancer.

The differences we observed in HCC incidence by age may relate to birth cohort differences in risk factors, such as hepatitis C and metabolic causes, which may vary by time period.[2,20,21] Hepatitis C is particularly prevalent among those born from 1945 to 1965.[22] Declines among younger ages could reflect less chronic hepatitis C infection with availability of effective hepatitis C treatment as well as increased awareness of high-risk behaviors, such as needle sharing.[9,23]

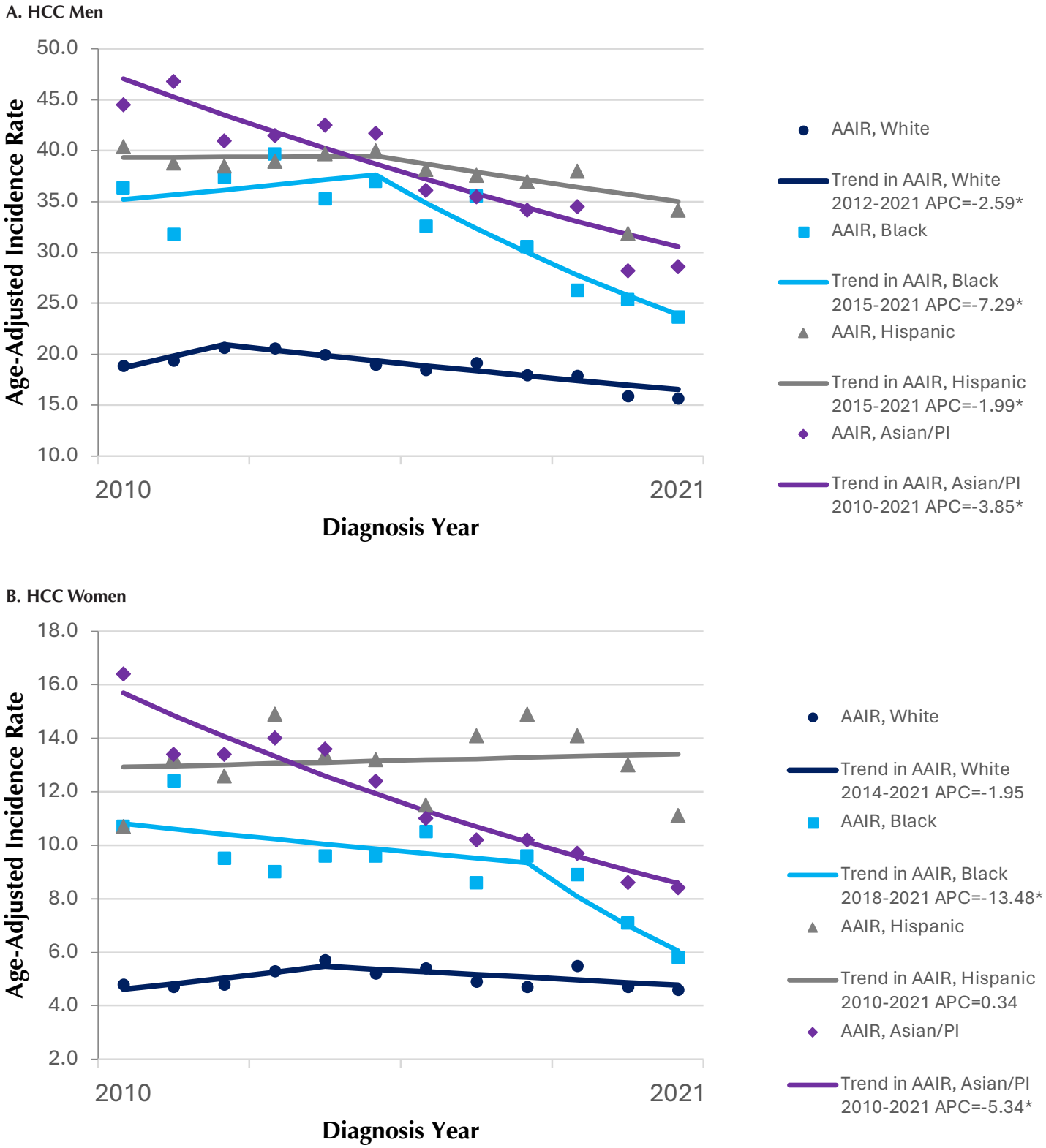
We found differences in incidence trends by race/ethnicity. Prior studies had differing results regarding HCC trends among Black patients, depending on age and sex, with some showing increases among men and older adults.[24-26] We found decreasing HCC incidence rates among Black patients in recent years. Our finding of Hispanic women not experiencing a decrease in HCC incidence rates could reflect the higher rates of nonalcoholic fatty liver disease and associated HCC among this group.[27,28] White patients have been found to have an intermediate prevalence (between Hispanic and Black patients) of nonalcoholic fatty liver disease,[28] possibly explaining the absence of decreasing incidence rates for White women, but more research is needed. Large decreases in HCC incidence rates for Asian/Pacific Islander patients have been previously noted in US studies, consistent with our finding.[25,29] Chronic hepatitis B is a significant risk factor for HCC and is more common among Asian Americas, especially those born outside the United States.[30] Prevention of chronic hepatitis B through

Figure 2. Trends in Hepatocellular Carcinoma (HCC) and Cholangiocarcinoma (CCA) Among Patients Aged ≥40 Years by Sex and Age, California, 2010–2021



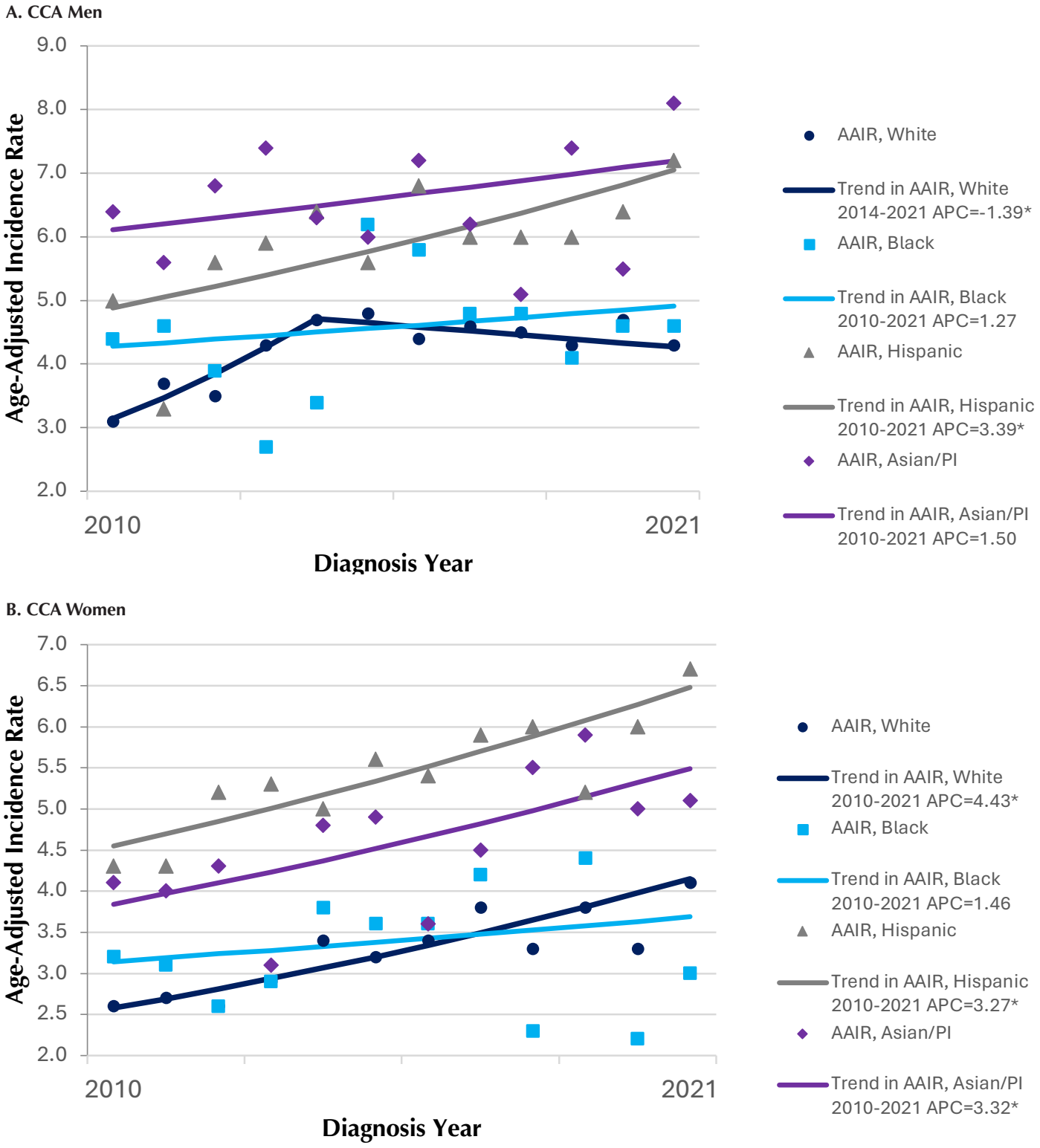
AAIR, age-adjusted incidence rates; APC, annual percent change. *Significantly different from zero at $P < .05$. A negative APC indicates decreasing rates while a positive APC indicates increasing rates. The APC for the most recent time segment detected by joinpoint is shown. If no joinpoint was detected, the APC for the entire interval is shown.

Figure 3. Trends in Hepatocellular Carcinoma (HCC) Among Patients Aged ≥40 Years by Sex and Race/Ethnicity†, California, 2010–2021



AAIR, age-adjusted incidence rates; APC, annual percent change; PI, Pacific Islander. *Significantly different from zero at $P < .05$. A negative APC indicates decreasing rates while a positive APC indicates increasing rates. The APC for the most recent time segment detected by joinpoint is shown. If no joinpoint was detected, the APC for the entire interval is shown. †*White* indicates non-Hispanic White; *Black* indicates non-Hispanic Black.

Figure 4. Trends in Cholangiocarcinoma (CCA) Among Patients Aged ≥40 Years by Sex and Race/Ethnicity,† California, 2010–2021



AAIR, age-adjusted incidence rates; APC, annual percent change; PI, Pacific Islander. *Significantly different from zero at $P < .05$. A negative APC indicates decreasing rates while a positive APC indicates increasing rates. The APC for the most recent time segment detected by joinpoint is shown. If no joinpoint was detected, the APC for the entire interval is shown. †*White* indicates non-Hispanic White; *Black* indicates non-Hispanic Black.

better screening and increases in vaccination rates are possible reasons for the decline.[31] Continued monitoring of HCC incidence among Asian/Pacific Islander patients is warranted given their high risk for chronic hepatitis B.

The observed trends for CCA are consistent with previous research showing increasing incidence rates overall and higher incidence among Hispanic and Asian/Pacific Islander patients and older individuals.[5,18,19] By race/ethnicity, increased incidence was mainly confined to women as were increases among those aged ≤74 years. White men were the only group with a significantly decreasing incidence of CCA. The pronounced incidence rate increases among women have been noted.[32] There is some evidence that hormonal factors, including higher levels of estrogen, may promote cholangiocarcinogenesis.[32-34] Other risk factors, such as cirrhosis, hepatitis B/C, diabetes, obesity, and nonalcoholic fatty liver disease, more often associated with HCC, have also been linked to CCA and could be contributing to the increasing incidence rates. However, the reasons for the ongoing increase are not entirely known[6,35] and should be the focus of future research.

This study had some limitations. We were unable to determine the underlying factors driving the changes in the trends and therefore cannot determine whether efforts should focus on hepatitis C/B screening or metabolic causes. In addition, our trends could have been impacted by missed early detection of cancers during the COVID-19 pandemic, as lower than expected numbers of liver cancers were found to be diagnosed during 2020 and 2021.[36,37] Lastly, we were unable to calculate rates and determine trends for American Indian patients because of their small number. However, we used high quality, population-based data from a large ethnically diverse state.

In conclusion, we found that, like US trends, HCC incidence rates in California have declined while CCA incidence rates have increased. However, HCC incidence declines were not observed for all groups. We identified high-risk groups where screening may be beneficial, including hepatitis C screening of older men and monitoring of Hispanic and White women for nonalcoholic fatty liver disease. Continued surveillance of HCC incidence among Asian/Pacific Islander patients is warranted to monitor for changing trends in this group at high risk for chronic hepatitis B. The ongoing rising trends for CCA, particularly among women, are worrisome. Hispanic and Asian/Pacific Islander patients are disproportionately affected by CCA. Future work should focus on identifying risk factors contributing to the increasing CCA incidence trends and screening of individuals with these risk factors should be considered. Given the changing etiology from viral to metabolic causes and variable incidence trends, liver cancer incidence should continue to be monitored. Despite the encouraging progress in HCC with overall declines in incidence, it still is among the most frequently diagnosed cancers worldwide[38] and ongoing surveillance is warranted.

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Original Article

Ascertainment of Hepatitis B and C Infection from Linked Data Sources for Residents of New York City Diagnosed with Liver or Intrahepatic Bile Duct Cancer

Margaret Gates Kuliszewski, ScD[a,b]; Baozhen Qiao, PhD[a]; Xiuling Zhang, PhD[a]; Holly Anger, MPH[c]; Maria J. Schymura, PhD[a,b]; Tabassum Insaf, PhD, MPH, MBBS[a,b]

Abstract: Background: Chronic infection with hepatitis B or C substantially increases risk of hepatocellular carcinoma. However, central cancer registries do not routinely collect information on hepatitis diagnoses. We evaluated the extent to which information on hepatitis B or C diagnosis could be ascertained from linked external data sources for cancers reported to the New York State Cancer Registry. Methods: We linked data for 14,747 New York City (NYC) residents diagnosed with liver or intrahepatic bile duct cancer during 2004–2018 to 2 data sources: (1) the NYC Viral Hepatitis Surveillance Registry, which collects information on reported probable and confirmed cases of hepatitis B and C from New York laboratories and health care providers, and (2) the New York Statewide Planning and Research Cooperative System (SPARCS), which captures hepatitis diagnosis codes from hospital inpatient stays and outpatient encounters. We determined whether documentation of hepatitis B or C was present in 1 or both data sources, assessed concordance between the data sources, and used multivariable-adjusted logistic regression to examine factors associated with discordance in hepatitis positivity. Results: Of the 14,747 cancer cases included, 3,972 had documentation in either data source of hepatitis B (26.9%), 7,599 had documentation of hepatitis C (51.5%), and 9,753 had either diagnosis (66.1%). There was moderate to substantial agreement between the 2 data sources. The percent of NYC patients with any unrecorded hepatitis infection was 12.7% for the hepatitis registry and 7.8% for SPARCS, and discordance in hepatitis positivity was more common in certain individuals, including those aged ≥70 years at cancer diagnosis and those with intrahepatic bile duct cancer, Hispanic ethnicity (hepatitis registry only), and Black or Asian race (SPARCS only). Conclusions: These results indicate that hospital discharge and public health surveillance data can be used to assess individual-level hepatitis B and C infection status in people diagnosed with liver cancer. Possible reasons for discrepancies between the data sources include incomplete reporting in the hepatitis registry, especially for earlier diagnosis years, differing case inclusion criteria, and differences in the linkage methods for the 2 data sources. This information can be used to enrich cancer registry data for epidemiologic analyses of hepatocellular carcinoma and other cancers.

Key words: *claims analysis, hepatitis, hepatocellular carcinoma, liver neoplasms, registries*

Introduction

Chronic infection with hepatitis B virus (HBV) or hepatitis C virus (HCV) substantially increases the risk of hepatocellular carcinoma (HCC). An estimated 44%–56% of HCC cases worldwide are related to chronic HBV, making HBV the leading cause of HCC globally.[1,2] A meta-analysis estimated a 22.5-fold increase in risk of HCC associated with chronic HBV.[1] Chronic HCV infection contributes to an estimated 21% of HCC cases globally and is associated with a 15- to 20-fold increase in risk of HCC.[1,3] HCV is a more common cause of HCC than HBV in western countries such as the United States, where HCV is an attributable factor for approximately 34% of HCC cases.[3]

HCC comprises approximately 75%–85% of cases of primary liver cancer, which is the sixth most common cancer and third leading cause of cancer death worldwide.[4] Incidence and mortality are lower in the United States, where liver cancer is the 13th most common cancer and 6th leading cause of cancer death.[5] However, the burden of liver cancer in the United States may be higher in urban areas with a greater number of individuals born outside the United States, such as in New York City (NYC). In addition, survival after liver cancer diagnosis is poor regardless of region, and in the United States, only 21.7% of liver cancer patients survive for at least 5 years after diagnosis,[5] highlighting the need for improvements in prevention, early diagnosis, and treatment.

Central cancer registries do not routinely collect information on viral hepatitis diagnoses. However, this information could enrich cancer registry data for epidemiology and outcomes research. For example, treatment with antiviral therapy before or after HCC diagnosis can

[a]New York State Cancer Registry, New York State Department of Health, Albany, New York. [b]College of Integrated Health Sciences, University at Albany, Rensselaer, New York. [c]New York City Department of Health and Mental Hygiene, New York, New York.

Address correspondence to Margaret Gates Kuliszewski, ScD, New York State Cancer Registry, New York State Department of Health, 150 Broadway, Suite 361, Albany, NY 12204. Email: maggie.gateskuliszewski@health.ny.gov.

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improve liver function and prognosis in individuals with hepatitis-related HCC, leading to better outcomes including improved disease-free and overall survival.[6-8] In this analysis, we evaluated the extent to which information on HBV and HCV diagnosis can be ascertained from 2 linked data sources for liver and intrahepatic bile duct cancer cases reported to the New York State Cancer Registry (NYSCR).

Methods

Study Population

Our study population included NYC residents diagnosed with liver or intrahepatic bile duct cancer between 2004 and 2018. Eligible cases were retrieved from the NYSCR Surveillance, Epidemiology, and End Results (SEER) Data Management System (SEER*DMS) database using the following criteria: SEER site recode, 21071 (liver) or 21072 (intrahepatic bile duct); behavior code, 3 (malignant); year of diagnosis, 2004–2018; and county at diagnosis, 5 counties of NYC (Bronx, Kings, New York, Queens, Richmond). Because 1 of the 2 linked data sources was limited to NYC residents, we restricted our analysis to this population.

Data Sources

Cases reported to the NYSCR who met the case inclusion criteria above were linked to 2 data sources: the NYC Department of Health and Mental Hygiene Viral Hepatitis Surveillance Registry (hepatitis registry) and the New York Statewide Planning and Research Cooperative System (SPARCS). The NYC Health Code mandates reporting of specific HBV and HCV laboratory tests to the NYC Department of Health and Mental Hygiene. The hepatitis registry contains information on all reportable viral hepatitis tests, as well as viral hepatitis case reports received from health care providers. We included hepatitis registry data on probable and confirmed cases of chronic HBV and chronic HCV that met current Council of State and Territorial Epidemiologists case definitions[9-11] and were reported during 1990–2019, although data are considered more complete after 1998. SPARCS is a comprehensive all-payer data reporting system that captures patient-level detail on individual characteristics, diagnoses and treatments, services, and charges. SPARCS captures hepatitis diagnosis codes from hospital inpatient stays and selected outpatient encounters, including outpatient visits to hospitals, hospital extension clinics, diagnostic and treatment centers, and diagnostic and treatment center extension clinics. HBV and HCV diagnoses were identified in SPARCS using the following codes from the *International Classification of Diseases, 9th* or *10th Revision* (ICD-9 and ICD-10): 0702, 0703, B16, B170, B180, B181, B191 for HBV infection and 0704, 0705, 0707, B171, B182, B192 for HCV infection. Some individuals were categorized as having HBV and HCV coinfection, while individuals without any of these ICD-9 and ICD-10 codes were classified as having no hepatitis infection. We included SPARCS data from discharge years 2002–2020, and we excluded HBV and HCV carriers (defined based on ICD-9 and ICD-10 codes V0261 and Z2251 for HBV carriers and V0262 and Z2252 for HCV carriers), since these would not be included as cases in the hepatitis registry. The cancer cases included in the analysis were restricted to diagnoses between 2004 and 2018 based on the overlap in dates of available data in the hepatitis registry and SPARCS. We restricted our analyses to cases with an address at cancer diagnosis within the 5 counties of NYC.

Linkage Methods

A data file of individuals from the hepatitis registry with a reported probable or confirmed chronic HBV or HCV infection diagnosed between 1990 and 2019 who had a NYC residence at the time of first report was prepared and securely shared with authorized staff at the NYSCR. The hepatitis registry and NYSCR data were then linked using probabilistic methods with the Match*Pro software and identifiers common to both data files including first name, last name, middle name, sex, birth date, Social Security number, phone number, and address. Cases with a linkage score ≥25 were reviewed and classified as a match or nonmatch. After linkage, identifiers were removed from the merged data file and the de-identified analytic file was retained by the NYSCR and securely shared with the NYC Department of Health and Mental Hygiene.

SPARCS claims data were linked with NYSCR data as part of an annual data linkage, resulting in a data file used for linkage projects, routine surveillance, and approved research projects. This linkage was conducted using deterministic matching methods in SAS following the NYSCR's 9-step process with different combinations of linkage variables including date of birth, sex, reporting permanent facility identifier (PFI), medical record number, zip code, address at diagnosis, and the patient's unique personal identifier, which is a composite field comprised of elements of the patient's name and Social Security number. The linkage process involved multiple sequential steps completed using SAS macro programs, followed by data checking using SAS code and manual review to resolve uncertain or duplicate matches, which were primarily multiple cancer cases matched to a single SPARCS claim. In some cases, cancer diagnosis information was also used to resolve uncertain or duplicate matches.

Statistical Analysis

We examined descriptive and clinical characteristics of the identified liver and intrahepatic bile duct cancers overall and by presence of HBV or HCV infection in either linked data source. Differences in patient characteristics by infection status were evaluated using *P* values from χ-square tests. We examined the percent of cancer cases with an HBV infection, HCV infection, or either HBV or HCV in each linked data source, and measured concordance between hepatitis registry and SPARCS infection status using simple κ statistics and 2 alternate measures of agreement that are less sensitive to prevalence and bias, prevalence and bias-adjusted κ statistics and chance-corrected AC1 (agreement coefficient) statistics.

Finally, we examined characteristics of patients with HBV or HCV infection recorded in only 1 data source. We used logistic regression to calculate multivariable-adjusted odds ratios (ORs) and 95% CIs for the association between each characteristic and unrecorded infection in each data

source. The final reduced logistic regression model for each data source included variables with a Wald *P* value ≤.1, with the following NYSCR variables considered for inclusion in the models: sex, age at cancer diagnosis, race, ethnicity, country of birth, marital status, tobacco history, county of residence, year of cancer diagnosis, cancer site, stage at cancer diagnosis, type of reporting source, microscopic confirmation, and vital status at the time of case selection from the NYSCR SEER*DMS database. All analyses were conducted using SAS version 9.4 (SAS Institute Inc).

Results

We identified and linked data for 14,747 individuals with first primary liver and intrahepatic bile duct cancers meeting the case inclusion criteria. Of these, 9,753 (66.1%) had an HBV or HCV infection documented in either linked data source, with 3,972 (26.9%) having an HBV infection and 7,599 (51.5%) having an HCV infection (Table 1). Evidence of coinfection with HBV and HCV was present for 1,818 individuals (12.3%).

Characteristics of individuals with vs without HBV or HCV differed (Table 1). Those with HBV infection were more likely to be male, aged <60 years at time of cancer diagnosis, Asian, non-Hispanic, married, and non-US born (or with unknown birthplace), residing in Kings or Queens County, and to have never used tobacco. Those with HCV infection were more likely to be male, aged 50–69 years at time of cancer diagnosis, Black, Hispanic, US-born, single, and current or past users of tobacco, and to reside in the Bronx. Cancer characteristics also differed, with those with HBV infection being more likely to have liver cancer, local stage disease, microscopic confirmation, and to still be alive at cancer case selection. Those with HCV infection were also more likely to have liver cancer and local stage disease, but in contrast, were less likely to have microscopic confirmation or to be alive at cancer case selection.

Of the 3,972 individuals with documentation of HBV infection, 12.8% were identified by the hepatitis registry only, 29.6% were identified by SPARCS only, and 57.7% were identified in both data sources (Table 2). For HCV, among 7,599 documented infections, 6.2% were identified by the hepatitis registry only, 20.5% by SPARCS only, and 73.3% in both data sources. Similarly, for infection with either HBV or HCV, 7.8% of infections were identified in the hepatitis registry only, 12.7% by SPARCS only, and 79.5% in both data sources.

We subsequently examined concordance between the 2 data sources (Table 3). For HCV infection and infection with either HBV or HCV, the 3 measures of agreement were similar and ranged from 0.72 to 0.74. For HBV infection, the 3 measures differed, likely due to the lower prevalence of HBV in our study population, and ranged from 0.66 for the simple κ to 0.83 for chance-corrected AC1. Overall, the measures of agreement indicated moderate to substantial agreement between the 2 data sources.

Finally, we examined factors associated with an unrecorded infection in 1 or both data sources among 9,753 individuals with evidence of HBV or HCV (Table 4). Females were less likely to have an unrecorded infection in SPARCS (OR, 0.68; 95% CI, 0.56–0.83), but no association was observed between sex and unrecorded infection in the hepatitis registry. Older individuals were more likely to have an unrecorded infection in both data sources, with stronger associations for individuals aged 70 years and older at cancer diagnosis (OR, 2.48; 95% CI, 1.93–3.20 for infection unrecorded in hepatitis registry and OR, 1.72; 95% CI, 1.31–2.24 for infection unrecorded in SPARCS). In SPARCS, individuals with Black, Asian, or other/unknown race were more likely than those with White race to have an unrecorded infection, while in the hepatitis registry, individuals with Black or Asian race were less likely than those with White race to have an unrecorded infection. In addition, in the hepatitis registry, Hispanic individuals were more likely than non-Hispanic individuals to have an unrecorded infection (OR, 1.46; 95% CI, 1.25–1.72). In SPARCS, ethnicity was not associated with an unrecorded infection. Differing associations between the hepatitis registry and SPARCS were also observed for country of birth, marital status, tobacco use history, and county of residence. People born outside the United States were more likely to have an unrecorded infection in the hepatitis registry (OR, 1.38; 95% CI, 1.18–1.62), as were married individuals (OR, 1.28; 95% CI, 1.10–1.49). Individuals with current or previous tobacco use were less likely to have an unrecorded infection in SPARCS, but tobacco history was unassociated in the hepatitis registry. Individuals who resided in Kings, New York, or Queens counties were more likely to have an undocumented infection in SPARCS when compared to individuals who resided in the Bronx, but no association was observed in the hepatitis registry.

Cancer characteristics were also associated with unrecorded infection in both data sources. Individuals with more recent cancer diagnoses were less likely to have an unrecorded infection and individuals with intrahepatic bile duct cancers were more likely to have an unrecorded infection in both data sources. More advanced stage at cancer diagnosis was associated with unrecorded infection in SPARCS, with ORs of 1.48 (95% CI, 1.19–1.83) for regional, 3.00 (95% CI, 2.40–3.74) for distant, and 1.80 (95% CI, 1.40–2.32) for unknown stage cancers. In contrast, stage at cancer diagnosis was not associated with unrecorded infection in the hepatitis registry. Similarly, type of reporting source was associated with unrecorded infection in SPARCS but not in the hepatitis registry. Cancers without microscopic confirmation were more likely to have an unrecorded infection in SPARCS (OR, 1.19; 95% CI, 1.01–1.41) and less likely to have an unrecorded infection in the hepatitis registry (OR, 0.86; 95% CI, 0.76–0.99). Vital status at cancer case selection also had differing associations in the 2 data sources, with alive individuals more likely to have an unrecorded infection in SPARCS (OR, 1.80; 95% CI, 1.45–2.22) and less likely to have an unrecorded infection in the hepatitis registry (OR, 0.77; 95% CI, 0.64–0.92).

In additional analyses, we separately examined factors associated with unrecorded HBV (Table 5) and unrecorded HCV (Table 6) in each data source. The associations with several factors differed for HBV vs HCV, particularly for the hepatitis registry, where associations with some variables were in opposite directions for unrecorded HBV and unrecorded HCV. For example, in the hepatitis registry,

Table 1. Characteristics of 14,747 Liver and Intrahepatic Bile Duct Cancers Diagnosed in New York City Residents in 2004–2018 and Reported to the New York State Cancer Registry, Overall and by HBV and HCV Infection Status*

	All cases	*HBV infection**		*P value†*	*HCV infection**		*P value†*
		Yes	**No**		**Yes**	**No**	
Total, n (%)	14,747	3,972 (26.9)	10,775 (73.1)		7,599 (51.5)	7,148 (48.5)	
Case characteristics, n (%)							
Sex				<.0001			<.0001
Male	10,469 (71.0)	3,238 (81.5)	7,231 (67.1)		5,687 (74.8)	4,782 (66.9)	
Female	4,278 (29.0)	734 (18.5)	3,544 (32.9)		1,912 (25.2)	2,366 (33.1)	
Age at cancer diagnosis, y				<.0001			<.0001
<50	1,519 (10.3)	815 (20.5)	704 (6.5)		516 (6.8)	1,003 (14.0)	
50–59	3,611 (24.5)	1,214 (30.6)	2,397 (22.2)		2,342 (30.8)	1,269 (17.8)	
60–69	4,770 (32.3)	1,207 (30.4)	3,563 (33.1)		2,943 (38.7)	1,827 (25.6)	
≥70	4,847 (32.9)	736 (18.5)	4,111 (38.2)		1,798 (23.7)	3,049 (42.7)	
Race				<.0001			<.0001
White	7,691 (52.2)	1,109 (27.9)	6,582 (61.1)		4,134 (54.4)	3,557 (49.8)	
Black	3,970 (26.9)	992 (25.0)	2,978 (27.6)		2,548 (33.5)	1,422 (19.9)	
Asian	2,803 (19.0)	1,813 (45.6)	990 (9.2)		769 (10.1)	2,034 (28.5)	
Other/unknown	283 (1.9)	58 (1.5)	225 (2.1)		148 (1.9)	135 (1.9)	
Hispanic ethnicity				<.0001			<.0001
Non-Hispanic	10,404 (70.5)	3,238 (81.5)	7,166 (66.5)		4,960 (65.3)	5,444 (76.2)	
Hispanic	4,343 (29.5)	734 (18.5)	3,609 (33.5)		2,639 (34.7)	1,704 (23.8)	
Country of birth				<.0001			<.0001
United States	5,764 (39.1)	952 (24.0)	4,812 (44.7)		3,582 (47.1)	2,182 (30.5)	
Non–United States	5,631 (38.2)	1,901 (47.9)	3,730 (34.6)		2,330 (30.7)	3,301 (46.2)	
Unknown	3,352 (22.7)	1,119 (28.2)	2,233 (20.7)		1,687 (22.2)	1,665 (23.3)	
Marital status				<.0001			<.0001
Single	4,678 (31.7)	1,229 (30.9)	3,449 (32.0)		2,801 (36.9)	1,877 (26.3)	
Married	6,453 (43.8)	2,087 (52.5)	4,366 (40.5)		2,908 (38.3)	3,545 (49.6)	
Separated/divorced	1,502 (10.2)	318 (8.0)	1,184 (11.0)		888 (11.7)	614 (8.6)	
Widowed	1,527 (10.4)	183 (4.6)	1,344 (12.5)		670 (8.8)	857 (12.0)	
Other/unknown	587 (4.0)	155 (3.9)	432 (4.0)		332 (4.4)	255 (3.6)	
Tobacco history				<.0001			<.0001
Never use	5,043 (34.2)	1,494 (37.6)	3,549 (32.9)		1,995 (26.3)	3,048 (42.6)	
Current use	2,922 (19.8)	836 (21.0)	2,086 (19.4)		1,987 (26.1)	935 (13.1)	
Previous use	4,264 (28.9)	1,063 (26.8)	3,201 (29.7)		2,385 (31.4)	1,879 (26.3)	
Unknown	2,518 (17.1)	579 (14.6)	1,939 (18.0)		1,232 (16.2)	1,286 (18.0)	
County of residence				<.0001			<.0001
Bronx	3,202 (21.7)	685 (17.2)	2,517 (23.4)		2,069 (27.2)	1,133 (15.9)	
Kings	3,903 (26.5)	1,207 (30.4)	2,696 (25.0)		1,956 (25.7)	1,947 (27.2)	
New York	3,091 (21.0)	810 (20.4)	2,281 (21.2)		1,641 (21.6)	1,450 (20.3)	
Queens	3,702 (25.1)	1,115 (28.1)	2,587 (24.0)		1,523 (20.0)	2,179 (30.5)	
Richmond	849 (5.8)	155 (3.9)	694 (6.4)		410 (5.4)	439 (6.1)	

Table 1, *cont.* Characteristics of 14,747 Liver and Intrahepatic Bile Duct Cancers Diagnosed in New York City Residents in 2004–2018 and Reported to the New York State Cancer Registry, Overall and by HBV and HCV Infection Status*

	All cases	*HBV infection**		*P value*†*	*HCV infection**		*P value*†*
		Yes	**No**		**Yes**	**No**	
Total, n (%)	14,747	3,972 (26.9)	10,775 (73.1)		7,599 (51.5)	7,148 (48.5)	
Case characteristics, n (%)							
Year of cancer diagnosis				.01			<.0001
2004–2008	4,284 (29.0)	1,201 (30.2)	3,083 (28.6)		2,272 (29.9)	2,012 (28.1)	
2009–2013	5,071 (34.4)	1,393 (35.1)	3,678 (34.1)		2,844 (37.4)	2,227 (31.2)	
2014–2018	5,392 (36.6)	1,378 (34.7)	4,014 (37.3)		2,483 (32.7)	2,909 (40.7)	
Cancer site				<.0001			<.0001
Liver	13,159 (89.2)	3,822 (96.2)	9,337 (86.7)		7,426 (97.7)	5,733 (80.2)	
Intrahepatic bile duct cancer	1,588 (10.8)	150 (3.8)	1,438 (13.3)		173 (2.3)	1,415 (19.8)	
Stage at diagnosis				<.0001			<.0001
Local	6,440 (43.7)	1,974 (49.7)	4,466 (41.4)		3,737 (49.2)	2,703 (37.8)	
Regional	3,366 (22.8)	907 (22.8)	2,459 (22.8)		1,724 (22.7)	1,642 (23.0)	
Distant	2,682 (18.2)	619 (15.6)	2,063 (19.1)		1,057 (13.9)	1,625 (22.7)	
Unknown	2,259 (15.3)	472 (11.9)	1,787 (16.6)		1,081 (14.2)	1,178 (16.5)	
Type of reporting source				<.0001			<.0001
Hospital inpatient	11,756 (79.7)	3,287 (82.8)	8,469 (78.6)		6,016 (79.2)	5,740 (80.3)	
Hospital outpatient/surgery center	2,403 (16.3)	600 (15.1)	1,803 (16.7)		1,356 (17.8)	1,047 (14.6)	
Other	588 (4.0)	85 (2.1)	503 (4.7)		227 (3.0)	361 (5.1)	
Diagnostic confirmation				<.0001			<.0001
Microscopically confirmed	9,219 (62.5)	2,597 (65.4)	6,622 (61.5)		4,272 (56.2)	4,947 (69.2)	
Not microscopically confirmed	4,922 (33.4)	1,274 (32.1)	3,648 (33.9)		3,047 (40.1)	1,875 (26.2)	
Unknown	606 (4.1)	101 (2.5)	505 (4.7)		280 (3.7)	326 (4.6)	
Vital status at cancer case selection				<.0001			<.0001
Deceased	10,937 (74.2)	2,615 (65.8)	8,322 (77.2)		5,779 (76.0)	5,158 (72.2)	
Alive	3,810 (25.8)	1,357 (34.2)	2,453 (22.8)		1,820 (24.0)	1,990 (27.8)	

HBV, hepatitis B virus; HCV, hepatitis C virus. Note: Percentages may not sum to 100 due to rounding.

*HBV and HCV infection defined as evidence of infection in either linked data source.

†*P* value from χ-square test.

Table 2. Hepatitis B and C Infection Status by Linked Data Source Among 14,747 Residents of New York City Diagnosed with Liver or Intrahepatic Bile Duct Cancer in 2004–2018 and Reported to the New York State Cancer Registry

Infection identified by:	*HBV infection*		*HCV infection*		*HBV or HCV infection*	
	n	**%**	**n**	**%**	**n**	**%**
Hepatitis registry only	507	12.8	471	6.2	756	7.8
SPARCS only	1,175	29.6	1,555	20.5	1,241	12.7
Both hepatitis registry and SPARCS	2,290	57.7	5,573	73.3	7,756	79.5
Total	3,972	100.0	7,599	100.0	9,753	100.0
Total percent of cancer patients with infection		**26.9**		**51.5**		**66.1**

HBV, hepatitis B virus; HCV, hepatitis C virus.

Table 3. HBV and HCV Positivity by Linked Data Source and Concordance Between Infection Status in the 2 Data Sources Among 14,747 Residents of New York City Diagnosed with Liver or Intrahepatic Bile Duct Cancer in 2004–2018 and Reported to the New York State Cancer Registry

Infection status	*Cancer patients with infection, %*		*Measures of agreement*		
	Identified by linkage with hepatitis registry	**Identified by linkage with SPARCS**	**Simple κ**	**Prevalence and bias-adjusted κ**	**Chance-corrected AC1**
HBV infection	19.0	23.5	0.66	0.77	0.83
HCV infection	41.0	48.3	0.72	0.73	0.73
HBV infection	57.7	61.0	0.72	0.73	0.74

AC1, agreement coefficient; HBV, hepatitis B virus; HCV, hepatitis C virus.

Table 4. Multivariable-Adjusted ORs and 95% CIs for Associations of Patient and Cancer Characteristics with Unrecorded Hepatitis B or C Infection by Data Source Among 9,753 New York City Residents with a Documented Hepatitis B or C Infection and a Liver or Intrahepatic Bile Duct Cancer Diagnosed in 2004–2018

	Infection not recorded in hepatitis registry			*Infection not recorded in SPARCS*		
	n	**%**	**OR (95% CI)***	**n**	**%**	**OR (95% CI)***
Overall	1,241	12.7		756	7.8	
Sex						
Male	898	12.0	Ref	604	8.1	Ref
Female	343	15.0	1.16 (1.00–1.34)	152	6.6	0.68 (0.56-0.83)
Age at cancer diagnosis, y						
<50	90	8.4	Ref	96	9.0	Ref
50–59	314	10.7	1.25 (0.97–1.61)	201	6.8	0.94 (0.72-1.22)
60–69	405	11.5	1.46 (1.14–1.87)	224	6.4	0.98 (0.75-1.27)
≥70	432	19.3	2.48 (1.93–3.20)	235	10.5	1.72 (1.31-2.24)
Race						
White	722	16.1	Ref	267	6.0	Ref
Black	292	9.9	0.77 (0.66–0.91)	247	8.4	1.54 (1.27-1.86)
Asian	200	9.3	0.60 (0.49–0.74)	221	10.3	1.78 (1.44-2.22)
Other/unknown	27	15.3	1.28 (0.83–1.98)	21	11.9	2.55 (1.54-4.23)
Ethnicity						
Non-Hispanic	740	10.7	Ref	594	8.6	Not in model*
Hispanic	501	17.6	1.46 (1.25–1.72)	162	5.7	Not in model*
Country of birth						
United States	429	11.3	Ref	287	7.6	Ref
Non–United States	567	15.8	1.38 (1.18–1.62)	301	8.4	0.90 (0.74-1.11)
Unknown	245	10.3	1.13 (0.93–1.39)	168	7.1	0.75 (0.58-0.96)
Marital status						
Single	360	10.8	Ref	258	7.7	Not in model*
Married	574	13.6	1.28 (1.10–1.49)	323	7.6	Not in model*
Separated/divorced	140	13.8	1.23 (0.99–1.53)	62	6.1	Not in model*
Widowed	118	15.8	1.00 (0.78–1.27)	62	8.3	Not in model*
Other/unknown	49	11.6	1.08 (0.78–1.50)	51	12.1	Not in model*

Table 4, *cont*. Multivariable-Adjusted ORs and 95% CIs for Associations of Patient and Cancer Characteristics with Unrecorded Hepatitis B or C Infection by Data Source Among 9,753 New York City Residents with a Documented Hepatitis B or C Infection and a Liver or Intrahepatic Bile Duct Cancer Diagnosed in 2004–2018

	Infection not recorded in hepatitis registry			*Infection not recorded in SPARCS*		
	n	**%**	**OR (95% CI)***	**n**	**%**	**OR (95% CI)***
Overall	1,241	12.7		756	7.8	
Tobacco history						
Never use	398	13.5	Not in model*	233	7.9	Ref
Current use	244	10.4	Not in model*	136	5.8	0.77 (0.61-0.97)
Previous use	383	13.2	Not in model*	169	5.8	0.73 (0.59-0.90)
Unknown	216	13.9	Not in model*	218	14.0	1.52 (1.22-1.90)
County of residence						
Bronx	315	13.5	Ref	124	5.3	Ref
Kings	299	11.4	0.94 (0.78–1.13)	214	8.1	1.39 (1.09-1.76)
New York	252	12.2	0.93 (0.78–1.13)	178	8.6	1.35 (1.05-1.73)
Queens	309	13.8	1.20 (0.99–1.44)	207	9.2	1.53 (1.20-1.97)
Richmond	66	13.9	1.15 (0.85–1.56)	33	7.0	1.35 (0.89-2.04)
Year of cancer diagnosis						
2004–2008	511	17.8	Ref	296	10.3	Ref
2009–2013	403	11.3	0.57 (0.50–0.66)	249	7.0	0.61 (0.50-0.73)
2014–2018	327	9.8	0.51 (0.43–0.60)	211	6.3	0.48 (0.39-0.59)
Cancer site						
Liver	1174	12.4	Ref	717	7.6	Ref
Intrahepatic bile duct	67	23.5	2.36 (1.75–3.17)	39	13.7	2.13 (1.47-3.08)
Stage at diagnosis						
Local	561	11.8	Not in model*	258	5.4	Ref
Regional	300	13.5	Not in model*	154	6.9	1.48 (1.19-1.83)
Distant	184	12.7	Not in model*	180	12.4	3.00 (2.40-3.74)
Unknown	196	14.8	Not in model*	164	12.4	1.80 (1.40-2.32)
Type of reporting source						
Hospital inpatient	1017	13.0	Not in model*	575	7.4	Ref
Hospital outpatient/surgery center	181	10.9	Not in model*	109	6.5	1.12 (0.89-1.40)
Other	43	15.2	Not in model*	72	25.4	3.01 (2.12-4.27)
Diagnostic confirmation						
Microscopically confirmed	761	13.2	Ref	426	7.4	Ref
Not microscopically confirmed	424	11.6	0.86 (0.76–0.99)	269	7.3	1.19 (1.01-1.41)
Unknown	56	16.8	1.25 (0.92–1.70)	61	18.3	1.25 (0.85-1.84)
Vital status at cancer case selection						
Deceased	996	14.1	Ref	544	7.7	Ref
Alive	245	9.1	0.77 (0.64–0.92)	212	7.9	1.80 (1.45-2.22)

HBV, hepatitis B virus; HCV, hepatitis C virus; OR, odds ratio. *Based on final reduced logistic regression models including factors with a Wald *P* value ≤0.1.

Table 5. Multivariable-Adjusted ORs and 95% CIs for Associations of Patient and Cancer Characteristics with Unrecorded HBV Infection by Data Source Among 3,972 New York City Residents with a Documented HBV Infection and a Liver or Intrahepatic Bile Duct Cancer Diagnosed in 2004–2018

	Infection not recorded in hepatitis registry			*Infection not recorded in SPARCS*		
	n	**%**	**OR (95% CI)***	**n**	**%**	**OR (95% CI)***
Overall	1,175	29.6		507	12.8	
Sex						
Male	905	27.9	Ref	427	13.2	Ref
Female	270	36.8	1.79 (1.45–2.21)	80	10.9	0.73 (0.55–0.95)
Age at cancer diagnosis, y						
<50	90	11.0	Ref	97	11.9	Ref
50–59	360	29.7	2.44 (1.85–3.23)	143	11.8	1.16 (0.87–1.55)
60–69	449	37.2	3.66 (2.77–4.82)	154	12.8	1.32 (0.99–1.76)
≥70	276	37.5	4.89 (3.62–6.60)	113	15.4	1.73 (1.26–2.38)
Race						
White	602	54.3	Ref	145	13.1	Ref
Black	384	38.7	0.72 (0.58–0.88)	137	13.8	1.13 (0.87–1.46)
Asian	172	9.5	0.19 (0.15–0.24)	212	11.7	0.93 (0.73–1.18)
Other/unknown	17	29.3	0.55 (0.29–1.03)	<16	†	1.81 (0.93–3.53)
Ethnicity						
Non-Hispanic	766	23.7	Ref	415	12.8	Not in model*
Hispanic	409	55.7	1.94 (1.57–2.41)	92	12.5	Not in model*
Country of birth						
United States	543	57.0	Ref	121	12.7	Not in model*
Non–United States	400	21.0	0.41 (0.33–0.51)	241	12.7	Not in model*
Unknown	232	20.7	0.44 (0.34–0.57)	145	13.0	Not in model*
Marital status						
Single	459	37.3	Not in model*	178	14.5	Ref
Married	456	21.8	Not in model*	252	12.1	0.81 (0.65–1.02)
Separated/divorced	144	45.3	Not in model*	28	8.8	0.58 (0.38–0.89)
Widowed	74	40.4	Not in model*	26	14.2	0.90 (0.56–1.44)
Other/unknown	42	27.1	Not in model*	23	14.8	0.79 (0.48–1.30)
Tobacco history						
Never use	316	21.2	Ref	181	12.1	Ref
Current use	325	38.9	1.98 (1.58–2.49)	96	11.5	0.90 (0.68–1.18)
Previous use	386	36.3	1.79 (1.45–2.22)	118	11.1	0.85 (0.66–1.10)
Unknown	148	25.6	1.02 (0.78–1.32)	112	19.3	1.58 (1.20–2.09)
County of residence						
Bronx	306	44.7	Not in model*	78	11.4	Not in model*
Kings	333	27.6	Not in model*	167	13.8	Not in model*
New York	241	29.8	Not in model*	99	12.2	Not in model*
Queens	236	21.2	Not in model*	144	12.9	Not in model*
Richmond	59	38.1	Not in model*	19	12.3	Not in model*

Table 5 *cont*. Multivariable-Adjusted ORs and 95% CIs for Associations of Patient and Cancer Characteristics with Unrecorded HBV Infection by Data Source Among 3,972 New York City Residents with a Documented HBV Infection and a Liver or Intrahepatic Bile Duct Cancer Diagnosed in 2004–2018

	Infection not recorded in hepatitis registry			*Infection not recorded in SPARCS*		
	n	**%**	**OR (95% CI)***	**n**	**%**	**OR (95% CI)***
Overall	1,175	29.6		507	12.8	
Year of cancer diagnosis						
2004–2008	356	29.6	Not in model*	193	16.1	Ref
2009–2013	439	31.5	Not in model*	150	10.8	0.59 (0.47–0.75)
2014–2018	380	27.6	Not in model*	164	11.9	0.62 (0.48–0.79)
Cancer site						
Liver	1,121	29.3	Ref	484	12.7	Not in model*
Intrahepatic bile duct	54	36.0	1.56 (1.04–2.35)	23	15.3	Not in model*
Stage at diagnosis						
Local	578	29.3	Ref	208	10.5	Ref
Regional	285	31.4	0.95 (0.77–1.17)	106	11.7	1.30 (1.01–1.69)
Distant	158	25.5	0.60 (0.47–0.77)	116	18.7	2.38 (1.82–3.12)
Unknown	154	32.6	0.91 (0.70–1.19)	77	16.3	1.51 (1.10–2.06)
Type of reporting source						
Hospital inpatient	975	29.7	Not in model*	394	12.0	Ref
Hospital outpatient/surgery center	179	29.8	Not in model*	91	15.2	1.45 (1.12–1.88)
Other	21	24.7	Not in model*	22	25.9	1.95 (1.14–3.33)
Diagnostic confirmation						
Microscopically confirmed	708	27.3	Not in model*	314	12.1	Not in model*
Not microscopically confirmed	431	33.8	Not in model*	172	13.5	Not in model*
Unknown	36	35.6	Not in model*	21	20.8	Not in model*
Vital status at cancer case selection						
Deceased	905	34.6	Ref	333	12.7	Ref
Alive	270	19.9	0.75 (0.61–0.93)	174	12.8	1.42 (1.13–1.80)

HBV, hepatitis B virus; OR, odds ratio. *Based on final reduced logistic regression models including factors with a Wald *P* value ≤.1. †Counts and percentages for counts <16 are suppressed.

unrecorded HBV was more likely among females, individuals ≥50 years of age at cancer diagnosis, and current/previous tobacco users and less likely among Asian individuals and people born outside the United States, whereas these associations were reversed for unrecorded HCV. The associations with unrecorded HBV vs unrecorded HCV were more similar in SPARCS, although some variables were associated with unrecorded HCV but not unrecorded HBV or vice versa.

Discussion

Our results indicate that linkages of cancer registry data with hospital discharge and public health surveillance data can be used to estimate HBV and HCV infection status in individuals diagnosed with cancer. Among the 14,747 liver and intrahepatic bile duct cancer cases included in our analysis, 26.9% had documented HBV infection, 51.5% had documented HCV infection, and 66.1% had either or both HBV and HCV documented. Although we observed moderate to substantial agreement between the 2 linked data sources, there were discrepancies, with 12.7% of infections unrecorded in the hepatitis registry and 7.8% unrecorded in SPARCS. Multiple patient and cancer characteristics were associated with unrecorded infection in each data source, suggesting that infections in certain subpopulations may be less likely to be captured in these databases.

The statistically significant associations observed between individual-level characteristics and unrecorded infection suggest the presence of patterns where hepatitis infections in certain subpopulations are less likely to be documented. Groups that were more likely to have an unrecorded infection in the SPARCS data included males, individuals aged 70 years and older at cancer diagnosis, individuals with non-White race, and those residing in certain counties of NYC, suggesting that these individuals may be less likely to receive hospital-based medical care

Table 6. Multivariable-Adjusted ORs and 95% CIs for Associations of Patient and Cancer Characteristics with Unrecorded HCV Infection by Data Source Among 7,599 New York City Residents with a Documented HCV Infection and a Liver or Intrahepatic Bile Duct Cancer Diagnosed in 2004–2018

	Infection not recorded in hepatitis registry			*Infection not recorded in SPARCS*		
	n	**%**	**OR (95% CI)***	**n**	**%**	**OR (95% CI)***
Overall	1,555	20.5		471	6.2	
Sex						
Male	1,189	20.9	Ref	361	6.3	Ref
Female	366	19.1	0.80 (0.69–0.94)	110	5.8	0.73 (0.57–0.92)
Age at cancer diagnosis, y						
<50	216	41.9	Ref	25	4.8	Ref
50–59	450	19.2	0.42 (0.34–0.52)	128	5.5	1.26 (0.80–1.97)
60–69	481	16.3	0.39 (0.31–0.48)	150	5.1	1.25 (0.80–1.96)
≥70	408	22.7	0.48 (0.38–0.60)	168	9.3	2.43 (1.55–3.81)
Race						
White	746	18.0	Ref	211	5.1	Ref
Black	376	14.8	0.99 (0.85–1.14)	190	7.5	1.56 (1.25–1.93)
Asian	403	52.4	3.72 (3.11–4.44)	57	7.4	1.59 (1.14–2.22)
Other/unknown	30	20.3	1.28 (0.83–1.97)	<16	†	2.44 (1.29–4.58)
Ethnicity						
Non-Hispanic	1,038	20.9	Not in model*	347	7.0	Not in model*
Hispanic	517	19.6	Not in model*	124	4.7	Not in model*
Country of birth						
United States	485	13.5	Ref	248	6.9	Ref
Non–United States	719	30.9	1.95 (1.67–2.27)	143	6.1	0.80 (0.62–1.03)
Unknown	351	20.8	1.59 (1.31–1.92)	80	4.7	0.57 (0.41–0.79)
Marital status						
Single	457	16.3	Ref	169	6.0	Not in model*
Married	752	25.9	1.29 (1.12–1.49)	171	5.9	Not in model*
Separated/divorced	158	17.8	1.20 (0.98–1.48)	51	5.7	Not in model*
Widowed	129	19.3	1.06 (0.83–1.34)	46	6.9	Not in model*
Other/unknown	59	17.8	1.04 (0.75–1.43)	34	10.2	Not in model*
Tobacco history						
Never use	531	26.6	Ref	126	6.3	Ref
Current use	311	15.7	0.68 (0.57–0.81)	83	4.2	0.66 (0.49–0.89)
Previous use	448	18.8	0.78 (0.67–0.92)	112	4.7	0.70 (0.53–0.92)
Unknown	265	21.5	0.87 (0.72–1.05)	150	12.2	1.50 (1.13–1.98)
County of residence						
Bronx	353	17.1	Not in model*	88	4.3	Ref
Kings	399	20.4	Not in model*	126	6.4	1.37 (1.02–1.82)
New York	325	19.8	Not in model*	121	7.4	1.46 (1.09–1.95)
Queens	398	26.1	Not in model*	112	7.4	1.59 (1.17–2.15)
Richmond	80	19.5	Not in model*	24	5.9	1.33 (0.82–2.15)

Table 6, *cont*. Multivariable-Adjusted ORs and 95% CIs for Associations of Patient and Cancer Characteristics with Unrecorded HCV Infection by Data Source Among 7,599 New York City Residents with a Documented HCV Infection and a Liver or Intrahepatic Bile Duct Cancer Diagnosed in 2004–2018

	Infection not recorded in hepatitis registry			*Infection not recorded in SPARCS*		
	n	**%**	**OR (95% CI)***	**n**	**%**	**OR (95% CI)***
Overall	1,555	20.5		471	6.2	
Year of cancer diagnosis						
2004–2008	664	29.2	Ref	170	7.5	Ref
2009–2013	534	18.8	0.58 (0.50–0.67)	170	6.0	0.74 (0.59–0.93)
2014–2018	357	14.4	0.45 (0.38–0.53)	131	5.3	0.61 (0.47–0.80)
Cancer site						
Liver	1,509	20.3	Ref	452	6.1	Ref
Intrahepatic bile duct	46	26.6	1.83 (1.27–2.64)	19	11.0	1.95 (1.17–3.25)
Stage at diagnosis						
Local	750	20.1	Not in model*	169	4.5	Ref
Regional	362	21.0	Not in model*	91	5.3	1.27 (0.97–1.67)
Distant	211	20.0	Not in model*	97	9.2	2.37 (1.78–3.14)
Unknown	232	21.5	Not in model*	114	10.5	1.62 (1.21–2.17)
Type of reporting source						
Hospital inpatient	1,285	21.4	Not in model*	352	5.9	Ref
Hospital outpatient/surgery center	226	16.7	Not in model*	65	4.8	1.01 (0.76–1.35)
Other	44	19.4	Not in model*	54	23.8	3.39 (2.30–4.99)
Diagnostic confirmation						
Microscopically confirmed	976	22.8	Ref	250	5.9	Not in model*
Not microscopically confirmed	520	17.1	0.81 (0.71–0.92)	176	5.8	Not in model*
Unknown	59	21.1	0.97 (0.70–1.35)	45	16.1	Not in model*
Vital status at cancer case selection						
Deceased	1,198	20.7	Ref	366	6.3	Ref
Alive	357	19.6	0.79 (0.67–0.94)	105	5.8	1.75 (1.32–2.33)

HCV, hepatitis C virus; OR, odds ratio. *Based on final reduced logistic regression models including factors with a Wald *P* value ≤ .1. †Counts and percentages for counts <16 are suppressed.

related to their hepatitis diagnosis or less likely to have a claim code for hepatitis due to other competing diagnoses. Similarly, those with intrahepatic bile duct cancers and more advanced stage cancers were also more likely to have an unrecorded infection in SPARCS, possibly due to competing diagnoses or medical provider unawareness of the patient's hepatitis diagnosis. In the hepatitis registry, groups that were more likely to have an unrecorded infection included individuals aged 60 years and older at cancer diagnosis, those with Hispanic ethnicity or non-US birthplace, married individuals, and those with intrahepatic bile duct cancers. These subpopulations may be less likely to be captured in the hepatitis registry due to geographic mobility or medical care outside of the catchment area or may have characteristics that tend to result in a diagnosis code in SPARCS without meeting the case definition for the hepatitis registry.

Our results highlight the importance of surveillance systems to identify hepatitis diagnoses within a population, including among cancer cases. Diagnosis and appropriate treatment of HBV and HCV is critical for reducing risk of hepatocellular carcinoma,[12] and among liver cancer patients, improving outcomes including survival.[6-8] A meta-analysis of antiviral treatment for HBV after HCC diagnosis and curative surgery reported that treatment with nucleoside and nucleotide analogues was associated with statistically significant improvements in recurrence-free survival and overall survival at 3 and 5 years following diagnosis.[6] Similarly, among patients with chronic HCV and diagnosis of HCC, several studies have reported associations between treatment with direct-acting antiviral therapy and reduced rates of cancer recurrence,[8] and studies of curative HCV treatment prior to HCC diagnosis have reported associations with improved 5-year overall survival.[7] Availability of data on HBV and HCV diagnosis, as a proxy for or in addition to information on antiviral treatment, has the potential to enhance cancer registry data and allow for more refined analyses of outcomes in patients with HCC.

Limitations of this analysis primarily relate to differences between the data sources that may have led to discrepancies in hepatitis positivity. The use of differing case inclusion criteria in the 2 data sources may have resulted in unrecorded infections, particularly for the hepatitis registry, as diagnoses reported in SPARCS may not have met the hepatitis registry's case definition. For example, the hepatitis registry uses current case definitions per the Council of State and Territorial Epidemiologists and Centers for Disease Control and Prevention guidance for viral hepatitis surveillance,[13] whereas the data in SPARCS reflect clinical diagnoses and definitions. SPARCS data do not capture treatment at some types of outpatient facilities such as physician offices outside of a hospital setting, likely resulting in some missed diagnoses and therefore unrecorded infections. Differences in the linkage methodologies (probabilistic vs deterministic) for the 2 data sources, including the variables used in the match, may also have contributed to differences. Although a probabilistic approach is generally preferred, the detailed multistep process routinely used for linking NYSCR and SPARCS data, along with manual reviews for uncertain and duplicate matches, minimizes the limitations of the deterministic approach. Data from the hepatitis registry may be less likely to include NYC residents who were diagnosed at facilities outside of NYC, resulting in the possibility of missed diagnoses due to reporting errors. In addition, data in the hepatitis registry likely did not capture individuals initially diagnosed with viral hepatitis in New York State outside of NYC who later moved into NYC. Further, data in the hepatitis registry are less complete prior to 1998, likely resulting in some unrecorded infections with earlier diagnosis dates. The hepatitis registry data file included individuals with chronic HBV or HCV, while the SPARCS data included diagnosis codes for both acute and chronic hepatitis. Although acute cases represent a small proportion of overall cases (approximately 2% of SPARCS cases), this may have contributed to some differences in hepatitis positivity between the 2 data sources for a small number of HBV cases but not for HCV cases, since acute HCV cases are given chronic status in the hepatitis registry. Finally, due to differences in the time period of hepatitis diagnoses in the 2 data sources, the analysis did not consider the timing of reported hepatitis infection in relation to cancer diagnosis. Although this would not be expected to impact the frequency of unrecorded infections for the period examined, the interval between documented hepatitis infection and cancer diagnosis would be important to consider in epidemiologic studies of HCC.

However, strengths of this analysis include the large and diverse study population of liver and intrahepatic bile duct cancers diagnosed in NYC over a 15-year period. The use of 2 independent linked data sources allowed for assessment of the feasibility of using different data sources, including discharge data, to assess HBV and HCV infection status in cancer patients reported to a central cancer registry. This information could be used to extend this work to other registries, and to facilitate epidemiologic studies of cancer outcomes. Availability of HBV and HCV data in population-based cancer registries would enable additional studies to examine associations of hepatitis with cancer characteristics, patterns of care, and survival in cancer patients.

This study indicates that linkages with discharge and public health surveillance data can be used to provide information on HBV and HCV infection in patients diagnosed with cancer. This information can be used to enrich cancer registry data for epidemiologic analyses of HCC and other cancers, potentially leading to information that will help to improve outcomes for individuals with hepatitis and cancer. For example, these data could facilitate analyses of treatment and survival among individuals with hepatitis and HCC and could help to inform programmatic work and clinical outreach for providers caring for this patient population. Depending on the research question of interest, case definitions and nature of reporting source should be considered when interpreting results from secondary data linkages with disease registries or hospitalization data.

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Original Article

Disparities in Colorectal Cancer Incidence and Mortality Rates in Arkansas and Associated Risk Factors

Daniela Ramirez Aguilar, MPH[a]; Johnna Berryhill, BS[b]; Melody Greer, PhD[c]; Jennifer Gan-Kemp, MBA, CRS[c]; Sudeepa Bhattacharyya, PhD[d]

Abstract: Colorectal cancer (CRC) is a common malignancy in the United States, ranking as the third-leading cause of cancer-related deaths. Early detection is crucial for prognosis, treatment, and survival, yet disparities persist in CRC outcomes based on age, sex, race, and geography. In Arkansas, a significant proportion of CRC cases are diagnosed at a late stage, with notable disparities observed among different demographic groups. In this study, we utilized data from the Arkansas Central Cancer Registry (ACCR) and the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program to analyze CRC incidence and mortality rates in Arkansas and examine the associated disparities and risk factors. Data were stratified by sex, race, age, geographic area, and stage at diagnosis. Temporal trends and age-adjusted rates were computed using SEER*Stat software, and a bootstrapped logistic regression model was developed to identify predictors of late-stage CRC diagnosis. The analysis revealed that men had higher CRC mortality and incidence rates compared to women, with a mortality rate ratio (MRR) of 1.47 and an incidence rate ratio (IRR) of 1.35. Black individuals exhibited higher CRC mortality and incidence rates than their White counterparts (MRR, 1.46; IRR, 1.29). Late-stage CRC diagnosis was more common among men and individuals of Black race. Temporal trends showed a decline in CRC incidence from 2001 to 2011, followed by an increase from 2011 to 2019. Individuals aged 18–49 years experienced a significant rise in CRC incidence, highlighting an emerging concern for early-onset CRC. Geographic analysis indicated higher CRC incidence in rural vs urban areas. Overall, significant disparities in CRC outcomes were observed by sex, race, age, and geography. The increase in CRC incidence among younger adults underscores the need for targeted screening and early detection strategies. Geographic disparities highlight the necessity of improving health care access and screening services in rural areas.

Key words: *Arkansas, colorectal cancer, epidemiology, SEER*Stat*

Introduction

Colorectal cancer (CRC) is among the most frequently diagnosed cancers in the United States and is the third-most-common cause of cancer-related death.[1] It is a slow-growing disease that typically begins within benign, precancerous polyps, with symptoms presenting once they have reached a considerably large size.[2,3] Although early detection and prevention have contributed to a decrease in incidence and mortality rates over time, a CRC diagnosis still raises concerning issues. For one, disparities remain by age, sex, race, and geographic area.[4–8] In the United States, CRC is considered a highly treatable disease when detected early; however, different populations are impacted by CRC with unequal outcomes.[9] Men have a higher incidence and mortality rate than women, and Black individuals have a higher rate of late-stage CRC diagnosis than White individuals.[10,11]

Another concern is the increase of early-onset CRC. Efforts were made to address the rise in CRC among adults younger than 50 years by updating the US Preventive Services Task Force's (USPSTF) CRC screening guidance to include adults aged 45 years and older.[12–17] The Arkansas General Assembly also established these same efforts for Arkansas by passing Act 779 in 2021. This act mandated health insurance companies to cover any follow-up examinations or laboratory testing related to colorectal cancer screening for patients aged 45 years and older, making life-saving screenings more accessible and affordable.[7] However, the impact of these efforts will likely not be observed until future years. Given these concerns, descriptive statistics are needed to assess baseline trends and rates to monitor the current CRC burden in Arkansas, a state with a high CRC late-stage diagnosis and mortality.[7]

The purpose of this study is to provide an epidemiological overview of CRC mortality and incidence in Arkansas, as well as to identify groups with higher odds of late-stage CRC diagnosis. This study supports past and ongoing Arkansas CRC research that has used population-based cancer data. As such, the Arkansas Central Cancer Registry (ACCR), a National Cancer Institute (NCI) Surveillance, Epidemiology and End Results (SEER) research support state, and a funded registry through the Centers for Disease

[a]Arkansas Central Cancer Registry, Arkansas Department of Health, Little Rock, Arkansas. [b]Arkansas State University, Jonesboro, Arkansas. [c]University of Arkansas for Medical Sciences, Little Rock, Arkansas. [d]University of Missouri-Kansas City.

Address correspondence to Daniela Ramirez Aguilar, MPH (email: Daniela.Ramirez-Aguilar@Arkansas.Gov), or Sudeepa Bhattacharyya, PhD (email: SBGK3@UMKC.edu).

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Control and Prevention (CDC)'s National Program of Cancer Registries (NPCR), was also utilized as our data source to provide an updated understanding of CRC in the rural state. In doing so, we anticipate our study will inform policies and interventions on cancer control and prevention and further CRC research.

Methods

All analyses were stratified by sex, race, age group, geographic area, and stage at diagnosis. Data were analyzed by two major racial groups in Arkansas and categorized as White and Black populations. Due to the low population of Hispanic and Asian American/Pacific Islander patients in Arkansas, these groups were excluded from this study's epidemiological and statistical modeling analysis. Age groups were grouped based on the USPSTF's 2016 CRC screening recommendations and they are presented as age-specific, rather than age-adjusted, rates. There were 3 age groups for analysis: *18–49 years, 50–75 years* (reference group), and ≥*76 years*. Geographic areas were categorized as *urban* or *rural* based on the 2013 Rural-Urban Continuum Codes (1–3, urban; 4–9, Rural). Staging for CRC was grouped by *early* (localized) and *late stage* (regional and distant). *Localized* CRC is defined as being confined to the primary site; *regional* CRC has spread directly beyond the primary site (regional extension) or to regional lymph nodes; and *distant* CRC has spread to other organs (distant extension) or remote lymph node. These were classified using a merged variable that spans the periods when 3 different staging schemes were used: SEER Summary Stage 2000, Derived Summary Stage, and Summary Stage 2018.

Epidemiological Data Source

All Arkansas rates, rate ratios, and trends were calculated using NCI's SEER*Stat (version 8.4.3). Mortality for CRC was used from the National Center for Health Statistics database while incidence was used from the US Cancer Statistics NPCR and SEER database. Comparative mortality and incidence rates reflect per 100,000 population and age-adjusted (using 19 age groups) by the direct method to the 2000 US standard population. Corresponding 95% CIs were calculated using modified gamma intervals.[18] To determine differences between subgroups, rate ratios were calculated; rates were considered statistically different if the 95% CIs of the rate ratios excluded 1.

Temporal rates were extracted from SEER*Stat's US Cancer Statistics NPCR and SEER incidence database and analyzed using SEER's Joinpoint regression program version 5.2.0. To maximize the number of cases available to assess recent patterns, we used CRC cases diagnosed during 2001–2020. Change in rates during 2001–2020 involved fitting a series of joined straight lines on a logarithmic scale to the trends in the annual age-adjusted rates. The trend of the line segment was used to quantify the annual percent change (APC). A 2-sided *t* test was used to test whether the APC was statistically different from zero ($\alpha < 0.05$). The overall model was analyzed using the data-driven weighted Bayesian information criterion (BIC) method. Due to the COVID-19 pandemic influencing the availability for the public to access health care services, including delays and reductions in cancer screening and diagnosis, the 2020 diagnosis year is plotted but excluded from the Joinpoint analysis to follow CDC's and NCI's documentation.[19–21]

Statistical Modeling

A separate de-identified case-level data set was requested from the ACCR for CRC cases diagnosed in 2013–2020. Python version 3.9 was used to analyze the case-level data set. The data set included case information by sex, race, age group, geographic area, stage at diagnosis, and risk factors (history of alcohol use, history of tobacco use, family history of cancer). Values marked as missing or unknown were grouped under *Unknown*. χ^2 Goodness of fit tests were utilized to determine if the proportions of demographic and risk factors significantly differed between the early- and late-stage cohorts. Row-wise complete cases were kept for modeling, and a bootstrapped multivariate logistic regression model was developed to examine the relationship between CRC staging (early-stage vs late-stage) and various predictors, including sex, race, tobacco status, alcohol status, family history of cancer, geographic area, and age group. We generated 1,000 bootstrapped samples to calculate the average odds ratio (OR) for each independent variable. Odds ratios and their corresponding 95% CIs were computed to assess the strength and precision of these associations.

Results

Age-Adjusted Rates

Arkansas men had a significantly higher CRC mortality rate ratio (MRR) and incidence rate ratio (IRR) compared to women (male-to-female MRR, 1.47; IRR, 1.35) (Table 1). Compared to the White population, Black individuals had higher CRC mortality and incidence rates (Black-to-White MRR, 1.46; IRR, 1.29). Late-stage CRC incidence was also significantly higher than early-stage incidence (late-to-early IRR, 1.89).

Incidence Temporal Trends

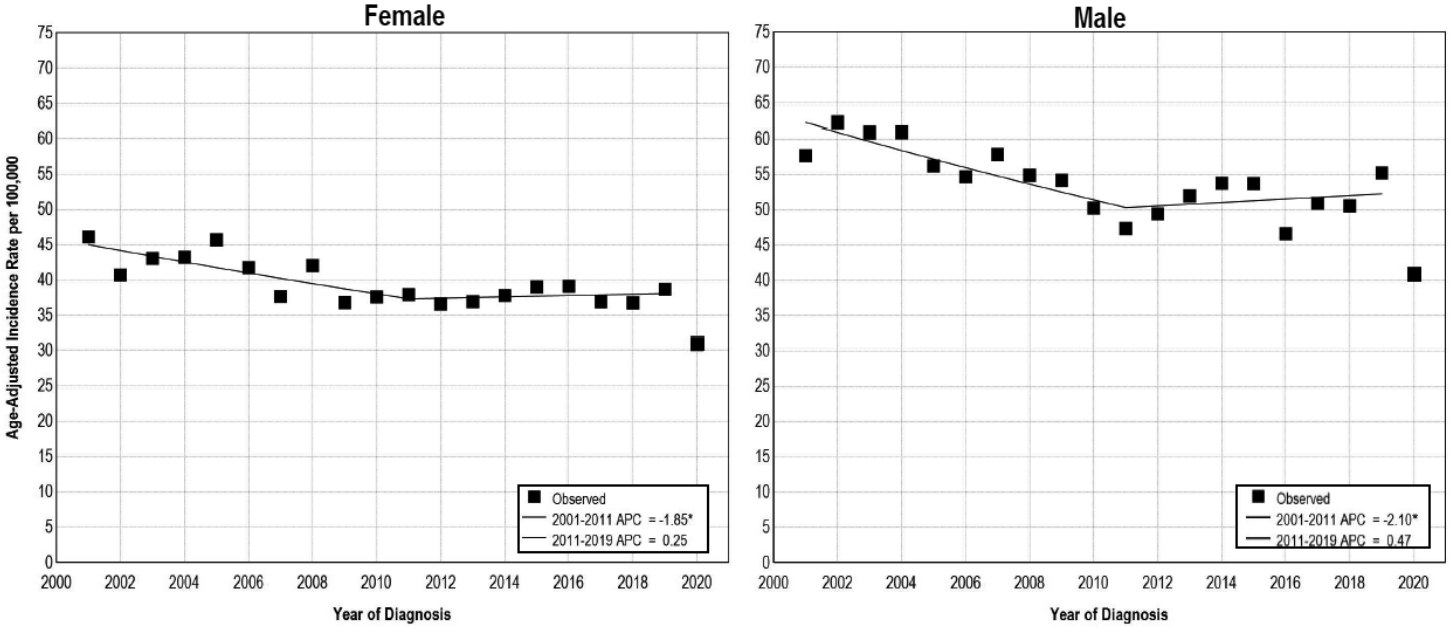
Incidence rates for both men and women declined from 2001–2011 for CRC and subsequently increased from 2011–2019 (APCs, 0.25% and 0.47%, respectively) (Figure 1). Black individuals had an APC decrease of 1.15% from 2001–2017, then increased for 2017–2019 (APC, 13.20%) (Figure 2). White individuals had a CRC incidence decrease of 2.07% ($\alpha \leq 0.05$) from 2001–2011, followed by an APC of 0.14% from 2011–2019. The overall trend rates were higher among those aged 50–75 years, followed by those aged ≥76 years and the group aged 18–49 years. However, the group aged 18–49 years was the only group with a significantly increasing APC (2.16%) over the study period (Figure 3). For geographic areas from 2011–2019, there were no significant APC changes between urban (0.09%) and rural counties (0.74%) (Figure 4). Early-stage CRC rates decreased from 2001–2019, with an APC of –2.18% ($\alpha < 0.05$), and late-stage CRC rates increased from 2012–2019, with an APC of 1.09% (Figure 5). Although the data showed some APC variation

Table 1. Colorectal Cancer Mortality and Incidence Age-Adjusted Rates by Characteristics, Arkansas, 2011–2020				
Variable	*Mortality rate*	*Mortality rate ratio*	*Incidence rate*	*Incidence rate ratio*
Overall	16.02 (15.60–16.44)		42.94 (42.25–43.64)	
Sex				
Female	13.20 (12.69–13.72)	Reference	37.00 (36.13–37.89)	Reference
Male	19.44 (18.76–20.15)	1.47 (1.40–1.55)*	49.86 (48.76–50.97)	1.35 (1.30–1.39)*
Race				
Black	22.50 (21.02, 24.00)	1.46 (1.36–1.58)*	52.93 (50.68–55.24)	1.29 (1.23–1.35)*
White	15.36 (14.92, 16.00)	Reference	41.17 (40.44–41.91)	Reference
Age group (y)[a]				
18–49	3.40 (3.07–3.73)	–	6.60 (6.28–6.93)	0.28 (0.27–0.30)*
50–75	38.08 (36.78–39.38)	–	23.23 (22.75–23.71)	Ref
≥76	121.06 (116.03–126.09)	–	11.91 (11.54–12.28)	0.51 (0.49–0.53)*
Geographic area				
Rural	18.03 (17.36–18.72)	1.25 (1.18–1.31)*	46.06 (44.96–47.18)	1.15 (1.11–1.18)*
Urban	14.51 (13.99 – 15.05)	Reference	40.18 (39.30–41.07)	Reference
Stage at diagnosis				
Early	–	–	13.49 (13.11–13.89)	Reference
Late	–	–	25.53 (25.00–26.07)	1.89 (1.83–1.96)*

[a]Age group rates reflected as age-specific (crude) rates. *Rate ratio is significantly different than reference group ($P < .05$)

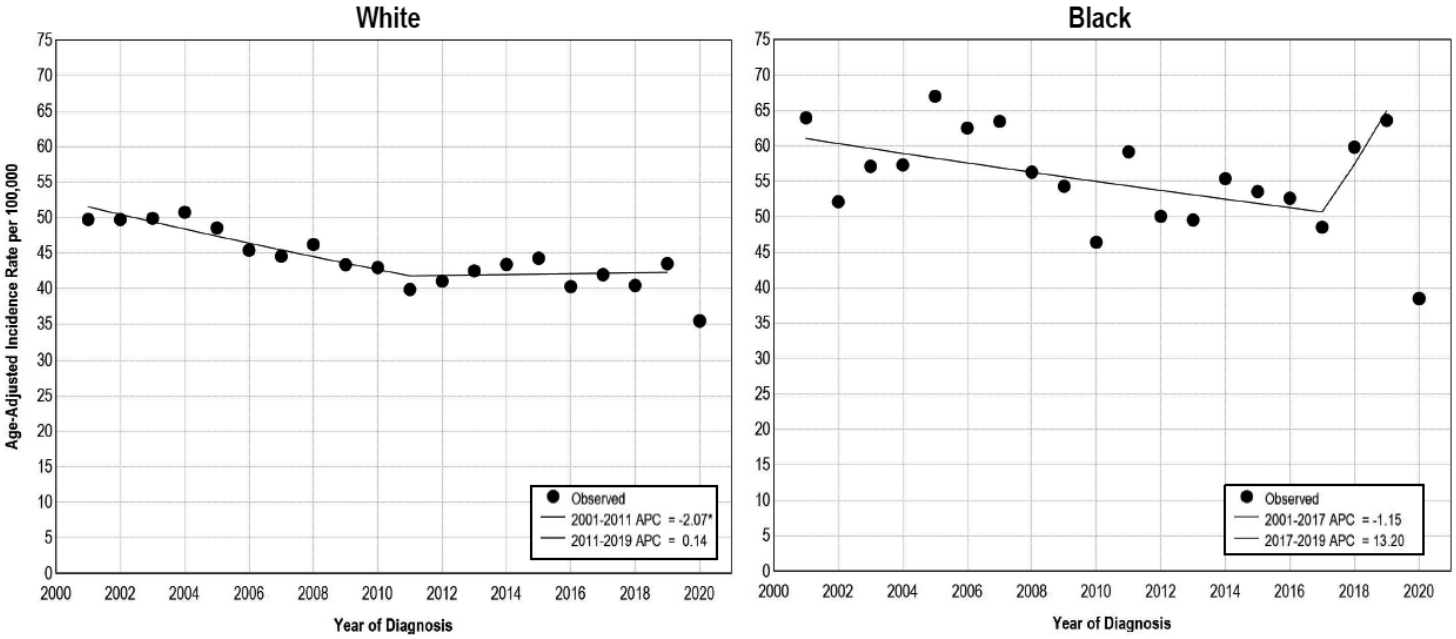
Dash (–) indicates unable to perform mortality rate/rate ratio for subgroup using National Center for Health Statistics database in SEER*Stat.

Figure 1. Colorectal Cancer Incidence Trends and Annual Percent Change (APC) By Sex, Arkansas, 2001–2020



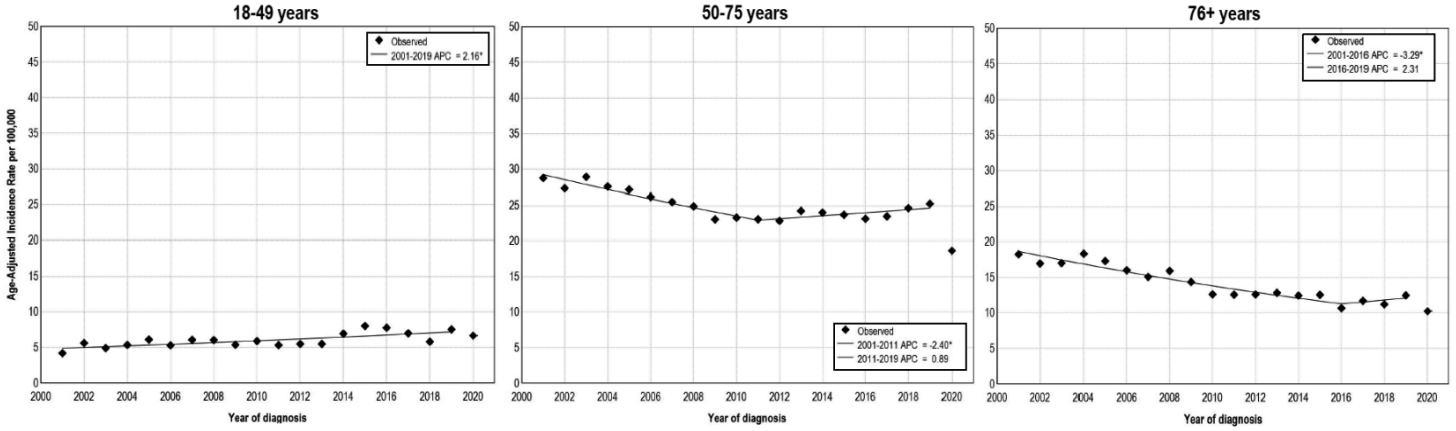
*APC is significantly different from zero at the $\alpha \leq 0.05$ level. Observed rates for 2020 were excluded from the model fitting.

Figure 2. Colorectal Cancer Incidence Trends and Annual Percent Change (APC) by Race, Arkansas, 2001–2020



*APC is significantly different from zero at the α ≤ 0.05 level. Observed rates for 2020 were excluded from the model fitting.

Figure 3. Colorectal Cancer Incidence Trends and Annual Percent Change (APC) by Age Group, Arkansas, 2001–2020



*APC is significantly different from zero at the α ≤ 0.05 level. Observed rates for 2020 were excluded from the model fitting.

for each group, the lack of statistical significance suggests that some of the observed differences were likely due to chance.

Late-Stage Analysis

All variables had a significance level of 0.05 according to the χ^2 goodness-of-fit test, not including unknown information. In the Arkansas 2013–2020 data set, approximately 2,617 (31.71%) were diagnosed at an early stage and 5,634 (68.28%) at a late stage (Table 2).

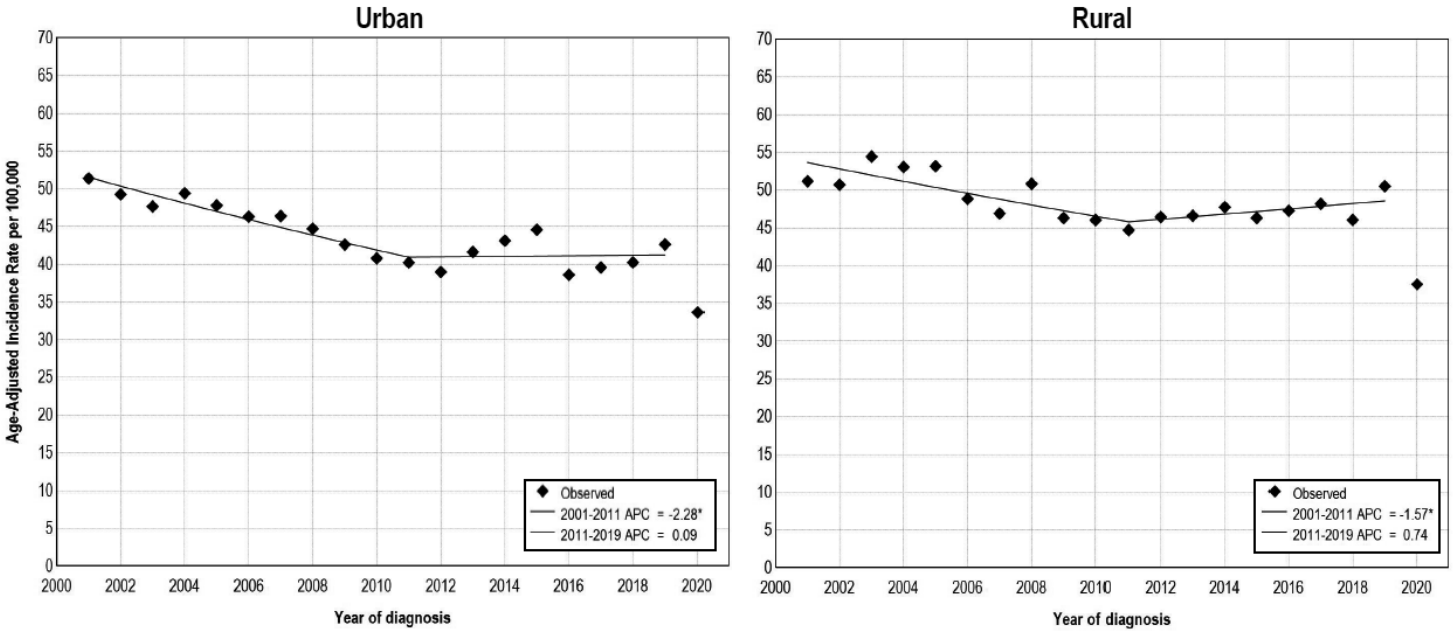
For our statistical model, a total of 162 cases were excluded due to incomplete row-wise information, leaving a total of 8,089 cases for further analysis. The multivariate analysis model included the *unknown* categories for the 3 risk factors. *Unknown* values for race and geographic area were excluded as there were only 6 of these cases.

In our statistical model, those aged 18–49 years had significantly higher odds of late-stage CRC diagnosis compared to those aged 50–75 years (OR, 2.030; 95% CI, 1.674–2.462) (Table 3, Figure 6). Those identified as current or former alcohol users had significantly lower odds of late-stage CRC diagnosis compared to those with no history of alcohol use (OR, 0.825; 95% CI, 0.722–0.942). Those with an unknown history of tobacco use have significantly lower odds of late-stage CRC diagnosis compared to those with no history of tobacco use (OR, 0.604; 95% CI, 0.448–0.826), and those with an unknown family history of cancer have significantly higher odds of late-stage CRC diagnosis compared to those with no family history of cancer (OR, 1.507; 95% CI, 1.196–1.899).

Discussion

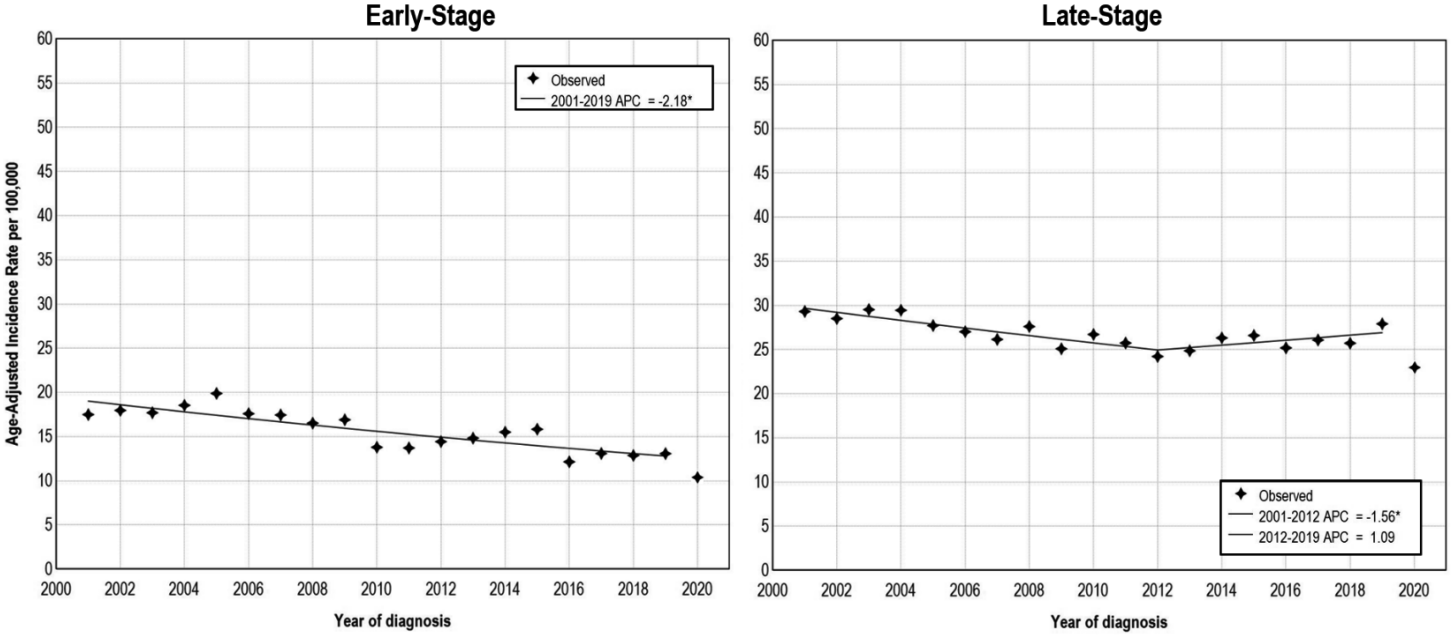
The findings from this epidemiological study reveal critical disparities and temporal trends in CRC incidence and mortality in Arkansas, highlighting significant demographic-, geographic-, and stage-specific differences. The

Figure 4. Colorectal cancer Incidence Trends and Annual Percent Change (APC) by Geographic area, Arkansas, 2001–2020



*APC is significantly different from zero at the α ≤ 0.05 level. Observed rates for 2020 were excluded from the model fitting.

Figure 5. Colorectal Cancer Incidence Trends and Annual Percent Change (APC) by Stage at Diagnosis, Arkansas, 2001–2020



*APC is significantly different from zero at the α ≤ 0.05 level. Observed rates for 2020 were excluded from the model fitting.

study indicates a marked disparity in CRC outcomes by sex, with men exhibiting significantly higher mortality and incidence rates compared to women. The age-adjusted MRR of 1.47 and IRR of 1.35 suggest that men are at a higher risk of both developing and dying from CRC. This disparity is consistent with national trends and may be attributable to differences in lifestyle factors, such as diet and physical activity, as well as potential biological differences in tumor characteristics between men and women.[10,22–24]

Our analysis reveals substantial racial disparities in CRC outcomes. Black individuals in Arkansas had higher CRC mortality and incidence rates compared to their White counterparts, with an MRR of 1.46 and an IRR of 1.29. This disparity aligns with broader national data indicating higher CRC burden among Black vs White populations.[25] This underscores the need for targeted interventions to improve CRC outcomes in Black communities. Potential contributing factors may include socioeconomic disparities,

Table 2. Initial Number of Colorectal Cancer Cases by Early and Late-Stage Diagnosis, Arkansas, 2013–2020

	Early stage, n (%)	*Late stage, n (%)*
Overall	2,617 (31.71)	5,634 (68.28)
Sex		
Female	1,233 (32.99)*	2,504 (67.01)*
Male	1,384 (30.66)*	3,130 (69.34)*
Unknown	0	0
Race		
Black	345 (29.39)*	829 (70.61)*
White	2,226 (32.18)*	4,692 (67.82)*
Unknown	1	5
Age group (y)[b]		
18–49	192 (20.06)*	765 (79.94)*
50–75	1,704 (32.13)*	3,600 (67.87)*
≥76	721 (36.23)*	1,269 (63.77)*
Unknown	0	0
Geographic area		
Rural	1,679 (31.84)*	3,595 (68.16)*
Urban	937 (31.54)*	2,034 (68.46)*
Unknown	1	5
Selected risk factors		
History of alcohol use		
None	1,259 (29.96)*	2,943 (70.04)*
Current/former	794 (31.05)*	1,763 (68.95)*
Unknown	564 (37.80)	928 (62.20)
History of tobacco use		
None	990 (30.99)*	2,205 (69.01)*
Current/former	1,171 (29.89)*	2,747 (70.11)*
Unknown	456 (40.07)	682 (59.93)
Family history of cancer		
No	746 (32.41)*	1,556 (67.59)*
Yes	1,234 (29.79)*	2,909 (70.21)*
Unknown	637 (35.27)	1,169 (64.73)

*Significance level of 0.05 according to $\chi 2$ goodness-of-fit test.

reduced access to health care, lower CRC screening rates, and delayed follow-up after abnormal screening results, besides potential biological differences.[24,26–28] Studies suggest that culturally tailored interventions, community-based outreach programs, and patient navigation services can effectively increase CRC screening uptake among minority populations.[29]

The temporal analysis of CRC incidence rates revealed a complex pattern over the study period. Caution is suggested in interpretation of APCs that were not statistically significant. Both men and women experienced a decline in incidence from 2001–2011, followed by an increase from 2011–2019, although the findings were not statistically significant. The observed increase in APC of 0.25% for men and 0.47% for women after 2011 warrants further investigation into potential contributing factors, such as changes in screening practices or environmental exposures. The APC increase of 13.20% among the Black population from 2017–2019 is particularly concerning and suggests a need for intensified public health efforts to address this rising trend.

Age-specific trends in CRC incidence were notable, with the highest rates observed among those aged 50–75 years. However, patients aged 18–49 years demonstrated a significant APC increase of 2.16% from 2001–2019, highlighting a worrying trend of rising CRC incidence in younger adults. This increasing incidence of early-onset CRC (ie, in patients aged 18–49 years) mirrors national trends. Recent studies have highlighted the growing burden of CRC in younger adults, potentially due to changes in diet, physical inactivity, obesity, and other environmental exposures.[30] The increased odds of late-stage diagnosis in this age group (OR, 2.030) emphasize the need for increased awareness and consideration of earlier screening strategies for younger populations, particularly those with risk factors.

Geographic analysis indicated that rural counties in Arkansas experienced a higher APC (0.74%) compared to urban counties (0.09%) from 2011–2019. This disparity aligns with prior research demonstrating that rural residents often face barriers to health care access, including fewer health care facilities, transportation challenges, and lower health literacy.[31] These structural barriers may contribute to delayed diagnoses and poorer outcomes. This emphasizes a need for public health strategies to prioritize improving health care access and screening services in rural regions to address these disparities. Evidence indicates that telehealth interventions and mobile screening units can help bridge this gap in rural communities.[32] However, caution is suggested in interpretation for both urban and rural areas from 2011–2019, as they were not statistically significant.

Late-stage CRC incidence was significantly higher than early-stage CRC, with a late/early IRR of 1.89. Additionally, early-stage CRC incidence from 2011–2019 has decreased (APC, –2.18%), while the incidence of late-stage CRC shows an APC increase of 1.09%, although caution is suggested in interpreting the latter, as the APC was not found to be significant. Overall, this shift towards later-stage diagnoses underscores the critical need for enhanced early detection efforts. The analysis of late-stage CRC diagnoses revealed that men and Black individuals had higher odds of late-stage diagnosis, reinforcing the necessity for targeted interventions in these groups.

The higher odds of late-stage diagnosis among those aged 18–49 years (OR 2.030) compared those aged 50–75 years are particularly alarming. This finding suggests younger individuals undergo less timely CRC screening, resulting in delayed diagnoses and poorer outcomes. Conversely, those aged ≥76 years had lower odds of late-stage diagnosis (OR, 0.893), which may reflect more consistent screening practices in this age group.

The significant results of this Arkansas-focused study align with national findings. The CRC diagnoses has shifted to more advanced disease, with an increasing proportion

Table 3. Colorectal Cancer Counts, Row Percent, and Odds Ratio (95% CI) by Characteristics Included for Multivariate Analysis Model, Arkansas, 2013–2020

Variable	*Early stage, n (%)*	*Late stage, n (%)*	*Odds ratio (95% CI)*
Overall	2,571 (31.78)	5,518 (68.22)	
Sex			
Female	1,213 (33.07)	2,455 (66.93)	Reference
Male	1,358 (30.72)	3,063 (69.28)	1.090 (0.971–1.224)
Race			
Black	345 (29.39)	829 (70.61)	1.055 (0.896–1.242)
White	2226 (32.19)	4,689 (67.81)	Reference
Age group (y)			
18–49*	182 (20.0)	728 (80.0)	2.030 (1.674–2.462)
50–75	1,675 (32.14)	3,536 (67.86)	Reference
≥76	714 (36.28)	1,254 (63.72)	0.893 (0.784–1.018)
Geographic region			
Rural	1,657 (31.82)	3,550 (68.18)	0.928 (0.827–1.042)
Urban	914 (31.71)	1,968 (68.29)	Reference
Selected risk factors			
History of alcohol use			
None	726 (32.5)	2,878 (69.97)	Reference
Current/former*	1,235 (30.03)	1,728 (68.95)	0.825 (0.722–0.942)
Unknown	558 (37.96)	912 (62.04)	0.786 (0.588–1.050)
History of tobacco use			
None	970 (31.1)	2,149 (68.9)	Reference
Current/former	1,150 (29.89)	2,697 (70.11)	1.113 (0.980–1.263)
Unknown*	451 (40.16)	672 (59.84)	0.604 (0.448–0.826)
Family history of cancer			
No	726 (32.5)	1,508 (67.5)	Reference
Yes	1,219 (29.82)	2,869 (70.18)	1.129 (0.990–1.289)
Unknown*	626 (35.43)	1,141 (64.57)	1.507 (1.196–1.899)

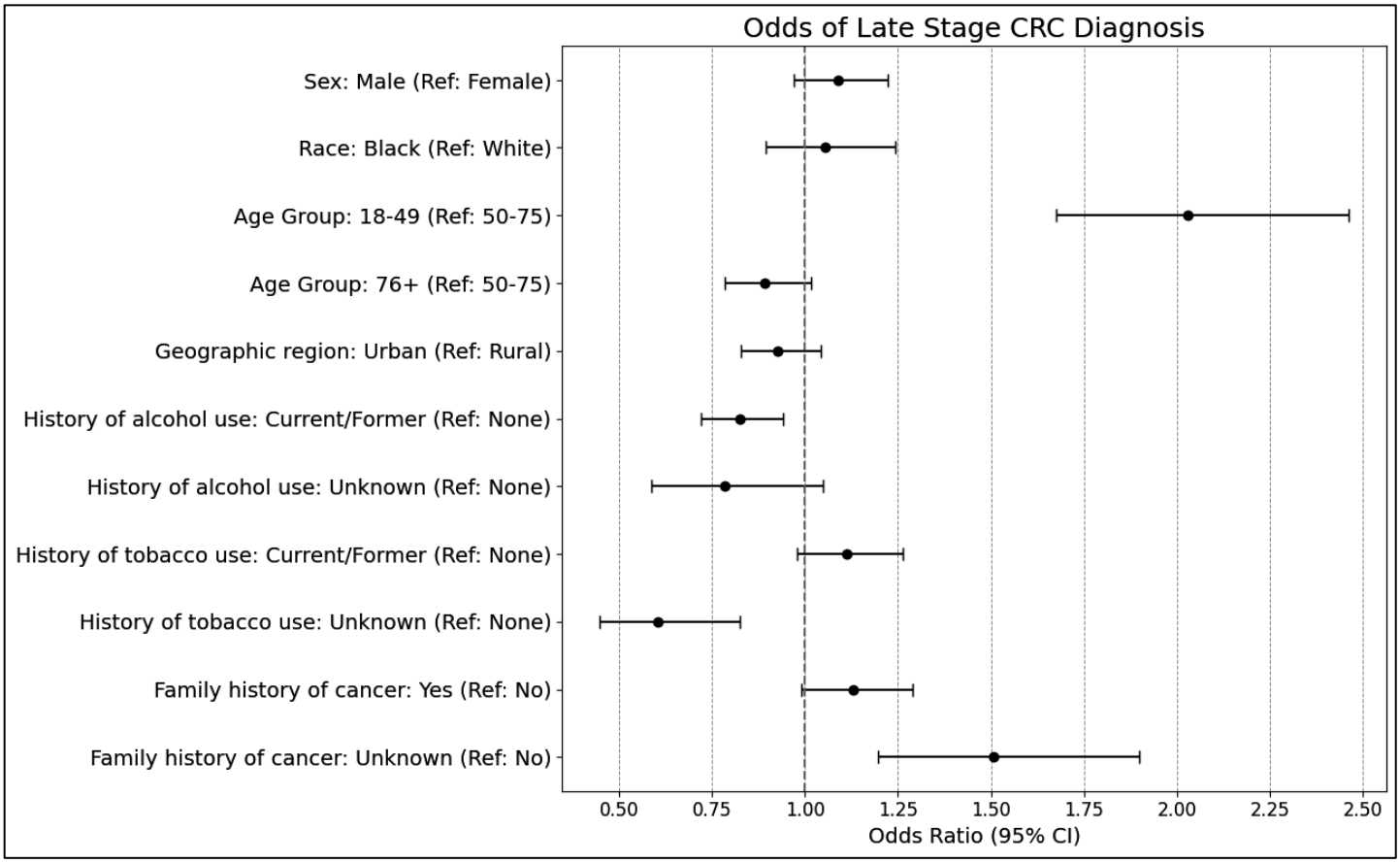
*Odds ratio is significant based on the 95% CI not including 1.

diagnosed at a regional or distant stage from the mid-2000s to 2019.[1] The increase not only for Arkansas but the United States may be attributable to screening rates. National findings reveal notable differences in colorectal cancer screening rates between men and women. Research indicates that, while colorectal cancer screening rates have generally increased over the past decades, men tend to have lower screening participation compared to women.[10,33] Factors that can contribute to this disparity include health behaviors specific to each group, such as females being more likely to engage in regular health check-ups and preventive care. Additionally, social and cultural factors, such as some men's reluctance to seek medical care or discuss sensitive health issues, may influence screening rates. Public health campaigns targeting men that have focused on reducing stigma and emphasizing the importance of CRC screening have shown promise in improving screening rates among men.[34]

Limitations

This study has a few limitations. One pertains to case reporting to the ACCR. Risk factor data items—tobacco use, alcohol use, and family history of cancer—are ACCR-required variables to be reported by hospitals and facilities that diagnose and/or treat cancer. Over 10% of the data were missing or coded as *9 - unknown,* a valid field entry. This primarily impacts the multivariate logistic regression where inclusion of the *unknown* group leaves questions about a case's relevant risk factor response, specifically for family history of cancer, which is statistically significant (OR, 1.507) but is left open for interpretation. Even though family history of cancer is reported for any cancer type, it is not specific to colorectal cancer. Also, in the analysis model, the sample size patients aged 18–49 years was small, and comparisons involving this age group do not reflect the latest USPSTF CRC screening recommendations.

Figure 6. Forest Plot of Odds Ratio and 95% CI of Colorectal Cancer for Late-Stage Diagnosis, Arkansas, 2013–2020



Caution is also advised when interpreting data that include diagnosis year 2020, as the COVID-19 pandemic disrupted health services, leading to delays and reductions in cancer abstracts reported to the ACCR. This disruption contributed to a decline in new CRC cases reported for that year. Moreover, the 2020 cancer data was preliminary at the time of the data request. Furthermore, age-specific rates are not standardized like age-adjusted rates by sex, race, geographic area, and age at diagnosis, which may affect comparisons.

Conclusion

This study highlights significant disparities in CRC incidence and mortality based on sex, race, age, and geography in Arkansas. The observed temporal trends and stage-specific differences underscore the urgency of tailored public health strategies to improve early detection, particularly among high-risk populations such as men, Black individuals, and younger adults. Addressing these disparities through targeted screening programs, education, and health care access improvements is crucial to reducing the CRC burden and improving outcomes in Arkansas. Age, race, and rurality should be prioritized in CRC screening efforts. This is particularly relevant for Black males, where two-thirds of the population diagnosed with CRC were disproportionately diagnosed at a later stage, predominantly in rural areas. Clearly, focused efforts to increase screening at an earlier age are necessary to address the disproportionate incidence rates faced by predominantly Black rural populations.

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Short Report

Implementing and Evaluating Modified Record Reporting in Ohio

Kaitlin R. Kruger, MS[a]; Emily C. Bunt, MA[a]

Abstract: Introduction: For many years, Ohio's hospitals experienced challenges related to state cancer reporting as they were unable to provide updated information after an abstract was initially submitted to the state central registry. For this reason, hospitals would hold their data to ensure they submitted the most complete and accurate data, especially for treatment. Ohio needed to find an automated method to receive updates for abstracts. Methods: In 2020, the Ohio Cancer Incidence Surveillance System (OCISS) met with hospitals, hospital software vendors, and other state registries to investigate the option of collecting modified records (M-records). In 2021, OCISS completed an M-record pilot with a small subset of hospitals and began requiring M-records from all reporting hospitals in 2022. OCISS now has over a full years' experience processing M-record submissions. Results: OCISS has found creative solutions to overcome challenges, and M-record processing has become one of the standard tasks completed by OCISS. While the overall registry volume increased due to M-record reporting, the workload of the central registry did not. Additionally, Ohio hospitals expressed appreciation for being able to provide updated information and no longer needing to hold on to their abstract until treatment is completed. Discussion: M-record reporting has improved Ohio's registry operations. Ohio's cancer data is more complete and is reported more quickly. Implementing M-record reporting was challenging; however, as data timeliness becomes increasingly important, Ohio is well positioned to improve cancer reporting timeliness by leveraging M-record reporting.

Key words: *central cancer registry, modified records, M-records, timeliness, updates*

Introduction

In the past, Ohio's hospitals experienced challenges related to state cancer reporting as they were unable to provide updated information after an abstract was initially submitted to the state cancer registry. Hospitals would hold their cancer abstracts to ensure the reporting of more complete treatment and staging information. This contributed to delays in reporting that exceeded the 6-month reporting timeline required by Ohio Administrative Code.[1] Ohio's central cancer registry, the Ohio Cancer Incidence Surveillance System (OCISS), explored modified record reporting as a solution for receiving updated information and timelier submissions from hospitals.

Modified records, or *M-records,* are full abstracts where the record type is M (North American Association of Central Cancer Registries [NAACCR] data item number 10).[2] These records can be submitted from hospitals with their own software if they make a change to an abstract after the initial state submission. M-records offer a method to update the central registry database efficiently through automated processes without creating extra work for hospital registries. Once the functionality is set up in the hospital software, the first submission of an abstract will be transmitted as a *Record Type A* abstract; updated information for that abstract will be transmitted as a *Record Type M* abstract (Figure 1).

Figure 1. Visualization of Modified Record Reporting and Data Flow to Central Registry

Source: Ohio Cancer Incidence Surveillance System, Ohio Department of Health, April 2024.

[a]Ohio Department of Health, Columbus, Ohio.

Address correspondence to Kaitlin Kruger. Email: Kaitlin.Kruger@odh.ohio.gov.

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With the NAACCR version 22 upgrade in mid-2022, OCISS began requiring M-records from all hospitals with their own software. This new requirement was defined in the Ohio reporting source manual as allowed by Ohio administrative code and communicated to hospital registries via email.[1,3] Throughout the first full year of M-record reporting in 2023, OCISS faced challenges and uncovered solutions that may be beneficial to share with other registries. While this new process took time to set up, Ohio has seen the benefits of M-record reporting and continues to collect M-records despite some of the challenges.

Methods

Phase 1: Information Gathering

Ohio investigated M-record reporting in 2020 by meeting with key stakeholders to understand this reporting method. Hospital registries provided information on how often they update abstracts after the initial submission, what types of updates are made, and common reasons why they need to make changes to an abstract. A survey of hospital registry software vendors explained what information the vendors would need from the central registry, what can be customized by the state, and any potential impact to hospital registry operations. Ohio also explored how M-records are handled within the Centers for Disease Control and Prevention's National Program of Cancer Registries (NPCR) Registry Plus products[4] to understand if central registry software settings would need to be taken into consideration prior to implementation. OCISS also discussed M-record reporting with other central registries to understand their experiences and requirements.

Phase 2: Exploratory Pilot Program

After discussing with vendors and hospitals, OCISS wanted to experience this new reporting method in real time with real data to determine if it would be feasible in Ohio. Throughout 2021 and early 2022, OCISS conducted an M-record pilot program with a small group of hospitals. These hospitals coordinated with their vendor to enable M-record functionality in their software. Their submissions moving forward included new cases as *Record Type A* and updated cases as *Record Type M*. OCISS received and processed M-records in a test environment to determine how the data would be handled on a copy of the main registry database. The pilot identified challenges that would need to be considered prior to rolling out M-record reporting, such as linkage and software settings, reporting frequency and volume, edits, and types of updates. After working through challenges, which is described in greater detail in the Results section, the pilot ultimately revealed that M-record reporting would be a feasible option for Ohio.

Phase 3: Requirement Finalization and Rollout

After concluding the pilot, OCISS worked closely with the advisory committee to finalize reporting requirements. The advisory committee is made up of hospital registry managers and OCISS data users (researchers and local health department epidemiologists). The reporting requirements specify the frequency of M-record reporting, submission years, and types of updates to submit. OCISS worked with the hospital software vendors to implement M-record functionality for all hospitals After the first year of M-record reporting in 2023, OCISS adapted their internal procedures and adjusted requirements. Ohio hospitals continue to report M-records in 2024.

As outlined in the OCISS reporting source manual,[3] Ohio hospitals are required to submit M-records annually in July. OCISS also limits M-record submissions to updates made on abstracts for the 2 most recent diagnosis years. This is to prioritize updates for the 12- and 24-month data. Additionally, updates are limited to changes made for specific data fields by using a list of data "trigger" fields. This means OCISS should only receive M-records if 1 or more of the data fields on this list are changed after the initial submission. Ohio's M-record trigger list now includes 83 required data items covering demographic, diagnostic, treatment, and staging information (Table 1).[3]

Results

Impact to Central Registry

Prior to M-record reporting, OCISS received an average of 120,000 abstracts each year, and about 70% of these abstracts required manual review for patient linkage, tumor linkage, or consolidation. In 2023, the first year of collecting M-records, OCISS received an additional 25,000 abstracts, and the overall reporting volume increased to over 150,000 abstracts (Table 2). After adjusting the central registry software settings, approximately 35% of all incoming data required manual review and 39% of M-records required manual review, which was decreased compared to previous years. While the overall registry volume increased due to M-record reporting, the workload of the central registry did not.

After rolling out M-record reporting, OCISS adjusted internal processing procedures. When M-records are submitted, any M-records submitted for diagnosis years prior to the 12-month and 24-month data are removed from file submissions. Additionally, OCISS holds on to these submissions to process them in batches every few months. If a hospital submits multiple files of M-records over the course of a few months, these files are compared to each other using Match*Pro and only the most recent M-record is accepted.[5] All M-record submissions from a facility are compared to the existing facility abstracts within the OCISS registry database, also using Match*Pro. Only cases that match an existing abstract are processed as updated cases (type M). If OCISS has not received an abstract for the patient or tumor, then these are processed as new cases (type A). This linkage is a manual process and only compares the patient and tumor data items. Individual treatment data items are not compared during the linkage process.

Challenges Faced by Hospitals

Some hospitals submit new cases as type M that should be submitted as type A abstracts. This is due to the way the

Table 1. List of Data Fields that Trigger a Modified Record in the Ohio Cancer Incidence Surveillance System (OCISS)

NAACCR Item No.	*NAACCR Item Name*
70	Addr at DX–City
80	Addr at DX–State
100	Addr at DX–Postal Code
160	Race 1
161	Race 2
162	Race 3
163	Race 4
164	Race 5
190	Spanish/Hispanic Origin
220	Sex
240	Date of Birth
390	Date of Diagnosis
400	Primary Site
410	Laterality
490	Diagnostic Confirmation
522	Histologic Type ICD-O-3
523	Behavior Code ICD-O-3
610	Class of Case
630	Primary Payer at DX
756	Tumor Size Summary
764	Summary Stage 2018
820	Regional Nodes Positive
1068	Grad Post Therapy Clin (yc)
1182	Lymphovascular Invasion
1200	RX Date Surgery
1210	RX Date Radiation
1220	RX Date Chemo
1230	RX Date Hormone
1240	RX Date BRM
1250	RX Date Other
1270	Date 1st Crs RX CoC
1280	RX Date DX/Stg Proc
1285	RX Summ–Treatment Status
1290	RX Summ–Surg Prim Site
1292	RX Summ–Scope Reg LN Sur
1294	RX Summ–Surg Oth Reg/Dis
1320	RX Summ–Surgical Margins
1340	Reason for No Surgery
1350	RX Summ–DX/Stg Proc
1380	RX Summ–Surg/Rad Seq
1390	RX Summ–Chemo
1400	RX Summ–Hormone
1410	RX Summ–BRM
1420	RX Summ–Other
1430	Reason for No Radiation
1506	Phase I Radiation Treatment Modality
1639	RX Summ–Systemic/Sur Seq
2230	Name–Last
2232	Name–Birth Surname
2240	Name–First
2250	Name–Middle
2315	Medicare Beneficiary Identifier
2320	Social Security Number
2330	Addr at DX–No & Street
2335	Addr at DX–Supplementl
3170	RX Date Mst Defn Srg
3250	RX Summ–Transplnt/Endocr
3816	Brain Molecular Markers
3817	Breslow Tumor Thickness
3827	Estrogen Receptor Summary
3835	Fibrosis Score
3838	Gleason Patterns Clinical
3839	Gleason Patterns Pathological
3840	Gleason Score Clinical
3841	Gleason Score Pathological
3842	Gleason Tertiary Pattern
3843	Grade Clinical
3844	Grade Pathological
3845	Grade Post Therapy Path (yp)
3855	HER2 Overall Summary
3890	Microsatellite Instability (MSI)
3915	Progesterone Receptor Summary
3920	PSA (Prostatic Specific Antigen) Lab Value
3926	Schema Discriminator 1
3927	Schema Discriminator 2
3932	LDH Lab Value
1172	*Post Transplant Lymphoproliferative Disorder-PTLD (added in v25)*
1174	*PD-L1 (added in v25)*
1291	*RX Summ–Surg Prim Site 2023 (added in v25)*
3829	*Esophagus and EGJ Tumor Epicenter (added in v25)*
3956	*p16 (added in v25)*
3960	*Histologic Subtype (added in v25)*
3964	*Brain Primary Tumor Location (added in v25)*

Italic formatting indicates fields added in v25.

Table 2. Ohio Cancer Incidence Surveillance System Reporting Volume by Year, Record Type, and Automated vs Manual Processing

Year	*Phase of M-record implementation*	*Total submissions*	*Record type A*	*Record type M*	*Automatic linkage, no. (%)*	*Manual review, no. (%)*
2020	Gathering Information	126,642	126,641	1	39,267 (31%); M-records: 0 (0%)	87,375 (69%); M-records: 1 (100%)
2021	Pilot program	107,887	107,655	232	31,385 (29%); M-records: 0 (0%)	76,502 (71%); M-records: 232 (100%)
2022	Roll out to all hospitals; updated linkage settings	135,867	128,462	7,405	79,865 (59%); M-records: 4,007 (54%)	56,002 (41%); M-records: 3,398 (46%)
2023	First full year of M-record submissions	156,351	130,486	25,865	101,589 (65%); M-records: 15,810 (61%)	54,762 (35%); M-records: 10,055 (39%)

Source: Ohio Cancer Incidence Surveillance System, Ohio Department of Health, April 2024.

data is exported from the hospital software. OCISS identifies these situations during the linkage process, notifies the hospital, and coordinates with the hospital's software vendor.

During the pilot, hospitals received a high volume of edit errors on M-record submissions for older diagnosis years.[6,7] All submissions are required to be 100% edit error free. Thus, to help reduce the burden of resolving edit errors, OCISS decided to limit the diagnosis years for M-record submissions to the preceding 2 years.

OCISS asks hospitals to follow a file naming convention for submissions. For files that do not follow these requirements, OCISS views the XML file to determine whether the file contains type A or M records. OCISS also added the *Record Type* field to the software display settings.

Lastly, not all hospital software vendors are able to accommodate an annual submission of M-records. For this reason, OCISS adapts the M-record reporting requirements based on the hospital's software capabilities. For example, if a hospital software program generates M-records every month, and the software functionality cannot be changed, OCISS will accept a monthly submission of M-records. In these scenarios, OCISS will compare each month's files to each other. If an M-record has been submitted for the same tumor multiple times over the monthly submissions, OCISS will only process the most recent M-record.

Challenges Faced by the Central Registry

Initially during the pilot, 100% of M-records required manual review, which would not be sustainable, so OCISS enabled settings that would permit automated processing of M-records to reduce this percentage. Additionally, most incoming M-records were not being matched to the existing A-record upon import into the main registry database, so OCISS enhanced the patient linkage settings, which further reduced the percentage of M-records requiring manual review. The primary enhancement to patient linkage settings was compensating for unknown Social Security number during linkage by adding a comparison for address at diagnosis. Other enhancements include comparing only the first letter of the middle name instead of requiring the whole middle name to match and comparing the birth date as a whole instead of in parts (year, month, day). Reducing the frequency of submissions and limiting the types of updates that are being submitted also helped decrease the overall number of M-records submissions.

OCISS determined that certain data fields at the central registry level should not be updated by an M-record, such as the geocode and survival data fields. These fields are excluded from M-record updates. In some situations, an M-record will overwrite a value that the central registry has populated on the consolidated record (for example, a known value reverted to "unknown" by an M-record). This occurs in approximately less than 2% of cases with an associated M-record. To address this, OCISS regularly reviews cases that may have had data fields overwritten by reviewing the database update history logs.

An ongoing challenge is multiple M-records being submitted for the same tumor. This is the primary reason for switching to an annual submission for M-records. OCISS processes M-records in batches so comparisons can be made for multiple files from the same facility. Additionally, OCISS receives M-records that do not contain any updates or changes for the data fields that are included on the specified trigger list. The hospital software vendors have been notified and are working on finding a solution.

Discussion

While it took a few years to implement modified record reporting in Ohio, OCISS has seen benefits to this process and will continue to collect and require M-records. M-records have been beneficial for data quality processes and procedures and hospital remediation plans to improve completeness, as well as providing an avenue to improve timeliness. Despite the challenges, OCISS has worked closely with hospitals and their software vendors to find creative solutions to continue to collect and process M-records. The OCISS advisory committee was an essential partner in the implementation of M-record reporting. They provided invaluable feedback on requirements, and many of the member hospitals participated in the pilot program. Communication and relationships with the software vendors, both hospital vendors and the central registry vendor, was critical for M-record implementation. OCISS will continue to collect and evaluate modified records to understand their impact on the registry's completeness, timeliness, and quality.

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Research and Data Use Winner

Interfacing with CDC Guidelines for Unusual Patterns of Cancer and Environmental Concerns: A 2023 Wisconsin Case Study

Lena Swander, MPH[a]; Jeffrey Bond, PhD[a]; Jessica Link Reeve, DrPH[a]

Background

Interfacing with the Centers for Disease Control and Prevention (CDC)'s *Guidelines for Unusual Patterns of Cancer and Environmental Concerns* 2022 remains a challenge for many state and territorial public health agencies.[1] The Wisconsin Cancer Reporting System (WCRS) received notice of a community cancer concern in February 2023. Cases of concern were pediatric and adolescent leukemias in a small, rural Wisconsin community.

Methods

We used the CDC guidelines to design aggregate tables and record-level case listings from the WCRS cancer incidence database. Data were prepared and approved for release in approximately 1 month's time (Figure 1). We provided data to the bureau leading this investigation. Challenges and key takeaways were documented.

Results

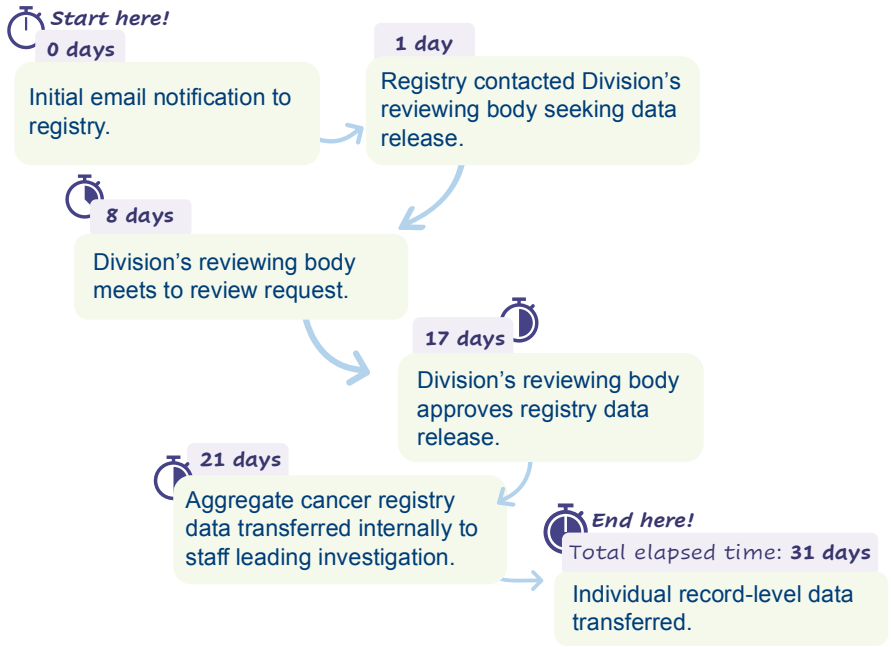
We experienced challenges applying Criteria 1–5 in Phase 2 of the CDC guidelines; specifically:

- Selecting appropriate reference population(s) for standardized incidence ratio (SIR) calculations (Figure 3).
- Reviewing geocoding quality for data used in mapping the geographic distribution of cancer cases.
- Communicating the many nuances of registry operations and data release practices, such as reporting schedules and excluding death-clearance only cases.
- Validating statistical models.

From these challenges, we developed 3 practical takeaways:

1. Cancer types should be clearly defined and documented by US Incidence Site Recode variables, like SEER (Surveillance, Epidemiology, and End Results Program) site or *International Classification of Childhood Cancer*. This standardizes proactive evaluation and routine monitoring recommended in the CDC guidelines. It also makes comparisons with publicly available cancer rates and data easier.

Figure 1. Data Transfer Timeline: Our Established, Efficient Data Transfer Process is Critical to Supporting Investigations in a Timely Fashion

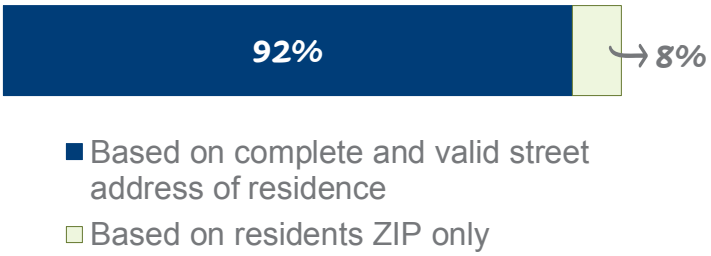


[a]Wisconsin Department of Health Services, Office of Health Informatics Wisconsin Cancer Reporting System.

Address correspondence to Lena Swander, MPH. Email: lena.swander@wi.gov.

This content was originally presented as a poster at the North American Association of Central Cancer Registries (NAACCR) 2024 Annual Conference, Boise, Idaho, June 2024.

Figure 2. Percent of Incident Tumors in County of Concern and 3 Neighboring Counties by Census Tract Certainty 2010 Code, 1995–20202



2. Support geocoding quality assessments, especially if staff plan to use registry geocoded variables for mapping activities and area of concern is small or rural. Include geocoding North American Association of Central Cancer Registries (NAACCR) data items in record-level cases shared for investigations such as:
   - #367, censusTractCertainty2010
   - #369, censusTractCertainty2020
3. Develop clear, explicit language to communicate your study's case inclusion criteria to others in public health. Instead of, "We excluded death clearance only (DCO) cases from your investigation dataset," try... "A small percentage of cancer cases are only reported to us through death certificates. This means we never received a detailed record of their diagnosis, so information like the year of diagnosis is unavailable for them. They make up a small percentage of total cases in our database, but if we included them in your dataset, they could affect your calculations and findings."

Conclusions

Strong working relationships between registry, environmental health staff, and the division's reviewing body were imperative to responsibly and efficiently apply the CDC guidelines. Many internal case-by-case decisions are made when operationalizing the CDC guidelines. These decisions should include registry staff throughout the response, as study populations in phase 2 will most often be created from our data.

Resources

To learn more about the CDC guidelines, visit **https://www.cdc.gov/cancer-environment/php/guidelines**. To learn more about requesting WCRS data, visit **https://www.dhs.wisconsin.gov/wcrs/researcherinfo.htm**.

References

1. Foster SL, Lavery AM, Condon SK, et al. *Guidelines for Examining Unusual Patterns of Cancer and Environmental Concerns*. Centers for Disease Control and Prevention; 2022. **https://cdc.gov/cancer-environment/php/guidelines/index.html**. Accessed May 13, 2023.
2. Internal cancer incidence databases. Wisconsin Cancer Reporting System, Office of Health Informatics, Wisconsin Department of Health Services.

Figure 3. Age-Group-Specific Expected Leukemia Cancer Rate Calculations, Observed Counts, SIR and 95% CI Calculation[2]

Age group	Observed cases in county (*O*)*	County of interest population (A)	State age-specific cancer rate (*B*)†	Expected cancer cases (A × B = *E*)
0–19 years	10	261,696	0.0000452	261,696 × 0.0000452 = 12
20–29 years	4	107,463	0.0000257	107,463 × 0.0000257 = 3
	14			***15***

SIR = O/E= 14/15 = **0.93**

$$\textbf{95\% CI} = \frac{(\sqrt{14} \pm \frac{1.96}{2})^2}{15} = \textbf{(0.51, 1.48)}$$

SIR, standardized incidence ratio.
*Number of leukemia cases, Wisconsin, 1995-2020.
†Number of leukemia cases, Wisconsin, 1995-2020, divided by the state population.

Standards and Registry Operations Winner

Cancer Registrar Workload and Staffing Study: Guidelines for Hospital Cancer Registry Programs

Laurie Hailer, MA, MEd[a]; Jacqueline Miller, BA[a]; Susan Chapman, PhD, RN[a]

Project Purpose

The objectives of this workload study were to:

- Update workload and staffing data for use by hospital registry managers and cancer program and industry leaders
- Develop guidelines for staffing needs and resources
- Explore future needs and skills of the cancer registry workforce

Registrar Lead Survey

The Registry Lead Survey (RLS) was sent to self-identified registry leaders from the National Cancer Registrar Association (NCRA) membership database. The RLS comprised 6 sections:

- Registry characteristics
- Staffing and administration
- Caseload size composition
- Registry procedures
- Data management and automation
- Respondent opinions and concerns

RLS respondent overview:

- A total of 237 respondents
- Most (60%) were registries serving single institutions
- Representation from all 10 US Department of Health and Human Services regions
- A total of 212 indicated they were a community hospital, private hospital, or hospital system
- Most (86%) had program accreditation

Multi-institution registries were more likely to have productivity standards in place for all positions (Table 1).

Table 1. Productivity Standards at Participating Registries

Productivity standards in place	All (n = 233	Multi-institution (n = 93)	Single institution (n = 140)
All positions	51.5%	61%	45%
Some positions	24.9%	26%	24%
None	23.6%	13%	31%

Multi-institution registries with higher caseloads had the highest number of cases per full-time equivalent (FTE) at 620. The mean for all respondents was 441 cases per FTE (Table 2).

Table 2. Mean Caseload for Single vs Multi-institution Registries by High, Medium, or Low Caseload Size

Cases per full-time equivalency (FTE) by registry type and size			
Caseload group	Multi-institution	Single institution	All
Highest 25%	620	583	597
Middle 50%	486	405	437
Lowest 25%	382	239	295
All	492	408	441

Regression results for hospital staffing guidelines:

- Single institution registries: 1.8 to 2.1 FTEs for every 1,000 cases
- Multi-institution registries: 1.6 to 1.9 FTEs for every 1,000 cases

Cancer Registrar Survey

The Cancer Registrar Survey (CRS) was sent to staff by the lead registrars. The CRS comprised 5 sections:

- Job information and activity log (daily activity tracker for 1 week)
- Job experience
- Time estimates—daily, weekly, monthly, annually
- COVID-19 supplement
- Stress and burnout supplement

CRS respondent overview:

- A total of 310 total responses
- Most (90%) respondents reported working full time
- Most cancer registrars (95%) reported being very or somewhat satisfied with the profession
- Most (71%) indicated having time to complete high-quality abstracts (Figure 1)

[a]University of California San Francisco, San Francisco, California.

This research study was supported by the National Cancer Registrars Association.

This content was originally presented as a poster at the North American Association of Central Cancer Registries (NAACCR) 2024 Annual Conference, Boise, Idaho, June 2024.

Figure 1. Cancer Registrar Survey: Do You Have Time to Complete High Quality Abstracts?

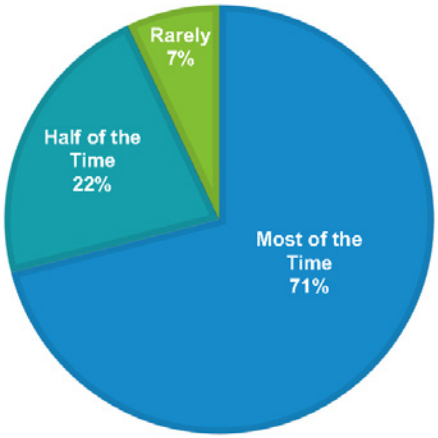
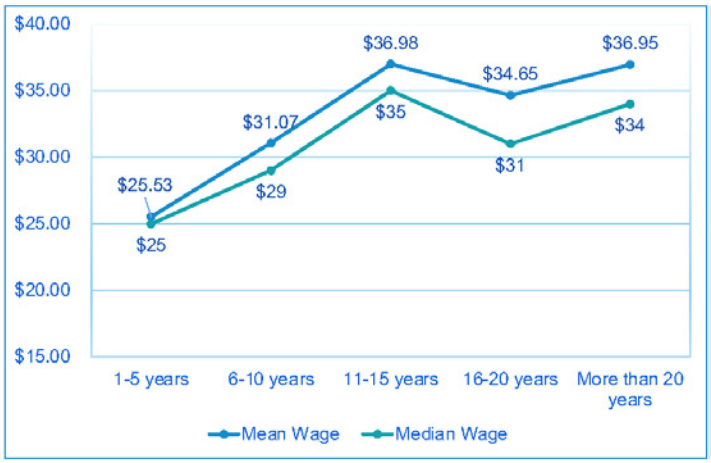


Figure 2. Reported Wages by Time in Profession



Staffing Guidelines and Considerations

Registry staffing considerations were varied and based mostly on caseload. There are several other factors to take into consideration when making staffing decisions:

- How does your registry compare to others by type and size? Single or multi-institution? High, middle, or low caseload?
- Do you do follow-up? Is it passive/active/automated? How many sources do you use?
- Do you perform concurrent abstracting? If so, how quickly?
- Are there additional responsibilities for staff (eg, cancer survey, staff meetings, training)?

Interview Findings

Contributing factors to industry-wide vacancies:

- Low wages (Figure 2)
- Registrar work often going unrecognized and feeling thankless at times
- Work often requiring the investigation of several sources and manual data entry
- Registrar work can be isolating
- Requiring in-person work
- Profession requiring a unique skillset that combines many areas of expertise
- A lack of people in the cancer registrar pipeline
- Burnout

Technology concerns:

- Interviewees felt strongly that technological innovations and automation will not eliminate the registrar role.
- New technologies are promising, but there are barriers to adoption and implementation (eg, resistance to new technologies, technology takes time to develop, financial/budgetary constraints).

Conclusions

Changes in workload include increased automation and a change of workplace, as 75% of respondents to the CRS reported working remotely after the pandemic. Contracting staff are a significant part of the workforce, and there are a variety of opinions on the quality of their work. There are new roles in data management and reporting up. The cancer registry field values the importance of real-time data.

Recommendations

Cancer registries can use workload studies to inform operational procedures, staffing guidelines, and productivity standards. NCRA should work with federal partners, standard-setters, and other national cancer registry associations to:

- Develop education and credentials to address future changes in cancer registrars' roles and responsibilities
- Develop and implement policies and programming that will advance the cancer registry workforce

Honorable Mention Winner

Cancer Incidence in Persistent Poverty Areas of California by Race/Ethnicity

Ani S. Movsisyan Vernon, PhD, MS; Frances B. Maguire, PhD, MPH; Brenda M. Hofer, MA; Arti Parikh-Patel, PhD, MPH; Theresa H.M. Keegan, PhD, MS

Introduction

Several studies have examined the relationship between living in persistent poverty areas (PPAs) and adverse cancer outcomes. However, the relationship between PPAs in California and disparities in specific cancer incidence rates and trends by race/ethnicity have remained unknown.

Purpose

To understand the differential impact of poverty on the cancer burden in California by race/ethnicity.

Methods

PPAs are defined as census tract of residence at time of diagnosis with a poverty rate of at least 20% for approximately 30 years. Using California Cancer Registry data, we identified patients diagnosed with 16 common cancers between 2006–2020.

We calculated age-adjusted incidence rates (AAIRs), rate ratios (RRs), average annual percent changes (AAPCs), and associated *P* values to facilitate comparisons between incidence rates and trends among patients living in PPAs and non-PPAs in California by race/ethnicity. Incidence rates per 100,000 persons each year were age-adjusted to the 2000 US standard population (Figures 1 and 2).

Results

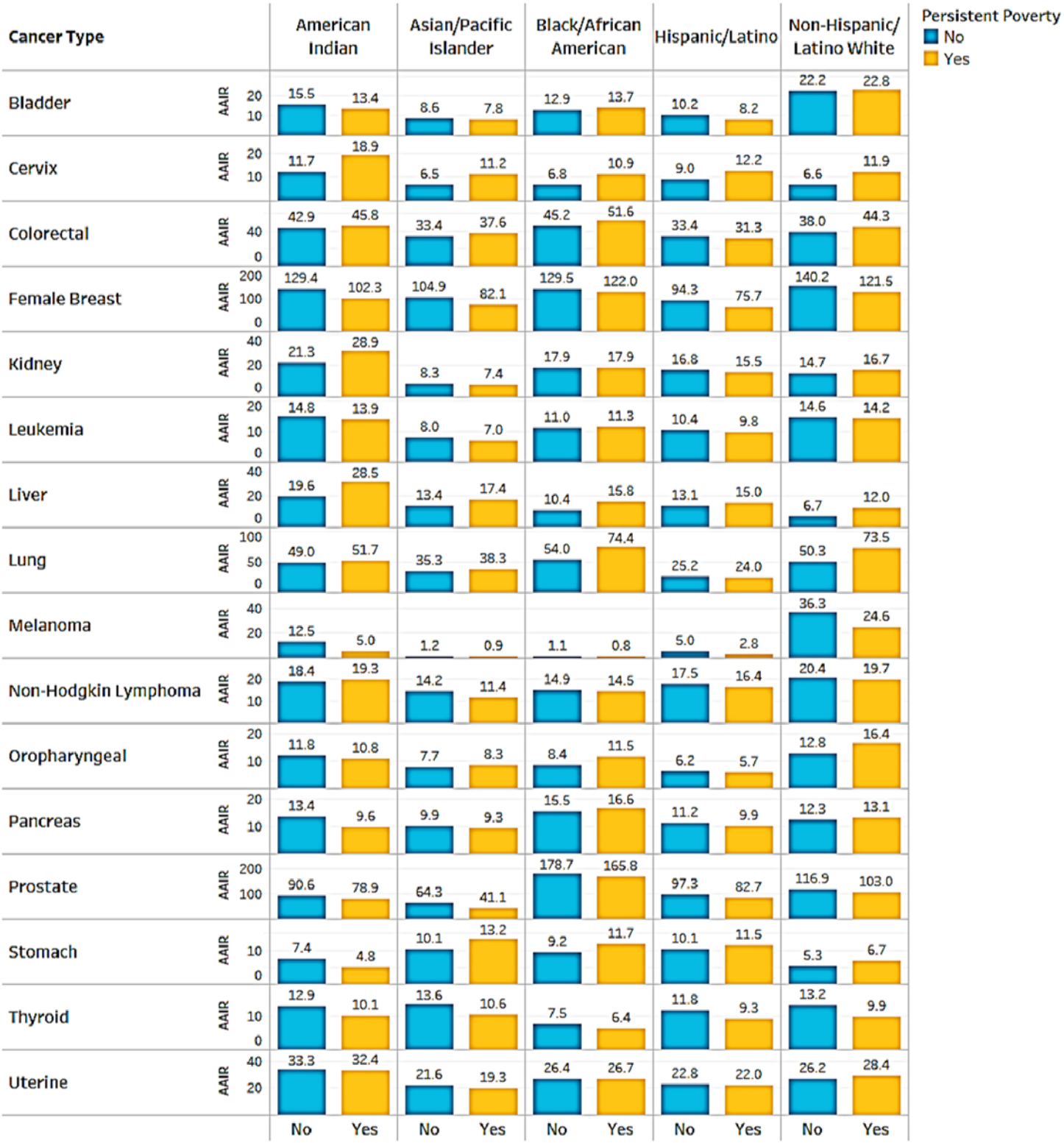
- Across all racial/ethnic groups, AAIRs of cervical and liver cancers were significantly higher among patients in PPAs versus non-PPAs.
- A significantly lower incidence of female breast cancer was observed in PPAs versus non-PPAs across all racial/ethnic groups.
- Incidence of colorectal cancer and non-Hodgkin lymphoma among Hispanic/Latinos increased significantly in PPAs (AAPCs, 0.4 and 1.2, respectively) and decreased in non-PPAs (AAPCs, –1.4 and –0.3, respectively).
- Thyroid cancer incidence among Black/African American patients significantly increased only in PPAs (AAPC, 4.7).
- Among American Indian patients, significant increases were observed for most cancers in non-PPAs, although trends for many cancers could not be calculated in PPAs due to small numbers.

Conclusion

Populations living in PPAs of California would benefit from public health interventions. Our findings of significantly higher AAIRs of cervical and liver cancers across all racial/ethnic groups among patients in PPAs versus non-PPAs call for additional research to understand possible risk factors and exposures those in PPAs have. More education about cancer screening and prevention might help reduce the observed disparities.

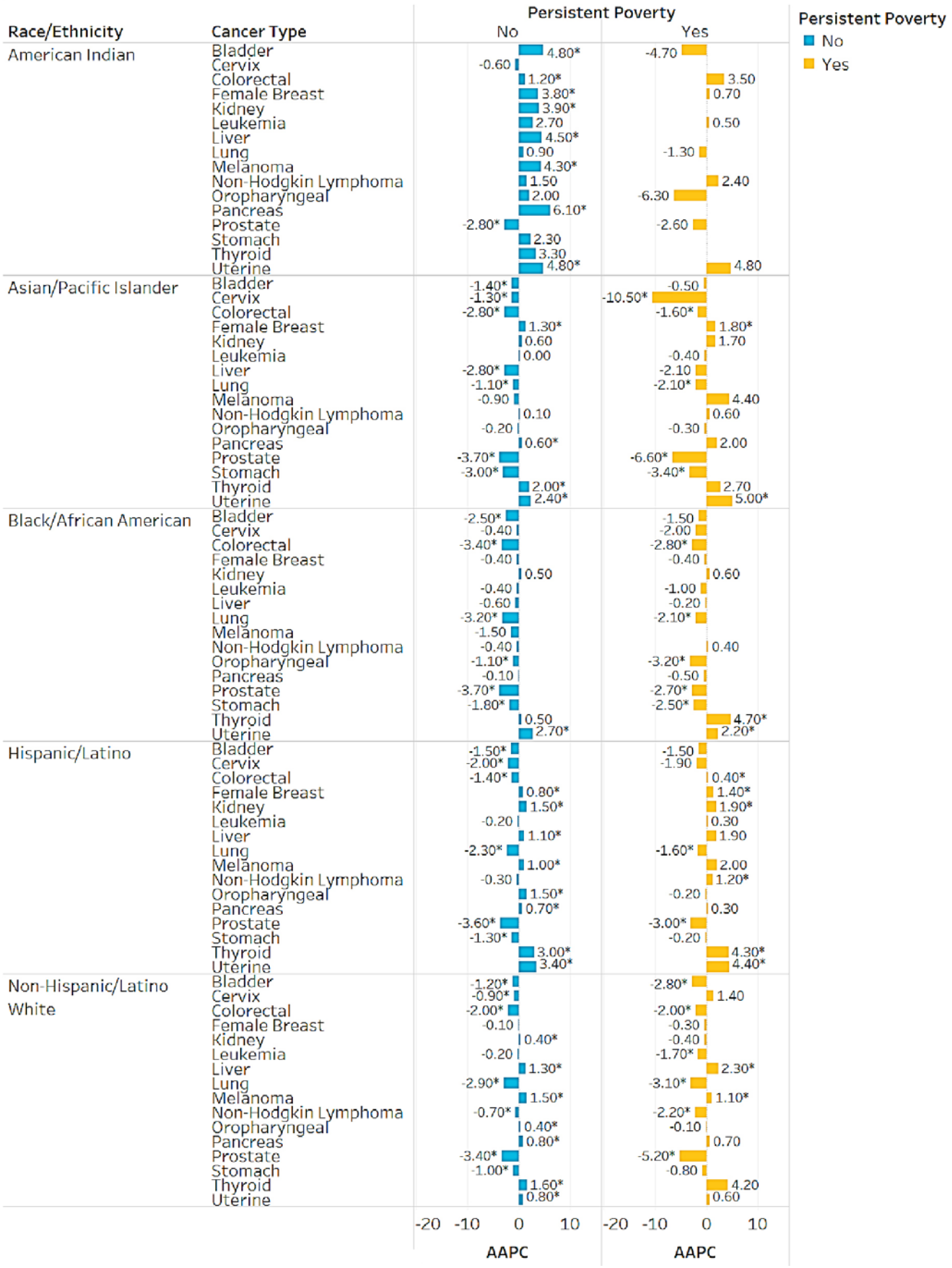
This content was originally presented as a poster at the North American Association of Central Cancer Registries (NAACCR) 2024 Annual Conference, Boise, Idaho, June 2024.

Figure 1. Age-Adjusted Incidence Rates (AAIRs) for 16 Common Cancers Among Patients by Persistent Poverty Area and Race/Ethnicity, 2006–2020



AAIR, age-adjusted incidence rate per 100,000 persons.

Figure 2. Average Annual Percent Change (AAPC) in Age-Adjusted Incidence Rates for 16 Common Cancers by Persistent Poverty and Race/Ethnicity, 2006–2019



Journal of Registry Management Continuing Education Quiz—WINTER 2024

AN EXAMINATION OF LIVER CANCER INCIDENCE IN CALIFORNIA

This quiz is derived from the article, "*An examination of liver cancer incidence in California*" by Fran Maguire, PhD and co-authors.

After reading the article and completing the quiz, participants will be able to:

- Identify the trends in the 2 main types of liver cancer
- Describe demographic patterns of liver cancer trends

1. Which of the following are the 2 main types of liver cancer?
   a) Hepatocellular carcinoma and cholangiocarcinoma
   b) Angiosarcoma and cholangiocarcinoma
   c) Angiosarcoma and hepatoblastoma
   d) Primary and secondary liver cancer
2. Which of the following most accurately describes trends in the rates of liver cancers?
   a) Declined since the 1970s
   b) Increased from 1970 to 2010 and then began to decline
   c) Increased since the 1970s
   d) Plateaued since 2010
3. Trends in incidence rates for the 2 main types of liver cancer are the same.
   a) True
   b) False
   c) Unknown if true or false
4. The main risk factors for the 2 main types of liver cancer are similar.
   a) True
   b) False
   c) Unknown if true or false
5. More effective treatment for hepatitis has led to decreased liver cancers rates.
   a) True
   b) False
   c) Unknown if true or false
6. Rising rates of obesity have led to decreased liver cancers rates.
   a) True
   b) False
   c) Unknown if true or false
7. How is the etiology of liver cancer changing?
   a) The etiology is not changing
   b) From individual behaviors to environmental exposures
   c) From viral to metabolic
   d) None of the above
8. Which age group had the highest incidence rate of liver cancers?
   a) 40–64 years
   b) 65–74 years
   c) ≥75 years
   d) It depends upon sex and cancer type
9. Which race/ethnic group has the lowest incidence rate of liver cancers?
   a) White
   b) Black
   c) Hispanic
   d) Asian/Pacific Islander
   e) It depends on sex
   f) It depends on cancer type
   g) None of the above
10. The general trends of liver cancer incidence in California are quite different from the general US trends.
    a) True
    b) False
    c) Unknown if true or false

Purchase Quiz to Earn CE:

1. Go to **http://www.cancerregistryeducation.org/jrm-quizzes**
2. Select quiz and "Add to Cart" (You may be prompted to login using your NCRA login).
3. Continue through the checkout process.
4. Once purchase is complete, the quiz will load automatically into "My Learning Activities" page.

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Multiple Author Index—Vol. 51 (2024)

A

B

C

Key Word Index—Vol. 51 (2024)

A

C

Title Index—Vol. 51 (2024)

National Cancer Registrars Association
CALL FOR PAPERS

The *Journal of Registry Management*, official journal of the National Cancer Registrars Association (NCRA), announces a call for original manuscripts on registry methodology or research findings related to the 7 subjects listed below and related topics.

Topics:

1. **Birth Defects Registries**
2. **Cancer Registries**
   a. **AJCC TNM Stage**
   b. **Cancer and Socioeconomic Status**
   c. **Cancer and Health Disparities**
3. **Trauma Registries**
4. **Recruitment, Training, and Retention**
5. **Public Relations**
6. **Quality Review**
7. **Registry Management**

Contributed manuscripts are peer-reviewed prior to publication. Manuscripts of the following types may be submitted for publication:

1. **Methodology Articles** addressing topics of broad interest and appeal to the readership, including methodological aspects of registry organization and operation.
2. **Research articles** reporting findings of original, reviewed, data-based research.
3. **Primers** providing basic and comprehensive tutorials on relevant subjects.
4. **"How I Do It" Articles** describe tips, techniques, or procedures for an aspect of registry operations that the author does particularly well. The "*How I Do It*" feature in the *Journal* provides registrars with an informal forum for sharing strategies with colleagues in all types of registries.
5. **Opinion papers/editorials** including position papers, commentaries, essays, and interviews that analyze current or controversial issues and provide creative, reflective treatments of topics related to registry management.
6. **Bibliographies** which are specifically targeted and of significant interest will be considered.
7. **Letters to the Editor** are also invited.

Address all manuscripts to: Nadine Walker, MS, ODS-C, Editor-in-Chief, *Journal of Registry Management,*
(703) 299-6640 ext. 327, JRMEditor@ncra-usa.org.

Manuscript submission requirements are given in "Information for Authors" found near the back of each *Journal* and on the NCRA website at **https://www.ncra-usa.org/About/Publications/Journal-of-Registry-Management**.

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- Primers providing tutorials on relevant subjects
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JRM invites submission of:

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- Letters to the Editor
- Specifically targeted bibliographies of significant interest

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1. LeMaster PL, Connell CM. Health education interventions among Native Americans: a review and analysis. *Health Educ.* 1995;21(4):521-538. doi:10.1177/109019819402100413
2. Hanks GE, Myers CE, Scardino PT. Cancer of the prostate. In: DeVita VT, Hellman S, Rosenberg SA. *Cancer: Principles and Practice of Oncology.* 4th ed. J.B. Lippincott Co.; 1993:1073-1113.

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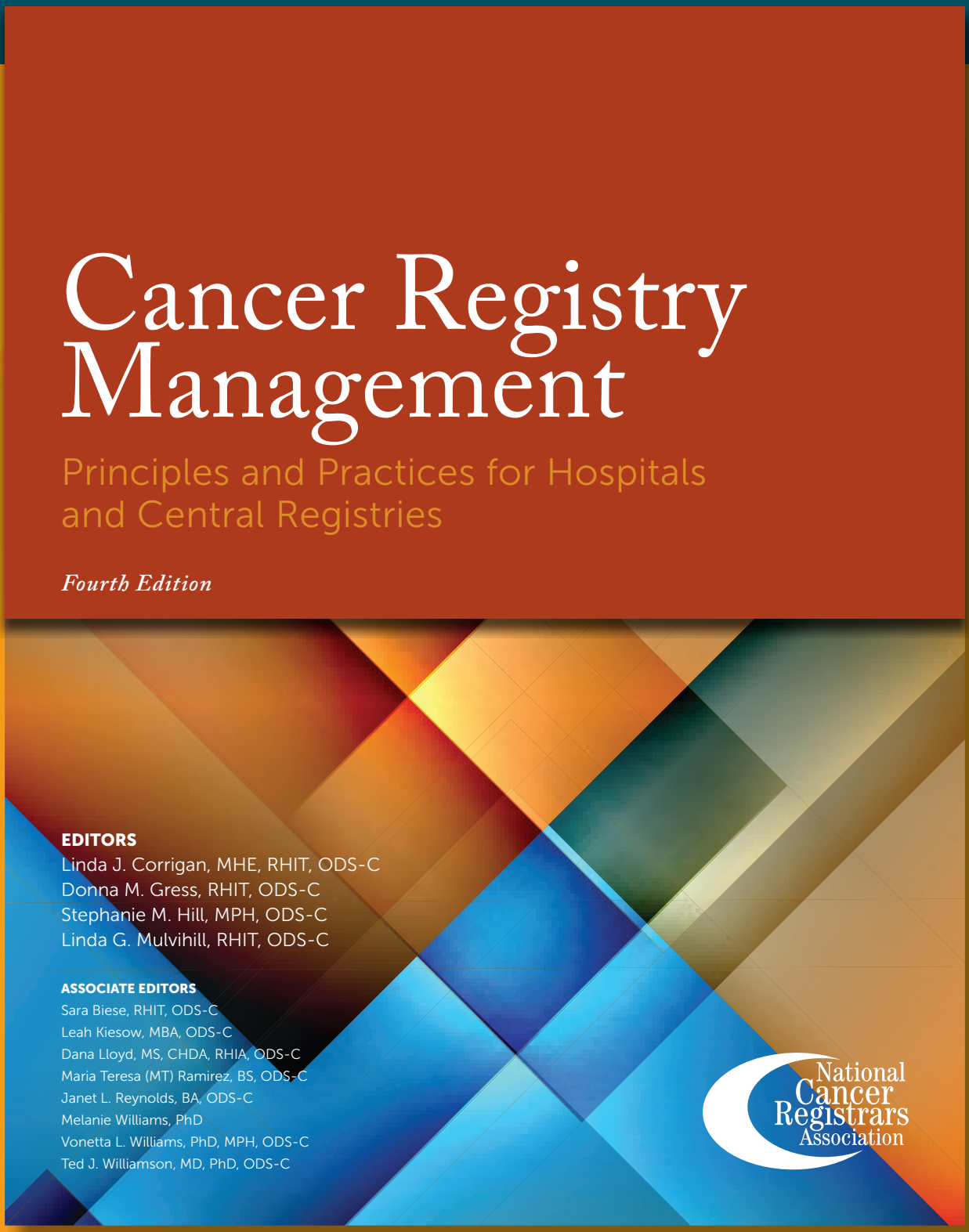

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