Cholangiocarcinoma incidence in 119,469,528 adults in the US: 2017-2024

Valerie Gunchick, MS[1], Amanda Nottke, PhD[2], David H Howard, PhD[3], Ruth M. Pfeiffer, PhD[4], Jill Koshiol, PhD[5], Juan W Valle, MB, ChB, MSc, FRCP[2,6]

[1]Division of Epidemiology, Department of Medicine, Vanderbilt-Ingram Cancer Center, Vanderbilt University Medical Center, Nashville, TN, USA. [2]The Cholangiocarcinoma Foundation, Herriman, UT, USA. [3]Winship Cancer Center, Department of Health Policy and Management, Emory University School of Public Health, Atlanta, GA, USA. [4]Division of Cancer Epidemiology and Genetics, Biostatistics Branch, National Cancer Institute, Rockville, MD, USA. [5]Division of Cancer Epidemiology and Genetics, Infections and Immunoepidemiology Branch, National Cancer Institute, Rockville, MD, USA. [6]Division of Cancer Sciences, University of Manchester, Manchester, UK.

Objective

- Calculate accurate incidence and prevalence statistics to enable adequate allocation of resources towards early identification and diagnosis

Background

- Cholangiocarcinoma (CCA) incidence is reportedly increasing
- Based on United States (US) cancer registries that included data up to 2018:
  - CCA incidence is 2-5 per 100,000 person-years (pys)
  - Incidence increased as much as 148.8% from 2001 to 2017 for intrahepatic CCA
- A systematic quantification of current CCA incidence is needed to understand the recent disease burden

Methods

- Calculated age- and sex- standardized incidence rates from 2017 through 2024
- Evaluated the Komodo Health Healthcare Map dataset, which includes ~330 million individuals' insurance claims from Medicare, Medicaid, and commercial insurance in the US
- Excluded participants aged <18 at the start of continuous enrollment (CE), missing sex or date of birth, with <90- or <180-day CE
- Used 2020 US Census population for sex and age-adjustment
- Assigned CCA subtype based on the highest percentage of claims, then cleaned according to published reports in literature[1-3]

To ensure proper case and subtype identification, we assessed:
- The procedure codes that indicated a CCA diagnosis
- The number of stents and days from diagnosis to death
- The percentages of: deaths, stents, liver transplants, CA19-9 evaluations, gemcitabine, cisplatin, pembrolizumab, and durvalumab, race/ethnicity, insurance type, and CE durations

Primary Analysis: Comparable with other literature
- Evaluated adults who had ≥180 days of CE as of Jan. 1, 2017, through Dec. 31, 2024, allowing a 45-day grace period
- Defined a CCA case as someone who had ≥1 inpatient claim or ≥2 outpatient claims ≥30 days apart with a CCA ICD-10 code
- Analyzed by year and subtype

Sensitivity Analyses: Tailored to CCA
- Decreased CE requirement to 90 days and shortened outpatient time requirement to ≥14 days to respect the commonly short survival of patients with advanced CCA
- Analyzed multiple CCA diagnosis definitions and crude rates

Reference DOIs: 1)10.1002/jhbp.916, 2)10.1016/j.ejso.2020.09.039, 3)10.1093/jnci/djj234, 4)10.1634/theoncologist.2015-0446, 5)10.1186/s12885-022-10286-z, 6)10.1093/oncolo/oyac150, 7)10.1186/s12876-022-02637-8, 8)10.1016/j.jhep.2019.03.013, 9)10.1186/s12876-016-0527-z, 10)10.1007/s10552-025-02038-8, 11)10.1097/hep.0000000000001200

Results

- 119,469,528 individuals with 334,557,446 pys from 2017 to 2024
- Incidence rate (95% confidence interval, CI) of 7.69 (7.60-7.78) CCA cases per 100,000 pys
  - Intrahepatic CCA: 4.91 (4.85-4.98)
  - Extrahepatic CCA: 2.06 (2.02-2.11)
  - Unspecified/overlapping: 0.63 (0.60-0.65)
- Net increases in incidence from 2017 to 2024 of 142.6% for CCA, 152.4% for IHCCA, and 136.5% for EHCCA
- Joinpoint analysis indicated an annual percent change and (95% CI) of 1.35% (-2.97%-5.86%) before March 2020 (+/- 6 mo.) and 9.57% (4.91%-14.47%) after

Table 1. Select patient characteristics

	CCA Cases	Non-CCA Cases
Count	30,418	119,439,110
Female	48.8%	54.6%
Median age [IQR]	68 [61, 75]	46 [31-60]
Median years enrolled [IQR]	4.0 [2.4, 6.0]	2.8 [1.4-5.3]
Insurance type		
Commerical	25.2%	66.1%
Medicaid	4.4%	11.1%
Medicare	63.9%	20.2%
Race/ethnicity		
Asian or Pacific Islander	4.2%	3.7%
Black or African American	11.2%	9.4%
Hispanic or Latino	10.8%	10.1%
Other	2.4%	3.3%
White	62.3%	43.5%

CCA: cholangiocarcinoma, IQR: interquartile range.

Table 2. Previous reports in literature

Manuscript	Years evaluated	Dataset	CCA Incidence	APC IHCCA	IHCCA net increase
Saha et al.[4]	1973-2012	SEER	1.18	2.30	128%
Koshiol et al.[5]	2001-2015	SEER	1.17	6.65	164%
Javle et al.[6]	2001-2017	SEER	3.65	6.77	149%
Jiang et al.[7]	2000-2018	SEER	1.10	7.70	280%
			IHCCA Mortality		
Bertuccio et al.[8]	2002-2012	WHO	1.04	5.1	143%
Yao et al.[9]	1999-2014	NCHS, CDC WONDER	3.00	N/A	136%
Kahn et al.[10]	1999-2020	CDC WONDER	2.04	3.55	208%
Vu et al.[11]	2000-2020	WHO	1.40	3.20	100%

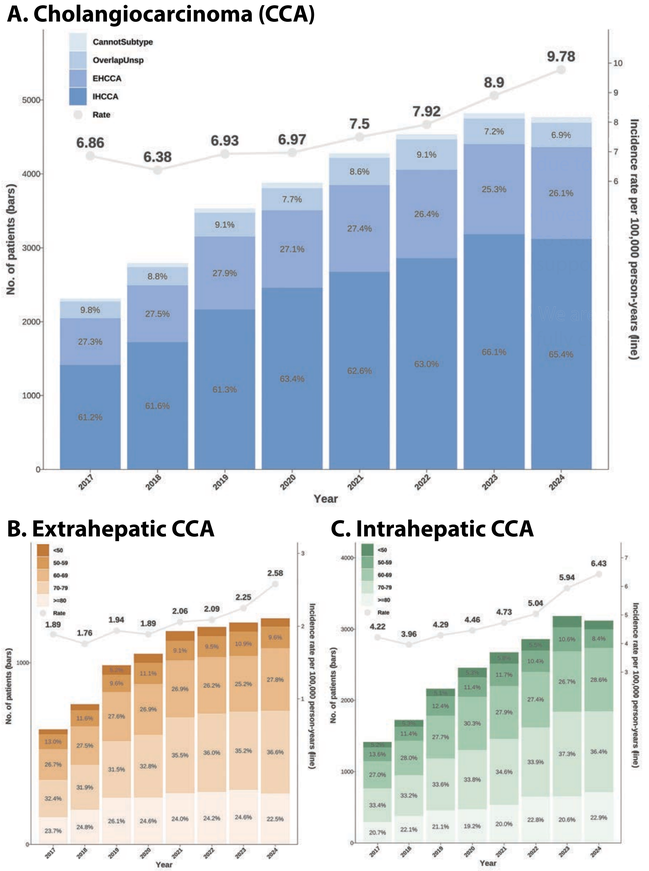

Figure 1. A. CCA. **B.** EHCCA. **C.** IHCCA. Bars depict the number of cases each year and the percentage of the subtype or age group as listed in the legends. Annual age- and sex-adjusted incidence rates per 100,000 person-years are shown on the lines. *CCA: cholangiocarcinoma, EHCCA: extrahepatic CCA, IHCCA: intrahepatic CCA.*

Patient Summary

- Cholangiocarcinoma (CCA) is considered a rare cancer, but, in many regions, that seems to be changing
- Tracking how often CCA is diagnosed helps identify trends and guide efforts in prevention, early diagnosis, and care
- We conducted one of the largest and most recent nationwide analyses of almost half of the US population's medical insurance data
- We calculated how many people developed CCA and its subtypes each year from 2017 to 2024

Key findings
- CCA diagnoses increased over time
- We observed a higher CCA rate than previously reported

Why this matters
- The rising number of cases suggests a growing disease burden
- More research is needed to understand causes, improve prevention, and detect CCA earlier

The bottom line
- CCA may still be uncommon, but it's not as rare as we once thought (~25,400 cases per year in the US compared to previous estimates of 8,000-10,000 cases per year)
- Understanding the increase is critical to improving outcomes for patients

Please contact Valerie Gunchick, Valerie.Gunchick@Vanderbilt.edu, with inquiries about this poster.