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Geographic distribution and demographic patterns of primary biliary cholangitis and autoimmune hepatitis in Colombia: a national population-based administrative study (2018-2024)

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Abstract

Background Autoimmune liver diseases, including primary biliary cholangitis (PBC) and autoimmune hepatitis (AIH), are rare chronic conditions with significant morbidity. However, population-based epidemiological data from Latin America remain limited. This study aimed to describe the geographic distribution and demographic patterns of PBC and AIH in Colombia between 2018 and 2024.

Methods A descriptive, cross-sectional population-based study was conducted using data from the Comprehensive Social Protection Information System (SISPRO) of the Colombian Ministry of Health. Individuals with at least 1 recorded diagnosis coded as K74.3 (PBC) or K75.4 (AIH) according to the International Classification of Diseases, 10th Revision (ICD-10), were identified. Administrative prevalence estimates were calculated per 100,000 population, using official population projections from the National Administrative Department of Statistics (DANE). Age- and sex-specific distributions were analyzed, and geographic variation was visualized using choropleth maps at the regional level.

Results A total of 6504 PBC cases and 11,225 AIH cases were identified. The estimated national administrative prevalence was 14.7 per 100,000 population for PBC and 17.0 per 100,000 for AIH. Both conditions showed marked female predominance. PBC was more frequent in women aged 50-69 years. However, AIH demonstrated a broader age distribution, affecting individuals from young adulthood to older age. Higher prevalence estimates were observed in multiple northern regions, particularly in the Caribbean region.

Conclusions This first nationwide administrative assessment of PBC and AIH in Colombia demonstrates marked sex differences and regional variation, highlighting the need to improve diagnostic awareness and strengthen epidemiological surveillance of autoimmune liver diseases in Latin America.

Keywords Primary biliary cholangitis, autoimmune hepatitis, epidemiology, administrative prevalence, Colombia

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Conflict of Interest: None

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Introduction

Autoimmune liver diseases (AILD), which include primary biliary cholangitis (PBC) and autoimmune hepatitis (AIH), are rare but important chronic conditions, as both can progress to cirrhosis if not diagnosed and treated rapidly. PBC is characterized by immune-mediated destruction of the intrahepatic bile ducts, whereas AIH is characterized as a hepatocellular inflammation with interface necrosis and elevated immunoglobulin G [1,2].

The global prevalence reported for PBC is estimated to be between 20 and 40 cases per 100,000 population for PBC, and between 15 and 20 per 100,000 for AIH [3-6]. These

figures vary between regions, probably because of genetic and environmental differences and differences in access to diagnosis [7,8]. In Colombia, both are recognized as orphan diseases [9], but there are no population studies quantifying their burden. The available information comes from isolated clinical series [10]. Given that access to specialized care varies between regions, there may be real or apparent differences in regional prevalence.

Individual Health Service Provision Records (RIPS) are mandatory in the Colombian health system and contain data on more than 500 million cases of care; hence, they have been used previously to estimate the prevalence of various diseases and procedures [11-14]. Since they include information on all patients affiliated with the health system (99.12% of the country's population), they are an invaluable source of information for estimating prevalence in Colombia [15].

The objective of this study was to estimate the prevalence of PBC and AIH by region, and to describe their demographic characteristics (age and sex) in Colombia, based on official SISPRO records for the period 2018-2024.

Materials and methods

An observational, descriptive, cross-sectional study was conducted using secondary administrative data from the Comprehensive Social Protection Information System (SISPRO), administered by the Colombian Ministry of Health and Social Protection. This record compiles nationwide healthcare information obtained from the RIPS, which include diagnostic codes assigned during healthcare attention within the national health system. Patients were identified with a diagnosis registered in the SISPRO database under ICD-10 codes K74.3 for PBC and K75.4 for AIH between 2018 and 2024.

Records with inconsistent demographic information or missing key variables were excluded. The diagnoses were not clinically validated and were based exclusively on ICD-10 coding, given the administrative nature of the database. Extracted variables included sex, age at the time of registration, and region of residence. Age was categorized into 5-year intervals for descriptive analyses.

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The administrative prevalence was calculated as the number of unique individuals with a recorded diagnosis of PBC or AIH divided by the corresponding year-specific national population projections obtained from the National Administrative Department of Statistics (DANE) [15]. Prevalence was expressed per 100,000 population. For the statistical analysis, categorical variables were reported as absolute frequencies and percentages. Administrative prevalence estimates were calculated overall and classified by sex, age group, and region. The administrative prevalence of the regions was graphically represented using choropleth maps generated with the Datawrapper software.

The study was considered of minimal risk, under Colombian regulations (Res. 8430/93), as it was based on anonymized secondary data. The study protocol was approved by the Ethics Committee of the Hospital Universitario San Ignacio (FM-CIE-1147-25).

Results

A total of 6504 cases with PBC and 11,225 with AIH were identified between 2018-2024. The estimated national administrative prevalence was 14.7 per 100,000 population for PBC and 17.0 per 100,000 for AIH during the period 2018-2024 (Table 1). During the study period, the number of cases of both conditions increased considerably after 2021.

For PBC, administrative prevalence increased from 13.3 per 100,000 population in 2018 to 15.3 per 100,000 in 2024 (15%). Meanwhile, the prevalence of AIH rose from 15.2 per 100,000 population in 2018 to 18.0 in 2024 (18%).

The geographic distribution by region is shown in Fig. 1. The highest administrative prevalence estimates were concentrated in the northern regions of the country, particularly in Atlántico, Bolívar and Córdoba, where the prevalence for both PBC and AIH reached up to 30 per 100,000 population. In contrast, southern regions, such as Amazonas, Guaviare and Caquetá, showed lower prevalence estimates (<5 per 100,000 population).

Fig. 2 and 3 present the distribution by age and sex. Overall, women accounted for 73% of cases for both conditions. In the case of PBC, the administrative prevalence was 21.2 per 100,000 among women and 7.8 per 100,000 among men, corresponding to a ratio of 2.7:1 (95% confidence interval [CI] 2.5-2.9). For AIH, the administrative prevalence was 25.4 per 100,000 in women and 9.2 per 100,000 in men, corresponding to a ratio of 2.8:1 (95%CI 2.6-3.0).

Age-specific analyses revealed an increasing trend in the prevalence of both diseases with increasing age. In PBC, the disease was rare below 30 years of age, while there was a substantial rise in prevalence above 45 years, with the greatest proportion of individuals being 60-74 years old. In AIH, there was an earlier rise in the disease, with a steady increase from about 40 years of age, and a peak being reached in those aged 55-69 years, with a subsequent drop in those over 75 years. In both PBC and AIH, over 80% of the cases were registered in people over 40 years of age, with over 70% being in women.

Table1 Epidemiological profile of autoimmune liver diseases in Colombia (SISPRO 2018-2024)

Variable	Autoimmune hepatitis	Primary biliary cholangitis
Administrative prevalence (per 100,000 population)	17.0	14.7
Female sex, %	74.7	73.2
Female-to-male ratio	2.8:1	2.7:1
Mean age, years (SD)	52.3 (14.1)	58.7 (12.8)
Age group (s) with the highest frequency (years)	30-49 and 60-69	60-74
Regions with the highest prevalence	Atlántico, Bolívar, Córdoba	Atlántico, Bolívar, Córdoba
Year with the highest number of recorded cases	2022	2022

Source: Comprehensive Social Protection Information System (SISPRO), Ministry of Health and Social Protection, Colombia, 2018-2024
SD, standard deviation

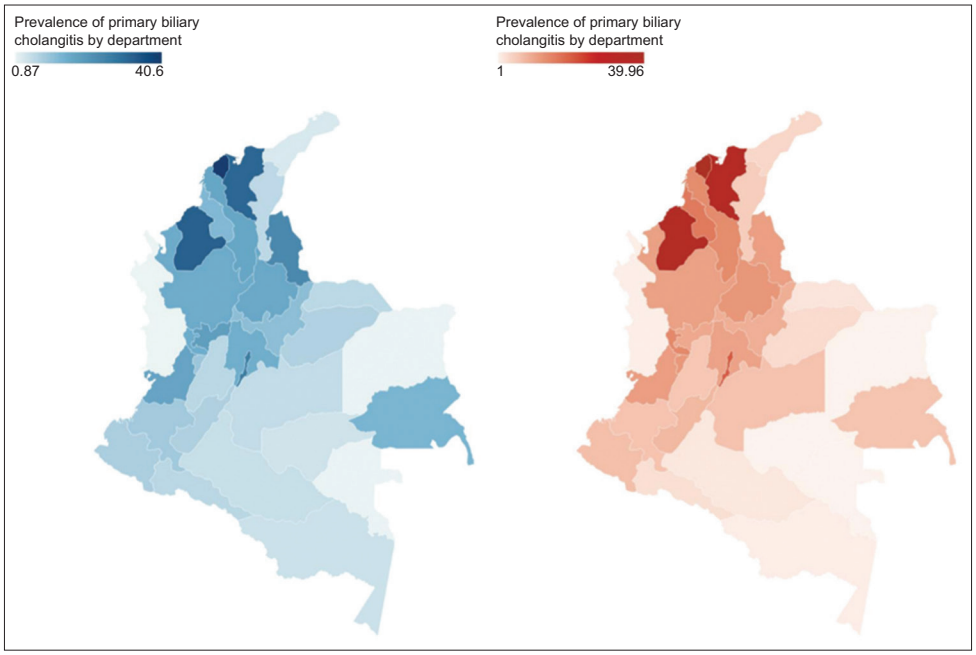

Figure 1 Prevalence of primary biliary cholangitis and autoimmune hepatitis per 100,000 inhabitants in Colombia by region, 2018-2024. Source: SISPRO/RIPS

Discussion

The objective of this study was to estimate the prevalence of PBC and AIH by region, and to describe their demographic characteristics in Colombia. Population-based epidemiological evidence of AILD in Latin America is scarce, as most of the data come from hospital-based case series or regional multicenter cohorts, rather than consolidated national registries.

In this context, our results (14.7 per 100,000 population for PBC and 17.0 per 100,000 for AIH) represent one of the first published population-based administrative prevalence estimates for autoimmune liver diseases in the region. In Mexico, a recent national study characterized the healthcare burden of autoimmune liver diseases, including AIH and PBC, showing that these conditions account for a substantial proportion of hepatology-related hospitalizations, despite their classification as rare diseases [16]. Similarly, the Latin American ALLATIN cohort reported that both AIH and PBC predominantly affect women, with a mean age at diagnosis in middle adulthood, and a considerable proportion of patients presenting with cirrhosis at the time of diagnosis [17,18]. However, these studies do not provide prevalence estimates adjusted to the general population.

In contrast, population-based data from high-income countries have reported higher prevalence estimates. A nationwide cohort study from the Netherlands described a prevalence of approximately 21.5 per 100,000 population for PBC [19], while a global meta-analysis estimated the prevalence of AIH at 15.6 per 100,000 population (95%CI 13.4-18.2) [20]. In several European countries, reported prevalence estimates for PBC reach up to 40 per 100,000 population in selected populations [21]. These differences may reflect variations in diagnostic practices, case identification and access to specialized care, rather than true epidemiological disparities.

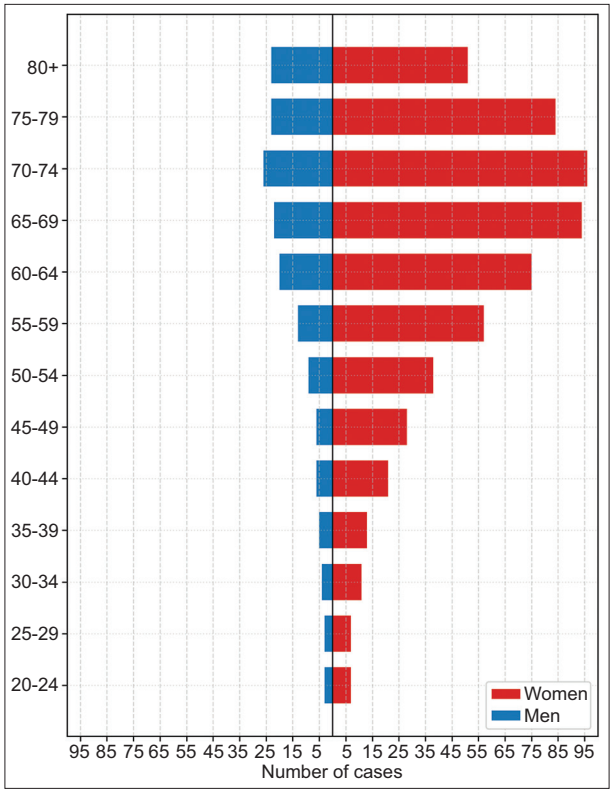

Figure 2 Distribution of patients with primary biliary cholangitis by age and sex, 2018-2024

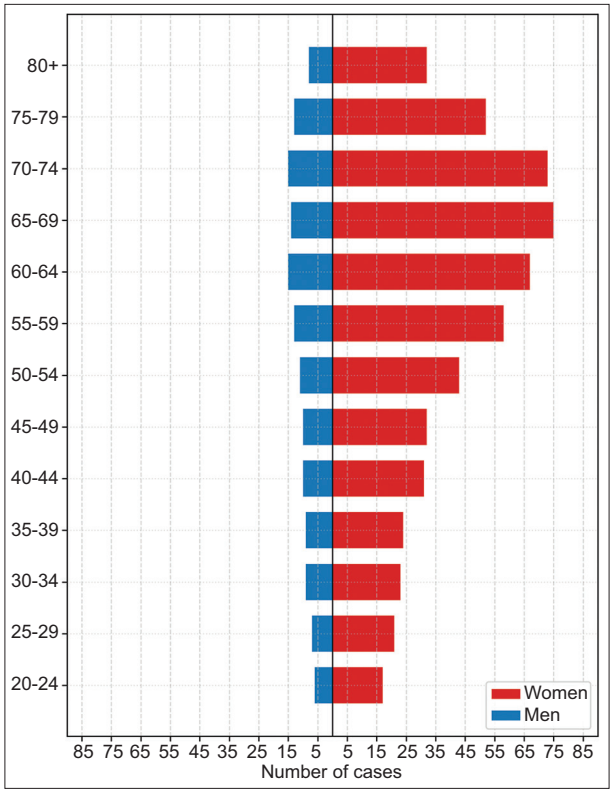

Figure 3 Distribution of patients with autoimmune hepatitis by age and sex, 2018-2024

The prevalence of PBC observed in our study is similar to that of AIH, contrasting with the traditional perception of PBC being a rarer condition in Latin America. Even though these findings should be interpreted with caution, given the short observation period and the administrative nature of the data, the observed trends may be related to the overall accessibility to immunological testing, such as antimitochondrial antibodies, as has been reported in other low- and middle-income countries [1,2].

An interesting finding is the concentration of cases of both PBC and AIH in the Caribbean region. This is probably due to a multifactorial phenomenon, as differences in genetic background have been proposed as potential contributors to autoimmune disease susceptibility, and previous population studies have described a higher proportion of European ancestry and autoimmune disorders in northern coastal regions of Colombia [22-24]. Another hypothesis could be that the regional variation is due to environmental exposure, such as chronic contact with pesticides, industrial solvents or infectious agents that could act as potential triggers, especially in the pathogenesis of PBC [25]. Last but not least, variations in healthcare access and administrative data quality could play a potential role, as regions with more developed healthcare infrastructure and robust data digitization systems tend to have better reporting rates in SISPRO.

The age at diagnosis clustered predominantly between 50 and 60 years. For PBC, the greatest disease burden was among patients aged 60-74 years, whereas AIH exhibited a bimodal age distribution, with an earlier peak between 30 and 49 years and a later peak between 60 and 69 years. This distribution aligns with findings from European and Asian cohorts, where the median age at diagnosis is generally reported in the sixth decade of life for PBC and the fifth decade for AIH [1,2,19,26].

Regarding sex distribution, our results reaffirm the well-recognized predominance of female patients for both PBC and AIH. Nevertheless, the female-to-male ratios identified in our cohort (2.7:1 for PBC and 2.8:1 for AIH) were lower than those described in European and North American cohorts, where ratios up to 4-6:1 for AIH and 9:1 for PBC have been described [1,2,8,26,27]. This comparatively smaller sex disparity in Colombia should be interpreted cautiously, as population level characteristics, including genetic admixture, have been suggested as potential modifiers of autoimmune disease susceptibility in Latin American populations. However, such hypotheses cannot be evaluated within the scope of the present administrative study [22,23].

This study had several limitations. First, the data were derived from administrative healthcare databases, with case identification based solely on ICD-10 codes, in the absence of detailed clinical, laboratory, immunological or histopathological information. As a result, the possibility of diagnostic misclassification or coding inaccuracies cannot be ruled out, and the prevalence estimates should be interpreted as administrative measures rather than as confirmed clinical prevalence. Moreover, although the use of anonymized unique identifiers helps minimize duplicate records, the structure of the

database does not permit independent validation of diagnoses or clear distinction between incident and prevalent cases. In addition, overlapping syndromes like AIH and PBC may be incompletely captured in administrative registries, which could affect regional prevalence estimates. That being said, this research could mark the foundation for future research incorporating standardized clinical registries and serological confirmation, which will be essential to more accurately characterize the true prevalence, geographic distribution and underlying determinants of autoimmune liver diseases in Colombia and Latin America.

In conclusion, PBC and AIH in Colombia display an epidemiological profile characterized by a clear female predominance, distinct age-related patterns and marked geographic heterogeneity. These findings highlight the need to strengthen epidemiological surveillance, enhance diagnostic awareness, and foster collaborative research initiatives aimed at improving the understanding of autoimmune liver diseases in Latin America.

AI disclosure

The authors used AI-assisted language editing tools solely to improve grammar, clarity, and readability during manuscript preparation. No AI tools were used to generate scientific content, perform data analysis, interpret results or draw conclusions. All final wording, scientific judgments, and interpretations were made by the authors, who take full responsibility for the content of the manuscript.

Summary Box

What is already known:

- Autoimmune liver diseases, such as primary biliary cholangitis (PBC) and autoimmune hepatitis (AIH), are rare conditions with limited population-based epidemiological data from Latin America
- Most available regional evidence comes from hospital-based series or multicenter cohorts, rather than national registries

What the new findings are:

- Using a nationwide administrative database, this study provides the first population-based overview of the geographic and demographic distribution of PBC and AIH in Colombia
- The findings reveal a marked female predominance and substantial regional heterogeneity, highlighting the need for improved surveillance and diagnostic awareness of autoimmune liver diseases in Latin America

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