DOI: 10.52054/FVVO.2025.153
Facts Views Vis Obgyn 2025;17(3):263-270

Race and ethnicity reporting in endometriosis literature: a systematic review

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ABSTRACT

Background: Accurate reporting of participants' race and ethnicity is essential for assessing the representativeness of study populations and for identifying potential disparities in diagnosis, treatment, and outcomes.

Objectives: To assess the quantity and quality of race and/or ethnicity reporting in the endometriosis literature.

Methods: A systematic review of all human studies reporting data about endometriosis as the primary objective published in 2022. Studies were identified from electronic searches of MEDLINE, Google Scholar, Web of Science, Scopus, ClinicalTrials.gov, and the Cochrane Library databases.

Main Outcomes Measures: The frequency and quality of participants' race and/or ethnicity reporting based on compliance with the guidelines set by the ICMJE. Study characteristics that influenced the reporting of race and/or ethnicity were assessed. Publications from journals that followed ICMJE recommendations were compared with those from journals that did not.

Results: 648/2054 (31.6%) articles met the inclusion criteria. Sixty-five studies (10.0%) reported participants' race and/or ethnicity, and the overall quality of this reporting was poor. The frequency of reporting did not differ between journals adhering to ICMJE guidelines and those that did not (24, 11% vs. 41, 9.5%; P=0.52), between studies involving national versus international populations (60, 92.3% vs. 5, 7.7%; P=0.28), or between male and female authors (33, 50.8% vs. 32, 49.2%; P=0.38) respectively. Race and/or ethnicity were reported more often in prospective than in retrospective studies (37, 56.9% vs. 18, 27.7%; P<0.001), and in multicentre compared to single-centre studies (44, 67.7% vs. 21, 32.3%; P<0.001).

Conclusions: The reporting of race and/or ethnicity in human-based endometriosis research remains both infrequent and inconsistent, including in journals claiming adherence to ICMJE standards. These results highlight the need for improved and uniform documentation of racial and ethnic data in endometriosis research.

What is New? Human-based articles focusing on endometriosis have a low frequency and quality of race and/or ethnicity reporting, even in journals claiming to follow ICMJE recommendations.

Keywords: Epidemiology, demographics, endometriosis, report, disparity

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Received: 02.05.2025 **Accepted:** 22.09.2025 **Publication Date:** 30.09.2025

Cite this article as: Raffone A, Doglioli M, Aguzzi A, Girardi L, De Meis L, Neola D, et al. Race and ethnicity reporting in endometriosis literature: a systematic review. Facts Views Vis Obgyn. 2025;17(3):263-270

Introduction

Endometriosis, a gynaecological disorder characterised by the ectopic growth of endometrial-like tissue outside the uterus,[1] has a significant burden on individuals worldwide, manifesting in dysmenorrhoea, chronic pelvic pain, infertility, and various other debilitating symptoms.[2,3]

Studies indicate that endometriosis affects individuals across diverse racial and ethnic backgrounds, albeit with variations in diagnosis, treatment and outcomes.[4-6] In this context, race is commonly understood as a socially constructed categorisation based on perceived physical traits such as skin colour, whereas ethnicity refers to shared cultural identity, including ancestry, language, and traditions.[7,8] Recent research found that Hispanic and Black women were less likely to receive a timely diagnosis of endometriosis, compared to their White counterparts, highlighting disparities in access to care and diagnostic delays.[9,10]

In recent years, there has been a growing recognition of the importance of addressing racial and ethnic disparities in healthcare research. Initiatives such as the National Institutes of Health (NIH) Revitalization Act of 1993 mandated the inclusion of minority individuals in clinical research to ensure that study findings are applicable to diverse populations.[11] Moreover, the International Committee of Medical Journal Editors (ICMJE) developed recommendations for race and/or ethnicity reporting. Specifically, these recommendations encourage researchers to explicitly state the racial and ethnic composition of their study populations and to consider these factors when interpreting study results. This reporting is intended to help identify health disparities and improve the relevance of clinical findings to different demographic groups.[12] Despite these efforts, there is still a lack of clarity regarding the impact of these initiatives on endometriosis literature to adequately represent and consider the experiences of diverse racial and ethnic groups.

This study aimed to assess the quantity and quality of race and/or ethnicity reporting in the endometriosis literature.

Methods

This systematic review adhered to an *a priori* study protocol that outlined the methods for search, strategy, study selection, data extraction and synthesis. The protocol was registered in the International Prospective Register of Systematic Reviews (ID: CRD42023486163). Two authors independently performed all steps, and discrepancies were resolved through discussion among all authors. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses 2020 checklist and flowchart[13] were followed to report the whole study.

Eligibility Criteria, Information Sources, Search Strategy

Searches were conducted in six electronic databases (i.e. MEDLINE, Google Scholar, Web of Sciences, Scopus, ClinicalTrials.gov and Cochrane Library) from January to December 2022 using different combinations of the following search terms: "endometriot*"; "endometrios*"; "endometriom*"; "rac*"; "ethni*". Since a cross-sectional analysis of the whole endometriosis literature was not feasible for our aim, we chose the above-mentioned literature screening period (January - December 2022) as a representative sample of the recent endometriosis literature. References from relevant studies were also screened.

Study Selection

We included all peer-reviewed, human-based primary research articles focusing on endometriosis.

A priori defined exclusion criteria were:

- Non–research-focused articles (i.e. editorials, commentaries, and letters to the editor);
- Reviews and meta-analyses;
- Case reports;
- Non-human studies;
- Articles reported in languages other than English.

Data Extraction

We extracted the following data from the included studies analysing the full-text manuscript and tables and figures: demographic information [(age and body mass index (BMI)], race and ethnicity. We recorded how race was categorized (i.e.., "race", "ethnicity", "race and/or ethnicity", "descent", "population", "ancestry", other, or not classified) and the method of classification (i.e. self-report, healthcare professionals' or researchers' perception, parent/caregiver report, national/government ID, personal/parent birth country, or unspecified methods such as clinical database review or institutional electronic medical record review). Additionally, we noted the journal name and whether it adhered to the ICMJE recommendations, the geographical scope (multi-country or single country), and the geographical region according to World Health Organization (WHO) classifications (Americas, African, European, Eastern Mediterranean, Southeast Asian, Western Pacific). This parameter was based on the research group's country of origin for studies examining national populations, and on the corresponding author's country of origin for international articles. We also recorded study design characteristics (retrospective or prospective, multicentre or single centre) and the corresponding author's gender (male or female).

Risk of Bias Assessment

Due to the inadequacy of standard risk of bias tools for evaluating race and ethnicity reporting, we assessed study quality using recommendations for the conduct, reporting, editing, and publication of scholarly work in medical journals as outlined by the ICMJE recommendations.[8] Specifically, we evaluated:

- "Who classified the individuals in terms of race and ethnicity";
- "Why the classification adopted in the study was used";
- "Whether the classification options were defined by the investigator or the participant";
- "Why race and ethnicity were reported in the study";
- "Whether the variable of race was defined in the article".

Statistical Analysis

Data were collected using Microsoft Excel (Version 2021), and descriptive statistics were computed for categorical variables. Chi-squared and Fisher's exact tests were employed to compare the study characteristics and the proportion of race and/or ethnicity reporting as well as differences between ICMJE and non-ICMJE journals. Statistical significance was set at *P*-value <0.05. All analyses were performed using Stata 17 software (StataCorp. 2021. Stata Statistical Software: Release 17. College Station, TX: StataCorp LLC).

Ethics Statement

The study was exempt from IRB approval due to the study design (systematic review of the literature).

Results

Studies Selection

From January 1, 2022, to December 31, 2022, 2,054 articles were published on endometriosis in indexed journals. At the end of the study selection process, 648 (31.6%) studies were included in our analysis (Figure 1).

Studies, Characteristics and Endpoints

Race and/or Ethnicity Reporting in All Indexed Journals

Among the 648 included articles, only 65 (10.0%) articles reported the race or ethnicity of the study participants (Table 1). Among the articles that reported race and ethnicity, the most common classification used was "ethnicity" (33, 50.8%), followed by "race and/or ethnicity" (43, 25.9%). The modality adopted to classify patients was frequently unspecified (44, 67.7%), followed by self-reporting by study participants (10, 15.4%) and perception of researchers (10, 15.4%).

The adherence to ICMJE recommendations for race and/or ethnicity reporting was notably low. Specifically, "who classified the individuals in terms of race or ethnicity" was reported in 2 studies (3.1%); "why the classification reported in the study was used" was never explained, "whether the classification options were defined by the investigator or the participant" were described in one study (1.5%), "why race was assessed in the study" was explained in 7 studies (10.8%) and "the variable of race within the text article" was defined in 20 studies (30.8%).

Comparisons Between Study Characteristics and Race and/or Ethnicity Reporting (Table 2)

Of the included articles, 149 (23.0%) were prospective studies and 305 (47.0%) were retrospective studies. There was a significantly higher frequency of prospective studies in articles reporting race or ethnicity compared to those that did not (37, 56.9% vs. 112, 19.2% *P*<0.001). Multicentric studies were more common in race-reporting articles than single-centre studies (21, 32.3% vs. 77,13.2%, *P*<0.001). Although the rate of studies examining international populations was higher in race-reporting articles, this difference was not statistically significant (5, 7.7% vs. 27, 4.6%).

WHO America region exhibited the highest consistency in reporting race or ethnicity (29, 44.6% vs. 61, 10.5%, *P*<0.001), with the United States (20, 44.4%) and Brazil (4,18.2%) being the most represented publishing countries. Conversely, the WHO Western Pacific region published the fewest race reporting articles (11, 16.9% vs. 230, 39.5%, *P*<0.001), with China (1, 0.6%) and Australia (6, 21.4%) representing the countries with the least reporting. The difference between the rate of race reporting and

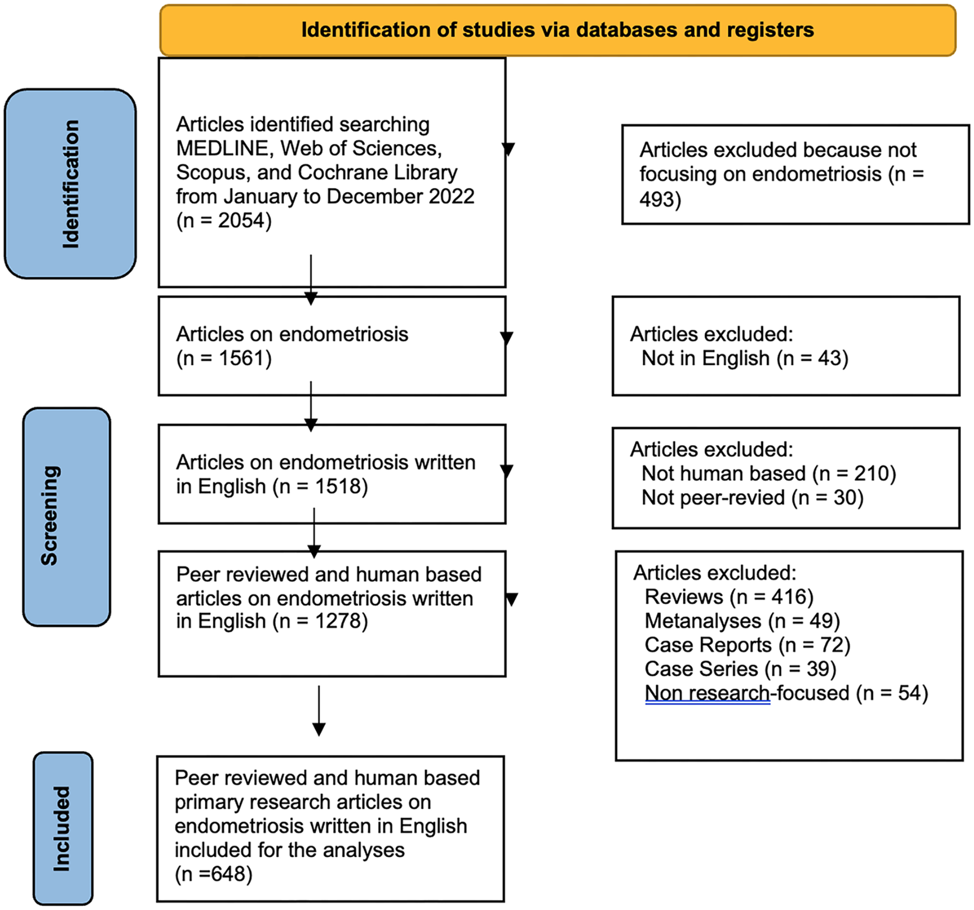

Figure 1. PRISMA 2022 flow diagram for new systematic reviews which included searches of databases and registers only.

race non-reporting articles in other WHO regions was not statistically significant.

Comparison Between Studies from ICMJE and Non-ICMJE Journals (Table 3)

Among the 648 included studies, 216 were published by journals adhering to ICMJE recommendations (33.3%). Demographic characteristics (patients' age and BMI) reporting was significantly higher in articles from ICMJE journals compared to non-ICMJE journals (118, 54.6% vs. 182, 42.1%, P=0.003). A minority of the articles, both from ICMJE (62, 20.4%) and non-ICMJE journals (104, 16.1%), reported participants' race or ethnicity; however, there was no statistical difference between the two groups (24, 11.1% vs. 41, 9.5%). The most common classification in both the ICMJE and non-ICMJE journals was "ethnicity" (9, 37.5% and 24, 58.5%, respectively), followed by "race and/or ethnicity" in ICMJE journals (8, 33.3%) and "race" in non-ICMJE journals (6, 14.6%). No statistical difference was observed between the ICMJE and non-ICMJE journals regarding the method of classification. In particular, the method of patients' classification in both the ICMJE and non-ICMJE journals was unspecified in most cases (15, 62.5% and 29, 70.7%, respectively), followed by "perception of healthcare professionals/researchers" in ICMJE articles (5, 20.8%) and "self-report" in non-ICMJE journals (7, 17.1%).

Quality of the Studies

Regarding the quality of race and/or ethnicity reporting, authors in non-ICMJE journals never reported "who classified the individuals in terms of race or ethnicity", while authors in ICMJE journals never reported "why the classification reported in the study was used". "Whether the classification options were defined by the investigator or the participant" was explained in one (4.2%) of the ICJME journals and in one (2.4%) of the non-ICMJE ones. Furthermore, "why race was assessed in the study" was clarified in 16.7% of ICMJE journals and in 7.3% of non-ICMJE journals.

Discussion

Main Findings

Our study showed low rates of race and ethnicity reporting in endometriosis literature, in terms of quantity and quality, regardless of the journal's statement of adherence to ICMJE recommendations.[12]

Table 1. Quantitative analyses of included studies.

	All included studies (648/2054, 31.6%)
Demographic characteristics reported (age AND body mass index)	300 (46.3%)
Race/ethnicity reported	**65 (10.0%)**
Classification reported	
Race	10 (15.4%)
Ethnicity	33 (50.8%)
Race/ethnicity	13 (20%)
Population	3 (4.6%)
Ancestry	1 (1.5%)
Not classified	5 (7.7%)
Method of classification	
Self-report	10 (15.4%)
Perception of health care professionals/researchers	10 (15.4%)
National registration identity	1 (1.5%)
Unspecified	44 (67.7%)

This finding is consistent with previous research highlighting inadequate reporting of social determinants of health in medical literature, particularly concerning race and ethnicity.[14-16] The underreporting of race and ethnicity in endometriosis studies not only obscures the true burden of the disease but also perpetuates inequalities in healthcare access and outcomes. These findings highlight the need to prioritise and standardise race and ethnicity reporting in endometriosis research.

Concerning adherence to reporting guidelines, such as those provided by the ICMJE, our study reveals poor adherence to recommended practices for race and ethnicity reporting. This finding is consistent with existing literature, which reported equally low rates of race reporting when analysing surgical and endometrial cancer literature.[17,18]

Furthermore, our analysis identifies significant disparities in race and ethnicity reporting based on study characteristics. Prospective studies and multicentric studies were more likely to report race and ethnicity compared to retrospective and single-centre studies, respectively. This result is in line with previous findings of a review focusing on surgical literature.[14,19]

Table 2. Rates of race and ethnicity reporting according to characteristics of included studies.

	All articles (648)	**Race reported (65)**	**Race not reported (583)**	***P*-value**
Study design				<0.001
Prospective	149 (23.0%)	37/65 (56.9%)	112/583 (19.2%)	
Retrospective	305 (47.0%)	18/65 (27.7%)	287/583 (94.1%)	
Other	194 (29.9%)	10/65 (15.4%)	184/583 (31.3%)	
Single-centre vs. multicenter study				<0.001
Single centre	550 (84.9%)	44/65 (67.7%)	506/583 (86.8%)	
Multicentre	98 (15.1%)	21/65 (32.3%)	77/583 (13.2%)	
National vs. international study				0.28
National	616 (95.1%)	60/65 (92.3%)	556/583 (95.4%)	
International	32 (4.9%)	5/65 (7.7%)	27/583 (4.6%)	
WHO region				<0.001
African	3 (0.5%)	1/65 (1.5%)	2/583 (0.3%)	0.27
Americas	90 (13.9%)	29/65 (44.6%)	61/583 (10.5%)	<0.001
South-East Asia	15 (2.3%)	0/65 (0%)	15/583 (2.6%)	0.39
European	264 (40.7%)	23/65 (35.4%)	241/583 (41.3%)	0.35
Eastern Mediterranean	35 (5.4%)	1/65 (1.5%)	34/583 (5.8%)	0.15
Western Pacific	241 (37.2%)	11/65 (16.9%)	230/583 (39.5%)	<0.001

WHO: World Health Organization.

Our study also highlights regional disparities in race and ethnicity reporting, with notable variations across WHO regions. These findings are consistent with previous studies, which found that randomised controlled trials enrolling United States patients had more race and/or ethnicity information than those recruiting an international population.[14,19]

Collectively, these findings highlight not only the inconsistency of race/ethnicity reporting but also the importance of examining the reasons why such information is often underreported.

Moreover, our findings also underscore the need for clinicians to recognise disparities in diagnosis and management, for policymakers to promote standardised reporting and inclusive research, and for researchers to integrate social determinants of health and adhere to international guidelines, in order to advance global health equity in endometriosis care and research.

Comparison with Existing Literature

One important explanation for the frequent omission of race and ethnicity data may be the limited representation of minority groups in many studies. Analyses across medical literature have shown that small subgroup sizes often restrict the possibility of meaningful statistical analysis and may discourage authors from reporting these variables.[14,18,19] For instance, Berger et al.[14] highlighted that race/ethnicity analyses in randomised trials were frequently underpowered to detect differences, while Maduka et al.[18] and Mitchell et al.[19] noted that small subgroup numbers reduce interpretability and contribute to inconsistent reporting practices. These findings suggest that the underreporting observed in endometriosis research may partly reflect methodological challenges rather than a lack of relevance. Nevertheless, transparent documentation of race/ethnicity remains important, particularly when guided by a clear hypothesis or when representation is sufficient to support analysis, as this enables the identification of disparities and improves the applicability of findings across populations.

Addressing racial and ethnic disparities in endometriosis research, therefore, appears essential for advancing health equity and improving outcomes for all individuals affected by the disease. By prioritising transparency, accountability, and inclusivity in race and ethnicity reporting, researchers, clinicians, policymakers, and funding agencies can work together to ensure that endometriosis research reflects the diversity of the population and informs strategies to address systemic inequities in healthcare access and outcomes.[20]

It has been demonstrated that endometriosis is less likely to be diagnosed in Black women and in Asian women, when compared with White women.[4] This difference seems to be related to a different clinical presentation among various race/ethnicities, a different socio-economic status or an implicit bias among health care

Table 3. Rates of race and ethnicity reporting among International Committee of Medical Journal Editors (ICMJE) and non-ICMJE journals.

	ICMJE (n=216, 33.3%)	**Non-ICMJE (n=432, 66.7%)**	***P*-value**
Demographic characteristics reported (Age AND body mass index)	118 (54.6%)	182 (42.1%)	0.003
Race and ethnicity reported	24 (11.1%)	41 (9.5%)	0.52
Classification reported			0.37
Race	4 (16.7%)	6 (14.6%)	
Ethnicity	9 (37.5%)	24 (58.5%)	
Race/ethnicity	8 (33.3%)	5 (12.2%)	
Population	1 (4.2%)	2 (5%)	
Ancestry	0	1 (2.4%)	
Not classified	2 (8.3%)	3 (7.3%)	
Method of classification			0.42
Self-report	3 (12.5%)	7 (17.1%)	
Perception of researchers	5 (20.8%)	5 (12.2%)	
National registration identity	1 (4.2%)	0 (0%)	
Unspecified	15 (62.5%)	29 (70.7%)	

providers to consider this diagnosis less likely in Black and Asian women.[5]

In addition to variation in disease prevalence and diagnosis among women of different races/ethnicities, literature reports the potential impact of this trait on the management of endometriosis with equal lesions' distribution.[5,21] According to Movilla et al.[10] study, Black or African American patients had the highest major postoperative complications and the lowest rates of minimally invasive surgery.[22-24] Moreover, a recent study suggests that race and/or ethnicity may influence disease severity, with Asian women being more likely to be diagnosed with stage III/IV endometriosis compared with White women.[25] This may be probably due to societal and economic factors impacting their access to care. Factors such as insurance coverage, referral networks, and access to high-volume surgeons are known to place patients from certain racial and ethnic groups at varying probabilities of accessing high-volume surgeons.[10] These findings support the hypothesis that diagnosing and treating highly prevalent diseases like endometriosis based on studies not reporting race and ethnicity may overlook potentially preventable adverse outcomes.[26,27]

Strengths and Limitations

The main strength of this study is that, to our knowledge, this is the first race-reporting systematic review on human-based peer-reviewed articles about endometriosis. Furthermore, this study employed a thorough search strategy across multiple databases and across various study characteristics, ensuring a comprehensive retrieval of relevant articles on endometriosis and maintaining methodological rigour in the data extraction and analysis process.

However, several limitations should also be acknowledged. First, the main limitation of the present systematic review is that, despite efforts to identify relevant studies, the limited availability of race and ethnicity data in endometriosis literature may have constrained the scope and generalizability of the findings. In particular, it appears unlikely to accurately identify how race and ethnicity were determined in studies based on the perception of researchers, since race is a social construct, not a biological one, but also based on clinical databases (e.g. Surveillance, Epidemiology, and End Results Program; National Cancer Database) and institutional electronic medical record review. Therefore, the method of race classification in most articles was labelled as "unspecified", as it was unclear whether race and/or ethnicity were established by self-reporting or other methods.

Second, in order to ensure a high-quality article review process, we decided to design a single year-focused review (i.e., 2022), with a subsequent potential selection bias. Further studies are needed to evaluate the race-reporting trend in endometriosis literature in other time frames.

Third, excluding studies reported in languages other than English might have created an impact on overall results; despite that, we *a priori* decided to establish this exclusion criterion to avoid the effect of potential mistranslation and lower quality of the included studies.

Another limitation is that our analysis was restricted to the reporting of race/ethnicity as documented in published studies. We could not incorporate broader social determinants—such as socioeconomic status, educational level, or insurance coverage—that interact closely with race and ethnicity and may provide a clearer understanding of disparities in access to care or diagnostic delay. In line with the WHO framework on the social determinants of health, it is important to recognise that health outcomes are the result of complex interactions between social, economic, and environmental conditions. Future investigations should integrate these dimensions and, where possible, apply statistical approaches such as two-way analyses to disentangle the respective contributions of social context and race/ethnicity.

Finally, the assessment of race/ethnicity reporting did not rely on a validated risk of bias tool and therefore cannot capture the underlying reasons why primary authors chose not to report these variables. The quality of race/ethnicity reporting assessment adopted was therefore exploratory and was intended as a descriptive appraisal, rather than a formal risk of bias evaluation, and was aimed at highlighting gaps in compliance with ICMJE recommendations.

Conclusion

Race and ethnicity are infrequently and poorly reported in international literature regarding endometriosis. This finding underscores the critical importance of addressing racial and ethnic disparities in endometriosis research and highlights the urgent need for improved race and ethnicity reporting practices. By identifying disparities, understanding their underlying causes, and proposing evidence-based inclusion of racially and ethnically diverse patient populations in clinical literature, we can move closer to achieving health equity in endometriosis care and beyond.

Acknowledgements: xxx

Contributors: Surgical and Medical Practices: A.R., D.R., Concept: A.R., L.D.M., M.G.V., R.S., Design: M.G.V., L.C., R.S., D.R., Data Collection or Processing: A.R., M.D., A.A., L.G., M.G., Analysis or Interpretation: A.R., M.D., A.A., L.G., M.G., M.G.V., D.R., Literature Search: M.D., A.A., L.G., L.C., Writing: M.D., A.A., L.G.

Funding: The authors declared that this study received no financial support.

Competing interests: No conflict of interest was declared by the authors.

Ethical approval: Not required.

Data sharing: The data supporting the findings of the article are archived and can be provided by the authors upon request.

Transparency: The manuscript provides a truthful, precise, and transparent account of the study. All significant elements of the research are included, and any deviations from the original plan (and, where relevant, the registered protocol) are clearly explained.

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