The reporting of race and ethnicity in cardiothoracic surgery literature

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Research investigating the reporting of race and ethnicity within human subjects’ studies across medical and surgical specialties consistently reveals variability of practices and widespread underreporting. This poses a significant challenge for health care providers attempting to interpret these data effectively. 1, 2 Although there continues to be ongoing discourse regarding the influence of race and ethnicity on health outcomes and responses to novel therapies, the accurate reporting of such demographic data remains crucial to provide evidence-based care to patients of diverse backgrounds.

The International Committee of Medical Journal Editors3 (ICMJE) recognizes the importance of clear and transparent reporting regarding the determination of race and ethnicity in research studies. They emphasize authors must explicitly outline their rationale for omission of such data in studies for which race or ethnicity are not included and encourage authors to interpret results associated with race and ethnicity in the context of their nature as social, rather than biological, constructs to promote transparency and rigor in their reporting, while also acknowledging the complexities surrounding race and ethnicity in biomedical studies.

Despite the wide dissemination of these guidelines, previous investigators have shown significant deficiencies in reporting. Of 153 major cardiovascular randomized clinical trials published between 1986 and 2019, deemed to be landmark in nature by established expert standards, of which 77% took place at least partly in the United States, only about half reported any racial or ethnic demographic. 4 Those that did not report racial and ethnic demographics did not state the reason for exclusion.

There are sparse data assessing the quality of reporting of these demographics in the cardiothoracic surgery literature, which hinders the interpretation of novel research findings and recent clinical trials (Figure 1). Despite efforts to establish guidelines for transparent and rigorous reporting, studies continue to demonstrate poor adherence to these standards, reflecting a persistent gap between policy and practice. Herein, we seek to highlight the importance of including race and ethnicity in cardiothoracic surgical studies to ensure the delivery of evidence-based care to all patients with diseases of the chest, regardless of their racial and ethnic backgrounds.

VALIDITY AND CLASSIFICATION OF RACE AND ETHNICITY IN BIOMEDICAL RESEARCH

The validity of race as a research variable has sparked intense debate. Proponents argue for the association...
between genetic differences and racial backgrounds, whereas critics contend that race is a social construct.\textsuperscript{5-8} Genetic structure within human populations is primarily shaped by historical mating patterns influenced by geographic barriers, which foster endogamous mating within an area, leading to genetic differentiation. Although ethnic subdivisions also emerge from social factors, including religion and culture, deliberations over whether race and ethnicity are primarily social or biological constructs persist.

Despite these ongoing debates, 1 unfortunate reality remains evident: Disparities in health care delivery persist across racial and ethnic groups, even after accounting for confounding factors such as bias and access to care.\textsuperscript{9} Genetic studies demonstrate substantial variability within and among racial groups, influencing disease susceptibility and treatment response, affirming the continued relevance of race and ethnicity in biomedical research and clinical practice, despite its complex social implications.\textsuperscript{10}

Moreover, it is imperative to recognize the correlation between structural racism and enduring health disparities among racial and ethnic minorities. A review of lung cancer risk and the domains of structural racism illustrates how minorities are disproportionately affected, facing increased environmental exposures to air pollution and established carcinogens due to segregation and poor housing quality, encountering barriers to access to primary care services, and experiencing unequal consequences for tobacco use from the criminal justice system.\textsuperscript{11} Although acknowledging the persistent disparities in health care outcomes among different racial and ethnic groups, interventions should be tailored to effectively address the needs of all individuals.

The framework provided by the 2000 US Census classification system, commonly used in biomedical studies, categorizes race into 5 major categories: African American or Black, White, Asian, Native Hawaiian or other Pacific Islander, and American Indian or Alaska Native. This classification offers a structured approach to navigating the
complex landscape of human diversity by utilizing the geographical origins of an individual’s lineage. Ethnic background, on the other hand, transcends strict classifications, encompassing a rich tapestry of cultural practices; historical narratives; social affiliations; and, often, a collective genetic legacy.

In the United States, ethnicity is typically categorized as “Hispanic” and “non-Hispanic;” however, classification will vary geographically, with other predominant groups appropriate for inclusion in other regions and countries. For example, East Asians, who constitute one-fifth of the global population and exhibit substantial genetic diversity, require further research initiatives to provide insight into population relationships, genetic differentiation, and admixture among major groups such as Chinese, Korean, and Japanese populations. Depending on the study’s demographics, the investigators must accurately capture and report race and ethnicity to enhance the collective knowledge about similarities and differences among groups.

Standardized classification systems provide a framework for collecting and presenting race and ethnicity data, ensuring that research findings accurately reflect the diversity of populations and facilitating efforts to address health disparities. Continued attention to the interplay among genetics, culture, and social factors is essential for promoting health equity and improving health care outcomes for individuals of all races and ethnicities.

DEFINING AND CAPTURING RACE AND ETHNICITY IN HEALTH CARE RESEARCH

While recognizing the significance of including race and ethnicity data in research, it’s imperative to acknowledge the challenges in capturing these demographics accurately and consistently. The electronic health record is the primary entry point for these data in the health care system, through primary care and office visits, emergency department visits, and in-patient admissions. The entry itself of these data could bring about discrepancies in the reporting. Due to the increasing diversity of populations included in studies, language or cultural barriers may exist which results in mismeasurement and possible exclusion of certain populations.

The methods used to collect race and ethnicity data vary across studies and health care settings, ranging from self-reporting surveys to administrative records. Different data collection methods may yield varying results, leading to inconsistencies and challenges in comparing findings across studies or populations. Details on race and ethnicity may be missing or incomplete due to factors such as nonresponse, refusal to disclose, or administrative errors. Missing data can introduce bias into analyses and limit the generalizability of research findings, particularly if certain racial or ethnic groups are disproportionately affected.

Existing classification systems may not adequately capture the diversity and fluidity of racial and ethnic identities, leading to oversimplification or misclassification of individuals. For example, administrative assumptions based on last names and appearances can lead to inaccurate data entries and fear of discrimination or repercussions may lead individuals to withhold or misrepresent their race or ethnicity, particularly in contexts where racial or ethnic disparities are prevalent. Additionally, individuals of multiracial backgrounds may face challenges in selecting a single racial or ethnic category, misrepresenting their accurate identity. It is crucial to recognize that individuals may choose to not disclose their race or ethnicity for various reasons. This complexity underscores the need for more inclusive and flexible data collection methods that allow for a more accurate representation of the diverse population.

For all clinical research involving human subjects, the National Institutes of Health (NIH) Policy and Guidelines on The Inclusion of Women and Minorities as Subjects in Clinical Research states “inclusion of the results of sex/gender, race/ethnicity and relevant subpopulations analyses is strongly encouraged in all publication submissions. If these analyses reveal no differences, a brief statement to that effect, indicating the groups and/or subgroups analyzed, will suffice.” Federal reporting is regulated by the Office of Management and Budget Directive No. 15: Race and Ethnic Standards for Federal Statistics and Administrative Reporting, which establishes standard classifications for the recording, collection, and presentation of race and ethnicity data. It emphasizes that these classifications are not scientific or anthropological but aim to provide compatible, non-duplicated data for federal agencies. The directive defines basic racial and ethnic categories, recommends a variety of data collection classifications for flexibility, outlines minimum acceptable categories for combined formats, and specifies presentation guidelines for race/ethnic data. Finally, it prohibits the use of the term “nonwhite” and provides options for presenting race/ethnic data in certain situations.

Noncompliance with NIH and ICMJE guidelines regarding the reporting of race and ethnicity in biomedical research not only compromises the validity and reliability of research findings but also perpetuates health inequities and undermines the ethical principles of scientific inquiry. Inaccurate or incomplete reporting of race and ethnicity data can impede efforts to develop targeted public health interventions and policies aimed at addressing health disparities and improving population health outcomes. It is essential for researchers, journal editors, and funding agencies to prioritize adherence to these guidelines to ensure the equitable provision of healthcare and the advancement of scientific knowledge.

CORRELATION OF RACE AND ETHNICITY WITH SURGICAL UTILIZATION AND HEALTH OUTCOMES

The correlation between race and socioeconomic status significantly influences access to healthcare and education,
affecting disease incidence and outcomes. Racial disparities in postoperative outcomes persist despite advances in healthcare, particularly affecting Black patients who often experience higher rates of morbidity and mortality compared with their White counterparts. Multiple studies in cardiothoracic surgery have similarly found disparities in both surgical utilization and postoperative outcomes linked to race and ethnicity. Minority racial and ethnic groups have less access to cardiothoracic surgeons despite having a higher burden of cardiovascular disease and higher rates of morbidity and mortality with interventions. For example, recent studies show aortic valve replacement rates within 6 months of aortic stenosis admission are lower for Black, Hispanic, and Asian people compared with their White counterparts, with 94.3% of the population being White patients compared with 3.6% Black, 1% Hispanic, 0.3% North American Native, and 0.7% Asian.

Other recent landmark trials in the field lack diversity in their clinical trial enrollment, such as the Cancer and Leukemia Group B (CALGB)/Alliance 140503 trial for perioperative mortality and morbidity after lobar versus sublobar resection for early-stage lung cancer, in which 90% of the study population were White patients, 6.5% were Black or African American, 0.9% were Asian, and 0.1% were American Indian/Alaska Native. When comparing these numbers to disease incidence from the Surveillance, Epidemiology, and End Results database from 2007 to 2018, Black men consistently had higher incidence of regional non–small cell lung cancer compared with other racial groups, with non–small cell lung cancer incidence among Black men being 33% higher than that of White men in 2018. In addition, disparities continue to exist in lung cancer screening, diagnosis, treatment, and outcomes among Hispanic and Black patients compared with non-Hispanic White populations.

Although these studies have brought existing disparities to light, many others do not include these demographics. Meaningful interventions to address disparities in cardiovascular surgical care require a nuanced understanding of the unique needs and challenges faced by all populations. This raises the question of whether the lack of data on disparities should influence a surgeon’s ability to cite the risks and benefits of an operation or intervention for patients when the large national databases upon which studies are based on may not be inclusive of all populations. By increasing diversity in clinical trial recruitment, the findings will be more generalizable, promoting equitable cancer care for all patients. Investing in research to enhance our understanding of existing disparities is essential for developing targeted interventions that effectively address the specific needs of disadvantaged racial and ethnic groups. In studies limited in access to demographic data, the authors should consider listing the fact in the manuscript limitations and consider how to address such challenges for future investigations.

INCREASED REPRESENTATION IN CLINICAL TRIALS: CALL TO ACTION AND FUTURE STEPS

While recognizing the complexities and sensitivities surrounding race and ethnicity, it is essential to leverage related insights to address health disparities effectively. Initiatives to increase accrual of minorities into clinical trials should be prioritized by researchers, as well as funding agencies and journal editors who are involved in the publication process. A systematic review of cancer clinical trials found enrollment rates for Black and Hispanic patients was disproportionately low, <6% for both despite representing 15% and 13% of the cancer population, respectively. Of the 8 randomized trials highlighted in the American Association for Thoracic Surgery 2023 Expert Consensus Document: Staging and Multidisciplinary Management of Patients With Early-Stage Non–small Cell Lung Cancer, 6 reported the race of their participants, 2 reported ethnicity, and 3 performed subgroup analyses based on race and ethnicity.

Interventions, such as, patient navigation systems, patient education campaigns, and outreach initiatives, should be utilized and further explored to increase uptake of minority patients into clinical trials (Table 1). Other factors have caused low participation of Black Americans in cancer clinical trials, such as mistrust of the medical system from previous violations by research studies, lack of diversity within the health care team, and lack of incentives for participation in the study. Solutions should be geared toward the well-established issues that permeate within communities of underrepresented patient populations.

Embracing diversity and inclusivity in research endeavors, coupled with genetic analyses, can pave the way for more equitable health care solutions and improved health outcomes for all individuals. Possible solutions could be to include more stringent regulations. For instance, noncompliance with NIH guidelines on the inclusion of racial and ethnic data in funded research may influence future funding opportunities. Journals could partake in adhering to ICMJE guidelines by asking for revisions for manuscripts that do not provide clear and transparent reporting of race and ethnicity data. In addition, clinical trials should be made more accessible to patients from low-resource areas to accurately represent the general population.

The accurate and comprehensive reporting of race and ethnicity in human subject studies is essential for advancing our understanding of health disparities and developing targeted interventions to address them. This is true for cardiothoracic surgery as much as any other medical realm. The
inclusion of patients’ ethnic or racial information is imperative for discerning and addressing disparities in disease prevalence, severity, and treatment responses. By adhering to established guidelines and adopting standardized approaches, cardiothoracic surgical researchers can ensure that our studies effectively capture the diverse demographic characteristics of our study populations. This practice will facilitate more robust analysis and ultimately contribute to improved health outcomes for all individuals with cardiothoracic surgical diseases, irrespective of their racial or ethnic backgrounds.

DECLARATION OF GENERATIVE AI AND AI-ASSISTED TECHNOLOGIES IN THE WRITING PROCESS

During the preparation of this work the author(s) used ChatGPT (Open AI) to proofread text. After using this tool/service, the author(s) reviewed/edited the content as needed and take(s) full responsibility for the content of the publication.

Conflict of Interest Statement

The authors presented no conflicts of interest.

The Journal policy requires editors and reviewers to disclose conflicts of interest and to decline handing or reviewing manuscripts for which they may have a conflict of interest. The editors and reviewers of this article have no conflicts of interest.

References


TABLE 1. Recommendations for readers, researchers, and journal editors to promote inclusivity and representation in cardiothoracic surgery research

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<th>Recommendations for readers</th>
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<th>Recommendations for journals and editors</th>
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<tr>
<td>❖ Critically assess studies that omit race and ethnicity data and consider potential biases</td>
<td>❖ Clearly justify any omission of race and ethnicity data</td>
<td>❖ Require authors to explain omissions of race and ethnicity data</td>
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<td>❖ Evaluate the validity of data collection methods</td>
<td>❖ Use classification systems that best represent the study’s cohort</td>
<td>❖ Enforce adherence to established guidelines</td>
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<tr>
<td>❖ Be cognizant of and support research that follows established guidelines for reporting race and ethnicity</td>
<td>❖ Develop inclusive and flexible data collection methods</td>
<td>❖ Require clear and detailed reporting of demographic data</td>
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<td>❖ Advocate for and seek out research that includes diverse populations to ensure generalizability</td>
<td>❖ Address language and cultural barriers in data collection</td>
<td>❖ Promote best practices for accurate and complete data reporting</td>
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<td>❖ Recognize the importance of addressing healthcare disparities in research</td>
<td>❖ Increase minority participation through navigation systems, education campaigns, and outreach initiatives</td>
<td>❖ Review submissions for compliance with reporting standards</td>
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<td>❖ Support efforts aimed at reducing disparities</td>
<td>❖ Adhere to National Institutes of Health and International Committee of Medical Journal Editors guidelines when possible</td>
<td>❖ Prioritize publishing studies with diverse participant populations</td>
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<td>❖ Highlight and promote research addressing healthcare disparities</td>
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**Key Words:** race, ethnicity, health disparities, socioeconomic status, clinical trials