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Article abstract

This Perspective sheds light on the major barriers behind Asian American invisibility in bioethics, such as the inconsistencies in defining a coherent identity in North American society, the systemic mechanisms of invisibility from history to healthcare based on immigration status, and scarcity of bioethics literature about their perspectives. The consequences of Asian American invisibility in bioethics and healthcare practises are also discussed, including a reflection of the interconnected mechanisms between academic bioethical theory and healthcare practises that perpetuate Asian American invisibility. Finally, recommendations are provided to begin a critical reflection of bioethical theory with Asian Americans in mind. This serves as the stepping-stone for future discussions on Asian American bioethics, to highlight a missing perspective in North American race-based activism regarding the equity, diversity, and inclusion of an underrepresented demographic.

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TÉMOIGNAGE / PERSPECTIVE

The Invisibility of the Asian American Identity in North **American Bioethics**

Katherine Huerne^a

Résumé

Cette perspective met en lumière les principaux obstacles à l'invisibilité des Américains d'origine asiatique dans le domaine de la bioéthique, tels que les incohérences dans la définition d'une identité cohérente dans la société nord-américaine, les mécanismes systémiques d'invisibilité de l'histoire aux soins de santé sur la base du statut d'immigrant, et la rareté de la about their perspectives. The consequences of Asian American littérature bioéthique sur leurs perspectives. Les conséquences de l'invisibilité des Américains d'origine asiatique dans les pratiques de bioéthique et de soins de santé sont également discutées, y compris une réflexion sur les mécanismes interconnectés entre la théorie bioéthique académique et les pratiques de soins de santé qui perpétuent l'invisibilité des Américains d'origine asiatique. Enfin, des recommandations sont formulées pour entamer une réflexion critique sur la théorie bioéthique en tenant compte des Américains d'origine asiatique. Il sert de tremplin pour les discussions futures sur la bioéthique des Américains d'origine asiatique, afin de mettre en lumière une perspective manquante dans l'activisme racial nordaméricain concernant l'équité, la diversité et l'inclusion d'un groupe démographique sous-représenté.

Abstract

This Perspective sheds light on the major barriers behind Asian American invisibility in bioethics, such as the inconsistencies in defining a coherent identity in North American society, the systemic mechanisms of invisibility from history to healthcare based on immigration status, and scarcity of bioethics literature invisibility in bioethics and healthcare practises are also discussed, including a reflection of the interconnected mechanisms between academic bioethical theory and healthcare practises that perpetuate Asian American invisibility. Finally, recommendations are provided to begin a critical reflection of bioethical theory with Asian Americans in mind. This serves as the stepping-stone for future discussions on Asian American bioethics, to highlight a missing perspective in North American race-based activism regarding the equity, diversity, and inclusion of an underrepresented demographic.

Mots-clés

asiatique, américain, bioéthique, invisibilité, inclusion, activisme Asian, American, bioethics, invisibility, inclusion, activisme

Kevwords

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INTRODUCTION

Until recently, bioethics did not prioritize discussions of structural racism and the effects of racial biases on social determinants of health (1). The aftermath of the COVID-19 pandemic brought race-based reflections to the forefront of bioethical theory, particularly for Black, Indigenous, and Latinx communities who fought for visibility against the perceivably White-majority body that dictates policy and approach in Western bioethics (1-4). In the wake of increasing anti-Asian hate crimes (5), it is critical to reflect on a similar issue, namely, the invisibility of the Asian American perspective in the bioethics community. Although Asians Americans are undoubtedly designated a racial minority, their voices are often underrepresented in activist movements of racial justice and inclusion. To reconcile this, I first provide evidence on the systemic barriers surrounding their invisibility in bioethics and medicine, with a discussion on the moral consequences of this invisibility. I then explore how the resulting invisibility leads to a practical knowledge gap for clinical healthcare practitioners about the Asian American demographic. Note that the term "Asian American" is used for conciseness to refer to anyone of Asian ancestry living in North America (i.e., Asian Canadians, Asian Mexicans, Asian Americans in the United States), with an awareness that although they have different histories of immigration and culture, they share similar structures of invisibility within bioethics representation regardless of the exact country of residence.

BARRIERS BEHIND THE INVISIBILITY OF THE ASIAN AMERICAN IDENTITY

Asian Americans – that is, individuals with Asian ancestry living in the American continent – represent a significant proportion of the North American population. In the US, they comprise about one quarter of immigrants who arrived since 1965 (6). Yet, a proportional emphasis of their perspectives has not been reflected in North American healthcare, leading to knowledge gaps and potential biases in practise between healthcare providers and patients. When mentioned, there is often conflation or

¹ The 2016 US census estimated about 21 million people (5.6%) to be Asian Americans, with the largest ethnic groups being Chinese, Filipino, and Indian (6). The 2016 Canadian census revealed there are roughly 6 million Asian Canadians (17.7% of the population), with four million (66%) originating from three countries: China, India, and the Philippines (7).



comparison between an "Asian" versus "Asian American" perspective. Therefore, it is important to explore key factors that contribute to the invisibility or conflation of these identities in bioethics.

Inconsistencies in defining a coherent identity for Asian Americans in North American society

Effective mobilization of race-based activism often starts with a clear and unified demographic, working towards a singular cause of advocacy (8,9). Unlike other racial minorities, however, the first barrier to Asian American invisibility is establishing a coherent identity to build solidarity from. Asian Americans are often asked, by outsiders and Asian Americans themselves, who belongs to the "Asian American" demographic? Does it also include those of South Asian descent who look visibly different from East-Asians? How many years must someone reside in North America to be considered "American"? Are they still considered "Asian American" if they immigrated to another North American country or practised a culture that is different than US American culture?

The existing legal definitions of this demographic seem insufficient at capturing Asian Americans as a unified racial or ethnic group. The US Centers for Disease Control and Prevention (CDC) defines "Asian Americans" to be people having origins from any country of the Far East, Southeast Asia, or the Indian subcontinent (10). However, census data only tracks race demography, which is not an analogous metric to view Asian Americans as a cultural identity. In other words, these statistics make no distinction between those who are of the "Asian" race, and those who adopt the "Asian American" ethnicity. The reality is that Asian Americans are both racially and ethnically heterogeneous, as they differ in appearance, genetics, or class, and can embody a spectrum of cultural values between "Asian" and "American". Although the identity is diverse, a working conception can focus instead on attributes that all Asian Americans possess, such as their perpetual treatment as being immigrants, to demarcate shared experiences within the Asian American community. This is why acknowledging cultural differences between Asians in the US or Canada, for example, should not illegitimatize the shared experiences of alienation they face in any North American country. Instead, a unified identity can be built from shared experiences of discrimination based on their visible appearance or residency status, akin to how solidarity movements begin for other racial minorities.

Systemic mechanisms of Asian American invisibility from history to healthcare

Establishing a unified Asian American identity does not forego their invisibility, which primarily concerns the attention that is given to Asian American perspectives and issues. At the core, it originates from the political treatment of Asian Americans, based on their immigration history, where it translates to racial prejudice at the social and practical level. The history of Asian immigration to North America is unique for each country, yet there are shared origins of Asian American invisibility through systemic exclusion as citizens of the country. In the US, Asian immigrants who arrived since the late 19th century were barred from legally obtaining citizenship until 1952 (12). The US Chinese Exclusion Act of 1882 led to 60,000 Chinese immigrants moving to Mexico, where they became Mexico's second-largest foreign ethnic demographic at the time. However, growing anti-Chinese movements led to the Torreón massacre and deportation of over 70% of Asians in Mexico (13). In Canada, Asians have immigrated since the late 18th century, but notably, the culmination of anti-Asian sentiment led to the Chinese Immigration Act of 1885, a \$50-500 head tax on Chinese immigrants who were barred from voting or returning to their country until 1947 (5).

As is the case for other racial minorities, the exclusion of Asian Americans translates to a pattern of underrepresentation in North American healthcare. How can their concerns and perspectives be recognized if their physical bodies are not formally recognized? The 2009 US Department of Health and Human Services report summarized the issues that Asian Americans face in healthcare: throughout US history, there had been scarce or sporadic funding of healthcare centred on Asian Americans as an explicit demographic of concern (14). Clinical data on a diversity of Asian subgroups were often conflated into one category of analysis (14). As a result, public health guidelines and practitioners often referred to general guidelines in the healthcare of Asian Americans, when in reality, the subgroups of Asian Americans differ biologically, socially, and psychologically (14). The scarcity of general baseline data on a diversity of Asian American subgroups further contributed to the knowledge gaps on healthcare issues specific to Asian Americans, such as mental health or diabetes (14). For example, Canada notably lacks an equivalent public health report of invisibility issues, despite recent studies reporting an increase in anti-Asian microaggressions and hate crimes in Canada since the beginning of the COVID-19 pandemic (15). Moreover, several special issues have emerged in the past few years highlighting race-based disparities in bioethics and healthcare, but Asian American advocacy consistently appear underrepresented or underdiscussed in these contexts beyond their inclusion as a "person of colour" (16-19). Thus, it is important to recognize that the priorities of North American bioethics are largely shaped by the activities of the dominant community. In the case of Asian Americans, the invisibility is shaped by the inattention given to them.

Scarcity of bioethics literature about Asian American perspectives

The final clue to the invisibility of Asian Americans is evident in what exactly is being said about this demographic within academic bioethics discourse. A cursory search of "Asian American bioethics" on PubMed, Scopus, and Google Scholar

² For example, the "Asian" race is defined according to US census categories as self-identified countries of origin from South Asian origins, East Asian, and Southeast Asian, and Oceania origins. This contrasts with the ethnic designation "Asian American" which represents any individual living in the continent of North America with racial ancestry from Asia.

³ "Race" is defined as the categorization of humans based on sociological, biological, or genetic similarities, while "ethnicity" is a categorization based on cultural,

³ "Race" is defined as the categorization of humans based on sociological, biological, or genetic similarities, while "ethnicity" is a categorization based on cultural religious, or linguistic similarities (11).

revealed relatively little literature demarcating a unified thought, or significant activism on this topic (see appendix for findings). The top hit, "Is there an Asian Bioethics?" is a short essay by Leonardo D. De Castro published in 1999, which argues against a single Asian standard of moral evaluation but does not speak to the diversity of Asian Americans within a Western-centric bioethics context (20). More recent results focus predominantly on comparing Asians to American culture, with the main theme of developing an "Asian Bioethics" (20) by comparing differences between "Asian cultural values" versus "White American cultural values" (21-23). Asian values are generalized by moral codes of discipline, hard work, frugality, educational achievement, balancing individual versus societal needs, and deference to authority – values that are shared across many Asian countries with Confucian influence (24). Discussions of Asian values are always portrayed in competition to Western political ideologies of individuality, democracy, and capitalism, where both sets of ideologies cannot peacefully exist. However, very few texts explicitly mentioned the possibility that Asian Americans could be ethnically or morally distinct from East Asian frameworks, indicating an implied conflation of East Asian and Asian American values. This is in addition to the scarcity of the total number of publications which centred Asian American perspectives at the forefront of discussion in peer-reviewed, academic databases within the biomedical and social sciences (25-27).

Within medical texts about Asian Americans, the discourse was mostly about diseases that referred to "Asians" as a monolithic race, as a form of racial profiling when making generalized statements, without consideration of differences within Asian subgroups. For example, Asians are known to suffer higher rates of liver and stomach cancer, tuberculosis, diabetes, hepatitis B, osteoporosis, lactose intolerance and nasopharyngeal carcinoma in comparison to White demographics (10). Many Asians also have reduced abilities to metabolize common Western pharmacological agents like proton pump inhibitors, nicotine, diazepam, and tricyclic antidepressants (10). However, if topics about Asian American perspectives are only limited to medical differences of diseases that affect the Asian race, then other aspects of Asian American wellbeing, such cultural attitudes affecting social determinants of health, become ignored. This hints at the real issue behind Asian American invisibility: in lieu of all the race-based Asian medical research, the Asian American identity is assumed to be monolithic and all-encompassed by biological racial differences. Asian Americans are thus conflated to either the "Asian" demographic (due to their physical or biological nature) or the "American" demographic (due to their assumed assimilation into Anglo-Saxon Protestant culture). While the published works are important, the current discourses reinforce invisibility through a misdirection of what Asian American perspectives should be about. What is published determines the core perspectives of Asian American bioethics, which in turn promotes the same narrative as authors build upon this foundation, unless a change in perspective is made. In essence, the mechanism behind their invisibility derives from systemic reinforcement of the same assumptions of Asian American bioethics through the structures of academic discourse.

THE CONSEQUENCES OF ASIAN AMERICAN INVISIBILITY

As gaps in theory translate to cognitive biases in practise, it is critical to understand how Asian American invisibility manifests at a practical level. A major consequence of this invisibility is that Asian American cultural differences often become generalized in everyday healthcare matters. Healthcare practitioners may be taught to interact with Asian Americans in ways that perpetuate ignorance of cultural differences, without realizing it. As we've seen, bioethicists often speak about Asian (or Asian American) moral values by aligning them to Eastern moral theories like Confucianism, collectivism, and community-based theories. For example, existing bioethics literature is replete with the narrative that Asian Americans prefer to act according to Confucian or Eastern-based concepts of collective autonomy than the Western-based concepts of individual autonomy (20). However, it is important to remember that Confucianist values only represent a sub-group of East Asians and do not encompass the diversity of South Asian and Southeast Asian-based moral frameworks, for example.

In reality, a significant population of Asian Americans do not wish to be treated solely based on an assumption of East Asian values. For example, many first and second-generation Asian Americans report a cultural and communication disparity between their Asian ancestors on topics such as mental health, disease treatment, and palliative care (28). In the "What You Don't Know - This American Life" podcast, US Asian American Lulu Wang speaks about the discomfort, confusion, and isolation she felt when her family refused to disclose a medical diagnosis to her Asian grandmother who had stage 4 lung cancer (29). Lulu mentioned the cultural disconnect in dealing with illness and death between the Asian values upheld by her family and her own Asian American values. This perspective was evidently shaped by the culture and environment of her life in the US; however, this discrepancy may not be emphasized explicitly in culturally sensitive care.

On the other hand, another form of generalizing Asian American perspectives can also occur when they are wholly equated to White (e.g., Anglo-Saxon) cultural values – because of their presumed status as a "model minority" and proximity to White privilege. In reality, Asian American cultural differences can conflict with Western healthcare practises, which leads to their healthcare issues being overlooked entirely. Existing bioethics literature revealed that on a practical level, language barriers prevent Asian Americans from seeking care within Western hospitals (10,30); or that generationally imbued shameful attitudes about mental illness prevent them from seeking professional care (21-23). While these experiences have been well documented, current pedagogies for providing culturally sensitive care may not be sensitive to this nuance and instead equate Asian Americans with Asian or East Asian values of Confucianism, Buddhism, or Hinduism (31). Thus, at the practical level, we can see that more work is needed to explicitly identify and address the challenges that Asian Americans may face in a Western-oriented healthcare system. Without doing so, it adds to another layer of their silencing, which may then exacerbate healthcare access and health disparities.

TOWARDS AN ASIAN AMERICAN BIOETHICS

This review does not seek to prescribe what should be included in an Asian American bioethics, but rather sheds light on the systemic barriers behind beginning a true and representative discourse on this project. A starting point is to adopt a nuanced understanding of Asian Americans as a distinct group with diverse perspectives but bound within race-based political systems of power and oppression (32). For bioethicists and healthcare practitioners, it means recognizing cultural differences apart from "White" or "Asian" bioethics. As Nicole Overstreet states on the engagement of bioethics with Black activism, "the field of bioethics will have to contend with its conspiratorial role in sustaining harm and violence toward oppressed groups in law, science, and medicine if it refuses to interrogate or theorize how social, political, and economic factors shape our understanding and practice of ethics" (33). The same interrogation must apply to the invisibility of Asian Americans.

Some practical recommendations can be made to those in the bioethics and medical community. Healthcare practitioners and those who work with Asian Americans should not assume racial or ethnic homogeneity of cultural values when engaging with healthcare behaviours and health disparities. A critical application of feminist intersectionality theory⁴ can help stakeholders understand the unique situations of Asian Americans as they differ from one another on other social fronts such as immigration status, wealth, education, family composition, sex, and gender. Finally, academic journals can empower Asian American perspectives by including their voices at an equal proportion to other racial demographics in broader conversations of social activism. Only through collective action and a unified goal to empower silenced voices, can the first steps be taken towards delineating a true and nuanced approach to Asian American bioethics.

CONCLUSION

This Perspective has highlighted some systemic barriers contributing to the Asian American invisibility in bioethics, and how this also permeates existing healthcare practises. It is important to examine the link between bioethics and healthcare practise as empirical evidence from healthcare research is used to inform bioethical theory, and vice versa. At the core, there is a conceptual misalignment or misunderstanding of Asian Americans as a distinct yet heterogenous body, whether by interacting with them in healthcare practices, or drawing race/ethnicity conclusions in data analysis. Not surprisingly, this leads to a practical knowledge gap about the Asian American demographic and their perspectives in bioethics. More attention is needed to amplify the unique perspectives of Asian Americans and their healthcare concerns within a Western-centric bioethics community.

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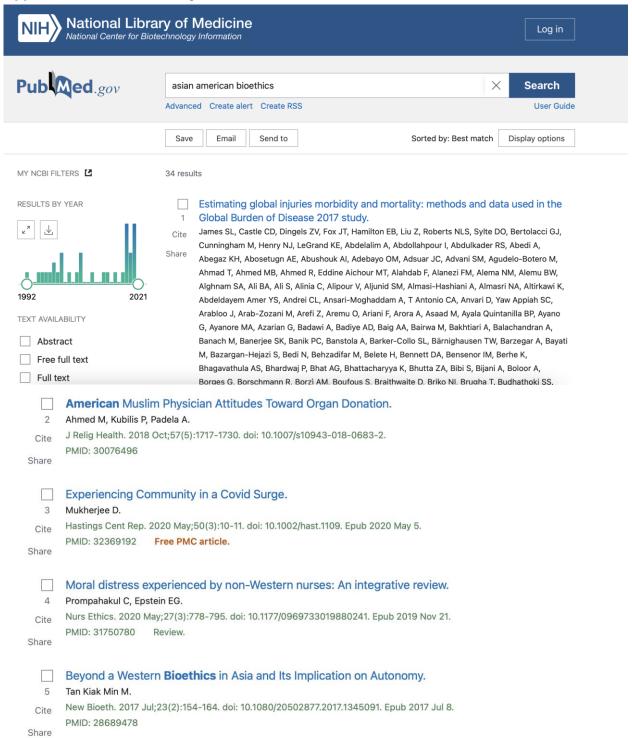
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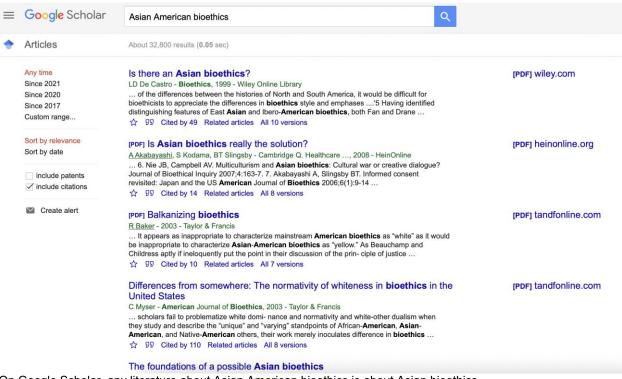
APPENDIX

Appendix A: PubMed Query Search for 'Asian American bioethics'



On PubMed, notice a lack of specifically addressing Asian American bioethics or Asian American health disparities in the context of Asian Americans. If Asian Americans are included as a demographic, they are one of many examples for another issue.

Appendix B: Google Scholar Query Search for 'Asian American bioethics'



On Google Scholar, any literature about Asian American bioethics is about Asian bioethics.

Appendix C: Google Scholar Query Search for 'Asian American bioethics'

Differences from somewhere: The normativity of whiteness in bioethics in the [PDF] tandfonline.com **United States** C Myser - American Journal of Bioethics, 2003 - Taylor & Francis ... Thus, as in the remarkably intransigent and structurally enduring colonial relations Said has revealed to exist between the non-European/ the Orient and the European/the West-underlying "Orientalism"—the very "Western" (and white) bioethics theory Carrese and Rhodes ... ☆ 💯 Cited by 110 Related articles All 8 versions [PDF] Balkanizing bioethics [PDF] tandfonline.com R Baker - 2003 - Taylor & Francis ... Finally, even if one could justify using the expression "white bioethics," its use is likely to undercut the aim of encouraging collaboration between "white" and "nonwhite" bioethicists, since the expression defines as "other," and thus alienates, the parties to the proposed col ... ☆ 55 Cited by 10 Related articles All 7 versions [PDF] White normativity and subsequent critical race deconstruction of bioethics [PDF] tandfonline.com KL Karsiens, JAM Johnson - 2003 - Taylor & Francis The discussion of white normativity, encompassing both white dominance and privilege in the field of bioethics requires a critical analysis of the inextricable relationship between the sociological construction of race, the role of cultural capital, and the development and ... ☆ 55 Cited by 12 Related articles All 7 versions [PDF] The unbearable whiteness of the mainstream: should we eliminate, or [PDF] tandfonline.com celebrate, bias in bioethics? S Arekapudi, MK Wynia - 2003 - Taylor & Francis ... This false bioethics hierarchy leads to the notion that "white bioethics" is the de facto "normal," and therefore a model that can be (and is being) applied across all cultures—both national and international. All of this, according to Myser, is a problem ...

Compare this (lack of) specificity to the prominent specificity in results about "white bioethics". Search Date: March 17, 2021

☆ 99 Cited by 14 Related articles All 7 versions