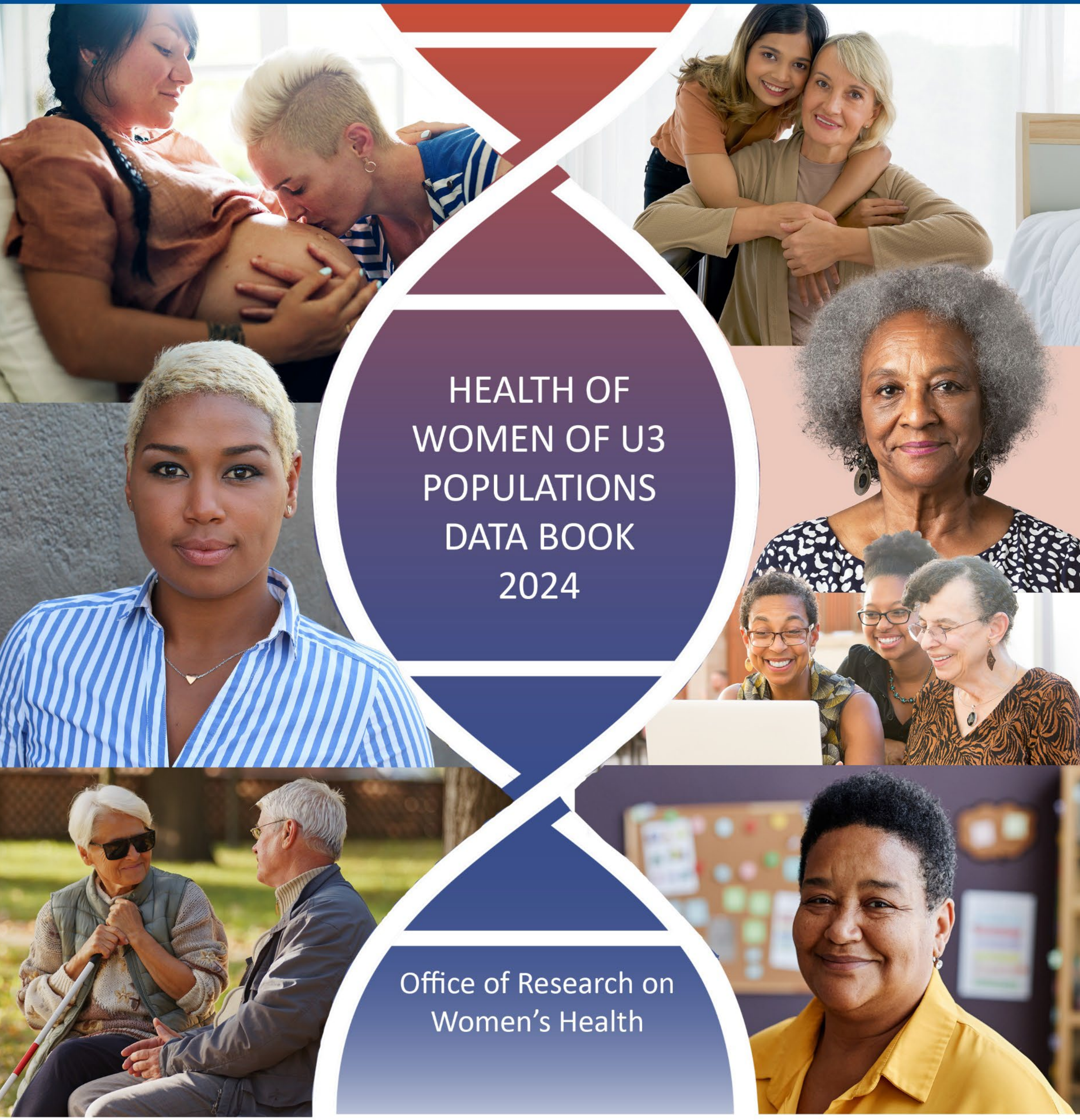
NATIONAL INSTITUTES OF HEALTH



HEALTH OF WOMEN OF U3 POPULATIONS DATA BOOK 2024

Office of Research on Women's Health

National Institutes of Health
Office of Research on Women's Health

Women of Understudied, Underrepresented, and Underreported Populations

Fifth Edition

Office of Research on Women's Health
Office of the Director
National Institutes of Health

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From the Director of the NIH Office of Research on Women's Health

In the ten years since the previous edition of the *Women of Color Health Data Book* was published, we have learned considerably more about the health of girls and women across the lifespan, defined as consideration of the female reproductive system, conditions and diseases that affect women disproportionately, and disorders that present differently in women. This fifth edition of the Health Data Book focuses specifically on the health of women of understudied, underrepresented, and underreported populations (U3), with particular attention to the ways in which socially determined categories and environments, systems, and policies intersect, resulting in different outcomes for individuals and communities.

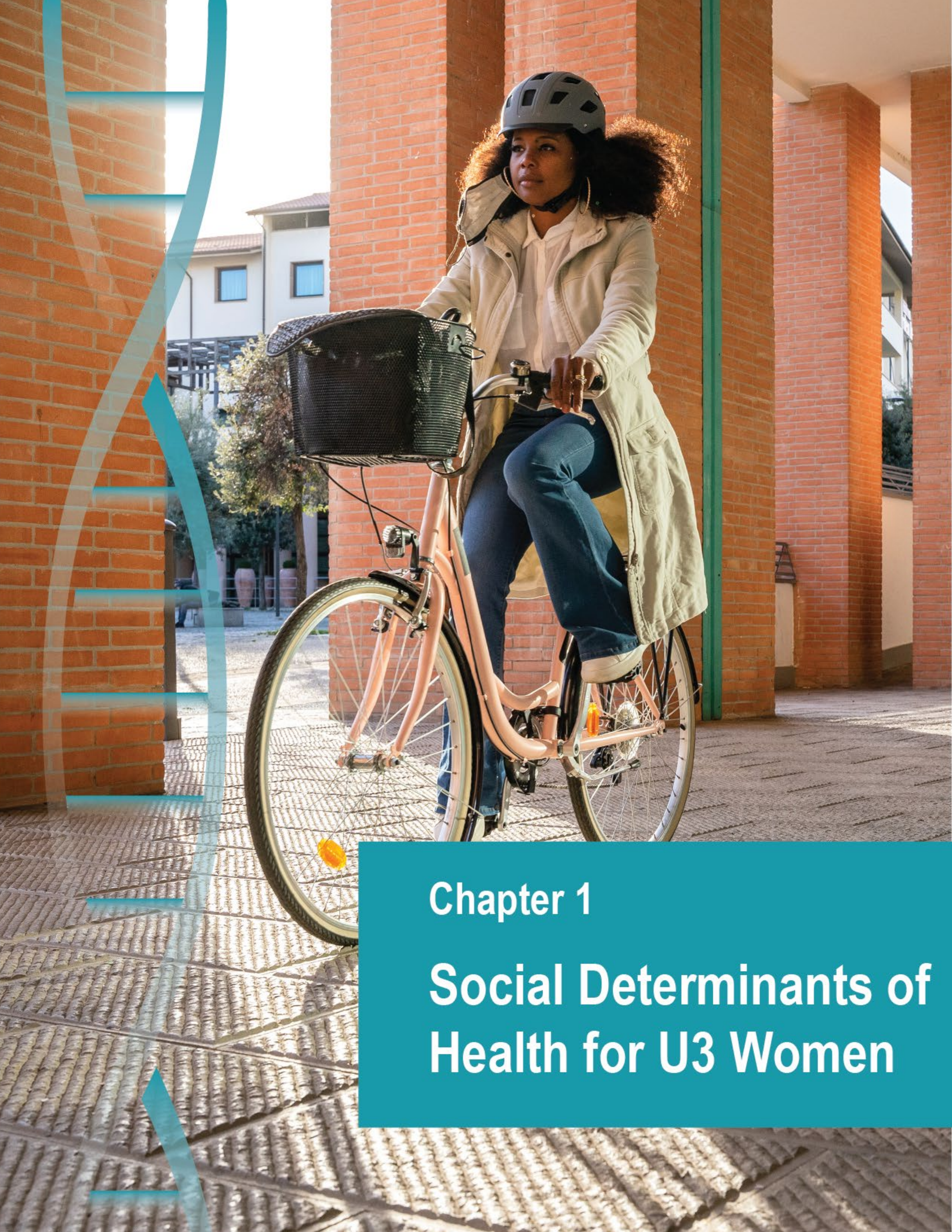
Despite the progress that has been made, many health disparities remain—specific populations of women in the U.S. continue to die during and after childbirth at rates much higher than those of our peer countries; women still die at greater rates than men with similar conditions (e.g., cardiovascular disease); and equitable high-quality care remains a critical issue for women. It is incumbent upon us to understand the full spectrum of determinants of health and illness, including sex, gender, and other social determinants of health, and to develop effective interventions to mitigate those differences. To that end, the ORWH works with the NIH Institutes Centers, and other Offices to strengthen NIH research on diseases, disorders, and conditions that affect women, advance efforts related to the consideration of sex as a biological variable across the research spectrum, and support the importance of taking a life course perspective.

In the past four decades, there has been a remarkable effort to document the complex and multifactorial construct known as health disparities and to describe the nuances of health inequities. In this edition, women's health outcomes are presented in detail by using data drawn from the most recent Census (2020). Recent research has confirmed that sex and/or gender differences exist at all scales of biology, from cellular to social. It has also become clear that extra-biological factors, such as environmental conditions, greatly affect women's health. Indeed, inattention to the importance of the social determinants of health hinders our ability to care for all women in ways most appropriate to their needs. Hence, we begin this new edition by framing the content of the subsequent chapters that focus on a specific category of disease in terms of the social determinants of health. By including relevant discussions of historical, cultural, and socio-geo-demographic factors that play a role in the health status of women, the information provided in the Health Data Book widens our knowledge base on how intersecting social identities, such as class, race, age, and gender converge to influence treatment outcomes and trajectories in U3 populations of women.

Through this and many other efforts, the Office of Research on Women's Health aims to be part of bold next steps to address inequities, provide culturally responsive, evidence-based care that is equitably applied, and thereby advance the health of all women.

Sincerely,

Janine Austin Clayton, M.D., FARVO
NIH Associate Director for Research on Women's Health
Director, NIH Office of Research on Women's Health



Chapter 1

Social Determinants of Health for U3 Women

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Social Determinants of Health for U3 Women

1.1 Introduction

In 2020, there were nearly 72 million women of underrepresented racial and ethnic communities in the U.S. This reflects a marked increase since the estimate of 56 million in the 2010 Decennial Census. Women of underrepresented racial and ethnic communities continue to experience a disproportionate burden of disease and adverse outcomes across a wide range of health conditions, from violence, autoimmune diseases, and mental illness to maternal morbidity and mortality and cancer.[1–6] The same is true for women in economically disadvantaged groups, women who live in underserved rural populations, and women of sexual and gender minority (SGM) groups.[7–11] While the disparities in their health are well documented, women of these populations remain largely understudied, underrepresented, and underreported (U3) in biomedical research.[11] The COVID-19 pandemic amplified health disparities for U3 women, who experienced higher case rates, severity, and mortality from COVID (see **Chapter 4**).[12] The pandemic created a mental health crisis fueled by the strain of lockdowns, loneliness, and social distancing measures, which caused undue burden for U3 women.[13–15] This disproportionate impact on U3 women reflects social and structural differences including employment as front-line workers, caregiving responsibilities, structural racism, residential segregation, public transportation needs, and preexisting medical conditions.[16–18] Such systemic disadvantages and structural inequities in the U.S. have long perpetuated a cycle of oppression for underrepresented communities, as various forms of discrimination intersect, exacerbating and impacting the health of U3 women.[19]

The primary purpose of *The Health of Women of U3 Populations Data Book* (hereafter the Data Book) is to highlight the current state of knowledge on the health of U3 women, including the ways that social and structural drivers perpetuate health disparities. It is the fifth in a series that includes the *Women of Color Health Data Book* published by the National Institutes of Health (NIH) Office of Research on Women's Health (ORWH) in 2014.[20] This Data Book expands upon the fourth edition by using an intersectional lens to explore data from national surveys and vital statistics on priority health issues with respect to race and ethnicity as well as rurality, economic status, sexual orientation, and gender identity. It also offers an opportunity for scientists interested in health equity research to consider some of the limitations and opportunities available in national-level data to reflect on the health status of women from a multidimensional and gendered perspective. Researchers can use this book to inform their ongoing studies or to offer insights for the development of new strategic research. This Data Book also underscores future directions for research and policy, illuminating the role that structural and societal factors have on health risks, and how strategic direction can enhance development and tailoring of equity-centered programs to promote health equity for U3 women.

The Data Book discusses priority health issues and their demonstrated impact on the quality of life and health outcomes of U3 women, including as major causes of death. While each priority health issue has a dedicated chapter, the discussion in this chapter about social determinants of health for U3 women creates a strong through-line illustrating the common root causes of observed disparities. The remaining chapters address the topics below:

- Chapter 2: Demographics
- Chapter 3: Data Methodology
- Chapter 4: Top 10 Causes of Death
- Chapter 5: Autoimmunity and Other Inflammatory Diseases
- Chapter 6: Cardiovascular Disease
- Chapter 7: Dementia
- Chapter 8: Female-Specific Cancers and Cancers that Disproportionately Affect Women
- Chapter 9: Human Immunodeficiency Virus (HIV)
- Chapter 10: Maternal Morbidity and Mortality
- Chapter 11: Menopause
- Chapter 12: Mental Health
- Chapter 13: Substance Use and Misuse
- Chapter 14: Violence Against Women and Trauma

1.2 U3 Women: An Intersectional Framework

ORWH developed the U3 framework to draw attention to the lack of research on persistent health and health care inequities among populations of U.S. women experiencing health disparities and to support research and evidence-based programs to address this gap with an intersectional, multidimensional and social determinants of health lens.[11] This framework also seeks to widen the knowledge base on how intersecting social identities such as class, race and ethnicity, gender identity, and sexual orientation, as well as historical, cultural, and geographic factors, converge to influence health status, disease, treatment, and health-related quality of life outcomes and trajectories in populations of women across the life course. As shown in **Figure 1-1**, the U3 framework recognizes the intersecting identities held by four diverse groups: 1) women of underrepresented racial and ethnic communities, 2) women in economically disadvantaged groups, 3) women who live in rural areas, and 4) women of SGM groups. In recognition of the full diversity of gender identity, ORWH uses the term “women” to “include all individuals who identify as women, including cisgender, transgender, and gender-diverse women.”[21]

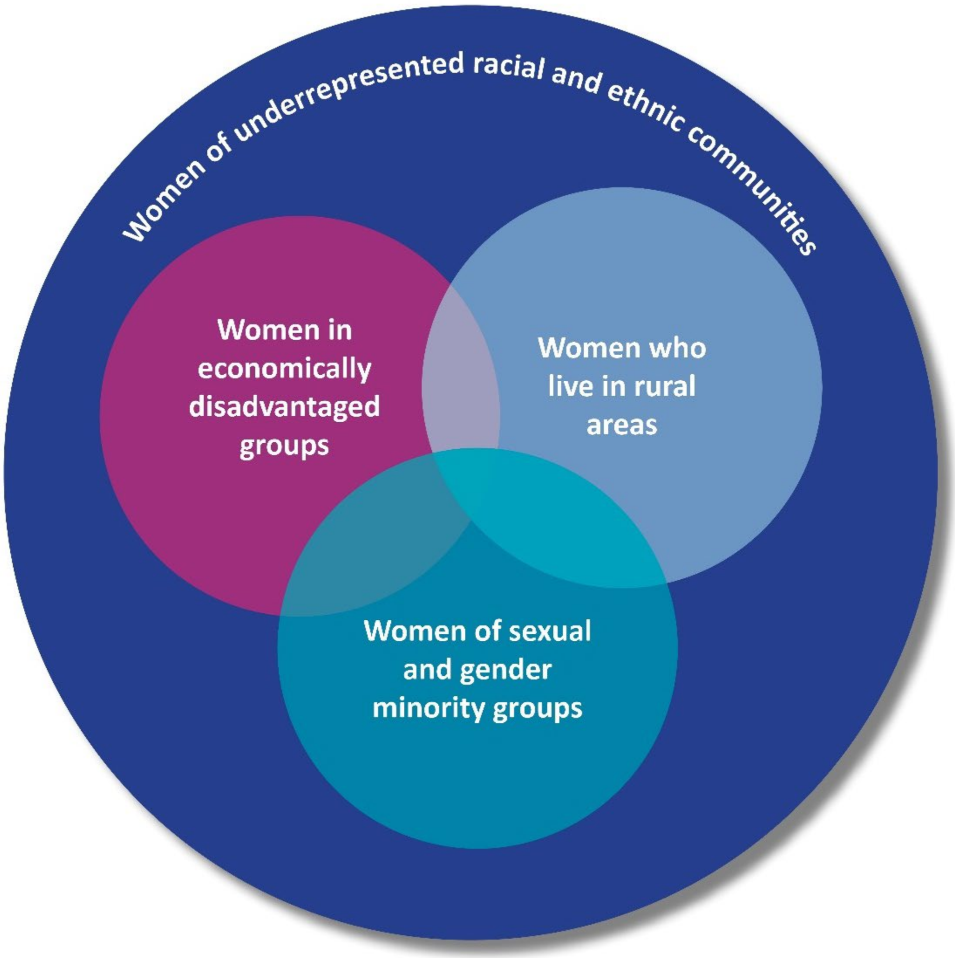

Figure 1-1: Inclusion criteria for underrepresented, understudied, and underreported (U3) women

When women hold multiple identities that are underrepresented, their disadvantage is compounded, leading to worse health outcomes.[4,22] Intersectionality considers how socially determined identity categories, such as race and gender, overlap and interact. As illustrated throughout this Data Book, multiple variables—including race and ethnicity, age, rurality, socioeconomic status (SES), and sexual orientation and gender identity—affect health and disease. These and other factors, such as educational attainment and disability status, can be taken into consideration in research design and analysis. For communities with underrepresented identities, bias in healthcare, stigma and discrimination, and social determinants of health create disparate health outcomes.[23] Coined by Kimberlé Crenshaw to understand the positionality of Black women in the U.S., the recognition of "intersectionality" has broadened the ability to investigate the complexities in human existence beyond dichotomous demographics.[24] Intersectionality enables an understanding of the synergistic and cumulative impact of occupying multiple identities, and how social, institutional, and organizational systems produce inequitable health outcomes. Using an intersectional lens allows for the conceptualization of composite personhood within a complex social environment.

While Crenshaw is credited with coining the term intersectionality in 1989, the concept of multiple mutually reinforcing systems of oppression was well articulated earlier by other U3 women, such as

Sojourner Truth in her 1851 speech "Ain't I a Woman?" and the Combahee River Collective, a Black lesbian feminist organization active in the 1970s.[25] Over the past 30 years, the concept of intersectionality has been taken up more broadly. For example, Lisa Bowleg explains the importance of intersectionality to public health as follows: "Intersectionality is a theoretical framework that posits that multiple social categories (e.g., race and ethnicity, gender, sexual orientation, SES) intersect at the micro level of individual experience to reflect multiple interlocking systems of privilege and oppression at the macro, social-structural level (e.g., racism, sexism, heterosexism)."[26]

More recently, scholars of intersectionality in health have underscored the imperative of looking beyond the health outcomes faced by populations of U3 women—important though this is—to focus on the root causes of the disparities themselves.[27,28] This shift will inform the development of equity-centered interventions that address root causes and work in ways that acknowledge the complex layering of social and structural barriers.[27,29]

1.3 Sex as a Biological Variable

Sex and gender are separate factors that influence health and often interact in many ways to influence each other.[30,31] It is important to differentiate between sex and gender in order to advance the science and the health of women. Precise use of language is important to enhance consideration of how biology and social drivers produce differences in disease, its progression, treatment, and overall health outcomes. As such, it is pivotal to the design and execution of research as well as the framing of this women's health Data Book. To begin the discussion, it is important to outline what distinguishes sex from gender. Sex is a biological concept that is based on physical characteristics (e.g., anatomy, genetics, physiology, and hormones), while gender refers to the multidimensional social and structural concept of social norms related to identity, expression, relationships, and power as they relate to perceived sex.[32,33] Definitions of gender change across time, cultures, and contexts.[32] Both sex as a biological variable and gender as a multidimensional social construct influence health outcomes.[34]

The historical exclusion of all women (including transgender and gender-diverse women) from biomedical research has limited the state of knowledge on how both sex and gender influence the ways that priority health conditions affect women and why they frequently affect women differently.[35] Historically, science and medicine have held an overreliance on male sex, including primary use of male mouse models by default.[36] Further, symptoms more commonly experienced by women, but different than those of men, are often referred to as "atypical."[37] The lack of inclusion has led to significant knowledge gaps regarding both diseases and conditions that disparately affect women and those that are female-specific, which limits the advancement of personalized medicine.[38,39] The result of male overrepresentation in science has limited women's health innovation, and contributed both to persistent inequities in healthcare, and to a lack of evidence-based interventions that target sources of difference beyond the reproductive organs.[39,40] According to Dr. Janine Austin Clayton, the associate director for women's health research at the NIH, "We literally know less about every aspect of female biology compared to male biology," which is one of the reasons ORWH highlights the importance of sex as a biological variable and intersectionality considerations in the design, conduct, and analysis of health in its signature programming.[41]

Women now account for roughly half of all participants in NIH-supported clinical research, which is subject to NIH's Policy on the Inclusion of Women in Clinical Research.[42] These strides in inclusion of women in biomedical research support ORWH's commitment to account for sex as a biological variable in all levels of research, including study design, analysis, interpretation of findings, and reporting of findings.[33]

1.4 Social Determinants of Health for U3 Women

Social determinants of health are “the conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.”[43] NASEM identifies two main root causes of health inequity 1) “the unequal allocation of power and resources—including goods, services, and the enforcement of civil rights—which manifest in unequal social, economic, and environmental conditions, also called the social determinants of health,” and 2) “systemic mechanisms that organize the distribution of power and resources differentially across lines of race, gender, class, sexual orientation, gender expression, and other dimensions of individual and group identity.”[44] Recognizing that these factors are complex, diverse, converging, interdependent, and evolving makes finding appropriate solutions an endeavor that leverages a range of research domains. To provide clarity on the interplay of these factors, the National Institute on Minority Health and Health Disparities (NIMHD) developed a multi-dimensional model depicting the domains at which social determinants affect health.[45] This model consists of five interconnected domains of influence that operate across multiple levels of influence, from individual factors to community policy levels:

- Biological
- Behavioral
- Sociocultural Environment
- Physical/Built Environment
- Healthcare System

NIMHD also developed a research framework that offers “multi-dimensional model that depicts a wide array of health determinants relevant to understanding and addressing minority health and health disparities.” The model specifies “that health outcomes can span multiple levels and includes a life course perspective component that emphasizes the importance of considering factors ranging across the lifespan in determining health disparities.”[45] Applying the NIMHD Research Framework to the health of U3 women allows for the development of a deeper understanding of the underlying causes of health disparities and the identification of potential strategies for promoting health equity for these populations, as illustrated by **Figure 1-2**.

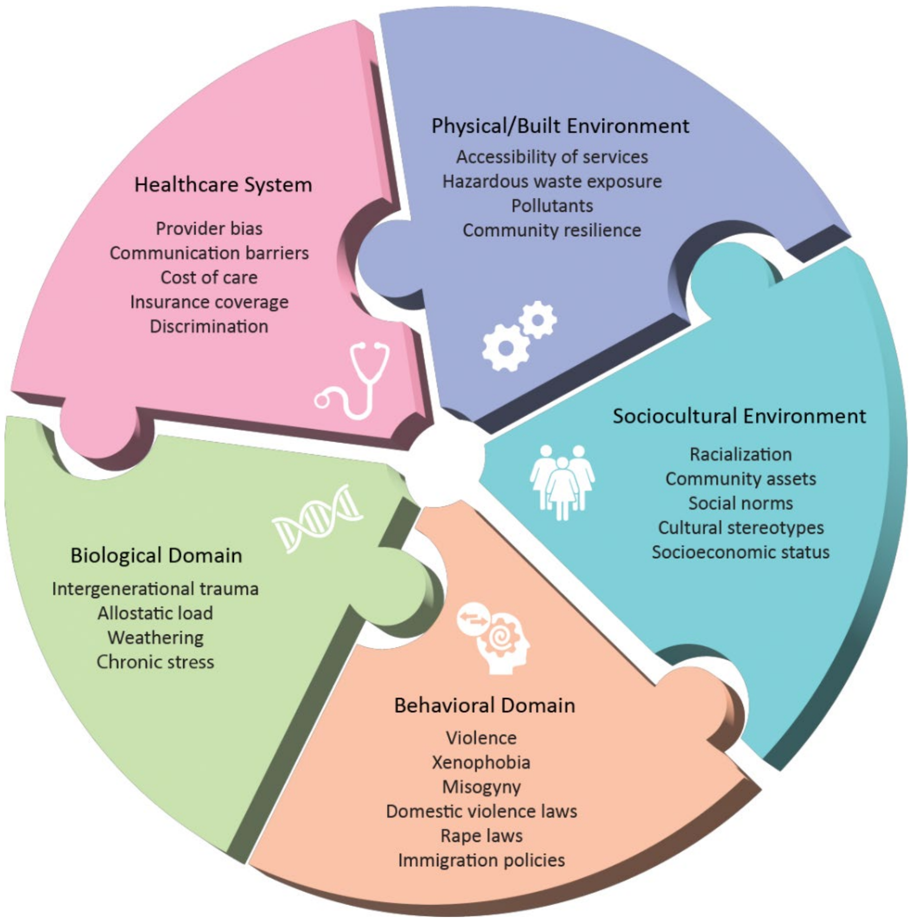

Figure 1-2: U3 Women Health Disparities Research Framework: Social determinants of health for U3 women

Source: Adapted from the NIMHD Minority Health and Health Disparities Research Framework

The sections below discuss each of these five domains and key examples of how they influence the health of U3 women.

1.4.1 Biological Domain

As noted above, biology is a relevant domain of influence on the health of U3 women. However, understanding it as a driver of health outcomes is clearest through the lens of its interaction with social exposures that accelerate biological aging for women of underrepresented racial and ethnic communities.[46] Biological and social factors influence health outcomes across the life course as well as across generations, with research showing that chronic stress can become embodied and passed on to children.[47,48] The intergenerational transmission of stress contributes to disparities in health and well-being, especially among women of underrepresented racial and ethnic communities.[46,49,50] Intergenerational trauma stemming from historical events and ongoing injustices can have lasting psychological, physical, behavioral, and social consequences, creating additional barriers to their well-being.[49,51] Addressing intergenerational trauma is crucial in promoting health equity, as targeted interventions and policies that acknowledge the unique challenges faced by underrepresented and underserved women can foster a more inclusive and accessible healthcare system.[52]

The influence of such factors decreases access to quality healthcare and increase risk for chronic illnesses for U3 women.[53,54] For example, biological vulnerability for U3 women can occur through weathering—the accelerated aging and deterioration of health due to chronic exposure to stress and adversity—which highlights the physical toll of these systemic disadvantages.[55] Allostatic load, which refers to the cumulative wear and tear on the body as a result of chronic stress, is associated with poorer outcomes in both physical and mental health.[55,56]

A life course perspective is essential to understanding the complex interplay of biological, social, and environmental factors that influence women's health throughout their lives.[57,58] This approach can identify critical periods when specific interventions or support may be most beneficial in promoting health and well-being.[50] For instance, adolescence is a critical period for establishing healthy habits such as physical activity, which can have a lasting impact on future health outcomes and reduce the risk of obesity, diabetes, and cardiovascular disease (CVD).[59] For women's health specifically, disorders or risks during pregnancy (e.g., diabetes, pre-eclampsia) can signify risk of chronic conditions later in life.[60] Menopause is an inflection point for aging—the accumulation of morbidity accelerates in the early postmenopausal period.[61]

1.4.2 Behavioral Domain

Understanding the behavioral domain and its influence on the health of U3 women requires an understanding of the constrained choices they make about their own health behaviors as well as the ways that historic and current laws and policies affect their health.[62–64] It also requires a focus on how individual behaviors and coping strategies are learned across generations. Violence provides a stark example of how the behavioral environment at the societal and community levels promotes the intergenerational transmission of trauma for U3 women across their life course. While violence is addressed separately in this Data Book (see **Chapter 14**), it is important to understand how the intersection of violence, racialization, and systemic disadvantages operates as an underlying determinant of the health of U3 women. Such intersections are not captured in existing data systems but understanding them is a necessary underpinning to designing programs to reduce disparities and improve the health of U3 women.

Violence against women is deeply ingrained in the fabric of society, with profound implications for the health and well-being of women and the broader community.[65,66] Structural violence is defined as "social structures that put people in harm's way."[67] It is shown through disparities in access to good and services, as well as joblessness and exploitation.[68] The impact of structural violence may include but is not limited to lack of economic opportunities, marginalization and oppression, as well as poor physical and emotional well-being.[68] It creates risks for individual women and compounds the harms experienced by women of U3 populations.[67,69] The historical legacy of violence toward women and the lack of accountability for perpetrators stems from colonial times and has been perpetuated by a legal system that has prioritized men's property ownership and privileges over the rights and autonomy of women.[70,71] For example, it was not until the early 1990s that marital rape was criminalized in all 50 states.[72] Despite these formal legal protections, dozens of jurisdictions across the U.S. still retain exemptions that allow men to rape their spouses without fear of prosecution or conviction.[73] The prevailing social attitudes and norms that produce such legal loopholes also prevent women from reporting violence committed against them.[74] In addition to systemic and overt racism, U3 women are subject to microaggressions that may include "subtle everyday experiences of racism."[75] Impacts of microaggressions include stress, anxiety, and depression.[76,77]

The legacy of violence and rape against Black women, for example, goes back to the inception of slavery.[70] Contemporary policing practices can perpetuate elements of excessive force and sexual violence, disproportionately affecting women of underrepresented racial and ethnic communities and resulting in heightened vigilance, anxiety, and mental health conditions.[78–80] Additional transmissible health and well-being impacts for U3 women include poverty, under- and unemployment, involvement in underground economies, unstable housing, homelessness, and loss of educational opportunities and/or lower educational attainment.[74,81] For lesbian, gay, bisexual, transgender, and queer/questioning (LGBTQ+) women, rejection by faith communities and loss of social group supports, and the resulting social isolation can have significant impact.[81] Decades of scholarship and activism have also called attention to the violence committed against lesbian, bisexual, and transgender women of underrepresented racial and ethnic communities—including hate crimes and police violence—and the role that LGBTQ+ women of underrepresented racial and ethnic communities have had in leading movements for their own safety and humanity.[25,82,83]

Xenophobia can exacerbate the marginalization of immigrant women of underrepresented racial and ethnic communities.[66,82,84] While immigrant communities and their experiences are diverse, structural barriers in the U.S. safety net, compounded by racism within the healthcare system, including healthcare providers minimizing the voice of women, can hinder access to medical care among immigrants lacking insurance coverage. High healthcare costs and limited coverage options may impede preventative and necessary care, contributing to a decline in overall health.[85,86] Even when they have legal status, many immigrant women lack access to civil benefits.[87] Fear of legal repercussions may deter immigrant women from seeking medical help, which can worsen existing health conditions and prevent timely, appropriate treatment.[87–89]

1.4.3 Sociocultural Environment

The sociocultural environment is derived from a wide range of influences including social norms, structural and interpersonal discrimination, and social networks that can positively or negatively impact individual and population health. In the U.S. context, structural racism, classism, and sexism contribute to a society in which opportunities and resources are unequally distributed, leading to disparities in income, education, and overall quality of life. For example, gendered caregiving expectations disproportionately place the burden of unpaid domestic labor on women, further hindering their economic and professional advancement.[90] A core element of the sociocultural environment relevant for U3 women is racialization, which has played a crucial role in shaping the experiences and identities of U3 women, and negatively impacting their health and well-being. This process involves the social construction of race categories and assigning social, economic, and political meanings to these classifications.[91,92] For instance, assumptions about SES are racialized: for example, society perpetuates the stereotype that women of underrepresented racial and ethnic communities are poor.[93] This assumption of poverty can result in women of underrepresented racial and ethnic communities receiving inequitable treatment because providers view them, for example, as less capable of paying for treatments.[94,95] Consequently, the racialization of SES contributes to disparities in healthcare access and outcomes for women, perpetuating an unjust and harmful system that ultimately impacts their overall health and well-being.

Studies of the health of U3 women often employ a deficit- or barriers-based framework that does not acknowledge the assets communities—including marginalized communities—hold and which are often underappreciated.[96,97] An asset-based framing recognizes and aims to identify and "mobilize community assets to support health and well-being."[98] Assessing the sociocultural environment through this framework can highlight protective and health-promoting effects from a community's assets. Health assets within a sociocultural environment or community could include resilience, sense of purpose, supportive networks, intergenerational solidarity, community cohesion, and housing.[99] Designing research on U3 women from an asset-based perspective repositions the lens to their viewpoint and can more effectively identify solutions to promote healthier outcomes.[99–102]

1.4.4 Physical/Built Environment

The physical environment encapsulates the space in which we live, work, and play, while the built environment is the spaces built by people, such as buildings, parks, and streets.[103] The design of the built environment and its features shape human health. Decades of research have documented disparities in healthcare access and outcomes between people living in rural and urban areas.[104–106] Individuals living in rural areas are more likely to have limited access due to a lack of providers and hospital closures, face long travel times getting to hospitals, have higher rates of chronic illness, and see poorer outcomes from those illnesses.[107,108] Limited healthcare access, particularly for underrepresented racial and ethnic communities and low-income individuals, exacerbates health disparities and perpetuates cycles of poverty. In addition, many studies have found that communities with low incomes are exposed to higher concentrations of air pollutants and exposure to other environmental hazards (e.g., "Superfund sites" or Environmental Protection Agency-designated hazardous waste sites that must be remediated). They are more likely to have older homes that may have asbestos or lead paint and pipes.[109–111] Women of underrepresented racial and ethnic communities are at increased risk of exposure to heavy metals, cigarette smoke and other air pollution, residential and agricultural pesticides, and crystalline silica present in mining and construction industries, which can lead to higher rates of inflammatory and respiratory diseases, cancer, and other health conditions.[112–114]

In urban contexts, the history of race-based residential segregation in the U.S. is a fundamental driver of health disparities across all aspects of neighborhood opportunities (e.g., healthy food access, school quality, proximity to employment, safety), so it is critical to acknowledge policy as central to geographic and racial variations in health status.[115–117] There are two types of policy solutions to rectify place-based inequities: 1) place-based policies (focused on improving the built and social environment of disadvantaged neighborhoods), and 2) people-based policies with a regional perspective (broader policies that target improving economic conditions, income inequality, and housing discrimination).[115] Because residential segregation is a result of multiple negative social drivers shaping the geographic distribution of individuals and communities of different racial and ethnic groups, racial and ethnic disparities across diseases and conditions are impacted by place-based policies.[116] The result of this layered disadvantage is that women of underrepresented racial and ethnic communities who reside in homogenous neighborhoods may experience a "double disadvantage," characterized by the fact that they are deprived of opportunities driven by racism and discrimination, as well as deficiencies in place- and neighborhood-based resources.[116]

1.4.5 Healthcare System

The healthcare system plays a pivotal role in addressing the focus areas outlined in this Data Book, as it governs the healthcare professionals and systems that women access to seek care. As a determinant of health, the healthcare system is influenced by the environment in which it operates and can perpetuate systemic disadvantages (e.g., sexism and racism). Factors such as inequitable delivery of high-quality healthcare, high healthcare costs, barriers to access, and structural racism and bias are notable characteristics of the healthcare system in the U.S.[52,118] Health insurance coverage is a fundamental determinant of healthcare access and utilization. Compared with women who have private insurance, those with unstable or no insurance coverage are disproportionately affected by a range of health challenges, including having a higher stage at diagnosis of breast cancer, experiencing poorer management of diabetes, receiving later and less frequent prenatal care, and suffering from severe maternal morbidity.[119–123] Despite recent federal efforts to improve the affordability of coverage, cost is still a barrier that leaves low-income workers who are not eligible for public assistance without adequate health insurance.[124] Studies show that even among those with private insurance, high deductible health plans create financial barriers to care, as adults with these plans are more likely to delay or forgo care due to high cost compared to those with a traditional plan.[125,126]

Data from the Current Population Survey (CPS) show an overall increase in the percent of women with different types of health insurance over time (**Figure 1-3**). The data also reveal that gaps in coverage across race and ethnicity have narrowed in the past decade. The vast majority of all women have some form of health insurance, with the highest percentages observed among White and Asian women. Coverage by private insurance is highest among White women and remained steady over time, while women in all other racial and ethnic groups saw increased proportions with private insurance over time. Coverage by public health insurance is highest among Black and Hispanic women and lowest for White and Asian women, with notable increases over time (CPS health data is not available for American Indian and Alaska Native [AI/AN] women). The percent of women who are uninsured decreased substantially over time for all groups. Hispanic women have the highest level of being uninsured—twice as high as Black women, nearly three times higher than Asian women, and four times higher than White women. The overall improvement in insurance coverage over time has been attributed to the introduction of the Affordable Care Act in 2013, which reduced—but did not eliminate—disparities in coverage for women of underrepresented racial and ethnic communities.[127] Research shows that disparities in healthcare coverage demonstrate that being both low income and a member of an underrepresented racial and ethnic community results in significantly lower odds of being insured.[128,129]

Healthcare policy is shaped by complex networks of insurers, providers, healthcare product manufacturers, federal agencies, and research. These policies, in conjunction with other factors, create a web of systems that can exacerbate the biological and social challenges U3 women face and the environments in which they exist.[130,131] Factors such as structural racism, provider bias, reduced access to specialty, complementary and alternative health services/therapies, insurance coverage disparities, and a history of medical abuses contribute to mistrust and discourage health-seeking behaviors among U3 women.[118,132,133]

The use of current racial categories and systematic racism within the healthcare system further compound the health disparities faced by U3 women. Discrimination, bias, and a lack of cultural sensitivity from healthcare professionals diminish the quality of care delivered, negatively affecting U3 women's health outcomes.[134] Recent evidence suggests that many women of underrepresented racial and ethnic communities experience inadequate communication during encounters with healthcare providers, are less likely to receive specialist referrals, and experience lower quality of general and specialty care compared with White women.[135] Studies show that a higher percent of Black patients report discrimination in healthcare compared with White patients. In a study conducted by the University of Chicago, Black patients were 2.5 times more likely than White patients to have negative patient descriptors in their electronic health records.[136] Other literature indicates communication errors when interpreters are used for non-English speaking populations.[137] Lack of access to preventive and comprehensive services, including medical, dental, and mental health, is another significant barrier for U3 women, as it leads to delayed diagnoses and treatment of health issues. This increases their risk for chronic illnesses and poor health outcomes in the long run.[88,138,139]

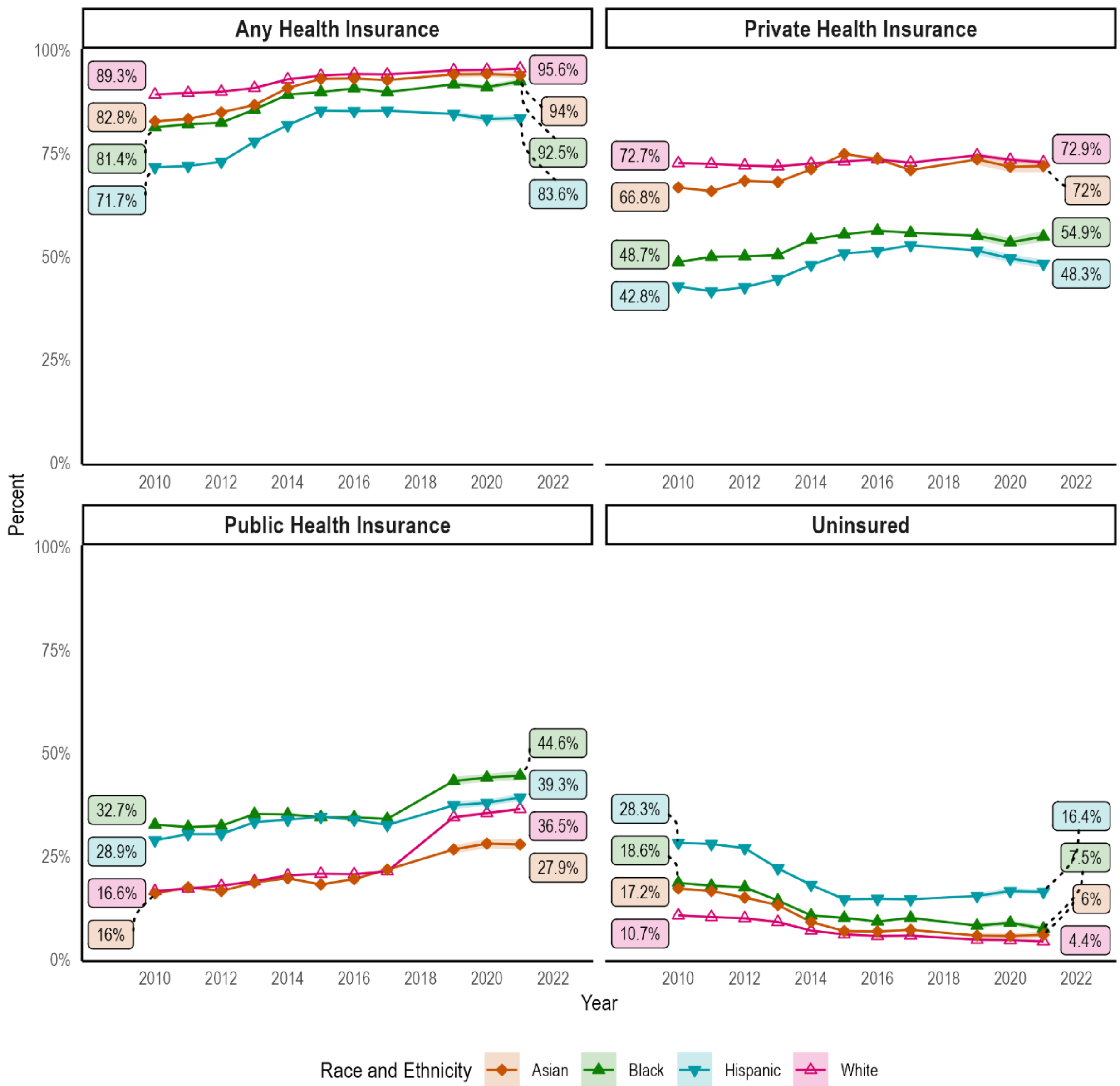

Figure 1-3: Percent of women with different types of health insurance over time, by race and ethnicity
Source: Current Population Survey 2010-2021 (standard errors not available before 2019)

1.5 Data Insights

Inadequacies in existing data collection methodologies underscore gaps in our understanding of the health status and priorities for U3 women. For example, current data collection practices often focus on citizenship as a proxy for immigration but overlook the presence of other categories between unlawful residency and citizenship, which are critical nuances. This hinders a comprehensive understanding of the needs of immigrant U3 women. Advancing the understanding of the social drivers of health for all U3 women also requires moving beyond the binary paradigm of race that centers White populations as the reference group against which all “other” populations are compared, and often distills data reporting down to comparisons of outcomes for Black vs. White populations.[140–142] This practice often results in a failure to capture the experiences of non-Black people of underrepresented racial and ethnic communities, rendering them and their health concerns less visible.[143,144] For women of underrepresented racial and ethnic communities, racialization intersects with gender, resulting in unique experiences of discrimination, marginalization, and systemic oppression.[24] Historically, racialization perpetuates stereotypes and prejudices, such as the false belief that Black women have a higher pain tolerance, resulting in an increased risk for adequate pain management and treatment in healthcare settings.[145–147]

Oversimplified framings of disparities erase the unique challenges faced by U3 women, compounding the effects of racism and sexism on their mental and physical health, economic opportunities, and social well-being.[22] Advocating for a more expansive view requires acknowledging and addressing the distinct health concerns and lived experiences of women of underrepresented racial and ethnic communities and incorporating their voices and perspectives in research and policymaking. By doing so, researchers can contribute to a more accurate and comprehensive understanding of the complex interplay between race and gender and develop targeted interventions and policies that address the unique needs and challenges faced by these women. Thus, discrimination underpins many of the contextual factors discussed throughout this Data Book.

1.6 Conclusions and Future Directions

When considering the health status of U3 women, it is essential to understand how structural and societal factors serve as the root causes of the disparities and challenges U3 women face. Social drivers of health profoundly impact women's mental, emotional, behavioral, physical, and economic well-being. U3 women have historically been relegated to the margins of public imagining, which has further compounded their experiences of discrimination. Being positioned in the margins has also rendered U3 women less visible to researchers and policymakers, leading to a lack of adequate representation in decision-making processes and the development of policies that inadequately address their needs. Addressing these complex, interconnected issues requires comprehensive and intersectional solutions that acknowledge and re-envision the systemic barriers that perpetuate inequality and injustice, while also specifically prioritizing the needs and experiences of U3 women who have been historically overlooked and underserved. Systemic barriers are deeply entrenched in how our society and systems function, yet they are mutable and can be changed through programming and enforceable policies that point to accountability of adherence. Prevention and response efforts that are informed by an intersectional lens and grounded in an understanding of the lived realities of U3 women is crucial for effectively improving their health outcomes.

This Data Book sheds light on the unique challenges that create health disparities for women who have historically been understudied, underrepresented, and underreported in health research. By examining the complex interplay of biological, cultural, and social factors, this Data Book provides an understanding of the health and well-being of U3 women, acknowledging their resilience and agency. The narratives in each chapter emphasize the importance of addressing the root causes of health inequity, improving data collection centered on the health needs of U3 women, and dismantling the structural and individual barriers that perpetuate health inequities. Presenting data and contextual factors, this Data Book serves as a call to action to prioritize the health and well-being of U3 women and to work collaboratively toward a future where all women can thrive.

1.7 Data Sources and Definitions

Data for all figures in this chapter can be accessed from the data annex located here: https://orwh.od.nih.gov/sites/orwh/files/docs/Chapter_1.xlsx

Current Population Survey (CPS), 2010-2017, 2019-2021

Variable Name	Variable Description	Variable Options
Any Health Insurance	Any private health insurance plan or public health insurance plan; people can be covered by more than one type of health insurance during the year.	Number; Number Margin of Error; **Percent; Percent Margin of Error**
Private Health Insurance	Private health insurance includes coverage provided through an employer or union, coverage purchased directly, or TRICARE.	Number; Number Margin of Error; **Percent; Percent Margin of Error**
Public Health Insurance	Public health insurance coverage includes Medicaid, Medicare, CHAMPVA (Civilian Health and Medical Program of the Department of Veterans Affairs), and care provided by the Department of Veterans Affairs and the military.	Number; Number Margin of Error; **Percent; Percent Margin of Error**
Uninsured	Individuals are considered to be uninsured if they do not have health insurance coverage for the entire calendar year.	Number; Number Margin of Error; **Percent; Percent Margin of Error**

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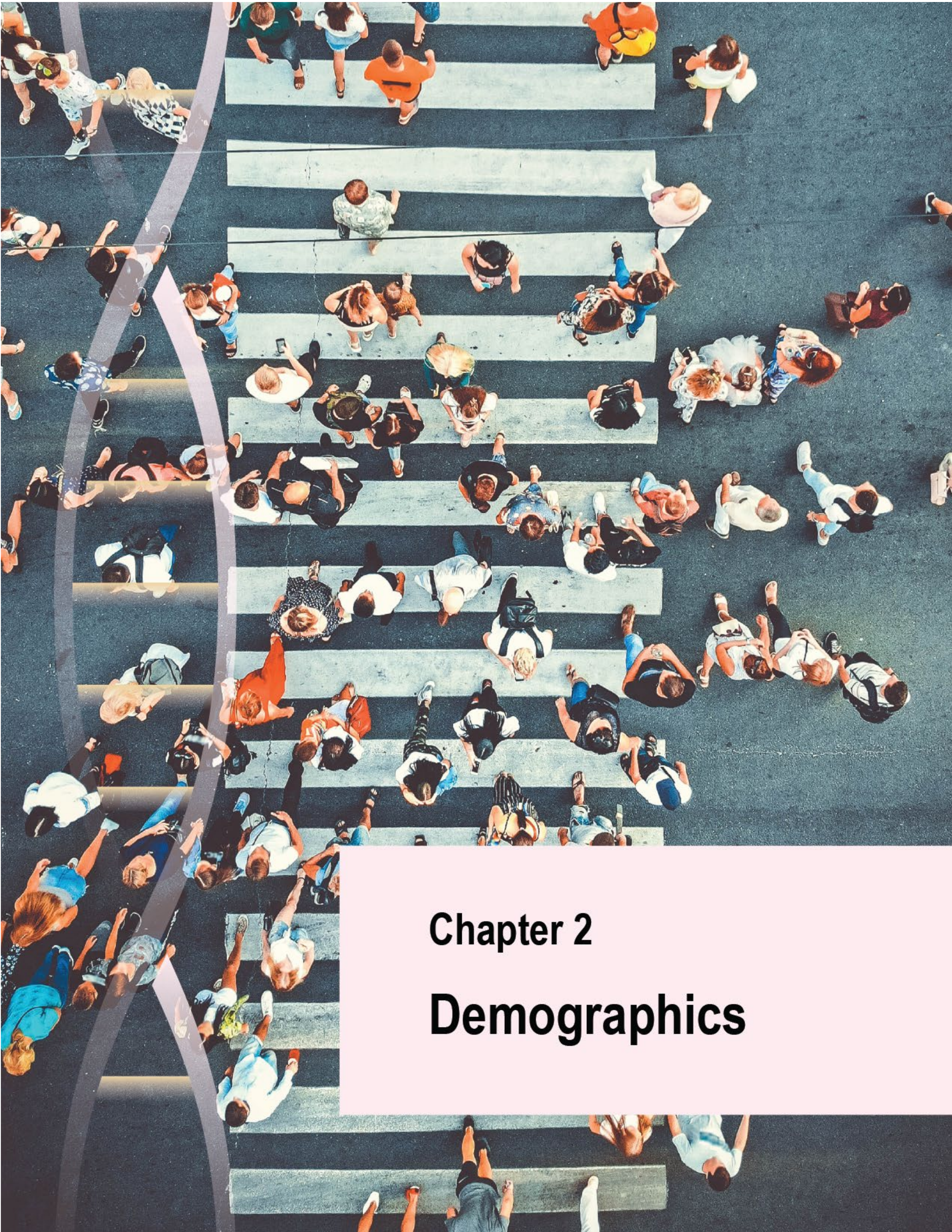

Chapter 2

Demographics

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Demographics

2.1 United States Demographic Overview

After decades of rapid increase, U.S. population growth began to slow after the year 2000, due to economic challenges and new immigration restrictions.[1] The nation's lowest growth rate in over a century was recorded from 2019-2020, at 0.35%.[1] While some of this decline is attributed to the impact of COVID-19, it also reflects a pattern of low fertility rates and increased mortality rates due to an aging population in the decade before the pandemic.[1] This overall decline masks some of the significant changes that have occurred in the racial and ethnic, age, and sex composition of the population, all of which have implications for the health of the nation. For example, women have higher levels of many health concerns but lower mortality rates than men, which has implications for the demographic distribution and priority health concerns over time.[2,3] The data presented in this chapter show that across most racial and ethnic groups, the proportion of young people is decreasing. The overall aging of the population has implications for public health and the burden of disease for priority conditions discussed in this book, such as cancers, cardiovascular disease (CVD), dementia, and menopause.

This chapter sets a foundation for understanding the diversity of the U.S. population and differences within and among population groups.[i] It provides context on the race and ethnicity terminology used in the chapters that follow and serves as a reference point for data and statistics in subsequent chapters. It underscores the importance of age distribution and sex differences, which have implications for population health and health disparities. It also highlights how the societal factors that affect the health of women of populations that are understudied, underrepresented, and underreported (U3) intersect with demographic transitions. The U3 framework recognizes the intersecting identities held by four diverse groups: 1) women of underrepresented racial and ethnic communities, 2) women in economically disadvantaged groups, 3) women who live in rural areas, and 4) women of sexual and gender minority (SGM) groups (see **Chapter 1**).

The U.S. Census Bureau collects demographic information to better understand the needs of communities and determine where federal funding is committed.[5] Understanding the definitions used by the federal government for classification of race and ethnicity is essential for interpreting Census data and population projections. The classifications below draw from the 1997 Office of Management and Budget (OMB) government-wide standards for race and ethnicity data collection, which are still the

[i] The U.S. Department of Health and Human Services (HHS) defines population group as "a group of individuals united by a common factor (e.g., geographic location, ethnicity, disease, age, gender). More specifically, in statistical analysis, it is any finite or infinite collection of people from which a sample is drawn for a study to obtain estimates for values that would be obtained if the entire population were sampled."[4]

current standard.[6, ii] Throughout this section, we align these classifications to the terminology used throughout the rest of this Data Book (see **Section 3.2.2**).

Ethnicity

There are two categories for data on ethnicity tracked by the Census, consisting of "Hispanic or Latino" and "Not Hispanic or Latino." This Data Book uses the term "Hispanic" for Hispanic or Latino (see **Section 3.2.2**). According to the Census Bureau:

- "The terms 'Hispanic,' 'Latino,' and 'Spanish' are used interchangeably. Some respondents identify with all three terms while others may identify with only one of these three specific terms. People who identify with the terms 'Hispanic,' 'Latino,' or 'Spanish' are those who classify themselves in one of the specific Hispanic, Latino, or Spanish categories listed on the questionnaire ('Mexican, Mexican Am., or Chicano,' 'Puerto Rican,' or 'Cuban') as well as those who indicate that they are 'another Hispanic, Latino, or Spanish origin.' People who do not identify with one of the specific origins listed on the questionnaire but indicate that they are 'another Hispanic, Latino, or Spanish origin' are those whose origins are from Spain, the Spanish-speaking countries of Central or South America, or another Spanish culture or origin. Origin can be viewed as the heritage, nationality group, lineage, or country of birth of the person or the person's parents or ancestors before their arrival in the U.S. People who identify their origin as Hispanic, Latino, or Spanish may be of any race."[7]

Race

Additionally, there are six racial groups.[8–10] Their definitions, per the Census Bureau, are shown below (the terminology used in other areas of this Data Book are indicated as well; see **Section 3.2.2**):

- **American Indian or Alaska Native (AI/AN)**— A person having origins in any of the original peoples of North and South America (including Central America) and who maintains tribal affiliation or community attachment. This category includes people who indicate their race as "AI/AN" or report responses such as Navajo Nation, Blackfeet Tribe, Mayan, Aztec, Native Village of Barrow Inupiat Traditional Government, or Nome Eskimo Community.[10] Respondents who identified themselves as AI/AN were asked to report their enrolled or principal tribe. Therefore, tribal data in tabulations reflect the written entries reported on the questionnaires. Some of the entries (for example, Metlakatla Indian Community and Umatilla) represent reservations or a confederation of tribes on a reservation.[8] The information on tribe is based on self-identification and therefore does not reflect any designation of federally or state-recognized tribe. The information for the 2020 Census was updated from 2010 to 2020 based on the annual Federal Register notice entitled "Indian Entities Recognized and Eligible to Receive Services from the United States Bureau of Indian Affairs," Department of the Interior, Bureau of Indian Affairs, issued by OMB, and through consultation with AI/AN communities and leaders.[9] This Data Book uses "American Indian and Alaska Native" (AI/AN).
- **Asian**—A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent, including, for example, India, China, the Philippine Islands, Japan, Korea, or Vietnam. It includes people who indicate their race as Asian Indian, Chinese, Filipino,

[ii] In 2022, OMB commenced a process of updating the standards to "better reflect the diversity of the American people". Details about the Interagency Technical Working Group on Race and Ethnicity Standards can be found on the OMB website.

Korean, Japanese, Vietnamese, and Other Asian, or provide other detailed Asian responses such as Pakistani, Cambodian, Hmong, Thai, Bengali, Mien, etc.[10] This Data Book uses "Asian" when the data do not separate out "Asian" and "Native Hawaiian and Pacific Islander" (see below).

- **Native Hawaiian or Other Pacific Islander (NHPI)**—A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands. It includes people who indicate their race as Native Hawaiian, Chamorro, Samoan, and Other Pacific Islander, or provide other detailed Pacific Islander responses such as Palauan, Tahitian, Chuukese, Pohnpeian, Saipanese, Yapese, etc.[10] This Data Book uses "Native Hawaiian and Pacific Islander."
- **Black or African American**—A person having origins in any of the Black racial groups of Africa. It includes people who indicate their race as "Black or African American" or report responses such as African American, Jamaican, Haitian, Nigerian, Ethiopian, or Somali. The category also includes groups such as Ghanaian, South African, Barbadian, Kenyan, Liberian, Bahamian, etc.[10] This Data Book uses "Black" for "Black" or "African American."
- **White**—A person having origins in any of the original peoples of Europe, the Middle East, or North Africa. It includes people who indicate their race as "White" or report responses such as German, Irish, English, Italian, Lebanese, and Egyptian. The category also includes groups such as Polish, French, Iranian, Slavic, Cajun, Chaldean, etc.[10] This Data Book uses "White."
- **Some Other Race (SOR)**—Includes all other responses not included in the "White," "Black," "AI/AN," "Asian," and "NHPI" race categories described above. Respondents reporting entries such as multiracial, mixed, interracial, or a Hispanic, Latino, or Spanish group (for example, Mexican, Puerto Rican, Cuban, or Spanish) in response to the race question are included in this category.[10] This Data Book uses "Other" for "Some other race."
- **Two or More Races**—People may choose to provide two or more races either by checking two or more race response checkboxes, by providing multiple responses, or by some combination of checkboxes and other responses. The race response categories shown on the questionnaire are collapsed into the five minimum race groups identified by OMB and the Census Bureau's "Some Other Race" category. For data product purposes, "Two or More Races" refers to combinations of two or more of the following race categories: 1) White, 2) Black or African American, 3) AI/AN, 4) Asian, 5) NHPI, and 6) Some Other Race.[10] This Data Book uses "Multiracial" for two or more races.

Table 2-1 shows the total U.S. population in 2020 by sex, and the total female population by race and ethnicity. In 2020, there were nearly 72 million women of underrepresented racial and ethnic communities, i.e., those women who identify as Hispanic or Latino (of any race) and those women who identify as non-Hispanic or Latino and AI/AN, Asian, Black, NHPI, some other race, or two or more races. Of the total population of 169 million women, approximately 42% were of underrepresented racial and ethnic communities and 58% were Non-Hispanic White women. The proportion of the population comprising women of underrepresented racial and ethnic communities in 2020 is a marked change since 2010, when they comprised approximately 36% of the female population.[11] **Table 2-1** also shows that women of all races and ethnicities accounted for just over half of the total population in both 2010 (50.8%) and 2020 (50.9%). However, the proportion of the total population who are women of underrepresented racial and ethnic communities has grown from 18% in 2010 to nearly 22% in 2020.

Note that data from the 2020 Census reflect improvements intended to better represent changes in national demographics as well as the increasing proportion of people who identify as Multiracial.[12] The Census Bureau offers this guidance for interpreting the categorizations below:

"…. (The) release of new 2020 Census data provides population counts of nearly 1,500 race and ethnicity groups and AI/AN tribes and villages…detailed groups reported in the race question have both 'alone' and 'alone or in any combination' counts. The 'alone' count represents the minimum number of people who identified as that detailed group, and includes respondents with only one response, such as Hungarian. The 'alone or in any combination' count represents the maximum number of people who identified as that detailed group. It includes respondents with only one response, such as Hungarian, and those with multiple, such as Hungarian *and* Romanian or Hungarian *and* Black or African American."[12]

Table 2-1: Population distribution of women, by race and ethnicity

Source: Census Bureau, Decennial Census, 2020

Total Population	Count (Alone)	Percent (Alone)	Count (Alone or in combination)	Percent (Alone or in combination)
Total U.S. Population	**331,449,281**	**100.00%**	**331,449,281**	**100.00%**
Total Male Population	162,685,811	49.08%	162,685,811	49.08%
Total Female Population	168,763,470	50.92%	168,763,470	50.92%
Race	**Count of Female Pop. (Alone)**	**Percent of Female Pop. (Alone)**	**Count of Female Pop. (Alone or in combination)**	**Percent of Female Pop. (Alone or in combination)**
Total Female Population	**168,763,470**	**100.00%**	**168,763,470**	**100.00%**
American Indian and Alaska Native	1,856,982	1.10%	4,955,458	2.94%
Asian	10,431,154	6.18%	12,504,093	7.41%
Black or African American	21,535,639	12.76%	24,572,519	14.56%
Native Hawaiian and Other Pacific Islander	344,223	0.20%	795,278	0.47%
White	103,499,485	61.33%	119,418,757	70.76%
Some Other Race	13,774,114	8.16%	24,988,403	14.81%
Two or More Races	17,321,873	10.26%	*N/A*	*N/A*
Hispanic or Latino and Race	**Count of Female Pop. (Alone)**	**Percent of Female Pop. (Alone)**	**Count of Female Pop. (Alone or in combination)**	**Percent of Female Pop. (Alone or in combination)**
Total Female Population	**168,763,470**	**100.00%**	**168,763,470**	**100.00%**
Hispanic or Latino (Of Any Race)	31,177,834	18.47%	31,177,834	18.47%
Not Hispanic or Latino	137,585,636	81.53%	137,585,636	81.53%
American Indian and Alaska Native	1,141,775	0.68%	3,476,262	2.06%
Asian	10,292,552	6.10%	12,062,792	7.15%
Black or African American	20,932,542	12.40%	23,192,198	13.74%
Native Hawaiian and Other Pacific Islander	310,563	0.18%	668,142	0.40%
White	97,084,152	57.53%	103,358,421	61.24%
Some Other Race	838,951	0.50%	2,343,268	1.39%
Two or More Races	6,985,101	4.14%	*N/A*	*N/A*

Figure 2-1 is a population pyramid illustrating age distribution of the total population by sex from 2020 Census data. It shows larger numbers of boys/men in all age bands up to 29 years, but higher numbers

of girls/women in all age bands starting at 30 years. The greatest difference is among people over 85, where women make up nearly twice as much of the population as men.

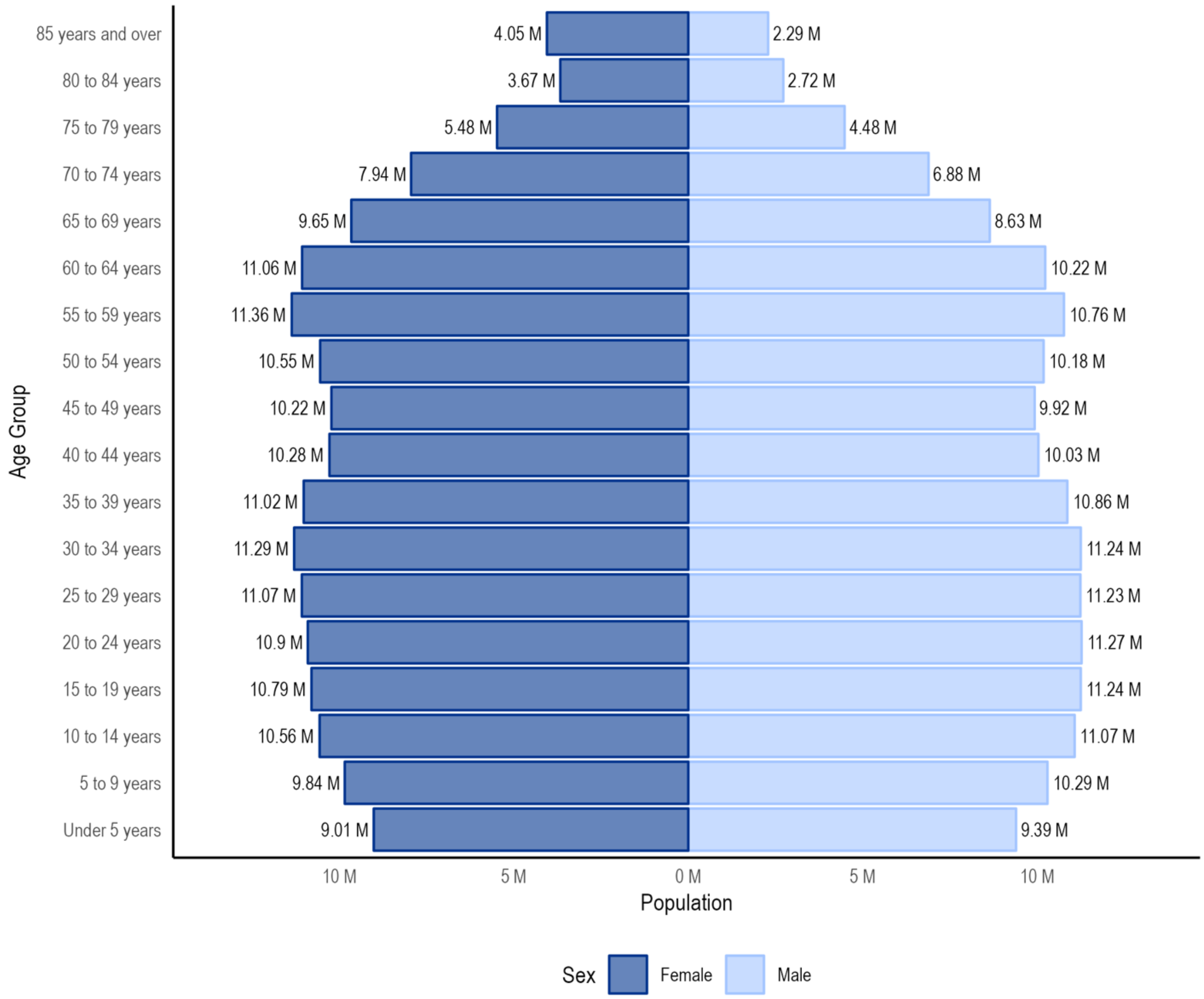

Figure 2-1: Population pyramid illustrating age distribution of the total population by sex
Source: Census Bureau, Decennial Census, 2020

Figure 2-2 depicts the age distribution of the total population over time by sex between 2010 and 2021. The data reveal an increasingly older population, with people aged 75 and older representing a larger proportion of the total population in 2021 compared with 2010. This increase is more marked among women than among men. The proportion of women aged 40-60 has decreased while the proportion of the population that is under age 40 has remained stable.

While these age patterns are clear for the overall population, they do not hold true across all racial and ethnic groups. U.S. Census data over the past decade show a demographic shift characterized by both a decrease in the proportion of the population that identifies as White (alone), and an increase in the proportion of the population that identifies with any other racial and ethnic group.[13, iii] For example, the White (alone) population decreased in every age category except 65 years and older, and the Black

[iii] Note that this book capitalizes all reference to racial and ethnic groups, in accordance with the NIH Style Guide, which acknowledges that this is a divergence from Associated Press style.[14]

(alone) population increased in all age categories except under age 18. All age categories grew for AI/AN alone, Asian alone, NHPI alone, and SOR alone populations; and the Multiracial population increased for every age category by over 164%. This reported increase in racial and ethnic diversity also brings diversity of age composition, as shown in the population pyramids in **Figure 2-3**. These show that AI/AN, Hispanic, and Multiracial populations skew younger, while the White population skews older with fewer people in the youngest category. These pyramids also reflect differences in mortality rates, as discussed in **Chapter 4.**

Projections of the composition of the population beyond the 2020 Census suggest that the proportion of the population that identifies with an underrepresented racial and ethnic community will continue to expand, while the proportion that identifies as White (alone) will continue to decrease.[15] **Figure 2-4** depicts the Census population projection for 2030-2060 by race and ethnicity, based on data from the 2020 Decennial Census based on the single-race or ethnicity categories (e.g., White alone rather than White alone or in combination).[16] It projects that the percent of the population identifying as Hispanic will increase by 30%, and the percent of the population identifying as White will decrease by 20%, while the Multiracial population will see a proportional increase of 70%. The proportion of the population that identifies as Black is expected to increase by 5%; the growth of the proportion of the population that identifies as NHPI is projected to remain similar across the projected years. It is notable that besides the White population, the AI/AN population is the only other group that is projected to proportionately decrease between 2020 and 2060. Projections are not available for the SOR category.

The projections in **Figure 2-4** reflect analyses of past trends as well as changes over time in how Census data are collected and how categories are defined. [iv]

This chapter presents the most recently available demographic data to provide a snapshot of the current distribution of the U.S. population by race, ethnicity, rurality, economic status, and sexual orientation and gender identity. Note that throughout most of this book, a family having an income above 200% of the federal poverty level (FPL) is used as a proxy for economic advantage, in alignment with OMB guidelines.[17] Further details on the definition used can be found in **Chapter 3**. However, in this chapter, 100% of FPL was used to distinguish between economically advantaged and disadvantaged, as the available in American Community Survey (ACS) data can be processed with only this FPL option when analyzing both sex and race and ethnicity. As with other measures relying on FPL, the analyses presented here offer an imperfect snapshot of economic status that underestimates the true poverty levels, given that those living at the poverty level are grouped with those who are above it (see **Section 2.3.2**).

[iv] Federal definitions used to measure race and ethnicity have evolved over more than 200 years. Details on the changes between 1790 and 2010 can be found on the U.S. Census website.

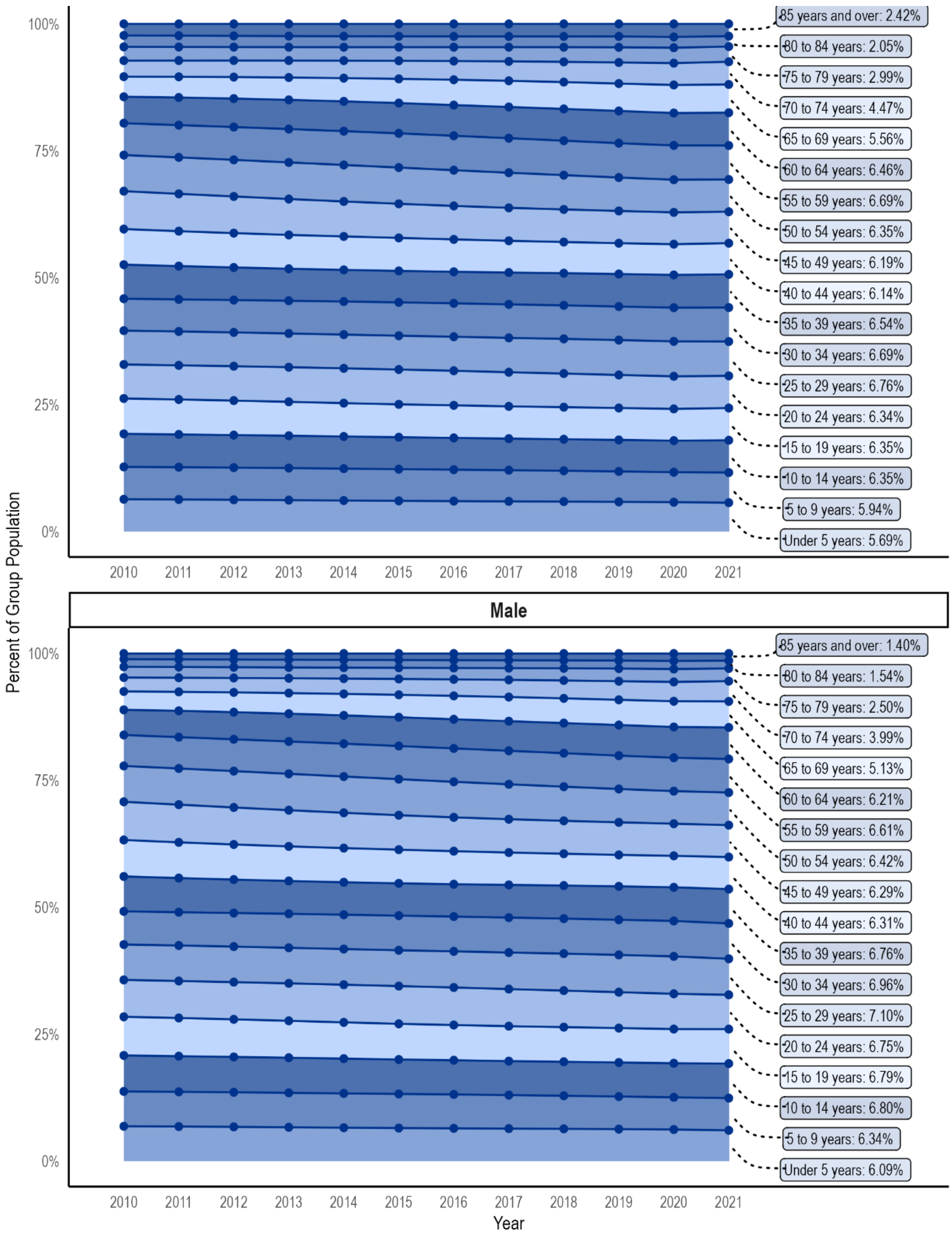

Figure 2-2: Age distribution of the total population over time by sex

Source: Census Bureau, American Community Survey (ACS) 5-year, 2010-2021

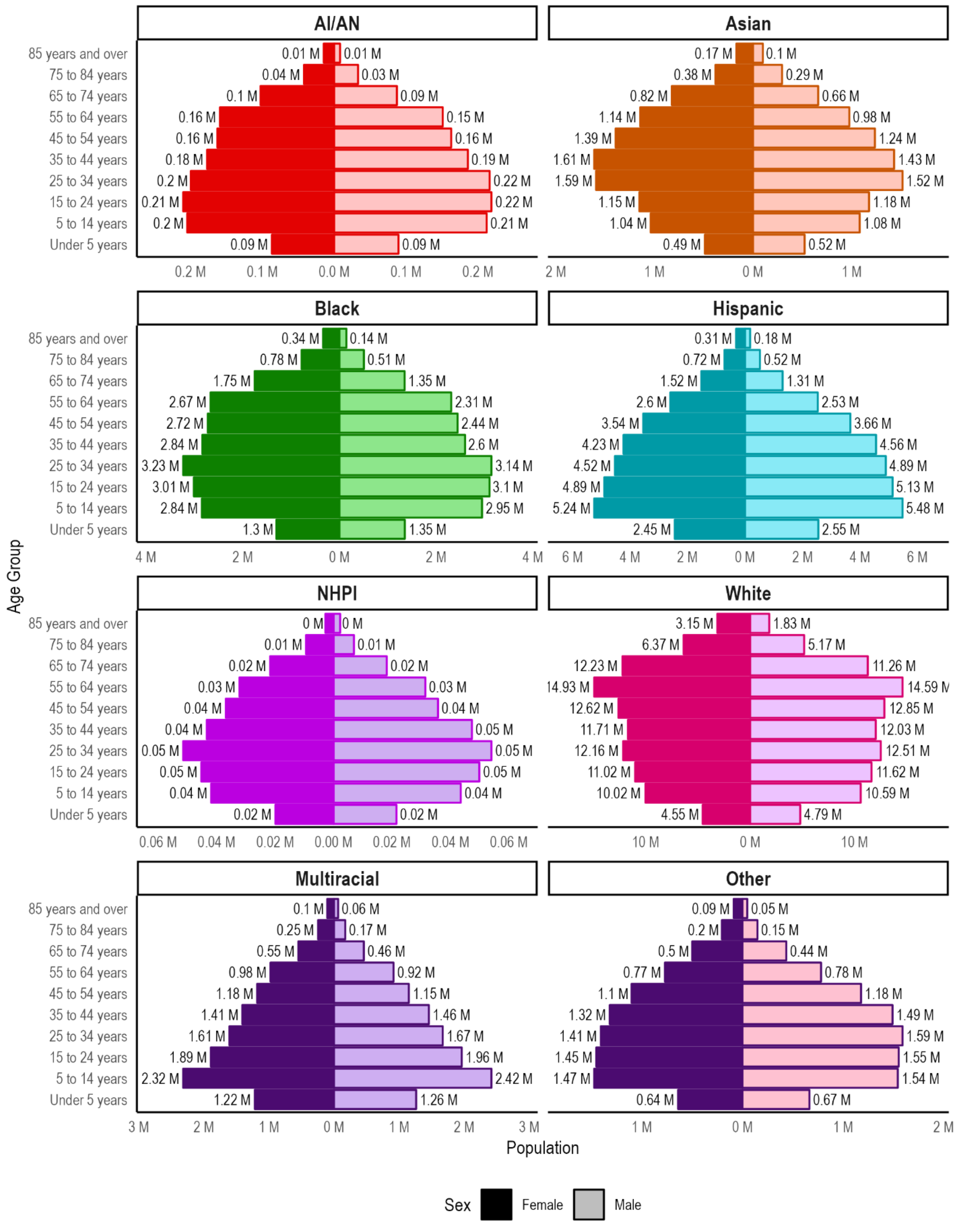

Figure 2-3: Population pyramids illustrating age distributions of the total populations, by sex and race and ethnicity

Source: Census Bureau, American Community Survey (ACS) 5-year, 2021

Figure 2-4: Projected population distribution for 2030-2060, by race and ethnicity
Source: Census Bureau, Population Projections, 2023

2.2 Demographics of Underrepresented Racial and Ethnic Communities

As discussed in Chapter 1, health inequities among women of underrepresented racial and ethnic communities also affect population health status, and health concerns have different priorities depending on the life stage. Demographic data that accurately reflect the diversity of the population can allow the government to better meet the needs of a diverse population while also redressing some disparities that create health risks for those who have been underrepresented and underreported. The sections below provide a synthesis of core demographic data for each of the racial and ethnic categories included in the 2020 Census. Note that unless otherwise specified, the data visualizations below are for each group “alone” rather than “alone or in combination.” Disaggregation of data specific to U3 women from public-use data sets is often problematic and perpetuates the invisibility and marginalization of U3 women in the health research and healthcare systems. The absence of accurate data on U3 women makes it difficult to accurately assess their specific needs and leaves their health outcomes compromised. Researchers, policymakers, and healthcare professionals need these data to better understand U3 women's unique health challenges and develop targeted interventions to address these disparities.

2.2.1 American Indian and Alaska Native Populations

The diverse peoples currently categorized as "American Indian and Alaska Native" have inhabited the lands now known as the United States for at least 10,000 years, with the most recent 500 years marked by violence and displacement (see **Chapter 1**).[18] Starting in 1890, the U.S. Census has had a racial category of "Indian," followed by "American Indian" or "Eskimo" in 1960, eventually shifting to the AI/AN category used today.[19] The year 1960 was also the first to allow for mail-in responses and self-report, which resulted in a 46.5% increase in the number of AI/AN people reported. Allowing for mail-in responses removed one source of undercounting, but indigenous communities are still undercounted.[19] In the 2010 Census, it was estimated that AI/AN populations were undercounted by 4.9%, the highest for any racial category.[20] This resulted in a more concerted effort in 2020 to reach indigenous populations. As of the 2020 Census, the population of AI/AN persons in the U.S. is distributed as shown in **Table 2-2**. Many of these tribal categories were new to the 2020 Census, including "Aztec" which was the largest AI/AN alone category. Between 2010 and 2020, the number of individuals identifying as solely AI/AN grew by 27.1%, while the number of individuals identifying as AI/AN and another race grew by 160%, demonstrating the importance of improved multiracial data collection.[21,22]

Figure 2-5 shows the age distribution of women who identify as AI/AN (alone) by age and percent of total population over time, with an observed gradual increase in the population in older age groups over time.

In 2021, 25% of AI/AN women (327,412) reported past-year income below the U.S. poverty level, while 75% (1,001,160) reported past-year income at or above the poverty level.[23] Due to colonization and subsequent federal policies, reservations (i.e., pieces of land the federal government allocated to tribes) have high levels of concentrated poverty and are subject to policies that limit tribal power and sovereignty, which impact the health of AI/AN populations.[24,25] **Figure 2-6** shows the percent of AI/AN population (men and women) by state, with Alaska as the only state where AI/AN people comprise more than 10% of the total population. AI/AN people account for smaller but noteworthy proportions of the state populations in New Mexico, South Dakota, and Oklahoma.

Table 2-2: Selected AI/AN population group counts

Source: Census Bureau, Census Detailed Demographic and Housing Characteristics File A, 2020

Detailed group	Count (Alone)	Percent (Alone)	Count (Alone or in Combination)	Percent (Alone or in Combination)
Alaska Native	**133,311**	**100.0%**	**241,797**	**100.0%**
Yup'ik (Yup'ik Eskimo)	9,026	6.8%	13,706	5.7%
Tlingit	7,792	5.8%	22,601	9.3%
Inupiat (Inupiaq)	5,674	4.3%	10,501	4.3%
Alaskan Athabascan	4,893	3.7%	11,514	4.8%
Aleut	4,878	3.7%	13,805	5.7%
Eskimo	3,337	2.5%	9,737	4.0%
Native Village of Barrow Inupiat Traditional Government	2,565	1.9%	3,824	1.6%
Nome Eskimo Community	1,914	1.4%	3,786	1.6%
Central Council of the Tlingit and Haida Indian Tribes	1,424	1.1%	3,003	1.2%
Native Village of Hooper Bay (Naparyarmiut)	1,384	1.0%	1,476	0.6%
American Indian	**2,159,802**	**100.0%**	**6,363,796**	**100.0%**
Navajo Nation	315,086	14.6%	423,412	6.7%
Cherokee	214,940	10.0%	1,513,326	23.8%
Choctaw	69,454	3.2%	255,557	4.0%
Lumbee Tribe Of North Carolina	54,293	2.5%	79,424	1.2%
The Muscogee (Creek) Nation	40,677	1.9%	121,581	1.9%
Chippewa	39,057	1.8%	130,048	2.0%
Apache	36,492	1.7%	129,589	2.0%
Blackfeet Tribe of the Blackfeet Indian Reservation of Montana	34,810	1.6%	297,899	4.7%
Cherokee Nation	31,432	1.5%	77,232	1.2%
Sioux	30,408	1.4%	126,571	2.0%
Canadian Indian	**7,723**	**100.0%**	**72,701**	**100.0%**
Chippewa/Ojibwe Canadian	1,149	14.9%	2,576	3.5%
Metis	855	11.1%	3,936	5.4%
French Canadian/French American Indian	610	7.9%	38,034	52.3%
Canadian Indian	564	7.3%	7,126	9.8%
Six Nations Canada	229	3.0%	809	1.1%
Latin American Indian	**766,112**	**100.0%**	**1,319,523**	**100.0%**
Aztec	387,122	50.5%	583,981	44.3%
Maya	180,359	23.5%	300,519	22.8%
Taino	28,346	3.7%	112,682	8.5%
Maya Central American	18,942	2.5%	21,542	1.6%
Mexican Indian	15,235	2.0%	34,005	2.6%

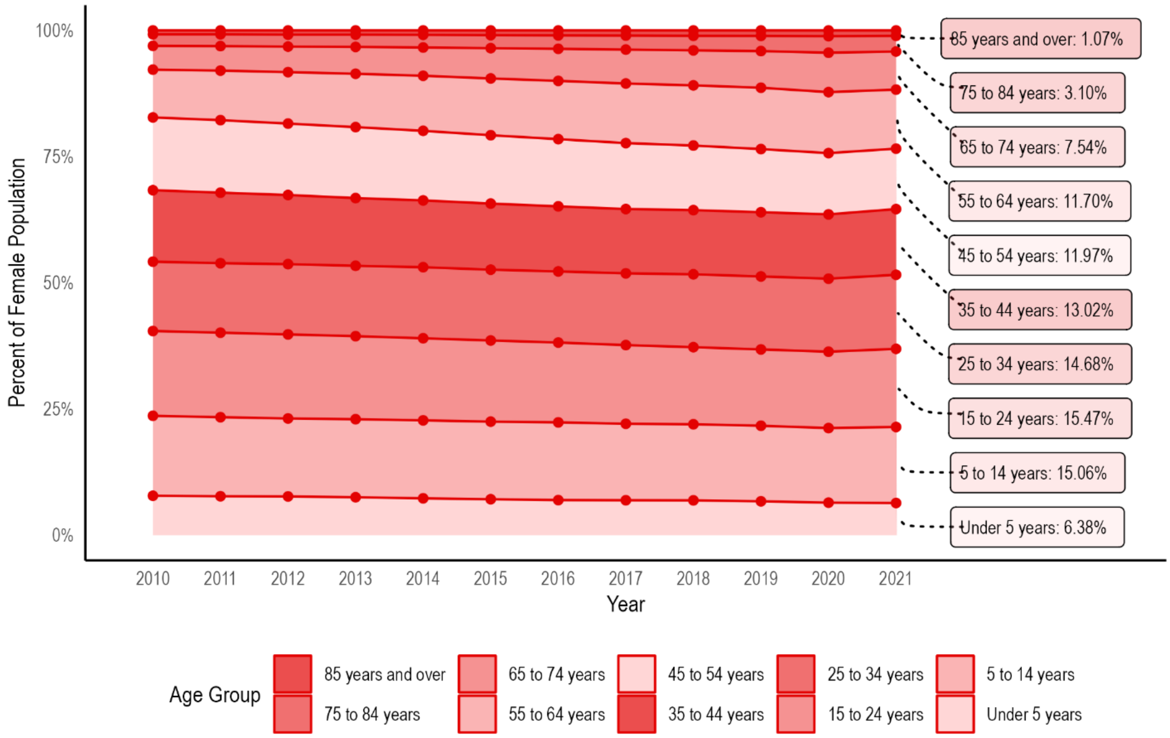

Figure 2-5: Age distribution of AI/AN women over time

Source: Census Bureau, American Community Survey (ACS) 5-year, 2010-2021

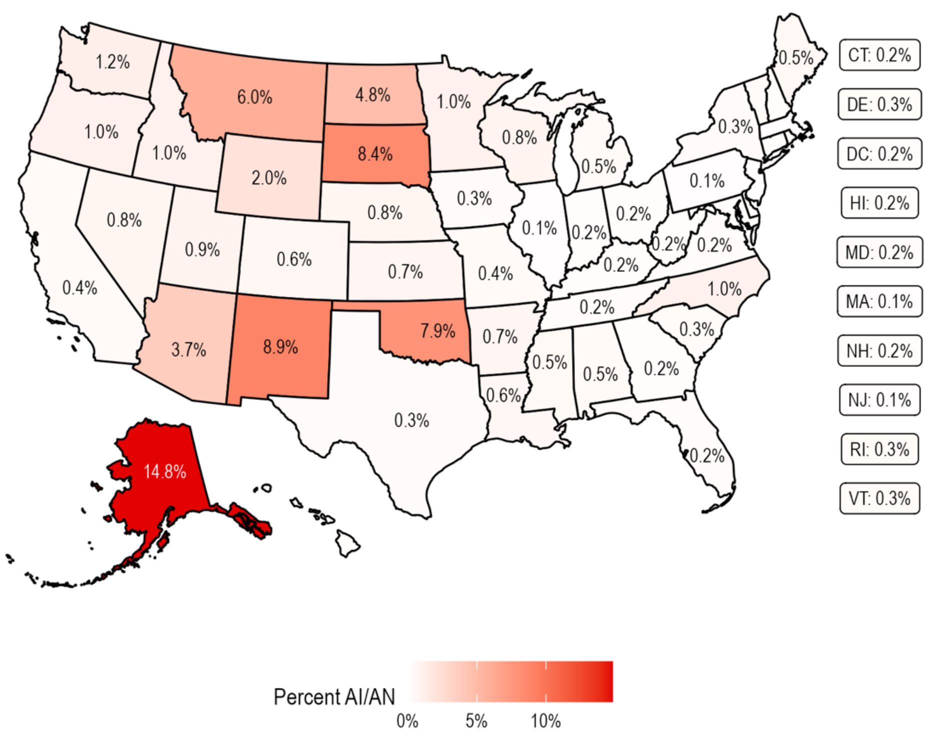

Figure 2-6: Percent of AI/AN population by state

Source: Census Bureau, Decennial Census, 2020

In the past decade, there has been a migration of AI/AN people from rural to urban areas, yet cultural ties and families often are still located on reservations.[26] As of 2021, there were 482,575 AI/AN women living in rural areas and 878,094 in non-rural areas.[23] In terms of geographic drivers of health, AI/AN people who live in rural reservation communities versus urban environments face different barriers to health services utilization and care. Transportation barriers affect access to healthcare for many AI/AN patients living in rural areas.

Table 2-3 shows the population count across major areas of residence, with the largest count of AI/AN people (alone and alone or in any combination) being in the Navajo Nation Reservation and Off-Reservation Trust Lands in Arizona, New Mexico, and Utah. While Arizona is not one of the five states with the highest percentage of the total population that identifies as AI/AN, it contains in whole or part four of the five largest American Indian Reservations.

Table 2-3: Five largest AI/AN population group village statistical areas and reservations

Source: Census Bureau, Census Detailed Demographic and Housing Characteristics File A, 2020

Geographical Areas	Count (Alone)	Count (Alone or in Combination)
Alaska Native Village Statistical Areas	-	-
Knik ANVSA, AK	5,334	10,959
Bethel ANVSA, AK	4,158	4,710
Barrow ANVSA, AK	2,652	3,127
Kenaitze ANVSA, AK	2,324	4,675
Kotzebue ANVSA, AK	2,117	2,411
American Indian Reservations	-	-
Navajo Nation Reservation and Off-Reservation Trust Land, AZ-NM-UT	157,901	160,552
Pine Ridge Reservation, SD-NE	16,326	16,904
Fort Apache Reservation, AZ	13,869	14,015
Gila River Indian Reservation, AZ	13,135	13,410
San Carlos Reservation, AZ	10,000	10,101

2.2.2 Asian Populations

Migration from Asia to the U.S. is documented as early as the 1500s and increased rapidly in the 19th century as global trades routes expanded, and labor shortages in Asia pushed people out in search of employment.[27,28] As this population of U.S. immigrants grew, so did immigration restrictions and racist rhetoric that fueled denial of equal protection under the law to Asian people.[27] These restrictions were not lifted until the 1960s. With subsequent waves of immigration from Asia, the descriptor and racial category "Asian" (as used in research, in academia, and by the U.S. Census) failed to encompass the wide array of ethnicities, cultures, languages, traditions, and histories experienced by the population in the category.[27]

The collection of demographic information by the U.S. Census has historically grouped Asian subgroups together, masking important differences in sociodemographic characteristics and the ability to distill disparities.[29] Race data was first collected for Chinese people in 1860, for Japanese people in 1870, and for other Asian subpopulations in 1910.[29] Not until 2000 did the Census Bureau separate "Asian" from "Pacific Islanders;" even so, much of the nation's understanding of racial and ethnic disparities in health is derived from national health surveys, which—until improvements from 2011 to 2021—classified race only at the aggregated level of "Asian."[30] As a result, inadequate sampling and aggregation of Asian subgroups has led to statistically unstable estimates (e.g., suggesting no between-subgroup difference in disease, when in fact more adequate samples would suggest otherwise).[29] Furthermore, few states collect Asian subgroup information on death records. For the states that do, coroner misclassification of race and ethnicity on death certificates is known to be greater for Asian populations (13% of deaths), as compared with Hispanic populations (7%) and Black and White populations (less than 1%).[29] In concordance with these widespread data challenges, Asian people in the U.S. have also been left out of major epidemiological cohort studies on chronic diseases and omitted in clinical trials.[29]

The population of people of Asian descent has increased from 3.5 million in 1980 to 23 million in 2022, with an estimated 60% of people of Asian descent living in the U.S. born outside of the country.[27] As of the 2020 Census, the Asian population in the U.S. is distributed as shown in **Table 2-4**, showing a diverse Asian diaspora. The largest population within this category alone or in any combination is Chinese, except Taiwanese, followed by Asian Indian.

Extant analysis of Census data shows that between 2010 and 2020 the Asian Indian (alone) population increased more than 50% to become the largest Asian (alone) population, to 4.4 million people.[31] The next largest Asian (alone) subgroup was Chinese, except Taiwanese alone, which increased 32% to a total of 4.1 million people. Among Asian subgroups, the fastest growth was seen among the Nepalese (alone) population, which grew nearly threefold (295.5%) over the past decade.[31] The only two subgroups to decrease were Japanese alone and Laotian alone, but Japanese in combination and Laotian in combination both increased.[31]

Figure 2-7 illustrates the age distribution of Asian women over time. The figure shows that the total population of Asian women is aging over time, similar to that of women of other racial and ethnic groups. ACS data show that in 2021 nearly 90% of Asian women (8,602,796) reported past-year income that was at or above the U.S. poverty level, with just over 10% (1,020,650) reporting incomes below the poverty level (see **Chapter 3**, for more detail on ACS as a data source).[23] More than 98% of Asian women (9,553,476) live in non-rural areas, while 2% (242,815) live in rural areas.[23] **Figure 2-8** shows the percent of Asian population by state. It shows that in Hawaii, Asian people comprise more than one third of the state's population. Asian people represent 15% of California's population followed by smaller proportions in New Jersey, New York, and Washington.

Table 2-4: Detailed Asian group counts

Source: Census Bureau, Census Detailed Demographic and Housing Characteristics File A, 2020

Detailed group	Count (Alone)	Percent (Alone)	Count (Alone or in Combination)	Percent (Alone or in Combination)
Afghan	129,949	0.7%	190,389	0.8%
Asian Indian	4,397,737	23.3%	4,768,846	19.8%
Bangladeshi	256,519	1.4%	273,050	1.1%
Bhutanese	39,565	0.2%	46,146	0.2%
Bruneian	107	0.0%	227	0.0%
Burmese	258,595	1.4%	276,322	1.1%
Buryat	560	0.0%	855	0.0%
Cambodian	280,364	1.5%	364,006	1.5%
Chinese, except Taiwanese	4,128,718	21.8%	5,205,461	21.6%
Filipino	3,076,108	16.3%	4,436,992	18.4%
Hmong	315,707	1.7%	335,919	1.4%
Indonesian	85,118	0.5%	153,115	0.6%
Japanese	741,544	3.9%	1,586,652	6.6%
Kalmyk	553	0.0%	951	0.0%
Kazakh	12,877	0.1%	19,080	0.1%
Korean	1,508,575	8.0%	1,989,519	8.3%
Kuki	62	0.0%	108	0.0%
Kyrgyz	7,036	0.0%	8,785	0.0%
Lahu	1,954	0.0%	2,339	0.0%
Laotian	188,906	1.0%	254,151	1.1%
Malay	1,639	0.0%	3,761	0.0%
Malaysian	25,429	0.1%	43,580	0.0%
Maldivian	151	0.0%	733	0.0%
Mien	17,915	0.1%	22,557	0.1%
Mizo	300	0.0%	914	0.0%
Mongolian	28,383	0.2%	40,182	0.2%
Nepalese	205,297	1.1%	219,503	0.9%
Pakistani	618,037	3.3%	687,942	2.9%
Pashtun	364	0.0%	1,175	0.0%
Sikh	48,321	0.3%	70,697	0.3%
Sindhi	185	0.0%	661	0.0%
Singaporean	8,131	0.0%	13,462	0.1%
Sri Lankan	69,694	0.4%	85,785	0.4%
Tai Dam	1,361	0.0%	2,834	0.0%
Taiwanese	259,317	1.4%	333,289	1.4%
Tajik	3,507	0.0%	8,245	0.0%
Thai	201,377	1.1%	326,758	1.4%
Timorese	67	0.0%	163	0.0%
Turkmen	1,452	0.0%	3,270	0.0%
Uzbek	30,716	0.2%	53,374	0.2%
Vietnamese	1,951,746	10.3%	2,293,392	9.5%

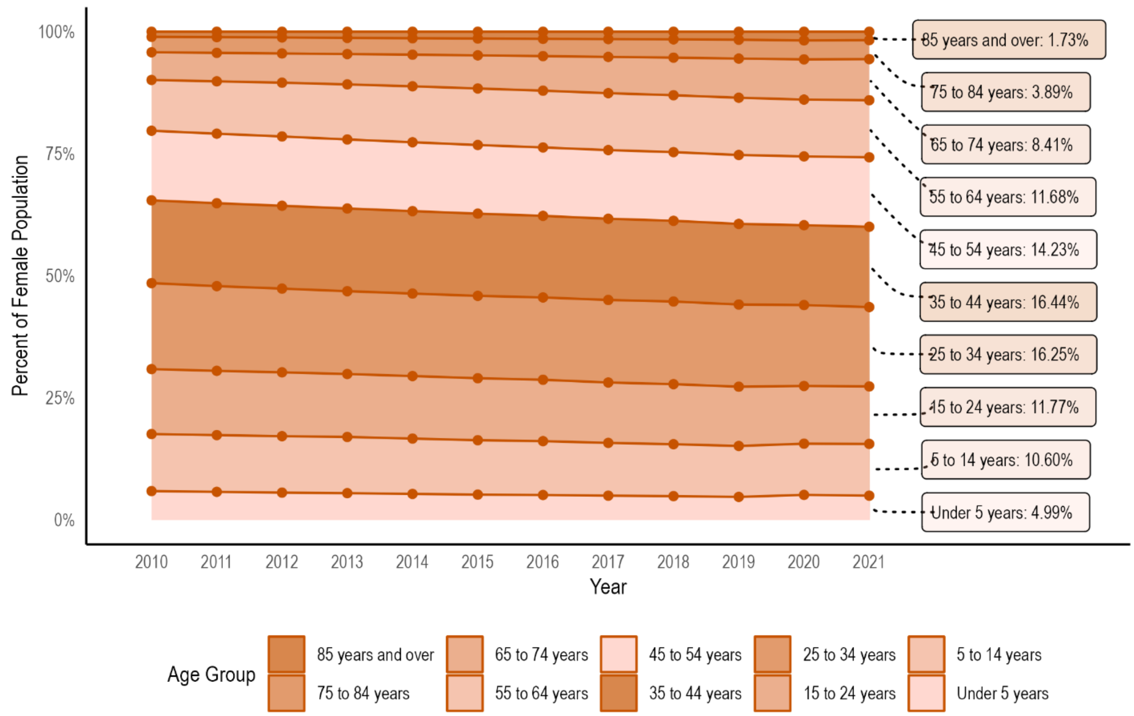

Figure 2-7: Age distribution of Asian women over time
Source: Census Bureau, American Community Survey (ACS) 5-year, 2010-2021

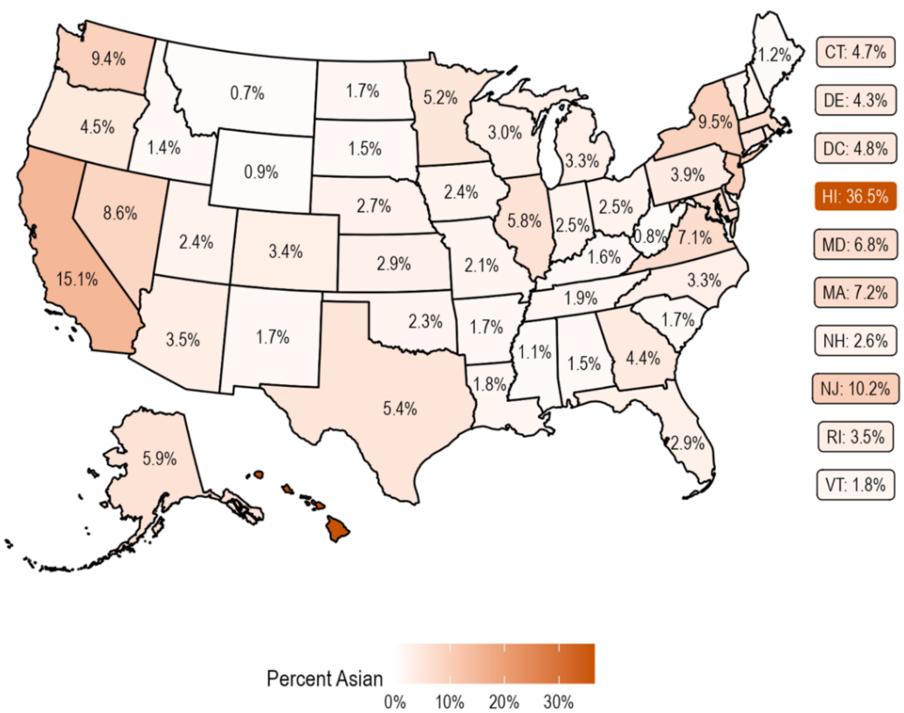

Figure 2-8: Percent of Asian population by state
Source: Census Bureau, Decennial Census, 2020

2.2.3 Native Hawaiian and Pacific Islander Populations

The history of contemporary Native Hawaiian populations is largely informed by colonization, starting with the underreporting of indigenous Hawaiians in the 1700s.[32] In 1900, Hawaii became a territory of the U.S. and started to be counted in the Census, with the categories "Hawaiian" and "Part-Hawaiian." The "Part-Hawaiian" category was later eliminated in 1970, which resulted in many people selecting another race, resulting in a "paper genocide."[33]

NHPI populations still face "the systematic erasure of Indigenous and marginalized peoples from population data."[34] The NHPI population experiences multiple layers of harm as a result of data aggregation practices. According to the 2021 ACS, a majority of Native Hawaiians also identify as at least one other race. Thus, over half of Native Hawaiians are made invisible in the data when combined with all other Multiracial populations. Similarly, when the Pacific Islander population is grouped with the Native Hawaiian population, any aggregate NHPI statistic primarily reflects the experience of the larger Native Hawaiian population—concealing any disparities.[34] Many of these NHPI groups have less access to healthcare (e.g., cancer prevention and control programs), which results in worse health outcomes.[35]

The composition of NHPI populations is shown in **Table 2-5**. Among all NHPI subgroups, Polynesian people comprise the largest populations, both alone or in any combination, followed by Micronesian and other NHPI groups not specified. Analysis of Census data shows that nearly all NHPI subgroups grew between 2010 and 2020.[36] The Native Hawaiian alone or in any combination population remained the largest group, growing by 29% to 527,000.[36] The fastest growth over the past decade was seen among the Chuukese alone (296%) and Papua New Guinean alone or in any combination (249%) populations.[36] This increase may be due in part to organizations like Count Us In that created culturally and linguistically competent resources for different communities in order to ensure a more representative count in the 2020 Census.[37]

Figure 2-9 illustrates the age distribution of NHPI women over time. The figure shows that the total population of NHPI women is aging over time, similar to that of women of other racial and ethnic groups. ACS data show that in 2021, 18% of NHPI women (53,397) reported past-year income below the U.S. poverty level, while the other 82% (244,991) reported incomes at or above this level.[23] About 10% of NHPI women (30,935) live in rural areas, while the majority (274,106) live in non-rural areas.[23]

Figure 2-10 illustrates the percent of NHPI individuals by state. The highest concentration of NHPI people is found in Hawaii, where they comprise 10% of the state's population. Alaska and Utah are the only other states where NHPI people are more than 1% of the population.

Table 2-5: Detailed NHPI group counts

Source: Census Bureau, Census Detailed Demographic and Housing Characteristics File A, 2020

Detailed group	Count (Alone)	Percent (Alone)	Count (Alone or in Combination)	Percent (Alone or in Combination)
Polynesian	**401,659**	**100.0%**	**988,519**	**100.0%**
Cook Islander	100	0.0%	545	0.1%
Easter Islander	55	0.0%	208	0.0%
French Polynesian	207	0.1%	754	0.1%
Maori	1,034	0.3%	7,664	0.8%
Native Hawaiian	199,880	49.8%	680,442	68.8%
Niuean	126	0.0%	569	0.1%
Rotuman	81	0.0%	377	0.0%
Samoan	133,148	33.1%	256,997	26.0%
Tahitian	882	0.2%	7935	0.8%
Tokelauan	44	0.0%	1,207	0.1%
Tongan	48,536	12.1%	78,871	8.0%
Tuvaluan	132	0.0%	399	0.0%
Wallisian and Futunan	8	0.0%	56	0.0%
Other Polynesian	2,534	0.6%	9,092	0.9%
Micronesian	**197,723**	**100.0%**	**298,892**	**100.0%**
Carolinian	531	0.3%	1,366	0.5%
Chamorro	70,704	35.8%	143,947	48.2%
Chuukese	10,500	5.3%	12,464	4.2%
Guamanian	10,583	5.4%	24,279	8.1%
I-Kiribati	291	0.1%	831	0.3%
Kosraean	1,644	0.8%	2,148	0.7%
Marshallese	47,300	23.9%	52,624	17.6%
Nauruan	23	0.0%	68	0.0%
Northern Mariana Islander	247	0.1%	553	0.2%
Palauan	7,431	3.8%	12,202	4.1%
Pohnpeian	3,809	1.9%	4,918	1.6%
Saipanese	514	0.3%	1,143	0.4%
Yapese	1,321	0.7%	2,066	0.7%
Other Micronesian	40,078	20.3%	45,364	15.2%
Melanesian	**37,217**	**100.0%**	**57,112**	**100.0%**
Fijian	36,285	97.5%	54,006	94.6%
New Caledonian	91	0.2%	265	0.5%
Ni-Vanuatu	101	0.3%	262	0.5%
Papua New Guinean	568	1.5%	1,453	2.5%
Solomon Islander	96	0.3%	220	0.4%
Other Melanesian	126	0.3%	937	1.6%
Other Native Hawaiian and Other Pacific Islander, not specified	**48,061**	**100.0%**	**261,391**	**100.0%**

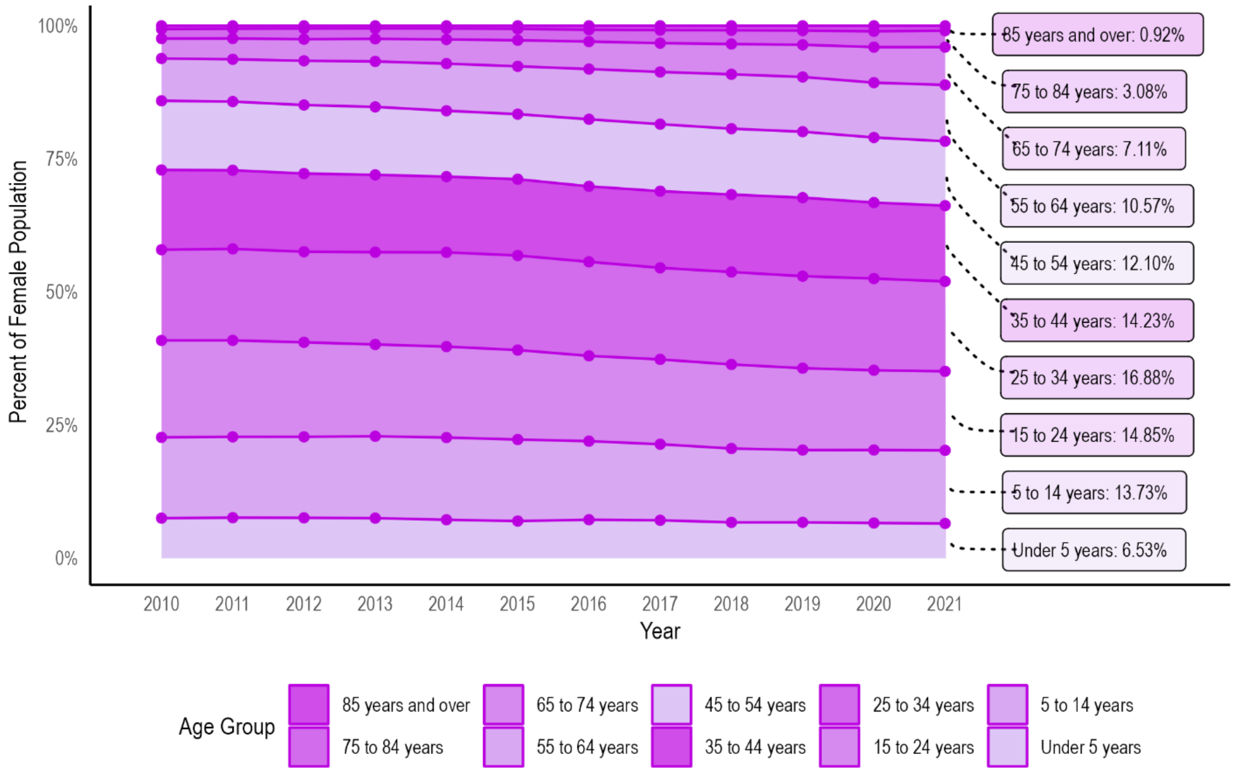

Figure 2-9: Age distribution of NHPI women over time

Source: Census Bureau, American Community Survey (ACS) 5-year, 2010-2021

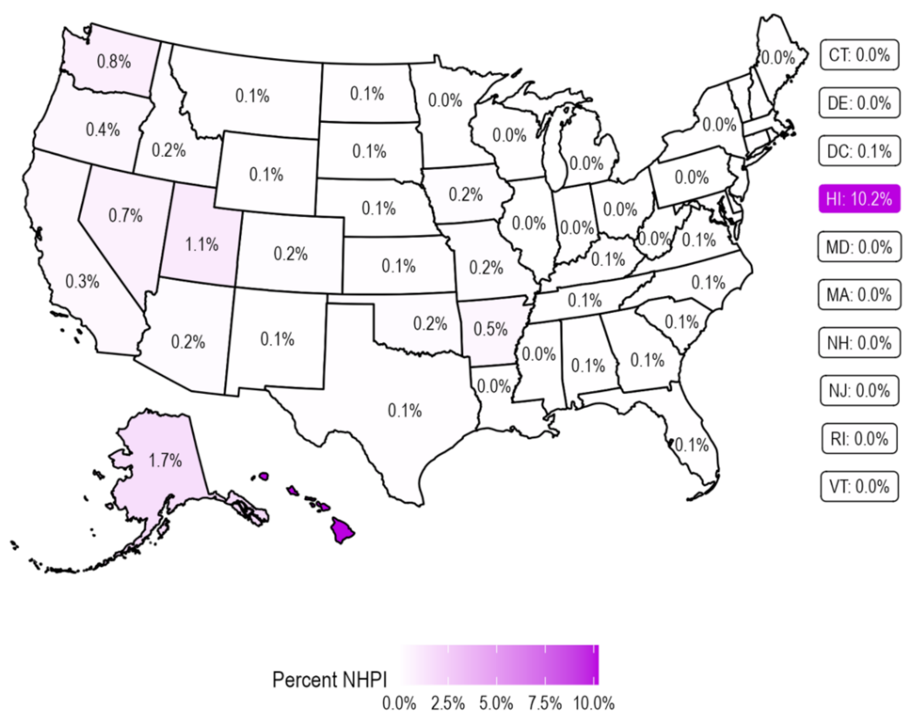

Figure 2-10: Percent of NHPI population by state

Source: Census Bureau, Decennial Census, 2020

Past population surveys have cited an inability to recruit enough NHPI respondents, focusing in turn on more easily accessible Asian subgroups and extrapolating findings—which additionally misconstrues and masks the unique health differences of NHPI populations. While there are still many gaps in the research of health disparities in the NHPI population, some progress has been made including the 1993 National Institutes of Health Revitalization Act, which established guidelines to include women and people from underrepresented racial and ethnic communities in clinical research and spurred significant findings for the NHPI population.[38] Further structural and institutional changes to create culturally competent study recruitment material and introduce community-based participatory approaches will advance the accurate documentation, equitable treatment, and improved health outcomes of NHPI individuals.[38]

2.2.4 Black or African American Populations

Beginning in the early 1500s, European colonizers abducted more than 12 million Africans and trafficked them to the Americas through the trans-Atlantic slave trade.[39] These Africans were enslaved and forced to suffer generations of physical, social, and mental brutalization.[39,40] When slavery was abolished in the U.S. nearly 400 years later, systematic discrimination and oppression persisted and continues to exacerbate the health status of American descendants of slavery today. Voluntary migration from sub-Saharan Africa to the U.S. began in the 1980s, roughly doubling each decade between 1980 and 2010.[41] Since the 1780s, when Black and African American persons were considered only 3/5 of a "free person," how society racializes status has been a key driver of health and health-related outcomes.[42,43] This is evident in the deception and abuse of Black research subjects during the Tuskegee syphilis study, the long-term harms of historical redlining on the environmental and economic health of Black families today, and centuries of other mistreatment that has had intergenerational effects (see **Chapter 1**).[42,43]

The development of the current approach to racial identification on Census forms has a long and complex history, with notable shifts in language identifying racial and ethnic categories including Black and African American persons.[44] When the U.S. Census first launched in 1790, the racial categories for the household population were "free white" persons, other "free persons" by color, and "slaves"—identified without the use of standard forms.[44] During 1850−1880, the codes white (W), black (B), and mulatto (M) were used; and the term "negro" appeared for the first time in the 1900 Census instruction manual, though it was not listed in the Census form itself.[44] Not until 1960 did the Census Bureau begin to use forms similar to those of the present day, a single form for an entire household, and capture "color or race" with categories; these included: "White, Negro, American Indian, Japanese, Chinese, Filipino, Hawaiian, Part Hawaiian, Aleut, [and] Eskimo." Notably, "black" did not appear on the form. Census-trackers were instructed to complete the race item by observation and were directed to indicate persons with Latin descent as "White" unless definitely "Negro," "Indian," or some other race.[44] In 1970, self-identification was fully put into place and the evolution of racial and ethnic categories continued, modifying the "Negro" category to "Black or Negro"—and then to "Black, African American, or Negro" in 1990.[44] The 2020 Census dropped the word "Negro," yielding a "Black or African American" response option.[45]

Noting the consequential impact of racial status in the U.S., as well as the history of associated questions in the U.S. Census, there are major concerns with how racial data are assessed and the quality of information about the Black population.[46] A historical and well-documented concern is Census undercounts and omissions, especially of Black men in their 20s, 30s, and 40s, living in large urban areas.[46,47] In the 2010 Census, the Black population had the highest net undercount rate of any racial or ethnic group (2.5%) with young and middle-aged Black men experiencing the highest rates.[47] Another major concern is with the current changes in racial classification; allowing persons to check multiple racial categories makes it even more difficult to ensure consistency with race categories between the

Census and vital events. For example, the 2010 Census experienced a higher net undercount rate for Black children aged 0-4 than any age group. However, the net undercount rate differed strikingly between "Black Alone" and "Black in Combination."[47] These differences can largely be attributed to inability to align race in birth certificates (where race is defined by the race of the parents) and self-reporting in the Census.[47] Analysis of the 2020 Census reveals a statistically significant undercount of 3.30% for the Black or African American alone or in combination population, which is not statistically different from the 2.06% undercount in 2010.[48]

Figure 2-11 illustrates the age distribution of Black/African American women over time. The figure shows that the total population of Black/African women is aging over time, akin to that of women of other racial and ethnic groups.

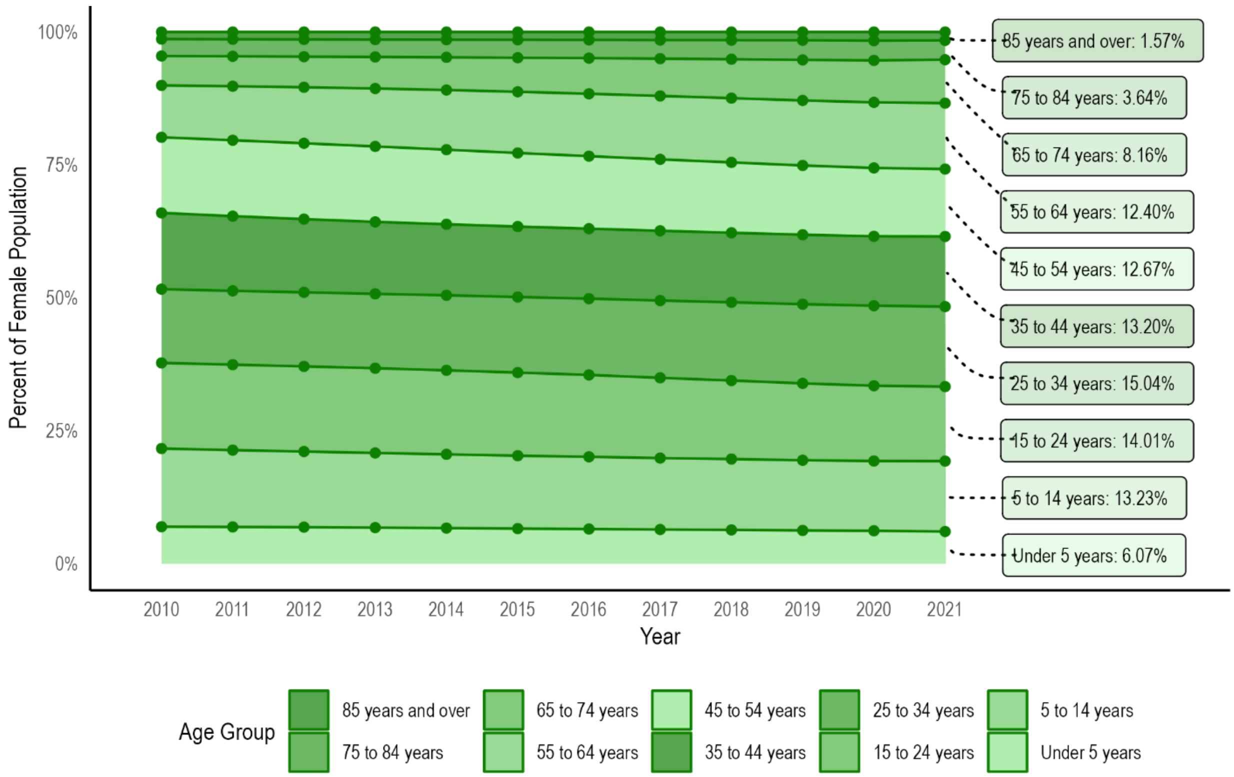

Figure 2-11: Age distribution of Black women over time

Source: Census Bureau, American Community Survey (ACS) 5-year, 2010-2021

Higher quality data is also needed to account for the diversity of the Black population, with implications for variations in health status by ethnic origin. For the first time in Census history, the 2020 Census made available a write-in area with examples for Black or African American people to report detailed responses.[49] Presently, Black or African American alone or in combination is the third largest racial or ethnic group in the U.S. The population breakdown is shown in **Table 2-6**.

Table 2-6: Selected detailed Black or African American group counts

Source: Census Bureau, Census Detailed Demographic and Housing Characteristics File A, 2020

Detailed group	Count (Alone)	Percent (Alone)	Count (Alone or in Combination)	Count (Alone or in Combination)
African American	**22,091,770**	**53.7**	**24,469,479**	**52.3**
Sub-Saharan African	**2,285,543**	**5.6**	**2,818,785**	**6.0**
Nigerian	493,188	1.2	604,077	1.3
Ethiopian	300,108	0.7	325,214	0.7
Somali	209,896	0.5	221,043	0.5
Ghanian	150,442	0.4	172,558	0.4
Caribbean	**2,147,086**	**5.2**	**2,615,988**	**5.6**
Jamaican	811,245	2.0	1,047,117	2.2
Haitian	916,277	2.2	1,032,737	2.2
Trinidadian and Tobagonian	131,109	0.3	194,364	0.4
West Indian	74,964	0.2	119,806	0.3
Other Black or African American	**14,417,192**	**35.1**	**17,167,725**	**36.6**
Other Black or African American, not specified	14,334,854	34.9	17,017,541	36.3

More than half of the Black alone population and Black alone or in combination population reported being African American. The largest sub-Saharan African groups were Nigerian, Ethiopian, Somali, and Ghanian, making up about half of the sub-Saharan African alone and sub-Saharan African alone or in any combination populations. Four Caribbean groups (Jamaican, Haitian, Trinidadian and Tobagonian, and West Indian) made up most of the Caribbean alone and Caribbean alone or in any combination populations. Caribbean alone and Caribbean alone or in any combination is the oldest Black regional group with 13-14% of their populations identifying as 65 and over.

In 2021, 23% of Black women (4,845,514) reported a past-year income that was below the U.S. poverty level, while the majority (77%; 16,171,167) reported incomes at or above this level.[23] It is notable that the proportion of Black women living in poverty is higher than all other racial and ethnic groups except for AI/AN women. Less than 10% of Black women (1,715,140) live in rural areas, compared with over 90% (19,943,837) who live in non-rural areas.[23] **Figure 2-12** shows the distribution of the Black population (men and women) by state in the U.S. in 2020, with the highest proportion in Washington, D.C. (40.9%), Mississippi (36.4%), Louisiana (31.2%) and Alabama (30.6%).

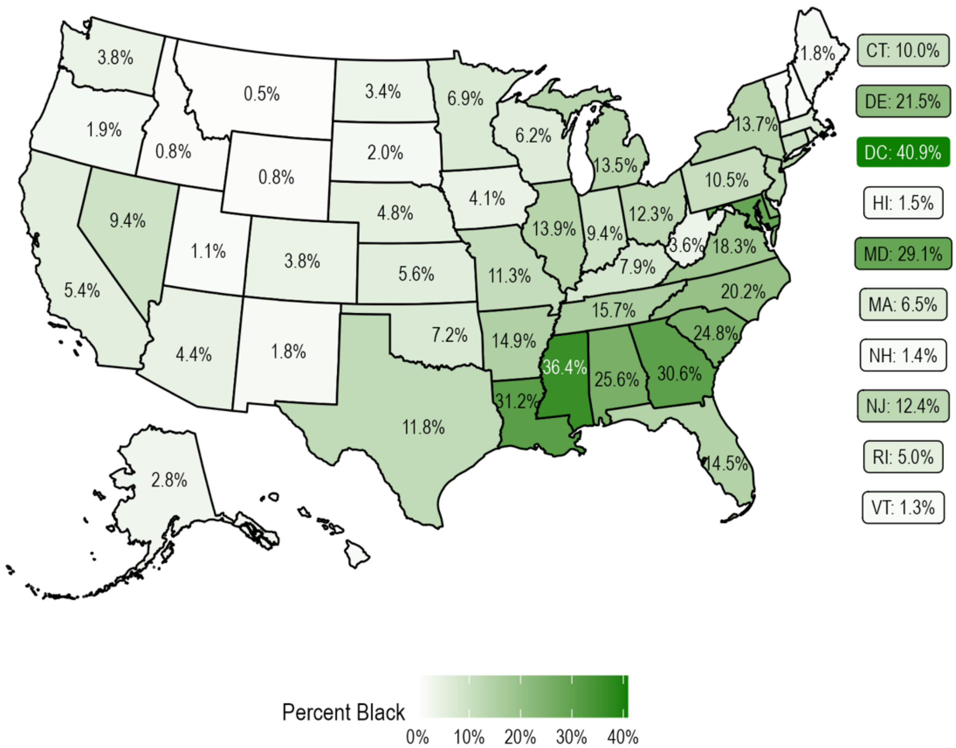

Figure 2-12: Percent of Black population by state
Source: Census Bureau, Decennial Census, 2020

2.2.5 Hispanic Populations

In the past three decades, the Hispanic population has tripled and has become increasingly diverse by national origin.[50] As of the 2020 Census, there are over 62 million individuals identifying as Hispanic or Latino in the U.S., by an increase of 11.6 million between 2010 and 2020. This growth can be attributed to births rather than immigration, as rates of immigration have decreased since the 2000s.[50]

The 1930 Census was the first time the data collection form included the "Mexican" category.[51] This category was then eliminated until 1970 when the Census Bureau first added a question about Hispanic origin to one of the forms sent to a sample population, with the question asking respondents to indicate "Mexican," "Puerto Rican," "Cuban," "Central or South American," "other Spanish," or "No, none of these."[51] This addition in 1970 and subsequent edits in 1980 to the question on Hispanic origin resulted from growing civil rights activism among Mexican American and Puerto Rican communities that centered on articulating that data on the demographic characteristics of these communities (differentiating them from European immigrants) would help address economic, educational, and other disadvantages.[52] By the 2010 Census, the question on Hispanic origin was preceded by instructions to answer both the questions on Hispanic origin and race, including the statement "For this Census, Hispanic origins are not races" and examples of different Hispanic subgroups.[52] Previous omissions of examples of Hispanic subgroups resulted in a miscount of individuals identifying as Salvadorans, Guatemalans, Dominicans, Colombians, etc.[52] Even with these developments in the Hispanic origin and race questions, there remain difficulties with accurately accounting for the Latino population. One of these is the finding that many respondents struggle with answering a separate question about race, often identifying only with their Latino and specific national origin heritage (in other words, "Latino" being equivalent to their race); this was further confirmed in the Census Bureau's 2015 National Content

Test, in which—when the Latino/Hispanic category was combined with other specific race groups—Latinos self-identified solely in the Latino/Hispanic category.[52]

Table 2-7 shows the count and percent of Hispanic populations in the U.S. by origin group. It shows that people of Mexican origin comprise the largest group, more than three times the size of the next largest group, those of Caribbean Hispanic origin.

Table 2-7: Selected Hispanic or Latino group counts

Source: Census Bureau, Census Detailed Demographic and Housing Characteristics File A, 2020

Detailed group	Count	Percent
Mexican	**35,850,702**	**57.7%**
Central American	**5,907,332**	**9.5%**
Costa Rican	167,940	0.3%
Guatemalan	1,669,557	2.7%
Honduran	1,061,585	1.7%
Nicaraguan	406,613	0.7%
Panamanian	215,633	0.3%
Salvadoran	2,342,001	3.8%
Other Central American	44,086	0.1%
South American	**4,048,060**	**6.5%**
Argentinean	276,081	0.4%
Bolivian	123,257	0.2%
Chilean	168,235	0.3%
Colombian	1,286,662	2.1%
Ecuadorian	775,529	1.2%
Paraguayan	26,079	0%
Peruvian	685,730	1.1%
Uruguayan	64,394	0.1%
Venezuelan	605,381	1%
Other South American	36,757	0.1%
Caribbean Hispanic	**10,049,681**	**16.2%**
Cuban	2,245,686	3.6%
Dominican	2,196,076	3.5%
Puerto Rican	5,601,863	9%
Other Caribbean Hispanic	5,839	0%
Other Hispanic, Latino, or Spanish	**6,224,353**	**10%**
Spaniard	978,978	1.6%
Spanish	866,356	1.4%
Spanish American	50,966	0.1%
All other Hispanic or Latino, not specified	2,252,782	3.6%
Hispanic	1,738,931	2.8%
Latino(a)	328,771	0.5%

There is significant variability among Hispanic subgroups across factors such as socioeconomic position, geography, education attainment, income, health behaviors, and cultural traditions. The assumption that the entire Hispanic population fares similarly across these dimensions, including forms of discrimination and health disparities, incorrectly assumes that observations in one subgroup can be generalized to another.[53,54] For example, as compared to other Hispanic subgroups, the Mexican American subgroup experiences a higher rate of diabetes, and the Puerto Rican subgroup experiences higher rates of asthma and infant mortality.[53]

Figure 2-13 shows the distribution of Hispanic women over time, with a gradual increase in the population in older age groups.

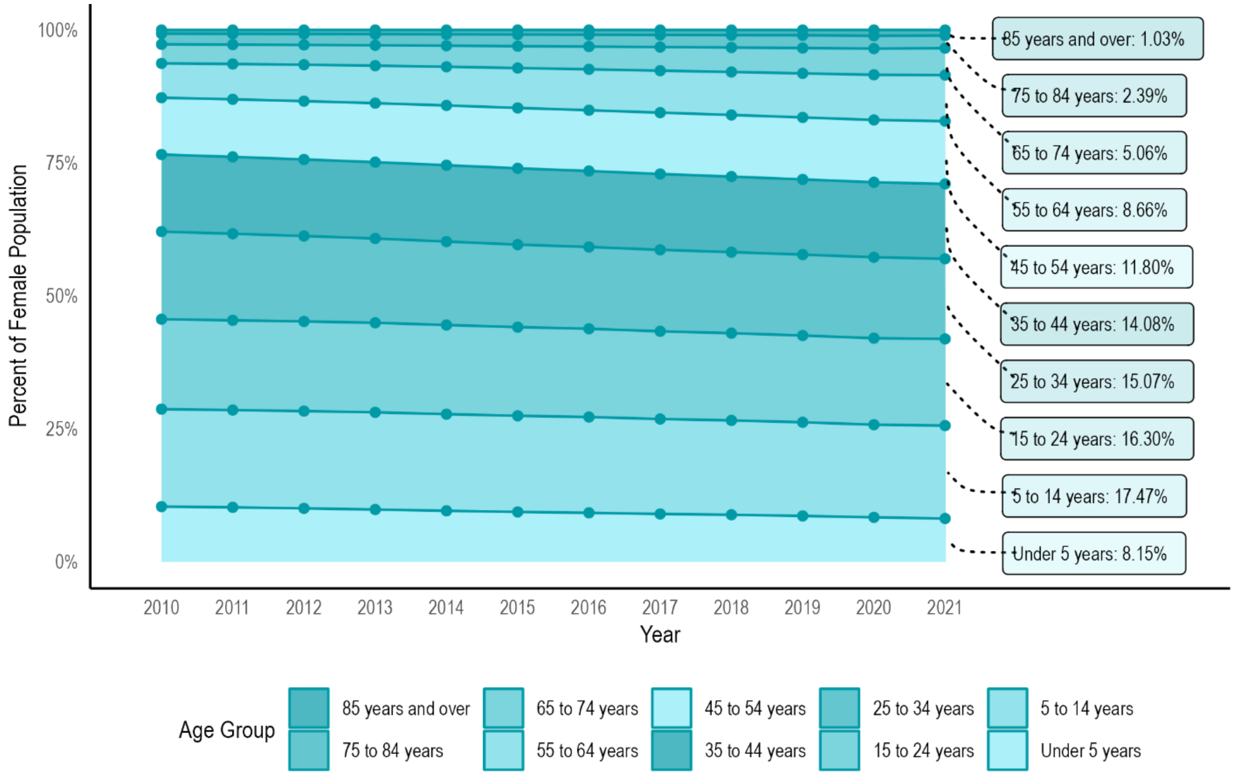

Figure 2-13: Age distribution of Hispanic women over time

Source: Census Bureau, American Community Survey (ACS) 5-year, 2010-2021

ACS data from 2021 show that 19.6% of Hispanic women (5,804,197) reported a past-year income that was below the U.S. poverty level, while the remaining 80.4% (23,823,853) reported incomes at or above this level.[23] **Figure 2-14** shows the percent of Hispanic population by state in 2020, revealing higher concentrations of Hispanic people in the Southwest U.S., California, Texas, Nevada and Florida compared with other regions of the country.

It is also significant to note that the makeup of the U.S. Hispanic population varies tremendously across major metropolitan areas. Overall, people identifying as Mexican make up 60% of U.S. Hispanics—dominating most metro areas in the Midwest, West, and South (with the notable exceptions of Miami and Orlando).[55] In the Northeast metro areas like New York and Boston, no origin group makes up more than 30% of the region's Hispanic population.[55] Other metro areas with distinctive enclaves include Orlando, Florida (Puerto Ricans account for 43% of Hispanic population); Miami, Florida (Cubans account for 40% of Hispanic population); and Washington, D.C. (Salvadorans account for 31% of Hispanic population).[55,56] As of 2021, 29,775,980 Hispanic women live in non-rural areas and 1,961,257 Hispanic women live in rural areas.[23]

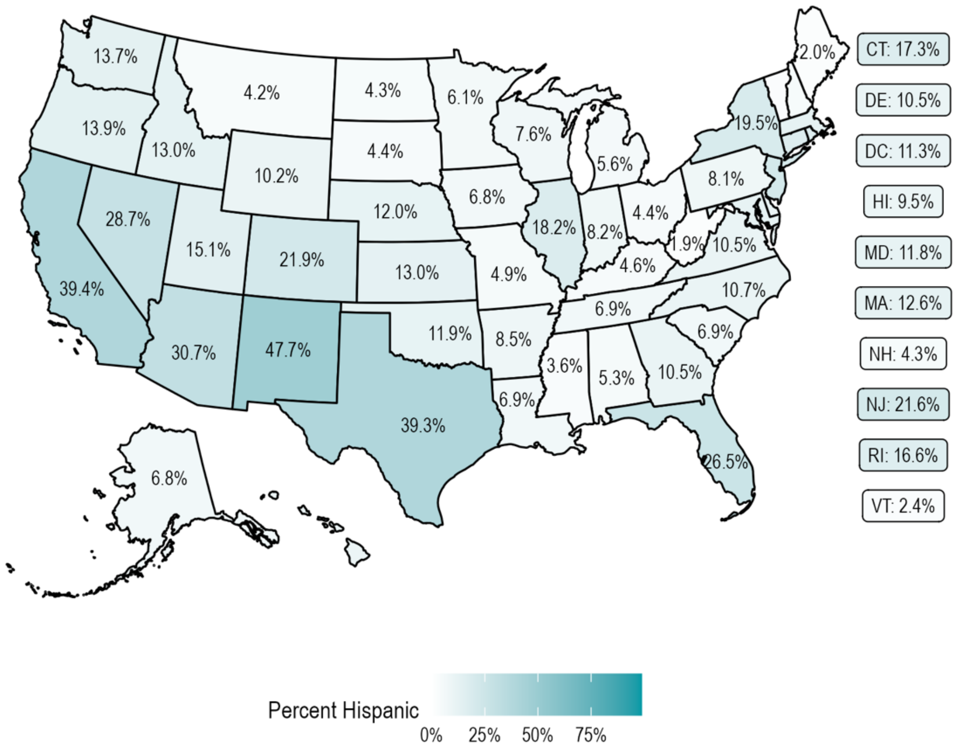

Figure 2-14: Percent of Hispanic population by state
Source: Census Bureau, Decennial Census, 2020

Moreover, even though a majority of the Latino/Hispanic population does not identify with the U.S. race categories, past disaggregated data reveal notable trends in the impact of race on the health of Hispanic population subgroups. Historically, among people identifying as Hispanic, those with a darker skin tone are more likely to be discriminated against (i.e., treated with suspicion, treated unfairly, subject to slurs), receive less education, and hold occupations with lower prestige.[53,57,58] This experience can impact physical and mental health and mortality, with Black (and darker-skinned) Hispanics having worse outcomes compared with White (and fair-skinned) Hispanics.[59,60,] Notably, racial categorization in the U.S. Census among the Hispanic population is likely dependent on nativity status (i.e., U.S. versus foreign-born), length of stay in the U.S., and language spoken; an individual's level of acculturation or assimilation and English proficiency could influence their likelihood of categorizing themselves into the U.S. racial categories.[54,58]

2.2.6 White Populations

The centuries-long migration of populations of European descent to what is now North America dates back as early as the 10th century, though systematic colonization by Europeans did not begin until late in the 15th century.[61] Racial identity was constructed and established in the U.S. through the system of settler colonialism (see **Chapter 1**).[62,63] The 2020 Census was the first time the White racial category (**Table 2-8**) included a write-in response area including German, Irish, English, Italian, Lebanese, and Egyptian as examples. In 2020, the largest subgroup of the White population was people of European descent (120 million White alone or 132 million White alone or in combination). The second largest subgroup was "other White," a group whose heritage is not Middle Eastern and North African (MENA). Of this "other White" subgroup, more than 90% are in the "other White not specified" category. Studies show that, despite being classified in the Census as "White," people with MENA heritage consistently report lived experiences and health outcomes that are significantly different from those of other non-Hispanic White populations. Since at least the 1880s, MENA people have immigrated to the U.S. and experienced systemic-level stigma and discrimination (e.g., Islamophobia, xenophobia), which increased following the 9/11 terrorist attack and subsequent political events including the Muslim travel ban and anti-immigration policies.[64,65] The 2020 change in Census categories was the first step in identifying the previously-invisible barriers that Americans identifying as MENA face in their daily lives. The detailed counts for the reported MENA populations are shown in **Table 2-8**, and reflect geographic-based classifications and the inclusion of Arabic-speaking groups (e.g., Egyptian, Jordanian), non-Arabic groups (e.g., Iranian, Israeli), and ethnic and transnational groups (e.g., Assyrian, Kurdish).

The largest three MENA groups, in total representing 46.9% of the 3.5 million people in the MENA alone or in any combination category, were Lebanese, Iranian, and Egyptian.[66] The Lebanese population was the largest MENA alone or in any combination group, accounting for 20% of the MENA alone or in combination population.[66] The Iranian population was the largest MENA alone group and the second largest MENA alone or in any combination group. Egyptian was the third largest MENA group, accounting for 12% and 11.3% of the MENA alone population and MENA alone or in any combination group, respectively.[66] The next largest groups (all with populations over 100,000) were those classified as "Other Middle Eastern and North African," "Arab," Syrian, Iraqi, Israeli, Palestinian, Moroccan, and Jordanian.[66]

Figure 2-15 shows the age distribution of White women over time. The data show flat proportions over time for women 44 years of age and younger, as well as aged 75 and older. The proportion of women who are 45-54 decreased over time, while those 65-74 comprised a larger proportion of the White female population in 2021 than in 2010.

In 2021, 10% of White women (9,830,827) reported past-year income below the U.S. poverty level, while 90% (86,941,914) reported past-year income at or above the poverty level.[23] These rates are on par with those observed for Asian women and are lower than rates for all other racial and ethnic groups. Geographically, just over 16% of White women (18,624,449) live in rural areas, while the majority (84%; 95,395,234) live in non-rural areas.[23] **Figure 2-16** shows the percent of White population by state in 2020. It shows that White people still comprise the majority of the population in nearly all states, with California, Hawaii, Maryland, New Mexico, Nevada, and Texas as the only exceptions. The highest concentration of White population is in Maine, followed closely by Vermont, West Virginia, and New Hampshire.

Table 2-8: Selected White group counts

Source: Census Bureau, Census Detailed Demographic and Housing Characteristics File A, 2020

Detailed group	Count (Alone)	Percent (Alone)	Count (Alone or in combination)	Percent (Alone or in combination)
White of European descent	**120,113,090**	**100.0%**	**132,046,363**	**100.0%**
Middle Eastern and North African	**2,544,154**	**100.0%**	**3,522,478**	**100.0%**
Algerian	30,439	**1.2%**	38,186	**1.1%**
Arab	170,437	**6.7%**	238,921	**6.8%**
Assyrian	42,372	**1.7%**	57,944	**1.6%**
Bahraini	673	**0.0%**	973	**0.0%**
Berber	1,750	**0.1%**	3,871	**0.1%**
Chaldean	47,029	**1.8%**	59,045	**1.7%**
Egyptian	313,720	**12.3%**	396,854	**11.3%**
Emirati	1,931	**0.1%**	2480	**0.1%**
Iranian	413,842	**16.3%**	568,564	**16.1%**
Iraqi	179,252	**7.0%**	212,875	**6.0%**
Israeli	137,023	**5.4%**	190,066	**5.4%**
Jordanian	102,919	**4.0%**	121,917	**3.5%**
Kurdish	19,755	**0.8%**	25,466	**0.7%**
Kuwaiti	5,204	**0.2%**	6,923	**0.2%**
Lebanese	328,137	**12.9%**	685,672	**19.5%**
Libyan	10,895	**0.4%**	13,681	**0.4%**
Moroccan	98,838	**3.9%**	147,528	**4.2%**
Omani	868	**0.0%**	1,336	**0.0%**
Palestinian	132,935	**5.2%**	174,887	**5.0%**
Qatari	452	**0.0%**	650	**0.0%**
Saudi	22,404	**0.9%**	30,563	**0.9%**
Syriac	1,670	**0.1%**	2,413	**0.1%**
Syrian	122,194	**4.8%**	222,196	**6.3%**
Tunisian	10,667	**0.4%**	15,270	**0.4%**
Yazidi	444	**0.0%**	630	**0.0%**
Yemeni	73,692	**2.9%**	91,288	**2.6%**
Other Middle Eastern and North African	228,229	**9.0%**	292,612	**8.3%**
Other White	**80,026,437**	**100.0%**	**101,683,636**	**100.0%**
Afrikaner	1,016	**0.0%**	2,272	**0.0%**
Australian	66,158	**0.1%**	119,495	**0.1%**
Cajun	82,330	**0.1%**	132,624	**0.1%**
Canadian	255,012	**0.3%**	580,491	**0.6%**
French Canadian	255,555	**0.3%**	933,740	**0.9%**
Greenlandic	103	**0.0%**	214	**0.0%**
New Zealander	13,527	**0.0%**	25,232	**0.0%**
Other White, not specified	76,293,559	**95.3%**	96,576,586	**95.0%**
Other White, specified	2,970,733	**3.7%**	3,149,168	**3.1%**
Pennsylvania German	86,856	**0.1%**	169,821	**0.2%**

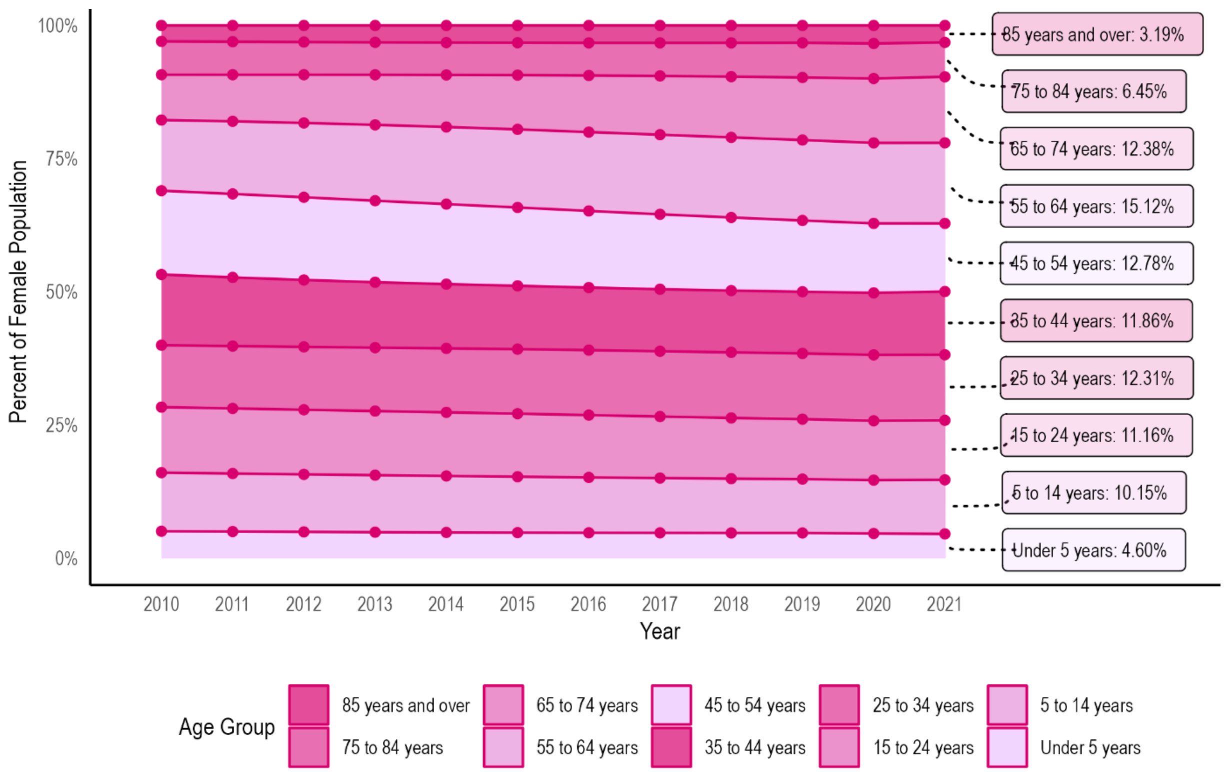

Figure 2-15: Age distribution of White women over time

Source: Census Bureau, American Community Survey (ACS) 5-year, 2010-2021

2.2.7 Multiracial Populations

Since the 1960s, the Census has attempted to define and report on multiracial categories. Enumerators were at first instructed to report individuals who were both White and any other race as the minority race; until respondents could select their own race, there was not a standard or reliable protocol for enumerators to delineate a person's race (relying solely on visual inspection and biased judgement).[67] Beginning in 2000, respondents were instructed for the first time that they could mark more than one single-race category to identify themselves.[67] Today, the Multiracial population is the fastest growing race category, more than doubling between 2010 and 2020.[22] This is due in part to improved data collection measures, which allow individuals to self-identify more accurately.[22] **Table 2-9** shows the 10 most common combinations reported by respondents who identified with two or more races in the 2021 ACS. The data show a total of almost 40 million people identifying as Multiracial, with the largest subcategory of respondents identifying as both a race other than those listed (i.e., SOR) and White. This group is seven times larger than the next largest group, which comprises people who identified as both Black and White. Out of the top 10 groupings, seven include White in combination with other races, while five include AI/AN, Black, or another unspecified race in combination with others. It is notable that among the top 10 groupings, none include individuals who identify as NHPI.

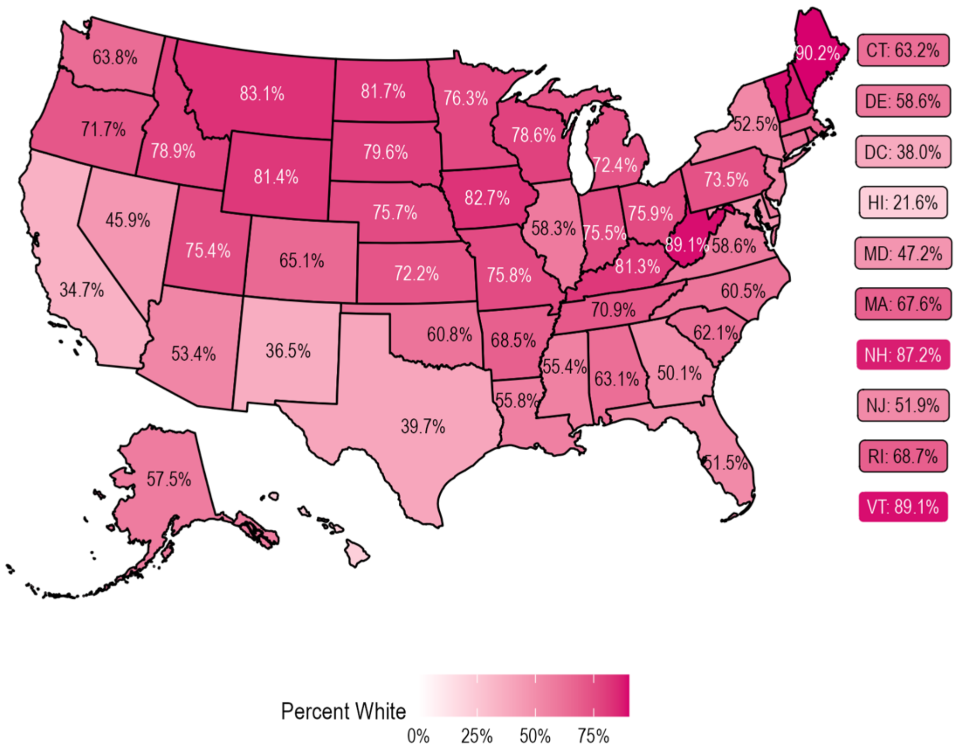

Figure 2-16: Percent of White population by state

Source: Census Bureau, Decennial Census, 2020

Table 2-9: Top 10 groupings for two or more races

Source: Census Bureau, American Community Survey (ACS) 1-Year, 2021

Detailed Race Grouping	Estimate	Margin of Error	AI/AN	Asian	Black	NHPI	White	Other
Some Other Race; White	26,508,463	±142,155	-	-	-	-	X	X
Black or African American; White	3,569,990	±56,560	-	-	X	-	X	-
American Indian or Alaska Native; White	3,212,437	±35,778	X	-	-	-	X	-
Asian; White	2,773,539	±43,289	-	X	-	-	X	-
Black or African American; Some Other Race	1,269,379	±38,915	-	-	X	-	-	X
American Indian or Alaska Native; Some Other Race; White	613,648	±26,831	X	-	-	-	X	X
Black or African American; Some Other Race; White	465,583	±21,371	-	-	X	-	X	X
American Indian or Alaska Native; Black or African American	462,571	±19,970	X	-	X	-	-	-
American Indian or Alaska Native; Black or African American; White	461,630	±18,518	X	-	X	-	X	-
American Indian or Alaska Native; Some Other Race	346,787	±20,072	X	-	-	-	-	X

Analysis of Census data suggests that the ability to mark more than one race has had the largest impact on the NHPI and AI/AN populations. From 2000 to 2010, the NHPI population had the largest percentage (56%) of people reporting one or more other races, followed by the AI/AN population (44%).[68] The availability of this information is important in that it may reveal key differences between the socio-structural conditions and health outcomes of, for example, an AI/AN person identifying as single race versus multiple races.

Figure 2-17 illustrates the age distribution of Multiracial women over time. The figure shows that the Multiracial women is aging over time while the proportion remained both small and stable for age groups 75 and older.

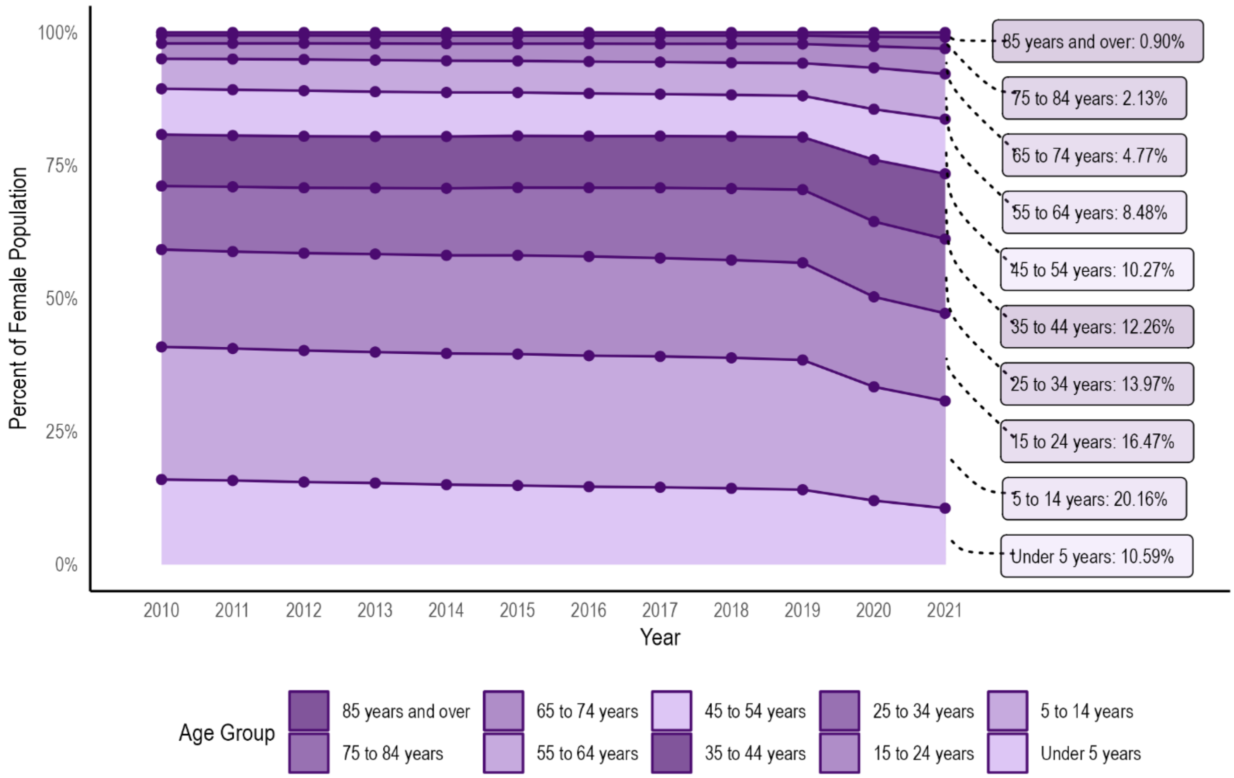

Figure 2-17: Age distribution of Multiracial women over time

Source: Census Bureau, American Community Survey (ACS) 5-year, 2010-2021

Among Multiracial women, 16% (1,826,029) reported past year income below the U.S. poverty level and 84% (9,494,179) reported income at or above the U.S. poverty level.[23] This was lower than the poverty rates for most other racial and ethnic groups except for Asian and White women. More than 90% of Multiracial women (10,764,025) live in non-rural areas and the remaining minority (9%; 1,032,747) live in rural areas.[23] **Figure 2-18** shows the distribution of the Multiracial population (men and women) by state in 2020. The data reveal that Hawaii is the state where Multiracial people comprise a larger share of the population (20%) than any other state, double that of the next two states, Alaska and Oklahoma.

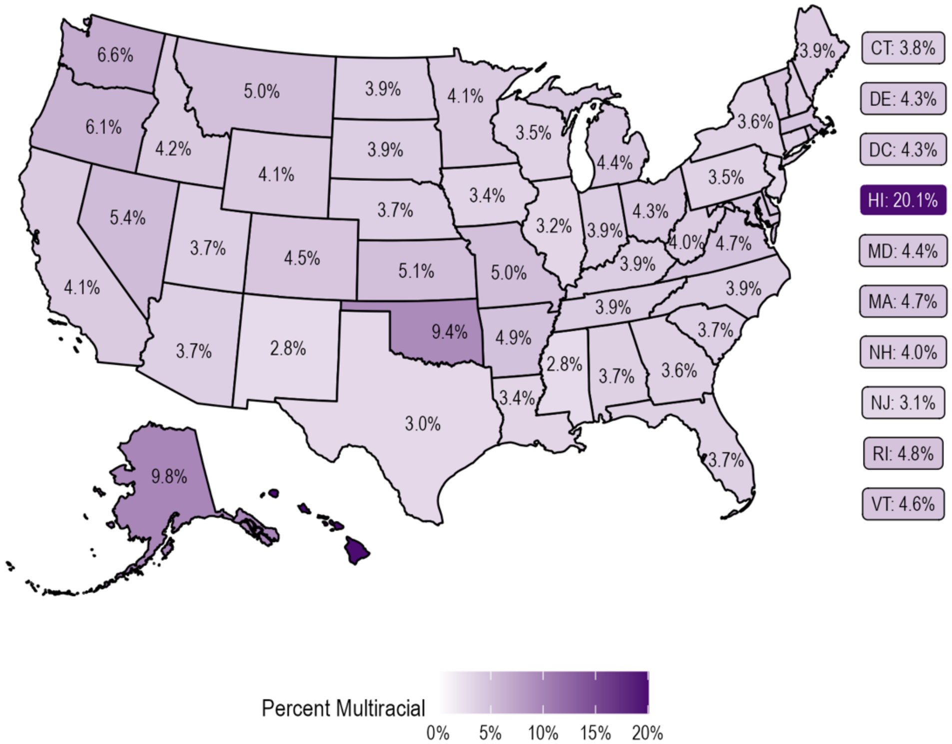

Figure 2-18: Percent of Multiracial population by state
Source: Census Bureau, Decennial Census, 2020

Census data show that the multiple-race AI/AN population has a different regional population dispersion pattern compared with the AI/AN alone population, and geography is a social determinant of health; as of 2010, there was a higher proportion of multiple-race AI/AN individuals living in the Northeast and a larger proportion of AI/AN alone individuals living in the West.[68]

2.2.8 Populations of Other Races

In 1910, Census workers identified people's race by observation, and the option to write "Ot" indicated that the person did not fall within the provided categories for race.[44] At the time, this category was not expected to result in large numbers. For the first time in the 2000 Census, respondents were able to mark SOR if they did not identify with the five OMB race categories, and write in their desired entry (e.g., Moroccan, South African, Belizean, or a Hispanic origin).[69] That year, an estimated 15.4 million people, 5% of the total U.S. population, identified as SOR.[69]

In 2020, for the first time in the U.S. Census Bureau history, officials counted 22 detailed groups classified as SOR. **Table 2-10** shows the five largest non-Hispanic SOR alone groups according to 2020 Census Bureau data.

Brazilian was the largest SOR group reported, followed by Guyanese, Cabo Verdean, Belizean, and Mauritanian. Write-in responses including "Mixed," "Biracial," or "Multiracial" are also counted into the SOR population, and the 2020 Census saw 467,447 Multiracial and Multiethnic write-in responses alone; of these, 63% reported being "Mixed," followed by "Biracial" and "Multiracial." ACS 5-year data show that 21% of women of other races (1,878,590) reported an income in the past 12 months to be below the U.S. poverty level and 79% (6,961,563) women of other races reported income in the past 12 months that was at or above the U.S. poverty level.[23] Distributed across metropolitan and nonmetropolitan areas, 453,409 women of other races live in rural areas and 8,867,437 women of other races live in non-rural areas.[23]

Table 2-10: Five largest non-Hispanic, Some Other Race alone groups

Source: Census Bureau, Census Detailed Demographic and Housing Characteristics File A, 2020

Detailed group	Count (Alone)	Count (Alone or in combination)
Brazilian	145,180	524,382
Guyanese	70,592	205,735
Cabo Verdean	29,507	113,022
Belizean	11,311	48,618
Mauritanian	1,013	5,644

Figure 2-19 depicts the age distribution of women of Some Other Race over time. The figure shows a gradual increase in the population in older age groups over time with a plateau in 2020-2021.

Figure 2-20 shows the distribution of the population of Some Other Race by state in 2020. The overall proportions are lower than for any other racial or ethnic group, and the largest proportion was in Massachusetts (1.3%), followed by New York and Rhode Island (1%).

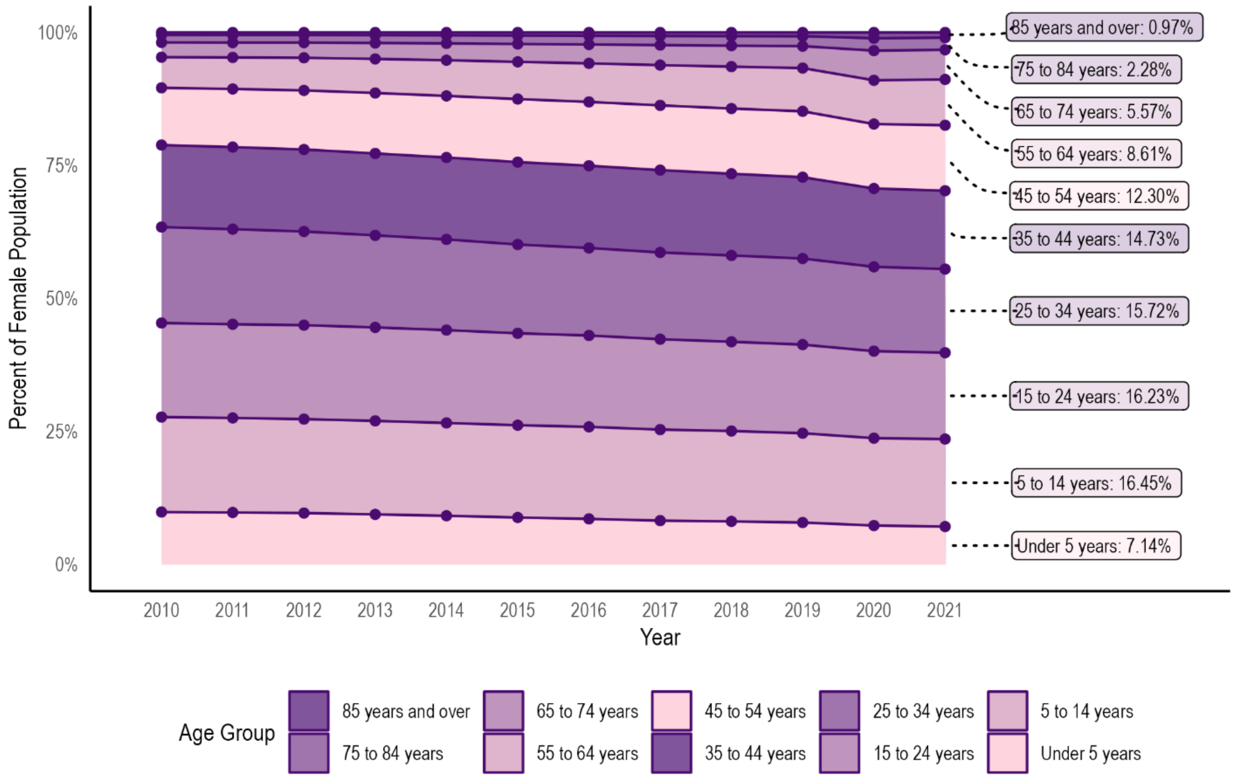

Figure 2-19: Age distribution of Some Other Race women over time

Source: Census Bureau, American Community Survey (ACS), 2010-2021

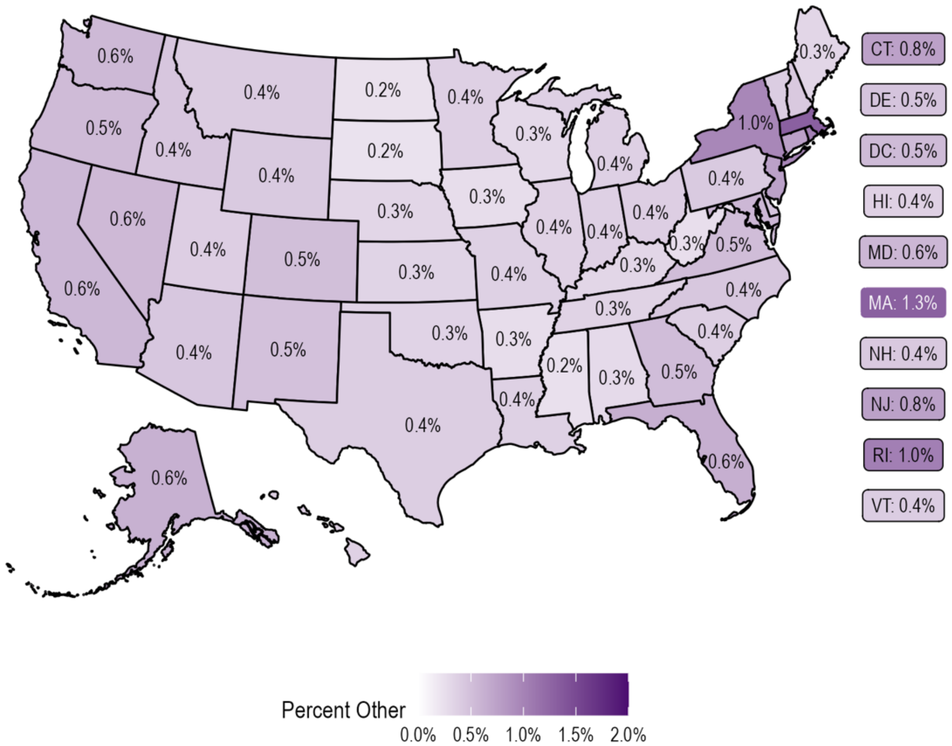

Figure 2-20: Percent of Some Other Race population by state

Source: Census Bureau, Decennial Census, 2020

Notable geographic trends include that nearly 12% of these responses were reported in the state of California with the term "Mixed" most often reported in the state; the term "Biracial" was most often reported in Ohio, Florida, and Pennsylvania.[70]

It is clear that this "other" category does not provide an accurate designation, translating to the real impacts of leaving entire populations out when tabulating morbidities and mortalities for all health outcomes. This concern has surfaced conversations about the problem of asking two separate questions on race and ethnicity in the Census with the finding that using a single combined question for race and ethnicity in the future would yield a more accurate portrait of the U.S. population, particularly for the large population who have self-identified as multiracial or multiethnic.[71]

2.3 Other U3 Populations

The U3 framework presented in **Chapter 1** illustrates the criticality of recognizing the intersecting identities held by women of underrepresented racial and ethnic communities. The framework prioritizes improving research and reporting by race and ethnicity about women: in economically disadvantaged groups who live in rural areas, and of SGM groups. The sections below provide population estimates for each of these groups by race and ethnicity.

2.3.1 Women in Underserved Rural Areas

As is discussed throughout this book, location and the built environment are core drivers of health outcomes (see **Chapter 1**), with women living in rural areas facing greater barriers to accessing preventive and specialist healthcare.[72,73] Using data from ACS, this book defines rurality using a population threshold of 50,000, in accordance with OMB standards.[74] This means that women are considered living in rural areas if they are not part of a metropolitan statistical area. Further details on the definition used here can be found in Chapter 3. Census data show that the percentage of the national population identified as rural increased from 10.3% in 2010 to 20.0% in 2020, though this increase is due more to changes in how urban areas are defined than a true increase in rurality.[75] **Figure 2-21** shows the percent of women living in rural areas by race and ethnicity. The figure shows that the percent of women living in rural areas is lowest among Asian women (2.5%). AI/AN women have the highest percent living in rural areas (35.5%), double that of the next highest group, White women (17.8%). The implications of these differences in rurality across race and ethnicity are discussed in each of the chapters that follows.

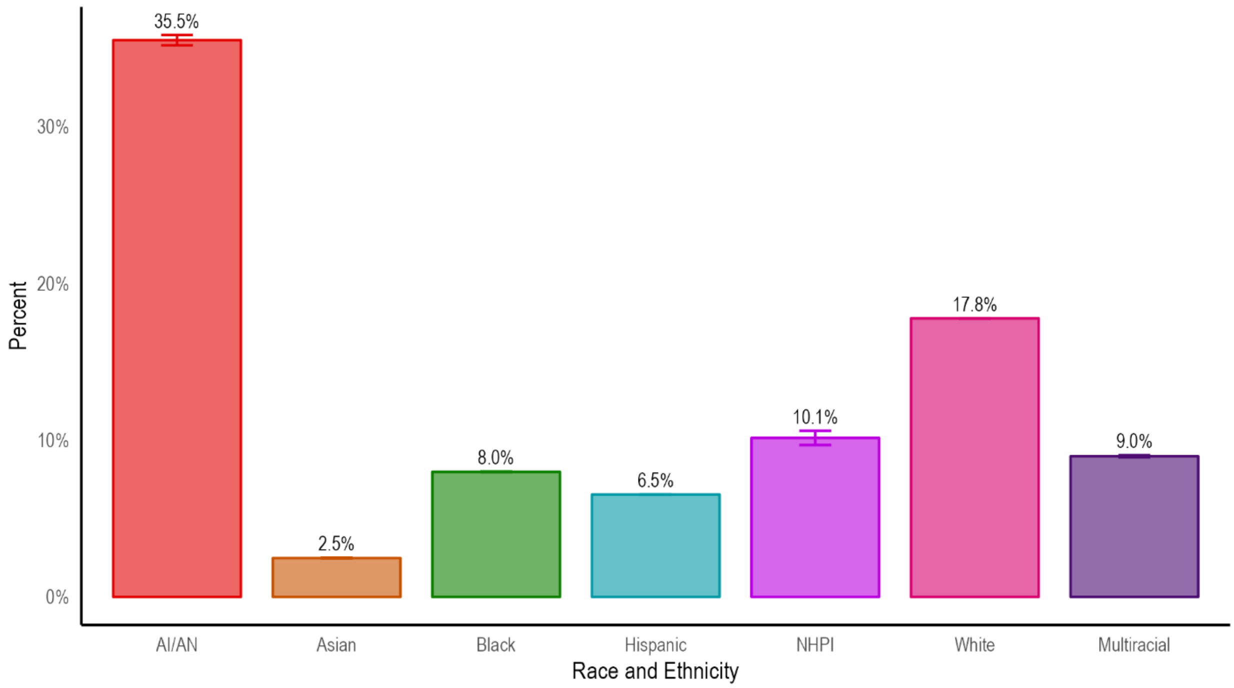

Figure 2-21: Percent of women living in rural areas, by race and ethnicity
Source: Census Bureau, American Community Survey (ACS) 5-Year, 2021

2.3.2 Women in Economically Disadvantaged Groups

Economic status is central to health and well-being across the life course (see Chapter 1).[76,77] Census estimates show that 37.9 million people in the U.S. were living in poverty in 2022—11.5% of the population, which did not represent a significant change from 2021 overall.[17] However, the poverty rate for Black individuals decreased to its lowest rate on record (17.1%) in 2022, while it increased to 25% among AI/AN people.[17] It is well established that economic disadvantage is associated with worse health outcomes, though evidence suggests that men experience greater health benefits from better economic status than do women.[78,79] Studies also underscore that economic advantage is more protective for the health of White populations than it is for people of underrepresented racial and ethnic communities.[80–82]

Throughout most of this book, a family income above 200% of the FPL is used as a proxy for economic advantage, in alignment with OMB guidelines.[17] Further details on the definition used here can be found in Chapter 3**.** However, in this chapter 100% of FPL was used to distinguish between economically advantaged and disadvantaged, as the available ACS data can be processed with only this FPL option when analyzing sex, race, and ethnicity. **Figure 2-22** shows that the percent of women with household income below 100% of the FPL by race and ethnicity. The figure shows the lowest percent observed among White and Asian women, which is over two times higher among Black and AI/AN women. The implications of these differences in economic status across race and ethnicity are discussed in each of the chapters that follow.

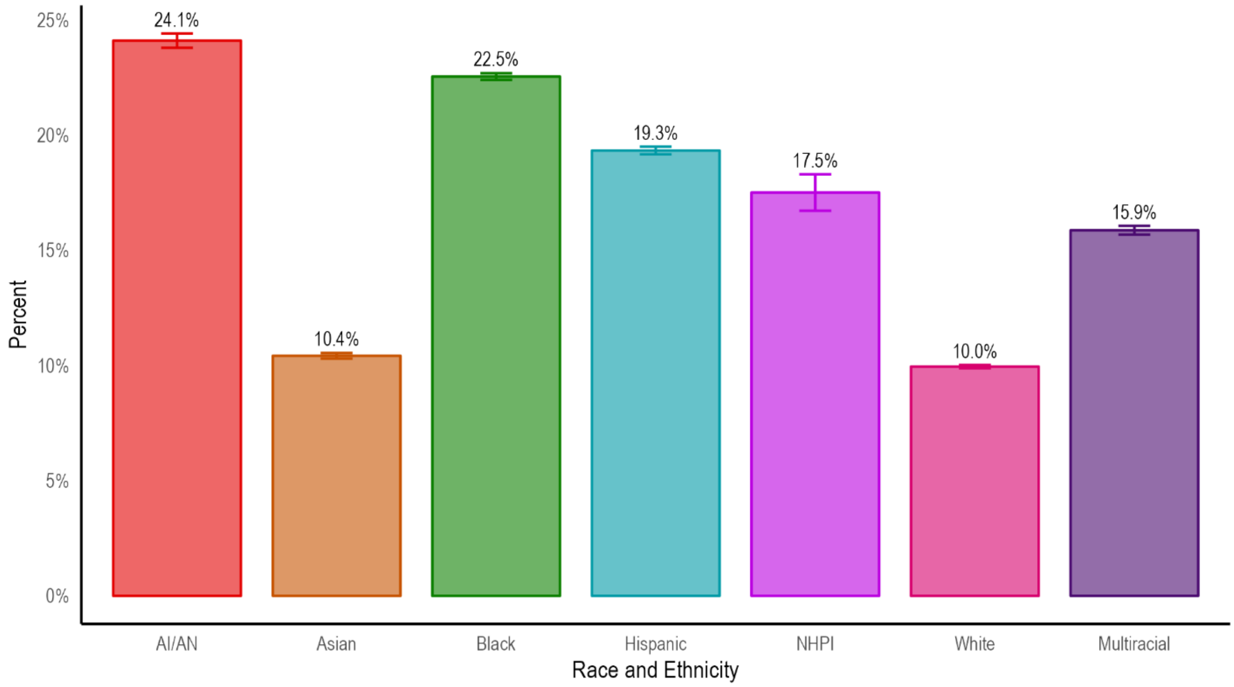

Figure 2-22: Percent of women with household income below 100% of the federal poverty level, by race and ethnicity

Source: Census Bureau, American Community Survey (ACS) 5-Year, 2021

2.3.3 Women of Sexual and Gender Minority Groups

Studies show that lesbian, gay, bisexual, transgender, and queer/questioning (LGBTQ+) people experience inequities across a wide range of health concerns, including disability, CVD, violent victimization, poor mental health, and substance use.[83–87] For the purposes of the data analyses in this book and in alignment with the U3 framework, women who identify as lesbian, bisexual, queer or questioning (LBQ) are represented in sections on sexual minority women. Individuals who identify as transgender, nonbinary, or any other identity that is not cisgender are included in discussions of gender minorities where data allow. More detail on the definitions used by the National Institutes of Health and the various sources included in this book can be found in **Chapter 3**.

Census and ACS data do not record sexual orientation or gender identity. In fact, as of 2017, only two national, federal surveys collected data about gender identity, and only two collected data about sexual orientation.[88] Of the 16 data sources used within this book, only 4 collected data on sexual orientation or gender identity. Further details on the data sources and how they operationalize these variables can be found in **Chapter 3**. This omission by most national surveys perpetuates the erasure of sexual and gender minorities and limits the ability to describe and study their health outcomes in public health research. Additionally, data gaps persist even in surveys that do ask questions on sexual orientation, as existing survey responses typically do not offer a wide enough range of options to fully capture the spectrum of sexual orientations or do not oversample people of diverse orientations to create robust estimates.[89] Unless surveys are specifically designed with SGM respondents in mind, the language used in surveys, combined with existing concerns over data privacy, may create unsafe environments for sharing sexual orientation without fear of stigma.[90]

The Census Bureau included questions about sexual orientation and gender identity in the Household Pulse Survey for the first time in 2021, and resulting estimates show that 8% of the adult population identifies as lesbian, gay, bisexual, or transgender (LGBT), while 85% identify as "non-LGBT," 4.2% identify as "other," and 2.9% did not respond to the relevant survey items.[91] This estimate is higher than other recent data, including estimates from Gallup showing that 7.2% of the adult population identifies as LGBT, with a higher proportion of women than men identifying as LGBT.[92] Other estimates suggest that among those who identify as LGBT, the majority (62%) are bisexual.[93] Estimates derived from Behavioral Risk Factor Surveillance System data are also lower than those from the Household Pulse Survey or Gallup studies, showing the LGBT population to be around 5.5% of U.S. adults.[94] However, it should be noted that Behavioral Risk Factor Surveillance System data includes sexual orientation and gender identity items as an optional module, and even in jurisdictions that opt to include the questions the level of missingness is up to 20% of all respondents.[95] While none of these values distinguish between sexual orientation and gender identity, some estimates show that between 0.6-1.6% of U.S. adults are transgender or nonbinary.[92,93] The data show an increase in this percentage of the population identifying as LGBT over the past decade for both women and men, though the percentage is consistently higher among women.[92] This change over time is likely due to the combined effect of improved data collection measures and the higher percentage of young adults who identify as LGBT, which Gallup estimates at 19.7% among Generation Z and 11.2% among Millennials in 2022.[92]

2.4 Conclusions and Future Directions

This chapter provides current population estimates and recent trends in the demographic composition of U3 population groups using the most recent Census data. While these data offer the most comprehensive picture of the demographic profile of the U.S., they also reveal limitations in capturing the diversity of U3 populations. For example, the Census race and ethnicity categories organize populations into groups that may share certain commonalities in heritage, culture, countries of origin, or migration patterns. These groupings allow researchers to study the relationships between demographic features and health outcomes. However, these categorizations are imperfect, as existing race and ethnicity categories fail to capture the complexity of racial and ethnic identity, particularly given the projected change in racial and ethnic composition of younger populations in the coming decades. The racial and ethnic classification of individuals in the U.S. directly and indirectly translates to resources and opportunities (economic, education, health, housing) that are available to them. This chapter also notes the significant gap in data that capture the spectrum of sexual orientations and gender identities represented across U.S. society. To address this gap, recent White House recommendations and best practices aim to improve data on the LGBTQ+ community by including sexual orientation and gender identity questions in all federal statistical surveys.[96]

As our cultural understanding about identity shifts, it is imperative that definitions of demographic categories continue to evolve to best capture how populations self-identify and the diversity within and between groups. Thus, understanding the rationale and current challenges of racial and ethnic classification is foundational to investigating underlying morbidity and mortality for U3 women, many of whom exist within a subset of these larger racial and ethnic populations. With an understanding of the rationale and limitations of current classifications of race and ethnicity, sexual orientation, and gender identity (including undercounts and omissions of individuals), it follows that our subsequent examinations of morbidity and mortality trends across disease areas will not be perfect. Future advancements in federal-level data collection will improve the quality and quantity of data available to accurately tabulate the impact of social drivers and health outcomes affecting U3 women.

2.5 Data Definitions and Sources

Data for all figures in this chapter can be accessed from the data annex located here: https://orwh.od.nih.gov/sites/orwh/files/docs/Chapter_2.xlsx

Decennial Census (Demographic Profile), 2020

Variable Name	Variable Description	Variable Options
DP1_0026C – DP1_0043C	Count!!SEX AND AGE!!Male population!!	Under 5 years; 5 to 9 years; 10 to 14 years; 15 to 19 years; 20 to 24 years; 25 to 29 years; 30 to 34 years; 35 to 39 years; 40 to 44 years; 45 to 49 years; 50 to 54 years; 55 to 59 years; 60 to 64 years; 65 to 69 years; 70 to 74 years; 75 to 79 years; 80 to 84 years; 85 years and over
DP1_0050C – DP1_0067C	Count!!SEX AND AGE!!Female population!!	Under 5 years; 5 to 9 years; 10 to 14 years; 15 to 19 years; 20 to 24 years; 25 to 29 years; 30 to 34 years; 35 to 39 years; 40 to 44 years; 45 to 49 years; 50 to 54 years; 55 to 59 years; 60 to 64 years; 65 to 69 years; 70 to 74 years; 75 to 79 years; 80 to 84 years; 85 years and over
DP1_0105C – DP1_0111C	Count!!HISPANIC OR LATINO BY RACE!!Total population!!Not Hispanic or Latino!!	White alone; Black or African American alone; American Indian and Alaska Native alone; Asian alone; Native Hawaiian and Other Pacific Islander alone; Some Other Race alone; Two or More Races

American Community Survey (ACS) 5-year, 2010-2021

Variable Name	Variable Description	Variable Options
B01001B_003E – B01001B_016E	SEX BY AGE (BLACK OR AFRICAN AMERICAN ALONE) Estimate!!Total:!!Male:	Under 5 years; 5 to 9 years; 10 to 14 years; 15 to 17 years; 18 and 19 years; 20 to 24 years; 25 to 29 years; 30 to 34 years; 35 to 39 years; 40 to 44 years; 45 to 49 years; 50 to 54 years; 55 to 59 years; 60 to 64 years; 65 to 69 years; 70 to 74 years; 75 to 79 years; 80 to 84 years; 85 years and over
B01001B_018E – B01001B_031E	SEX BY AGE (BLACK OR AFRICAN AMERICAN ALONE) Estimate!!Total:!!Female:	Under 5 years; 5 to 9 years; 10 to 14 years; 15 to 17 years; 18 and 19 years; 20 to 24 years; 25 to 29 years; 30 to 34 years; 35 to 39 years; 40 to 44 years; 45 to 49 years; 50 to 54 years; 55 to 59 years; 60 to 64 years; 65 to 69 years; 70 to 74 years; 75 to 79 years; 80 to 84 years; 85 years and over
B01001C_003E – B01001C_016E	SEX BY AGE (AMERICAN INDIAN AND ALASKA NATIVE ALONE) Estimate!!Total:!!Male:	Under 5 years; 5 to 9 years; 10 to 14 years; 15 to 17 years; 18 and 19 years; 20 to 24 years; 25 to 29 years; 30 to 34 years; 35 to 39 years; 40 to 44 years; 45 to 49 years; 50 to 54 years; 55 to 59 years; 60 to 64 years; 65 to 69 years; 70 to 74 years; 75 to 79 years; 80 to 84 years; 85 years and over
B01001C_018E – B01001C_031E	SEX BY AGE (AMERICAN INDIAN AND ALASKA NATIVE ALONE) Estimate!!Total:!!Female:	Under 5 years; 5 to 9 years; 10 to 14 years; 15 to 17 years; 18 and 19 years; 20 to 24 years; 25 to 29 years; 30 to 34 years; 35 to 39 years; 40 to 44 years; 45 to 49 years; 50 to 54 years; 55 to 59 years; 60 to 64 years; 65 to 69 years; 70 to 74 years; 75 to 79 years; 80 to 84 years; 85 years and over
B01001D_003E – B01001D_016E	SEX BY AGE (ASIAN ALONE) Estimate!!Total:!!Male:	Under 5 years; 5 to 9 years; 10 to 14 years; 15 to 17 years; 18 and 19 years; 20 to 24 years; 25 to 29 years; 30 to 34 years; 35 to 39 years; 40 to 44 years; 45 to 49 years; 50 to 54 years; 55 to 59 years; 60 to 64 years; 65 to 69 years; 70 to 74 years; 75 to 79 years; 80 to 84 years; 85 years and over

Variable Name	Variable Description	Variable Options
B01001D_018E – B01001D_031E	SEX BY AGE (ASIAN ALONE) Estimate!!Total:!!Female:	Under 5 years; 5 to 9 years; 10 to 14 years; 15 to 17 years; 18 and 19 years; 20 to 24 years; 25 to 29 years; 30 to 34 years; 35 to 39 years; 40 to 44 years; 45 to 49 years; 50 to 54 years; 55 to 59 years; 60 to 64 years; 65 to 69 years; 70 to 74 years; 75 to 79 years; 80 to 84 years; 85 years and over
B01001E_003E – B01001E_016E	SEX BY AGE (NATIVE HAWAIIAN AND OTHER PACIFIC ISLANDER ALONE) Estimate!!Total:!!Male:	Under 5 years; 5 to 9 years; 10 to 14 years; 15 to 17 years; 18 and 19 years; 20 to 24 years; 25 to 29 years; 30 to 34 years; 35 to 39 years; 40 to 44 years; 45 to 49 years; 50 to 54 years; 55 to 59 years; 60 to 64 years; 65 to 69 years; 70 to 74 years; 75 to 79 years; 80 to 84 years; 85 years and over
B01001E_018E – B01001E_031E	SEX BY AGE (NATIVE HAWAIIAN AND OTHER PACIFIC ISLANDER ALONE) Estimate!!Total:!!Female:	Under 5 years; 5 to 9 years; 10 to 14 years; 15 to 17 years; 18 and 19 years; 20 to 24 years; 25 to 29 years; 30 to 34 years; 35 to 39 years; 40 to 44 years; 45 to 49 years; 50 to 54 years; 55 to 59 years; 60 to 64 years; 65 to 69 years; 70 to 74 years; 75 to 79 years; 80 to 84 years; 85 years and over
B01001F_003E – B01001F_016E	SEX BY AGE (SOME OTHER RACE ALONE) Estimate!!Total:!!Male:	Under 5 years; 5 to 9 years; 10 to 14 years; 15 to 17 years; 18 and 19 years; 20 to 24 years; 25 to 29 years; 30 to 34 years; 35 to 39 years; 40 to 44 years; 45 to 49 years; 50 to 54 years; 55 to 59 years; 60 to 64 years; 65 to 69 years; 70 to 74 years; 75 to 79 years; 80 to 84 years; 85 years and over
B01001F_018E – B01001F_031E	SEX BY AGE (SOME OTHER RACE ALONE) Estimate!!Total:!!Female:	Under 5 years; 5 to 9 years; 10 to 14 years; 15 to 17 years; 18 and 19 years; 20 to 24 years; 25 to 29 years; 30 to 34 years; 35 to 39 years; 40 to 44 years; 45 to 49 years; 50 to 54 years; 55 to 59 years; 60 to 64 years; 65 to 69 years; 70 to 74 years; 75 to 79 years; 80 to 84 years; 85 years and over
B01001G_003E – B01001G_016E	SEX BY AGE (TWO OR MORE RACES) Estimate!!Total:!!Male:	Under 5 years; 5 to 9 years; 10 to 14 years; 15 to 17 years; 18 and 19 years; 20 to 24 years; 25 to 29 years; 30 to 34 years; 35 to 39 years; 40 to 44 years; 45 to 49 years; 50 to 54 years; 55 to 59 years; 60 to 64 years; 65 to 69 years; 70 to 74 years; 75 to 79 years; 80 to 84 years; 85 years and over
B01001G_018E – B01001G_031E	SEX BY AGE (TWO OR MORE RACES) Estimate!!Total:!!Female:	Under 5 years; 5 to 9 years; 10 to 14 years; 15 to 17 years; 18 and 19 years; 20 to 24 years; 25 to 29 years; 30 to 34 years; 35 to 39 years; 40 to 44 years; 45 to 49 years; 50 to 54 years; 55 to 59 years; 60 to 64 years; 65 to 69 years; 70 to 74 years; 75 to 79 years; 80 to 84 years; 85 years and over
B01001H_003E – B01001H_016E	SEX BY AGE (WHITE ALONE, NOT HISPANIC OR LATINO) Estimate!!Total:!!Male:	Under 5 years; 5 to 9 years; 10 to 14 years; 15 to 17 years; 18 and 19 years; 20 to 24 years; 25 to 29 years; 30 to 34 years; 35 to 39 years; 40 to 44 years; 45 to 49 years; 50 to 54 years; 55 to 59 years; 60 to 64 years; 65 to 69 years; 70 to 74 years; 75 to 79 years; 80 to 84 years; 85 years and over
B01001H_018E – B01001H_031E	SEX BY AGE (WHITE ALONE, NOT HISPANIC OR LATINO) Estimate!!Total:!!Female:	Under 5 years; 5 to 9 years; 10 to 14 years; 15 to 17 years; 18 and 19 years; 20 to 24 years; 25 to 29 years; 30 to 34 years; 35 to 39 years; 40 to 44 years; 45 to 49 years; 50 to 54 years; 55 to 59 years; 60 to 64 years; 65 to 69 years; 70 to 74 years; 75 to 79 years; 80 to 84 years; 85 years and over
B01001I_003E – B01001I_016E	SEX BY AGE (HISPANIC OR LATINO) Estimate!!Total:!!Male:	Under 5 years; 5 to 9 years; 10 to 14 years; 15 to 17 years; 18 and 19 years; 20 to 24 years; 25 to 29 years; 30 to 34 years; 35 to 39 years; 40 to 44 years; 45 to 49 years; 50 to 54 years; 55 to 59 years; 60 to 64 years; 65 to 69 years; 70 to 74 years; 75 to 79 years; 80 to 84 years; 85 years and over

Variable Name	Variable Description	Variable Options
B01001I_018E – B01001I_031E	SEX BY AGE (HISPANIC OR LATINO) Estimate!!Total:!!Female:	Under 5 years; 5 to 9 years; 10 to 14 years; 15 to 17 years; 18 and 19 years; 20 to 24 years; 25 to 29 years; 30 to 34 years; 35 to 39 years; 40 to 44 years; 45 to 49 years; 50 to 54 years; 55 to 59 years; 60 to 64 years; 65 to 69 years; 70 to 74 years; 75 to 79 years; 80 to 84 years; 85 years and over

American Community Survey (ACS), 1-year

Variable Name	Variable Description	Variable Options
B02003_015E – B02003_025E	Estimate!!Total:!!Population of two or more races:!!Population of two races:!!	Various options https://api.census.gov/data/2022/acs/acs1/variables.html
B02003_027E – B02003_046E	Estimate!!Total:!!Population of two or more races:!!Population of three races:!!	Various options https://api.census.gov/data/2022/acs/acs1/variables.html

Census Population Projections, 2023

Variable Name	Variable Description	Variable Options
Total (in percent)	Projected Population Distribution by Race and Hispanic Origin: 2022-2060 Population total (all ages combined) in each year	Not Hispanic or Latino: One race: White, Black or African American, American Indian and Alaska Native, Asian, Native Hawaiian and Other Pacific Islander; Not Hispanic or Latino: Two or More Races; Hispanic or Latino

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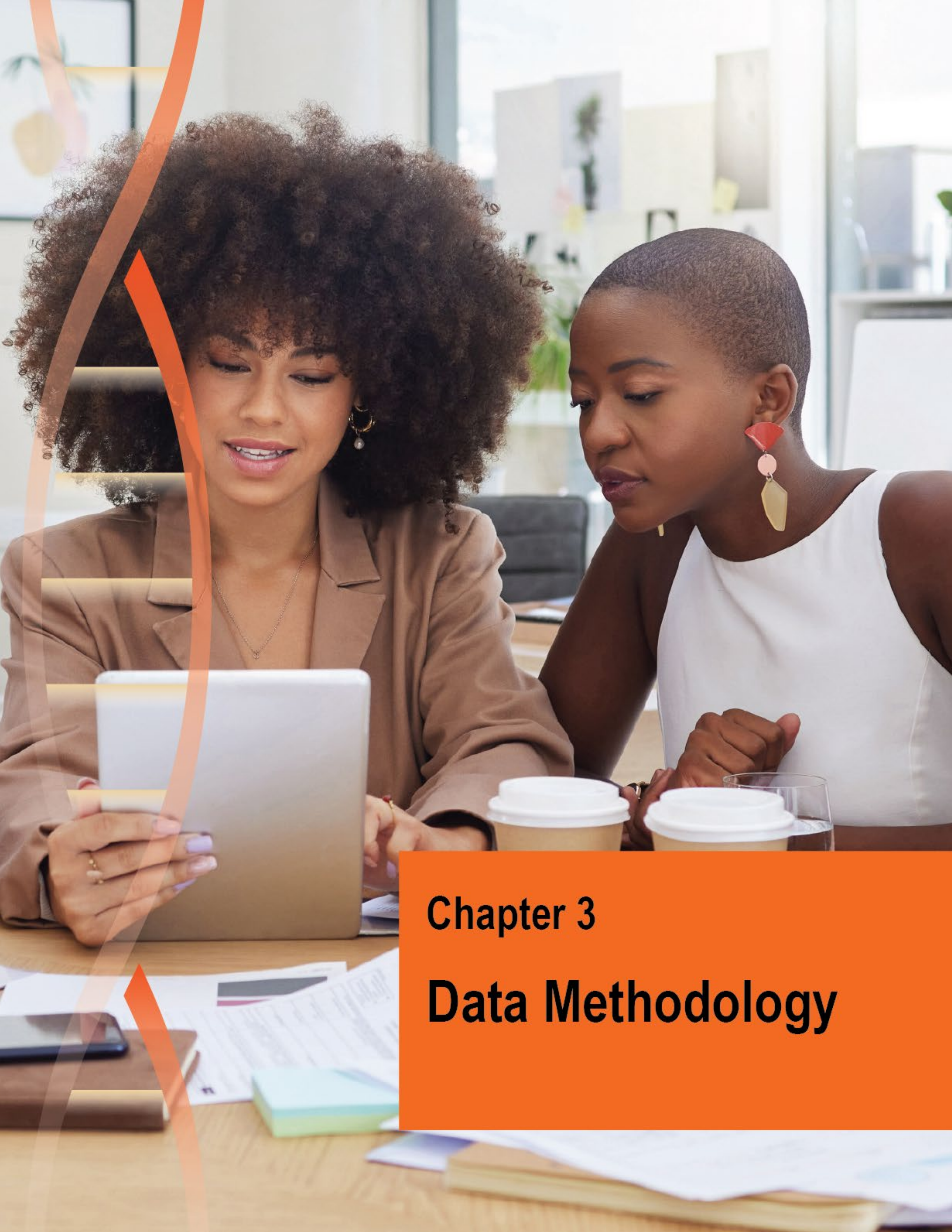

Chapter 3

Data Methodology

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Data Methodology

3.1 Data Source Overview

This chapter provides context on the 15 data sources used within the *Health of Women of U3 Populations Data Book*. It serves as a reference for readers to understand how the variables were defined and coded and provides high-level discussion on data interpretation. This chapter also highlights opportunities and limitations of using national, publicly available health data sources to describe the current health status and health trends experienced by understudied, underrepresented, and underreported (U3) women. The Office of Research on Women's Health (ORWH), within the National Institutes of Health (NIH), leveraged the National Institute on Minority Health and Health Disparities' (NIMHD's) definition of populations that experience health disparities to draw attention to persistent disparities in women of these populations. These include women of underrepresented racial and ethnic communities, persons in economically disadvantaged groups, persons in underserved rural areas, sexual and gender minority (SGM) groups, and persons with disabilities. Accordingly, ORWH has designated this group as U3 women.[1]

Together, the data presented and the body of peer-reviewed literature cited within this book provide a snapshot of the state of U3 women's health, exploring priority intersections where the data allow. Data in the chapters that follow are presented with a discussion of estimates and trends for each topic and subtopic for all women, highlighting sex- and gender-related differences when relevant. Next, the data examine outcomes for all women across each racial and ethnic group, presenting the intersection between sex and race and ethnicity. Finally, where the data allow, this Data Book examines the multiple intersections between sex, race and ethnicity, rurality, economic status, sexual orientation, and gender identity. While these factors alone do not cover the entire scope of identities that are understudied, they present a strong foundation for understanding the contours of women's health and health disparities in the U.S.

3.1.1 Data Selection and Inclusion

Many publicly available, nationally representative data from reputable sources were initially scoped for use within this Data Book. Datasets were prioritized and selected for inclusion if they met the following minimum criteria. The datasets had to:

1. Provide nationally representative data from public datasets;
2. Contain information on at least one priority health condition;

3. Include demographic/health insurance coverage information, or top 10 causes of death for women; [v]
4. Allow for stratification by sex or gender; and
5. Allow for stratification by race and ethnicity.

When multiple sources included variables on similar topics, secondary priorities informed how preferred datasets were selected. However, in order to ensure at least one data source would be available to address all priority health topics, a data set could be included without meeting both of these secondary priorities. These additional priorities included that the datasets should:

6. Allow for stratification by at least one additional U3 variable (economic status, rurality, or sexual orientation and gender identity); and/or
7. Contain multiple vintages or years of data to establish time trends or create pooled estimates.

An overview of the datasets used to generate analyses and visualizations in this book and their attributes, listed alphabetically by the data source name, can be found in **Table 3-1**. The table provides the following columns:

- Data Source Name: The full names of each data source with hyperlinks to the primary website
- Abbreviation: Abbreviations for each data source used in the following tables, as well as in figure captions and variable descriptions in later chapters
- Data Type: The public health data type categorized as either survey data, surveillance data, or vital records
- Data Download Modality: The modality through which the data were accessed, categorized as Application Programming Interface (API), Downloaded Tables/Reports, Online Dashboards, Online Query Systems, or Public Use Files (PUF). When applicable, additional hyperlinks are included to the online system if they differ from the primary website
- Department: The federal department or departments which sponsored the data source
- Agency: The federal agency or agencies which operate and maintain the data source
- Year(s) in Data Book: The data vintages included in this analysis. The term "data vintage" is used here to describe the period in which data were collected to convey to the temporal aspect of the data analyzed for this publication
- Data Update Frequency: The frequency for which data sources are collected, updated, and released
- # of Race and Ethnicity Categories: The number of distinct race and ethnicity categories provided through the modality in which the data were accessed
- Rural, Econ, SO, GI: The availability of priority variables relevant to the analyses of U3 women with a check mark (✓) to indicate the presence or absence of data on rurality, economic status (Econ), sexual orientation (SO) and gender identity (GI)

The selection of data vintages prioritized the inclusion of as much data as possible from 2010 to the present, except in cases where the data source cautioned against trend comparisons across specific vintages due to significant changes to survey instrument, sampling methodologies, or data structures. In

[v] Priority health conditions for the purposes of this Data Book are autoimmune and other inflammatory diseases, cardiovascular disease, dementia, female-specific cancers and cancers that disproportionately affect women, HIV, maternal morbidity and mortality, menopause, mental health, substance use and misuse, and violence against women and trauma.

such cases, only data vintages released after significant changes were included. The National Health Interview Survey (NHIS), for example, began collecting data over 60 years ago and is one of the key datasets used in this analysis. It underwent a survey redesign as recently as 2019. Similarly, the National Survey on Drug Use and Health (NSDUH) changed its data collection mode in 2021. Both sources recommend against comparing data prior to and following survey changes.[2,3]

The 15 datasets used within this book fall primarily into three public health data categories: 1) survey data, 2) surveillance data, and 3) vital records data (see the Data Type column in **Table 3-1**). Of the 15 sources, seven are population surveys generating cross-sectional data used to track population trends and inform priorities in public health. These nationally representative surveys allow for efficient, cost-effective data collection from carefully selected samples, and tend to be operated, maintained, and supported by Federal agencies. The survey data included within this book were generated through studies that employ rigorous sampling and weighting methods, and the data are well documented and continuously maintained; many have been administered for 20 or more years. Many of these surveys were designed to provide high-level, cross-sectional data based on the priority health topics and concerns of their respective agencies and have been adapted over time to respond to technological advancements, changes in public voice, and priorities of administrations. Despite the rigor in sampling and study design, survey data are subject to several limitations including nonresponse bias, recall bias, challenges in language and communication of survey questions, balance between consistency of survey items versus updating or modernizing questions. While many surveys oversampled different subgroups to ensure national representation across regional, social, and/or demographic factors (e.g., age, race, ethnicity, SES) this book aims to explore multiple demographic intersections, which may result in a limited sample for certain population denominators (i.e., Native Hawaiian and Pacific Islander [NHPI] women who identify as lesbian, gay, bisexual, or queer). As a result, there may not be adequate statistical power to detect true differences between groups, particularly for less common health conditions and/or risk factors. In these situations, results should be interpreted with caution with additional attention given to existing literature on the topic.

Data from surveillance systems represent 5 of 15 sources included in this book. Surveillance systems and their reported data provide "ongoing, systematic collection, analysis, interpretation, and dissemination of data regarding a health-related event for use in public health action to reduce morbidity and mortality and to improve health."[4] These data can provide information on prevalence, incidence, and mortality rates for priority health topics over time. However, underreporting and misclassification are known limitations of surveillance data. Within the context of U3 populations, the biases in the data systems may be further exacerbated by a lack of trusted relationships between the health system(s) through which data collection occurs and the communities that may be experiencing reportable health conditions. Data from surveillance systems may be interpreted as a lower bound or conservative estimate of the true impact of the health event.

Vital records data from the National Vital Statistics System (NVSS) comprise the remaining 4 of the 15 included datasets. This system provides data on "all births and deaths in the U.S. and provides the most complete and continuous data available to public health officials at the national, state, and local levels, and in the private sector."[5] Continuous improvements to NVSS data quality, including the switch from a single Asian and Pacific Islander (API) group to Asian and NHPI groups and the addition of a Multiracial category, have shown the impact and importance of data disaggregation in unmasking disparities, as shown across many chapters of this book.

Table 3-1: Overview of Included Data Sources

Data Source Name & Abbreviation	Data Type	Data Download Modality	Dept./Agency	Year(s) in Data Book	Update[vi]	#R&E[vii]	Rural	Econ	SO	GI
American Community Survey (5-Year) (ACS)	Survey	ACS API	Commerce/ Census Bureau	2010-2021	Annual	8	✓	✓	N/A	N/A
Current Population Survey (CPS)	Survey	Downloaded Tables /Reports	Commerce/ Census Bureau; Labor/BLS	2010-2017; 2019-2021	Monthly; Quarterly; Yearly	4	N/A	✓	N/A	N/A
National Crime Victimization Survey (NCVS)	Survey	Online Dashboard NCVS Dashboard (N-DASH)	Justice/ BJS	2010-2022	Annual	4	N/A	N/A	N/A	N/A
National Electronic Injury Surveillance System – All Injury Program (NEISS-AIP)	Surveil-lance Data	Online Data Query System WISQARS	HHS/CDC; U.S. Consumer Product Safety Commission	2010-2020	Annual	4	N/A	N/A	N/A	N/A
National Health and Nutrition Examination Survey (NHANES)	Survey	PUF (Public Use File)	HHS/CDC	2009-2020	Biennial (Even Years)	5 (2009-2010) 6 (2011-2020)	N/A	✓	N/A	N/A
National Health Interview Survey (NHIS)	Survey	PUF	HHS/CDC	2019-2022	Annual	6	✓	✓	✓	N/A
National HIV Surveillance System (NHSS)	Surveil-lance Data	Online Data Query System AtlasPlus	HHS/CDC	2010-2021	Annual	7	✓	N/A	N/A	✓
National Survey on Drug Use and Health (NSDUH)	Survey	PUF	HHS/ SAMHSA	2021	Annual	7	✓	✓	✓	N/A
National Violent Death Reporting System (NVDRS)	Surveil-lance Data	Online Data Query System WISQARS	HHS/CDC	2018-2021	Annual	7	✓	N/A	N/A	N/A
National Vital Statistics System (NVSS) – Life Expectancy	Vital Records	Downloaded Tables/Reports	HHS/CDC	2019	Annual	5	N/A	N/A	N/A	N/A
National Vital Statistics System (NVSS) – Linked Birth & Infant Death Records	Vital Records	Online Data Query System CDC WONDER	HHS/CDC	2010-2021	Annual	5 (Bridged Race); 6 (Single Race)	N/A	N/A	N/A	N/A
National Vital Statistics System (NVSS) – Natality	Vital Records	Online Data Query System CDC WONDER	HHS/CDC	2010-2022	Annual	7	✓	✓	N/A	N/A
National Vital Statistics System (NVSS) – Underlying Cause of Death	Vital Records	Online Data Query System CDC WONDER	HHS/CDC	2010-2021	Annual	5 (2010-2020); 7 (2018-2021)	✓	N/A	N/A	N/A
Surveillance, Epidemiology, and End Results Program (SEER)	Surveil-lance Data	Online Data Query System Cancer Query Systems (CanQues) Online Dashboard SEER*Explorer	HHS/NIH	2010-2020	Annual	5	N/A	N/A	N/A	N/A
Youth Risk Behavior Survey (YRBS)	Survey	PUF	HHS/CDC	2013, 2015, 2019, 2021	Biennial (Odd Years)	7	N/A	N/A	✓	N/A

[vi] Data update frequency

[vii] #R&E stands for the number of race and ethnicity categories.

The Data Download Modality column in **Table 3-1** refers to the modality through which the data and values were obtained, queried, or downloaded. It also includes the interface through which data are publicly available to researchers or data consumers, which may be distinct from the data sources official webpages. For example, AtlasPlus from Centers for Disease Control and Prevention's (CDC's) National Center for HIV, Viral Hepatitis, STD, and TB Prevention (NCHHSTP) is an interactive tool that allows users to query data collected from the National HIV Surveillance System (NHSS). Additionally, a single data source may provide multiple data access option types that range from a high degree of user specification to a high degree of accessibility; this includes options such as restricted use files, public use files, online data analysis or visualization tools, or pre-tabulated reports and tables. The most comprehensive files that were available without the need for additional software, licensing, or approval, were obtained and visualized for this book. As a result, some variables captured in the original data sources were not available in all data download modes.

Public use files (PUFs) for survey data, like NSDUH, National Health and Nutrition Examination Survey (NHANES), and NHIS, have prepared, de-identified data that correspond to each sampled respondent. These files and their codebooks can be downloaded from the official webpage of the dataset and allow for the creation of estimates based on the intersection of priority U3 variables. For other datasets, like the Current Population Survey (CPS), pre-aggregated data tables of variables based on population characteristics (e.g., age or race) are used, which minimizes additional data processing and summarization. Finally, some datasets like NVSS, NHSS, or National Violent Death Reporting System (NVDRS) were obtained through online data query systems such as CDC WONDER, AtlasPlus, or WISQARS, respectively. Online data query systems provide access to datasets through request forms that allow the user to choose the groupings, demographics, and variables of interest, which are then returned to the user as summarized tabular data with appropriate data suppression. These query systems are common for surveillance data and vital statistics and can provide more flexibility than the pre-aggregated tables but may have limitations in providing multiple intersections or disaggregating topics.

This Data Book includes NVSS data from four distinct topic areas: life expectancy, linked birth and infant death records, natality, and underlying causes of death. In many cases, these topic areas are handled separately because their request forms, available through CDC WONDER, contain different variables and demographic stratifications. For example, only the natality and underlying causes of death data include variables that can be used to stratify by rurality.

Table 3-2 provides an outline of the datasets that each chapter of the Data Book uses to produce analysis and figures. Some datasets, like NHANES and NHIS, appear in multiple chapters of the Data Book. Others are exclusive to one chapter, like NVDRS in **Chapter 14**. The data definitions presented in the following section are consistent for each dataset throughout the chapters.

3.2 Data Definitions

One challenge in presenting a cohesive story about diverse populations of women across multiple data sources is deriving a set of common terms that are categorically aligned when data collection systems may differ in variables presented and the definitions assigned. This is particularly relevant for variables important for analyzing the health of U3 women: multiple valid definitions and categorizations for racial and ethnic identity, rurality, economic status, sexual orientation, and gender identity exist across data sources and require systematic alignment. The following sections define terms used throughout this book across visuals and tables and how they were operationalized across the data sources.

Table 3-2: Associated Data Sources by Data Book Chapter

Order	Chapter	Data Sources
1	Social Determinants of Health for U3 Women	ACS; CPS (Health Insurance Coverage)
2	Demographics	ACS
3	Data Methodology	All
4	Top 10 Causes of Death	NVSS
5	Autoimmune and Other Inflammatory Diseases	NHANES; NHIS
6	Cardiovascular Disease	NHANES; NHIS; NVSS
7	Dementia	NHIS; NVSS
8	Female-Specific Cancers and Cancers that Disproportionately Affect Women	NHIS; NVSS; SEER
9	Human Immunodeficiency Virus (HIV)	NHSS; YRBS
10	Maternal Morbidity and Mortality	NVSS
11	Menopause	NHANES; NVSS
12	Mental Health	NSDUH; NVSS; YRBS
13	Substance Use and Misuse	NSDUH; NVSS; YRBS
14	Violence Against Women and Trauma	NCVS; NEISS-AIP; NVDRS

3.2.1 Sex and Gender

As a data book on the health of U3 women, it is essential to ensure that the entire population of women is included across all data sources for comparison purposes. Funding for women's health research is rarely commensurate to the burden of the disease compared to conditions with a male predominance, this book aims to leverage existing data to elevate statistics centered around women.[6] Chapter 1 provides an in-depth discussion of the nuances between the terms "sex" and "gender" and how these distinct factors impact the health of women across their life (see Chapter 1). While there is a distinct difference in the concepts, experiences, and health impact captured by these terms, sex and gender are often conflated to represent a binary categorization between female and male or women and men. This treatment of sex and gender as synonymous terms is reflected across many of the data sources used within this book. While this book intends to include all persons who were identified as female at birth and those who are not cisgender males, the lack of availability for both sex and gender variables coupled with the inconsistency of definitions do not allow for complete capture of these populations. The variable names used to capture sex and/or gender across each data source are presented in **Table 3-3**, as well as a column denoting whether or not the data source provides an explicit discussion of how sex and gender were defined in the variable definitions according to the method used to query the data.

As seen in **Table 3-3**, sex and gender are used to capture a female/male dichotomy across 14 of the 15 relevant data sources. The variable names and variable options presented in the table represent the data that were available through the modality in which the data were accessed (i.e., online data query system, PUF, tables/reports). It is important to note that this may not represent the full range of variables and variable options that were originally collected but what was available to public data consumers.

Table 3-3: Sex and Gender Variables

Data Source Abbreviation	Data Download Modality	Year	Variable Name	Variable Options	Documentation on Sex versus Gender
ACS 5-Year	ACS API	2010-2021	Sex	Male; Female	N
CPS	Downloaded Tables/Reports	2010-2017; 2019-2021	Sex	Male; Female	N
NCVS	N-DASH	2010-2022	Sex	Male; Female	N
NEISS-AIP	WISQARS	2010-2020	Sex	Male; Female	Y
NHANES	PUF	2009-2018	RIAGENDR	Male; Female	N
NHIS	PUF	2019-2022	SEX_A	Male; Female	N
NHSS	AtlasPlus	2010-2021	Gender Sex	Male; Female; Transgender Woman; Transgender Man; Additional Gender Identity (AGI) Male at Birth; Female at Birth	Y
NSDUH	PUF	2021	IRSEX	Male; Female	N
NVDRS	WISQARS	2018-2021	Sex	Male; Female	Y
NVSS – Life Expectancy	CDC WONDER	2019	Sex	Male; Female	N
NVSS – Linked Birth/Infant Death Records	CDC WONDER	2010-2021	Implicit Maternal Sex	Female	N
NVSS – Natality	CDC WONDER	2010-2022	Implicit Maternal Sex	Female	N
NVSS –Underlying Cause of Death	CDC WONDER	2010-2021	Gender	Male; Female	N
SEER	CanQues/ SEER*Explorer	2010-2020	Sex	Male; Female	Y
YRBS	PUF	2013, 2015, 2019, 2021	Q2	Male; Female	N

Most notably, in NHSS, separate variables were provided to capture sex (as male at birth, female at birth) and gender (with male, female, transgender woman, transgender man, and additional gender identity [AGI]). For NVSS Linked Births and Infant Death Records and NVSS Natality data sources, the CDC WONDER query system provides data associated with each birth separated by maternal and paternal characteristics. As a result, the maternal characteristics section implicitly contains individuals whose sex is female at birth and does not provide additional information on the gender identity of the birthing person. Documentation was available for NEISS-AIP, NVDRS, and the Surveillance, Epidemiology, and End Results Program (SEER), which provided clarification on distinctions between sex and gender in the original data sources and provided additional options for transgender or intersex identities. However, in this book, data from those sources were obtained through online query sources (WISQARS, AtlasPlus, CanQues), which suppressed or omitted those options in accordance with the CMS cell suppression policy.[viii]

The collection of both sex and gender variables for demographic data provide more complete and relevant information. ORWH and NIH are currently supporting research to identify best practices in the measurement of sex and gender.

[viii] The policy states that "no cell containing a value of 1 to 10 can be reported directly." Policy can be accessed on the Health and Human Services website: https://www.hhs.gov/guidance/document/cms-cell-suppression-policy

3.2.2 Race and Ethnicity

The data analysis in this book upholds the governing principle of the Federal Interagency Technical Working Group on Race and Ethnicity Standards, that "race and ethnicity are sociopolitical constructs."[7] Despite best intentions to elevate the health status of U3 women, this book recognizes that by using existing race and ethnicity stratifications, the analysis may perpetuate harms associated with grouping diverse identities under flattened labels, as there is often great diversity within racial and ethnic groups. This book aligns as much as possible with current Census categorizations of race and ethnicity, which often set the standard across other national data sources.[8] Race and ethnicity are presented as a single variable to capture non-overlapping groups and follow the NIH Style Guide while still maintaining fidelity to the data source.[9] More detailed descriptions of the heritage groups under each race and ethnicity category are in **Chapter 2**. As much as the data allow, this book aligns to the categories listed below in alphabetical order, including terms implemented to accommodate inconsistencies in the data sources (abbreviated labels are used consistently across data visualizations and figures):

- **AI/AN**: American Indian and Alaska Native alone (non-Hispanic)
- **Asian**: Asian alone (non-Hispanic)
- **API:** Asian and Pacific Islander (non-Hispanic); an aggregated category used when the data do not separate out "Asian" and "NHPI" groups
- **Black**: Black or African American alone (non-Hispanic)
- **Hispanic**: Hispanic or Latino (any racial groups)
- **NHPI**: Native Hawaiian and Pacific Islander alone (non-Hispanic)
- **Multiracial**: Two or more races alone (non-Hispanic)
- **White**: White alone (non-Hispanic)
- **Other**: Some Other Race alone (non-Hispanic); this group does not include individuals with missing data and/or those who did not self-report their race or ethnicity. Additionally, the term "other" is used with caution and is not intended to suggest othering or marginalization, but rather to capture any self-identification that is not included or represented in the categories available within that data source. Additionally, it is important to note that the "other" category is not comparable across data sources.

Table 3-4 shows the race and ethnicity categories available across all datasets used within this book. The column titles reflect the abbreviated labels used across the figures (where relevant), while data within the tables provide the full labels by the respective data sources and codebooks. While most datasets provide a combined single race and ethnicity variable, other datasets like NVDRS and NVSS are marked with a caret symbol (^) in the columns for variable name and Hispanic ethnicity and provide separate variables for race and ethnicity. In these cases, data are recoded to best align with the categories previously specified, where all individuals identified as "Hispanic or Latino" are considered "Hispanic" regardless of any racial identification, and all individuals identified as "Not Hispanic or Latino" are classified by their racial identification.

Datasets marked with an asterisk symbol (*) indicate sources of data that have disaggregated or additional race and ethnicity groups across the years included in the book. For example, the race and ethnicity variables available for query from NVSS – Underlying Cause of Death through CDC WONDER varied by year and query topic. Data were queried from the "2018-2021: Underlying Cause of Death by Single-Race Categories" data request form that included a Multiracial category and separate Asian and NHPI categories as well as the "1999-2020: Underlying Cause of Death by Bridged-Race Categories" data request form that had a combined API category and no Multiracial category available.

Table 3-4: Race and Ethnicity Variables

Data Source Abbreviation	Year	Variable Name	AI/AN	API	Asian	Black	Hispanic (Hisp)	Multiracial	NHPI	White	Other
ACS 5-Year	2010-2021	Race and Ethnicity	AI/AN Alone	N/A	Asian Alone	Black or African American Alone	Hisp or Latino	Two or More Races	NHPI Alone	White Alone	Some Other Race Alone
CPS	2010-2017; 2019-2021	PRDTRACE; ^PEHSPNON	N/A	N/A	Asian only	Black only	^Hisp Origin	N/A	N/A	White only	N/A
NCVS	2010-2022	Victim race/Hisp origin	N/A	N/A	N/A	Black	Hisp	N/A	N/A	White	Other
NEISS-AIP	2010-2020	Race/Ethnicity	N/A	N/A	N/A	Black	Hisp	N/A	N/A	White non-Hisp	Other non-Hisp
NHANES	2009-2010; *2011-2018	RIDRETH1; *RIDRETH3	N/A	N/A	*Non-Hispanic Asian	Non–Hisp Black	Mexican American; Other Hisp	Other Race – including Multiracial	N/A	Non-Hisp White	Other Race – including Multi-Racial
NHIS	2019-2022	HISPALLP_A	Non-Hisp AI/AN and any other group	N/A	Non-Hispanic Asian only	Non-Hisp Black/African American only	Hisp	N/A	N/A	Non-Hisp White only	Other single and multiple races
NHSS	2010-2021	Race/Ethnicity	AI/AN	N/A	Asian	Black/African American	Hisp/Latino	Multiracial	NHPI	White	N/A
NSDUH	2021	NEWRACE2	Non-Hisp AI/AN	N/A	Non-Hispanic Asian	Non-Hisp Black/African American	Hisp	Non-Hisp more than one race	Non-Hisp NHPI	Non-Hisp White	N/A
NVDRS	2018-2021	Race; ^Ethnicity	AI/AN	N/A	Asian	Black	^Hisp; Non–Hisp	More than one race	NHPI	White	N/A
NVSS – Life Expectancy	2010-2019	Hisp origin and race	Non-Hisp AI/AN	N/A	Non-Hispanic Asian	Non-Hisp Black	Hisp	N/A	N/A	Non-Hisp White	N/A
NVSS – Linked Birth/Infant Death Records	2010-2021	Mother's Single Race; ^Mother's Bridged Race/ Hisp Origin; *Mother's Bridged Race	AI/AN	*API	Asian	Black or African American	^Mexican; Puerto Rican; Cuban; Central or South American; Other and Unknown Hisp	N/A	NHPI	White	More than one race
NVSS – Natality	2010-2015; 2016-2022	Mother's Single Race; ^Mother's Hisp Origin	AI/AN	N/A	Asian	Black or African American	^Hisp or Latino; Not Hisp or Latino	More than one race	NHPI	White	N/A
NVSS – Underlying Cause of Death	2010-2020; *2018-2021	Race; ^Hisp Origin; *Single Race 6	AI/AN	API	*Asian	Black or African American	^Hisp or Latino; Not Hisp or Latino	*More than one race	*NHPI	White	N/A
SEER	2010-2020	Race Ethnicity	AI/AN non-Hisp	API non-Hisp	N/A	Black non-Hisp	Hisp	N/A	N/A	White Non–Hisp	N/A
YRBS	2013, 2015, 2019, 2021	RACEETH	AI/AN	N/A	Asian	Black or African American	Hisp/Latino	Multiple	NHPI	White	N/A

^ Indicates that the data source provided separate race and ethnicity variables, and the data has been processed to create a single non-overlapping race and ethnicity variable.

* Indicates that the variable has been disaggregated or differentially available in the data across years or query sources.

The categories Black, Hispanic, and White were uniformly available across all data sources, while the other race and ethnicity categories are included inconsistently across sources. Nine datasets had separate "Asian" and "NHPI" groups, three datasets (NVSS – Linked Birth/Infant Death Records, NVSS – Underlying Cause of Death, and SEER) used the aggregated API category, and four (CPS, NHANES, NHIS, and NVSS – Life Expectancy) included only an aggregated "Asian" group. Two datasets (NCVS and National Electronic Injury Surveillance System – All Injury Program [NEISS-AIP]) did not include any "Asian," "NHPI," or "API" variable. In the case of NCVS, the "API" was included within the "other" variable in the available data. Other variables more sparsely accounted for among the datasets include "AI/AN," "Multiracial," and "other."

3.2.3 Rurality

Rurality is a critical consideration for understanding the health of U3 women: rural communities are more likely to lack healthcare providers, have difficulty accessing care due to cost and distance and have worse self-rated health.[10] The number of physicians available in rural areas is significantly lower than urban areas: 12.7 per 10,000 people in nonmetropolitan areas compared to 33.6 in metropolitan areas.[11] More than 65% of the Health Resources and Services Administration (HRSA) designated Primary Care Health Professional Shortage Areas and 60% of Mental Health Professional Shortage Areas were located in rural areas in 2022.[11] The data presented in the following chapters are intended to provide additional nuance in priority health conditions for women living in rural areas compared to women living non-rural areas across all races and individuals of Hispanic versus Non-Hispanic origins.

This Data Book defines populations living in rural areas according to the 2010 Office of Management and Budget (OMB) definition of rurality, which distinguishes counties as metropolitan (containing a core urban area of 50,000 or more population), micropolitan (containing a core urban area of at least 10,000 but less than 50,000 population) or neither (counties with less than 10,000 population).[12] Both metropolitan labels and a population threshold of 50,000 were used to determine rurality depending on the data available across each data source. Thus, women living in counties that are not part of a metropolitan statistical area are included in the "rural" category. The term urban, though describing higher-level concentrated population counts in an area, has been used to marginalize populations and reinforce race and poverty-related stereotypes.[13–16] This book uses the term "not rural" instead of the term "urban" to describe women who are not classified within the category of women in rural areas.

Table 3-5 provides the variables used to define rurality across all the data sources. Of the 15 datasets, 8 did not have a suitable geographic variable to define rurality, including County Federal Information Processing System (FIPS) that could have been mapped to the OMB definition. Five of 15 datasets provided a rural/non-rural classification scheme, and 2 of 15 provided a County FIPS that could be mapped to the OMB definition (American Community Survey [ACS] and NHSS).

Table 3-5: Rurality Variables Across Data Sources

Data Source Abbreviation	Data Download Modality	Year	Variable Name	Variable Options & Rurality Mapping
ACS 5-Year	ACS API	2010-2021	County FIPS	OMB Mapping
CPS	Downloaded Tables/ Reports	2010-2017; 2019-2021	N/A	N/A
NCVS	Online Dashboard N-DASH	2010-2022	N/A	N/A
NEISS-AIP	Online Data Query System WISQARS	2010-2020	N/A	N/A
NHANES	PUF	2009-2018	N/A	N/A
NHIS	PUF	2019-2022	URBRRL	Nonmetropolitan = Rural Large central metro = Not Rural Large fringe metro = Not Rural Medium and small metro = Not Rural
NHSS	Online Data Query System AtlasPlus	2010-2021	FIPS	OMB Mapping
NSDUH	PUF	2021	COUNTYP4	Nonmetro = Rural Large Metro = Not Rural Small Metro = Not Rural
NVDRS	Online Data Query System WISQARS	2018-2021	Metro/Non-Metro	Non-Metro = Rural Metro = Not Rural
NVSS – Life Expectancy	Online Data Query System CDC WONDER	2010-2019	N/A	N/A
NVSS – Linked Birth/ Infant Death Records	Online Data Query System CDC WONDER	2010-2021	N/A	N/A
NVSS – Natality	Online Data Query System CDC WONDER	2010-2021	2013 Metro/ Nonmetro	Nonmetro = Rural Metro = Not Rural
NVSS – Underlying Cause of Death	Online Data Query System CDC WONDER	2010-2021	2013 Urbanization	Micropolitan (Nonmetro) = Rural NonCore (Nonmetro) = Rural Large Central Metro = Not Rural Large Fringe Metro = Not Rural Medium Metro = Not Rural Small Metro = Not Rural
SEER	Online Data Query System CanQues//SEER*Explorer	2010-2020	N/A	N/A
YRBS	PUF	2013, 2015, 2019, 2021	N/A	N/A

Note that datasets with County FIPS in the variable name column follow the OMB mapping scheme, which considers counties with fewer than 50,000 populations rural and counties with 50,000 or greater populations not rural based on annual ACS population counts within each county.

Multiple definitions for rurality were considered initially, including the U.S. Census definition of urban areas, U.S. Department of Agriculture (USDA) Rural-Urban Commuting Area Codes for census tracts, Federal Office of Rural Health Policy definitions for variable geographies, and USDA Frontier and Remote Area Codes for ZIP codes. While many of these definitions may offer greater precision at smaller geographic levels like the Census Tract, ZIP Code, or ZIP Code Tabulation Areas levels, the choice to adopt a county-level rural classification was in part due to limitations in geographic variables available across the selected data sources. The public use data sources in this book omit such geographic data to protect respondent privacy. The geo-coded variables provided in the public use data are often presented at higher aggregate levels, often as urban/rural or metro/non-metro classifications. As a result, the rurality classifications used across this book may undercount rural respondents who live on the peripheries of counties that fall under the definition of non-rural, but whose experiences (especially in terms of access to the healthcare system) more closely resemble those of respondents in rural areas.

For ACS data, county-level estimates are provided without explicit rurality labels. To assign counties as rural and not rural, county-level population counts from ACS data were matched to OMB definitions using County FIPS codes for each corresponding year of available data. Counties with < 50,000 residents were classified as rural, and counties with ≥ 50,000 were classified as not rural, according to the 2010 OMB definition. NHSS through AtlasPlus was able to generate county-level estimates that could be mapped to OMB definitions. However, estimates by sex, race, and ethnicity at the county level were largely unavailable due to data suppression policies.

3.2.4 Economic Status

In addition to underserved rural populations, women in socioeconomically disadvantaged groups are an NIH-designated health disparity population. The inverse associations between socioeconomic status (SES) and both physical and mental health have been long observed and documented throughout the course of a woman's lifetime (see **Chapter 1**).[17] Despite these known relationships, barriers including systemic barriers, trial design barriers, and participant barriers result in the under inclusion of women in clinical research—particularly women of underrepresented racial and ethnic communities. Ensuring that the risks and benefits of clinical research participation for economically vulnerable populations are appropriately addressed is an essential part of both ethical and regulatory considerations.[18,19]

While SES is a gradient and multi-faceted, the following section operationalizes a definition for women of economically disadvantaged groups and provides comparisons with women that are not considered economically disadvantaged across the racial and ethnic groups available in the data. This Data Book uses federal poverty level (FPL) to define economic status. FPL is derived from data and guidelines by the Census Bureau, OMB, and U.S. Department of Health and Human Services (HHS). The Census Bureau follows directives set by OMB to create multiple sets of income thresholds based on the number of members within a household. As described by the Census, "if a family's total income is less than the family's threshold, then that family and every individual in it is considered as living in poverty. The official poverty thresholds do not vary geographically, but they are adjusted for inflation using the Consumer Price Index. The official poverty definition uses money income before taxes and does not include capital gains or non-cash benefits (such as public housing, Medicaid, and food stamps)."[20] HHS updates annual poverty guidelines based on the formal thresholds defined by the Census Bureau and OMB. FPL is used in 4 of 15 data sources to denote economic disadvantage. The balance—11 of 15 data sources—did not use FPL or include proxies that could be used to map the data to the economic status variable (**Table 3-6**). Within this Data Book, 200% or two times the FPL threshold was chosen to define "low-income family" based on the current thresholds used by Health Resources and Services Administration.[21] One exception to this threshold was used in the Demographics **Chapter 2** where 100% of the FPL threshold was used to distinguish between economically advantaged and disadvantaged, as the data available through the ACS API dataset provided only the one FPL option to capture national populations by both sex and race and ethnicity.

Table 3-6: Economic Status Variables

Abbreviation	Data Download Modality	Year	Variable Name	Variable Options & U3 Econ Mapping
ACS 5-Year	ACS API	2010-2021	B17001(A-H)	Income in the past 12 months below poverty level (FPL) = Economically Disadvantaged Income in the past 12 months at or above poverty level (FPL) = Economically Advantaged
CPS	Downloaded Tables/Reports	2010-2017; 2019-2021	N/A	N/A
NCVS	N-DASH	2010-2022	N/A	N/A
NEISS-AIP	WISQARS	2010-2020	N/A	N/A
NHANES	PUF	2009-2018	INDFMPIR	≤ 2.0 FPL = Economically Disadvantaged > 2.0 FPL = Economically Advantaged
NHIS	PUF	2019-2022	POVRATTC_A	≤ 2.00 FPL = Economically Disadvantaged > 2.00 FPL = Economically Advantaged
NHSS	AtlasPlus	2010-2021	N/A	N/A
NSDUH	PUF	2021	POVERTY3	Living In Poverty (FPL) = Economically Disadvantaged Income Up to 2X Fed Pov Thresh (FPL) = Economically Disadvantaged Income More Than 2X Fed Pov Thresh (FPL) = Economically Advantaged
NVDRS	WISQARS	2018-2021	N/A	N/A
NVSS - Life Expectancy	CDC WONDER	2019	N/A	N/A
NVSS - Linked Birth / Infant Death Records	CDC WONDER	2010-2021	N/A	N/A
NVSS - Natality	CDC WONDER	2010-2015; 2016-2022	N/A	N/A
NVSS - Underlying Cause of Death	CDC WONDER	2010-2021	N/A	N/A
USCS/SEER	CanQues	2010-2020	N/A	N/A
YRBS	PUF	2013, 2015, 2019, 2021	N/A	N/A

3.2.5 Sexual Orientation and Gender Identity

The third NIH-designated health disparity population explored in this book is women who belong to a sexual or gender minority populations. The NIH Style Guide provides definitions for sexual orientation, gender identity, and sexual and gender minority (SGM) populations as follows:[9]

- Sexual orientation: Sexual attraction, behavior, and identity.
- Gender identity: An individual’s sense of being a man, woman, boy, girl, genderqueer, nonbinary, etc. This identity is not necessarily visible to others.
- Sexual and gender minority population: SGM populations include, but are not limited to, individuals who identify as lesbian, gay, bisexual, asexual, transgender, Two-Spirit, queer, and/or intersex. Individuals with same-sex or -gender attractions or behaviors and those with variations in sex characteristics are also included. These populations also encompass those who do not self-identify with one of these terms but whose sexual orientation, gender identity or expression, or reproductive development is characterized by non-binary constructs of sexual orientation, gender, and/or sex.

Recent studies suggest that SGM people are willing to provide information about sexual orientation and gender identity in healthcare contexts, though fear of stigma and homophobia may still result in under-identification.[22] Additionally, recent White House recommendations and best practices aim to reduce this underreporting by including sexual orientation and gender identity questions in all federal statistical surveys.[23] The following section delineates the availability of publicly available sources to provide health statistics on the subset of women who are also "sexual minority" (SM) and "gender minority" (GM).[24] **Table 3-7** shows the sexual orientation and gender identity definitions used across included data sources. While some data sources (e.g., NSDUH) plan to update and expand demographic questions to include details on sexual orientation and/or gender identity, across the data sources used within this book, variables on sexual orientation or gender identity were present in only 4 of the 15 data sets: NHIS, NHSS, NSDUH, and Youth Risk Behavior Survey (YRBS).

Table 3-7: Sexual Orientation and Gender Identity Variables

Abbreviation	Data Download Modality	Year	Variable Name	Variable Options & Mapping for Sexual Orientation and Gender Identity
ACS	ACS API	2010-2021	N/A	N/A
CPS	Downloaded Tables/Reports	2010-2017; 2019-2021	N/A	N/A
NCVS	N-DASH	2010-2022	N/A	N/A
NEISS-AIP	WISQARS	2010-2020	N/A	N/A
NHANES	PUF	2009-2018	N/A	N/A
NHIS	PUF	2019-2022	ORIENT_A	Bisexual = SM (LBQ) Gay/Lesbian = SM (LBQ) Don't know the answer = SM (LBQ) Something Else = SM (LBQ) Straight = Not SM (Heterosexual) Refused = Not SM (Refused/Missing)
NHSS	AtlasPlus	2010-2021	Gender	Transgender Woman = GM Transgender Man = GM Additional Gender Identity (AGI) = GM Male = Not GM Female = Not GM
NSDUH	PUF	2021	SEXIDENT	Bisexual = SM (LBQ) Lesbian or Gay = SM (LBQ) Straight = Not SM (Heterosexual)
NVDRS	WISQARS	2018-2021	N/A	N/A
NVSS – Life Expectancy	CDC WONDER	2019	N/A	N/A
NVSS – Linked Birth /Infant Death Records	CDC WONDER	2010-2021	N/A	N/A
NVSS – Natality	CDC WONDER	2010-2015; 2016-2022	N/A	N/A
NVSS – Underlying Cause of Death	CDC WONDER	2010-2021	N/A	N/A
SEER	CanQues/ SEER*Explorer	2010-2020	N/A	N/A
YRBS	PUF	*2021; 2013, 2015, 2019	*Q65; Q66/Q67/ Q68	Gay or lesbian = SM (LBQ) Bisexual = SM (LBQ) *I describe my sexual identity some other way = SM (LQB) *I am not sure about my sexual identity (questioning) = SM (LBQ) Not sure = SM (LBQ) Heterosexual (straight) = Not SM (Heterosexual) *I do not know what this question is asking = Not SM (Refused/Missing)

* Indicates that the variable has been disaggregated in the book's data across years.

Throughout this Data Book, variables for sexual orientation have been aligned into one of three categories: "lesbian, bisexual, queer or questioning" (LBQ), "heterosexual," and "refused/missing." The LBQ category is intended to capture all sexual orientations based on self-identification as gay, lesbian, bisexual, questioning, and other types of orientations that are not heterosexual/straight. The heterosexual category captures all self-identified responses that are heterosexual or straight. The refused/missing category captures all respondents who refused to answer the question or had missing values in the original data. Across datasets, the "I don't know" response options were coded under the LBQ question intended to capture questioning respondents, though depending on the data source's specific wording this may not distinguish between respondents who are unsure of their sexual orientation (questioning identity) and those who were unclear about what the question was asking. Coding for this option is intended to err on the side of inclusivity.

Only four datasets (NHIS, NHSS, NSDUH, and YRBS) included a sexual identity or sexual orientation variable. In the case of YRBS, additional sexual identity categories were added in their 2021 survey. The categories "I describe my sexual identity some other way," "I am not sure about my sexual identity (questioning)," and "I do not know what this question is asking" were added alongside the already-existing categories of "heterosexual (straight)," "bisexual," "gay or lesbian," and "not sure." These additions point to a trend of expanded inclusion to incorporate the broadest level in current and future surveys. Questions on gender identity were sparse in the scoped datasets that met the inclusion criteria for this book. Only one dataset, NHSS, had different variables for sexual identity and gender identity and contained information that could be mapped to the gender identity variable.

3.3 Data Methodology

3.3.1 Data Processing

Data across 15 datasets were processed and labeled in alignment with the data definitions described above for the various U3 women by race and ethnicity groups, rurality status, economic status, sexual orientation, and/or gender identities. While this book visualizes and presents figures that describe and compare the health status for women with intersectional identities, the analyses in this book do not include any statistical tests or analyses intended to suggest statistically significant differences between groups. Observations from these figures are intended to provide baseline background information, which researchers may use to further their own analyses in U3 women in medical and health research.

3.3.2 Data Visualization

The figures and visuals in this book show the current state and historical trends in health outcomes aligned with the topic of the individual chapter. Data visualizations provide multiple perspectives from which the reader might view differences across several indicators of population health for U3 women. Topics are introduced with a broad overview of the health condition as it relates to sex and/or gender differences when applicable; then visuals examine the intersection of sex and/or gender across racial and ethnic groups. Finally, as the data allow, visuals show the intersection of race and ethnicity across the U3 populations explored in this book highlighting comparisons by rurality, economic status, and sexual orientation and gender identity.

Colors, shapes, and data labels are used intentionally throughout this book to help distinguish among groups or within stratified elements. For comparisons between women and men, a dark saturated blue and/or a circle shape is used to represent women, while a light blue and/or a square shape is used to represent men. For comparisons between race and ethnicity, the following colors and shapes represent all possible groups.

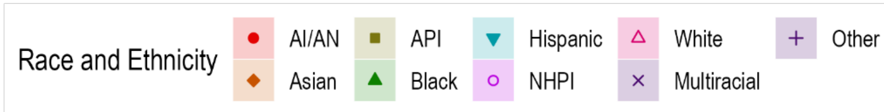

Figure 3-1. Race and Ethnicity Legend Color and Shape Codes

In bar charts that show intersections with race and ethnicity, a horizontal bar with the respective color codes is used to reinforce visual consistency. For comparisons that involve U3 categories, the dark saturated blue represents the U3 groups of interest (economically disadvantaged, rural, sexual and gender minorities), while the lighter blue represents the comparison groups (economically advantaged, not rural, heterosexual and cisgender).

3.3.3 Definitions of Data Estimates

This section discusses the common types of data values that are included in this book and their definitions, the inclusion and interpretation of standard errors or uncertainty estimates, time trends, and pooled data. Three types of measures are often presented in this book; they capture both morbidity and mortality associated with disease:

- **Prevalence**: The number of existing cases/events in a population at a specified time.
- **Incidence**: The number of new cases/events in a population within a specified time period.
- **Mortality**: The number of deaths per 100,000 population within a specified time period.

Data produced from national surveys are intended to provide nationally representative estimates for populations specified within each source. Data from surveillance systems and vital statistics are identified as case counts, crude estimates, or age-adjusted estimates. Age adjustment accounts for both different frequencies of the occurrence among different age groups and differences in the age distribution within specific populations. However, based on suppression rules or missing population denominators, crude estimates and age-adjusted estimates were not available across all groups and years used in this publication. In those instances, case counts were visualized instead.

3.3.4 Standard Errors, Uncertainty Estimates, and Missing Data

Whenever possible, this book presents uncertainty estimates for all data values presented. National surveys (as labeled in **Table 3-1** employ complex survey weighting and variance estimation described in their technical documentation to account for survey features including sampling methodology, clustering, non-response adjustments, and post-stratification adjustments. All data processing, survey weighting, and variance estimation for survey data as listed in **Table 3-1** were conducted using R Statistical Software (v4.2.2; R Core Team 2021) and the R ‘survey’ and ‘srvyr’ packages.[25–28] Survey data was used to calculate percentages or proportions of the population represented by the sampled data. Error bars on bar charts and shaded ribbons for line plots reflect the standard errors of the reported estimate for all survey data. Standard errors may not be applicable across all estimate types in surveillance data or vital statistics data systems sources.

The standard error is the measure of the precision of a statistic (e.g., mean, proportion) from a sample. A small standard error for a sample statistic indicates a more reliable estimate of the population parameter. A large standard error indicates a less reliable estimate of the population parameter. Standard error intervals can be calculated by adding and subtracting the standard error from an estimate (such as a proportion) to create error bars that are displayed in a figure (bar chart, line graph, etc.). When comparing a percentage or proportion in the figures, non-overlapping standard error intervals (bars) between groups suggest that the observed differences may indicate a true difference but do not guarantee a true difference. In contrast, when standard error intervals (bars) do overlap between groups, this may either suggest that there is no meaningful difference or that the sampled data may be underpowered to detect a true difference if one exists. As noted previously, the analyses in this book do not include formal statistical tests to evaluate the differences in estimates between groups and therefore, definitive conclusions regarding observed differences presented in the figures are limited.

Data from surveillance data systems were collected from online query tools and provided summarized data and pre-calculated crude and age-adjusted estimates of prevalence and incidence. Not all surveillance data provided pre-calculated errors, and data from these systems were subject to different levels of data suppression resulting in unavailable data. Figures that do not provide pre-calculated errors are noted in the caption and description as appropriate. The estimates from these figures should be interpreted with caution and should not be considered as estimates that were calculated without errors.

Data from vital statistics present complete counts of both case numerators, population parameters, crude rates, and age-adjusted rates for births and deaths for the total population. These data also provide standard errors. Given that these data are complete case counts, however, these standard errors are not due to sampling variation. Rather, standard errors for these data are calculated to account for random variation and for use in statistical testing. Even though these data are intended to represent complete population results, errors and missing data still exist within the data. As noted in the NVSS documentation, “estimates that are unreliable because of large sampling errors, low precision, small denominators, or small numbers of events” are flagged in the data and omitted from further visualization.[29]

3.3.5 Time Trends and Pooled Estimates

As seen in **Table 3-1**, while some data sources used in this book are collected on an annual basis and have 10 or more years of comparable data, other datasets may be collected less frequently or have limited data vintages available for trend comparisons. The data in this book provide a series of cross-sectional views of the various health measures rather than longitudinal or cohort data. Time trends can be used to identify emergent disparities, progress toward equitable outcomes, or stability of health outcomes within the population.

There are many drivers that may influence change over time, including random variation in sampled populations, new national-level interventions (changes to healthcare coverage policies), external shocks (economic crises, global pandemics), knowledge gains within the medical field, or continued efforts of long-standing public health infrastructure systems. Most notable to the interpretations of time trends, in this book, is the impact of the COVID-19 pandemic declared by the World Health Organization in March 2020. Most data and trends in this book include data collected prior to and throughout the COVID-19 pandemic, and as such, should be interpreted considering this context. COVID-19 revealed the underlying disparities that have been long present and revealed gaps and areas of growth within the public health infrastructure and research (see **Chapter 4**). Many data collections and public health systems encountered interruptions or had to redirect efforts to attend to emergent pandemic needs. This, coupled with non-response rates across surveys higher than in prior years, led to challenges in national datasets.

This Data Book also presents data that have been pooled across multiple cross-sectional years. Pooled data are used to help provide more robust estimates with smaller standard errors and are useful particularly when creating estimates for smaller population groups or nested intersection groups for infrequent or uncommon conditions (e.g., AI/AN women in rural areas with uterine cancer). Pooling across survey cycles within a study was conducted using the study-provided pooled weights, or using pooled weights calculated according to documentation provided by the study. For vital statistics and some surveillance data used for this book, pooled estimates were directly pulled from the data download source. Data from other surveillance data that provided full numerator and denominator counts were aggregated across years to re-calculate pooled crude estimates. Figure captions are labeled to specify when multiple vintages of data are pooled to generate estimates. Prior to pooling the data, overall trends were examined for the measure to ensure there were not any notable changes in the health measure for the available years of data. However, pooled data may obscure time trends among specific groups and subgroups across the pooled years. Even with pooled estimates, the standard errors for certain subgroup intersections may remain large (especially, for example, regarding certain health topics for SGM populations).

3.4 References

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Chapter 4

Top 10 Causes of Death

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Top 10 Causes of Death

4.1 Defining Causes of Death

Mortality data provide critical information to track priority public health challenges, estimate life expectancy, document disparities between demographic groups, and ultimately inform policy and other interventions seeking to improve health.[1] Trends in the leading causes of death reflect the shifting social, political, medical, economic, and health state of a society.[2] The National Vital Statistics System (NVSS) is the U.S. intergovernmental data sharing platform that "collects and disseminates the Nation's official vital statistics."[3] As such, NVSS data and reports track the characteristics of those who have died, generate projections of life expectancy, and compare trends in U.S. mortality across population groups. NVSS has reported on the top causes of death annually by race and ethnicity, sex, and age, allowing for comparisons over time since 1952.[4] NVSS uses information from death certificates to identify and rank causes of death using codes from the International Classification of Diseases (ICD).[3,4] Importantly, the National Center for Health Statistics (NCHS) uses the NVSS dataset to generate age-adjusted death rates for the U.S.[5]

4.1.1 Life Expectancy

Life expectancy, a standard statistical measure estimating span of life at birth, has increased overall in the U.S. for most of the past 60 years.[6] In 2011, however, the rate of increase plateaued and it subsequently decreased for the first time between 2020 and 2021. This lower life expectancy is explained by "increase in mortality due to COVID-19 (50.0% of the negative contribution), unintentional injuries (15.9%), heart disease (4.1%), chronic liver disease and cirrhosis (3.0%), and suicide (2.1%)."[7] These and other sources of increased fatalities during the same period, such as drug overdose deaths, vary by sex, geography, age, and economic factors, and the complex interplay of race and ethnicity with social drivers of health discussed in Chapter 1.[8] In 2021, the average life expectancy for women in the U.S. was 79.3 years compared with 73.5 years for men.[5] Among babies born in the U.S. in 2019, girls are projected to live between 3 and 6.8 years longer than boys.[7] **Figure 4-1** shows the life expectancy at birth by sex, race and ethnicity; within each racial and ethnic group, women have longer life expectancies compared with men. Overall, the lowest life expectancy is among American Indian and Alaska Native (AI/AN) people, at 71.8 years for women and 68.6 years for men. The highest life expectancy is among Asian populations, at 87.4 years among women and 83.5 years among men.

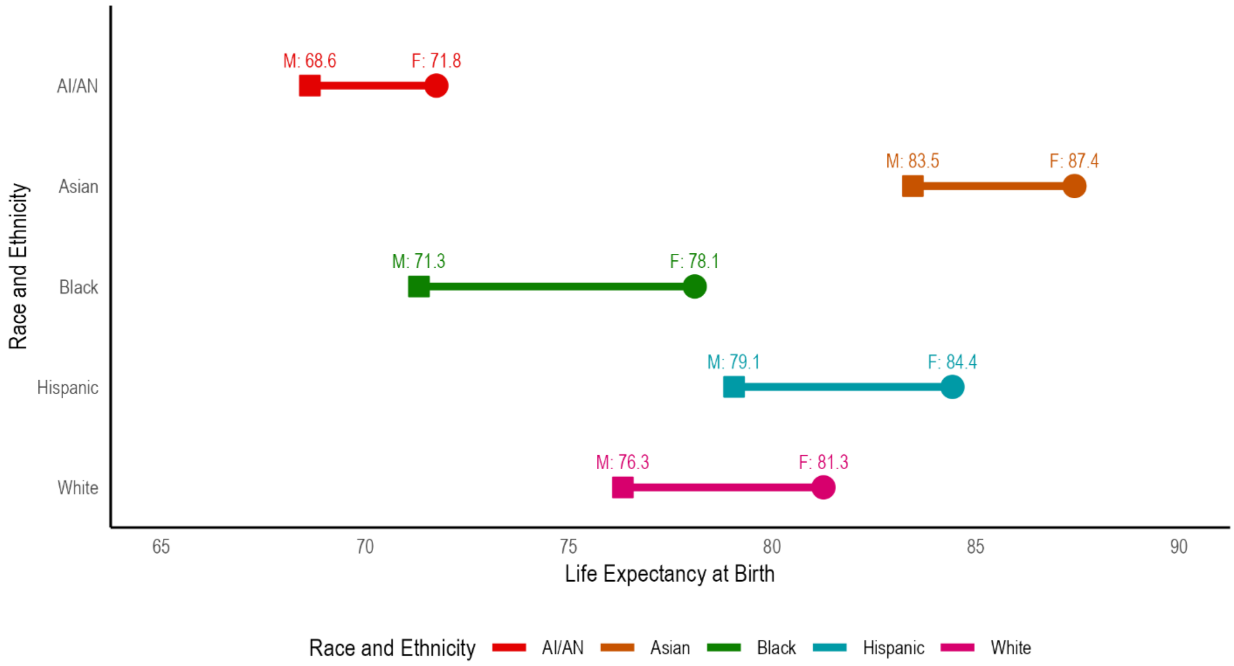

Figure 4-1: Life expectancy at birth, by sex and race and ethnicity
Source: National Vital Statistics System (NVSS) – Life Expectancy, 2019

It is well documented that women live longer on average than men in the U.S., as in most countries around the world.[5] In the U.S., this gap has decreased in recent decades, due in part to shifts in health behaviors that drive the top causes of death discussed throughout this chapter.[9] Because they live to older ages than men, women are more likely to experience chronic disease, poorer health, higher health services utilization, and morbidity, a phenomenon known as the gender health paradox.[10,11] Research on this paradox underscores the need to focus on the quality of life lived rather than just on the quantity of life.[9] Conversely, it is also essential to explore how social drivers like chronic stress are linked to shorter lifespans and higher disability throughout the life course, which is critical to the study of the health and lives of women of understudied, underrepresented, and underreported (U3) populations as defined in Chapter 1.[12,13]

4.2 Causes of Death in Women

The top causes of death nationally vary by sex, gender, and a range of other population characteristics. The data presented below highlight these differences for the top 10 causes of death for women and men, and then for U3 women by racial and ethnic group and rurality. For the past decade, heart disease has been the leading cause of death for both women and men, a trend that holds true across most racial and ethnic groups.[14] Heart disease is an umbrella term that refers to a range of conditions affecting the heart. Among these, coronary heart disease (CHD) affects the larger coronary arteries on the surface of the heart. It is the most common type of heart disease in the U.S. and is the leading cause of death for women.[15,16] **Figure 4-2** illustrates the mortality rate over time for the top 10 causes of death for women and men. The figure shows the heart disease death rate is higher for men than women (211 per 100,000 men and 130 per 100,000 women). Stroke, also a cardiovascular disease, is the third ranked cause of death for women and the sixth ranked cause of death for men. See Chapter 6 for an in-depth discussion of CVD among U3 women.

Cancers are the second leading cause of death for both men and women, although cancer mortality rates are higher in men than women (173 per 100,000 men and 127 per 100,000 women). **Chapter 8** provides more detail on the prevalence and incidence of and mortality due to cancers that are female-specific or disproportionately affect women.

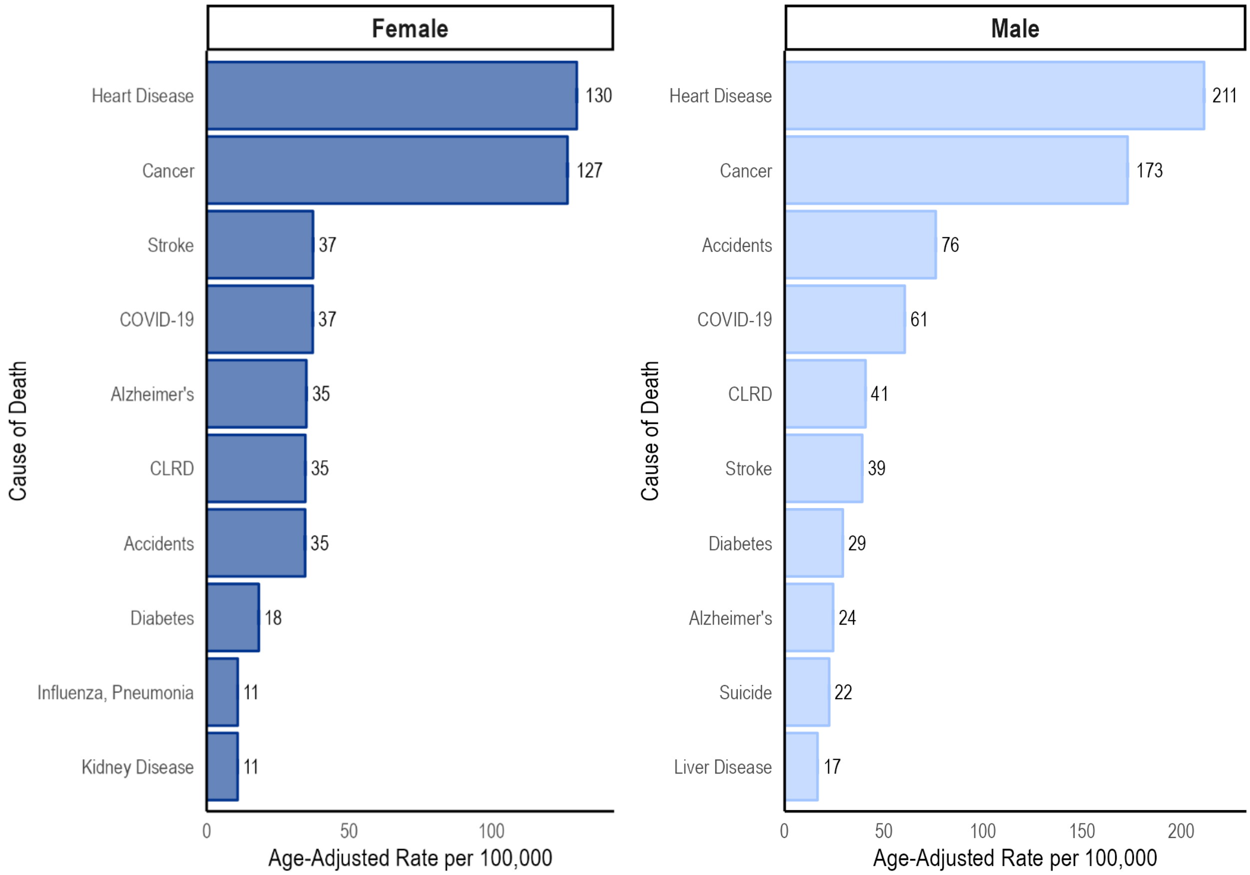

Figure 4-2: Top 10 causes of death for women and men, age-adjusted rates per 100,000 population
Source: National Vital Statistics System (NVSS) – Underlying Cause of Death, Pooled 2018-2021

There are prominent sex differences in other top 10 causes of deaths, in particular deaths by accidents, COVID-19, Alzheimer's disease (AD), suicide, liver disease, influenza, and kidney disease. Men's mortality rate due to accidents is nearly double that of women, and men's COVID-19 death rate is more than 1.5 times higher than that of women. Gender norms and differences in risk-taking behavior contribute to high rates of accidents, suicide, and liver disease in men.[17,18] Regarding AD, while women are at greater risk overall of developing and dying from the disease with a rate of 35 deaths per 100,000 compared to 24 deaths per 100,000 for men, the risk of developing vascular dementia is greater among men.[19] **Chapter 7** provides a more detailed discussion of AD among U3 women.

Figure 4-3 shows the mortality rate over time for the top 10 causes of death among women. The figure shows one in five U.S. women died of heart disease, with the rate being highest among Black, AI/AN, and Hispanic women (see data on these populations groups below) in 2021.[14] Overall, heart disease affects women in significantly different ways compared to men, as is discussed in more detail in **Chapter 6**. These differences are due to both biological and social determinants. For example, the steroid hormone estrogen has favorable effects on women's vasculature and lipid profiles prior to menopause, a cardiovascular benefit that wanes with age. The average female heart size and blood vessel diameter are smaller, and the muscular walls are thinner than in the male heart, contributing to the predisposition among women to coronary microvascular disease.[20] Other risks for heart disease that disproportionately impact women include anemia (especially during pregnancy), hormonal birth control use, and autoimmune disease diagnosis.[20] Women are also more likely to have heart attack symptoms historically labeled as "atypical" (although they are more common among women) leading to delays in diagnosis and treatment.[21]

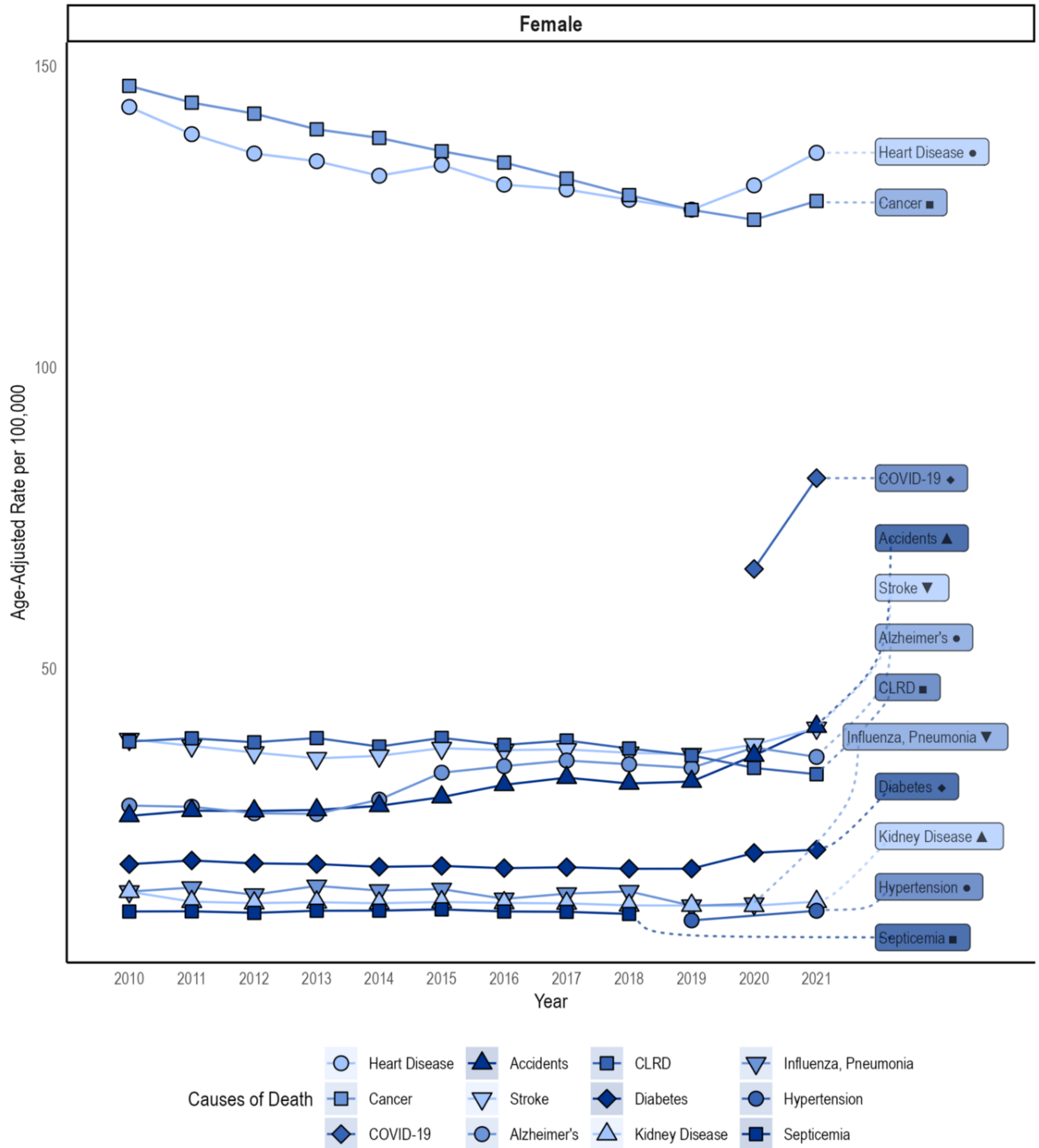

Figure 4-3: Top 10 causes of death over time, age-adjusted mortality rates per 100,000 women

Source: National Vital Statistics System (NVSS), 2010-2021

Social determinants that play a role in heart disease morbidity and mortality are economic, social, environmental, and psychosocial in nature.[22] Lower SES, lower education levels, unemployment, and being uninsured or underinsured are associated with worse heart disease outcomes.[23] Perceived racism and discrimination may contribute to the development of heart disease, and structural racism and barriers to healthcare access can complicate its detection and treatment.[24,25] Social determinants are associated with underlying biological mechanisms linked to heart disease, such as excess stress hormones, inflammation, immune cell function, and cellular aging.[22]

Within cancer, the second leading cause of death for women, the three most common cancers claiming women's lives are lung, breast, and colorectal. These also account for nearly half of all new cancer diagnoses in U.S. women.[26,27] Other common cancers that are female specific (e.g., endometrial, cervical, and ovarian cancers) are covered in more detail in **Chapter 8**. Following heart disease and cancer, the next leading causes of death among women (in order of magnitude) are COVID-19 (for 2020 and 2021), stroke, accidents, chronic lower respiratory disease, AD, diabetes, influenza, and kidney disease (see **Figure 4-3)**. The rates for each of these causes have remained relatively stable over the past decade except for COVID-19, which emerged in 2020.

4.1.2 Causes of Death for Populations of U3 Women

Disaggregating data on causes of death illustrates disparities affecting U3 women's lifespan (see **Chapter 1**). This section presents NVSS data from the past decade showing the top causes of death among women of underrepresented racial and ethnic communities. While data elsewhere in this book show differences among U3 women based on economic status, sexual orientation, and gender identity, NVSS data on mortality rates allow for comparisons only by sex and rurality, thereby limiting the extent of this analysis. Results presented below highlight that the top causes of death vary in subpopulations of U3 women by ranking (1 through 10) as well as in magnitude (rates per 100,000 population). For example, the leading cause of death for AI/AN women from 2010-2020 was heart disease, accounting for an estimated 120 deaths per 100,000 women. For Asian women, the top cause of death was cancer, accounting for an estimated 80 deaths per 100,000 women. Though heart disease and cancer are ranked as leading causes of death for AI/AN and Asian women, respectively, the absolute death rate for the top cause is almost twice as high for AI/AN women compared with Asian women. It is striking to note that absolute increases in mortality rates were most pronounced in AI/AN women compared with all other sex and race and ethnicity groups and during the COVID-19 pandemic.

Spotlight: COVID-19

The emergence of COVID-19 in December 2019 resulted in more than one million deaths and six million hospitalizations in the U.S. The pandemic brought unprecedented challenges for the public health system and exacerbated existing health disparities. Rates of infection, testing, vaccination, hospitalization, and death varied significantly by sex, race and ethnicity, and geography. Women, who comprise over 77% of front-line workers in healthcare and social services and a majority of informal (often unpaid) caregivers, were disproportionately affected by COVID-19.[28]

The data presented in this chapter show that COVID-19 was among the top three leading causes of death for women across racial and ethnic groups, but it was, upon its emergence, the top cause of death for AI/AN, Hispanic, and Native Hawaiian and Pacific Islander (NHPI) women. The COVID-19 mortality rate for AI/AN, Black, Hispanic, and NHPI women was at or above 100 deaths per 100,000 women. These high rates reflect social and structural differences including employment in essential work, structural racism and residential segregation, reliance on public transportation, and preexisting medical conditions.[29–31] While data on Long COVID-19 are limited by inconsistent reporting and treatment, available evidence suggests considerable gender, racial, and ethnic differences in symptoms and reporting. Recorded rates of Long COVID-19 do not match recorded rates of infection and hospitalization, as White non-Hispanic women comprise the large majority of Long COVID cases while women of underrepresented racial and ethnic communities experienced higher case rates and severity of COVID-19.[32,33] Patients with a Long COVID-19 diagnosis are less likely to live in areas with high poverty, though these areas saw high rates of both infection and death.[32,34]

As the nation continues to recover, the pandemic offers critical lessons for how to better protect the health of U3 women in future pandemics. This will require continuing work to address structural and policy-level factors that perpetuate their vulnerability in public health emergencies and ensuring data collection more accurately captures the fullness of their identities.

4.1.3 Causes of Death for Women of Underrepresented Racial and Ethnic Communities

4.1.3.1 American Indian and Alaska Native Women

The AI/AN population overall continues to experience lower life expectancies than other racial and ethnic groups across many disease categories (as shown in **Figure 4-1**). **Figure 4-4** displays data for the mortality rate over time for the top 10 causes of death among AI/AN women. It reveals that mortality rates for AI/AN women remained relatively constant with a few notable trends. Heart disease and cancer rates decreased over time, though both remained leading causes of death. There are varying causes for the same disease, such as heart disease. For instance, high exposure to toxic metals in groundwater places AI/AN people at increased risk for heart disease, thereby reinforcing the role of social drivers of health.[35] The data also show that the COVID-19 pandemic had a significant impact on AI/AN women beginning in 2020, when it displaced heart disease and cancer as the top cause of death. AI/AN women had a higher rate of death from COVID-19 related causes than all other racial and ethnic groups, a risk that is attributed to a range of social drivers of health, including lack of access to healthcare, limited trust in non-Native healthcare providers due to historical trauma and ongoing discrimination, and lack of indoor plumbing to support recommended infection prevention.[36–40] These disparities among AI/AN communities highlight the need for improved health services infrastructure, coupled with intentional collaboration with AI/AN community members and tribal leaders to ensure the health and well-being of this population.[41]

Accidents are the fourth leading cause of death for AI/AN women; the mortality rate from accidents has increased over time, rising from fewer than 50 deaths per 100,000 women in 2010 to over 85 deaths per 100,000 women in 2021, with a steep increase between 2018 and 2021. Risk factors for unintentional injuries and accidents in the AI/AN population are attributable to rural environments, lack of traffic safety in those environments, and the comparatively high proportion of adults among the AI/AN population.[42] Rates of deaths by liver disease, which is a fifth leading cause of death, also rose in this population of women. Liver disease may be initiated in some cases by obesity, hepatitis B and C exposure, and chronic alcoholism.[43] Mortality rates of alcohol-associated liver disease also increased among AI/AN populations overall, due in part to systemic failures such as underfunded resources and insufficient preventive care, which further highlight the need for policy interventions that include alcohol screenings in tribal and rural communities.[44,45] Two causes of death dropped from the top 10 for AI/AN women over the past decade: septicemia as of 2015 and influenza as of 2020, which were supplanted by COVID-19 and kidney disease. However, it is important to underscore that AI/AN populations continue to be overrepresented in both sepsis and influenza cases and deaths.[46,47]

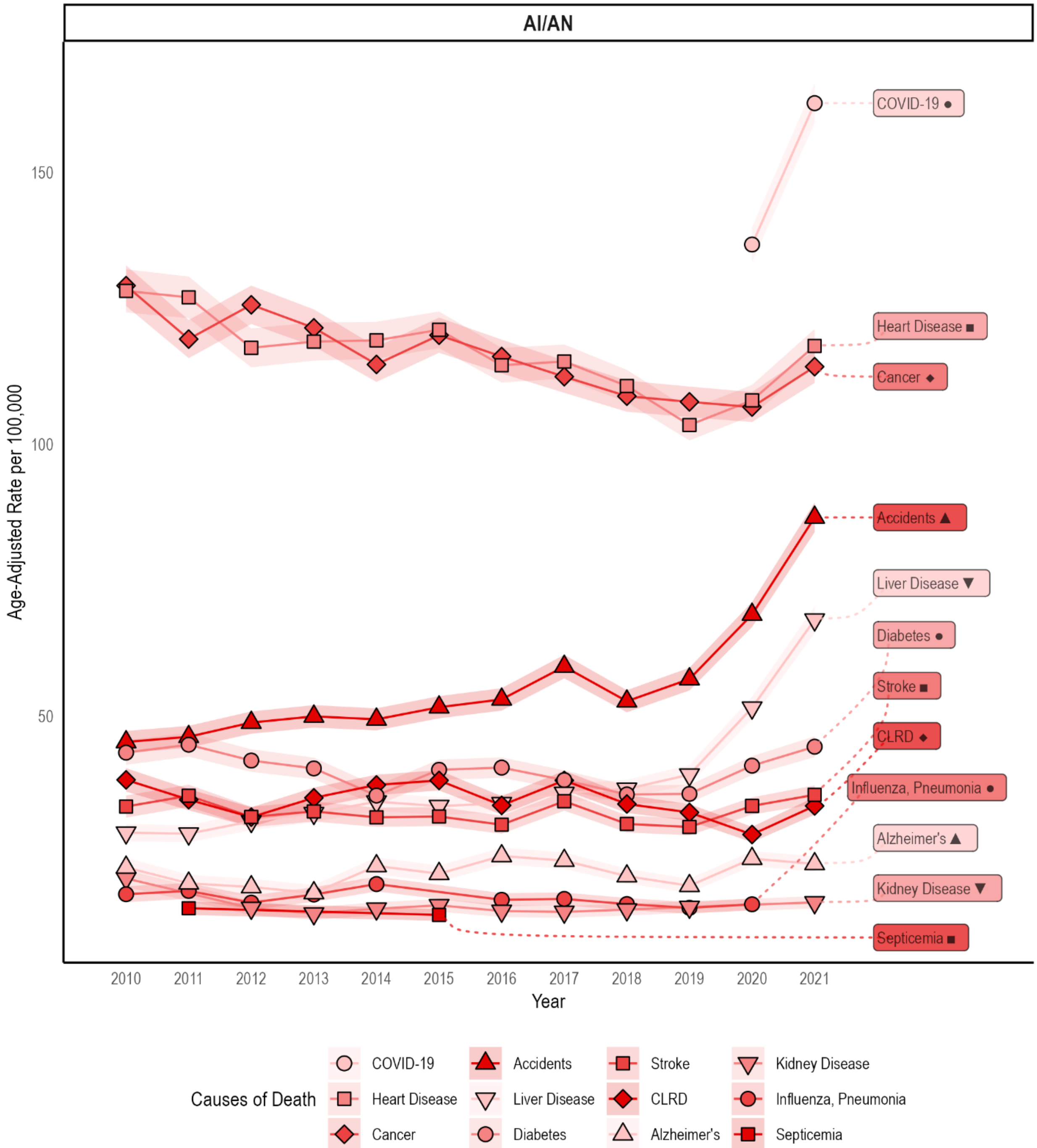

Figure 4-4: Top 10 causes of death over time, age-adjusted mortality rates per 100,000 AI/AN women
Source: National Vital Statistics System (NVSS), 2010-2021

4.1.3.2 Asian Women

As noted previously, Asian women have higher life expectancies than women of all other racial and ethnic groups in the U.S. (details about the diverse subpopulations included under the Asian category are in [Chapter 2](). It is important to note that this aggregate category does not allow for assessment of how causes of death vary across Asian subpopulations and the variation between (and within) them in average household incomes, educational attainment, and insurance coverage, as well as in health outcomes.[48] **Figure 4-5** illustrates the mortality rate over time for the top 10 causes of death among Asian women. The leading causes of death were cancer, followed by heart disease and stroke. It is only among the Asian population that cancer (as opposed to heart disease) is the leading cause of death in both women and men.[49] One component of this mortality risk may include lower rates of cancer screening among Asian populations compared with other racial and ethnic groups, which is not adequately explained by factors such as income or access to care but is more credibly related to health literacy.[49] Furthermore, research shows that breast cancer risks may be higher among immigrant Asian women compared to their U.S. born counterparts, and that this difference is more pronounced for immigrants who have lived more than half of their lives in the U.S.[50] These differences likely result from the cumulative effect of additional structural barriers and forms of discrimination that immigrant women experience, including language barriers, differences in medical beliefs and insurance coverage, and environmental exposures in their countries of origin (see **Chapter 1**).[51–53]

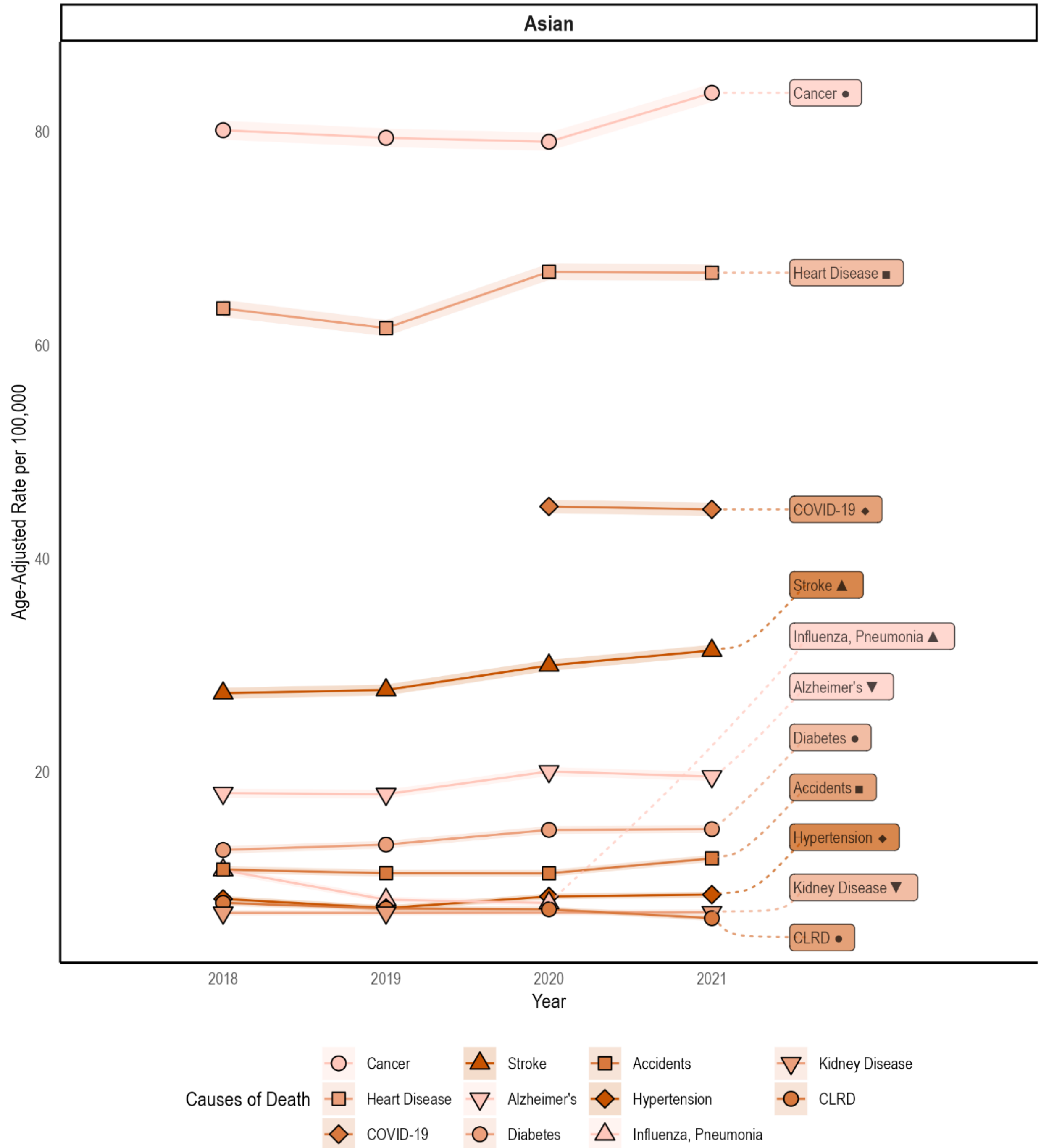

Figure 4-5: Top 10 causes of death over time, age-adjusted mortality rates per 100,000 Asian women

Source: National Vital Statistics System (NVSS), 2018-2021

The data also show that diabetes has consistently been the sixth ranked cause of death among Asian women. Diabetes-specific mortality has increased since 2018, which aligns with research showing a growing diabetes epidemic among Asian populations in the U.S. and across Asia.[54–56] Studies also show that Asian people overall develop diabetes at younger ages and at a lower body mass index than White people.[55–57] As noted above, the Asian population is not monolithic. For example, studies found Filipina and Korean women had higher rates of diabetes than other subpopulations.[48,58,59]

Beginning in 2020, COVID-19 became the third leading cause of death for Asian women. Estimates show that specific subgroups of Asian women experienced greater losses in life expectancy due to COVID, with Chinese women experiencing the largest declines (between 2.0 and 2.4 years) during the first year of the pandemic. Vietnamese women also experienced large declines in life expectancy, which continued into the second year of the pandemic, when the life expectancy decreased by 0.9 years for this subgroup.[60] Estimates of life expectancy across Asian subgroups are limited by currently available data and inconsistent disaggregation and classification of subgroups.

4.1.3.3 Black Women

Black women have the highest heart disease burden compared with women of other racial and ethnic groups and men of some racial and ethnic groups as well. **Figure 4-6** displays the mortality rate over time for the top 10 causes of death among Black women. Black women's death rates from heart disease and other causes are multifactorial and related to systemic disadvantages faced by U3 women, including discrimination, exclusion from clinical studies, underlying social determinants of health, and inequities in access to healthcare.[25,61] Black women and their communities have also been the targets of racist institutions and policies, ranging from slavery to segregation and redlining, leading to neighborhoods with fewer parks, less fresh food and more air pollution, and making ZIP codes a predictor of poor health among Black women.[62] While heart disease has been consistently the leading cause of death for Black women, data show a marked increase occurring in 2020, coinciding with the start of the COVID-19 pandemic. This finding reflects other research showing that during the pandemic, Black people experienced nearly threefold higher rates of cardiovascular disease (CVD) mortality in comparison with White people, 13.8% versus 5.1%, respectively. This further highlights the need for policy-level changes and cultural sensitivity in patient care.[63]

Cancer was the second leading cause of death for Black women, with an overall downward trend over time. Deaths attributable to cancer declined for Black women from nearly 175 per 100,000 deaths in 2010 to less than 150 per 100,000 deaths in 2021. Disparities in cancer outcomes, such as the disproportionate mortality among Black women from cervical and breast cancers, are discussed in **Chapter 8**.

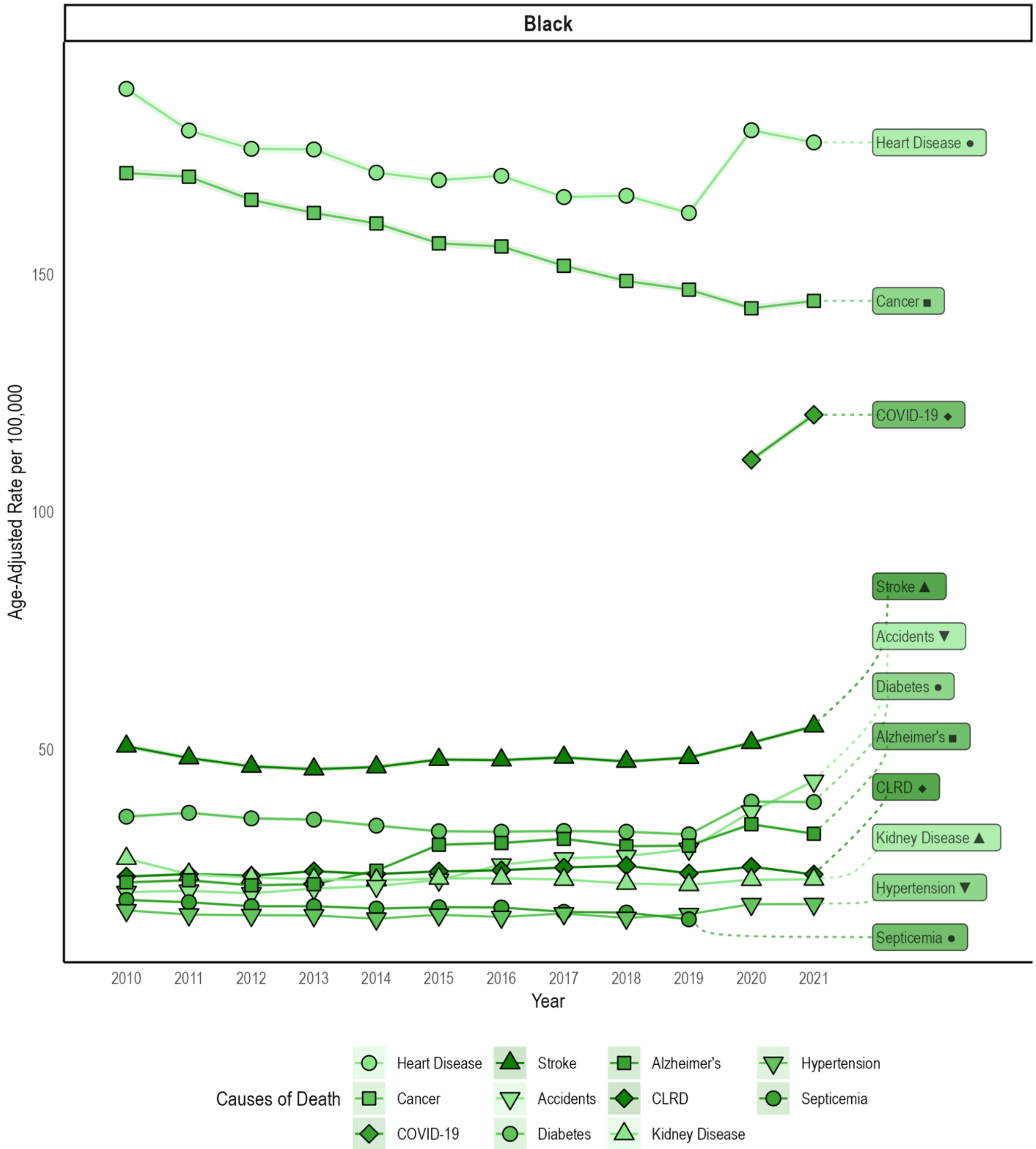

Figure 4-6: Top 10 causes of death over time, age-adjusted mortality rates per 100,000 Black women
Source: National Vital Statistics System (NVSS), 2010-2021

Similar to the impact of COVID-19 on other racial and ethnic groups, COVID-19 was the third leading cause of death for Black women in 2020. Significant risk factors for COVID-19 among Black Americans included comorbidities such a hypertension, diabetes, obesity, and concomitant CVD.[64] Studies have documented social factors also contributed to this elevated risk among Black women: instances of medical mistreatment and denial of testing services for Black patients, higher representation among frontline and low-wage workers, and limited opportunities to practice social distancing (e.g., working from home).[65] These factors placed Black women at increased risk of COVID-19 exposure and negatively impacted their health outcomes and increased their disease burden and mortality rates.[66]

4.1.3.4 Hispanic Women

Hispanic women have the second highest life expectancy at birth among racial and ethnic groups in the U.S. For more details about the diverse subpopulations included under the Hispanic category see Chapter 2. It is important to note that this aggregate category does not allow for assessment of how causes of death vary across Hispanic subpopulations. **Figure 4-7** shows the mortality rate over time for the top 10 causes of death among Hispanic women. Heart disease and cancer have been the most common causes of death, but both show an overall downward trend over time. In 2021, the mortality rates for cancer and heart disease were both 93 per 100,000 Hispanic women, lower than all other groups except Asian and Multiracial women.

Stroke, as the third leading cause of death for Hispanic women during most of the past decade, had a mortality rate only one-third as high as the top two causes. Research suggests that an increased rate of stroke among Hispanic people is largely explained by gaps in education, insurance status, and socioeconomic status, with elevated stroke risk in Hispanic women (particularly those aged 70 and older) in comparison with Hispanic men.[67]

Similar to AI/AN women, COVID-19 became the top cause of death for Hispanic women in 2020 and 2021, exceeding mortality rates attributable to all other causes of death by at least 10%. As was the case with other groups of U3 women, sociocultural factors and preexisting health disparities intensified poor health outcomes related to the COVID-19 pandemic. COVID-19 related risk factors for Hispanic people included essential and frontline worker status, where the nature of occupations required employees to continue working through the national emergency, including those who were immunocompromised or had preexisting health conditions.[68] Furthermore, Hispanic women's access to vaccination, medical treatment, and health insurance coverage were impacted by diverse factors, ranging from socioeconomic status and preexisting medical conditions to language barriers and immigration and citizenship status.[69]

Hispanic women's rate of death from diabetes rose each year from 2017 to 2021. The prevalence and incidence of type-2 diabetes in Hispanic women is higher than the national average, caused in part by social factors like decreased access to healthcare, cultural ones like a traditional diet that is carbohydrate rich, and biological ones like higher insulin resistance, and a genetic susceptibility to obesity.[70,71] Studies also suggest that Hispanic women express difficulty monitoring diabetes due to its time-intensive nature, and are less likely to be concordant with prescribed medications, especially if they have limited English proficiency.[71]

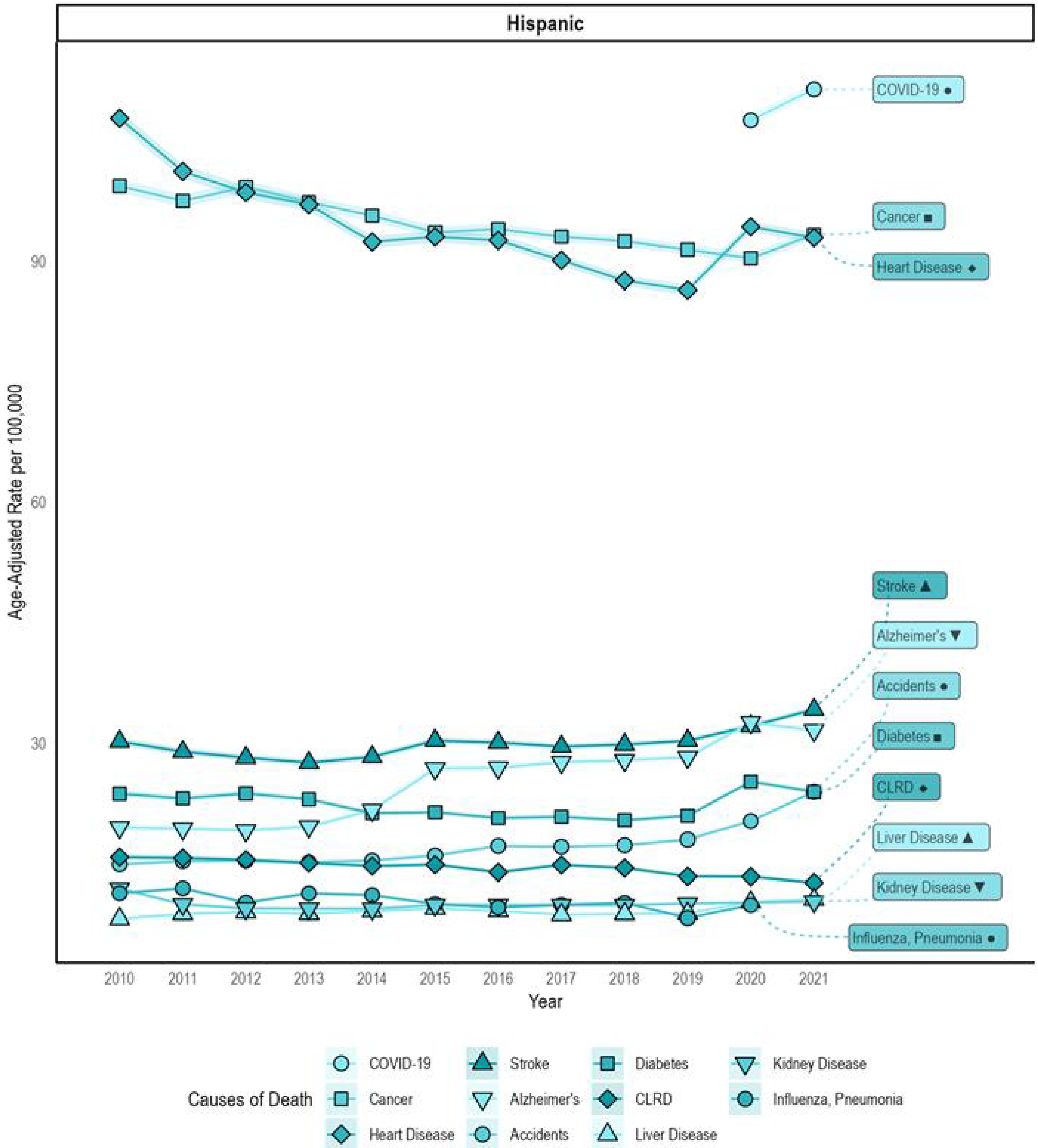

Figure 4-7: Top 10 causes of death over time, age-adjusted mortality rates per 100,000 Hispanic women

Source: National Vital Statistics System (NVSS), 2010-2021

4.1.3.5 Native Hawaiian and Pacific Islander Women

Figure 4-8 shows the mortality rate over time for the top 10 causes of death among NHPI women. Data on the health and social determinants-related impacts on NHPI women's health are often not collected in ways that enable disaggregation like for other racial and ethnic groups. Until 2018, NHPI women in the NVSS were categorized as Asian or Pacific Islander, making direct comparison impossible. Despite the challenges, data from the NVSS show the leading causes of death among NHPI women from 2018-2021 were COVID-19, cancer, heart disease, diabetes, and stroke. The data also reveal high all-cause mortality rates among NHPI women compared to other groups, which is explained by the overlap of structural barriers and conditions that amplify risk such as higher rates of smoking, weight gain, promoting dietary behavior and alcohol consumption.[43] Lack of access to traditional foods and environmental degradation alongside other sociocultural influences may have undermined the effectiveness of interventions targeting the metabolic health of NHPI women.[72]

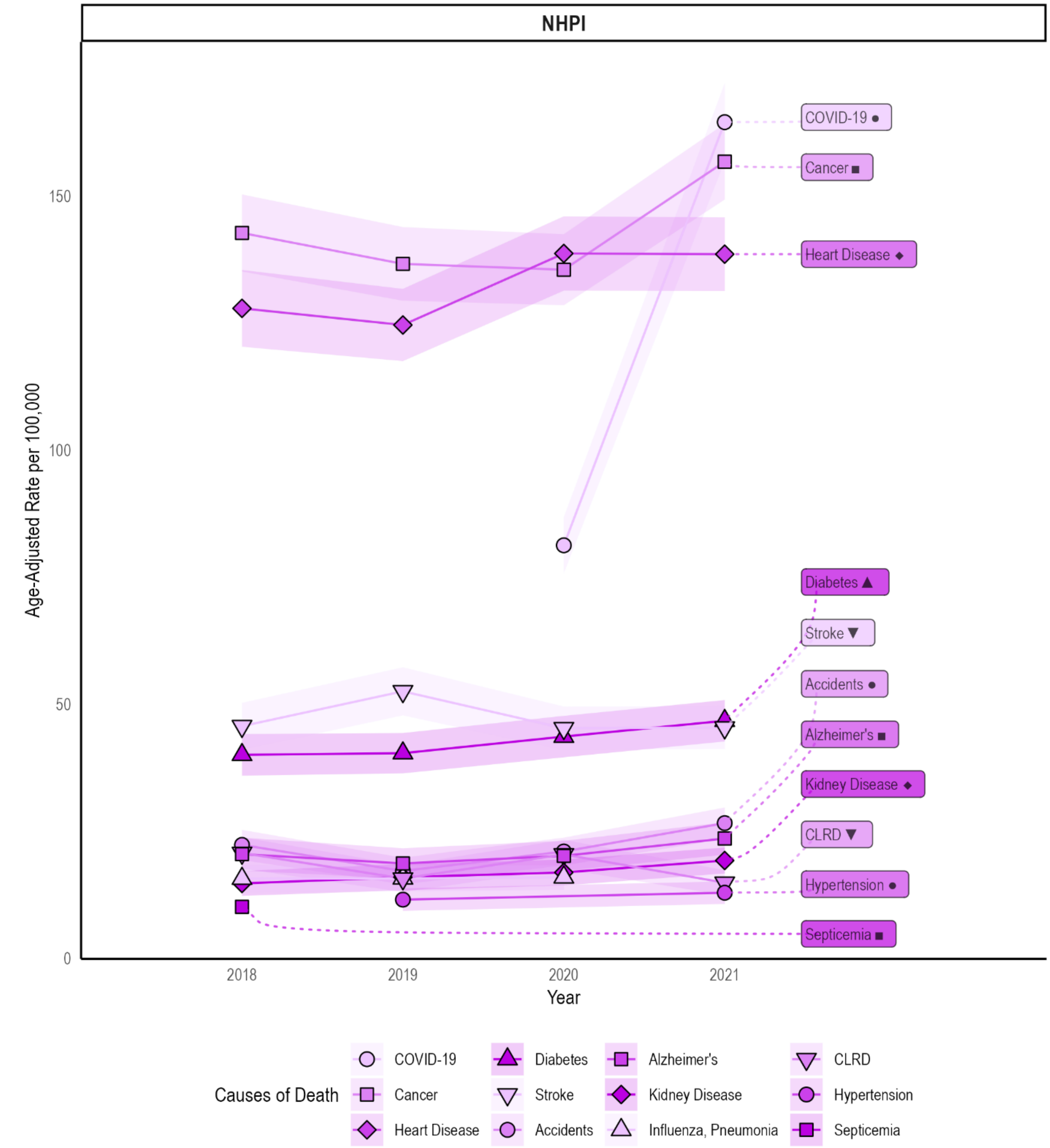

Figure 4-8: Top 10 causes of death over time, age-adjusted mortality rates per 100,000 NHPI women

Source: National Vital Statistics System (NVSS), 2018-2021

The data also show that COVID-19 related mortality for NHPI women was the leading cause of death in 2021. Although NHPI women are often grouped with Asian women in surveys, significant distinctions in leading causes of death exist between the two populations: NHPI women experienced substantially more COVID-19 related deaths in comparison to Asian women. As is the case for many other diseases and chronic conditions, NHPI women were at increased risk of COVID-19 due to factors such as socioeconomic inequities, preexisting medical conditions, and lack of health insurance coverage.[73]

The noted data limitations indicate that the magnitude of the disease burden for NHPI people may be underestimated. A growing body of research supports the need to disaggregate data describing this and other racial and ethnic groups to recognize the historical, social, and cultural differences that can contribute to variable health outcomes across subpopulations).[74,75] The rate of death from cancer among NHPI women rose from 2020 to 2021, overtaking heart disease. Possible causes include high comorbidity rates, and social determinants such as lack of access to transportation.[76,77] It is notable that in 2020, breast cancer screening among NHPI and Asian women declined 97% due to COVID-19, compared with the previous five-year average.[78]

4.1.3.6 White Women

Though White women are not an underrepresented racial or ethnic group, and therefore not included under the U3 framework, data about them can provide a useful comparison point for discussions about how social and structural drivers affect women's health. **Figure 4-9** displays the mortality rate over time for the top 10 causes of death among White women. It shows that heart disease and cancer tracked closely together as the top two causes of death over the past decade, similar to other racial and ethnic groups of women.

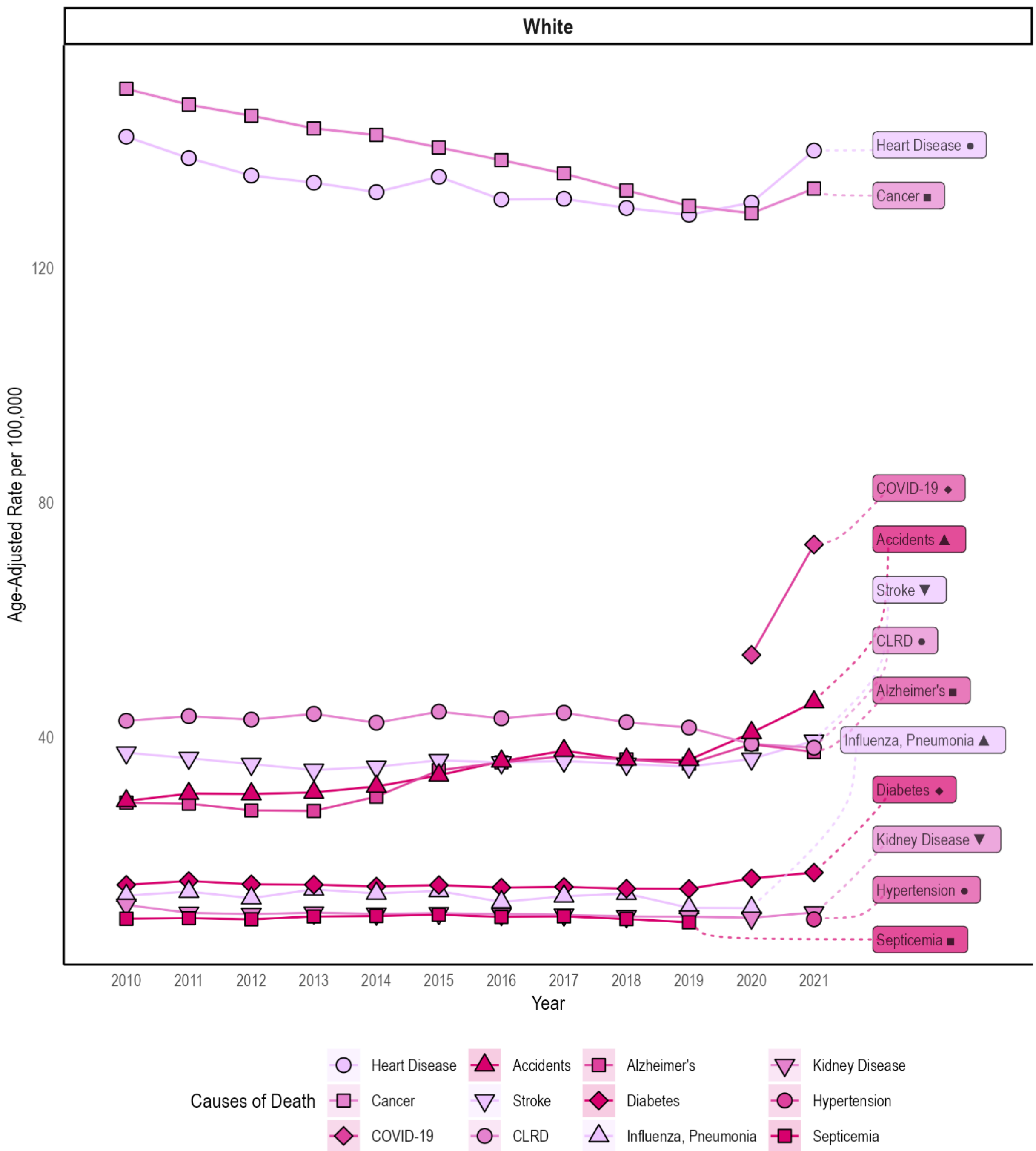

Figure 4-9: Top 10 causes of death over time, age-adjusted mortality rates per 100,000 White women

Source: National Vital Statistics System (NVSS), 2010-2021

COVID-19 was the third leading cause of death in 2020 and 2021 among White women. White women experienced substantially lower rates of COVID-19 related deaths compared with other racial and ethnic groups except for Asian and Multiracial women. Rates of accident-related deaths steadily rose for White women, with a rapid increase in 2020-2021. Centers for Disease Control and Prevention (CDC) data suggest that accidents are most attributable to women under the age of 44, with the risk of accident-related deaths decreasing with age.[14]

4.1.3.7 Multiracial Women

The top causes of death among Multiracial women are cancer and heart disease. **Figure 4-10** shows the mortality rate over time for the top 10 causes of death among Multiracial women. Note that NVSS data specifying a multiple race category became available in 2018. When interpreting this figure, it is important to note limitations in the collection of data on Multiracial people due to the small sample size and sparse data. Historically, multiple race responses have not been routinely collected through federal studies and surveys and states continue to collect and/or report multiple race data inconsistently. Even after revised federal policies allowed a Multiracial response in the 2000 Census and surveys thereafter, many researchers have either excluded the multiple race category data to simplify their analyses or categorized all Multiracial people into a single group. In doing so, researchers are assuming that people identifying as multiple races are—on average—the same as people identifying as single race.[79] However, there are distinct differences across Multiracial backgrounds that are lost when aggregating the data in this way.[79]

Within these limitations, the data available suggest that Multiracial women experience causes of death on par with other groups of women. The leading cause of death for Multiracial women is cancer, followed closely by heart disease; this is congruent with the leading causes of death for women overall. Noticeably different for Multiracial women is the appearance of perinatal complications among the top-ranked causes of death. The paucity of data for Multiracial women, however, creates difficulties in fully assessing the scale of this risk and offering insights for programming and policy interventions to prevent such outcomes.

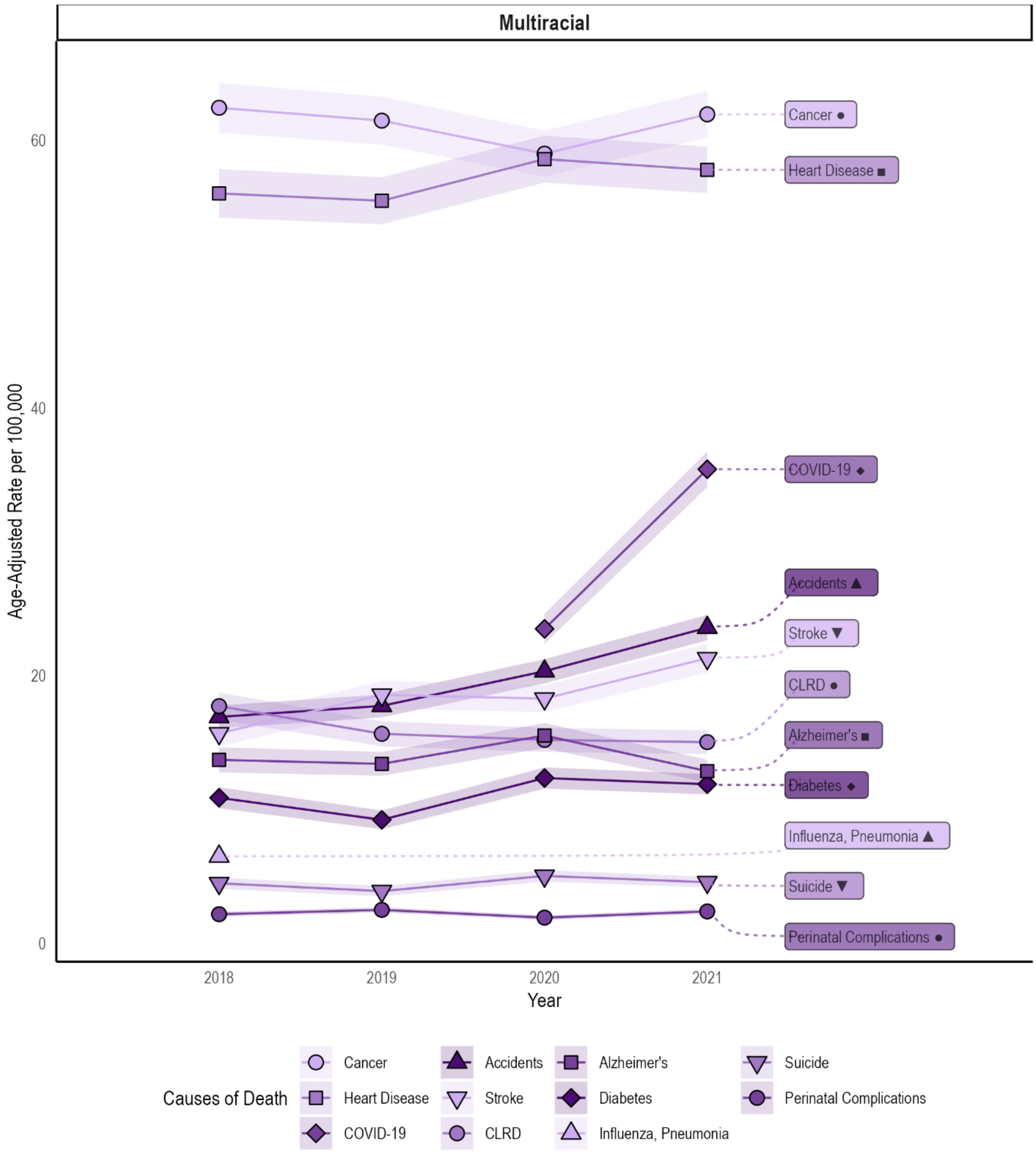

Figure 4-10: Top 10 causes of death over time, age-adjusted mortality rates per 100,000 Multiracial women

Source: National Vital Statistics System (NVSS), 2018-2021

4.1.4 Other Intersectional Considerations for U3 Women

A full assessment of the causes of death across the intersections of U3 identities is limited by the data availability within NVSS, which does not include variables for economic status, sexual orientation, or gender identity. Yet research shows that these factors have significant influence on health outcomes (see **Chapter 1**). Across all racial and ethnic groups, lower SES is associated with factors such as disability, premature mortality, and development of conditions such as heart disease and depression.[80] Research shows that economic status can serve as a protective factor: those with low incomes have higher rates of behavioral and environmental risk factors, such as smoking, obesity, and exposure to environmental risks.[79] Exposure to discrimination, stigma, and violence, and higher rates of poor physical and mental health are associated with worse health status for women of sexual and gender minority (SGM) groups.[81]

NVSS data do allow for analysis by rurality, which is a key determinant of healthcare access and therefore health outcomes. **Figure 4-11** shows the mortality rate over time for the top 10 causes of death among women by race and ethnicity and rurality. The figure shows that women in rural areas in each racial and ethnic group experienced higher mortality rates across nearly all leading causes of death compared with women in non-rural areas.

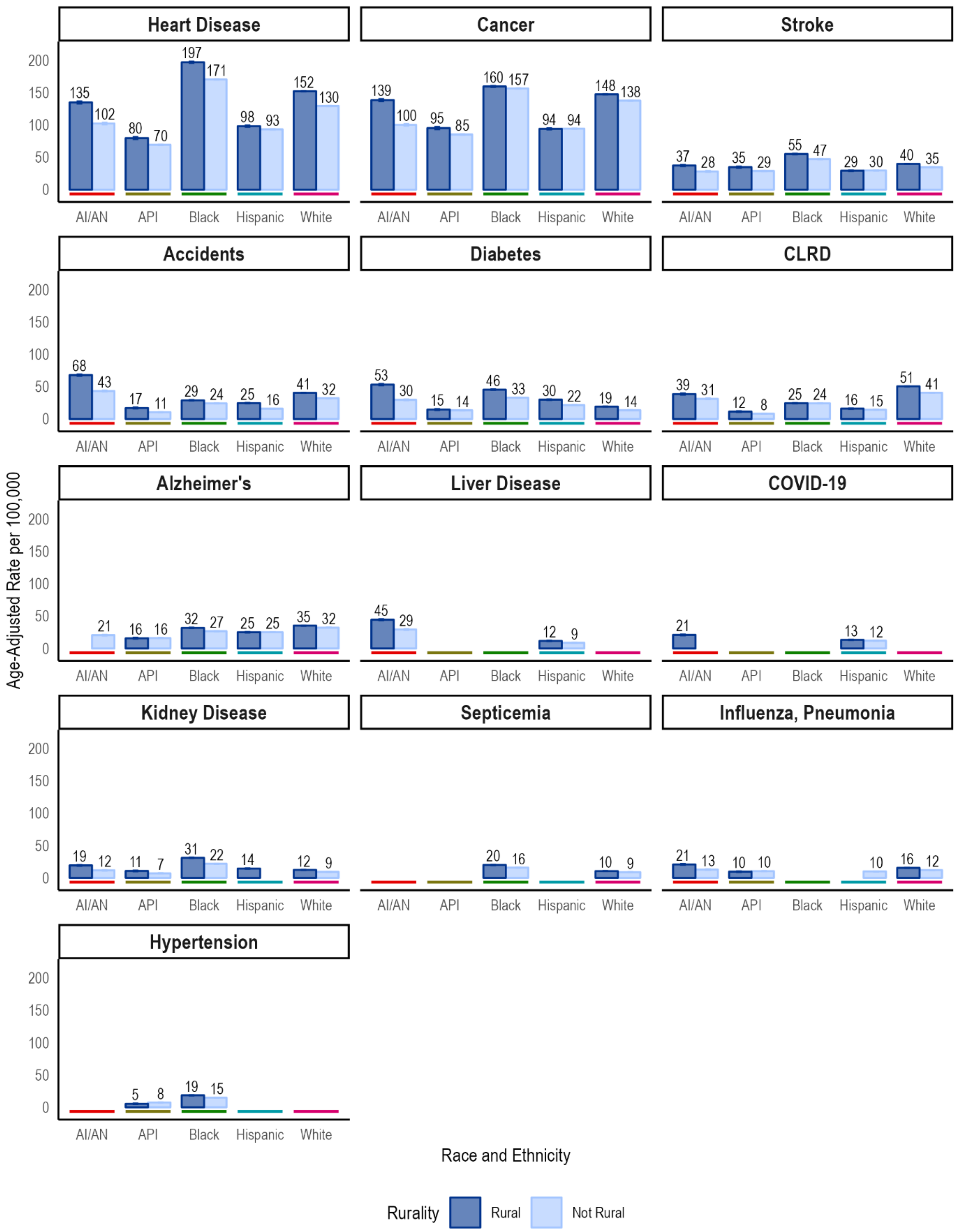

Figure 4-11: Top 10 causes of death, age-adjusted mortality rates per 100,000 women, by race and ethnicity, and rurality

Source: National Vital Statistics System (NVSS), Pooled 2010-2020

Health professional shortages in rural communities, lack of adequate health insurance coverage, and transportation-related limits on timely access to care all contribute to geographic disparities in rural communities.[82] One notable exception is the stroke mortality rate among Hispanic women, which shows minor differences in death rates for Hispanic women living in rural and non-rural areas (29 versus 30 deaths per 100,000, respectively). There appears to be no difference by rurality for Asian and Pacific Islander (API) women in mortality from AD or influenza, or for Hispanic women in mortality from AD.

Figure 4-11 also reveals critical differences in the lower-ranked causes of death for some of the smaller populations. For example, the missing bar for COVID-19 deaths among AI/AN women in non-rural areas suggests that this was not a leading cause of death for that population when pooled across 2010-2020. It is also important to note that COVID-19 mortality rates in 2020 were particularly impactful for Hispanic women in both rural and non-rural areas and for AI/AN women in rural areas. COVID-19 mortality from a single year superseded mortality rates associated with septicemia and hypertension, which were pooled across 10 years of data.

4.3 Conclusions and Future Directions

NVSS data document the disparities in top 10 causes of death for women across racial and ethnic groups. Black, Hispanic, and AI/AN women die at much higher rates and have the least favorable outcomes across most diseases.[83] The data underscore how the sociocultural environment and healthcare system are often the root cause of mortality disparities seen among U3 women (see **Chapter 1**). Yet the data also do not allow for analysis by some key factors, including sexual orientation, gender identity, and economic status, resulting in lack of documentation of disparities for some U3 groups. To develop better emergency preparedness and equity-focused public health strategies, robust surveillance data collection and tracking are needed for causes of death across populations. Future research on the causes of death for U3 populations would benefit from data collection that produces comprehensive, standardized data for all categories of U3 women. This includes prioritizing consistent and robust disaggregation of racial and ethnic identity categories to allow for analysis of trends within and between racial and ethnic groups, which is particularly important for the visibility of AI/AN and NHPI populations, whose health status and mortality risk are often misunderstood due to both data failures and the limited number of researchers trained in small-population epidemiology.[84] It also requires greater effort to collect data that allow for intersectional analysis that will uncover how sex, gender, race and ethnicity, rurality, economic status, sexual orientation, and gender identity interact to increase or reduce mortality risk.

4.4 Data Sources and Definitions

Data for all figures in this chapter can be accessed from the data annex located here: https://orwh.od.nih.gov/sites/orwh/files/docs/Chapter_4.xlsx

National Vital Statistics System (NVSS) – Underlying Cause of Death, 2010-2021

Label	ICD-10 113 Cause List
Accidents	#Accidents (unintentional injuries) (V01-X59, Y85-Y86)
Alzheimer's	#Alzheimer disease (G30)
Cancer	#Malignant neoplasms (C00-C97)
CLRD	#Chronic lower respiratory diseases (J40-J47)
COVID-19	#COVID-19 (U07.1)
Diabetes	#Diabetes mellitus (E10-E14)
Heart Disease	#Diseases of heart (I00-I09, I11, I13, I20-I51)
Hypertension	#Essential hypertension and hypertensive renal disease (I10, I12, I15)
Influenza, Pneumonia	#Influenza and pneumonia (J09-J18)
Kidney Disease	#Nephritis, nephrotic syndrome, and nephrosis (N00-N07, N17-N19, N25-N27)
Liver Disease	#Chronic liver disease and cirrhosis (K70, K73-K74)
Perinatal Complications	#Certain conditions originating in the perinatal period (P00-P96)
Septicemia	#Septicemia (A40-A41)
Stroke	#Cerebrovascular diseases (I60-I69)
Suicide	#Intentional self-harm (suicide) (*U03, X60-X84, Y87.0)

National Vital Statistics System (NVSS) – Life Expectancy, 2019

Variable Name	Variable Description
Expectation of life at age x (e_x)	Value for Expectation of life at age x, for ages 0-1 (years)

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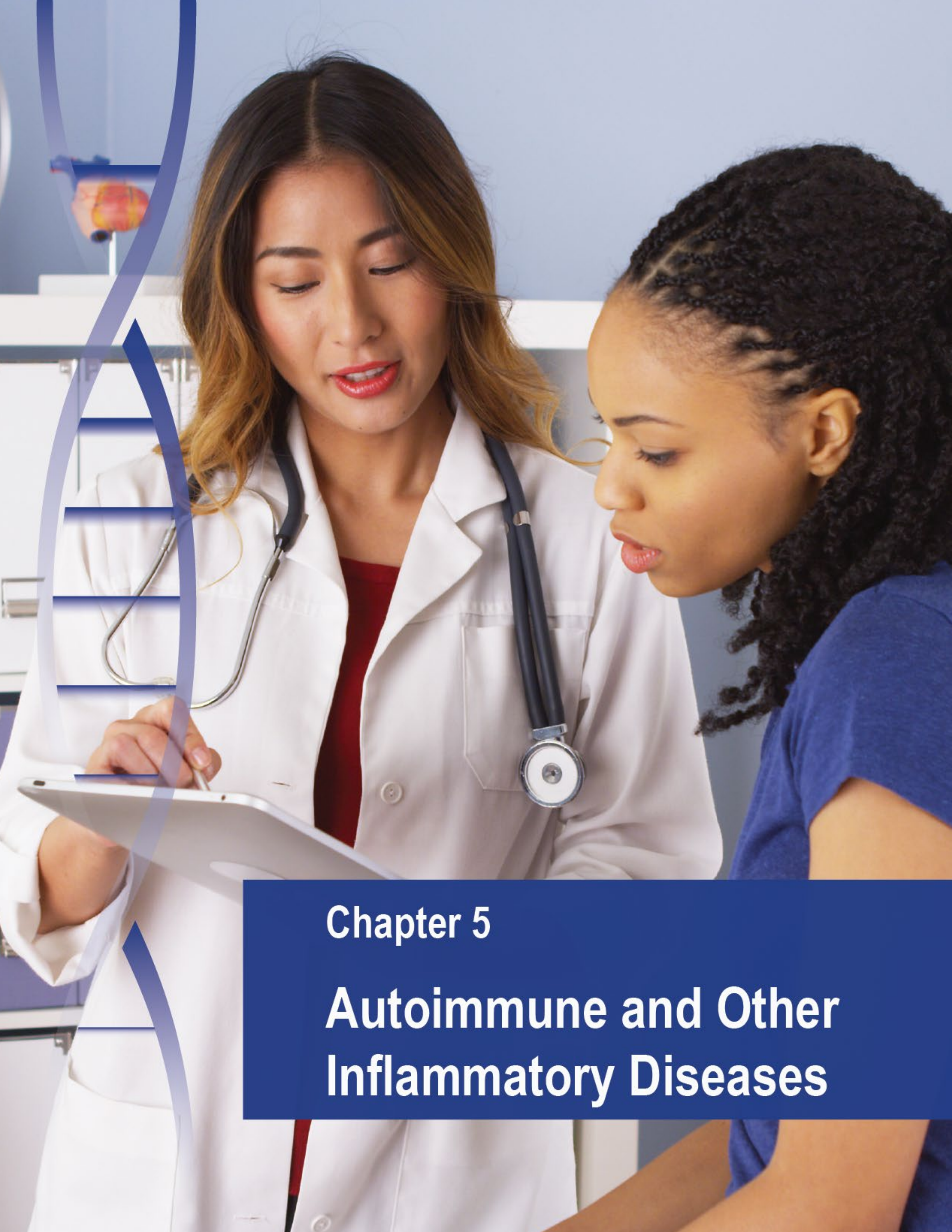

Chapter 5

Autoimmune and Other Inflammatory Diseases

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Autoimmune and Other Inflammatory Diseases

5.1 Defining Autoimmune and Other Inflammatory Diseases

Autoimmune diseases are conditions that occur when the immune system attacks healthy cells, tissues, and organs in the body.[1,2] Autoimmune diseases are the third most common disease category, affecting roughly 8% of the population in the U.S.[3,4] An additional 10-32% of people in the U.S. possess autoantibodies, which can be markers for autoimmune disease and development.[4–7] There are up to 150 conditions (depending on the source) classified as autoimmune diseases, that affect an estimated 50 million adults in the U.S.[1,4] These conditions are chronic and in many cases debilitating, and include conditions such as multiple sclerosis (MS), rheumatoid arthritis (RA), inflammatory bowel disease, lupus (also called systemic lupus erythematosus), autoimmune thyroid disease, and type 1 diabetes. The average age of onset differs by autoimmune disease, with RA typically occurring among adults in their 60s, lupus between ages 15 and 45, and MS between ages 20 and 40.[8–10]

Symptoms of autoimmune diseases are manifold, depending on the organs affected, but often include inflammation, pain in the joints or muscles, skin rash, fever, or fatigue.[11] However, many patients with autoimmune diseases experience delays in diagnosis or avoid seeking care as the symptoms are nonspecific, wax and wane in severity, and often overlap with symptoms for other conditions.[12,13] Further, there is no single test to confirm presence of autoimmune disease, which contributes to delayed diagnosis for patients with autoimmune diseases.[14] The treatments for these conditions, such as immunosuppressants, often have side effects that affect quality of life and can place burden on families due to their chronic nature and high medical costs.[2,4,15] While autoimmune diseases are chronic illnesses without any known cures, patients may experience remission and emerging science holds the promise that autoimmune diseases may be curable in the future.[16,17]

Due to the multiplicity of disorders and the challenges related to diagnosis, no single data source contains comprehensive, national-level data describing the incidence, prevalence, or outcomes from these conditions. Often inflammatory diseases are grouped with autoimmune diseases in key data collections and their subsequent reporting, as shown in the data presented in this chapter. By way of example, the National Health Interview Survey (NHIS) monitors the health of the U.S. population on a broad range of health topics and allows for analysis by many demographic and socioeconomic characteristics; it is one of the only publicly available, nationally representative sources of information on autoimmune diseases and related conditions.[18] A notable limitation of the NHIS data on autoimmune diseases is captured within a question regarding diagnoses of “some form of arthritis, RA, gout, lupus, or fibromyalgia”: the data combine autoimmune diseases with other inflammatory diseases, resulting in imprecise estimates of the true prevalence of autoimmune disorders alone and limiting accurate understanding of the burden these conditions have on the health of women. As such, this chapter discusses these inflammatory diseases, including osteoarthritis, gout, and fibromyalgia as well.

5.2 Autoimmune and Inflammatory Diseases in Women

The disproportionate burden of autoimmune and inflammatory diseases on women is clear: nearly 80% of those with an autoimmune disease are women and women have an increased risk of being diagnosed with multiple autoimmune diseases (polyautoimmunity).[3,19,20] **Figure 5-1** illustrates the percent of people who report an arthritis, RA, gout, lupus, or fibromyalgia diagnosis by sex. The figure shows that the overall prevalence of autoimmune and inflammatory disease is higher among women than men. As noted in the discussion above, NHIS combines autoimmune and other common inflammatory diseases, which limits the ability to decipher the true prevalence and burden of autoimmune disease among women separately from other inflammatory diseases. Additionally, NHIS does not capture the age of onset of disease or diagnosis, limiting the ability to document when onset occurs across the lifespan of women.

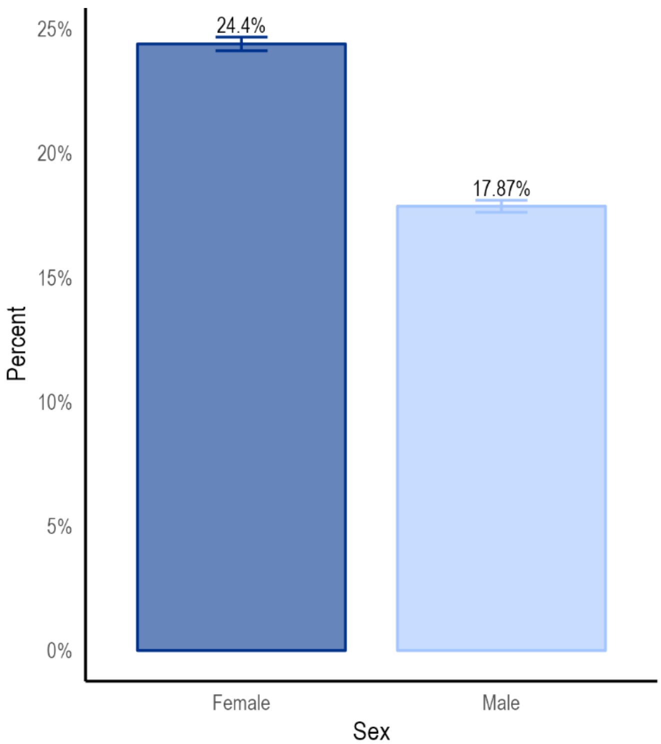

Figure 5-1: Percent of people who report an arthritis, rheumatoid arthritis, gout, lupus, or fibromyalgia diagnosis, by sex

Source: National Health Interview Survey (NHIS), Pooled 2019-2022

Several sex-specific factors influence the increased prevalence of autoimmune disorders among women. Hormonal and physiological changes, such as the onset of puberty and hormonal changes that occur during pregnancy and menopause, can increase the risk and/or severity of systemic autoimmune conditions such as lupus.[19] Earlier onset of menopause, for example, is associated with an increased risk of developing RA.[19,21,22] Genetic differences are also associated with increased risk of autoimmune disease because many genes associated with immune pathways are located on the X chromosome.[23] Research suggests that the increased prevalence of autoimmune diseases in women may be related to

Xist, which is involved in the molecular process by which one of the X chromosomes in women is inactivated.[24,25]

Research is needed to better understand how gender as a social and structural variable influences risk, prevalence, and progression of autoimmune diseases and responses to immunotherapy.[26] Gender norms and relations can influence the diagnosis and treatment of autoimmune diseases: the dismissal of women's symptoms as psychosomatic is described as contributing to delays in diagnosis of disease.[27] Misdiagnosis can lead to significant treatment delays and magnify mistrust of healthcare professionals.[27,28] Communication dynamics also create barriers to the spectrum of treatment options, adherence to treatment protocols, and continuity of treatment.[29,30]

Unlike most autoimmune disorders, type 1 diabetes is equivalently common among women and men and is most commonly diagnosed during childhood.[31] **Figure 5-2** demonstrates the percent of people who report a type 1 diabetes diagnosis by sex. It shows that there is no meaningful difference by sex. Unlike other autoimmune diseases, its symptoms are well-known and there are specific tests for type 1 diabetes, which may lead to a timely diagnosis. Indeed, autoantibody screening in family members at risk for type 1 diabetes can identify candidates for targeted therapy that has been shown to reduce the risk of progression.

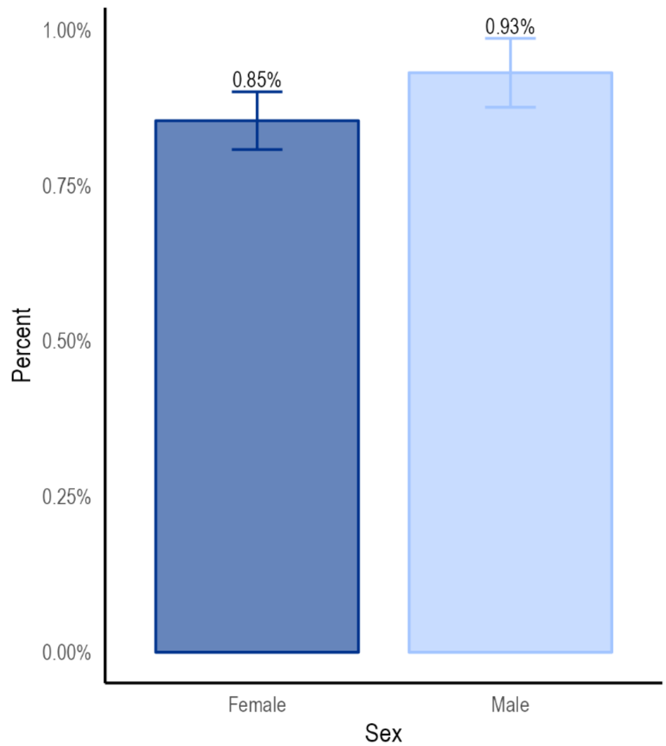

Figure 5-2: Percent of people who report a type 1 diabetes diagnosis by sex
Source: National Health Interview Survey (NHIS), Pooled 2019-2022

5.3 Autoimmune and Inflammatory Diseases in Populations of U3 Women

The heightened risk of autoimmune disease and other inflammatory disorders among understudied, underrepresented, and underreported (U3) women (see **Chapter 1**) is evident as studies increasingly identify a range of social and structural drivers that are contributing factors. For example, research highlights the impact of stress and traumatic events on immune responses and the development or exacerbation of autoimmune disease, although the exact pathway is not fully understood.[32,33] Women of underrepresented racial and ethnic communities are more likely to experience racism and sexism, and the related stress may contribute to their disproportionate burden of autoimmune and other chronic diseases.[34,35] Such experiences can contribute to chronic inflammation and lead to heightened risk or exacerbation of autoimmune diseases.[36] Trauma related to racism and sexism, for example, can result in post-traumatic stress disorder (PTSD), which has been linked to the increased risk of RA, MS, inflammatory bowel disease, and psoriasis (see **Chapter 14**).[37–40] Several recent studies have assessed the link between autoimmune and inflammatory diseases and adverse childhood events such as neglect, abuse, substance use or mental illness in the home, or domestic violence. Findings underscore a stress-related pathway that shows U3 women are at higher risk of adverse childhood events, autoimmune diseases, and inflammatory diseases.[41–43]

A growing body of research is documenting the bidirectional relationship between COVID-19 and autoimmunity, noting both that people with existing autoimmune conditions are at higher risk of infection with COVID-19 infection and that COVID-19 infections may induce new onset of autoimmune diseases.[44–46] One case-control study of over 3.8 million participants found that the incidence of new RA, lupus, and type 1 diabetes was nearly three times higher among COVID-19 cases compared with controls.[47] Further, more severe courses of COVID-19 are associated with greater risk of common autoimmune diseases.[48] This is of particular significance for U3 women, who experienced higher rates of COVID-19 infection, greater severity of COVID-19, and higher mortality rates compared with other populations of women (see **Chapter 4**).[49–52]

5.3.1 Autoimmune and Inflammatory Diseases Among Women of Underrepresented Racial and Ethnic Communities

Despite the growing clinical evidence base and efforts to collect data about autoimmune and inflammatory diseases, population estimates still underrepresent the true prevalence of disease, particularly among women belonging to underrepresented racial and ethnic communities. As discussed earlier in the chapter, potential explanations for the underdiagnosis of autoimmune diseases include the wide range symptoms that may be intermittent, as well as the multiple laboratory tests required to confirm a diagnosis.[13,53] Due to the often prolonged process of diagnosis, inadequate patient-provider communication (see **Chapter 1**) can be particularly harmful for women with autoimmune and inflammatory diseases.[54,55] Poor provider communication has been documented, for example, for Black, Asian, and Hispanic patients diagnosed with inflammatory arthritis.[56] The effects of poor provider communication can be observed in patient psychosocial status as well as in their health outcomes.[57,58]

Multiple risk factors are shown to influence the development of autoimmune disease, including environmental exposures, behavioral factors, and comorbid conditions such as obesity and smoking.[59] Evidence shows that women of underrepresented racial and ethnic communities live and work in places that disproportionately expose them to environmental pollutants such as phthalates, pesticides, silica, and mercury when compared with other populations of women.[60,61] Women of underrepresented racial and ethnic communities are more likely to face place-based inequities from high-poverty, historically segregated neighborhoods and occupying spaces on or near lands contaminated with lead, solvents, and endocrine-disrupting chemicals that have been linked to increased incidence and prevalence of autoimmune disease.[60,62–65] Furthermore, studies show that while toxic chemicals in beauty products are a source of exposure for all women, those products typically marketed to women of underrepresented racial and ethnic communities (including products such as hair straighteners, skin lighters, and some feminine hygiene products) contribute to higher exposures and risk.[66–68] Such exposures are thought to increase the risk of autoimmune and inflammatory diseases over the life course by interfering with endocrine signaling.[62,63,66]

Research also demonstrates that social and structural drivers lead to disparate impacts of diseases such as lupus and RA for American Indian and Alaska Native (AI/AN) and Black women compared with women of other racial and ethnic groups.[13,69–72] In some U.S. regions, Black women develop lupus at younger ages and are diagnosed at rates up to three times that of White women. Studies have linked these rates to elevated exposures to heavy metals, air pollutants, pesticide, and crystalline silica present in mining and construction industries.[69,73,74] Further, federally subsidized housing, disproportionately occupied by families from underrepresented racial and ethnic communities, is frequently closer in proximity to water source contamination and Superfund sites.[75,76] Collectively, this evidence suggests the clustering of key environmental exposures and policies that perpetuate and exacerbate health risks for some communities.

Figure 5-3 shows the percent of people who report an arthritis, RA, gout, lupus, or fibromyalgia diagnosis by sex and race and ethnicity. Across all racial and ethnic groups, women consistently have a higher prevalence of these diseases compared with men. Large disparities by sex are seen among the Black and Hispanic populations, with Black women and Hispanic women having a prevalence of inflammatory diseases approximately 50% higher than Black and Hispanic men. The limited years of available data make it difficult to generate separate estimates for specific autoimmune and inflammatory diseases, which may mask the potential differences within disease type among women of underrepresented racial and ethnic communities. Furthermore, the estimates for the AI/AN and Multiracial populations are based upon relatively small sample sizes, resulting in large standard errors.

In the NHIS data, AI/AN and White women appear to have the highest percentage of reported autoimmune and inflammatory disease, while Asian men have the lowest. **Figure 5-3** illustrates the percent of people who report an arthritis, RA, gout, lupus, or fibromyalgia diagnosis by sex, race, and ethnicity. The figure shows the high prevalence of autoimmune and inflammatory diseases among White women which conflicts with findings from other data sources which assert that women of underrepresented racial and ethnic communities are disproportionately affected by autoimmune diseases such as lupus, RA, type 1 diabetes, and MS.[77,78] This may reflect discrepancies in how data are collected (i.e., from electronic health records or surveys), time-to-diagnosis that can be even longer for women of underrepresented racial and ethnic communities, and, in the case of survey instruments, differences in the diseases that are included in survey items, as noted above.

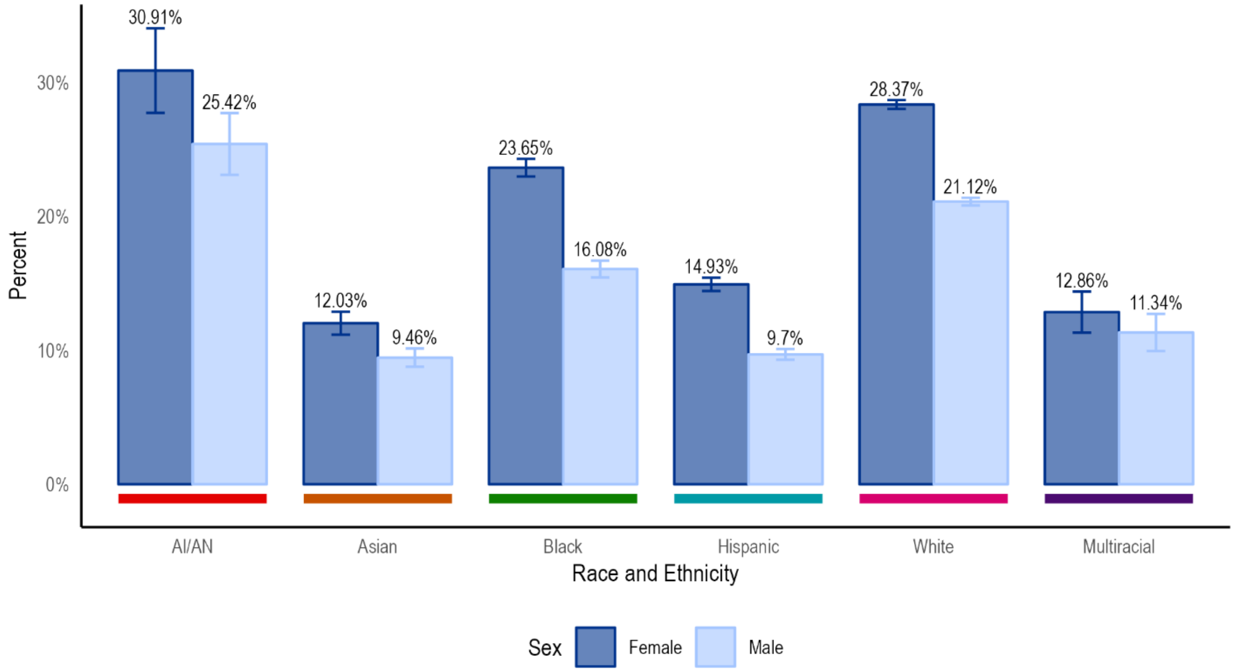

Figure 5-3: Percent of people who report an arthritis, rheumatoid arthritis, gout, lupus, or fibromyalgia diagnosis, by sex and race and ethnicity

Source: National Health Interview Survey (NHIS), Pooled 2019-2022

The National Health and Nutrition Examination Survey (NHANES) collects data on arthritis prevalence alone, complementing the NHIS, providing additional knowledge of the burden of arthritis specifically. **Figure 5-4** demonstrates the percent of people who report an arthritis (including osteoarthritis, degenerative arthritis, RA, and psoriatic arthritis) diagnosis by sex, race, and ethnicity. It shows that between 2009 and 2020, women had a higher prevalence of arthritis diagnoses compared with men across all racial and ethnic groups. It is notable that there are no data on the AI/AN population, highlighting a significant gap in data relevant to understanding the prevalence of autoimmune and inflammatory diseases in this population for the years 2009-2020.

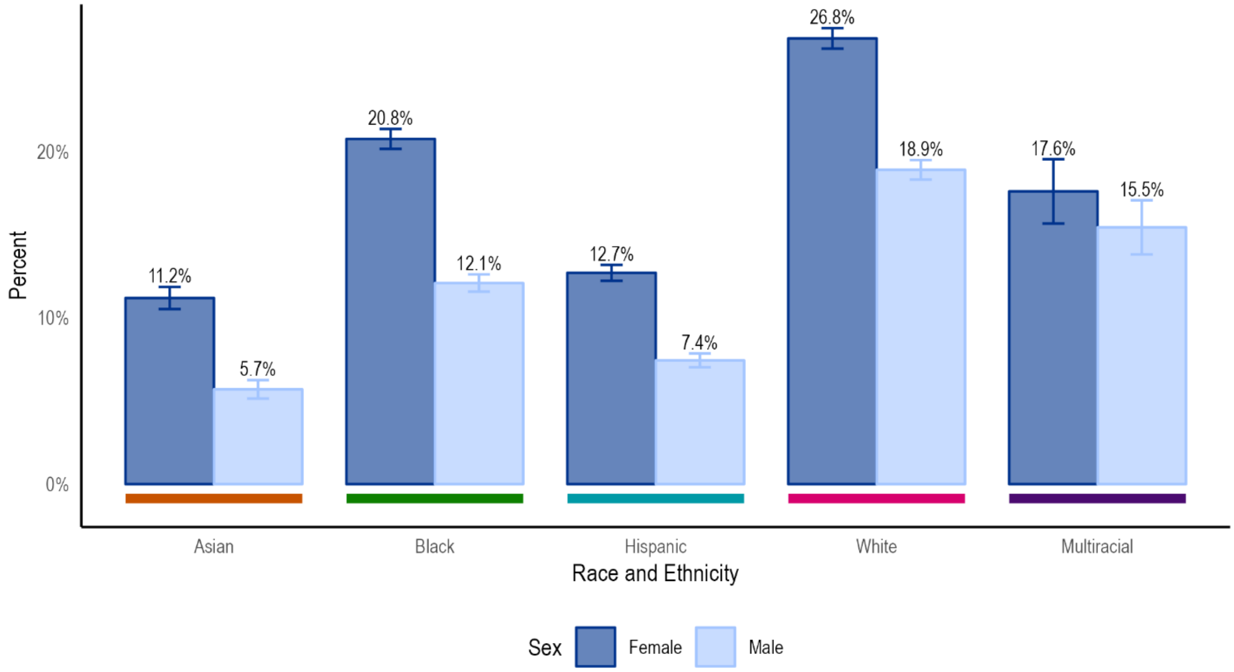

Figure 5-4: Percent of people who report an arthritis (including osteoarthritis, degenerative arthritis, rheumatoid arthritis, and psoriatic arthritis) diagnosis, by sex and race and ethnicity
Source: National Health and Nutrition Examination Survey (NHANES), Pooled 2009-2020

Figure 5-5 shows the percent of people who report an arthritis diagnosis by sex, race and ethnicity, and arthritis type. Among those reporting they received an RA diagnosis, there is no difference by sex for Black, Hispanic, and Multiracial populations while men appear to have a higher percentage among Asian and White populations. Across both sexes, White and Multiracial populations have a lower percentage of reported RA diagnoses while Asian, Black, and Hispanic populations have a higher percentage. The highest percentage across all types of arthritis was found for osteoarthritis or degenerative arthritis, followed by the “don’t know” response, indicating that respondents received a diagnosis of some form of arthritis but could not report on which type. For example, one-third of Asian women with an arthritis diagnosis did not know their specific arthritis diagnosis, followed by a quarter of Hispanic and Black women. White and Multiracial women were least likely to report not knowing their type of arthritis. These results highlight the patient-level knowledge gaps related to autoimmune and inflammatory disorders. These gaps in knowledge may additionally reflect challenges in diagnosis and communication pathways that prevent many women from receiving the information they need to receive quality care and manage their conditions. Further, they raise questions about the true prevalence and impact of specific forms of arthritis on women’s health, as RA is known to be more common among women.

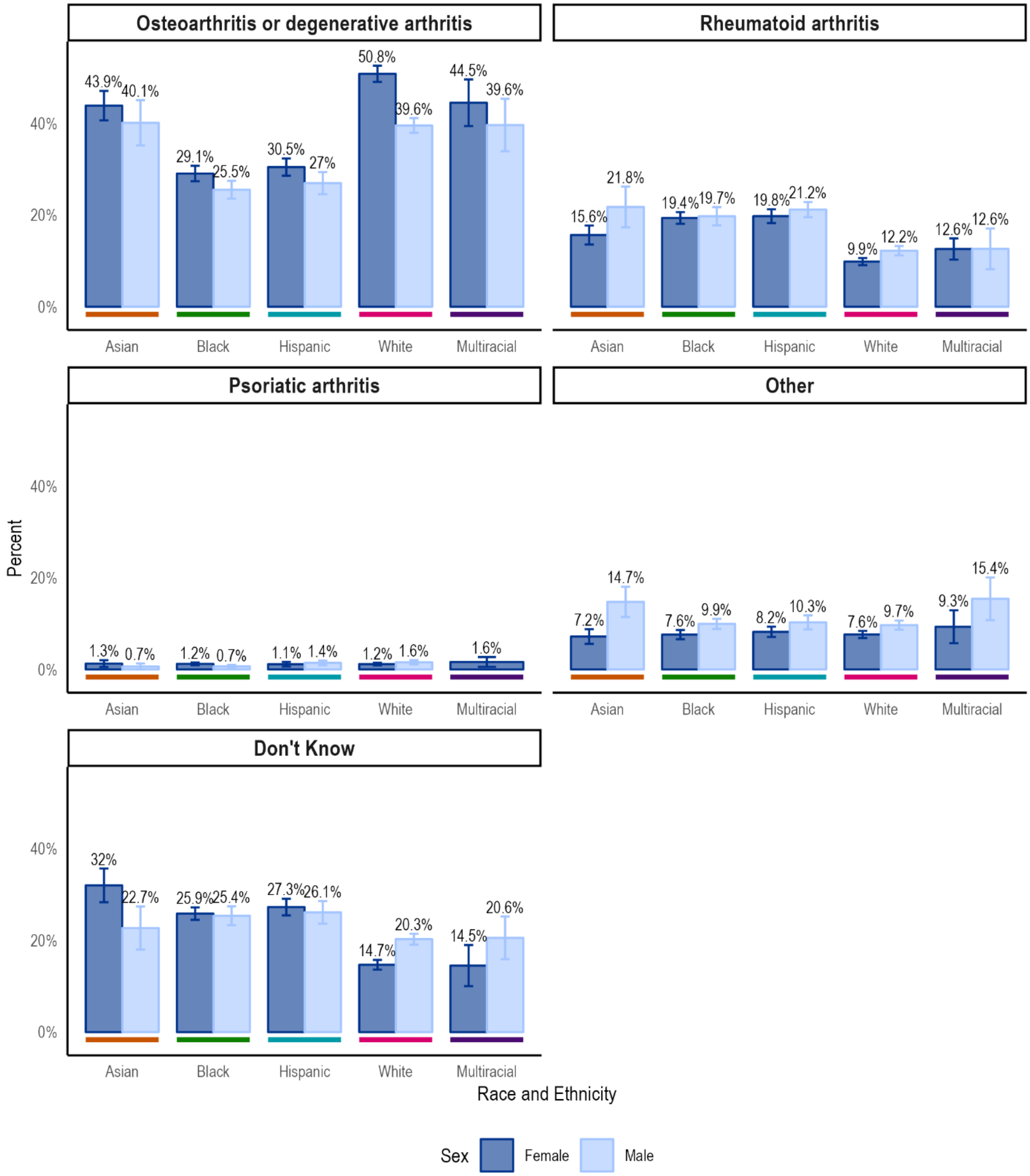

Figure 5-5: Percent of people who report an arthritis diagnosis, by sex, race and ethnicity, and arthritis type

Source: National Health and Nutrition Examination Survey (NHANES), Pooled 2009-2020

Figure 5-6 shows the percent of people who report a type 1 diabetes diagnosis by sex and race and ethnicity. The figure reveals no clear pattern. This is in large part due to relatively small sample sizes, as the data are presented by sex and race and ethnicity, resulting in large standard errors of among all groups except for White populations. The standard errors are particularly large for estimates for AI/AN and Multiracial populations, underscoring the importance of assessing type 1 diabetes status across adequately powered samples of all racial and ethnic groups to enable precise estimates of disease prevalence.

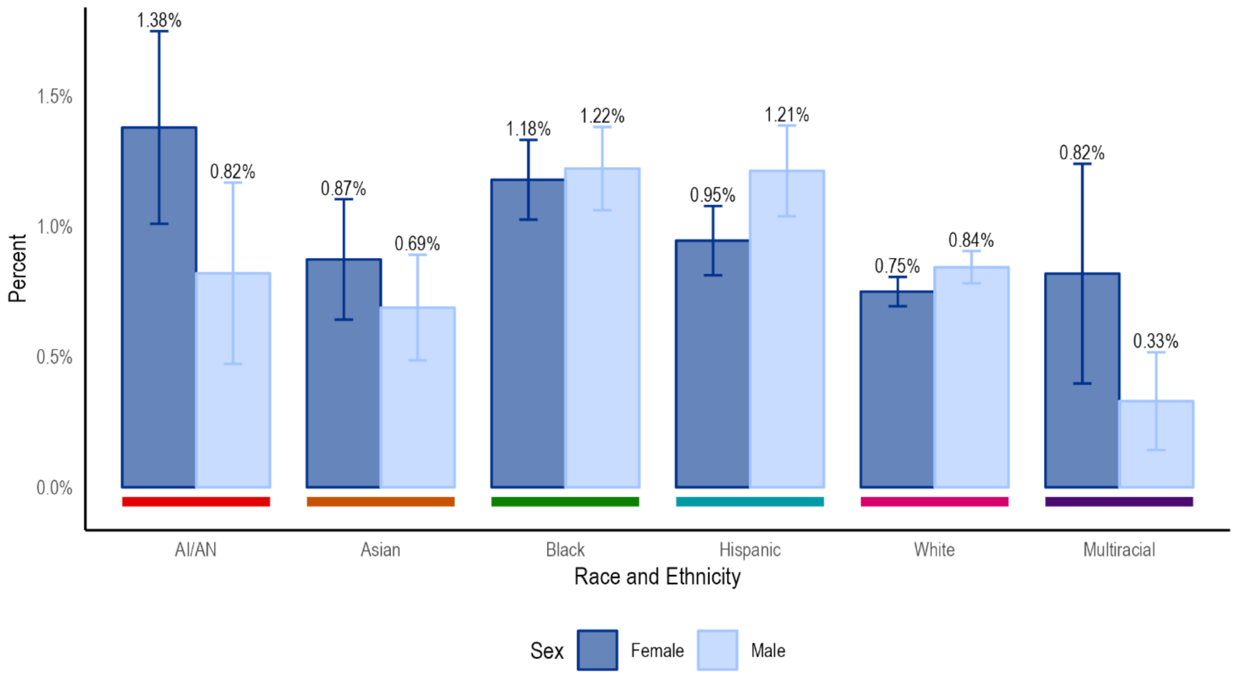

Figure 5-6: Percent of people who report a type 1 diabetes diagnosis, by sex and race and ethnicity
Source: National Health Interview Survey (NHIS), Pooled 2019-2022

NHIS data continue to show an overall lower prevalence of type 1 diabetes when compared with national statistics from the Centers for Disease Control and Prevention (CDC), with research showing steady increases in this prevalence, particularly among Asian, Black, and Hispanic youth. These trends may be due to increased testing and risk factors such as enteroviral infections, early childhood diet, and environmental toxins.[79,80]

Autoimmune and inflammatory diseases are associated with elevated risk of poor pregnancy outcomes such as low birth weight, stillbirth, preterm birth, and preeclampsia and these risks are elevated in U3 women (see Chapter 10).[81–86] Among pregnant women with lupus, Black women experience the highest rates of preventable pregnancy complications.[69,70,87] Similar disparities are observed in pregnancy outcomes among underrepresented racial and ethnic communities with rheumatic diseases.[88] Research suggests that such differences may be due to racial disparities in the quality of healthcare encounters (see Chapter 1). For example, healthcare providers may withhold treatment (e.g., pain medication) based on biased notions about medication adherence and pain tolerance, resulting in Black individuals receiving substandard treatment compared with White individuals. [89,90]

5.3.2 Other Intersectional Considerations Relevant to U3 Women

Multiple social determinants of health and structural barriers influence the risk of autoimmune and inflammatory disease development, severity of symptoms, and treatment outcomes, including rurality, economic status, and sexual orientation.[28,91] The sections that follow discuss trends in autoimmune and inflammatory disease prevalence for women of underrepresented racial and ethnic communities by intersections with rurality, economic status, and sexual orientation.

5.3.2.1 Rurality

Figure 5-7 displays the percent of women who report an arthritis, RA, gout, lupus, or fibromyalgia diagnosis, by race and ethnicity and rurality. Meaningful interpretation is difficult due to the relatively large standard errors as a result of small sample sizes, particularly among rural populations for all but Black and White women. The larger sample size of White women facilitates the interpretation of those estimates, which show a higher prevalence of autoimmune and inflammatory disease among women living in rural areas compared with those living in non-rural areas. Similarly, among Black women, those living in rural areas have approximately 1.5 times higher prevalence compared with those living in non-rural areas.

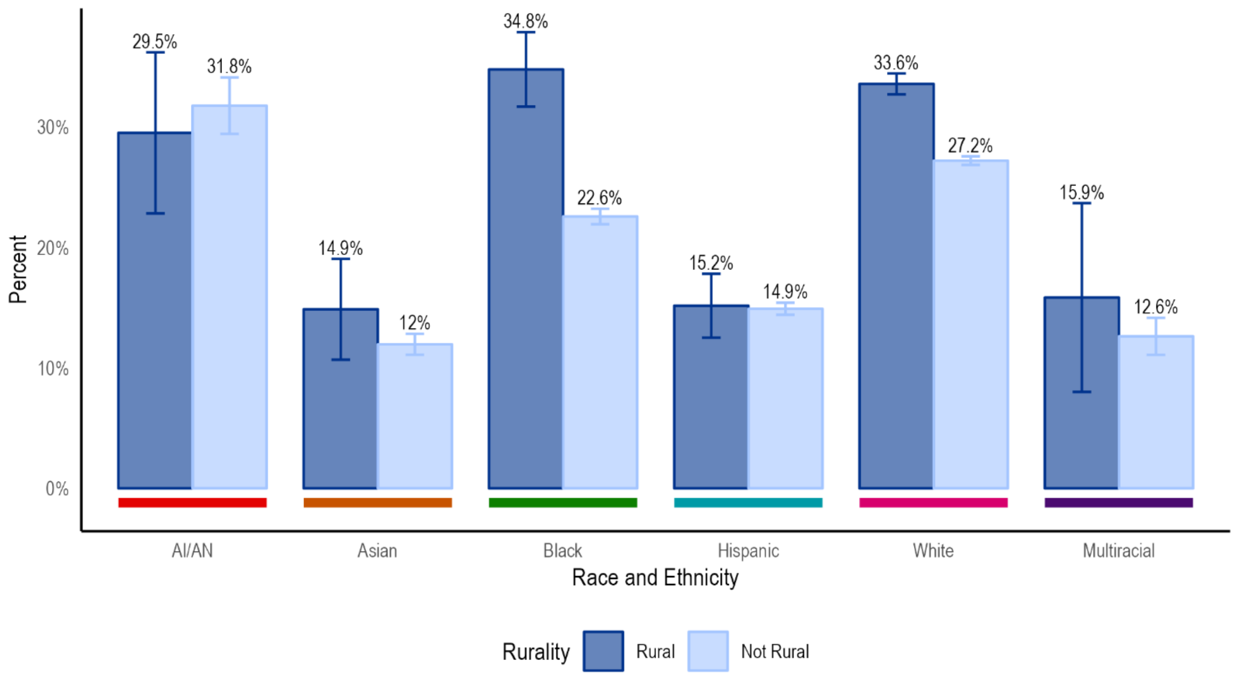

Figure 5-7: Percent of women who report an arthritis, rheumatoid arthritis, gout, lupus, or fibromyalgia diagnosis, by race and ethnicity, and rurality

Source: National Health Interview Survey (NHIS), Pooled 2019-2022

The gap between the demand for and the supply of rheumatology clinical expertise is well documented, and it impacts people living in rural areas to a greater degree than those living in areas that are not rural, as 90% of adult rheumatologists practice in urban metropolitan areas.[92,93] This gap results longer distances to receive specialist care among patients living in rural areas. The distance to providers impacts diagnosis pathways and time to initiation of treatment, which can exacerbate health disparities.[94] Among all patients with RA, for example, those living in rural areas are significantly less likely to report in-person specialist visits than those living in areas that are not rural, a divide that increased during the COVID-19 pandemic.[95] During that time, patients in rural areas experienced more interruptions in receiving RA medications.

Figure 5-8 shows the percent of women who report a type 1 diabetes diagnosis by race, ethnicity, and rurality. As the figure shows, type 1 diabetes diagnosis does not have a clear pattern across rurality and race and ethnicity. The estimates provided have large standard errors particularly among rural residents across all racial and ethnic groups. This underscores the importance of focused data collection for type 1 diabetes among U3 women and across all racial and ethnic groups, particularly in rural areas, to facilitate accurate estimates of trends in disease prevalence.

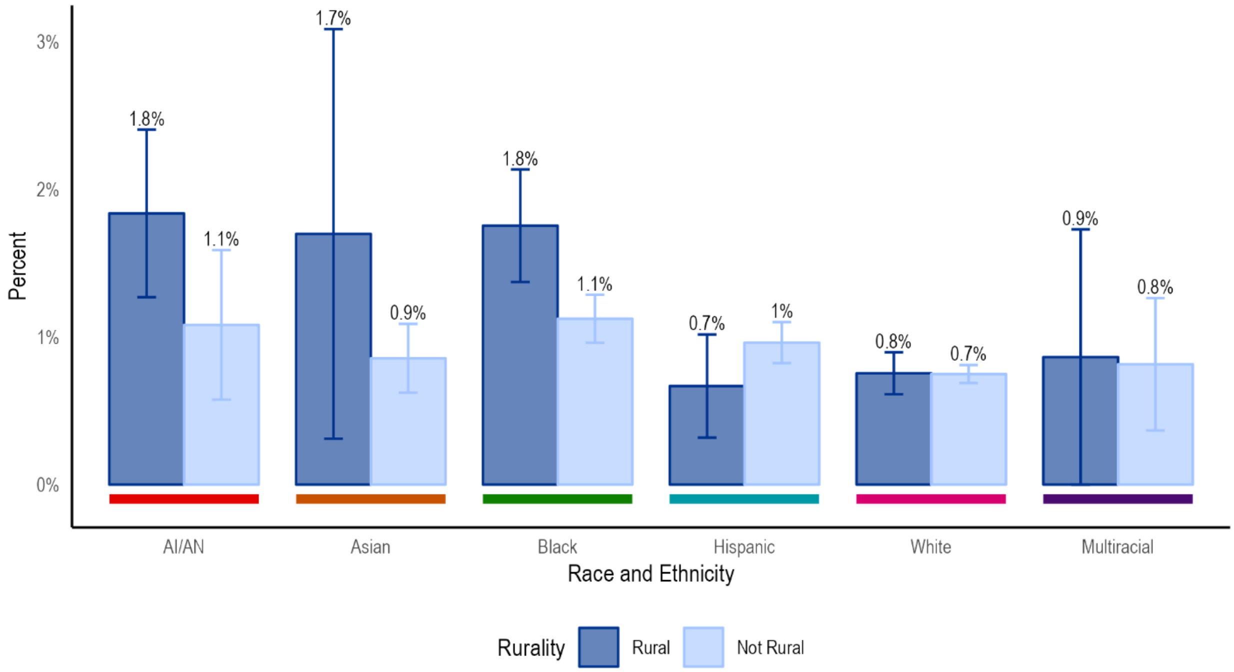

Figure 5-8: Percent of women who report a type 1 diabetes diagnosis, by race and ethnicity, and rurality

Source: National Health Interview Survey (NHIS), Pooled 2019-2022

While the data presented here do not suggest a clear pattern of disparities by rurality, prior research identified a unique set of structural and social drivers that affect the health of women in rural areas, such as access to health screenings and specialty care, cumulative disadvantage, and higher rates of health risk behaviors (see **Chapter 1**).[96–99] Social stigma and privacy concerns due to a lack of anonymity among healthcare providers in rural areas are also barriers to accessing care.[99]

5.3.2.2 Economic Status

Figure 5-9 displays the percent of women who report an arthritis, RA, gout, lupus, or fibromyalgia diagnosis by race, ethnicity, and economic status. The figure shows that women in economically disadvantaged groups experience consistently higher prevalence of autoimmune and inflammatory disease. Regardless of economic status, AI/AN and White women have the highest prevalence of inflammatory disease, while Asian and Multiracial women have the lowest prevalence. There appear to be large disparities in autoimmune and inflammatory disease across economic status, particularly among AI/AN, Black, White, and Multiracial women.

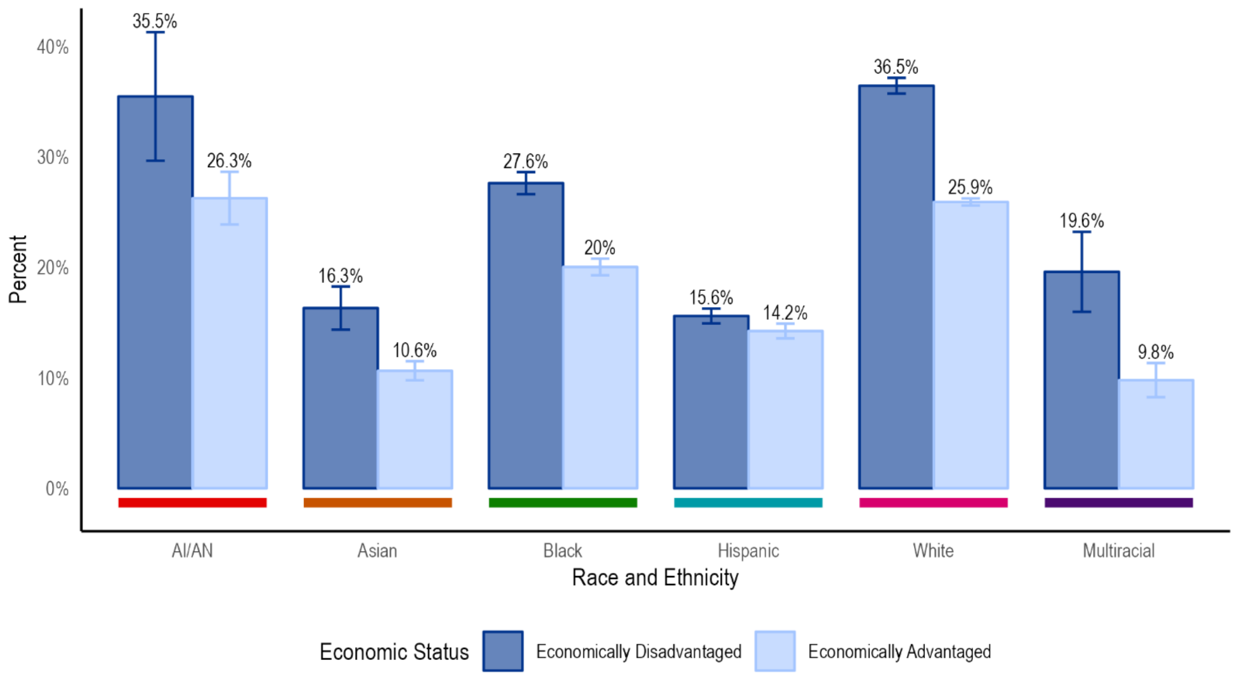

Figure 5-9: Percent of women who report an arthritis, rheumatoid arthritis, gout, lupus, or fibromyalgia diagnosis, by race and ethnicity, and economic status
Source: National Health Interview Survey (NHIS), Pooled 2019-2022

Figure 5-10 shows the percent of women who report an arthritis diagnosis by racial and ethnic, economic status, and arthritis type. Differences by economic status can be detected within some race and ethnicity groups reporting RA and those reporting inflammatory diseases (osteoarthritis or degenerative arthritis). For RA, Black, White, Hispanic, and Multiracial economically disadvantaged women have a higher prevalence compared to women in economically advantaged groups of the same race and ethnicity respectively. By contrast, women in economically advantaged groups have a higher percentage of osteoarthritis or degenerative arthritis across all race and ethnicity groups. Notably, there are no data on AI/AN women, highlighting an important gap in understanding the prevalence of types of arthritis within this population.

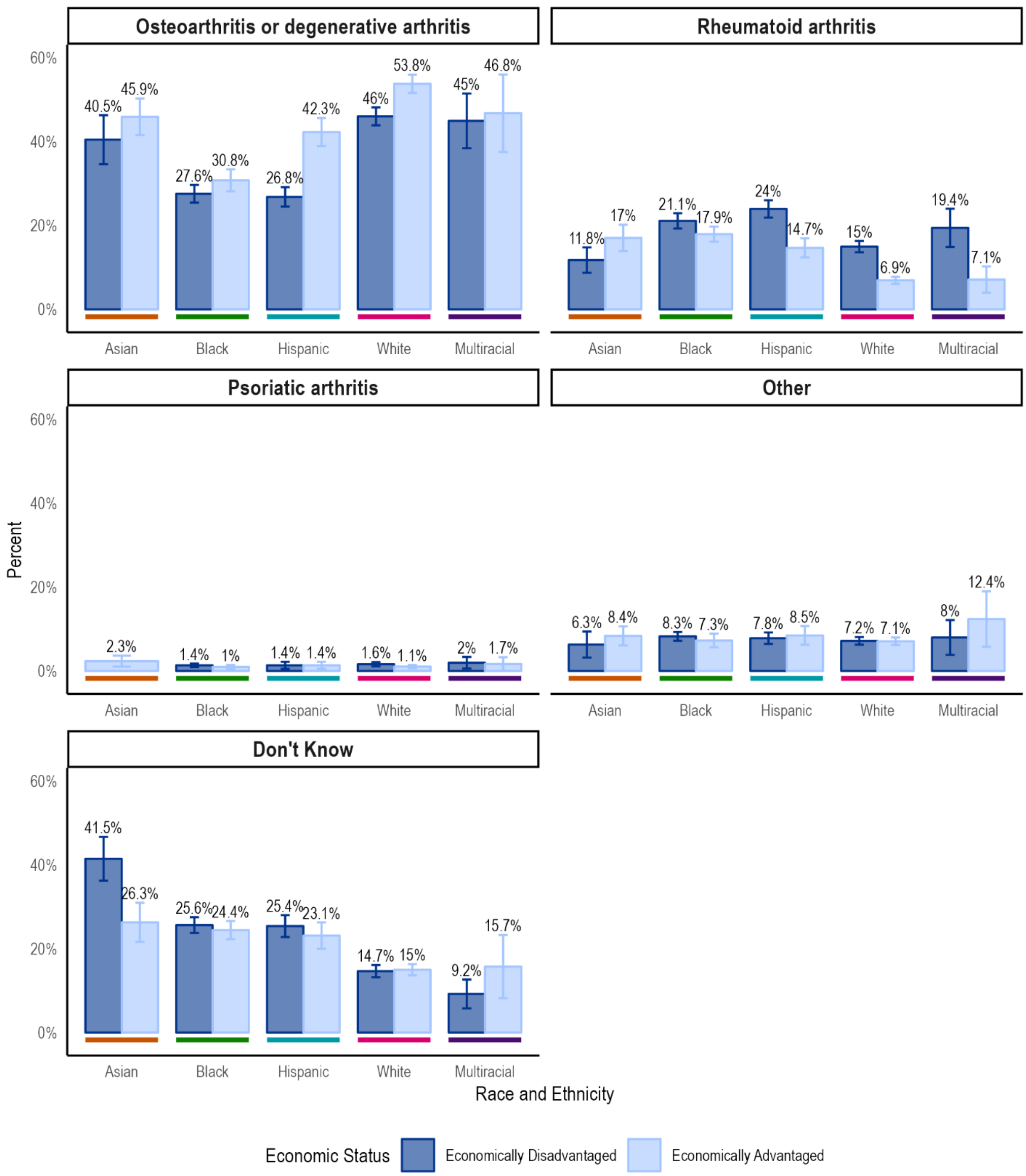

Figure 5-10: Percent of women who report an arthritis diagnosis, by race and ethnicity, economic status, and arthritis type

Source: National Health and Nutrition Examination Survey (NHANES), Pooled 2009-2020

The data also show that Asian women who are economically disadvantaged are more likely than women of other racial and ethnic groups to report not knowing the type of arthritis they have. For Hispanic and White women, prevalence of osteoarthritis or degenerative arthritis is higher among those who are economically advantaged compared with women who are economically disadvantaged.

Figure 5-11 shows the percent of women who report a type 1 diabetes diagnosis by race, ethnicity, and economic status. For all race and ethnic groups (except Multiracial), the prevalence of type 1 diabetes is higher among women who are economically disadvantaged relative to economically advantaged women. However, the standard errors among the pooled estimates are large, limiting the interpretation of the observed prevalence differences by economic status. Nevertheless, for Black women, economic status appears to be associated with an increased likelihood of type 1 diabetes, as those who are economically disadvantaged have a prevalence that is nearly double that of women who are economically advantaged. A similar pattern is observed for White women by economic status.

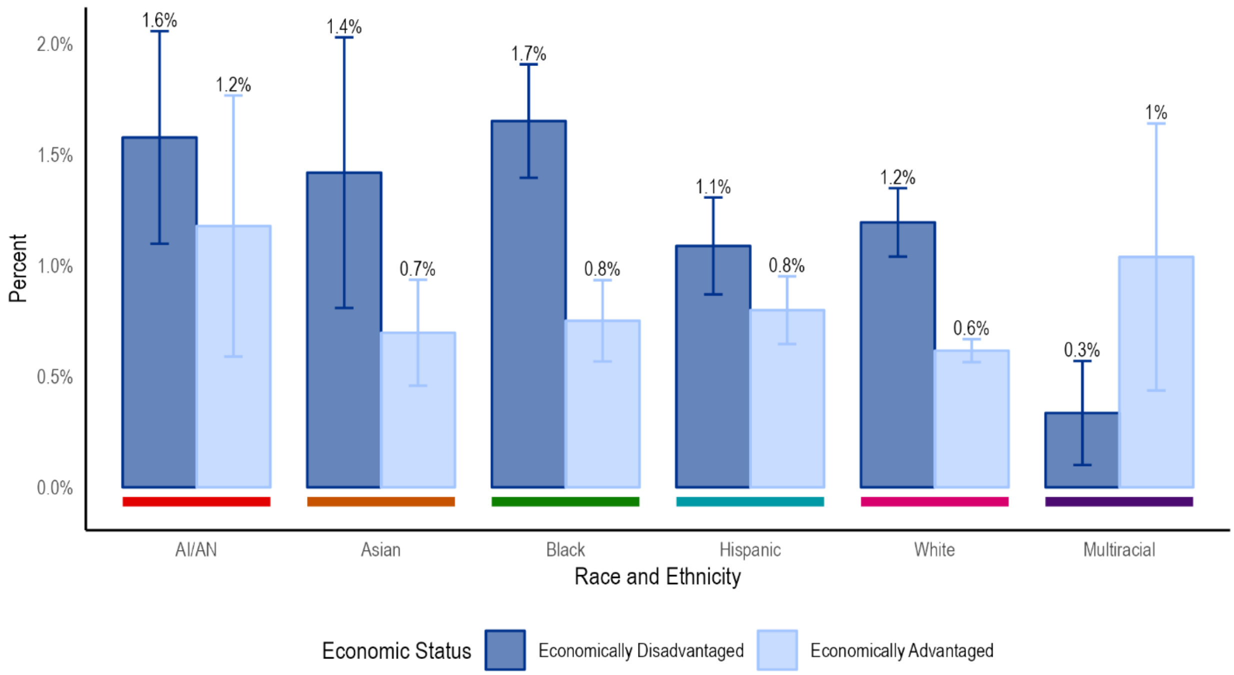

Figure 5-11: Percent of women who report a type 1 diabetes diagnosis, by race and ethnicity, and economic status

Source: National Health Interview Survey (NHIS), Pooled 2019-2022

The observed disparities may be perpetuated by socioeconomic factors such as income, access to safe neighborhoods, and living in areas with high pollution, which have been shown to increase risk of autoimmune disease.[28,62,63,91,100–102] Disparities may also be related to the social and structural barriers to healthy food options that U3 women disproportionately face.[103–105]

Studies highlight the importance of early treatment initiation to improve symptoms and physical functioning for patients. In the case of RA, for example, insurance type has been demonstrated to impact care seeking, especially given that the complexity of disease management may require close monitoring and frequent intervention. Medicaid patients travel longer distances to seek care from specialists who accept Medicaid, and are more likely receive care from a general practitioner or through an emergency department as opposed to a rheumatologist, which may contribute to adverse outcomes.[91,106] Additionally, the long pathway to diagnosis means that individuals who are economically disadvantaged may be less likely to seek and continue treatment due to financial barriers.[107] A study of nearly 200,000 RA patients found that those with private insurance were 87% more likely to begin treatment with a biological drug compared with those using Medicaid.[108]

5.3.2.3 Sexual Orientation

Among all racial and ethnic groups, nearly all respondents in the NHIS data identified as heterosexual, and only small numbers identified as lesbian, bisexual, queer or questioning (LBQ) or did not identify their sexual orientation. **Figure 5-12** shows the percent of women who report an arthritis, RA, gout, lupus, or fibromyalgia diagnosis by race and ethnicity and sexual orientation. The data suggest that heterosexual Black women have a higher prevalence of the noted conditions than LBQ Black women. For the other racial and ethnic groups, large standard errors limit definitive conclusions regarding autoimmune and inflammatory disease differences by sexual orientation. This underscores the importance of improving data collection on sexual and gender minority (SGM) populations.

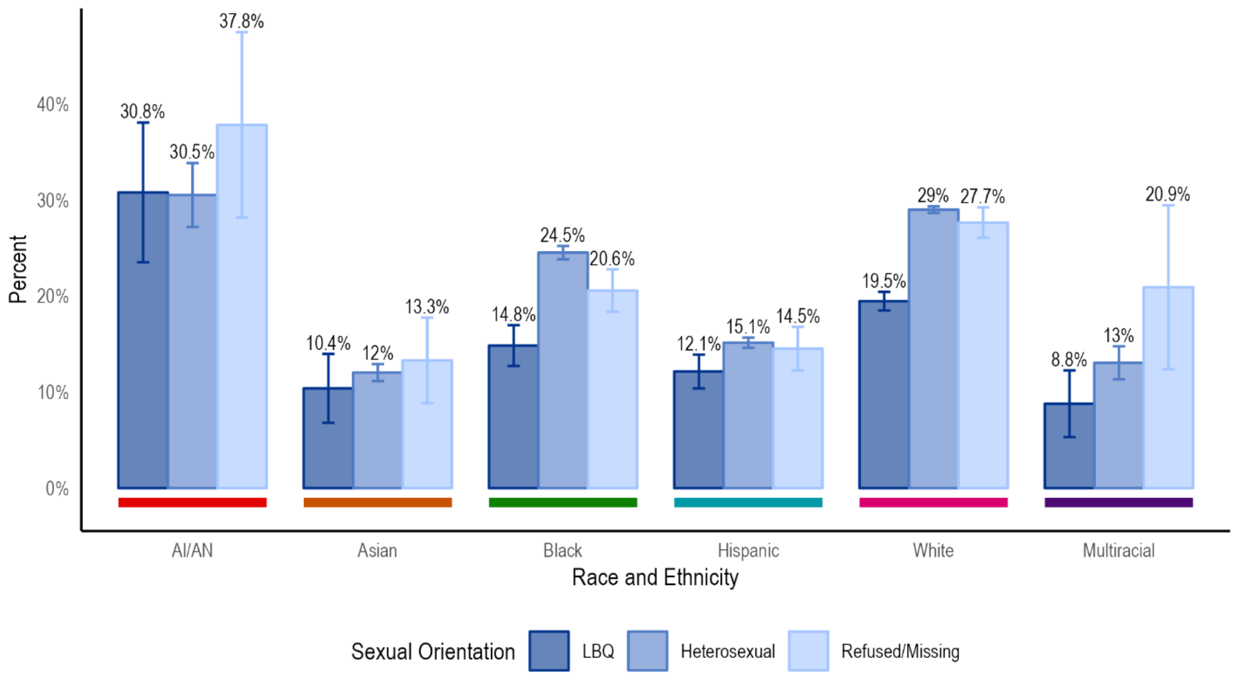

Figure 5-12: Percent of women who report an arthritis, rheumatoid arthritis, gout, lupus, or fibromyalgia diagnosis, by race and ethnicity, and sexual orientation

Source: National Health Interview Survey (NHIS), Pooled 2019-2022

Although there are few studies linking risk factors of autoimmune and inflammatory disease with prevalence among the SGM population, it has been well documented that SGM individuals chronically experience high levels of discrimination and marginalization including in healthcare settings, which creates barriers to diagnosis and treatment.[109] Associated psychosocial stress and weathering affect health and risk of disease as well as accelerating disease-related declines.[110] Further, psychosocial stressors experienced by SGM women are associated with other comorbidities that exacerbate immunosuppression, such as smoking and dietary practices that increase risk for obesity.[110,111] Therefore, there is an acute need for inclusive care for SGM individuals seeking evaluation for and support with management of autoimmune diseases.

5.4 Conclusions and Future Directions

The findings presented in this chapter highlight the increased prevalence of autoimmune and inflammatory diseases among women belonging to underrepresented racial and ethnic communities, rural women, and women who are economically disadvantaged. This chapter also notes the significant data gaps in nationally representative datasets related to these conditions. Surveys that collect data on specific autoimmune diseases rather than grouping multiple diseases together in one question would allow for greater clarity on prevalence, allow exploration of risk factors, and support the tailoring of outreach and educational materials. Additionally, data describing the age of disease onset and diagnosis would enhance patient and provider knowledge on disease symptoms and progression. Future research should examine the root causes of autoimmune disease disparities (such as genetic, environmental exposure, and social factors), the diversity of symptoms in U3 women, and the pathways to increase access to the continuum of treatment strategies and screening tests for autoimmune disease and drug discovery trials/health education programs focused on U3 women. Future research should also expand the evidence base around community engaged and culturally appropriate healthcare for U3 women (see **Chapter 1**). Finally, identifying strategies to decrease the time to diagnosis for U3 women is a critically important step in reducing avoidable disease-related suffering for U3 women experiencing autoimmune diseases.

5.5 Data Sources and Definitions

Data for all figures in this chapter can be accessed from the data annex located here:
https://orwh.od.nih.gov/sites/orwh/files/docs/Chapter_5.xlsx

National Health Interview Survey (NHIS), 2019-2022

Variable Name	Variable Description	Variable Options
ARTHEV_A	Have you ever been told by a doctor or other health professional that you had some form of arthritis, rheumatoid arthritis, gout, lupus, or fibromyalgia?	**Yes;** No; Refused; Not Ascertained; Don't know
DIBTYPE_A	According to your doctor or other health professional, what type of diabetes do you have? Is it type 1, type 2, or some other type? If you don't remember or weren't told, that's OK.	**Type 1;** Type 2; Other type of diabetes; Refused; Not Ascertained; Don't Know

National Health and Nutrition Examination Survey (NHANES), 2009-2020

Variable Name	Variable Description	Variable Options
MCQ160A	Has a doctor or other health professional ever told {you/SP} that {you/s/he} had arthritis?	**Yes**; No; Refused; Don't know; Missing
MCQ195	Which type of arthritis was it?	**Osteoarthritis or degenerative arthritis; Rheumatoid arthritis; psoriatic arthritis; Other;** Refused; **Don't know;** Missing

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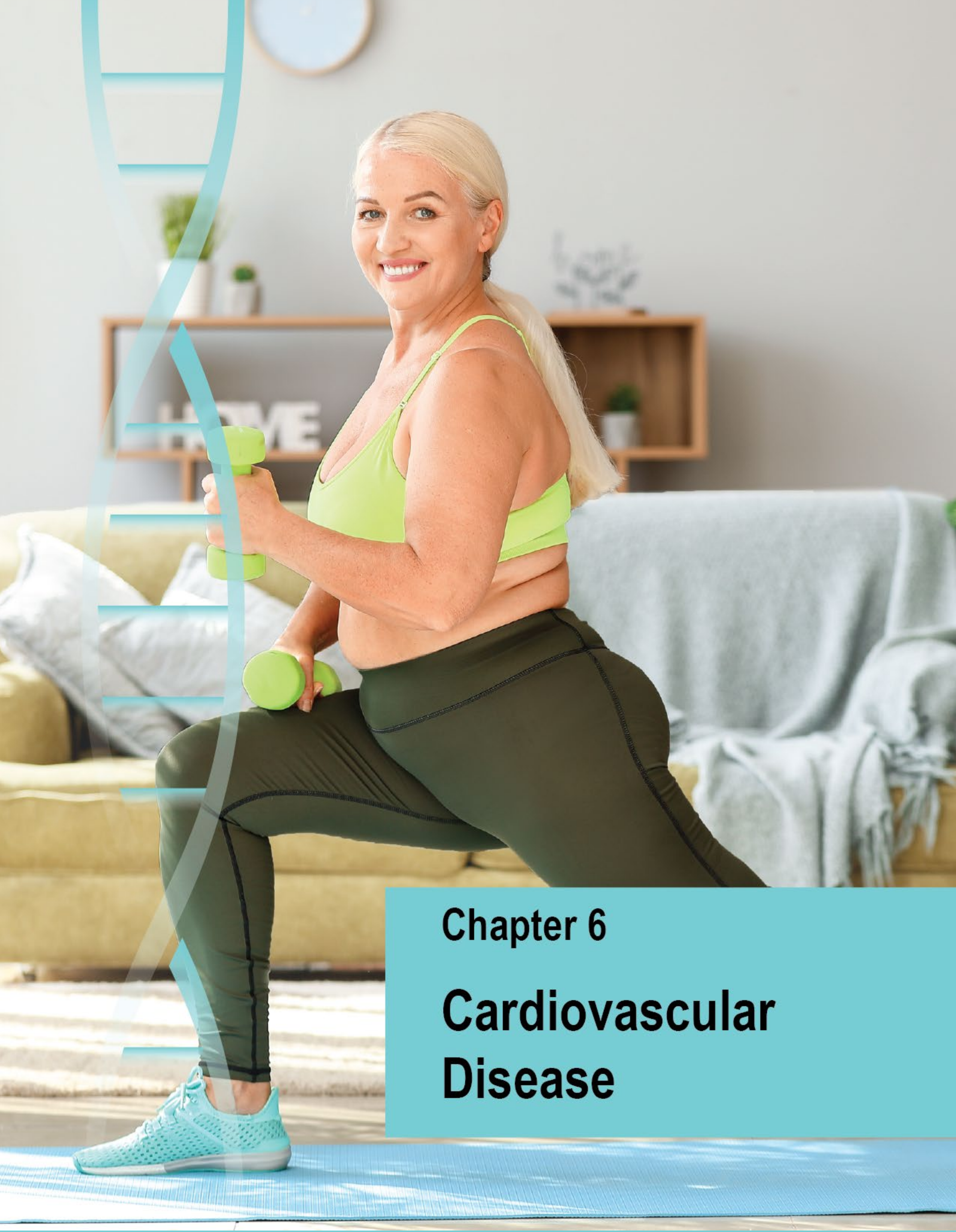

Chapter 6

Cardiovascular Disease

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Cardiovascular Disease

6.1 Defining Cardiovascular Disease

Cardiovascular disease (CVD) encompasses a range of conditions of the heart and blood vessels and has been one of the leading causes of death among men and women in the U.S.[1,2] The primary cause of CVD is atherosclerosis where the healthy endothelial lining of the arteries becomes injured leading to fatty deposits or plaques and the formation of blood clots inside the arteries. This process leads to arteries narrowing and hardening, causing a reduction in blood flow to downstream tissues or organs.[3] Approximately half of U.S. adults have a cardiovascular condition. Mortality from CVD declined from 2010-2019 but has increased from 2019-2022 to 454.5 deaths per 100,000 population, similar to 2010 levels.[4–6] Recent literature highlights that behavioral risk factors and underlying biological, social, and structural determinants—factors such as housing, nutrition, exercise, tobacco and alcohol use, poverty, and stress—play a significant role in the onset and progression of CVD (see **Chapter 1**).[7]

The spectrum of CVD conditions is diverse, and the age of disease onset varies by the type of condition, with the risk for disease development and progression significantly increasing with age.[8] Common CVD conditions include hypertension, congestive heart failure, arrhythmias, cerebrovascular disease, atherosclerosis, valvular heart disease, and coronary heart disease (CHD), which is also known as coronary artery disease.[3,9,10] Among these conditions, CHD is a significant cause of mortality: "in 2020 in the United States, CHD was the leading cause (41.2%) of deaths attributable to CVD followed by stroke (17.3%), other CVD (16.8%), high blood pressure (12.9%), heart failure (9.2%), diseases of the arteries (2.6%)."[5] CHD may cause chest pains, commonly referred to as angina, and in severe cases may result in a heart attack or stroke if there is a complete blockage of the artery.[11] The majority of CVD mortality is due to ischemic heart disease, which accounted for 550,000 deaths in 2019.[12] CVD may originate from diseases of the circulatory system and forms of essential hypertension and hypertensive renal diseases, with these conditions exerting additional stress on the cardiovascular system.[13]

Symptoms of CVD are multifarious and can be nonspecific, ranging from asymptomatic to a more common clinical presentation such as chest pain, indigestion, nausea or vomiting, fatigue, shortness of breath, swollen veins, confusion, or difficulty speaking.[7,10,14,15] The invasiveness of treatments for cardiovascular conditions varies depending on the type of CVD and its severity, ranging from lifestyle changes and medication to nonsurgical catheter-based interventions and surgery.[2] Nearly 80% of CVD cases are preventable through lifestyle changes, with clinicians emphasizing the importance of maintaining a healthy body weight, smoking and alcohol cessation, early medical intervention, adequate sleep, and managing other health conditions or risks such as stress, diabetes, obesity, hypertension, and high cholesterol, all of which are associated with increased risk of CVD.[16,17]

6.2 Cardiovascular Disease in Women

While men have a higher prevalence of CVD compared with women, CVD remains the leading cause of death for women in the U.S. (see **Chapter 4**), with over 60 million women affected.[5] **Figure 6-1** shows the percent of people who report being diagnosed with CHD by sex, which is the leading cause of deaths attributable to CVD.

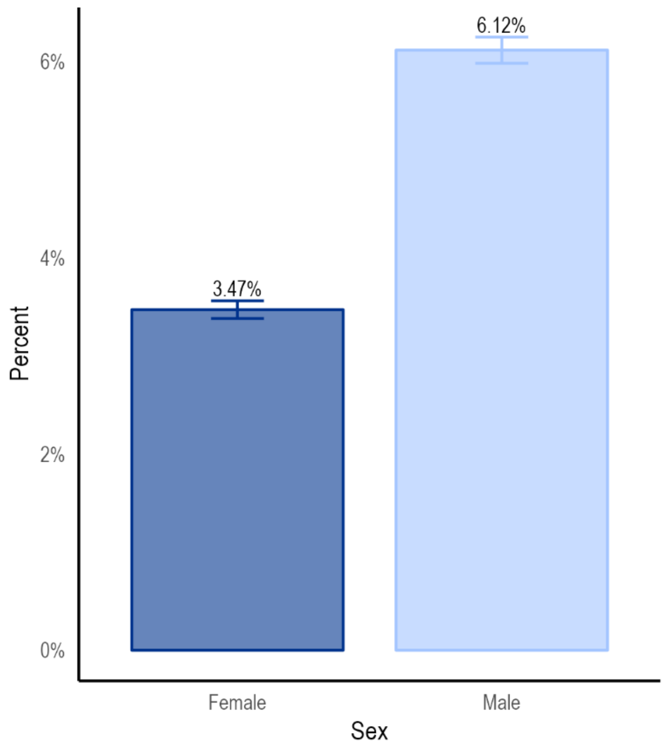

Figure 6-1: Percent of people who report a coronary heart disease diagnosis by sex
Source: National Health Interview Survey (NHIS), Pooled 2019-2022

The clinical characteristics of CHD often present differently in women compared with men, leading to potential misdiagnosis or delayed diagnosis.[9] Angina, for instance, a common symptom of CHD, presents differently by sex.[18] CHD symptoms considered "atypical" in men, such as nausea and vomiting; neck, jaw, abdomen, or back pain; and shortness of breath, are more common in women.[18] Further complicating diagnosis, women make up between 60% and 80% of patients with suspected Ischemia with no obstructive coronary arteries (INOCA) undergoing invasive evaluation.[19,20] INOCA poses a significant challenge due to its frequent underdiagnosis and undertreatment, which can lead to poorer health outcomes.[21,22] Diagnoses are delayed or missed in at least half of all cases because standard angiography, which focuses on visualizing large blockages, often misses the underlying causes of INOCA symptoms in women.[23] These causes can include microvascular dysfunction or coronary spasm. Similarly, myocardial infarction with no obstructive coronary arteries (MINOCA) also disproportionately affects women and is characterized by acute myocardial ischemia despite normal angiography results, leading to similar diagnostic difficulties.[24,25]

Women with CHD are more likely to experience angina during everyday activities, whereas men typically experience worsening angina with exercise.[9] **Figure 6-2** illustrates the percent of people who report an angina diagnosis by sex. The figure shows a gap in the percent of women and men who reported being diagnosed with angina.

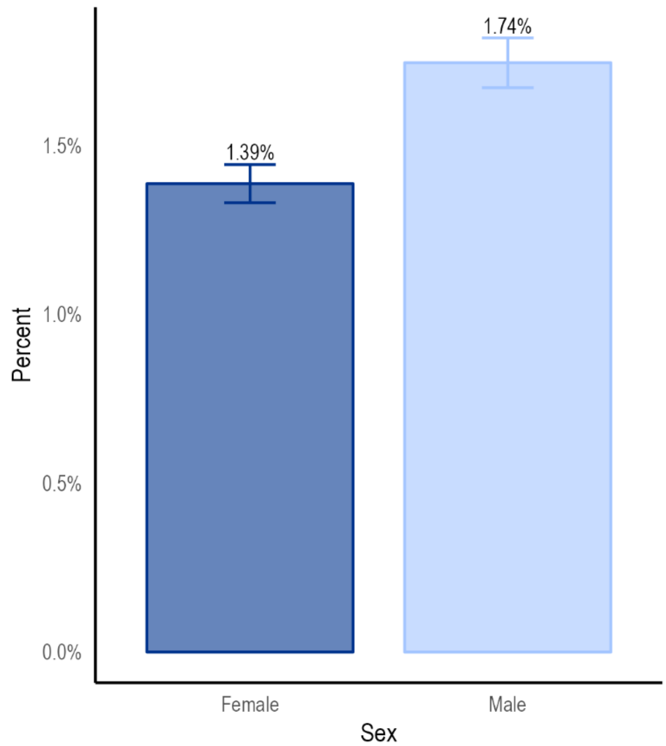

Figure 6-2: Percent of people who report an angina diagnosis by sex
Source: National Health Interview Survey (NHIS), Pooled 2019-2022

This gap may reflect actual sex differences in prevalence, but it is also likely due to delayed diagnosis and misdiagnosis, particularly among women 50 years of age or younger.[9,26]

Figure 6-3 shows the percent of people who report a heart aback diagnosis by sex. The figure demonstrates that heart attack is twice as common among men compared with women, a disparity that may be partially attributed to the different symptom presentation in women. While chest pain is a typical heart attack symptom, it is not always experienced by women who may instead present with symptoms such as pain, tightness, or pressure in the upper abdomen, as well as shortness of breath, nausea or vomiting, and fatigue.[27] Varying symptoms among women may contribute to misdiagnosis or delays in seeking and receiving appropriate medical attention. Moreover, national data demonstrate a concerning trend of substandard care for women with symptoms of heart attack. Women are less likely to receive resuscitation, be administered aspirin, or be transported to the hospital via ambulance compared with men.[28,29] These differences highlight the importance of broadening our understanding of heart attack symptoms.

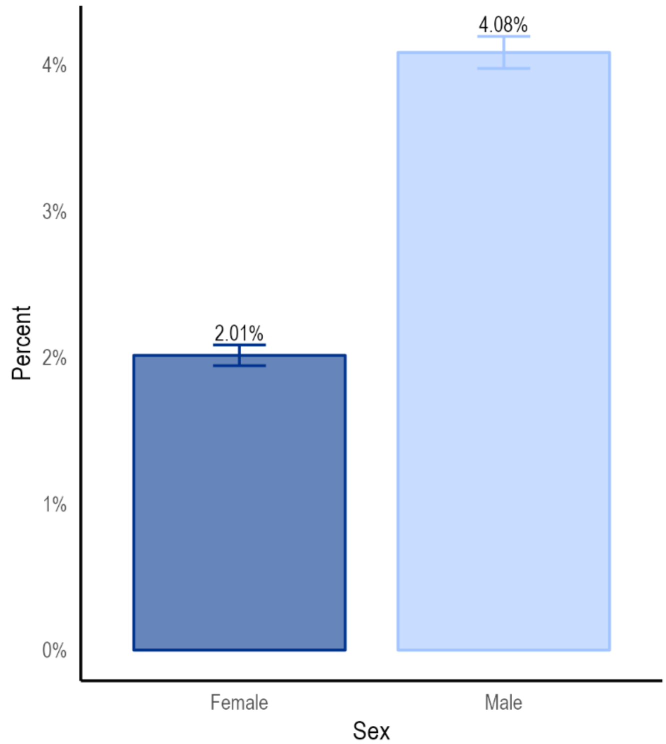

Figure 6-3: Percent of people who report a heart attack diagnosis by sex
Source: National Health Interview Survey (NHIS), Pooled 2019-2022

Women have unique risk factors for stroke. **Figure 6-4** displays the percent of people who report a stroke diagnosis by sex. The figure shows that the pooled estimate of stroke prevalence between 2019 and 2022 was higher among women than among men. Prevalence of stroke remains higher among women throughout their lifespan compared with men, as stroke risk increases with age, and women on average live longer than men.[30] Hypertension stands out as a primary risk factor, with data indicating that over 40% of women have elevated blood pressure or are on medication to control it.[31] Additional risk factors specific to women include pregnancy-related high blood pressure, the use of certain contraceptives (particularly among women who smoke), and higher rates of depression (see **Chapter 10**).[30,32] Furthermore, pregnancy complications (e.g., preterm delivery, gestational diabetes, and placental abruption) increase the odds of developing CVD risk factors.[33] Other pregnancy-related complications may also impose a greater risk of CVD later in life, including hypertension and diagnosed anemia.[9,34]

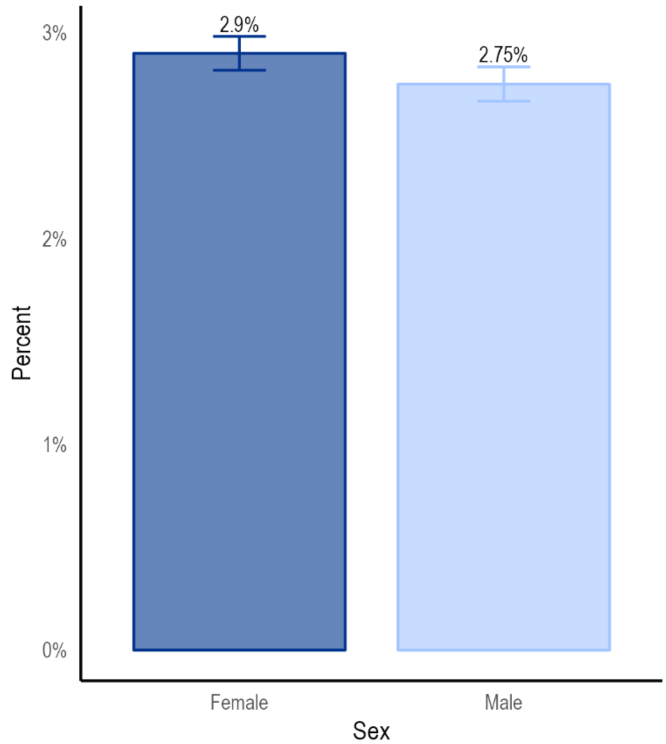

Figure 6-4: Percent of people who report a stroke diagnosis by sex
Source: National Health Interview Survey (NHIS), 2019-2022

Figure 6-5 shows the mortality rates for CVD subtypes by sex. Over the past decade, the age-adjusted mortality rate due to all diseases of the circulatory system remained stable for both men and women, with the rate for men (281.5 deaths per 100,000 men in 2021) being approximately 40% higher than that for women (192.1 deaths per 100,000 women in 2021). Mortality rates for major CVD, the most prevalent subset of diseases of the circulatory system, also remained consistent, with a similar gap between men and women. Heart disease ("diseases of heart") accounts for the majority of the CVD deaths in both men and women, and the gap is more pronounced, with the mortality rate for men (219.5 deaths per 100,000 men in 2021) being 60% higher than that of women (135.6 deaths per 100,000 women in 2021). However, higher male mortality is less pronounced for essential hypertension, hypertensive renal disease, and cerebrovascular diseases. While the overall mortality rate for other diseases of the circulatory system is low, the rate for men (9 deaths per 100,000 men in 2021) is still 40% higher than that for women (6.4 deaths per 100,000 women in 2021).

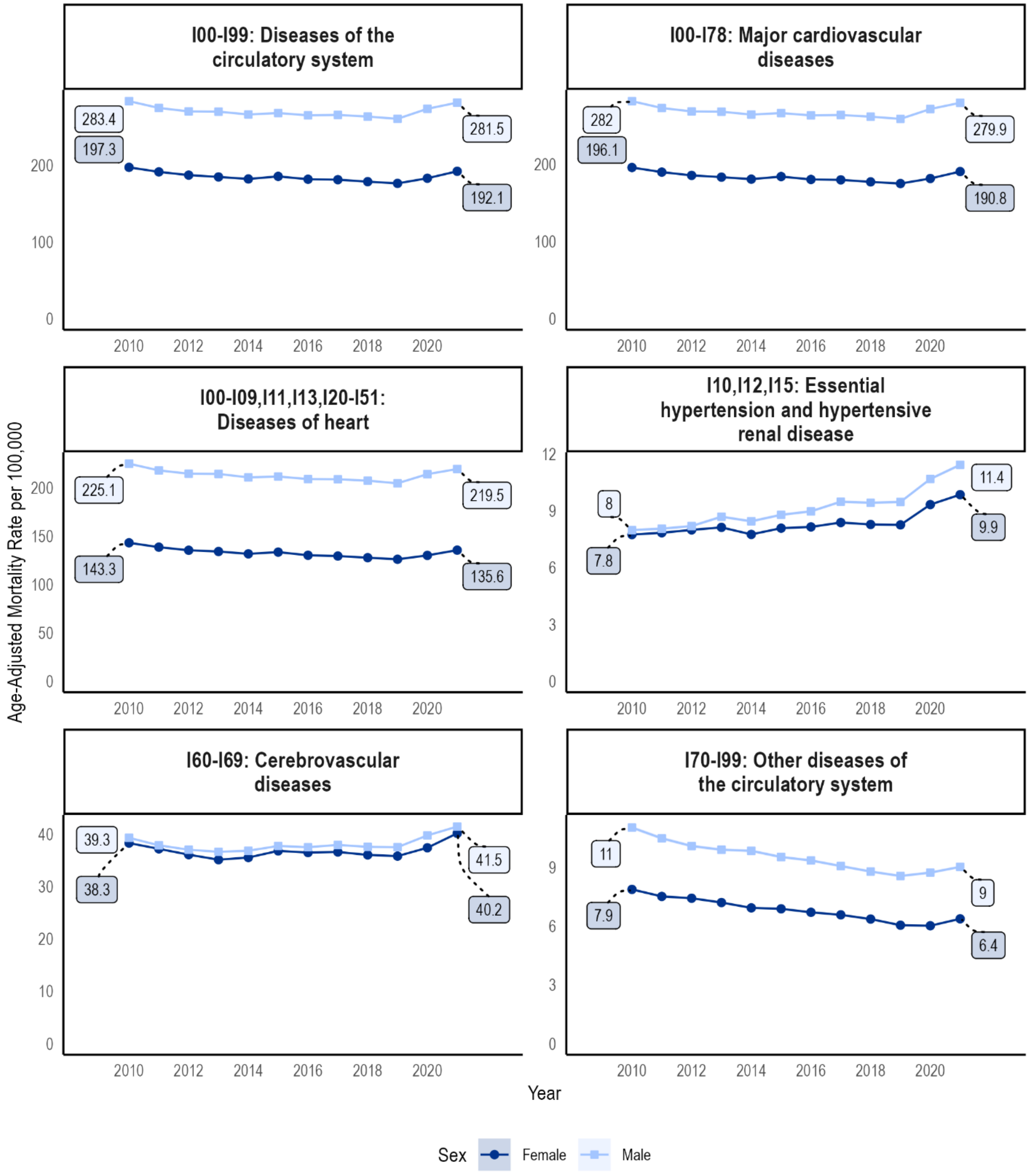

Figure 6-5: Age-adjusted mortality rate of cardiovascular disease subtypes (indexed by ICD-10 codes) per 100,000 population over time by sex

Source: National Vistal Statistics System (NVSS), 2010-2021[i]

[i] The standard error for NVSS mortality rates is much narrower than for prevalence estimates, as NVSS data are collected from vital registration systems and therefore capture a larger population.[35]

The higher prevalence and mortality rates of CVD among men may undermine suspicion of disease in women, thus triggering less aggressive diagnostic evaluation for female patients.[18,27] Further, women face unique sex-specific risk factors that contribute to overall risk and are often underrecognized. For instance, sex hormones during endocrinological transitions are associated with the increase in CVD risk among women.[36,37] Sex-specific risks are important to improve risk assessment in women and provide more precise prevention and treatment.

Over a decade of research has associated an accelerated accumulation of risk factors including elevated blood pressure, body mass index (BMI), obesity, and body fat distribution, during the menopause transition that contributes to increased CVD prevalence later in life for women.[38,39] While endogenous estrogen may protect against CVD by maintaining arterial flexibility and positively affecting blood lipids, hormonal changes during natural or surgical menopause, such as decreased estrogen levels, can increase the risk of CVD in older women (see **Chapter 11**).[9,36,40] Other research shows an association between declining testosterone levels during menopause and increased heart failure.[28,37] Additionally, autoimmune and other inflammatory diseases, which are more prevalent in women and linked to endocrinological transitions like menopause, increase CVD risk (see **Chapter 5**).[9,41] Polycystic ovary syndrome is the most common endocrine disorder in women and increases cardiometabolic risks. The syndrome is underdiagnosed and, even when recognized, is underinvestigated and undertreated in terms of its association with increased CVD risks.[42]

Biological determinants, such as differences in cardiovascular physiology, also increase the risk of CVD among women. The female heart and blood vessels are smaller and comprised of thinner muscular walls when compared to these structures in men, making disease in smaller arteries of the heart more probable and difficult to diagnose, and potentially causing treatment delays.[9,37]

A significant proportion of women remain uninformed that CVD is a leading cause of death among their demographics. Literature points to misconceptions of perceived risk and gender norms as contributing factors to poor CVD awareness among women of all ages.[43–45] Despite its significance to women's health, the detection and clinical guidelines for CVD are primarily based on research conducted on men.[29,46] These gaps in knowledge of CVD risk and gender-specific clinical guidelines highlight the need for enhanced screening, education, and communication between healthcare clinicians and female patient populations regarding their CVD risk and burden.[44,45]

6.3 Cardiovascular Disease in Populations of U3 Women

In addition to the sex-specific risk factors noted earlier, the research data available on understudied, underrepresented, and underreported (U3) women show they face unique disparities related to CVD due to social drivers of health that affect their ability to access appropriate care. These factors can negatively impact the prevention of chronic conditions and diseases and hinder effective health management throughout the lives of U3 women (see **Chapter 1**). The section that follows presents findings on CVD prevalence for U3 women by race and ethnicity, rurality, economic status, sexual orientation, and gender identity.

6.3.1 Cardiovascular Disease Among Women of Underrepresented Racial and Ethnic Communities

Multiple comorbid health conditions, social deprivation, and lifestyle factors place U3 women at a greater risk for developing CVD. Risk factors for CVD include hypertension, diabetes, obesity, physical inactivity, alcohol use, smoking, and inadequate sleep.[14] U3 women, who often are afflicted with multiple risks, have disproportionate burden contributing to the observed disparities in CVD outcomes.[47,48] BMI is often used to screen for the CVD risk factor of obesity.[49] A BMI in the healthy range is between 18.5 and 25 kg/m^2 while a BMI over 25 kg/m^2 is considered overweight and a BMI over 30 kg/m^2 falls within the obesity range.[49] **Figure 6-6** shows the estimates for BMI by sex and race and ethnicity over time. Data demonstrate that Black women have the highest BMI across all racial and ethnic groups while Asian women have the lowest BMI. These findings align with a recent publication by the AHA showing that obesity-related CVD mortality tripled between 1999 and 2020, with Black women experiencing the highest obesity-related CVD mortality compared with other racial and ethnic groups.[50]

While National Health and Nutrition Examination Survey (NHANES) does not provide data for the American Indian and Alaska Native (AI/AN) population, other research indicates that after accounting for sociodemographic factors AI/AN individuals are 23% more likely to report obesity than White individuals. This gap is even wider for some Native subgroups, such as those in the Pacific Coast region where AI/AN people are 28% more likely to report obesity compared with White individuals.[51] Structural determinants, such as travel time to primary care services, residence in settings with lower educational attainment, and frequent residence changes contribute to this disparity among AI/AN populations.[52–54] Research on the food insecurity paradox—"the coexistence of both obesity and food insecurity"—shows that individuals who face a scarcity of food resources due to economic disadvantage are more likely to be obese.[55,56] This observed association is strongest and most consistent among women who live in high-income countries but are in economically disadvantaged groups.[56,57]

While BMI continues to be used as a standard indicator for obesity, it has faced scrutiny in the past decade about its overall accuracy and its use as a singular predictor of mortality risk.[58,59] Researchers and practitioners have increasingly noted that the measure is calibrated to the physiology of White men and thus does not accurately reflect the health status and risk profile of women, especially women of underrepresented racial and ethnic communities.[60,61] Recent literature suggests that other methods may be more appropriate for predicting CVD incidence better than other obesity indices, including waist to height ratio, waist circumference, and waist-to-hip ratio.[62–64] Other research has suggested that percent body fat is a better indicator for overall health, particularly among Black women.[65,66]

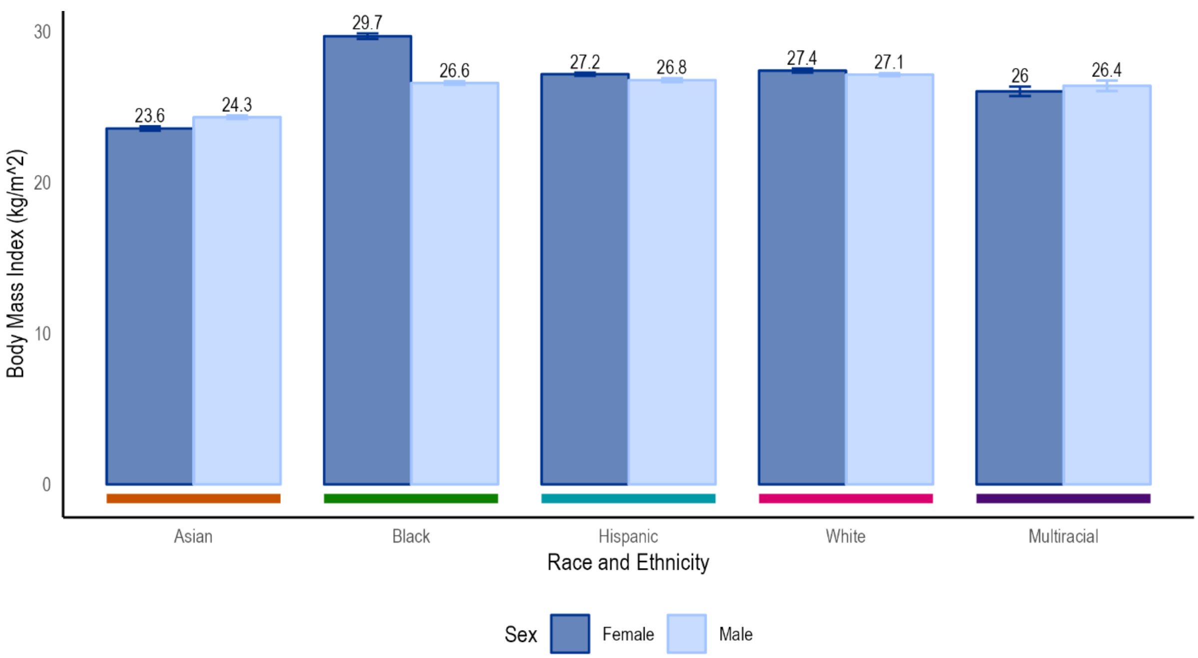

Figure 6-6: Body Mass Index (kg/m^2), by sex and race and ethnicity
Source: National Health and Nutrition Examination Survey (NHANES), Pooled 2009-2020

Figure 6-7 shows the percent of people who report a coronary heart disease by sex and race and ethnicity. Across all racial and ethnic groups, men consistently exhibit a higher prevalence of CHD compared with women. This gap in CHD diagnoses may be due to differences in clinical presentation between men and women, as previously discussed in this chapter. The AI/AN population appears to have the highest prevalence of CHD. This finding aligns with national data from the Office of Minority Health which reported that AI/AN individuals are 50% more likely to be diagnosed with CHD when compared with White individuals.[47] The data show that White men also have a high prevalence of CHD, nearly twice that of White women. The Multiracial population has the lowest CHD prevalence relative to other racial and ethnic groups.

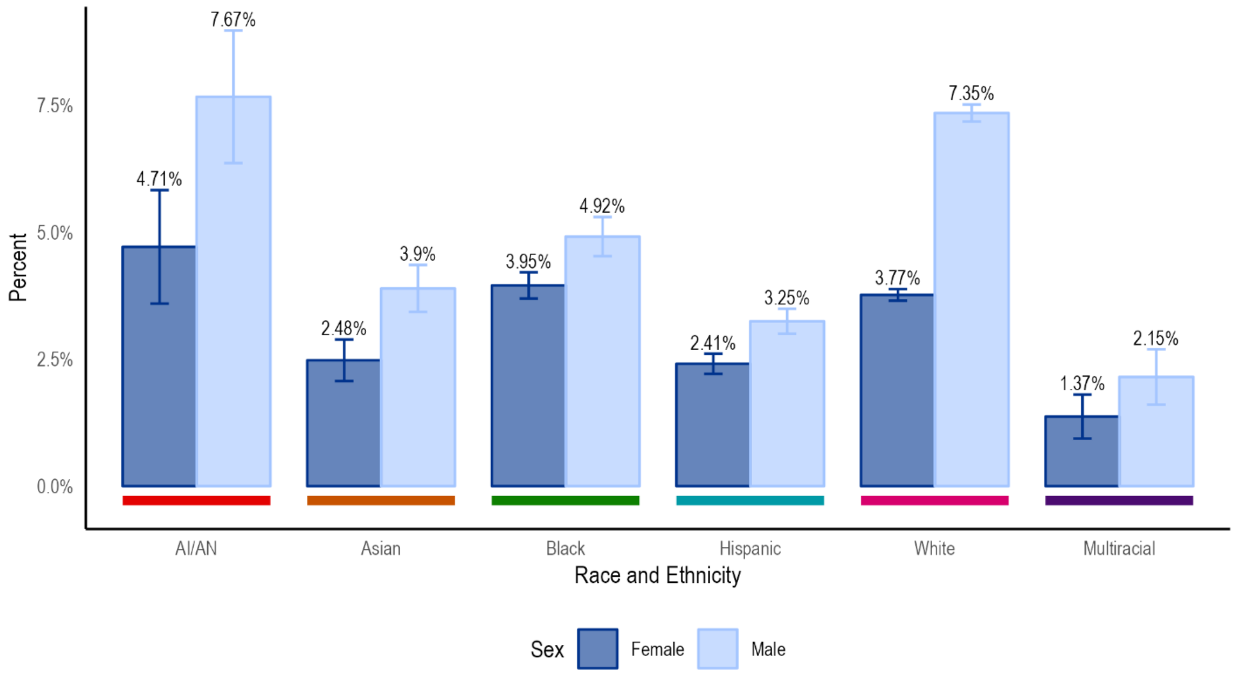

Figure 6-7: Percent of people who report a coronary heart disease diagnosis, by sex and race and ethnicity

Source: National Health Interview Survey (NHIS), Pooled 2019-2022

Similarly, the pooled estimates in **Figure 6-8** shows the percent of people who report an angina diagnosis by sex and race and ethnicity. The figure reveals a higher angina prevalence among the AI/AN population compared with other racial and ethnic groups. Angina prevalence among men and women is similar across Asian, Black, Hispanic, and Multiracial populations. Among AI/AN and White populations, men tend to have a higher prevalence of angina compared to women. These sex differences may stem from less conventional symptom presentation in women, leading to frequent misdiagnosis.[18,67] Research suggests that women, especially those from underrepresented racial and ethnic communities, face longer wait times and are less likely to be admitted to the hospital and to receive comprehensive evaluations when reporting chest pain compared with men and White women, potentially contributing to observed gender disparities in angina prevalence.[68]

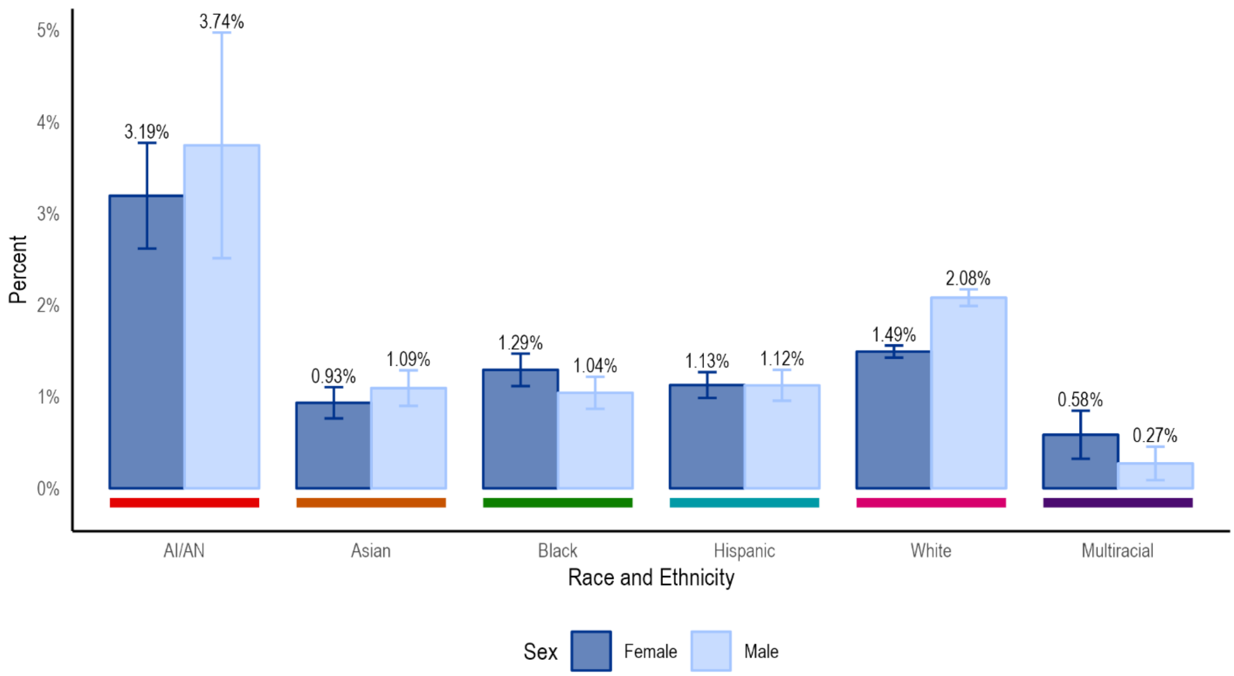

Figure 6-8: Percent of people who report an angina diagnosis, by sex and race and ethnicity
Source: National Health Interview Survey (NHIS), Pooled 2019-2022

Figure 6-9 displays the percent of people who report a heart attack diagnosis, by sex and race and ethnicity. The figure shows an overall trend of men exhibiting a higher prevalence of heart attacks compared to women. Among Asian, Hispanic, White, and Multiracial populations, percent of self-reported heart attacks in men are approximately twice those in women. This disparity is not observed in the AI/AN population, for whom the prevalence of heart attacks is higher than all groups. This difference between the AI/AN population and other groups, especially for AI/AN women, is corroborated by existing literature. A recent study found that AI/AN women aged 65 or younger had a premature myocardial infarction mortality rate of 26% compared to 16% among women of other races.[69] This disparity may reflect delays in receiving care due to inadequate screening and treatment for heart attack risk factors, coupled with a lack of awareness of heart attack symptoms among AI/AN women.[70] While **Figure 6-9** also suggests that Black men have a higher prevalence of self-reported heart attack (3.29%) compared to Black women (2.24%), the estimated prevalence for Black women likely underrepresents the actual heart attack prevalence. Less than 40% of Black women are aware that chest pain is a symptom of heart attack and even fewer recognize that pain in the shoulder, neck, or arms could also be among the possible symptoms.[71]

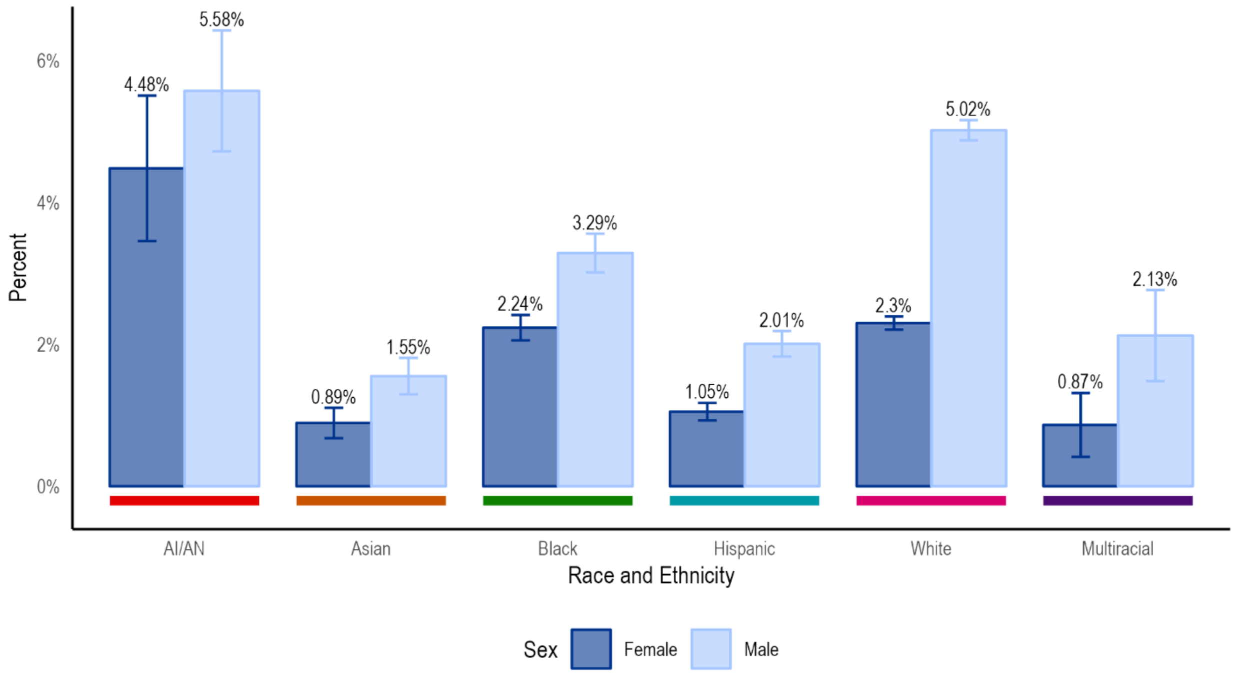

Figure 6-9: Percent of people who report a heart attack diagnosis, by sex and race and ethnicity
Source: National Health Interview Survey (NHIS), Pooled 2019-2022

Data on stroke prevalence lack a consistent pattern by sex across race and ethnicity. **Figure 6-10** shows the percent of people who report a stroke diagnosis, by sex and race and ethnicity. The highest prevalence is among AI/AN men, followed by Black women and AI/AN women. High stroke prevalence among Black women may be linked to increased rates of obesity, diabetes, and hypertension, which are key risk factors.[72] Psychological stress, including stress related to the experience of racism, contributes to hypertension development, particularly affecting Black women compared to White women.[73–75] Sickle cell disease, prevalent in the Black population, significantly increases stroke risk.[76,77]

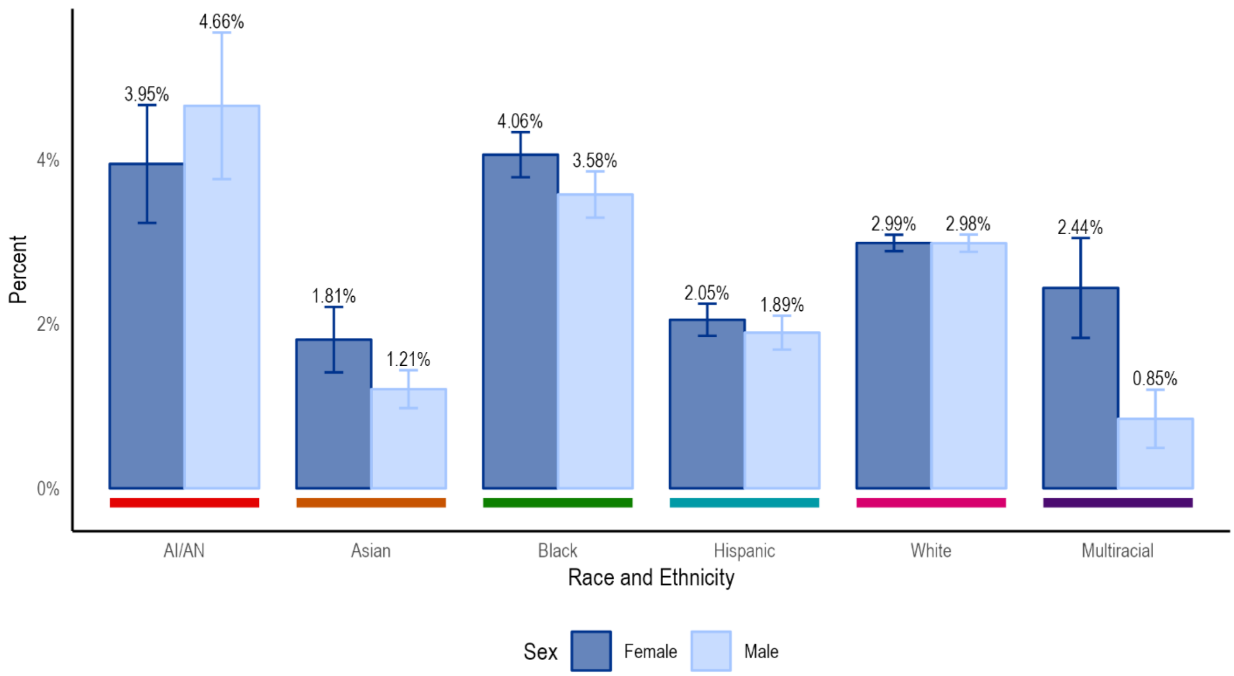

Figure 6-10: Percent of people who report a stroke diagnosis, by sex and race and ethnicity
Source: National Health Interview Survey (NHIS), Pooled 2019-2022

Data for congestive heart failure show no clear pattern across sex or race and ethnicity categories. **Figure 6-11** displays the percent of people who report a congestive heart failure diagnosis by sex and race and ethnicity. The prevalence of congestive heart failure among Asian men is three times higher than among Asian women. For all other racial and ethnic groups, the data do not demonstrate any meaningful difference by sex. This high prevalence of congestive heart failure among Black people, and specifically Black women, may contribute to the 3.5 times likelihood of postpartum cardiomyopathy mortality (a form of heart failure) among Black women in comparison to White women (see **Chapter 10**).[78] These differences in congestive heart failure prevalence among Black women may be attributed to a combination of unique risk factors that Black women face such as residing in poverty-dense and racially segregated neighborhoods, coupled with potential for biased clinical decision-making.[79–81]

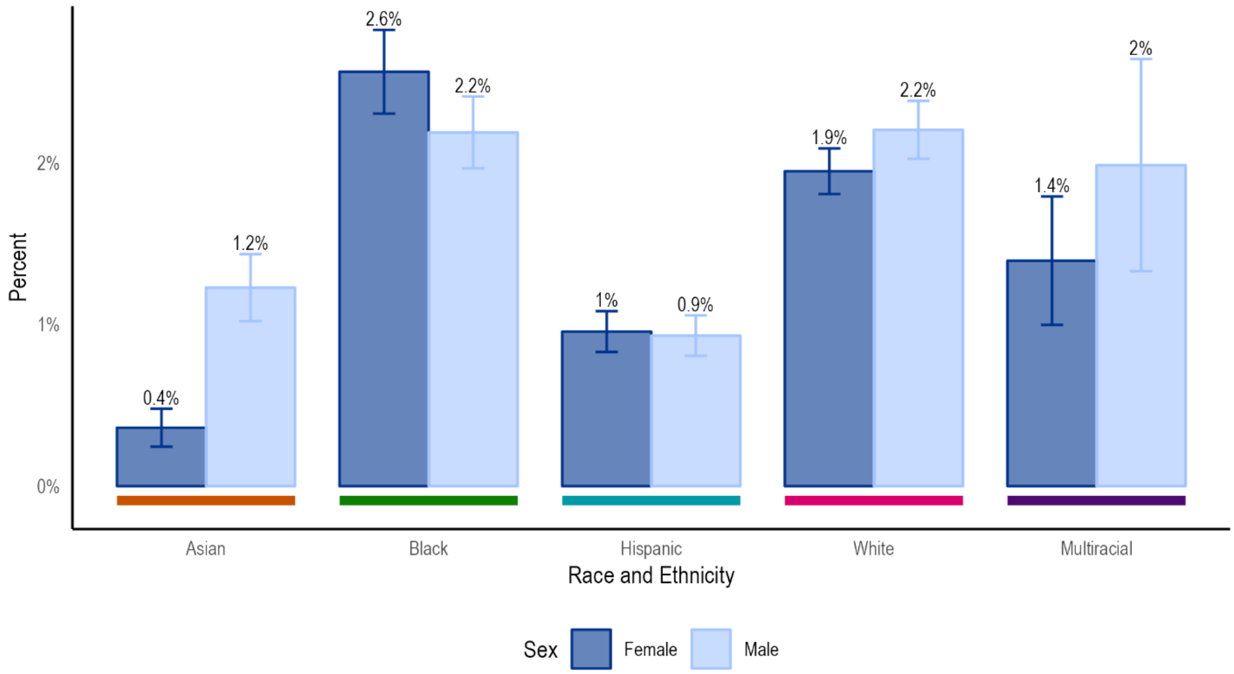

Figure 6-11: Percent of people who report a congestive heart failure diagnosis, by sex and race and ethnicity

Source: National Health and Nutrition Examination Survey (NHANES), Pooled 2009-2020

Figure 6-12 displays the mortality rate for the CVD subtypes by sex and race and ethnicity. The figure shows that men generally have higher rates of CVD mortality compared with women overall and in within-group comparisons for each race and ethnicity category. This difference is most pronounced for Black men, who have the highest mortality rates across all circulatory diseases. Black men's overall mortality rates from any diseases of the circulatory system, and from the subset of conditions that comprise major CVD, is 50% higher than that of Black women. This trend remains consistent for heart and cerebrovascular diseases, for which Black men have a mortality rate 60% and 20% higher than that of Black women, respectively. Black women consistently have higher CVD mortality compared with women in other racial and ethnic groups. Native Hawaiian and Pacific Islander (NHPI) and White populations have similar mortality rates from these diseases, higher than rates for AI/AN, Asian, Hispanic, and Multiracial populations. Asian and Multiracial populations consistently have the lowest mortality rates for CVD compared with other racial and ethnic groups.

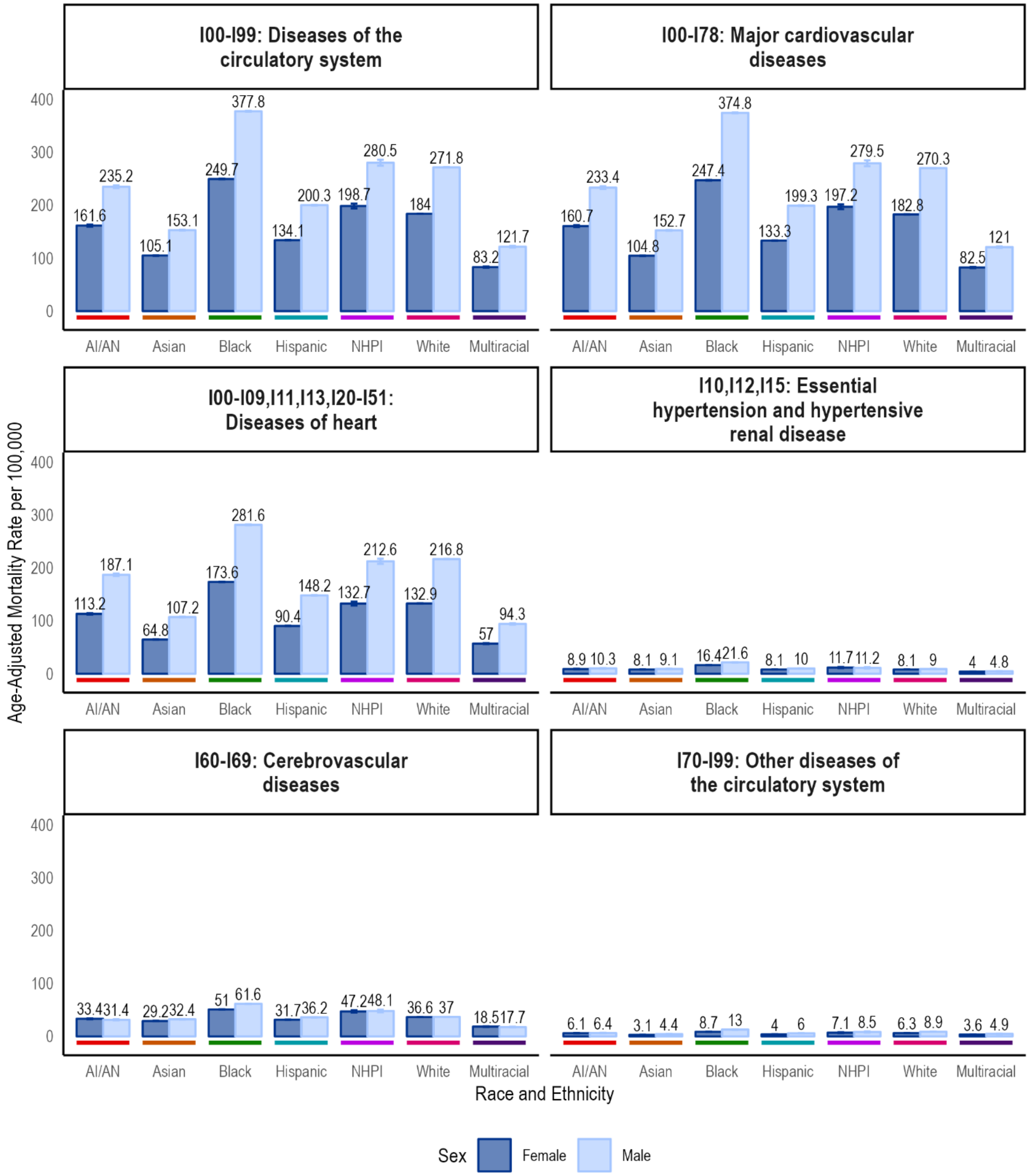

Figure 6-12: Age-adjusted cardiovascular disease subtypes (indexed by ICD-10 codes) mortality rate per 100,000 population, by sex and race and ethnicity

Source: National Health and Nutrition Examination Survey (NHANES), Pooled 2010-2021

Higher CVD mortality rates among Black women may be attributed to the disproportionate impact of social drivers faced by U3 populations, limiting individual ability to address and manage risk factors such as diabetes, obesity, hypertension, and high cholesterol.[47,82] Childhood social factors such as education, income, and healthcare access also contribute to heart health and CVD risk.[79,83] Racism and sexism experiences heavily affect CVD mortality in Black women.[84,85]

6.3.2 Other Intersectional Considerations Relevant to U3 Women

CVD is linked to multiple social and structural determinants of health (see **Chapter 10**) which is reflected in higher CVD prevalence among populations facing these barriers.[86,87] The sections that follow discuss CVD prevalence among women of underrepresented racial and ethnic communities based on the intersections of rurality, economic status, and sexual orientation.

6.3.2.1 Rurality

Women in rural areas face a unique set of structural and social determinants of health that affect CVD prevalence, outcomes, and mortality. **Figure 6-13** shows the mortality rate for CVD subtypes among women by race and ethnicity and rurality. The figure reveals that across almost all racial and ethnic groups, women in rural settings have higher CVD mortality rates compared with women in non-rural settings. Major CVD account for the highest portion of mortality, with the highest rates among Black women in rural settings. Black women in non-rural areas also have the highest mortality rates when compared with other populations of women in non-rural areas. Across rurality, White women have the second highest mortality rates, followed by AI/AN women. Mortality rates for Hispanic women are similar in settings that are rural and not rural. Asian and Pacific Islander (API) and Hispanic women in rural areas have slightly lower mortality rates from essential hypertension and hypertensive renal disease compared with API and Hispanic women living in areas that are not rural. Notably, there are no data on Asian or Multiracial women across rurality indicating a substantial gap in data. In the available data, Hispanic women have the lowest rates of mortality for CVD and the smallest difference in mortality across rurality.

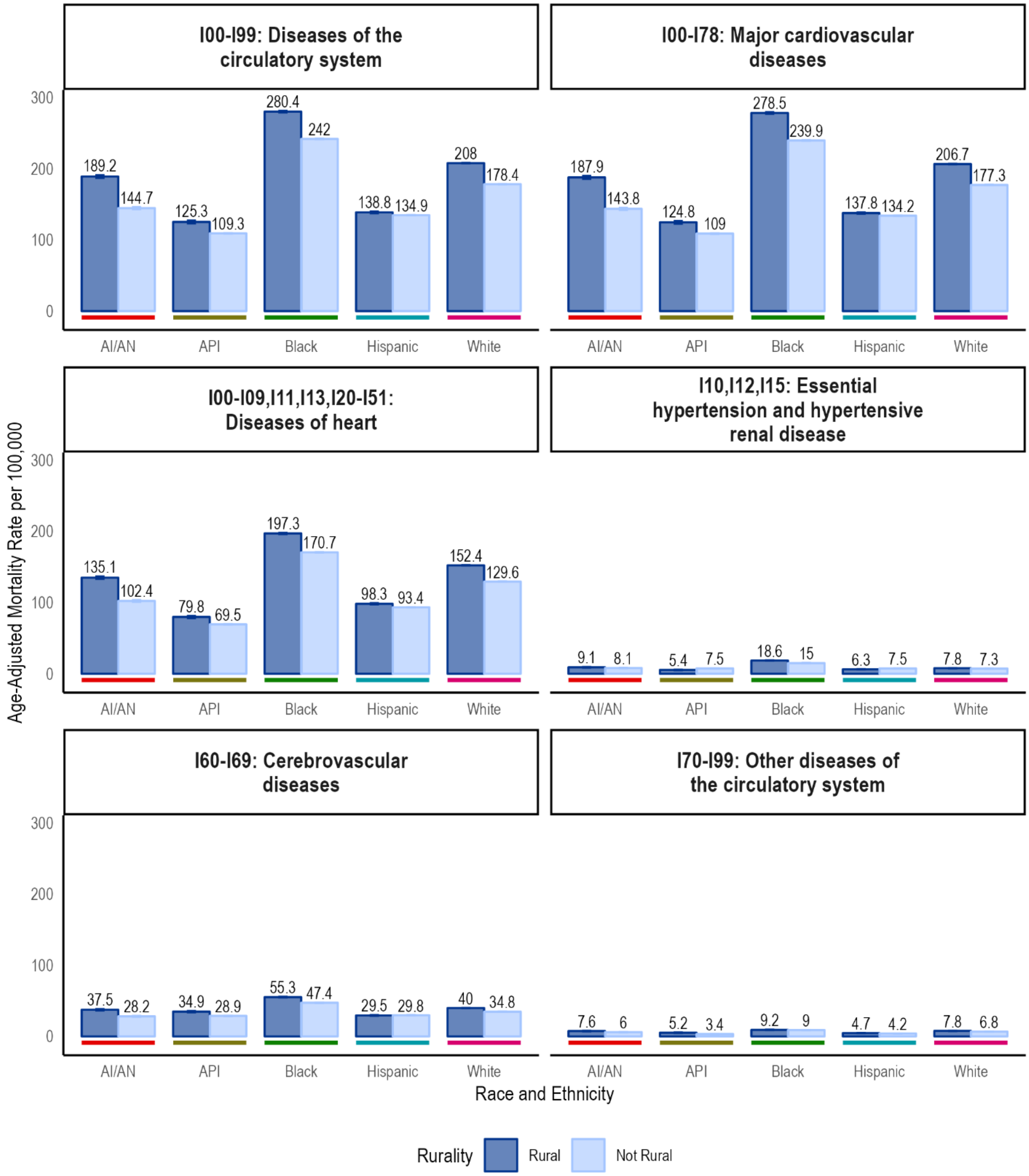

Figure 6-13: Age-adjusted cardiovascular disease subtypes (indexed by ICD-10 codes) mortality rate per 100,000 women, by race and ethnicity, and rurality

Source: National Vital Statistics System (NVSS), Pooled 2010-2021

Differences in CVD prevalence and mortality across rurality may be attributable to the disproportionate comorbidities including obesity, diabetes, and hypertension, that affect women living in rural settings which contribute to the disparities in the development and severity of CVD.[88] Evidence suggests that these disparities contribute to increased CVD incidence among women in rural settings who belong to underrepresented racial and ethnic populations.[89,90] Additionally, social determinants that affect the health of women in rural areas such as access to health screenings and specialty care, insurance coverage, SES, public health infrastructure, and higher rates of health risk behaviors contribute to differences in CVD risk factors, incidence and mortality (see **Chapter 1**).[91] Women residing in rural areas may encounter difficulties in obtaining a CVD diagnosis and treatment due to limited access and other challenges in accessing specialist consultations.[92]

Figure 6-14 displays the percent of women who report a coronary heart disease diagnosis by race, ethnicity, and rurality. The figure shows a higher prevalence of CHD among rural residents compared to non-rural residents, noting that the large standard errors for the prevalence estimates among rural residents limits the interpretation of the differences. For example, the prevalence of CHD among AI/AN women in rural areas has a relatively large standard error interval (consistent with a smaller sample size) that overlaps with the standard error interval of AI/AN women in non-rural areas. As a result, it is difficult to draw conclusions as to whether this is a meaningful difference. Black women exhibit an overall higher prevalence of CHD and a stark disparity based on rurality, with Black women in rural areas having 70% higher prevalence of CHD compared with Black women in non-rural areas. Asian women appear to have the overall lowest prevalence of CHD, regardless of rurality.

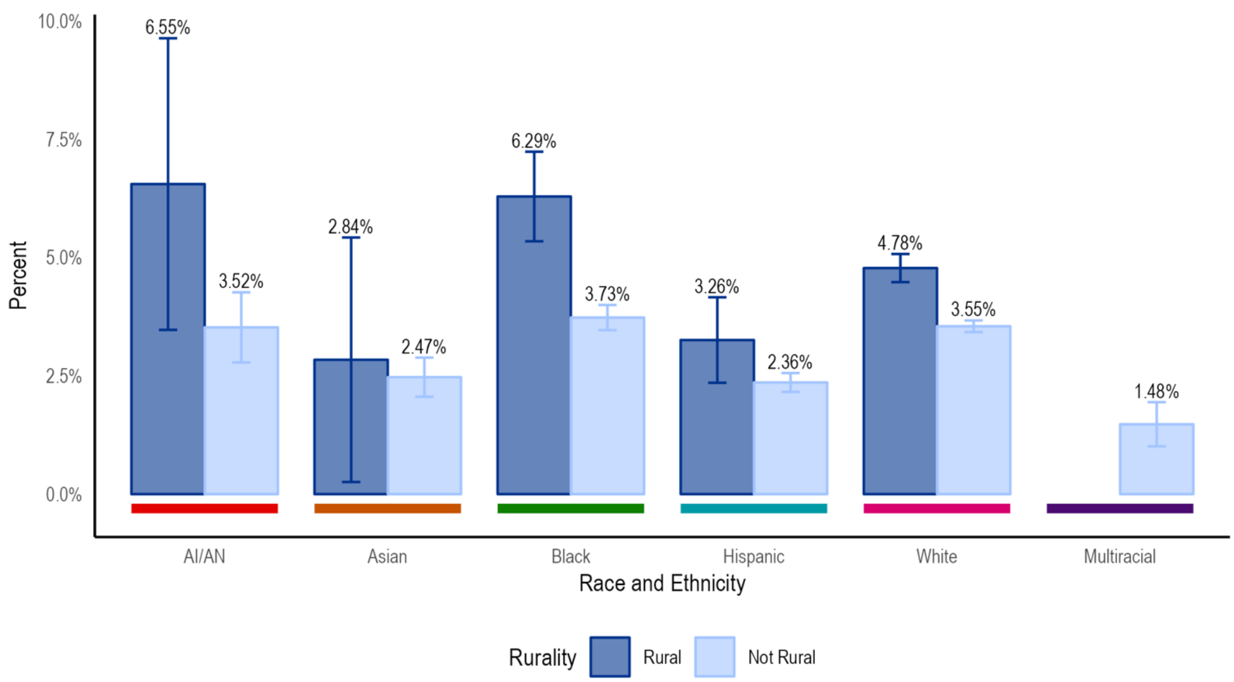

Figure 6-14: Percent of women who report a coronary heart disease diagnosis, by race and ethnicity, and rurality

Source: National Health Interview Survey (NHIS), Pooled 2019-2022

Similar data challenges arise when examining angina prevalence across rurality. **Figure 6-15** shows the percent of women who report an angina diagnosis by race and ethnicity and rurality. The data challenge is shown through a lack of data for Asian and Multiracial women in rural areas as well as large standard errors for rural AI/AN, Black, and Hispanic populations. Although the prevalence estimates are relatively low across all groups displayed, Black women appear to have similar angina prevalence across rurality while Hispanic women have the highest disparity across rurality. Hispanic women in rural areas have a higher prevalence of angina compared with Hispanic women in non-rural areas. White women also have a significant difference in angina diagnosis across rurality as White women in rural settings have a higher prevalence of angina than White women in non-rural settings.

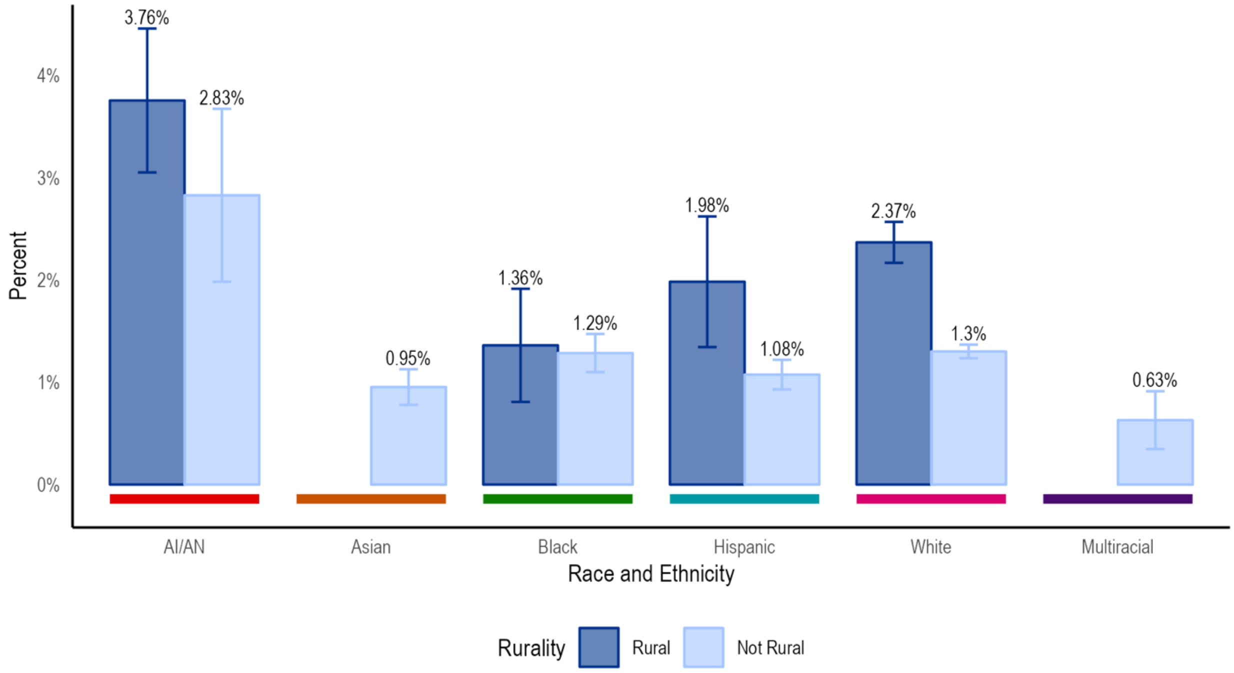

Figure 6-15: Percent of women who report an angina diagnosis, by race and ethnicity, and rurality
Source: National Health Interview Survey (NHIS), Pooled 2019-2022

Figure 6-16 shows the percent of women who report a heart attack diagnosis by race and ethnicity and rurality. As the figure shows, there is no clear pattern across rurality for percent of women who have experienced a heart attack. Large standard errors particularly among rural AI/AN and Asian populations continue to limit the interpretation of any observed differences between rural and non-rural groups. A higher percentage of rural AI/AN women experienced a heart attack when compared with all other women. White women who live in rural areas have 60% more heart attack diagnoses compared with White women who do not live in rural areas. In addition, it is important to note that modes of transportation are important for time-critical events such as heart attacks. Emergency medical service response times are longer in rural areas compared with urban areas and distance to medical facilities is greater.[93]

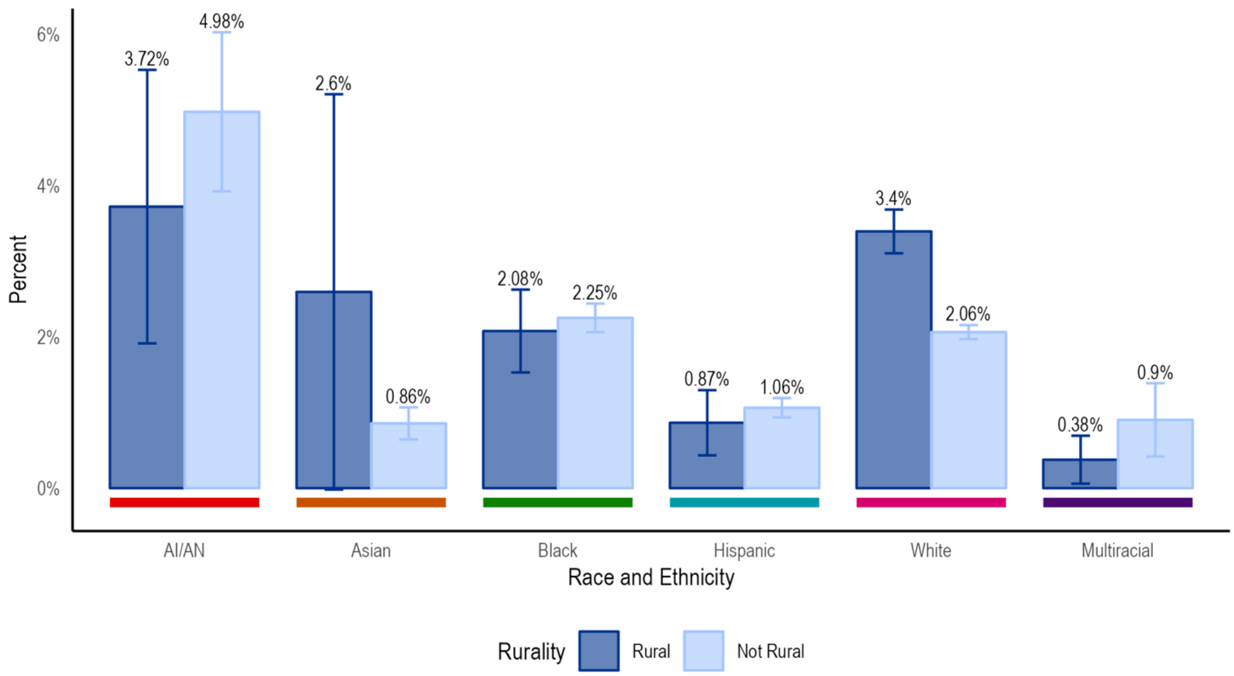

Figure 6-16: Percent of women who report a heart attack diagnosis, by race and ethnicity, and rurality
Source: National Health Interview Survey (NHIS), Pooled 2019-2022

Figure 6-17 displays the percent of women who report a stroke diagnosis, by race and ethnicity and rurality. As observed previously, there is a lack of data that represent Multiracial women in rural areas. Additionally, there are large standard errors for the AI/AN and Black populations particularly among rural residents. Black women in rural settings have the highest prevalence of stroke and have the most striking difference across rurality. Prior research indicates that Black and Hispanic individuals living in rural settings are less likely to have health care coverage and have less access to quality preventative care in comparison to White individuals living in rural settings, which may be one plausible explanation for the disparities conveyed in the data.[94]

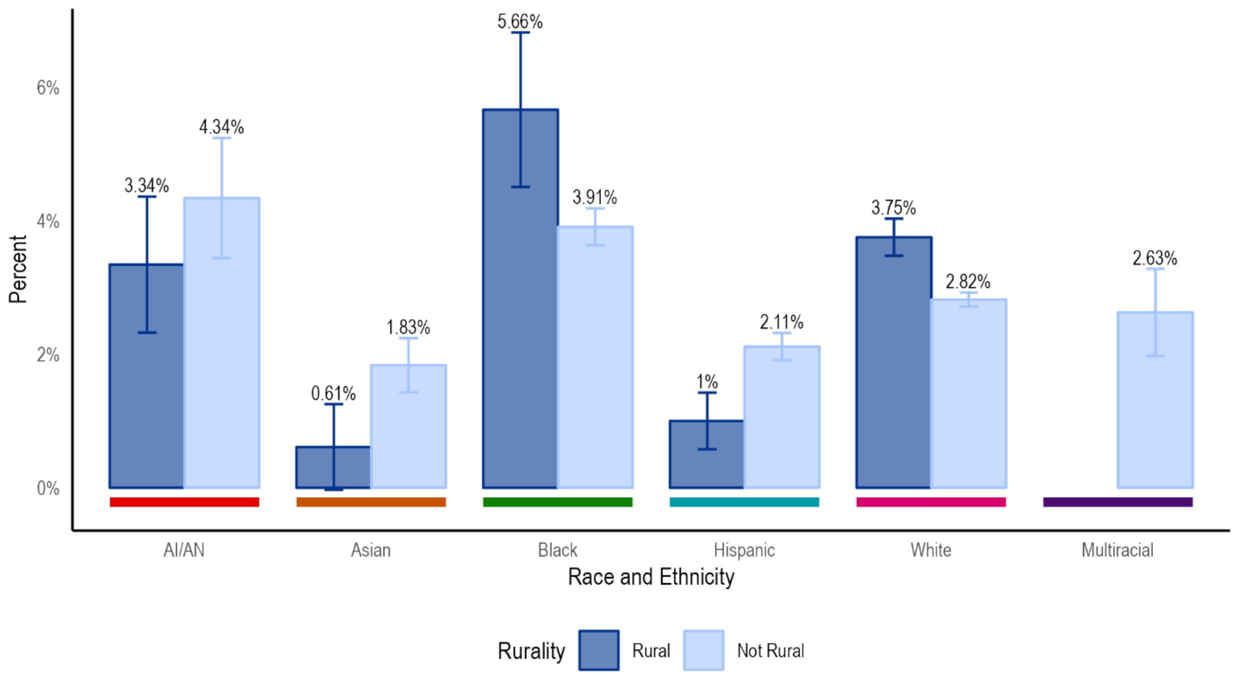

Figure 6-17: Percent of women who report a stroke diagnosis, by race and ethnicity, and rurality
Source: National Health Interview Survey (NHIS), Pooled 2019-2022

6.3.2.2 Economic Status

There are pronounced disparities in CHD among U3 women when data are stratified by economic status. **Figure 6-18** shows the percent of women who report a coronary heart disease diagnosis, by race and ethnicity and economic status. The figure reveals that the economically disadvantaged women have a higher prevalence of CHD diagnosis that across all racial and ethnic groups. AI/AN women who are economically disadvantaged appear to have the highest prevalence of CHD compared with other populations of women who are economically disadvantaged. Meaningful interpretation of the difference in magnitude of CHD among AI/AN women is difficult to assess due to the sizable standard errors for this population. White women who are economically disadvantaged also have a highest prevalence of CHD with a prevalence more than two times that of their economically advantaged counterparts. Similarly, Asian and Hispanic women who are economically disadvantaged have more than two times the prevalence of CHD compared with Asian and Hispanic women who are economically advantaged. Additionally, there is a large disparity among Black women across economic status as Black women who are economically disadvantaged have a CHD prevalence approximately nearly twice that of Black women who are economically advantaged. The lowest prevalence of CHD is among Multiracial women; however, estimates are difficult to interpret due to small sample sizes that affect the standard errors.

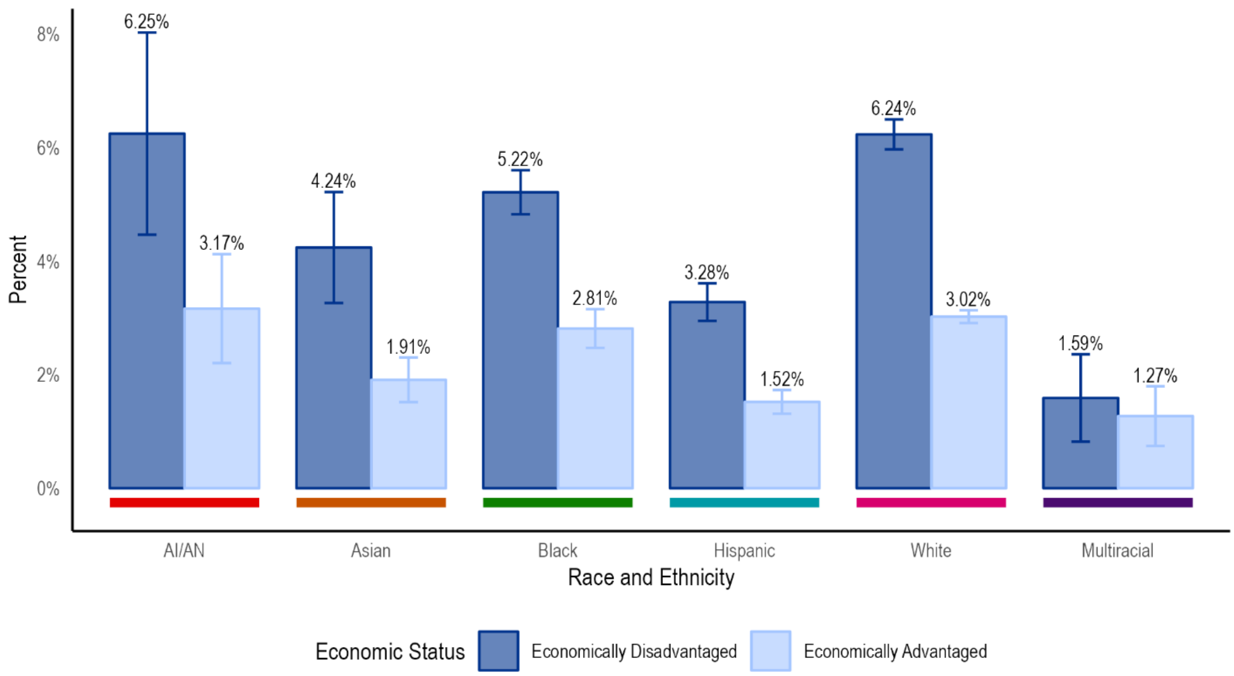

Figure 6-18: Percent of women who report a coronary heart disease diagnosis, by race and ethnicity, and economic status

Source: National Health Interview Survey (NHIS), Pooled 2019-2022

Figure 6-19 illustrates the percent of women who report an angina diagnosis, by race and ethnicity and economic status. Similar to CHD, women who are economically disadvantaged have a higher prevalence of angina when compared with women who are economically advantaged across all racial and ethnic groups apart from Multiracial women. AI/AN women who are economically disadvantaged have the highest prevalence of angina and White women who are economically disadvantaged have the second highest prevalence of angina. The clearest difference by economic status is among the Asian population; the prevalence among women who are economically disadvantaged is approximately four times that of women who are economically advantaged. As seen previously, there are large standard errors of these estimates among the AI/AN population which is a recurring theme across CVD data.

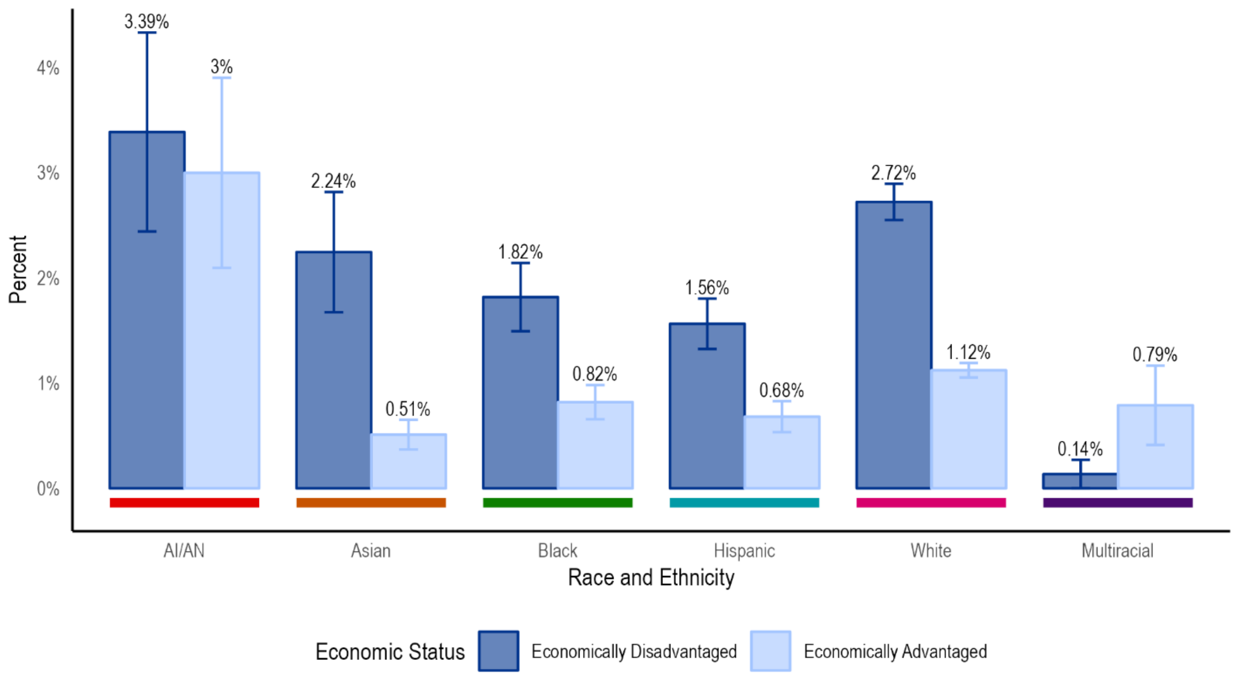

Figure 6-19: Percent of women who report an angina diagnosis, by race and ethnicity, and economic status

Source: National Health Interview Survey (NHIS), Pooled 2019-2022

Figure 6-20 shows the percent of women who report a heart attack diagnosis, by race and ethnicity and economic status. Heart attack prevalence across economic status where women who are economically disadvantaged continue to have a higher prevalence of disease when compared with women who are economically advantaged for all populations of women except for Multiracial women. AI/AN women who are economically disadvantaged have a strikingly high prevalence of heart attacks when compared with other populations. This prevalence is almost 40% higher than the next highest prevalence of heart attack among White women who are economically disadvantaged. However, the standard errors among the AI/AN population data are notably large. Black women who are economically disadvantaged have the third highest heart attack prevalence while Asian and Hispanic populations have similar estimates of disease diagnosis.

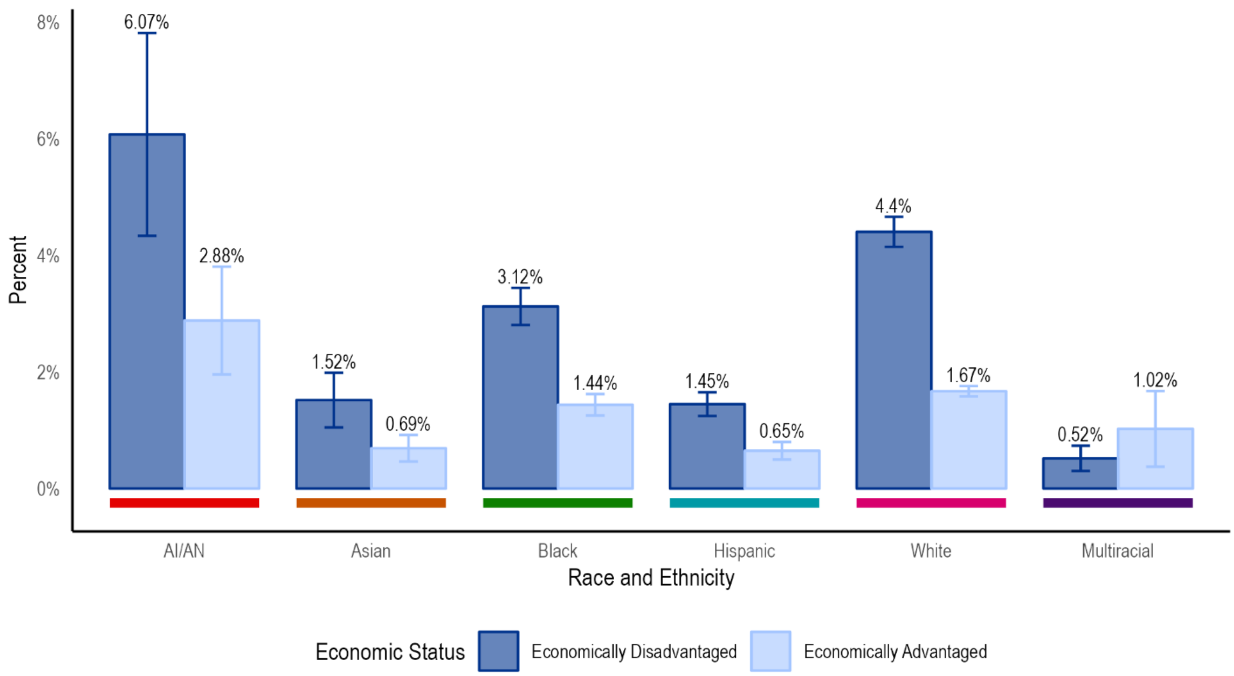

Figure 6-20: Percent of women who report a heart attack diagnosis, by race and ethnicity, and economic status

Source: National Health Interview Survey (NHIS), Pooled 2019-2022

Stroke prevalence is consistently higher among women who are economically disadvantaged compared to women who are economically advantaged across race and ethnicity. **Figure 6-21** shows the percent of women who report a stroke diagnosis, by race and ethnicity and economic status. Black women who are economically disadvantaged have the highest estimate of stroke and have a prevalence of 2.5 times that of Black women who are economically advantaged. White women have a similarly striking disparity while the Hispanic population has the lowest prevalence of stroke overall. The sample size for Multiracial women remains limited with overlapping standard error intervals across economic status, driven largely by estimate for the economically disadvantaged group.

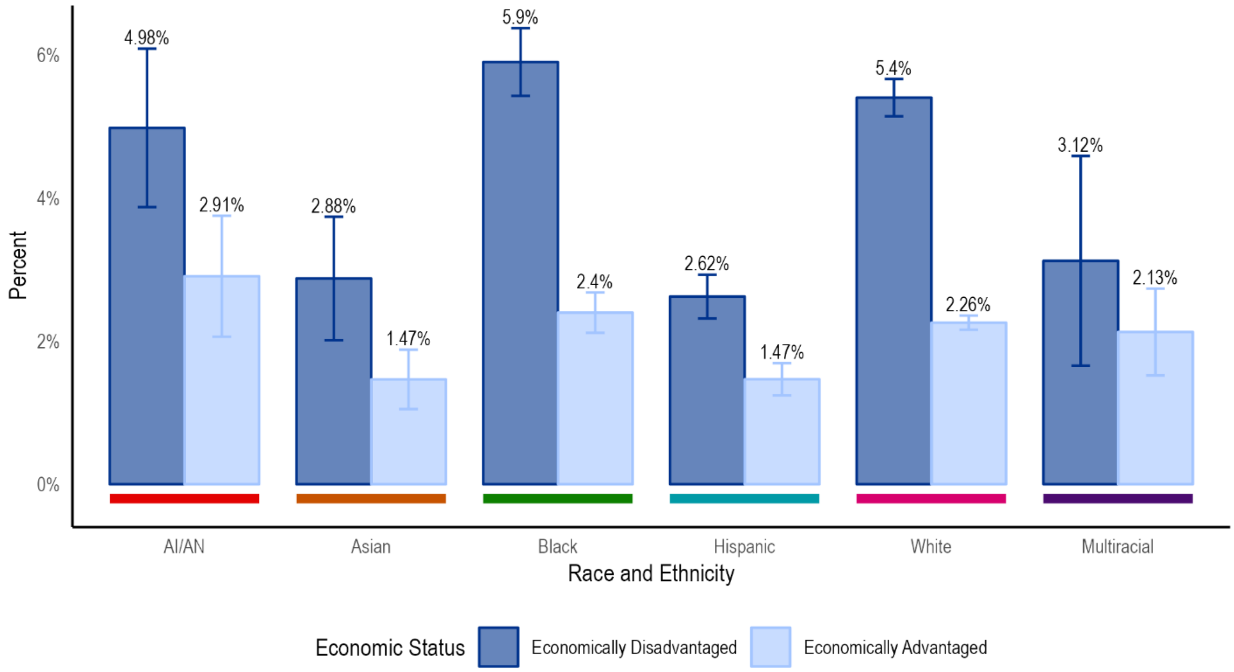

Figure 6-21: Percent of women who report a stroke diagnosis, by race and ethnicity, and economic status

Source: National Health Interview Survey (NHIS), Pooled 2019-2022

Figure 6-22 illustrates the percent of women who report a congestive heart failure diagnosis, by race and ethnicity and economic status. The figure shows that there is a higher congestive heart failure prevalence among women who are economically disadvantaged compared with women who are economically advantaged. Notably, there are no data estimates among the AI/AN population, which highlights an important data gap. Additionally, there is substantial error among Multiracial women who are economically disadvantaged. This prevalence data shows that White women who are economically disadvantaged have the highest estimate of congestive heart failure among all groups and are diagnosed nearly 2.5 times more than White women who are economically advantaged. Black women have the second highest prevalence of disease, while Multiracial women who are economically advantaged have the lowest prevalence of disease.

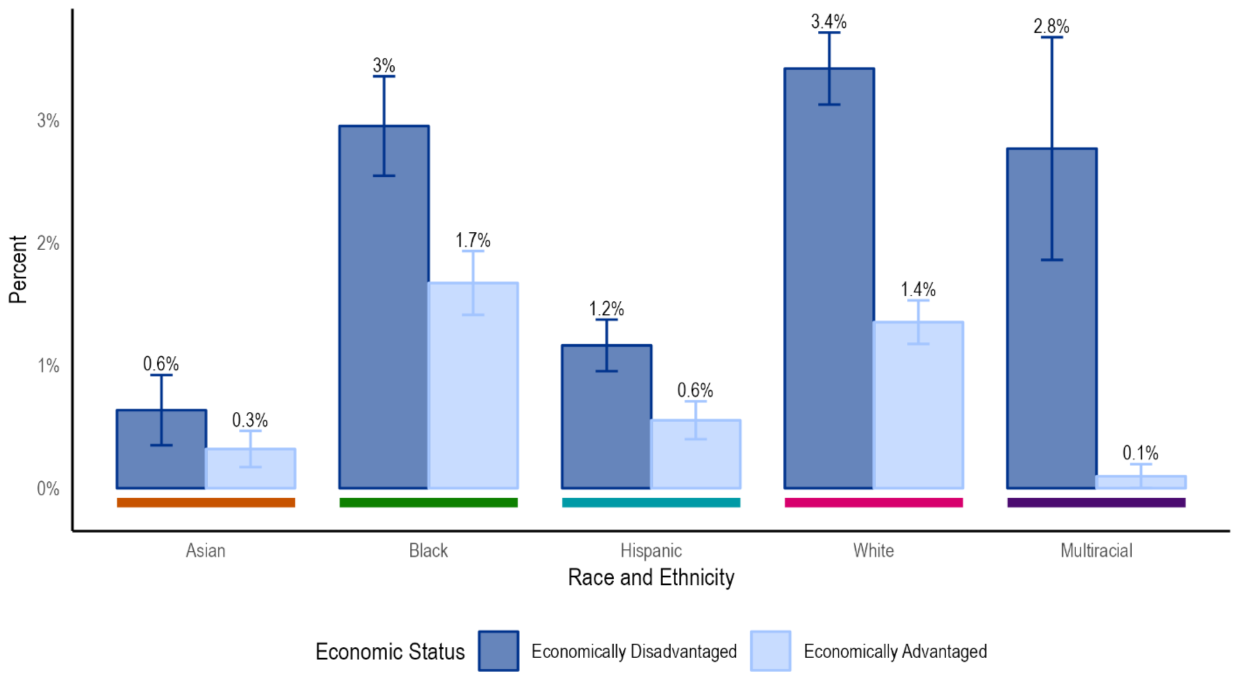

Figure 6-22: Percent of women who report a congestive heart failure diagnosis, by race and ethnicity, and economic status

Source: National Health and Nutrition Examination Survey (NHANES), Pooled 2009-2020

Disparities in CVD prevalence data are reflective of literature showing that economic disadvantage increases CVD risk in women.[95] Food insecurity worsens the risk, for example, with one study showing a six times greater CVD prevalence in food-insecure households.[96,97] Exposure to particulate matter, noted by the EPA, correlates with heart attacks and CVD-related mortality.[98] There is a growing body of literature that suggests psychosocial factors like depression, anxiety, and increased caregiving responsibilities worsen CVD outcomes, disproportionately affecting economically disadvantaged women (see **Chapter 1**).[99–102]

6.3.2.3 Sexual Orientation

The data do not conclusively demonstrate whether sexual orientation influences the risk of CHD among women across racial and ethnic groups. **Figure 6-23** illustrates the percent of women who report a CHD diagnosis by race and ethnicity, and sexual orientation (lesbian, bisexual, queer and questioning (LBQ) or heterosexual). Except for White women, heterosexual women across all racial and ethnic groups appear have a higher CHD prevalence. However, the standard error intervals overlap which is likely a result of smaller sample sizes. White women were 40% more likely to refuse to answer and/or not provide a response to this question compared with any other group. Notably, no refusals or skipped responses were observed among Multiracial women, although this observation may be influenced by the small sample size. The highest observed prevalence of CHD is among heterosexual AI/AN women, followed by heterosexual Black women. However, there is notable variability of the estimates within these populations as evidenced through the standard errors. Among all the intersections presented, LBQ Multiracial women have the lowest observed CHD prevalence.

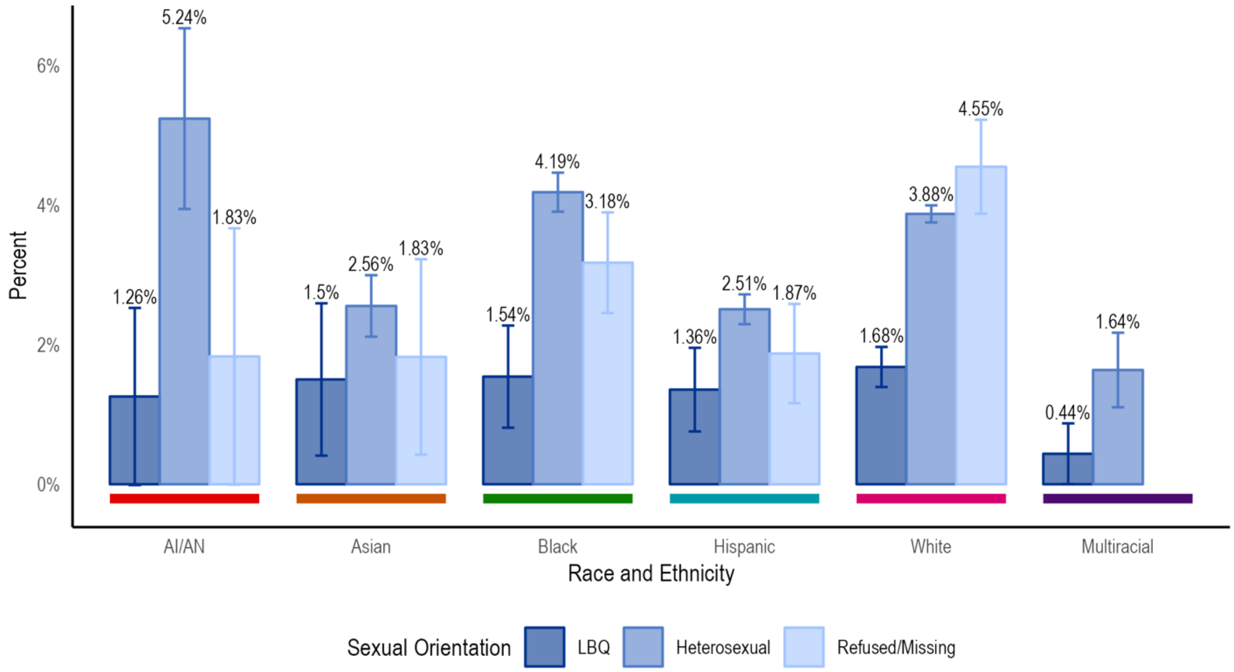

Figure 6-23: Percent of women who report a coronary heart disease diagnosis, by race and ethnicity, and sexual orientation

Source: National Health Interview Survey (NHIS), Pooled 2019-2022

Figure 6-24 illustrates the percent of women who report an angina diagnosis, by race and ethnicity and sexual orientation. The figure indicates no consistent pattern of percentage of women reporting angina by sexual orientation. However, there is a notable difference within the AI/AN population, with LBQ AI/AN women more than five times as likely to be diagnosed with angina than the next highest LBQ population and more than five times more likely than heterosexual AI/AN women. These estimates have relatively large standard errors that limit the interpretability of the results. The next highest population of angina prevalence is among LBQ Asian women, with similarly large standard errors of the estimates. Notably, there are no Multiracial women who identified as LBQ or refused to answer or skipped this question, which indicates a need for improved data collection. Heterosexual Black and White women had a higher prevalence of angina compared with LBQ Black and White women.

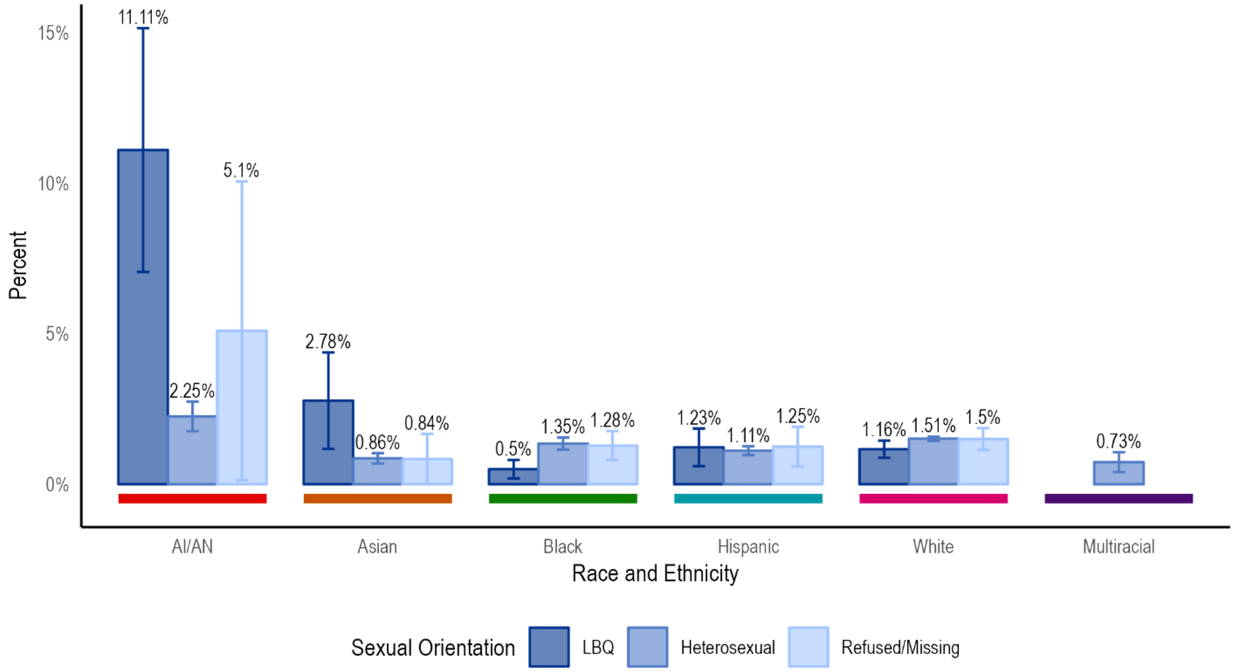

Figure 6-24: Percent of women who report an angina diagnosis, by race and ethnicity, and sexual orientation

Source: National Health Interview Survey (NHIS), Pooled 2019-2022

Similarly, data do not demonstrate whether sexual orientation increases the risk of heart attack across racial and ethnic groups. **Figure 6-25** illustrates the percent of women who report a heart attack diagnosis, by race, ethnicity, and sexual orientation. It appears that heterosexual AI/AN women have the highest prevalence of heart attack followed by LBQ AI/AN women, though the standard error intervals overlap due to small sample sizes. AI/AN respondents refused to answer or skipped this question more than other populations of women. LBQ Multiracial women also have a strikingly high prevalence of heart attack compared with heterosexual Multiracial women; however, these estimates have overlapping standard error intervals as well. The lowest prevalence of heart attack is among LBQ Asian women and heterosexual Multiracial women.

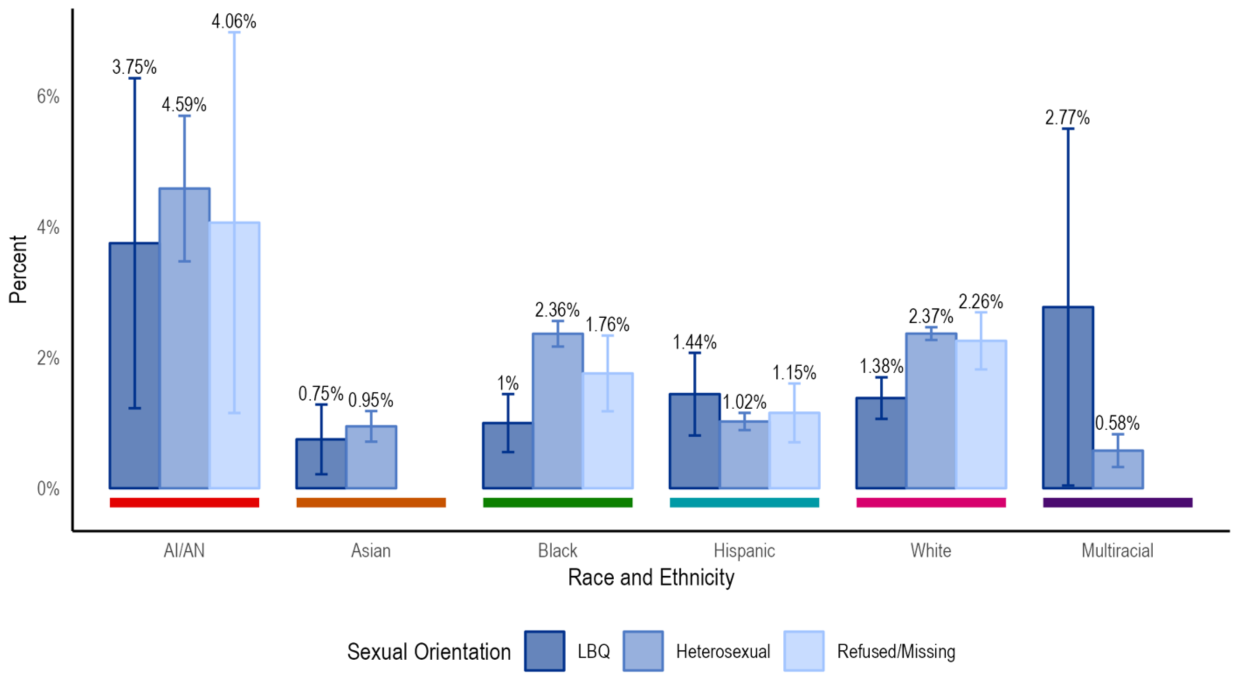

Figure 6-25: Percent of women who report a heart attack diagnosis, by race and ethnicity, and sexual orientation

Source: National Health Interview Survey (NHIS), Pooled 2019-2022

A growing body of research has explored the range of unique challenges and risk factors of CVD among LBQ individuals. The sexual and gender minority (SGM) population exhibits increased CVD in part due to psychosocial factors related to stress from marginalization and discrimination.[103,104] Additionally, research has found that SGM women exhibit elevated CVD risk due to a variety of factors including increased tobacco, alcohol, and illicit drug use.[105] Differences in estimates of CVD incidence and prevalence across LBQ women highlight the gaps in existing data collection practices and longitudinal studies using CVD indicators.[106]

6.4 Conclusions and Future Directions

The findings in this chapter underscore the stark CVD disparities across race and ethnicity, rurality, economic status, and sexual orientation. Significant data gaps exist regarding CVD prevalence among the Multiracial population and LBQ individuals. A critical observation from the CVD prevalence data is the disproportionate effect of CVD on the AI/AN and Black populations of women. Additionally, Black women experience higher rates of CVD mortality compared with other U3 groups while AI/AN women experience a higher prevalence across numerous CVD-related diseases. Efforts to further investigate links between race and ethnicity and specific CVD diseases such as angina and congestive heart failure with other social determinants of health and driving factors unique to women will improve data collection and analysis supporting clinical practice.

6.5 Data Definitions and Sources

Data for all figures in this chapter can be accessed from the data annex located here:
https://orwh.od.nih.gov/sites/orwh/files/docs/Chapter_6.xlsx

National Health Interview Survey (NHIS), 2019-2022

Variable Name	Variable Description	Variable Options
ANGEV_A	Have you EVER been told by a doctor or other health professional that you had...Angina, also called angina pectoris?	**Yes**; No; Refused; Not Ascertained; Don't Know
CHDEV_A	Have you EVER been told by a doctor or other health professional that you had...Coronary heart disease?	**Yes**; No; Refused; Not Ascertained; Don't Know
MIEV_A	Have you EVER been told by a doctor or other health professional that you had...A heart attack, also called myocardial infarction?	**Yes**; No; Refused; Not Ascertained; Don't Know
STREV_A	Have you EVER been told by a doctor or other health professional that you had...A stroke?	**Yes**; No; Refused; Not Ascertained; Don't Know

National Health and Nutrition Examination Survey (NHANES), 2009-2010, 2011-2012, 2013-2014, 2015-2016, 2017-2020 pre-pandemic

Variable Name	Variable Description	Variable Options
BMXBMI	Body Mass Index (kg/m^2)	Range of Values: 11.9 to 92.3

National Vital Statistics System (NVSS) − Underlying Cause of Death, 2010-2021

Variable Name	Variable Description
ICD-10 113 Cause List	I00-I78; Major cardiovascular diseases
ICD-10 113 Cause List	I00-I09,I11,I13,I20-I51; Diseases of heart
ICD-10 113 Cause List	I10,I12,I15; Essential hypertension and hypertensive renal disease
ICD-10 113 Cause List	I60-I69; Cerebrovascular diseases
ICD-10 113 Cause List	I70; Atherosclerosis
ICD-10 113 Cause List	I71-I78; Other diseases of circulatory system

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Chapter 7

Dementia

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Dementia

7.1 Defining Dementia

Dementia is "the loss of cognitive functioning—thinking, remembering, and reasoning—to such an extent that it interferes with a person's daily life and activities" that occurs mainly in people older than 65 years of age.[1] Of the four most common types of dementia (Alzheimer's disease or AD, frontotemporal dementia, Lewy body dementia, and vascular dementia), approximately 60-80% is attributable to AD.[2] Substantial morbidity directly results from the cognitive decline caused by Alzheimer's disease and related dementias (ADRD). Additionally, complications associated with malnutrition, dehydration, or infection ultimately result in death.[3,4]

While healthy cognitive aging does involve some slowing of information processing, processing speed, and behavior, ADRD are not a normal part of aging and are not inevitable. There is no single universally accepted test, instrument, or exam that determines whether someone has dementia. Diagnosis of dementia (including AD) typically involves a battery of cognitive tests and instruments, often including physical and neurological exams, brain imaging, and laboratory tests. In some research study settings (e.g., Chicago Health and Aging Project, Framingham Heart Study, and Health and Retirement Study) all participants will undergo longitudinal assessment for cognitive function.[5–7] However, outside of these research studies, dementia is considered underdiagnosed in the general population and underdiagnosis is of particular concern among the Black and Hispanic population.[8–10]

Up to 40% of dementia cases can be prevented or delayed through lifestyle interventions such as smoking cessation and management of hearing loss; control of other medical conditions such as diabetes, depression, and obesity, which are associated with increased risk; as well as early intervention with medication.[11,12]

7.2 Dementia in Women

As of 2024, there are an estimated 6.9 million people aged 65 and older living with AD in the U.S., which corresponds to approximately one in nine individuals.[13] The strongest risk factor for AD is age—the prevalence of AD ranges from approximately 5% in individuals aged 65-74 years to approximately 13% in individuals aged 85 years and older.[14] Given the rapidly aging U.S. population, ADRD are projected to increasingly burden the U.S. healthcare and public health systems. For example, it is expected that the number of individuals diagnosed with AD will double by the year 2050 (compared to 2024).[15]

Nearly two-thirds of individuals in the U.S. with AD are women and according to the Alzheimer's Association, approximately one in five women are at risk for AD, compared to one in ten men.[14] Additionally, AD is the fifth leading cause of death for women in the U.S. (see Chapter 4). While there are a number of plausible reasons for the difference in the burden of AD between men and women, the largest factor appears to be age. On average, women live longer than men and that results in more women living into ages where AD risk is highest. Whether there are unique risk factors for dementia among women beyond advanced age is an area of extensive research.[13] Hypotheses include gender differences in risk factors such as educational attainment and occupation, as well as differences in health behaviors and rates of pre-existing cardiovascular disease.[14] Biologic differences, such as interactions of estrogen with *APOE4*, the strongest genetic risk factor for AD, play a role in the development of dementia.[16] Also, biological factors may create more severe symptomology (behavioral disinhibition) among women compared with men.[17,18] Studies show that social and structural factors may also influence dementia risk for women. More women than men live in poverty, experience wage gaps, and contend with limited availability of caregiving supports and work-family policies; these chronic stressors can increase the susceptibility of the aging brain to cognitive decline and other neuropathologic insults.[19,20] Educational attainment is a protective factor for cognitive decline, and in older cohorts women have lower overall years of education compared with men.[21–23]

The National Health Interview Survey (NHIS), conducted by the U.S. Census Bureau, monitors trends in a range of illnesses, medical care use, health insurance coverage, and disability, including estimates of dementia diagnosis. It is important to note that estimates of dementia from this study rely on self-report by a person living with dementia or a "knowledgeable proxy"[i]. As a result, the prevalence estimates assume (1) that a study participant has been diagnosed with dementia, and (2) has been informed of their dementia diagnosis, and (3) that the dementia diagnoses is reported accurately by the participant or a knowledgeable proxy. The resulting estimates from NHIS will therefore be an underestimate of the true clinical prevalence (see **Spotlight: NHIS Dementia Data**). Nevertheless, **Figure 7-1** shows the estimated proportion of people aged 65 and older who have been diagnosed with dementia from NHIS. Consistent with previously published studies, the proportion who report ever being diagnosed with any form of dementia is higher among women over the age of 65 compared to men. However, the difference between women and men in NHIS is smaller than observed in previously published reports.[14]

[i] NHIS interviewing procedures specify that "Information about the sample adult is collected from the sample adult herself or himself unless she or he is physically or mentally unable to do so, in which case a knowledgeable proxy can answer for the sample adult."

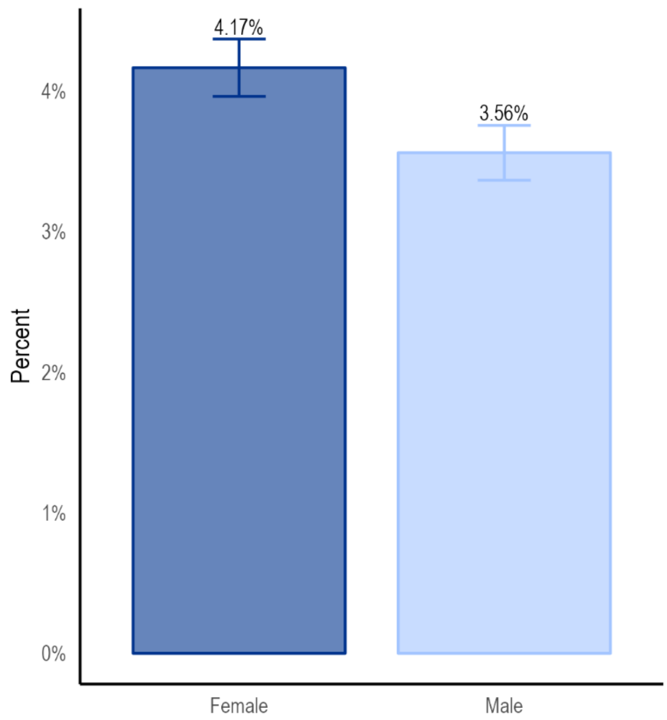

Figure 7-1: Percent of people aged 65 and older who report a dementia diagnosis (including Alzheimer's disease) by sex

Source: National Health Interview Survey (NHIS), Pooled 2019-2022

Women are burdened with higher AD-specific mortality rates compared to men, as shown in **Figure 7-2**. Over the past decade, the age-adjusted mortality rate due to AD was consistently higher for women compared with men. Between 2010 and 2021, the difference between age-adjusted rates for women and men increased from approximately 6 to 11 more deaths per 100,000 population in women than in men. These higher mortality rates may be explained in part by women's higher overall prevalence and age-dependent susceptibility, as well as their longer life expectancy and years lived with dementia.

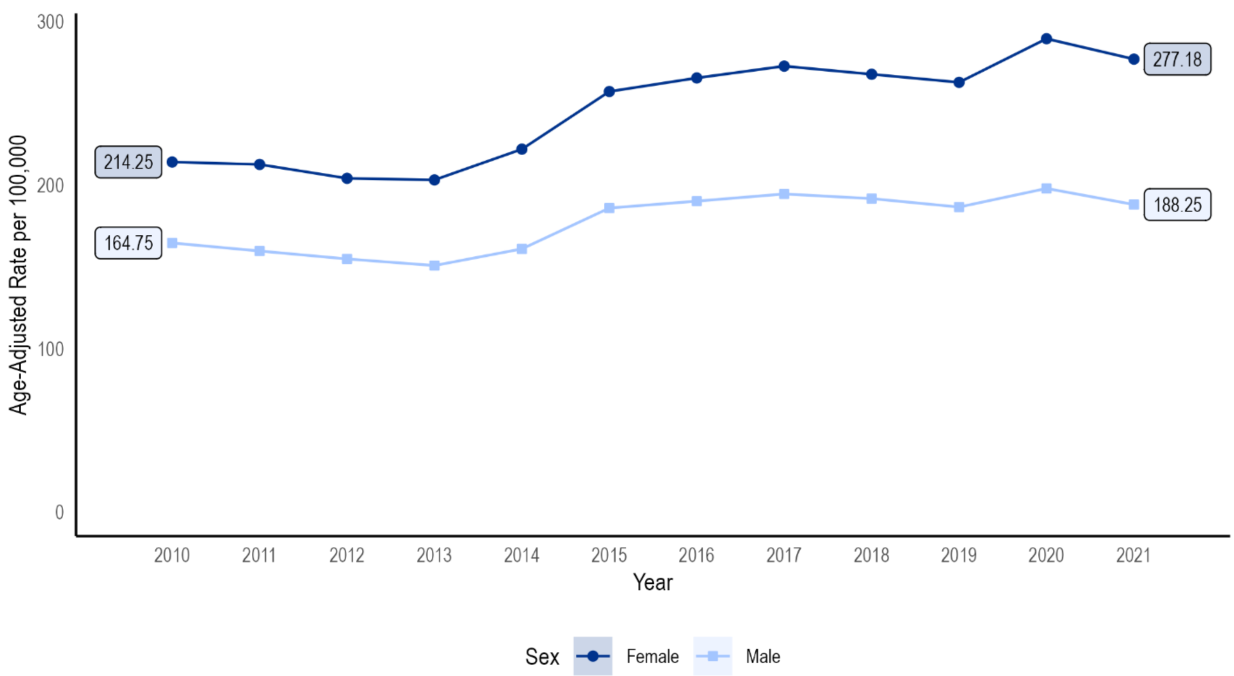

Figure 7-2: Age-adjusted Alzheimer's disease mortality rate per 100,000 population aged 65 and older over time by sex

Source: National Vital Statistics System (NVSS) Underlying Cause of Death, 2010-2021

It is important to note that the standard errors for mortality rates are much narrower than for estimated percentages, as National Vital Statistics System (NVSS) data are collected from vital registration systems and therefore capture a larger population and do not rely on self-report.

7.3 Dementia in Populations of U3 women

Marked disparities in dementia diagnosis, treatment, and outcomes exist for women in understudied, underrepresented, and underreported (U3) populations, and studies show these may be due to discrimination, racialization, and chronic stress, as well as other social and structural drivers (see **Chapter 1**). Women in underserved rural areas, those who are economically disadvantaged, and women in some sexual and gender minority groups appear to have higher prevalence of dementia at earlier ages. It is important to note that for these comparisons, data interpretation is often limited by small sample sizes corresponding to large standard errors (see **Spotlight: NHIS Dementia Data**). Recent studies have adopted a life course perspective that considers disparities attributable to socioeconomic disadvantages, including education level, financial health, employment barriers, higher instances of traumatic life events, and poor access to physical and mental health resources and treatment. In addition, increased rates of chronic medical conditions such as depression, obesity, hypertension, and diabetes significantly impact dementia-free life expectancy across populations of U3 women.[24–27] These ADRD disparities are amplified in some underserved communities by a perception that cognitive impairment is a normal part of aging and/or hesitancies to discuss cognitive impairment with providers.[28] Environmental exposure, such as air and noise pollution, which are more common in high-poverty historically segregated areas and in underrepresented racial and ethnic communities based on neighborhood, can increase the risk for dementia.[29,30] In fact, food insecurity, which is a marker of economic disadvantage, is associated with cognitive decline.[31]

Spotlight: NHIS Dementia Data

First fielded in 1957, the National Health Interview Survey (NHIS) has established credibility as a source of collecting nationally representative data to track progress toward objectives across a range of federal health priorities. NHIS added a dementia measure in 2019. Collecting this data will allow the U.S. Department of Health and Human Services (HHS) to track progress toward national health objectives and to estimate prevalence over time among all populations. However, such data obtained from a single survey item can limit the complexity of the analyses that can be conducted, which may oversimplify important nuances in trends and disparities.

Notably, three of the four years the dementia measure was collected overlapped with the COVID-19 pandemic, which limited people's ability to seek medical care and could have resulted in an undercount of new dementia diagnoses. This is particularly likely among marginalized women who may have had even less access to care than in previous years. The response rate for the 2020 survey was unusually low due to the pandemic. By design, NHIS does not sample populations in long-term care institutions. With over 800,000 Americans currently residing in long-term care facilities and over 40% of these diagnosed with AD, estimates presented here likely underestimate true prevalence for dementia diagnoses.[32,33]

7.3.1 Dementia Among Women of Underrepresented Racial and Ethnic Communities

Figure 7-3 shows that from 2019-2022 for all racial and ethnic groups, women had a higher estimated percentage of dementia diagnoses compared with men. The highest estimated percentages are for Hispanic women, followed by Asian women, Black women, and American Indian and Alaska Native (AI/AN) women. The sex difference for White people is minimal, suggesting no real difference in the prevalence between White women and men from the NHIS (note that other studies show a higher prevalence among White women compared to White men). Among both women and men, the lowest pooled percentages were among Multiracial respondents, though the samples sizes and large standard errors limit definitive conclusions.

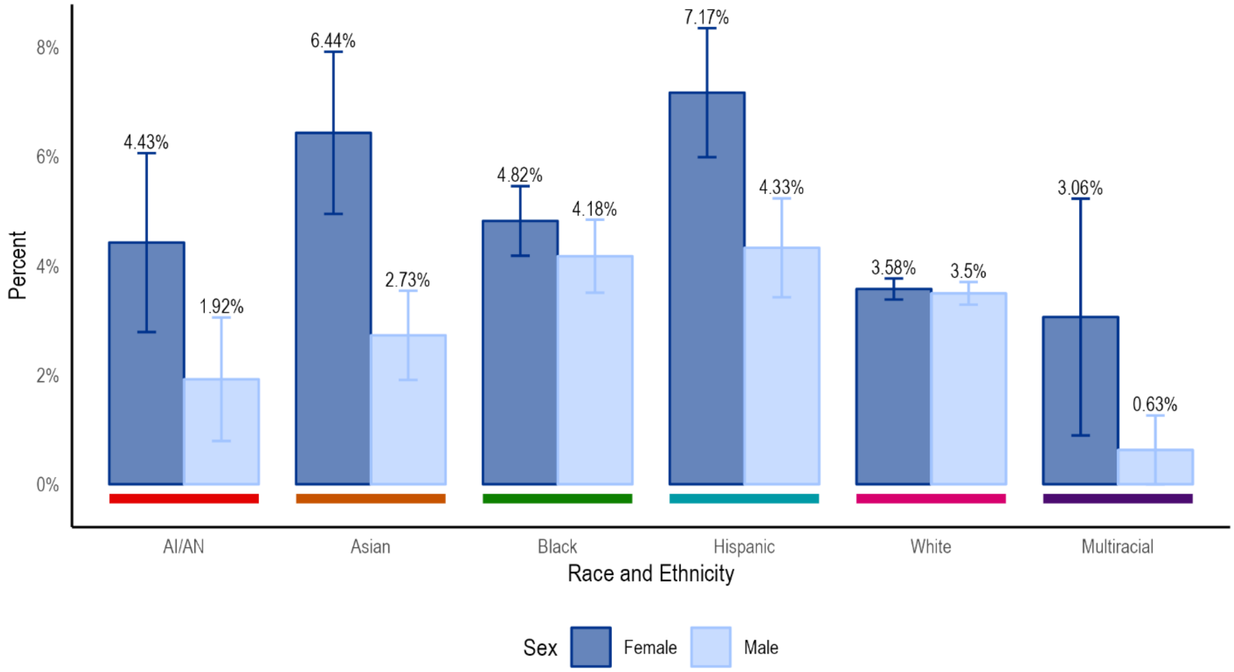

Figure 7-3: Percent of people aged 65 and older who report a dementia diagnosis (including Alzheimer's disease), by sex and race and ethnicity

Source: National Health Interview Survey (NHIS), Pooled 2019-2022

It is notable that the data presented here contradict findings from other research, showing that older Black adults are up to two times more likely to have ADRD compared with older White adults.[34,35] As noted previously, this may reflect differences in sampling strategies for NHIS and research instruments for the data sources. However, these results are also consistent with the underdiagnosis of dementia among Black individuals. Diagnosis of significant cognitive decline in women of underrepresented racial and ethnic communities is often delayed, hampering opportunities for links to early intervention for mild disease.[36] Delayed and missed diagnoses are attributed in part to discrimination U3 women experience in the healthcare system, which leads to distrust, discomfort, and avoidance of healthcare encounters.[37] Black patients have twice the risk of underdiagnosis of ADRD, putting them at risk for delayed access to links for early intervention for mild disease.[36]

Exploring age differences in AD prevalence also offers useful insights. **Figure 7-4** shows the prevalence of dementia among women aged 65 and older by race and ethnicity. For all racial and ethnic groups, the highest estimated prevalence of dementia is among women aged 85 and older, with the highest estimates among Hispanic and Asian women in this age group.

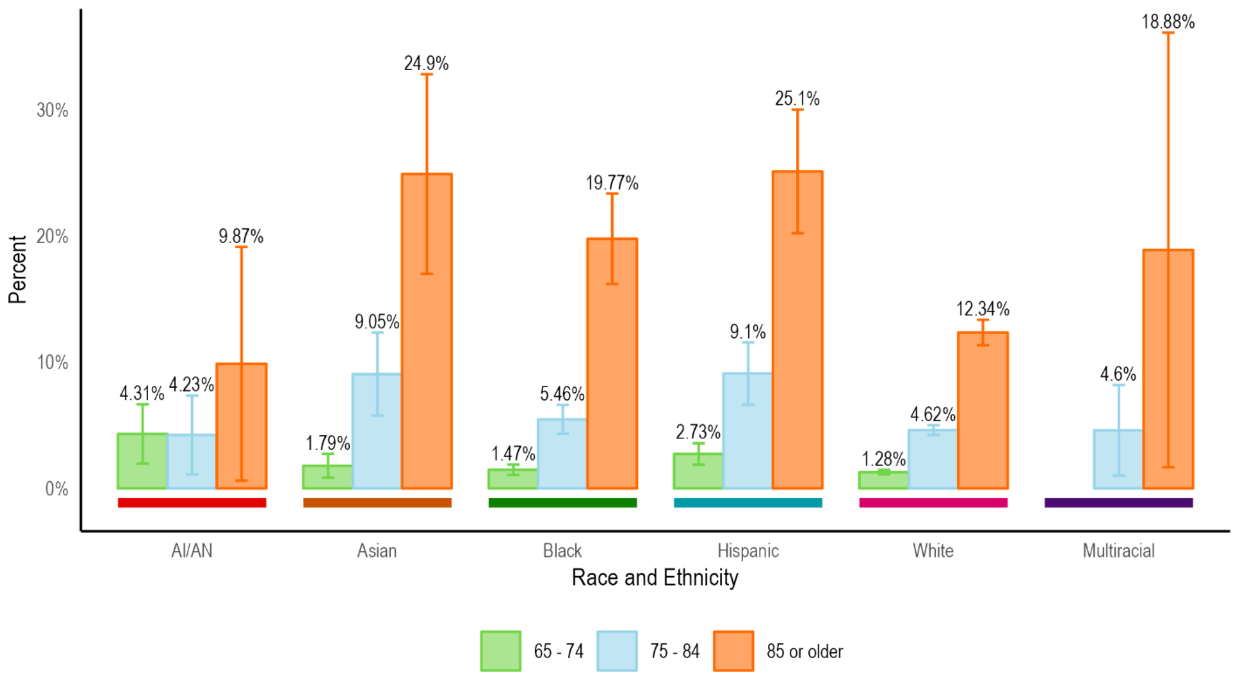

Figure 7-4: Percent of women aged 65 and older who report a dementia diagnosis (including Alzheimer's disease), by race and ethnicity, and age group

Source: National Health Interview Survey (NHIS), Pooled 2019-2022

As a result of environmental and social factors (see **Chapter 1**), Black women have higher rates of obesity, diabetes, and hypertension, which are all associated with the development of dementia.[38] For example, more than two decades of research has explored the ways that gendered racism accelerates cellular aging, especially among Black women, which affects their health and longevity.[39,40] In AI/AN populations for whom diabetes and cardiovascular disease (CVD) are higher than in other communities, an association between these chronic conditions and dementia has also been identified.[41] AI/AN women have the highest proportion of dementia diagnoses before the age of 60, though the proportion is very low (below 1%). These social and cultural differences extend into treatment outcomes and survival differences for patients with AD. There is a lower mortality risk for Black and Hispanic patients when compared to White patients, which has significant implications for the magnitude of financial burdens for persons living with dementia and their families.[42]

A growing body of research has explored how stigma related to dementia diagnoses may differ across racial and ethnic groups. A meta-analysis concluded that Black, Asian, and Hispanic people are more likely than White people to believe that a dementia diagnosis should not be shared beyond the family.[43] Studies have highlighted that stigma is associated with limited knowledge about dementia, lower levels of education and acculturation, and, among some Asian subgroups (i.e., Korean and Chinese), shame related to the diagnosis.[43,44] A more recent study drawing on data from the Asian American Quality of Life Survey found varying degrees of stigmatizing beliefs across Asian subgroups and concluded that limited English proficiency increased the odds of holding stigmatizing beliefs about dementia. Such stigma is associated with a reluctance to utilize available resources, which leads to delays in diagnosis and treatment.[45]

Pooled mortality rates (2018-2021) demonstrate AD-associated mortality was higher among women in every racial and ethnic group compared to their male counterparts (**Figure 7-5**). The highest rate was among White women, followed by Black women, and Hispanic women. The mortality rate for Asian women was nearly two times lower, and for Multiracial women was over 2.5 times lower, than the rate for White women. While AD is ranked as the fifth leading cause of death for women (see **Chapter 4**), this ranking is likely skewed by an overrepresentation of White women, who have longer life expectancy than Black and AI/AN women.[46] For women of most other racial and ethnic groups, other causes of death, such as cancers, CVD, and in recent years, COVID-19, outpace AD and reduce lifespan.

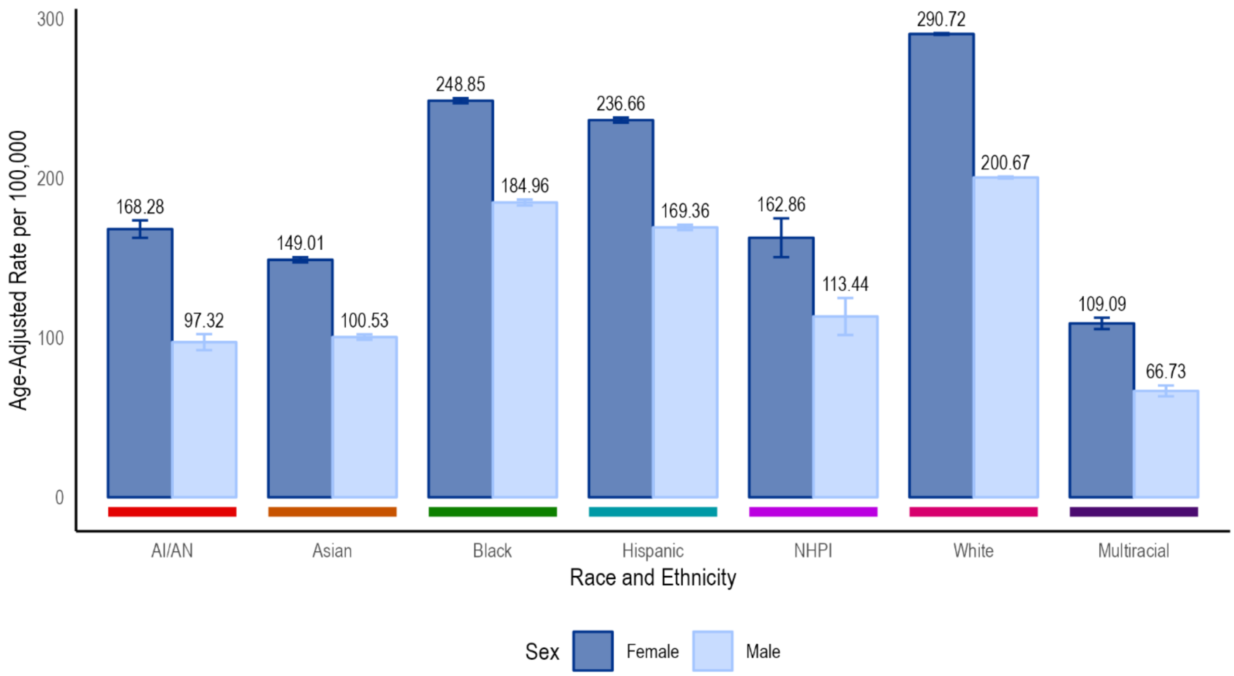

Figure 7-5: Age-adjusted Alzheimer's disease mortality rate per 100,000 population aged 65 and older, by sex and race and ethnicity

Source: National Vital Statistics System (NVSS) Underlying Cause of Death, Pooled 2018-2021

Figure 7-6 demonstrates that AD mortality rates were consistently higher for White women, followed by Black and Hispanic women, and these rates have been increasing over time between 2010 and 2021. In 2018, Multiracial was added as a race category, and the Asian and Pacific Islander (API) group was disaggregated into Asian and Native Hawaiian and Pacific Islander (NHPI) groups. Women in these groups have lower age-adjusted mortality rates relative to White, Black, and Hispanic populations, and Multiracial women appear to have the lowest rates as of 2021.

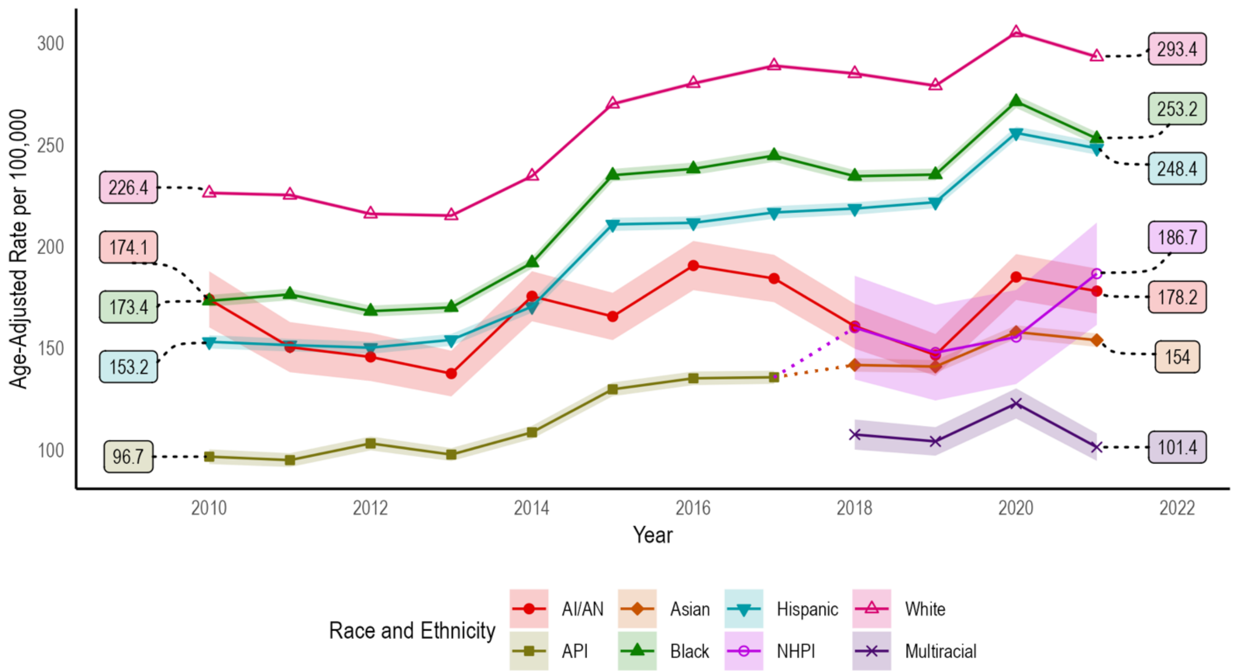

Figure 7-6: Age-adjusted Alzheimer's disease mortality rate per 100,000 women aged 65 and older over time, by race and ethnicity

Source: National Vital Statistics System (NVSS) Underlying Cause of Death, 2010-2021

7.4 Other Intersectional Considerations Relevant to U3 Women

Studies note that an intersectional lens is important for examining rates of dementia in U3 women as these populations often experience intersecting cumulative disadvantage and structural contexts from fewer educational opportunities, lower occupational complexity, lower income, barriers to accessing high-quality healthcare, and limited access to recreational opportunities—factors that can perpetuate inequities in cognitive impairment through unequal distribution of opportunities.[47] More than two decades of research has explored the ways that gendered racism accelerates cellular aging, which affects health and longevity.[39,40,48] The stress of structural and social inequities has been linked to elevated rates of chronic conditions, like diabetes, CVD, hypertension, and obesity, and dementia development for both AI/AN and Black women.[38,41,49,50] The myriad of social exposures that lead to disease/multimorbidity also exert an influence on treatment outcomes for patients with ADRD. The sections that follow explore trends and differences in dementia prevalence among women based on four core intersections: race and ethnicity, rurality, economic status, and sexual orientation.

Eighty percent of Black patients report experiencing barriers, including institutional discrimination, to accessing adequate healthcare for dementia.[38] Treatment of ADRD and dementia often involves in-patient care, which is not normalized or equally accessible for every population. Families of Black and Hispanic patients with dementia may be more likely to provide home care, due to cultural expectations around caretaking responsibilities.[43] While extended care at home may be preferred, evidence suggests that Black and Hispanic patients with dementia enter nursing facilities with higher levels of physical and cognitive impairment than White patients.[43,51]

Dementia care can be further complicated for those with limited English proficiency, or for whom English is not their first language, as many individuals with dementia who lose their language skills may revert to their first language.[52,53] Limited English language proficiency may lead to delayed diagnosis. Access to adequate dementia care may be a challenge due to the perceived high demands of healthcare staff,[52] but this may also lead to misdiagnosis. Disparities may be worsened by a lack of representation of women with dementia in clinical trials and compounded by historic barriers to participation in research based on language, race and ethnicity, or culture.[54,55] This research limitation makes identifying causality between any determinant of health and dementia difficult.[56]

7.4.1 Rurality

Figure 7-7 shows pooled percentages of dementia by race and ethnicity, and rurality. Overall, the highest percentage of reported dementia is seen among Hispanic women in rural areas (12.65%). Rurality appears to be of minimal impact for Black women, Multiracial women, and White women. The lowest estimated percentage is among AI/AN women living outside of rural areas, although sample sizes are quite small (n=4). Similarly, it is notable that small samples and corresponding large standard errors limit definitive conclusions particularly among rural residents.

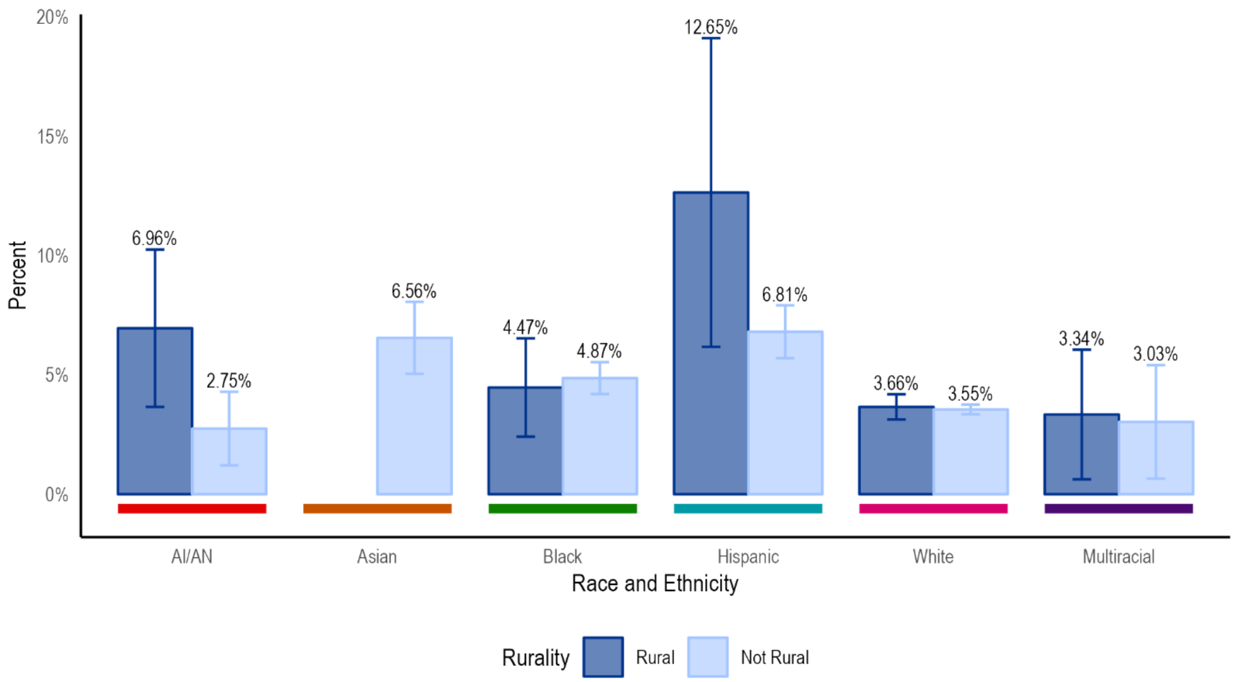

Figure 7-7: Percent of women aged 65 and older who report a dementia diagnosis (including Alzheimer's disease), by race and ethnicity, and rurality

Source: National Health Interview Survey (NHIS), Pooled 2019-2022

Figure 7-8 shows trends in AD mortality rates between 2010 and 2021 by race and ethnicity, and rurality. For White and Black women, mortality rates are consistently higher for women in rural areas compared with women in non-rural areas. While White and Black women exhibit similar rates in 2020 (41.58/100,000 and 41.07/100,000 respectively), changes in mortality rates represent a larger proportional increase for Black women, a 15-percentage point shift between 2010 and 2020, compared with a 9-percentage point increase for White women. For AI/AN, API, and Hispanic women, mortality rates associated with AD overlap for women living in rural and non-rural areas, suggesting that rurality does not meaningfully contribute to differences in mortality rate. It is important to view these results within the context of systematic barriers that result in late and missed diagnoses and in failures in existing data systems to accurately record racial and ethnic identity for AI/AN, API, and Hispanic women.

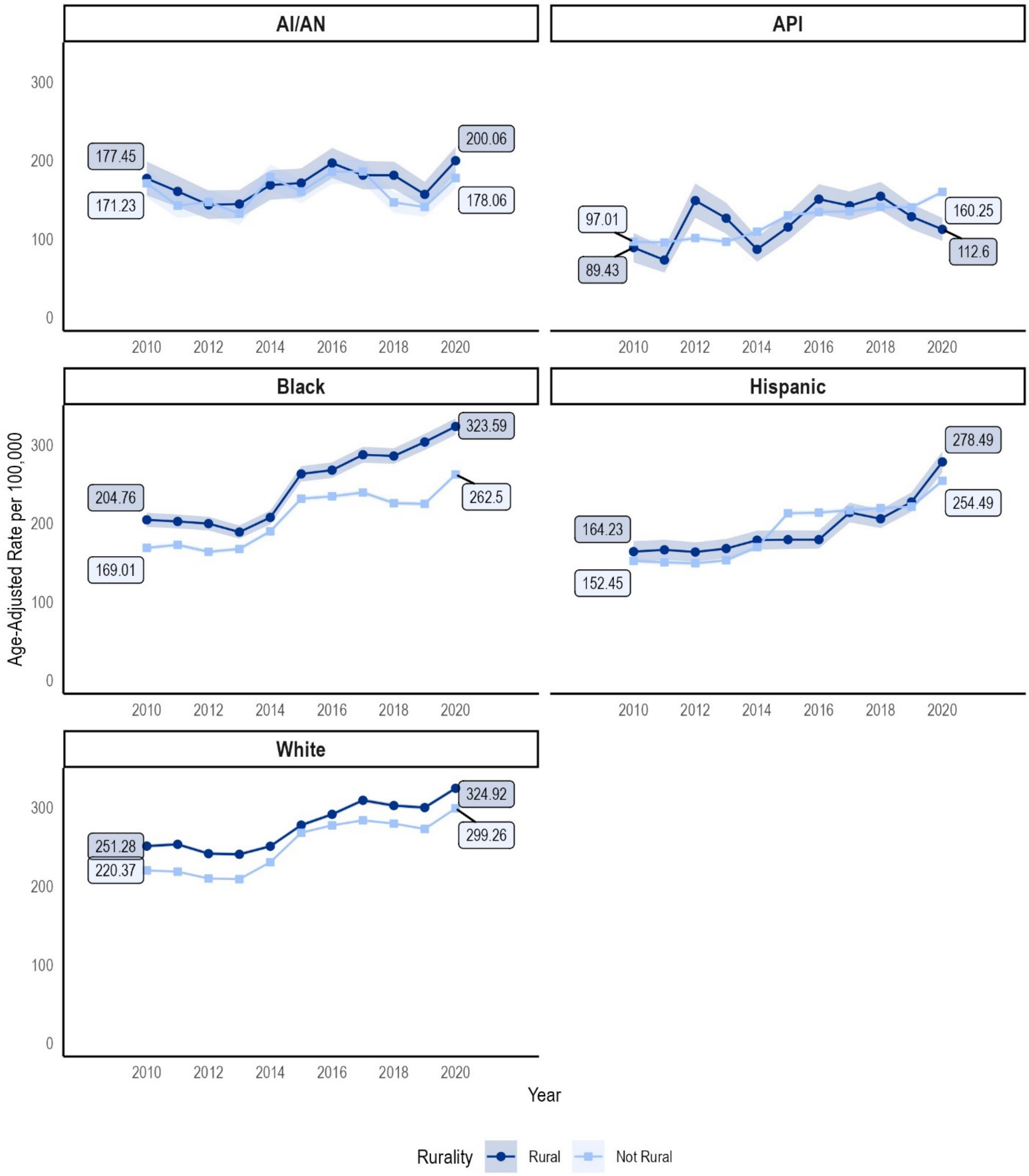

Figure 7-8: Age-adjusted Alzheimer's disease mortality rate per 100,000 women over time, by race and ethnicity, and rurality

Source: National Vital Statistics System (NVSS) Underlying Cause of Death, 2010-2020

Despite the noted data limitations, rurality is a well-established determinant of access to health screenings and quality care. Women in rural areas have lower life expectancy, and face a range of structural and social drivers, including lack of access to quality and specialty care (see **Chapter 1**). For example, women living in rural areas are less likely than those in urban areas to receive screening and treatment for ADRD, and in turn may experience higher emergency department healthcare utilization for related symptoms.[57–59] Primary care providers in rural areas report that patients are not likely to discuss memory issues themselves, particularly if the patient has other pressing health issues, but will wait until a family member brings it forward.[28] This has implications for late and missed diagnoses, as well as more rapid disease progression.

7.4.2 Economic Status

Figure 7-9 shows the estimated percentage of dementia by economic status across race and ethnicity. As observed in the figure, the percentage of women reporting a dementia diagnosis tends to be higher among economically disadvantaged women of underrepresented racial and ethnic communities. The highest observed estimated percentage is among Asian women who are economically disadvantaged (8.7%). The largest effects of economic advantage appear among AI/AN women and Multiracial women; for both groups, economically advantaged women have 3.5 times lower estimated percentage than women who are economically disadvantaged. The difference between Black, Hispanic, Multiracial, and White women who are economically disadvantaged and those who are economically advantaged is minimal. White women have an overall lower prevalence irrespective of economic status.

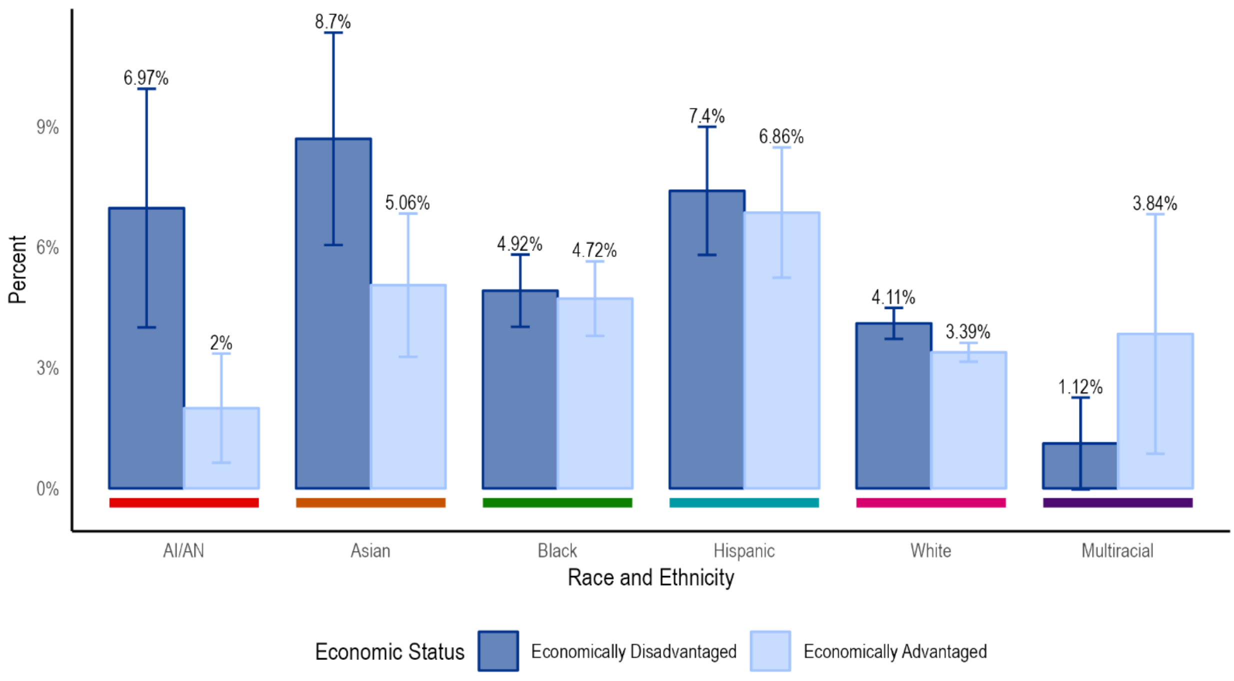

Figure 7-9: Percent of women aged 65 and older who report a dementia diagnosis (including Alzheimer's disease), by race and ethnicity, and economic status
Source: National Health Interview Survey (NHIS), Pooled 2019-2022

The disparity between economically disadvantaged and economically advantaged may be perpetuated by elements like food insecurity and living in areas with high pollution, which have been shown to increase risk of dementia.[29–31] Economically disadvantaged women may receive a lower quality of dementia care compared to individuals who don't rely exclusively on Medicaid coverage.[60] Additionally, many economically disadvantaged women require non-English-speaking care, which can be less readily available and more expensive, further perpetuating disparities.[52]

Another factor directly linked to access to high quality nursing facilities is a patient's insurance coverage, which significantly varies among racial and ethnic populations.[60] **Figure 7-10** shows the percentage of women 65 and older with dementia by insurance type and, race and ethnicity. The overall pattern shows that estimated percentage of dementia is lower among women with private coverage or Medicare Advantage across all groups. Conversely, the estimated percentage of dementia is highest among women who are dual eligible (covered by both Medicare and Medicaid), for all racial and ethnic groups except Asian women, for whom estimated percentage is slightly higher or nearly the same among those with Medicare Advantage. Dual eligibility is correlated with lower income and worse overall health status. Notably, given the smaller sample sizes, the large standard errors limit definitive conclusions regarding the estimates particularly among dual eligible women.

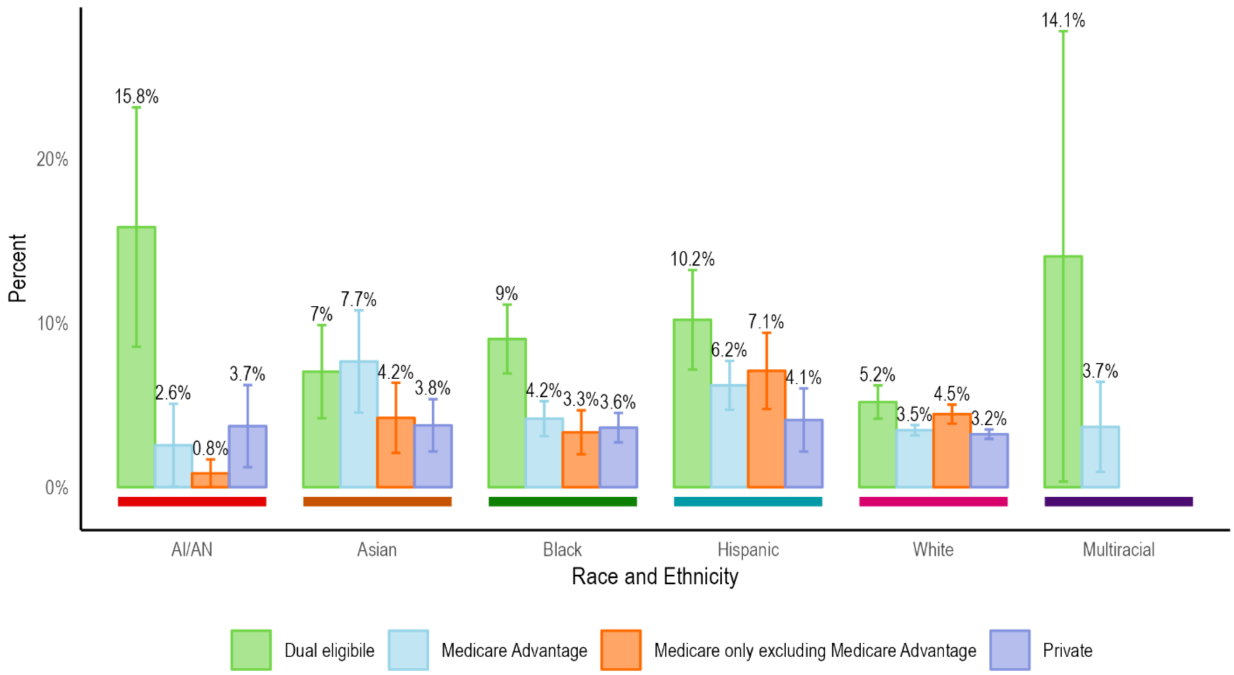

Figure 7-10: Percent of women aged 65 and older who report a dementia diagnosis (including Alzheimer's disease), by race and ethnicity, and insurance type

Source: National Health Interview Survey (NHIS), Pooled 2019-2022

7.4.3 Sexual Orientation and Gender Identity

NHIS data report binary sex (male/female) but not the full spectrum of gender identity, and available data do not demonstrate whether sexual orientation may exacerbate risk of dementia for women across racial and ethnic groups. Prevalence appears similar among racial and ethnic groups who identify as lesbian, bisexual, queer and questioning (LBQ) compared with other groups (**Figure 7-11**). Large standard errors limit definitive conclusions. Hispanic women who refused to answer or skipped this question had a higher percentage of reported dementia than that of any other group. None of the AI/AN, Asian, or Multiracial respondents identified as LBQ. Among Asian women, estimated percentage is higher among women who did not answer the question compared with those who identified as heterosexual, though again large standard errors accompany the estimates. Nearly all White respondents identified as straight, while very few identified as LBQ or refused to answer. Among all the intersections presented here, the lowest estimated percentage observed was for heterosexual Multiracial women (3.49%) and heterosexual White women (3.49%), followed closely by LBQ White women and those who did not answer the question.

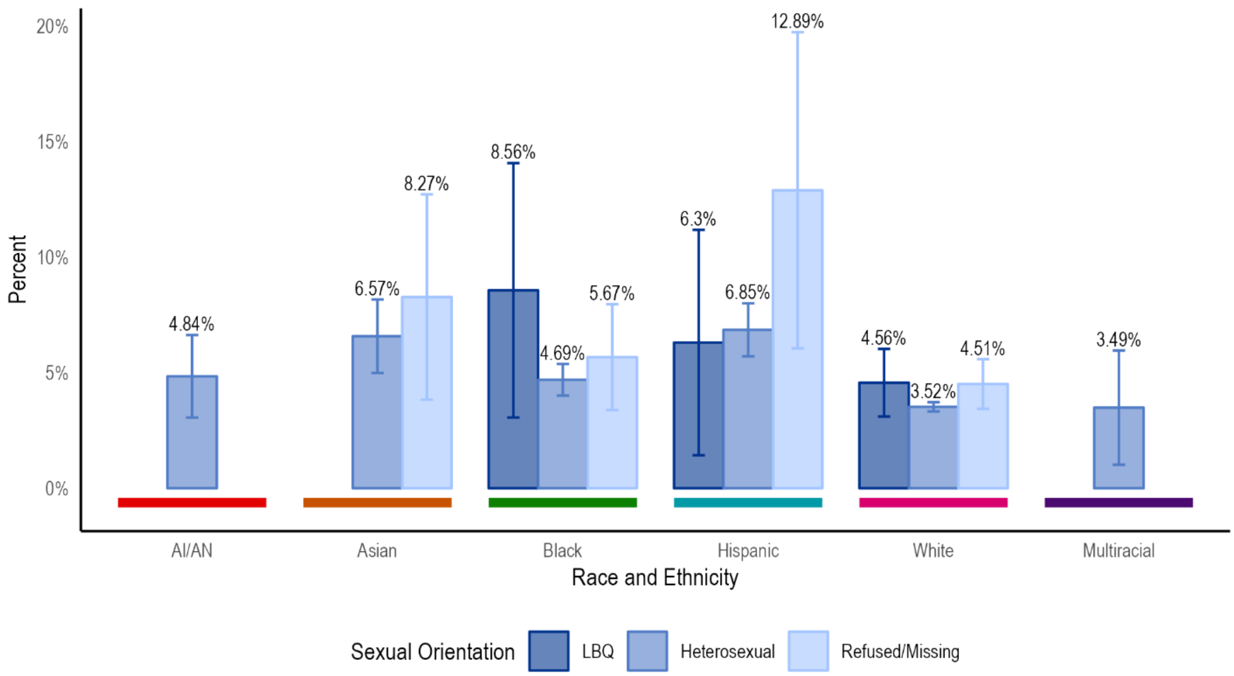

Figure 7-11: Percent of women aged 65 and older who report a dementia diagnosis (including Alzheimer's disease), by race and ethnicity, and sexual orientation

Source: National Health Interview Survey (NHIS), Pooled 2019-2022

A growing body of research has explored the range of unique challenges that make dementia diagnosis and care more challenging for SGM women. Many SGM individuals lack social support, which would help to identify the early symptoms of dementia.[61,62] Additionally, caregivers report lower knowledge about the specific care needs of SGM adults, particularly surrounding gender-affirming care for transgender people.[61,63] The lack of social support in tandem with the stress of experiencing stigma and prejudice means transgender people have a higher risk of developing dementia compared to cisgender people.[64] Lifetime experiences of discrimination in healthcare settings also create barriers for SGM women seeking care for dementia, as they may avoid services altogether or feel they need to hide their sexual orientation and/or gender identity from care providers.[62,65]

7.5 Conclusion and Future Directions

The findings discussed in this chapter demonstrate the importance of addressing dementia as a crucial women's health issue, particularly due to the significant disparities experienced by women in comparison to men. Moreover, the data presented likely underestimate the true extent of dementia and the challenges faced by U3 women. Additional years of data and increased sample sizes, particularly for Multiracial women and NHPI women, are needed to understand trends, as discussed further in the data chapter. The same is true with respect to SGM women (see **Chapter 3**).

Future research should investigate structural interventions, alongside individual-level strategies focused on U3 women's health behaviors. It is imperative to continue expanding the evidence base on culturally responsive dementia care for women belonging to underrepresented racial and ethnic communities, as well as SGM women.[65] As clinical research continues to document the long-term impacts of COVID-19, it will also be important to explore the link between (long) COVID and cognitive impairment, which may increase the risk of dementia. This will be essential for the health of U3 women, who were disproportionately affected by COVID-19 (see **Chapter 4**).[66,67]

7.6 Data Sources and Definitions

Data for all figures in this chapter can be accessed from the data annex located here: https://orwh.od.nih.gov/sites/orwh/files/docs/Chapter_7.xlsx

National Health Interview Survey (NHIS), 2019-2022

Variable Name	Variable Description	Variable Options (if applicable)
COVER65_A	Health insurance hierarchy 65 – This hierarchy deduplicates reports of both private and Medicare Advantage coverage giving preference to Medicare Advantage in the hierarchy.	**Private; Dual Eligible; Medicare Advantage; Medicare only excluding Medicare Advantage;** Other coverage; Uninsured; Don't Know
DEMENEV_A	Have you ever been told by a doctor or other health professional that you had dementia, including Alzheimer's disease?	**Yes;** No; Refused; Not Ascertained; Don't Know

National Vital Statistics System (NVSS), Underlying Cause of Death, 2010-2021

Variable Name	Variable Description	Variable Options (if applicable)
ICD-10 113 Cause List	#Alzheimer disease (G30)	N/A

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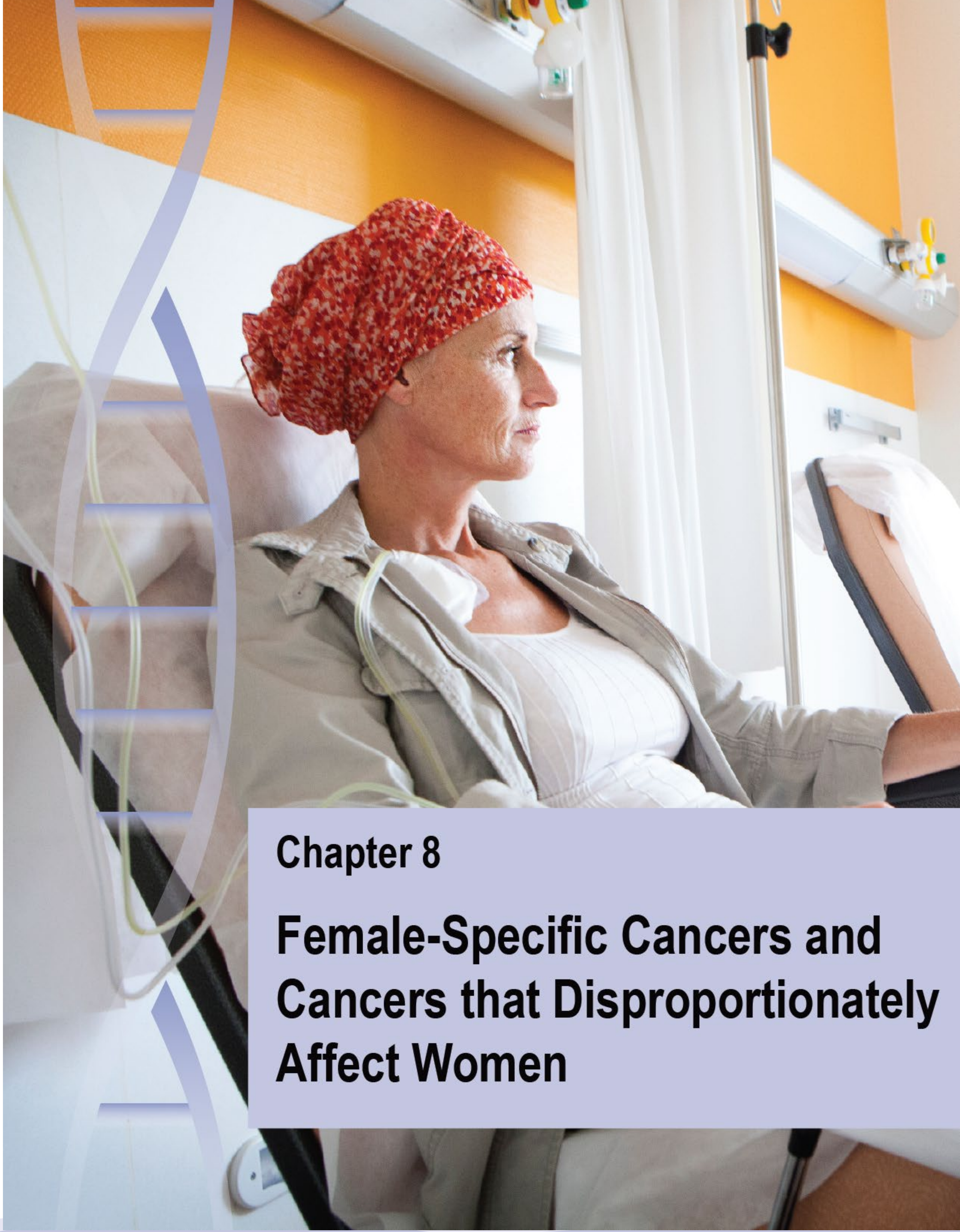

Chapter 8

Female-Specific Cancers and Cancers that Disproportionately Affect Women

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Female-Specific Cancers and Cancers that Disproportionately Affect Women

8.1 Defining Cancer

Cancer has been among the top two leading causes of death in the U.S. for more than 75 years.[1,2] Over the past decade, cancer death rates have continued to decline and overall incidence rates have remained stable, partially attributable to effective interventions targeting modifiable risk factors such as smoking.[2–4] However, incidence has increased for 6 of the top 10 cancers, including breast, uterine, cervical, and oral cancers associated with human papillomavirus.[5] Endometrial cancer is a notable exception to the overall trend, as both incidence and mortality have risen steadily rising since the late 1990s, with the most prominent increase among Black women.[6–8] Cancer surveillance systems typically report data on the sites where cancers develop, with the most common sites including skin, lungs, breasts, prostate, colon and rectum, and cervix and uterus with additional classification based upon histologic subtype.[9] A range of biologic, social, environmental, and economic conditions influence cancer incidence and outcomes.[10,11]

The burden of cancer in the U.S. is described in this chapter using data from four major national-level datasets: the National Survey of Family Growth (NSFG), National Health Interview Survey (NHIS), Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute (NCI), and National Vital Statistics System (NVSS) (see **Chapter 3**). NSFG reports on data elements pertaining to the general and reproductive health of non-institutionalized people aged 15-49, including cancer screening rates using Papanicolaou tests (Pap smears or Pap tests) and pelvic exams.[12] The U.S. Department of Health and Human Services (HHS) uses data from NSFG to plan health services and programs including those specific to cancer.[13] NHIS is another major source of cancer statistics, including through the annual Cancer Control Supplement, which collects data to estimate cancer screening rates, the prevalence of cancer, cancer types, and age at time of diagnosis.[14] Reports on national-level cancer incidence and mortality use combined data from the National Program of Cancer Registries (NPCR); NCI's Surveillance, Epidemiology, and End Results (SEER) program; and mortality data from Centers for Disease Control and Prevention's (CDC) National Center for Health Statistics (NCHS).[15] NVSS collects and shares the nation's vital statics, including statistics on cancer-related mortality.[16] Using these data, it is possible to capture the rates, stage distribution, risks, and trends of cancer morbidity and mortality in the U.S. However, these sources do not report on biases associated with who receives treatment, treatment outcomes, and other factors relevant to exploration of health disparities.[17]

8.2 Cancers that Disproportionately Affect Women and Female-Specific Cancers

Overall cancer incidence and mortality rates are lower among women than men in the U.S. population, reflecting differences in life expectancy as well as sex-specific cancer disease site risk.[5] In most shared anatomic sites (i.e., sites that are not sex specific), women experience lower cancer risk and better survival outcomes than men.[18,19] Higher cancer risk in males for most cancer sites (except thyroid and gallbladder) persists, for example, even after adjustment for known risk factors.[20] While the differences in cancer diagnosis and outcomes for women are complex and not well understood, research suggests they are likely due to differences in both endogenous factors (e.g., hormonal and metabolic differences), and exogenous factors (e.g., lifestyle behaviors and environmental exposures).[21]

In the U.S., the average risk of a woman developing any type of cancer is 39.5%, or 1 in 3 women, and the risk of death from any cancer is 17%, or 1 in 6 women.[22] For men in the U.S., the lifetime risk of developing any cancer is 41.6% (nearly 1 in 2) and the risk of dying from any cancer is 19% or nearly 1 in 5.[22] Among men, prostate cancer is the most common cancer diagnosis (expected to account for 299,010 new cases among men in 2024), while lung cancer causes the most deaths, expected to account for 65,790 deaths among men in 2024.[5] Among women, breast cancer is the most common (expected to account for 310,720 new cases among women in 2024), and—as with men—lung cancer claims the most lives (expected to account for 59,280 deaths among women in 2024).[5] Although overall cancer incidence rates at the population level are flat or declining, between 1975 and 2015, cancer incidence rates for women 25 to 39 years old increased at a faster rate than among men of the same age group or women of older age groups. [23,24] The remainder of this chapter will focus on cancers that disproportionately affect women and female-specific cancers. For these cancers, the four national-level datasets predominantly report on breast, uterine, ovarian, cervical, and others (such as vaginal and vulvar cancers).

Among those cancers that disproportionately affect women or are female-specific, the most common are breast cancer (13.0% average risk or 1 in 8 women), uterine cancer (3.1% average risk or 1 in 32 women), ovarian cancer (1% average risk or 1 in 87 women), and cervical cancer (0.7% average risk or 1 in 152 women).[5,22] Notably, both cervical and uterine cancer incidence rates can be distorted when data is not adjusted for the prevalence of hysterectomy, the second most common surgery for women performed in the U.S.[25,26] Stage at diagnosis is a key determinant of cancer outcomes, including mortality and survival. SEER's cancer staging system ("Summary Stage") defines the stages as follows: "localized cancer is confined to the primary site; regional cancer has spread directly beyond the primary site (regional extension) or to regional lymph nodes; and distant cancer has spread to other organs (distant extension) or remote lymph nodes."[27] Some cancers are unstaged (the stage is unknown or unspecified at diagnosis). **Figure 8-1** shows the 5-year relative survival rates for breast, uterine, ovarian, and cervical cancer, illustrating that across sites the survival rates are highest for localized diagnoses and worst for distant diagnoses.

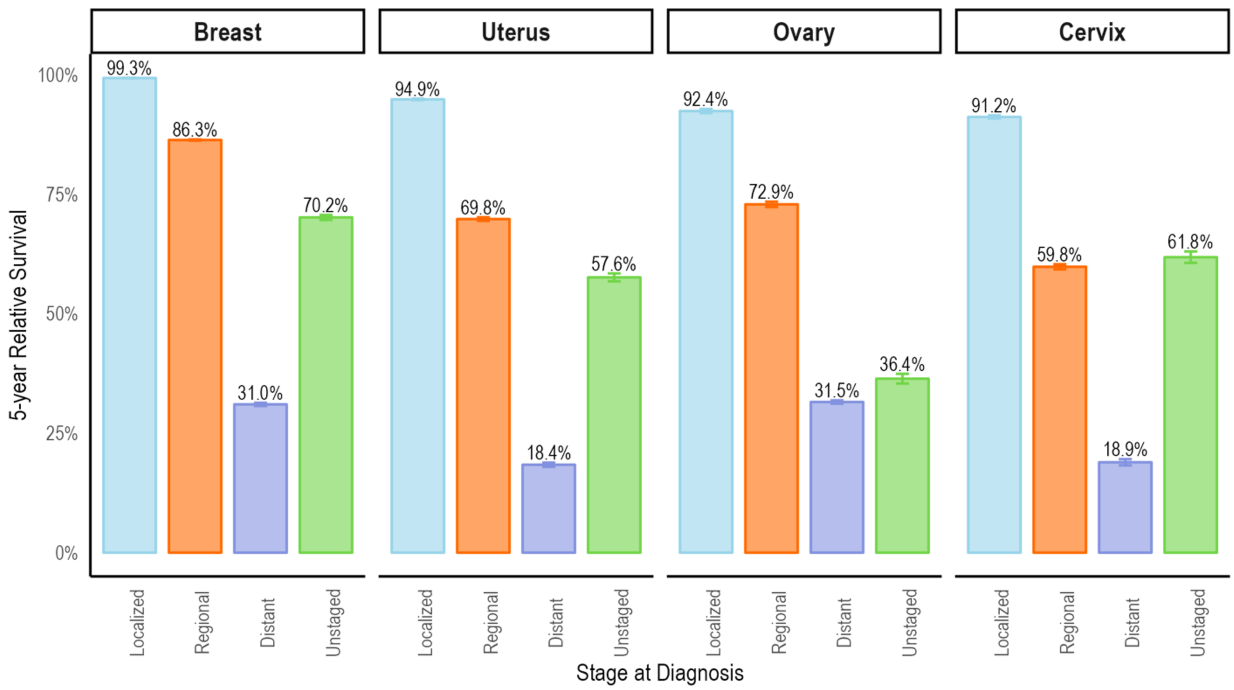

Figure 8-1: Five-year relative survival rate among women, by cancer type and stage at diagnosis
Source: Surveillance, Epidemiology, and End Results (SEER), Pooled 2013-2019

8.2.1 Breast Cancer

In 2024, there will be more than 310,000 new breast cancer cases among women in the U.S., with more than 42,000 women dying of breast cancer that same year.[5] While breast cancer incidence rates have risen by 0.5% each year for the past two decades, overall mortality from breast cancer has decreased by more than 40% since its peak in 1989.[22,28] Risk factors for breast cancer are a combination of modifiable risk factors (such as alcohol intake, body weight, and physical inactivity) and non-modifiable risk factors like sex and age.[29] Regular mammograms and clinical breast exams continue to be the recommended methods for screening for breast cancer.[30] While breast cancer does affect men, it is rare: men account for approximately 1% of breast cancers diagnosed in the U.S.[5,31] This difference is reflected in **Figure 8-2**, which illustrates the percent of women and men who report a breast cancer diagnosis, by race and ethnicity. Women's prevalence of breast cancer is substantially higher than that of men. The data reveal some additional differences by race and ethnicity, which will be discussed in greater depth later in this chapter.

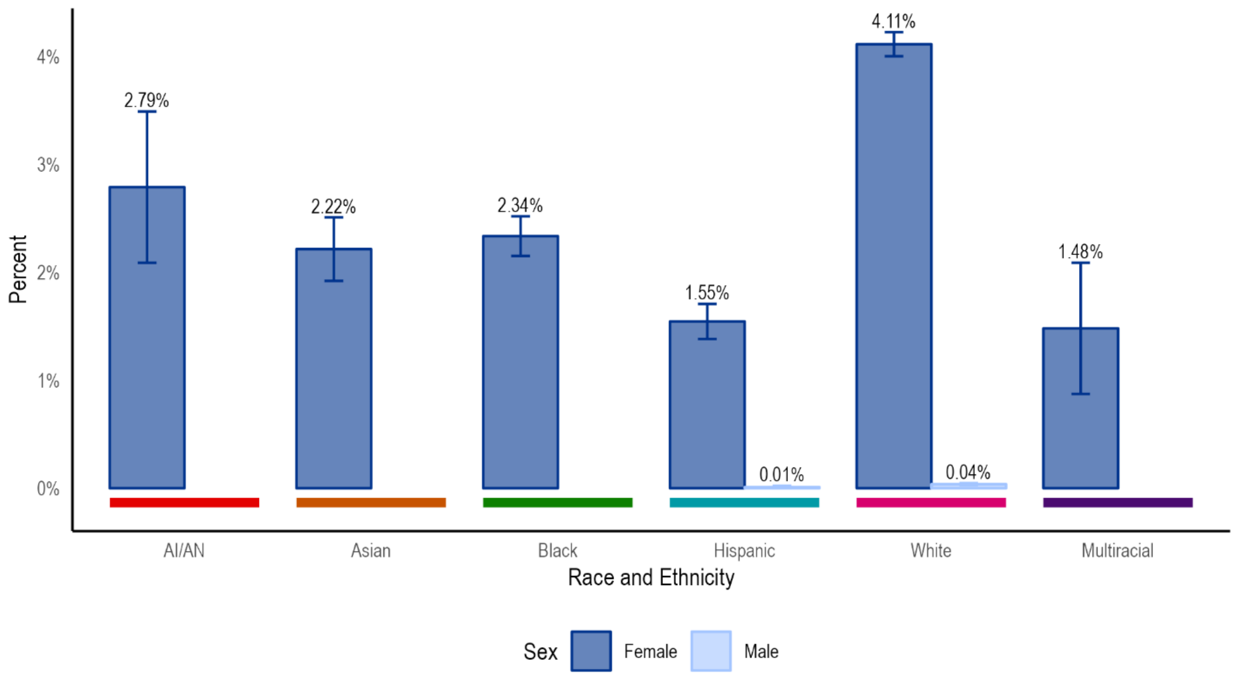

Figure 8-2: Percent of people who report a breast cancer diagnosis, by sex and race and ethnicity
Source: National Health Interview Survey (NHIS), Pooled 2019-2022

Figure 8-3 shows the age-adjusted incidence rate of female-specific cancers and cancers that disproportionately affect women per 100,000 women. The data illustrate that incidence of breast cancer exceeds that of other cancers that are female-specific or disproportionately affect women by more than four-fold, followed by uterine and ovarian cancers.

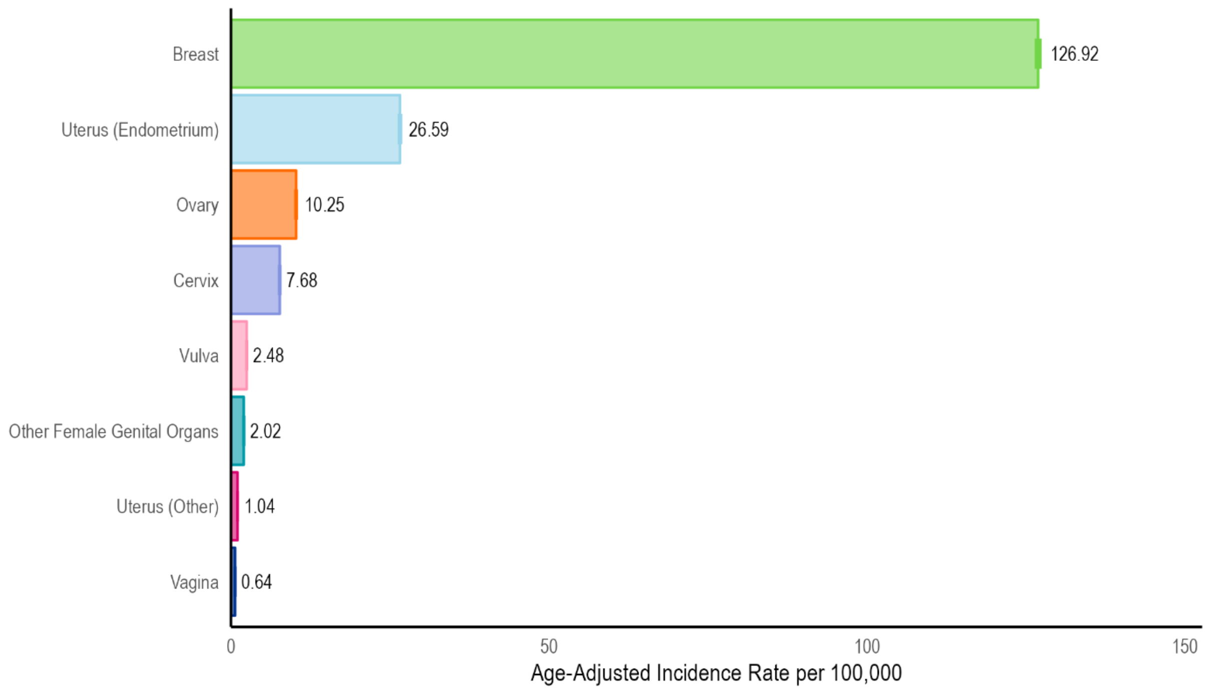

Figure 8-3: Age-adjusted incidence rate of female-specific cancers and cancers that disproportionately affect women per 100,000 women

Source: Surveillance, Epidemiology, and End Results (SEER), Pooled 2016-2020

8.2.2 Gynecologic Cancers

Over 116,000 women in the U.S. will be diagnosed with cancers of the female reproductive tract in 2024, with an estimated 33,850 women dying from a gynecologic cancer this year.[5] **Figure 8-4** shows the cumulative gynecologic cancers incidence rate per 100,000 women, by cancer type and age range. The "all" age denotes incidence for each cancer type among women of all ages, showing the greatest frequency of cancer in the uterus (endometrium), ovary, and cervix within the genital system. The data show that the overall incidence of uterine cancers is 26.6 cases per 100,000 women, with the majority of these (17.2 cases) being diagnoses among women before age 64. The cumulative incidence of uterine cancers rises steeply with age, increasing by approximately 15 additional cases per 100,000 between the ages of 39 and 64, while new cancers in the vulva, other genital organs, uterus (other than endometrium), and vagina remain relatively low and stable across the life course. Ovarian cancer is the only gynecologic cancer for which new diagnoses are noted among women before the age of 20. However, these are primarily germ cell tumors which have a distinct biological behavior compared to the more common epithelial ovarian cancers.

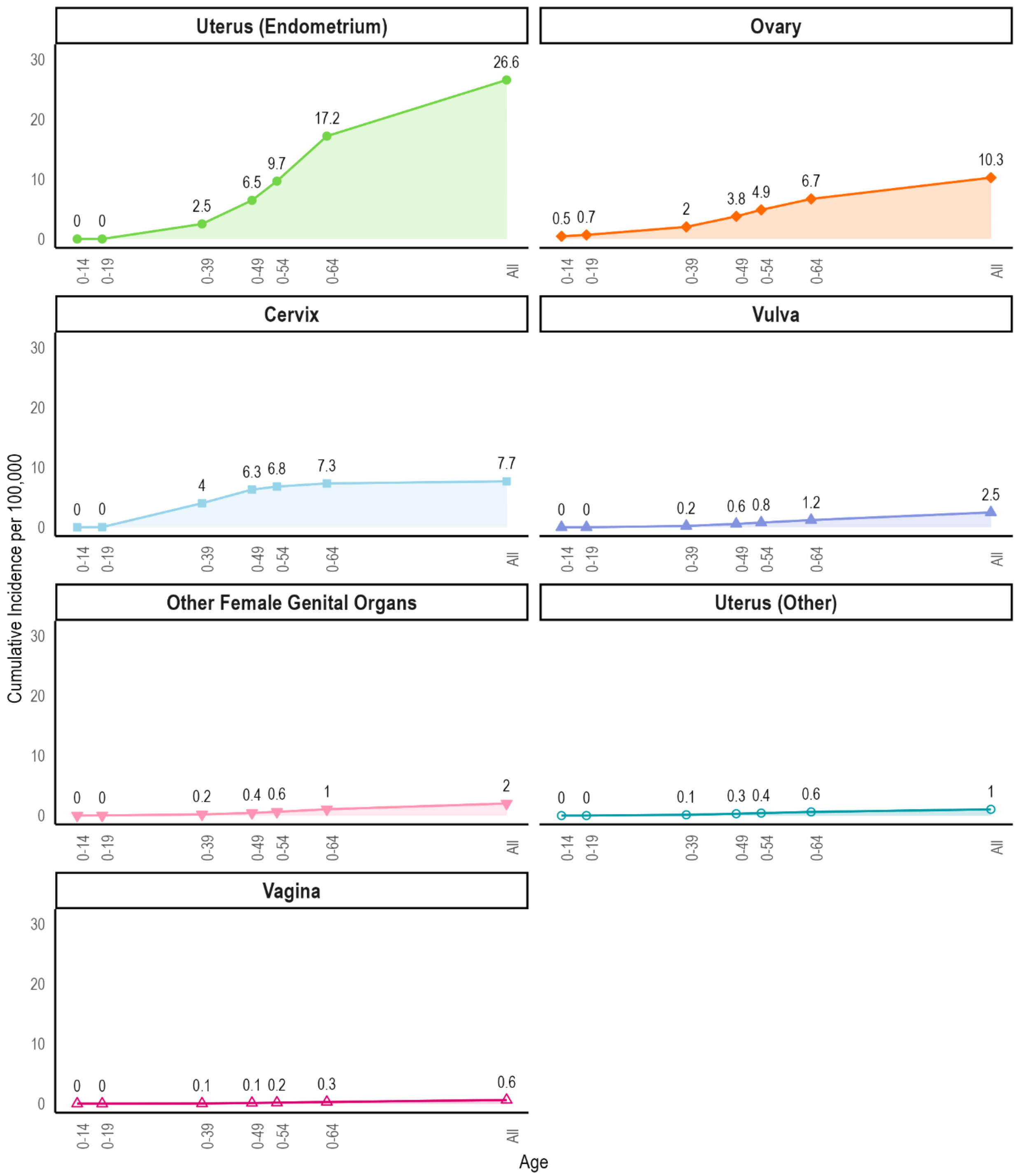

Figure 8-4: Cumulative gynecologic cancers incidence rate per 100,000 women, by cancer type and age range

Source: Surveillance, Epidemiology, and End Results (SEER), Pooled 2016-2020

8.2.2.1 Uterine Cancer

The most commonly diagnosed gynecologic cancer is uterine cancer (67,880 new cases in 2024) of which the vast majority (>90%) is endometrial cancer.[28,32] Endometrial cancer is the cancer disease site most strongly associated with obesity. Metabolic syndrome and conditions involving excess estrogen are also associated with an increased risk of endometrial cancer.[8] Uterine sarcoma, the much rarer subtype of uterine cancer that forms in the muscle (myometrium) of the uterus, comprises between 2% and 5% of all uterine cancers.[33,34] Recent studies underscore the importance of using hysterectomy-adjusted analyses to assess incidence rates of endometrial cancer, noting that accounting for hysterectomies provides more accurate estimates of incidence and trends over time.[32,35] Mortality rates for endometrial cancer are rising, in contrast to most other cancers.[8,36]

8.2.2.2 Ovarian Cancer

More than 19,600 new ovarian cancer cases will be diagnosed in 2024, representing 2% of all new cancer cases among women.[5] Recent evidence suggests that a large proportion of ovarian cancer originates not in the ovary but in the fallopian tube.[37] As a screening option that improves mortality has not been identified, prevention strategies, including salpingectomy at the time of hysterectomy or in lieu of tubal ligation, are recommended.[38,39] For the past 20 years, ovarian cancer diagnoses have declined, likely due to an increase in oral contraceptive use and identification of women at increased genetic risk who are at risk for this disease who are candidates for risk-reducing surgery.[40] Family history of breast or ovarian cancer is the strongest risk factor for disease and several inherited genetic mutations, including the breast cancer 1 (*BRCA1*), breast cancer 2 (*BRCA 2*), and other genetic mutations in the homologous recombination genes (e.g., *ATM*, *RAD51)*, predispose women to ovarian cancer.[41,42] Women who carry these experience increased ovarian cancer risk at ages younger than women without these mutations.[43] For women with these deleterious mutations, prophylactic surgery to remove the at-risk organs is recommended. Ovarian cancer will account for 12,740 deaths in 2024, 4% of all cancer deaths among women.[5] The high ovarian cancer lethality rate is tied to the late stage at diagnosis: most ovarian cancer is diagnosed at advanced stages. Recently, the rate of decline in ovarian cancer deaths has accelerated from a 1.5% annual decrease from 1998-2015 to a 2.7% annual decrease from 2015-2020.[5]

8.2.2.3 Cervical Cancer

Nearly all cervical cancers are caused by human papillomavirus (HPV).[44] Exposure to HPV primarily occurs through sexual contact, for which the average age of sexual debut among women is 17.1 years.[13] For HPV transmission to result in cancer, cellular changes on the cervix must be unresolved by the immune system or treatment through excision. A latency period of approximately 12 years during which the virus effects progress to cancerous changes is typical.[45,46] Incidence rates declined following the introduction of cervical cancer screening with the Pap test in the 1950s, which checks for precancerous lesions (cell changes on the cervix that might become cervical cancer if not treated appropriately). The estimated number of new cases in 2024 are expected to be 13,820, representing 1.4% of all new cancer cases among women.[5]

Despite advances in screening with HPV testing and the availability of an HPV vaccine since 2006, rates of cervical cancer have declined less than 1% annually since the early 2000s.[47,48] HPV vaccination during adolescence is recommended for boys and girls for primary prevention of HPV-related malignancies.[49] This recommendation was expanded to individuals up to 26 years old who did not receive this preventive service earlier.[50] In 2021, 58.5% of adolescents aged 13-15 years received the recommended doses of HPV vaccine, below the Healthy People 2030 target of 80%.[51] Still, since vaccination began in the early 2000s, "infections with HPV types that cause most HPV cancers and genital warts have dropped 88% among teen girls and 81% among young adult women."[49]

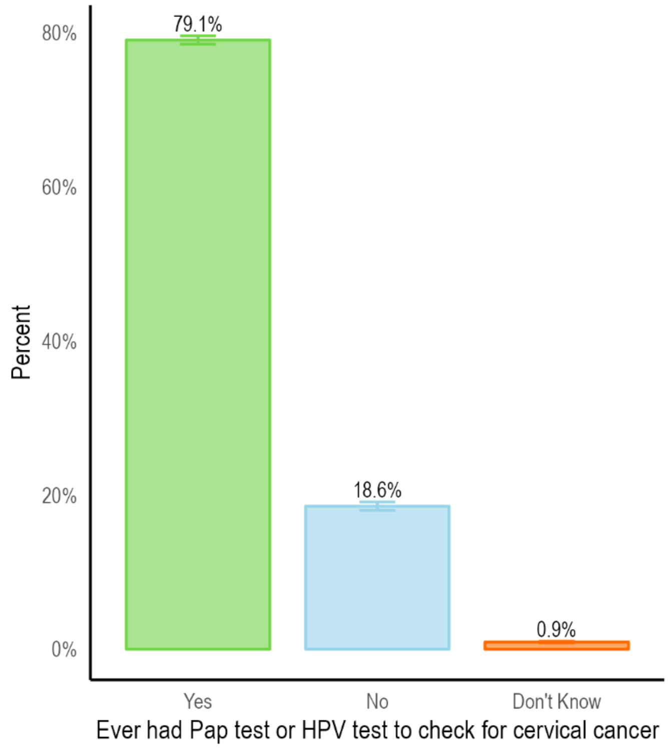

Figure 8-5: Percent of women who report ever being screened for cervical cancer
Source: National Health Interview Survey (NHIS), 2021

Guidance on cervical cancer screenings has changed in the past decade to allow for less frequent testing (from yearly to every three to five years for women 21-65 depending on testing type). As of 2018, the U.S. Preventative Services Task Force recommends screening for cervical cancer in women aged 21-29 years using cervical cytology every three years, and for women 30 to 65 years using either cervical cytology alone (every three years), high-risk HPV testing alone (every five years), or co-testing with high risk HPV and cytology (every five years).[52,53] **Figure 8-5** shows the percent of women who report ever being screened for cervical cancer with either a Pap test or HPV test. The majority of women (79%) have had at least one cervical cancer screening, while less than one percent reported not knowing if they had been screened.

8.2.2.4 Other Gynecologic Cancers

Other gynecologic cancers, such as vulvar and vaginal cancers, are rare.[54,55] Vulvar cancer accounts for only 0.7% of all new cancer cases among women.[5] In 2024, there will be an estimated 6,900 new cases of vulvar cancers and 1,630 deaths.[5] While vulvar cancer primarily affects women ages 65 and older, a recent increase in incidence among younger women is linked to HPV infection rates.[56,57] Similarly, HPV infection is a known cause of vaginal cancers, accounting for two-thirds of all cases.[58] In 2024, there will be an estimated 8,650 new vaginal cancers cases and 1,870 deaths.[5]

8.3 Cancers in Populations of U3 Women

Disparities remain for understudied, underrepresented, and underreported (U3) in cancer screening, treatment, stage at diagnosis, and mortality as measured by age, race and ethnicity, rurality, economic status, and sexual orientation. Heterogeneity in cancer rates and subtypes, as well as survival rates between racial and ethnic groups, underscores the importance of examining the context of differential health outcomes and identifying areas where the available data fall short (see **Chapter 1**). The sections that follow explore trends among U3 women for breast cancer and gynecologic cancers (cervical, ovarian, uterine, vulvar, and vaginal cancers). When available, the literature is used to support observations for other reproductive and non-reproductive cancers affecting women.

8.3.1 Cancers Among Women of Underrepresented Racial and Ethnic Communities

8.3.1.1 Breast Cancer

Figure 8-6 shows the age-adjusted breast cancer incidence rate per 100,000 women, by race and ethnicity and age at diagnosis. Postmenopausal women are at increased risk for breast cancer, with the highest incidence seen among women aged 70-79. The figure shows that White women aged 70-79 had the highest incidence rate (497 cases per 100,000 women) followed by Black, American Indian and Alaska Native (AI/AN), Hispanic, and Asian and Pacific Islander (API) women.

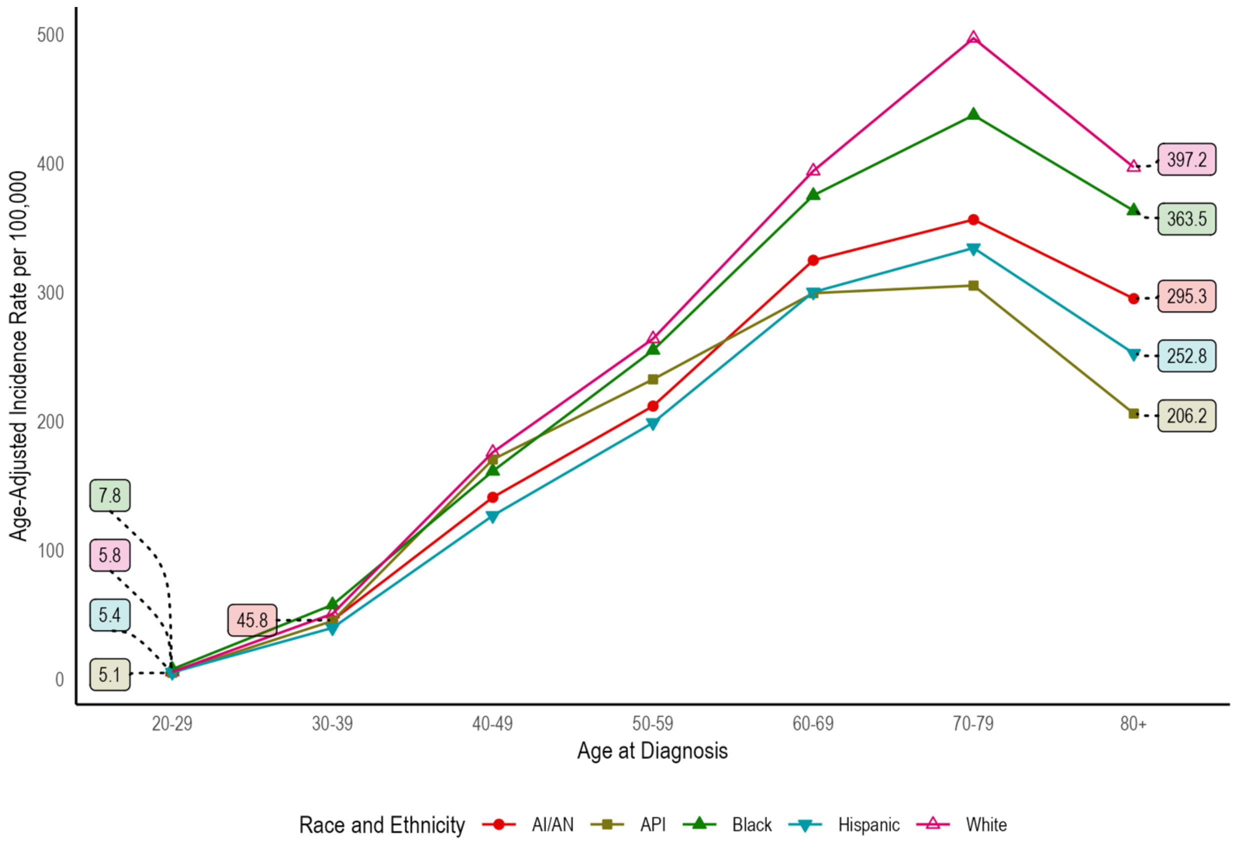

Figure 8-6: Age-adjusted breast cancer incidence rate per 100,000 women, by race and ethnicity, and age at diagnosis

Source: Surveillance, Epidemiology, and End Results (SEER), Pooled 2016-2020

Recently, studies have found that young Asian American women born outside of the U.S. have a higher risk of breast cancer than Asian American women who are born in the U.S.[59] This may be due to changes in acculturation during critical periods, environmental factors, and healthcare practices (i.e., simplistic domestic screening). Researchers have also identified multiple gaps in the state of understanding predictors of breast cancer (e.g., breast density) in women from underrepresented racial and ethnic communities.

Figure 8-7 shows the percent of breast cancer cases by stage at diagnosis among women, by race and ethnicity. The data reveal clear patterns—Black and Hispanic women are most likely to be diagnosed with breast cancer at later stages, while White women are more likely to be diagnosed while the cancer is still localized.

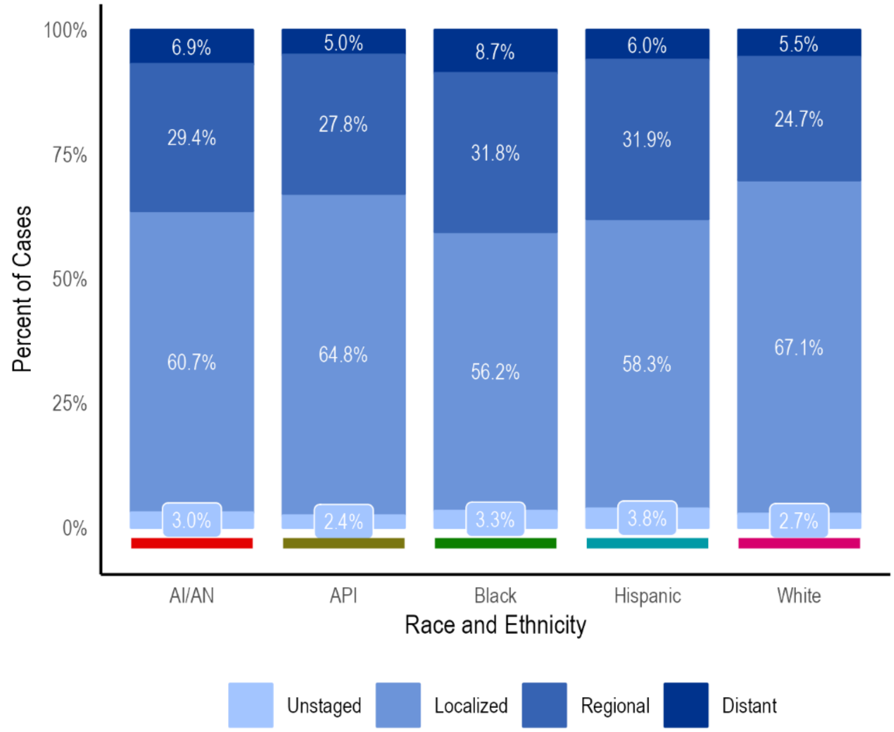

Figure 8-7: Percent of breast cancer cases, by stage at diagnosis among women and by race and ethnicity

Source: Surveillance, Epidemiology, and End Results (SEER), Pooled 2011-2020

Extant literature confirms that API, AI/AN, and Hispanic women have increased odds of late-stage diagnosis and are less likely to receive standard treatments including surgery and radiation compared with White women.[60,61] These disparities carry over to breast cancer mortality disparities. **Figure 8-8** shows the five-year breast cancer relative survival rate among women, by race and ethnicity, and stage at diagnosis, revealing that survival rates for all groups are lower at later stages of diagnosis. Across race and ethnicity categories, survival rates are high when breast cancer is diagnosed early (localized stage). More variation is seen in survival rates across racial and ethnic groups for regional diagnoses, with Black women, whose survival rate is 79%, comparably lower than API and White women. Survival rates drop precipitously for those patients with distant disease. AI/AN and API women have the highest survival rate for distant diagnoses, followed by White and Hispanic women. The survival rate for Black women with distant disease is lower than that of any other group.

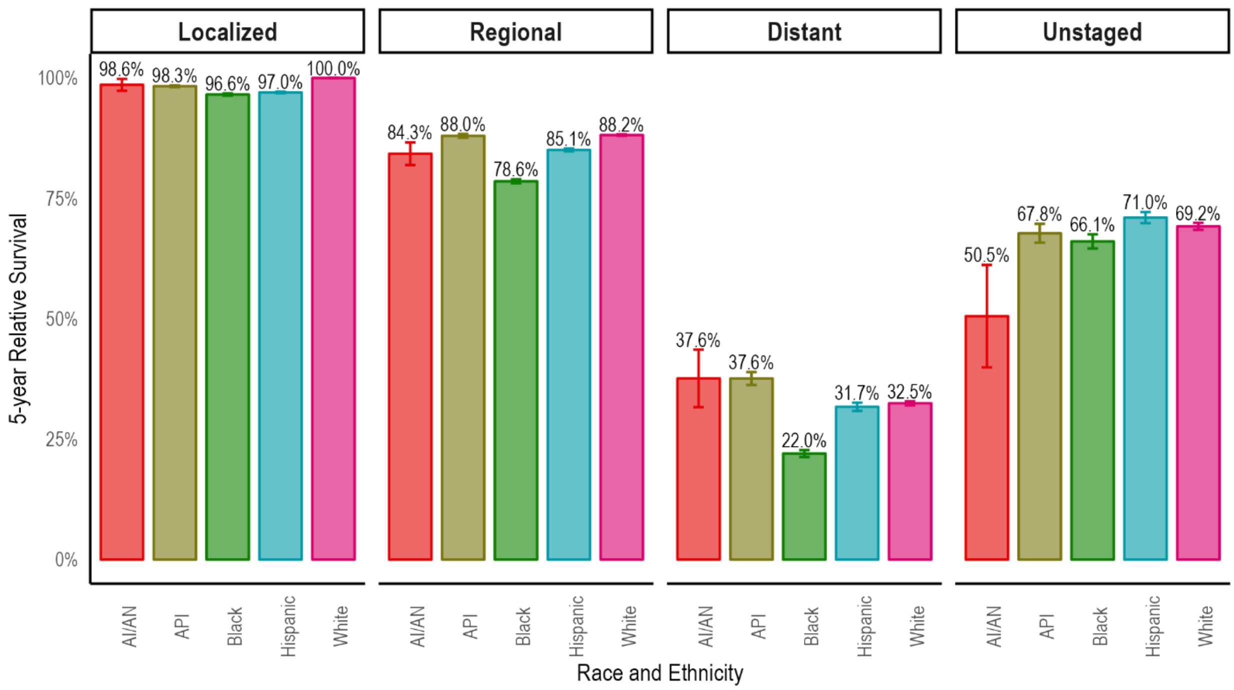

Figure 8-8: Five-year breast cancer relative survival rate among women, by race and ethnicity, and stage at diagnosis

Source: Surveillance, Epidemiology, and End Results (SEER), Pooled 2013-2019

Figure 8-9 shows the age-adjusted breast cancer mortality rate per 100,000 women over time, by race and ethnicity from 2010-2021. Despite a lower incidence rate compared with White women (**Figure 8-6**), Black women experienced the highest breast cancer-related mortality of all racial and ethnic groups in the past decade. Presumably resulting from the intersection of multiple social and structural factors, breast, cervical, and endometrial cancer have among the largest racial disparities for Black women of all disease sites.[62]

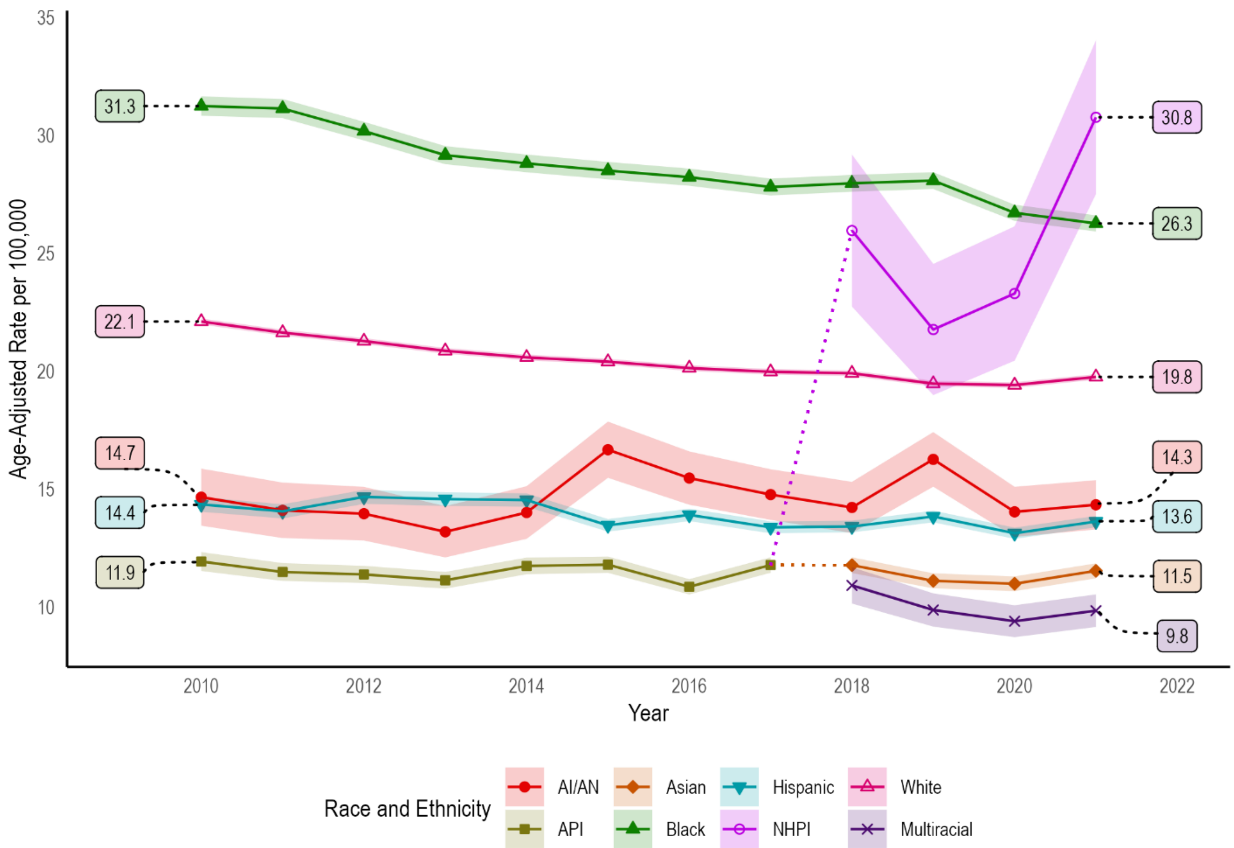

Figure 8-9: Age-adjusted breast cancer mortality rate per 100,000 women over time, by race and ethnicity

Source: National Vital Statistics System (NVSS) – Underlying Cause of Death, 2010-2021

From 2010 to 2017, the breast cancer mortality rates for Native Hawaiian and Pacific Islander (NHPI) and Asian women were categorized within the combined API category. In 2018, the disaggregated data for NHPI women became available and it was apparent that the smaller population of NHPI women has higher mortality rates from breast cancer. This unobscured difference underscores the importance of disaggregating data to the subgroup level wherever possible.

The disparate prevalence of triple-negative breast cancer, a subtype that is particularly aggressive and believed to be caused by a combination of biological and structural risk contributes to the disproportionate breast cancer mortality among Black women.[63,64] Estimates from 2010-2019 show that incidence of triple-negative breast cancer was highest among Black women (33.8 cases per 100,000 women), nearly double the incidence among White women (17.5 cases per 100,000 women) and more than double the incidence among AI/AN (14.7 cases per 100,000 women), Hispanic (14.7 per 100,000 women), and Asian (12.4 cases per 100,000 women) women.[65]

8.3.1.2 Gynecologic Cancers

The sections that follow provide data on incidence rates, diagnosis patterns by stage, survival rates, and mortality rates across the most common gynecologic cancers.

8.3.1.2.1 Uterine Cancer

Figure 8-10 illustrates the age-adjusted endometrial cancer incidence rate per 100,000 women, by race and ethnicity, and age at diagnosis. For all racial and ethnic groups, the highest incidence rates occur among women aged 60-69, with Black women having the highest incidence (127.5 cases per 100,000 women) and the lowest among API women (73.85 cases per 100,000 women). Cancers of the endometrium are most common. Estimates of endometrial cancer incidence typically do not adjust for hysterectomy rates, which are higher among Black women, meaning that they underestimate the true degree of the disparity.[8,32,35]

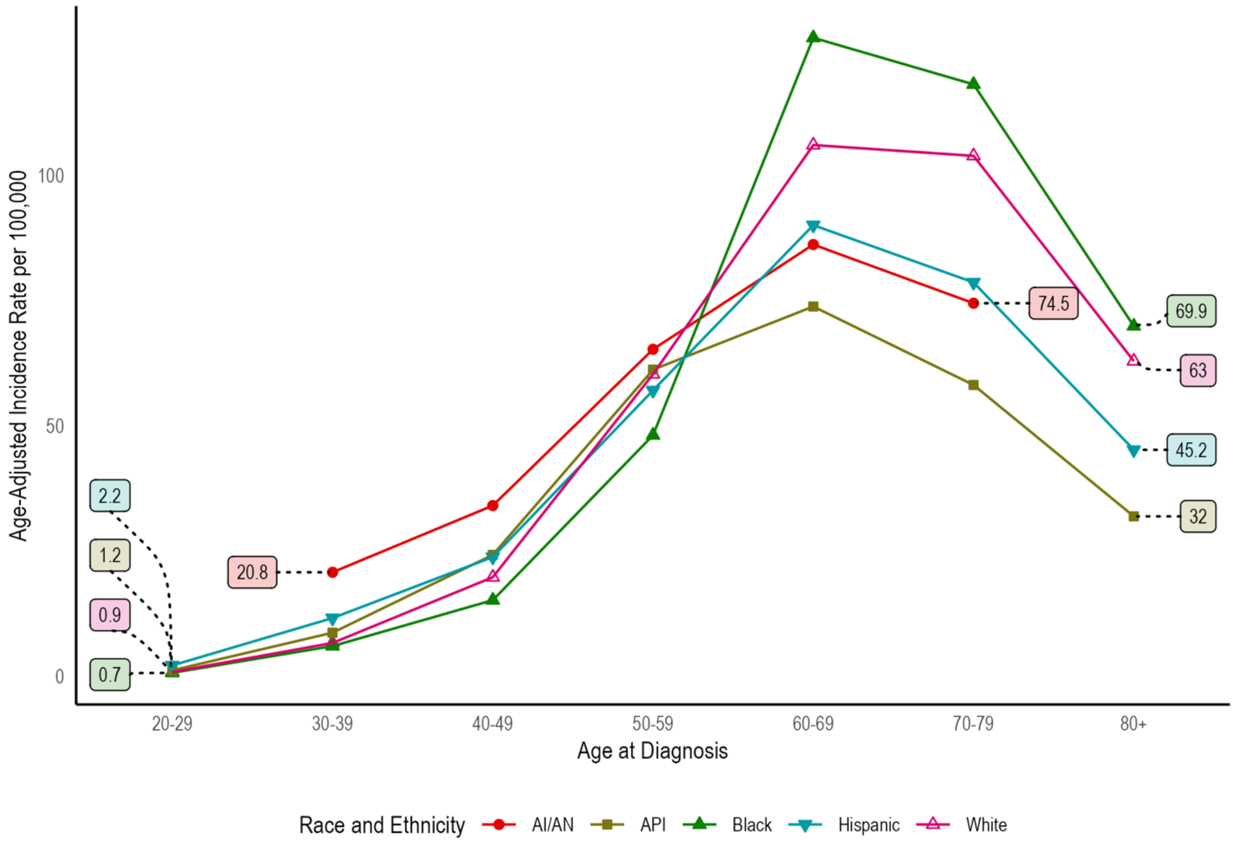

Figure 8-10: Age-adjusted endometrial cancer incidence rate per 100,000 women, by race and ethnicity, and age at diagnosis

Source: Surveillance, Epidemiology, and End Results (SEER), Pooled 2016-2020

Figure 8-11 shows the age-adjusted uterine cancers (excluding endometrial cancer) incidence rate per 100,000 women, by race and ethnicity, and age at diagnosis. The incidence of these uterine cancers was less than 10 cases per 100,000 women. Still, Black women experience the highest incidence at all ages beginning at age 40, followed by Hispanic women. White and API women have similar incidence rates before age 60, with a higher rate for White women after age 60. Data are not available for incidence among AI/AN women due to data suppression (i.e., there were not enough recorded cases to generate an estimate for this population).

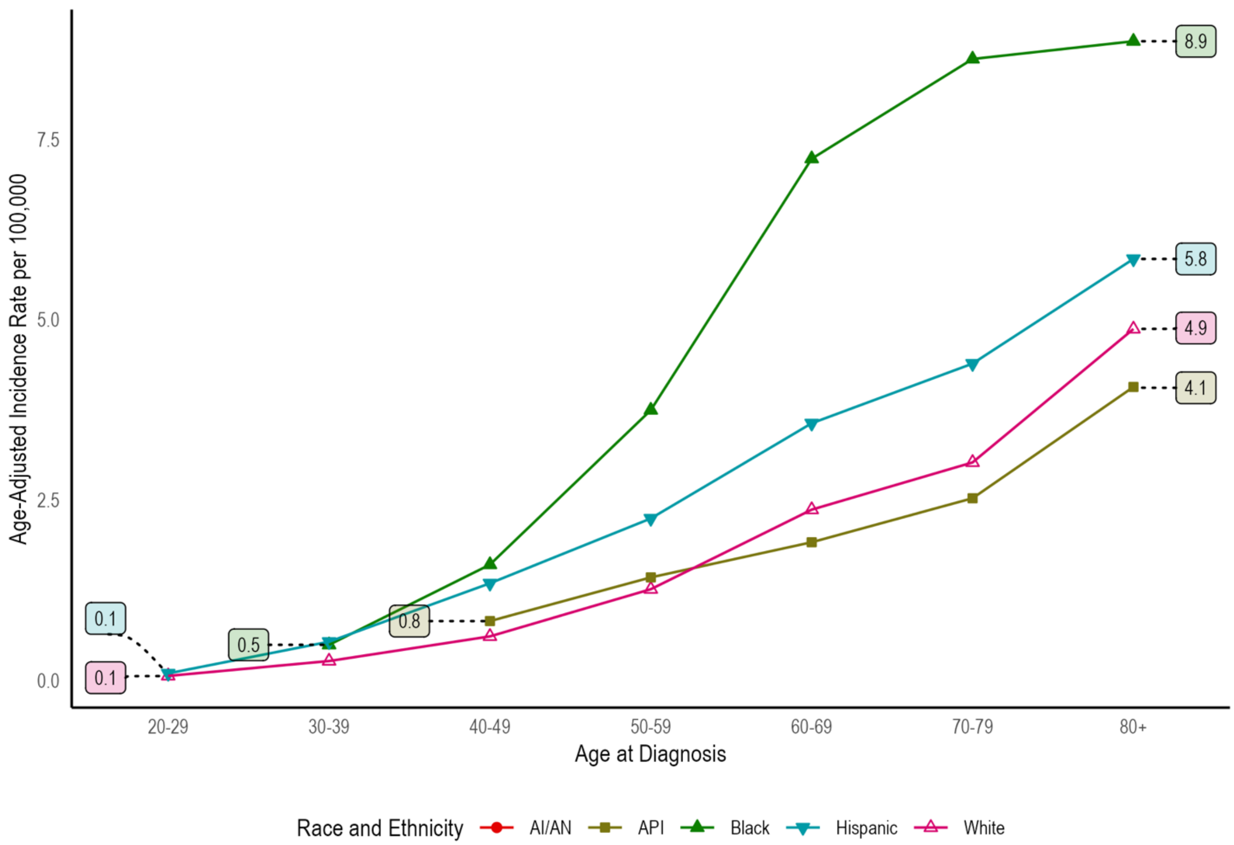

Figure 8-11: Age-adjusted uterine cancers (excluding endometrial cancer) incidence rate per 100,000 women, by race and ethnicity, and age at diagnosis

Source: Surveillance, Epidemiology, and End Results (SEER), Pooled 2016-2020

Figure 8-12 shows the percent of uterine cancer cases by stage at diagnosis, by race and ethnicity. The data illustrate that most uterine cancer diagnoses occur while the cancer is still localized. However, the differences across racial and ethnic groups are pronounced for uterine cancer: Black women are least likely to be diagnosed with localized cancers and nearly twice as likely to receive a diagnosis at the distant stage compared with women of any other racial and ethnic group. Studies have demonstrated that Black women are less likely to receive appropriate diagnostic evaluation for postmenopausal bleeding, which is associated with endometrial cancer detection at advanced stages.[66]

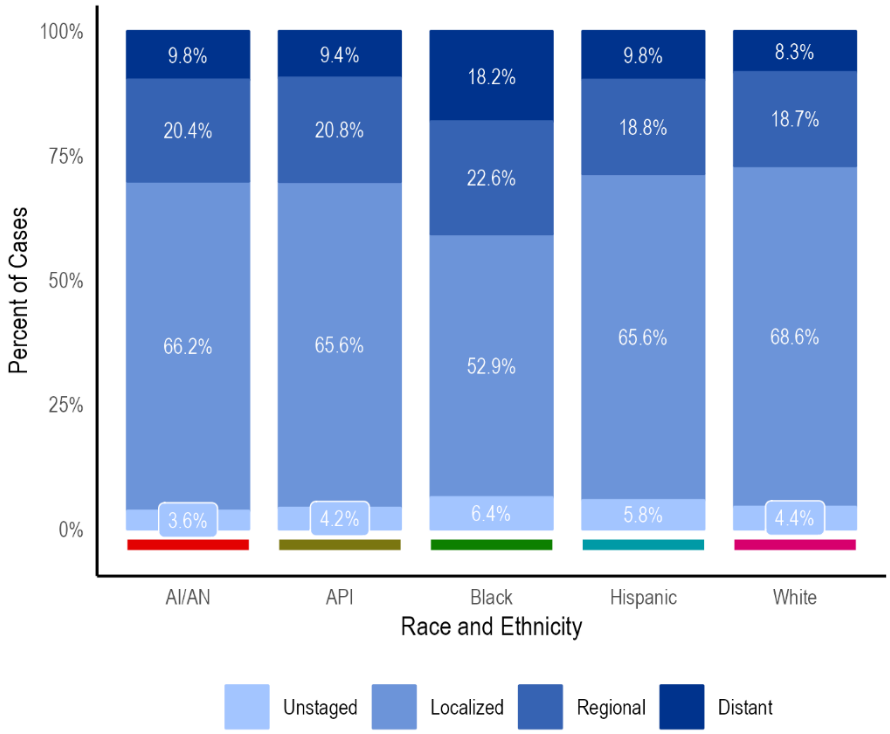

Figure 8-12: Percent of uterine cancer cases, by stage at diagnosis and race and ethnicity
Source: Surveillance, Epidemiology, and End Results (SEER), Pooled 2011-2020

Advanced stage at diagnosis and a lack of healthcare that follows current medical guidelines are major contributors to racial and ethnic disparities for outcomes from uterine cancer.[67] For example, Black women are less likely to receive evidence-based care despite having the highest risk for the most aggressive histology types.[68] Some estimates show that Black women have a 30% lower incidence rate of endometrial cancer compared with White women but experience 80% higher mortality rates.[69] However, treatment adherence is a stronger predictor of improved survival among White women than among women of underrepresented racial and ethnic communities, suggesting other social and structural drivers of this disparity.[70] Additionally, obesity—which is a strong risk for the development of endometrial cancer, and other comorbidities that are more common among U3 women—may complicate treatment.[71,72]

Figure 8-13 shows the five-year uterine cancer relative survival rate, by race and ethnicity, and stage at diagnosis. For all groups, survival is higher at earlier stages of diagnosis (localized). The data reveal a clear pattern of difference, with Black women having the lowest survival at every stage.

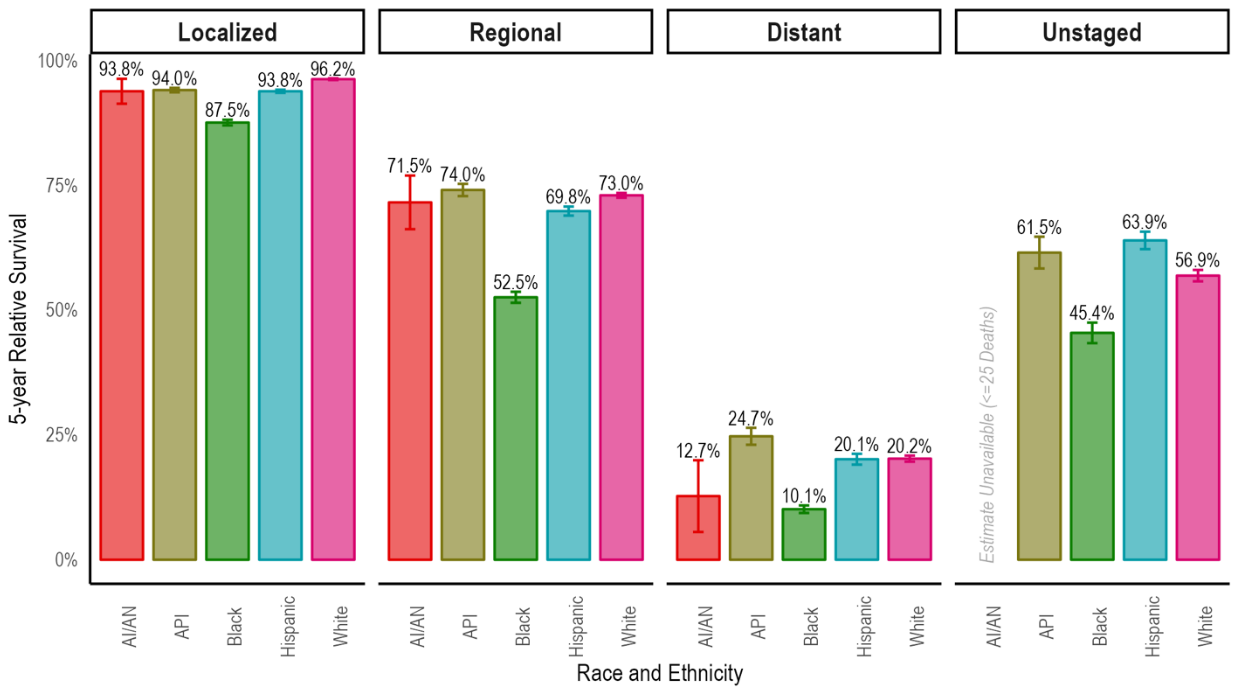

Figure 8-13: Five-year uterine cancer relative survival rate, by race and ethnicity, and stage at diagnosis

Source: Surveillance, Epidemiology, and End Results (SEER), Pooled 2013-2019

When examining uterine cancer survival overall, additional disparities emerge. **Figure 8-14** shows the age-adjusted uterine cancer mortality rate per 100,000 women, by race and ethnicity, as reported by NVSS Underlying Cause of Death data in 2021. NHPI women experience the highest mortality rate (20 deaths per 100,000 women), double that of the next highest group, which is Black women (9.84 deaths per 100,000 women). Because NHPI women are aggregated in cancer incidence reports, this trend was not discernable above in **Figure 8-10**.

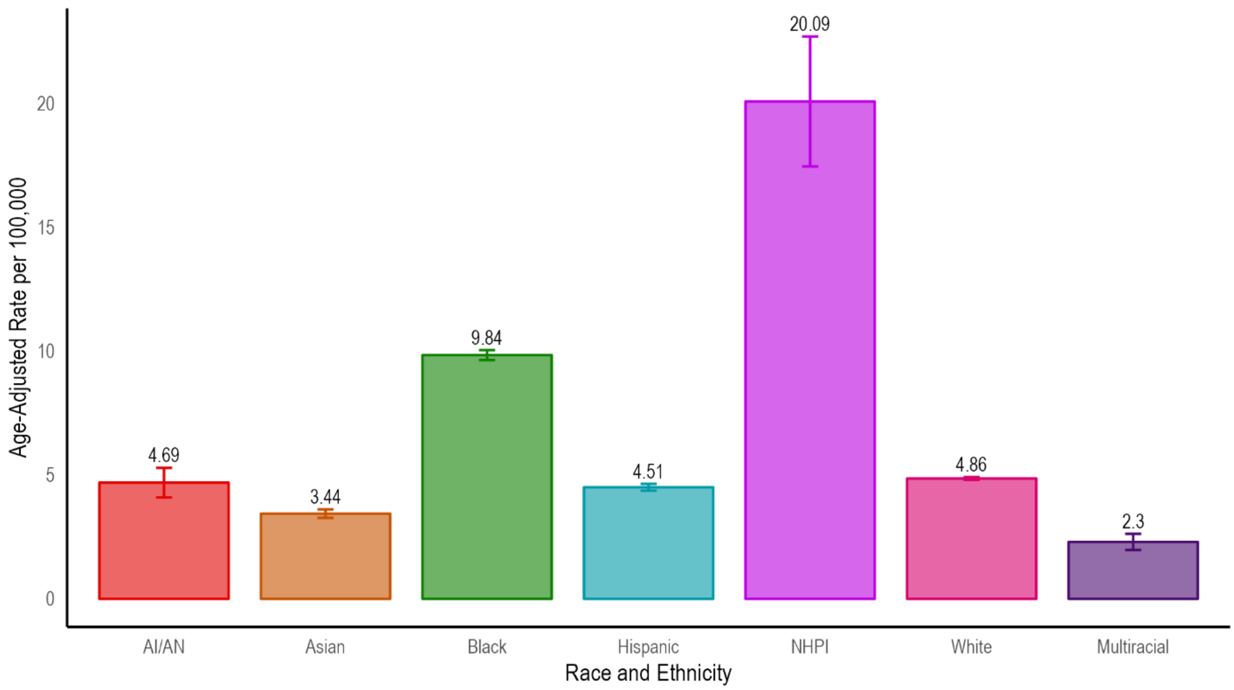

Figure 8-14: Age-adjusted uterine cancer mortality rate per 100,000 women, by race and ethnicity
Source: National Vital Statistics System (NVSS) – Underlying Cause of Death, 2021

In fact, women with NHPI ancestry in the U.S. and around the globe experience the highest risk of developing uterine cancer.[73] In the U.S., Black women experience the next lowest survival outcome, with AI/AN, White, Asian, Hispanic, and Multiracial following thereafter. Much of the disparity in survival rates is attributable to later-stage diagnoses among women of underrepresented racial and ethnic communities.

Despite the consistent documentation of notable racial disparities in uterine cancer prevalence, incidence, and mortality, there continues to be a knowledge and intervention gap. This limits efforts to address the role of healthcare systems in early diagnosis, qualitative studies to capture the perspective of women of underrepresented racial and ethnic communities diagnosed with endometrial cancer and uterine cancer at large, and lack of intervention studies to reduce persistent treatment inequities by race.[74]

8.3.1.2.2 Ovarian Cancer

Figure 8-15 shows the age-adjusted ovarian cancer incidence rate per 100,000 women, by race and ethnicity, and age at diagnosis, using SEER for 2016-2020. It shows that women of all racial and ethnic groups experience an increased risk for ovarian cancer with age. At ages 70-79, AI/AN women experience the highest incidence of ovarian cancer (48 cases per 100,000 women) compared with women of all other racial and ethnic groups. Prior to age 70, women of all racial and ethnic groups experienced a similar rate of increase in ovarian cancer incidence, excluding API women whose rates largely plateaued at 25 per 100,000 cancers from ages 50-59 onward.

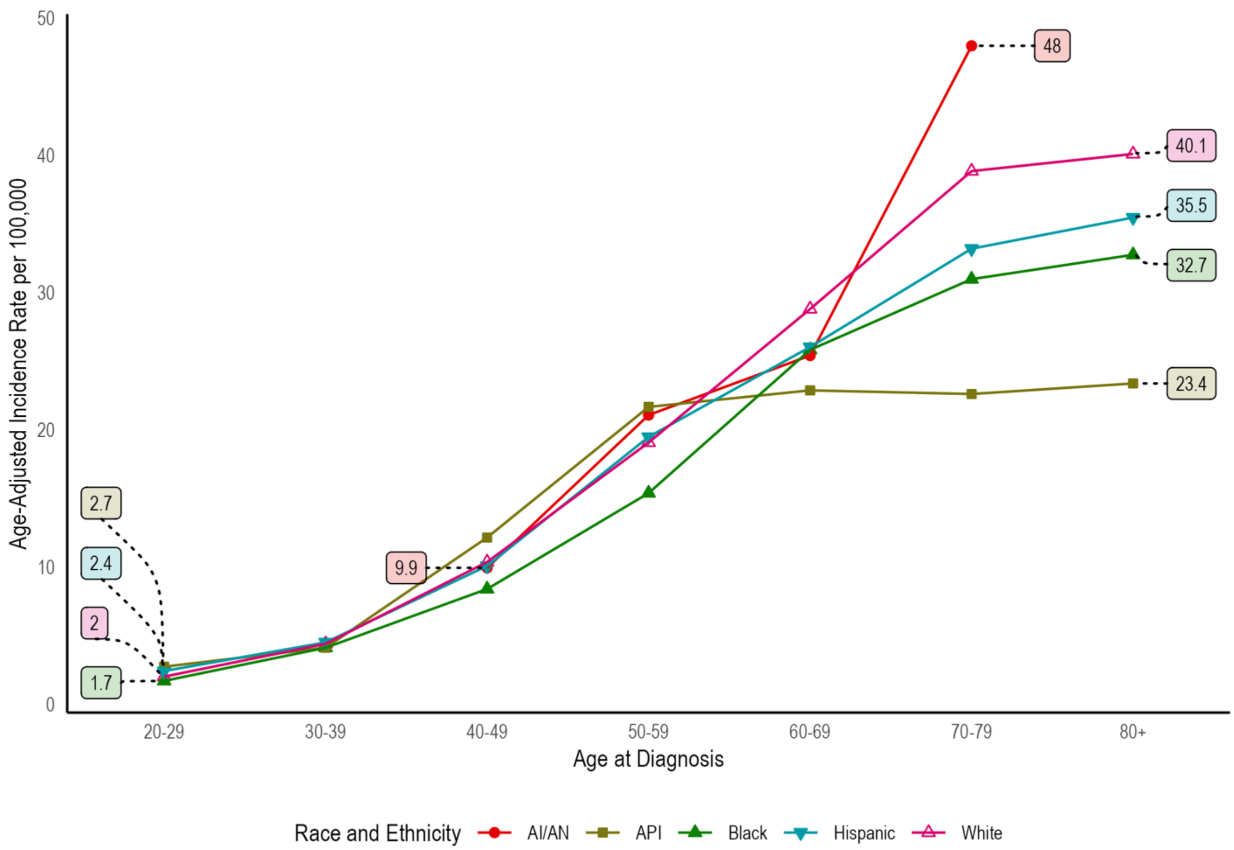

Figure 8-15: Age-adjusted ovarian cancer incidence rate per 100,000 women, by race and ethnicity, and age at diagnosis

Source: Surveillance, Epidemiology, and End Results (SEER), Pooled 2016-2020

As noted for other cancer subtypes, these statistics aggregate Asian women with NHPI women despite their heterogeneity. Studies reveal that, historically, Asian American women who are of Indian or Pakistani descent have had the highest rate of ovarian cancers, while Korean women had the lowest incidence.[75] Genetic testing proves unequivocally useful for ovarian cancer detection and universal testing has been recommended for women with ovarian cancer since 2013. Access to and utilization of genetic testing rates is low among Black women, women experiencing poverty, or women lacking insurance.[76]

Ovarian cancer is most commonly diagnosed in the distant stage (**Figure 8-16**). This holds true across race and ethnicity, with the majority of ovarian cancer diagnoses among Black, AI/AN, and White women occurring in the distant stage compared with just under half among API and Hispanic women.

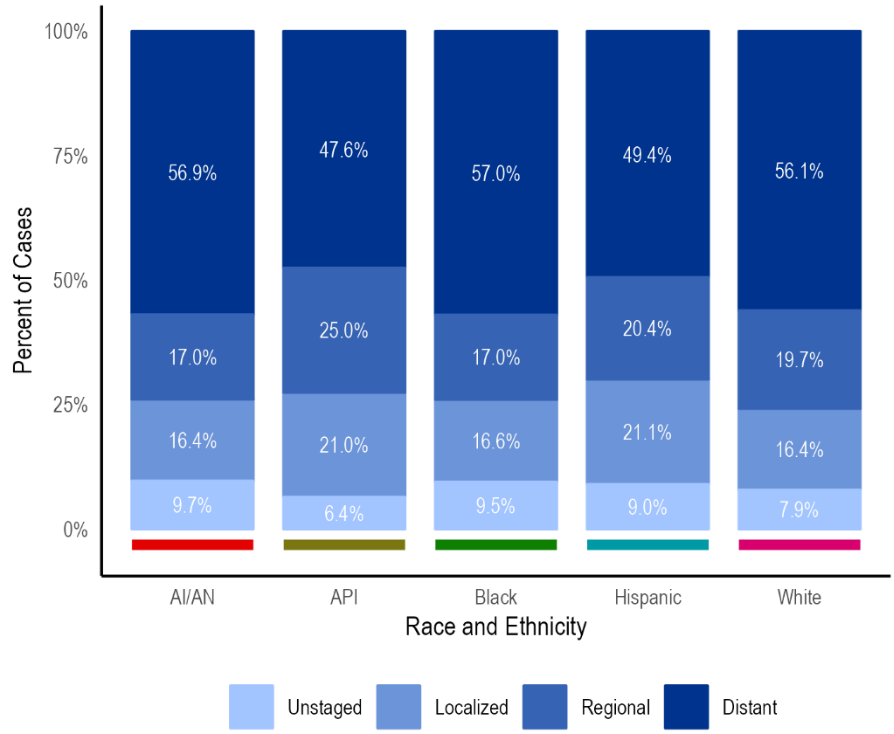

Figure 8-16: Percent of ovarian cancer cases, by race and ethnicity, and stage at diagnosis

Source: Surveillance, Epidemiology, and End Results (SEER), Pooled 2011-2020

Disparities in receipt of guideline-adherent care have been well documented: Black women are less likely to receive ovarian cancer that matches national guidelines, have less access to experienced specialty surgeons, and have a high comorbidity burden.[77,78] Studies show that these disparities are largely mitigated when comparable treatments are received, which means the difference in ovarian cancer survival is primarily attributed to unequal access to quality care, a consequence of lower SES, differences in health insurance, and other factors.[79]

SEER data also provides a comparison of five-year ovarian cancer relative survival rate, by race and ethnicity, and stage at diagnosis (**Figure 8-17).** For ovarian cancer, a consistently lower five-year survival at later stages of diagnosis is apparent. Black women again have lowest survival across most points of comparison. For unstaged cancers, White women have the lowest survival rate.

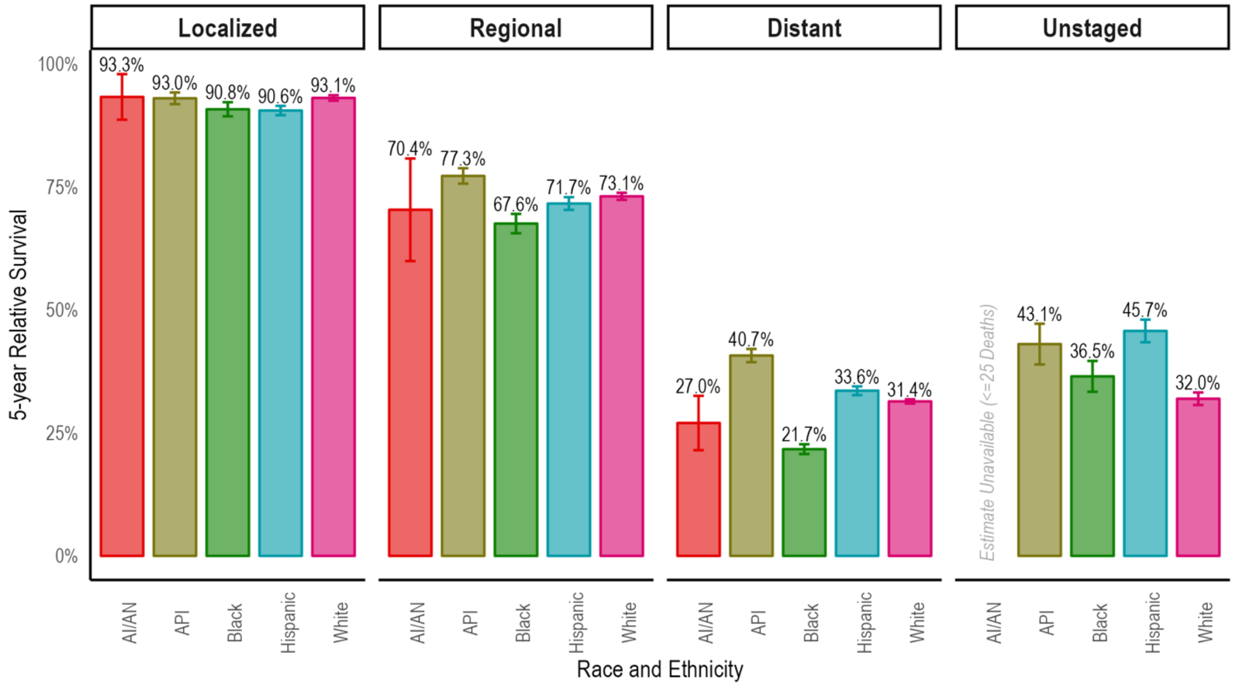

Figure 8-17: Five-year ovarian cancer relative survival rate, by race and ethnicity, and stage at diagnosis

Source: Surveillance, Epidemiology, and End Results (SEER), Pooled 2013-2019

The highest ovarian cancer mortality rates in 2021 were among White women (6.37 deaths per 100,000 women), followed by AI/AN women (5.89 deaths per 100,000 women) and Black women (5.51 deaths per 100,000 women) (**Figure 8-18**). Due to relatively small sample sizes, the estimates for the age-adjusted rate of ovarian cancer mortality among AI/AN and Multiracial women correspond with larger standard errors.

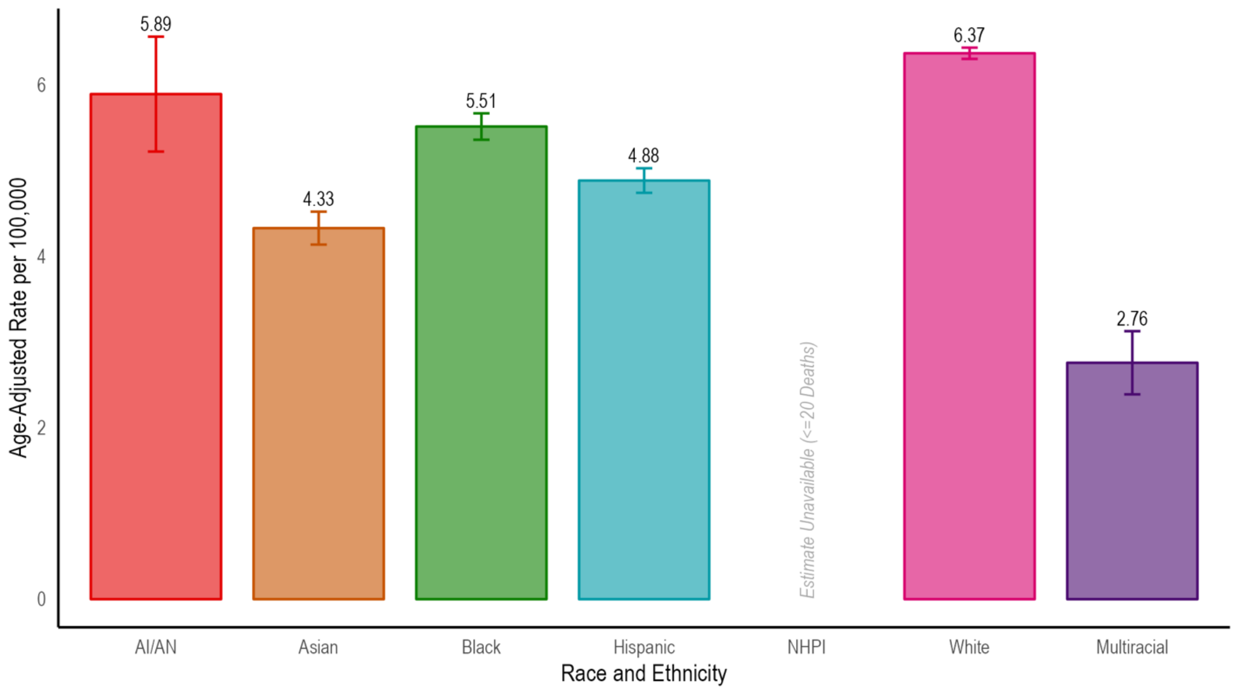

Figure 8-18: Age-adjusted ovarian cancer mortality rate per 100,000 women, by race and ethnicity
Source: National Vital Statistics System (NVSS) – Underlying Cause of Death, 2021

Studies examining ovarian and uterine cancer rates within the Indian Health Service (IHS) regions found that among AI/AN women in the Pacific Coast and Southern Plains, ovarian cancer mortality is higher; in the Northern Plains, uterine cancer mortality is higher in AI/AN women.[80] The burden of ovarian and other cancers in AI/AN women may be even higher than evident in these data, resulting from such classification and collection issues.[81]

8.3.1.2.3 Cervical Cancer

Reported levels of up-to-date cervical cancer screening are observed across racial and ethnic groups, though they are highest among White women (83.8%) and lowest among Asian women (67.2%), as shown in **Figure 8-19**. Estimates for AI/AN and Multiracial women are consistent with other racial and ethnic groups but given the smaller sample size, the standard errors of the estimates are larger for these two groups.

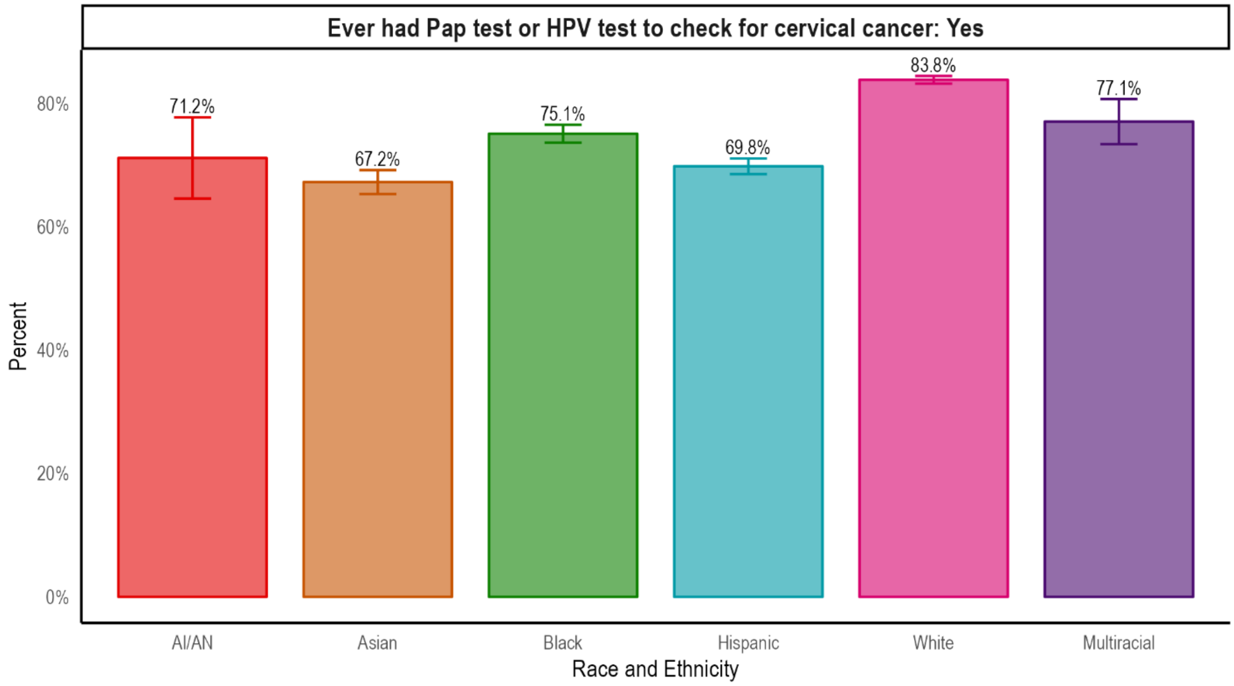

Figure 8-19: Percent of women who report ever being screened for cervical cancer, by race and ethnicity

Source: National Health Interview Survey (NHIS), 2021

Figure 8-20 shows the percent of women who report receiving a Pap or HPV test at their most recent cervical cancer screening, by race and ethnicity. More than 90% of women across racial and ethnic groups report having a Pap test at their most recent screening. The lowest percentage was among Hispanic women (90.5%), while the highest was among Multiracial (95.3%) and AI/AN (94.3%) women. Across all groups, a small percentage of women reported not knowing whether they had received a Pap test, though this was more common among Asian and Hispanic women. Recent HPV tests were less common than Pap tests across all groups, with White (28.7%) and AI/AN (28.9%) women being least likely to report having been tested. Black women were least likely (14.8%) and Asian women were most likely (22.3%) to report not knowing whether they had received an HPV test at their most recent cervical cancer screening. These findings echo results of other studies showing low rates of follow-up after abnormal cervical cancer screening by Black women and delayed follow-up by Black and Hispanic women.[82]

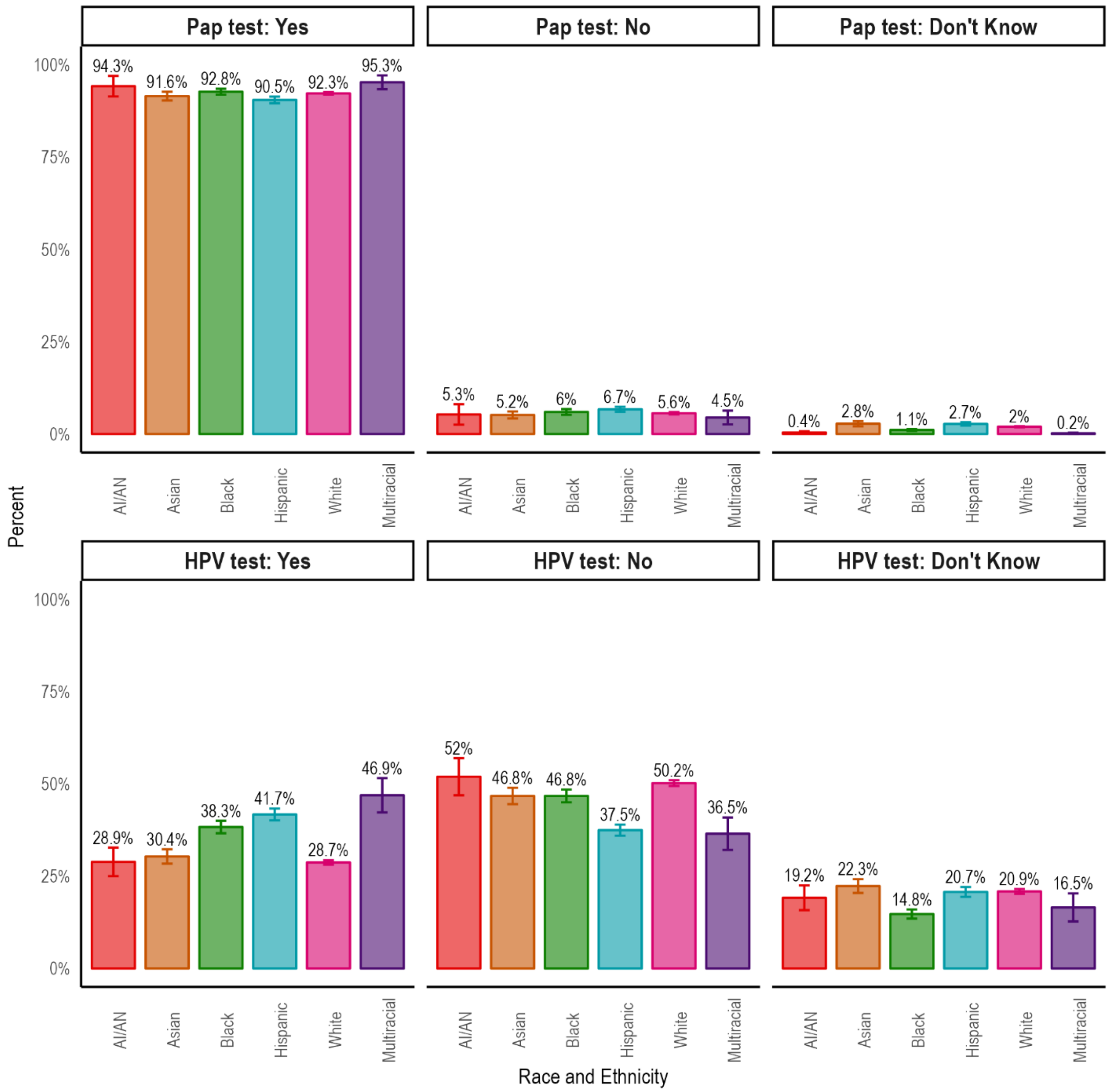

Figure 8-20: Percent of women who report receiving a Pap or HPV test at their most recent cervical cancer screening, by race and ethnicity

Source: National Health Interview Survey (NHIS), 2021

Most cases of invasive cervical cancer result from underscreening or failure to follow up on abnormal screens. More than half of patients diagnosed with cervical cancer in the U.S. have never been screened or been inadequately screened, and underscreening is associated with advancing stage at diagnosis.[83,84] Older age, Black or Asian race, Hispanic ethnicity, low English-language proficiency, rural residence, and being underinsured or uninsured are factors associated with underscreening.[85,86] Nearly one-quarter of women with an abnormal cervical cancer screening test do not receive diagnostic follow-up putting them at risk for the untreated precancerous lesions that can progress to cancer.[87] **Figure 8-21** reveals differences in cervical cancer stage at diagnosis by stage, and race and ethnicity. Diagnoses during the localized stage are the most common, with the lowest percentage of localized disease observed among

Black women (34.2%). Diagnoses in the regional stage account for more than a third of diagnoses across race and ethnicity, and are most common among Black women, followed by API, AI/AN, and Hispanic women and least common among White women. Black women were more likely than women of other groups to receive a distant stage diagnosis, accounting for nearly 1 in 5 diagnoses.

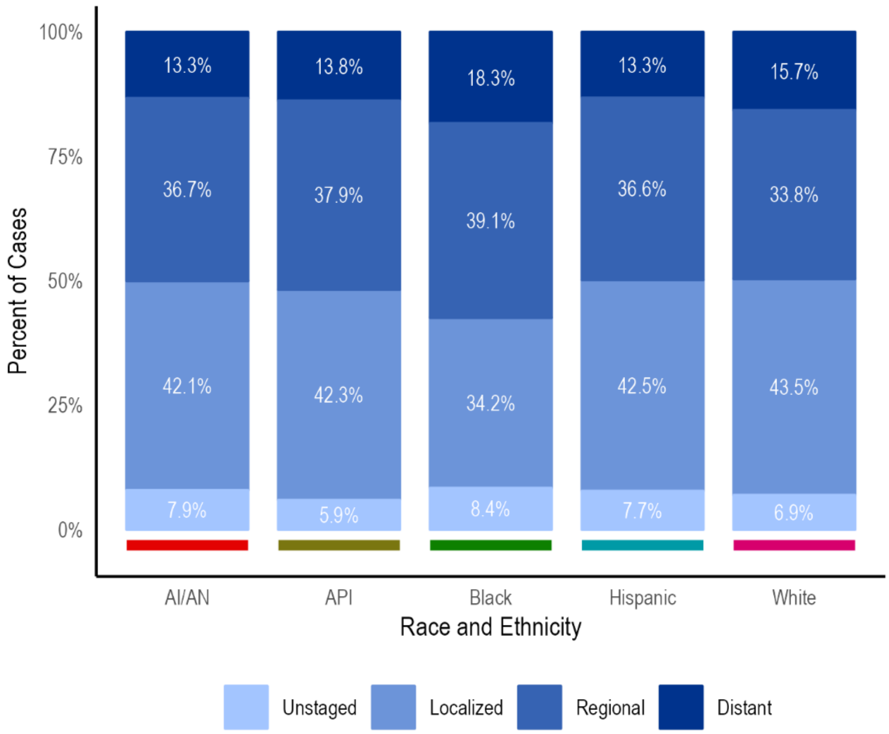

Figure 8-21: Percent of cervical cancer cases, by race and ethnicity, and stage at diagnosis
Source: Surveillance, Epidemiology, and End Results (SEER), Pooled 2011-2020

Figure 8-22 shows age-adjusted cervical cancer incidence rate per 100,000 women, by race and ethnicity, and age at diagnosis. Data are available for women starting at age 20, as cases at younger ages are exceedingly rare. As shown in the figure, the highest incidence of cervical cancer for most racial and ethnic groups can be observed between the ages of 40 and 49. Notably, AI/AN women of reproductive age experienced the highest age-adjusted incidence.

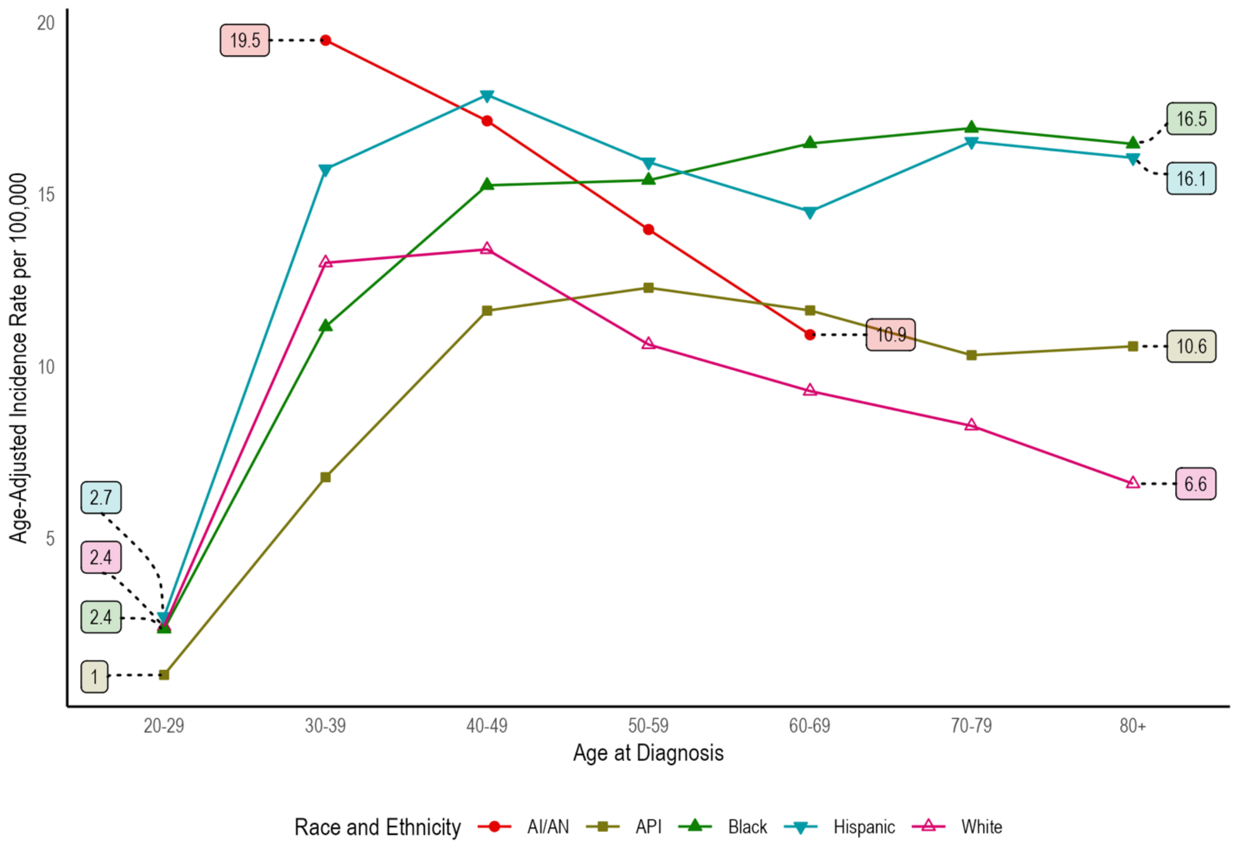

Figure 8-22: Age-adjusted cervical cancer incidence rate per 100,000 women, by race and ethnicity, and age at diagnosis

Source: Surveillance, Epidemiology, and End Results (SEER), Pooled 2016-2020

The disparities for AI/AN women may be explained by lower rates of screening due to social and structural barriers to care. AI/AN women face many of the same barriers to screening as other underserved racial and ethnic communities, which include lack of transportation, lack of childcare options, negative perception of Western medicine and its providers, and experiences of poor patient-provider communication. They may face an added layer of barriers, as IHS and tribal health providers are challenged by a health system that is designed primarily for acute and episodic care (see **Chapter 4**).[88,89]

The difference in cervical cancer five-year survival rates across race and ethnicity, and stage at diagnosis is illustrated in **Figure 8-23.** The data reveal a pattern of decreasing survival with increasing stage at diagnosis and age. As with the other types of cancer discussed in this chapter, Black women have lower cervical cancer survival at every point of comparison, though it is notable that where data are available for AI/AN women, the standard error interval overlaps with those for Black women for localized and distant stage diagnoses.

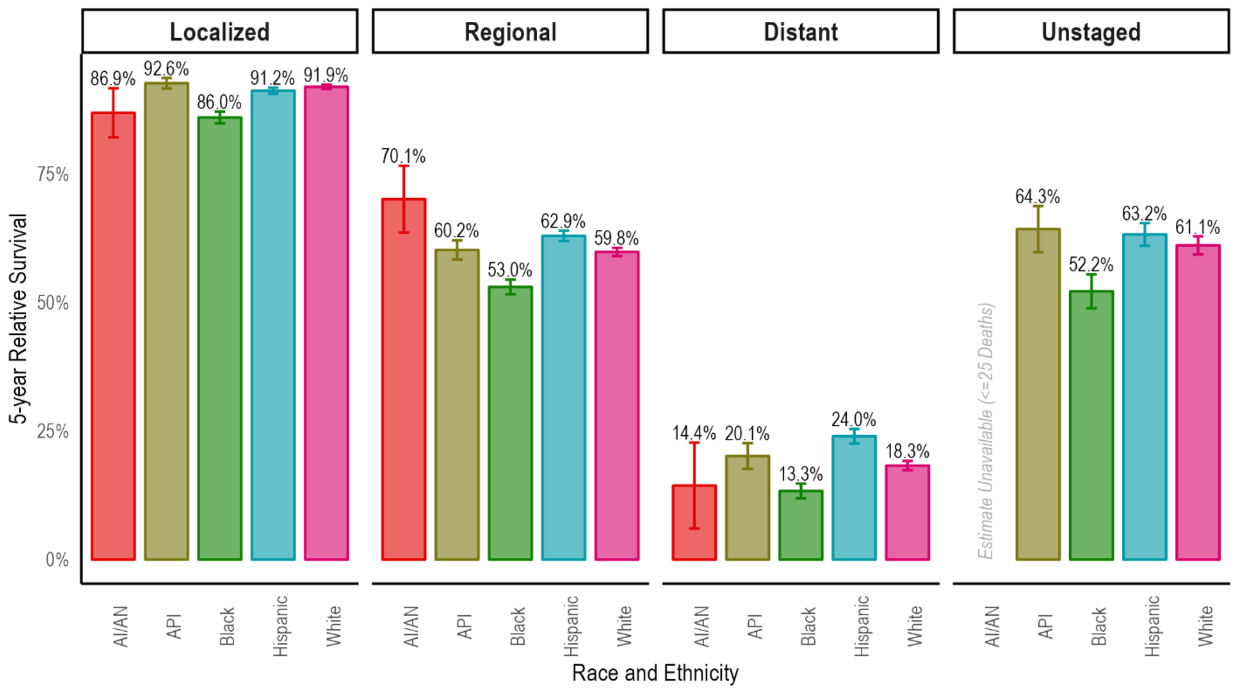

Figure 8-23: Five-year cervical cancer relative survival rate, by race and ethnicity, and stage at diagnosis

Source: Surveillance, Epidemiology, and End Results (SEER), Pooled 2013-2019

Black women are 75% more likely to die from cervical cancer compared with White women.[85] Additionally, Black women and women of other underrepresented racial and ethnic communities continue to experience significant barriers to standard cancer therapies, which further perpetuates a cycle of poor access to life-extending therapies, decreased screening and enrollment in clinical trials, and limited treatment options.[90] This contributes to cervical cancer having one of the largest cancer survival rate gaps for Black women. As shown in **Figure 8-24**, the age-adjusted cervical cancer mortality rates for 2021 also reveal differences by race and ethnicity. AI/AN women had the highest rate of mortality from cervical cancer (4.11 deaths per 100,000 women), followed by Black women (3.26 deaths per 100,000 women). Rates for Hispanic and White women were just over 2 deaths per 100,000 women. The lowest cervical cancer mortality rates were among Asian women (1.75 deaths per 100,000 population) and Multiracial women (1.36 deaths per 100,000 women). An estimate for NHPI women was not available due to the small number of recorded deaths, i.e., fewer than 20.

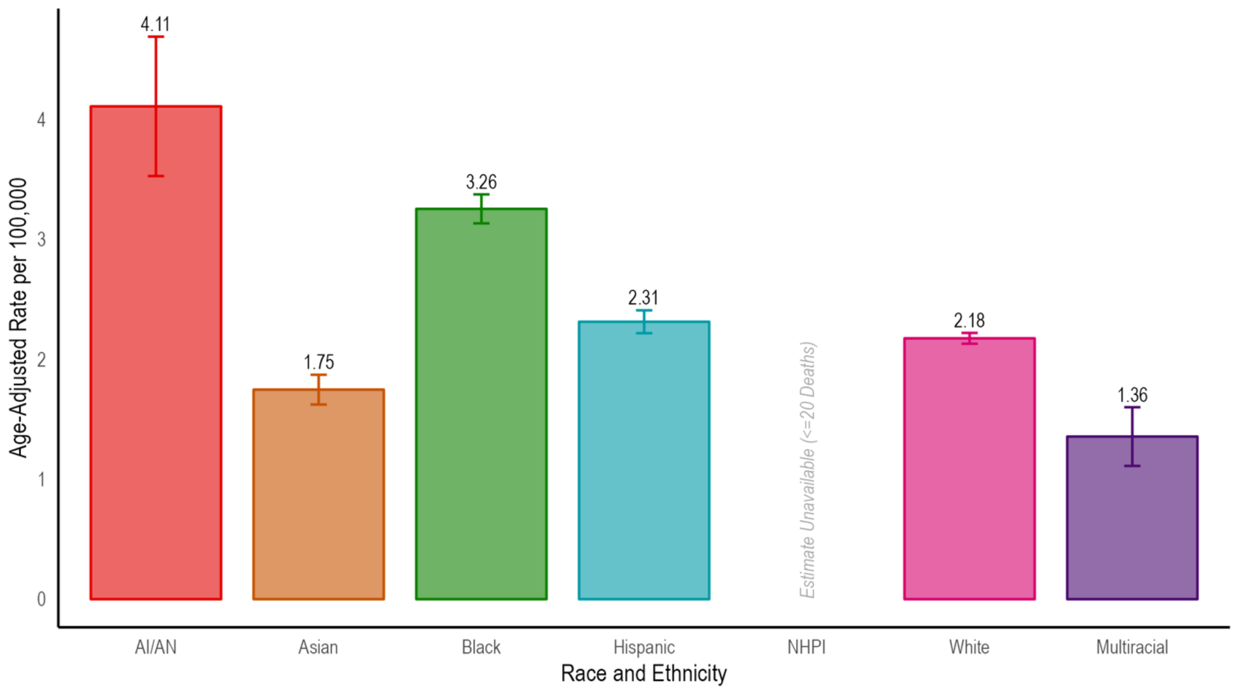

Figure 8-24: Age-adjusted cervical cancer mortality rate per 100,000 women, by race and ethnicity
Source: National Vital Statistics System (NVSS) – Underlying Cause of Death, 2021

8.3.1.2.4 Other Gynecologic Cancers

Vaginal and vulvar cancers are relatively rare, but still affect a subset of women. While a primary diagnosis of vaginal cancer is especially rare (it is defined as a "disease without evidence of cervical or vulvar cancer or history of either within the past five years"), it can occur both as a primary and as a metastasis from distant sites including the colon, pancreas, and breast.[91] **Figure 8-25** shows the age-adjusted vaginal cancer mortality rate per 100,000 women over time, by race and ethnicity, from 2010-2021. While the standard error intervals overlap for several of the years, the overall trend shows that Black women experienced the highest rates of vaginal cancer, followed by White women and Hispanic women.

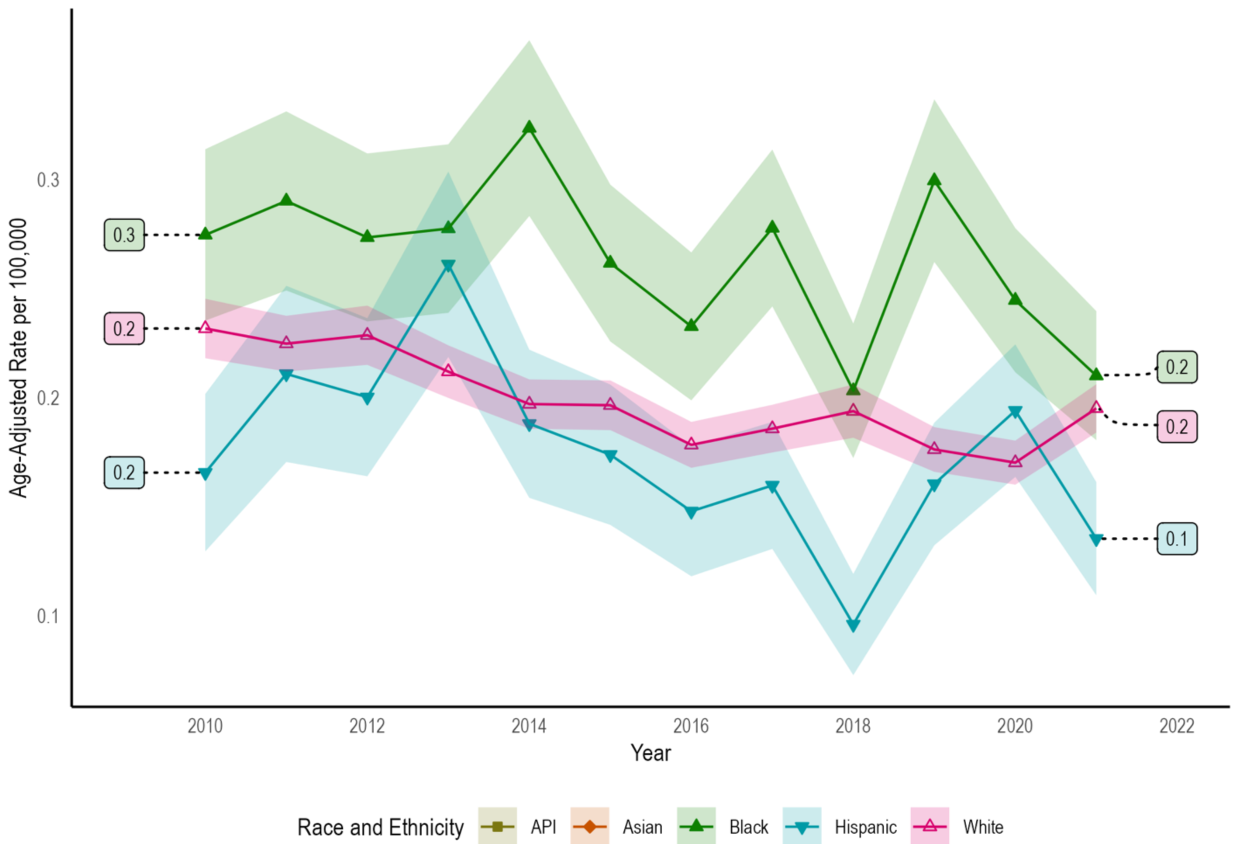

Figure 8-25: Age-adjusted vaginal cancer mortality rate per 100,000 women over time, by race and ethnicity

Source: National Vital Statistics System (NVSS) – Underlying Cause of Death, 2010-2021

Vulvar cancer is becoming more common as the population ages because it is primarily a disease that affects older women.[92] As shown in **Figure 8-26,** vulvar cancer mortality rates are increasing for all racial and ethnic groups except for Asian women. White women consistently show the highest rate over time, reaching a peak of 0.7 per 100,000 in 2021.

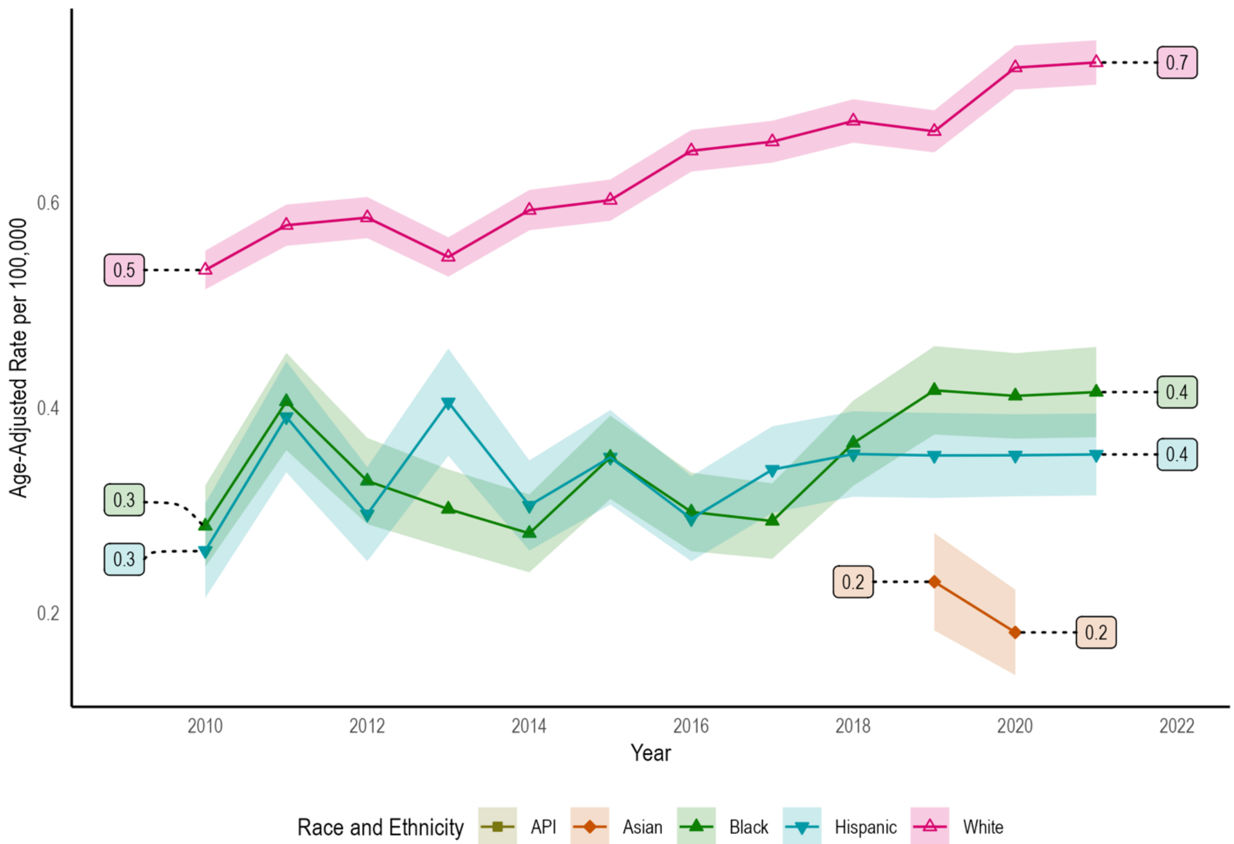

Figure 8-26: Age-adjusted vulvar cancer mortality rate per 100,000 women over time, by race and ethnicity
Source: National Vital Statistics System (NVSS) – Underlying Cause of Death, 2010-2021

8.3.2 Other Intersectional Considerations Relevant to U3 Women

There are other considerations that should be taken into account to understand the impact of cancer on U3 women. Rurality, economic status, and sexual orientation are discussed below.

8.3.2.1 Rurality

The rates, drivers, and determinants of cancer subtypes in U3 women are the result of intersectional dynamics and exacerbating factors. **Figure 8-27** shows the age-adjusted breast cancer mortality rate per 100,000 women, by race and ethnicity, and rurality. The data demonstrate comparable mortality rates within racial and ethnic groups except for AI/AN women for whom the urban-rural divide does reveal a difference, with women in rural areas experiencing higher rates of mortality. However, other research demonstrates that people of underrepresented racial and ethnic communities experience greater poverty and lack of access to care in rural areas, which exposes these populations to elevated cancer risks and poor survival outcomes.[93] For example, one study found adverse impacts of rurality combined with low SES evident when examining the breast cancer survival rates.[94] Other research has found that U3 women residing in rural settings experience higher cancer incidence and lower survival rates associated with lower rates of cancer screening and socio-structural risk factors.[70,95,96]

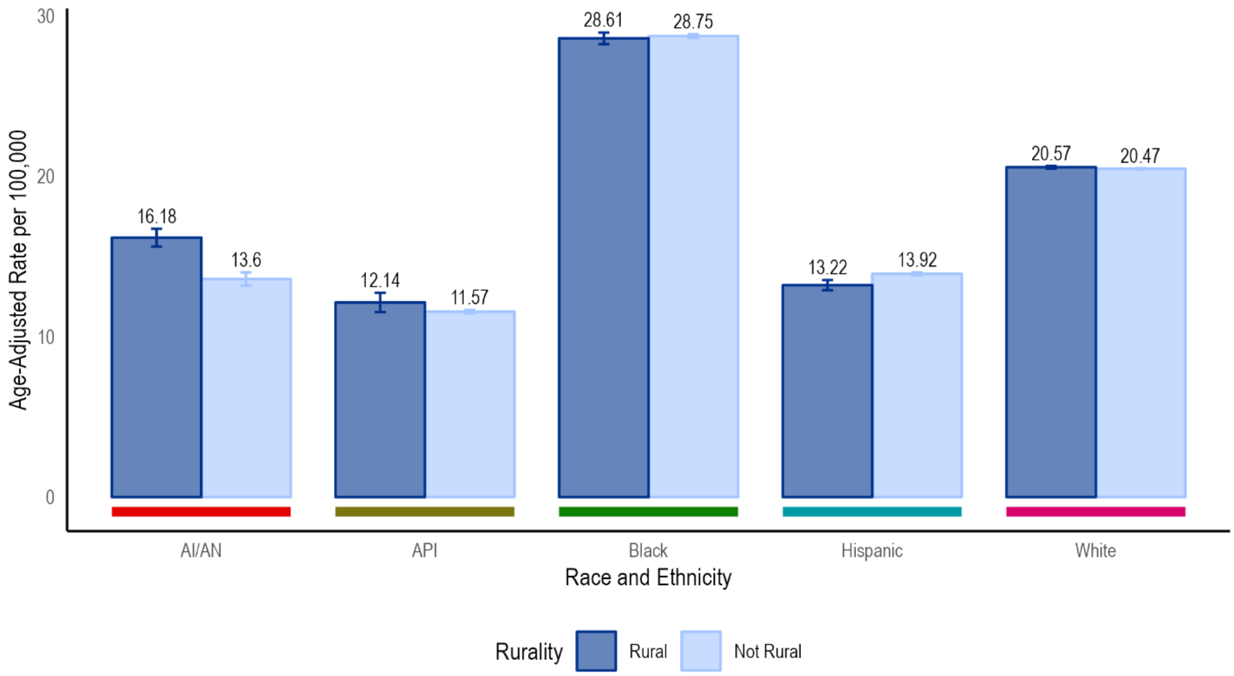

Figure 8-27: Age-adjusted breast cancer mortality rate per 100,000 women, by race and ethnicity, and rurality

Source: National Vital Statistics System (NVSS) – Underlying Cause of Death, Pooled 2010-2020

Extant analysis of SEER data shows that Black and Hispanic women have increased odds of breast cancer mortality, even when rurality is considered.[60] Similar results are observed for uterine cancers. As shown in **Figure 8-28**, uterine cancer (endometrial and other) mortality rates are comparable by rurality for AI/AN, Hispanic, and White women. For API and Black women, there is a marked difference, which indicates higher mortality among API women in rural areas compared with those in non-rural areas, and the inverse relationship for Black women (i.e., lower mortality rates in rural areas).

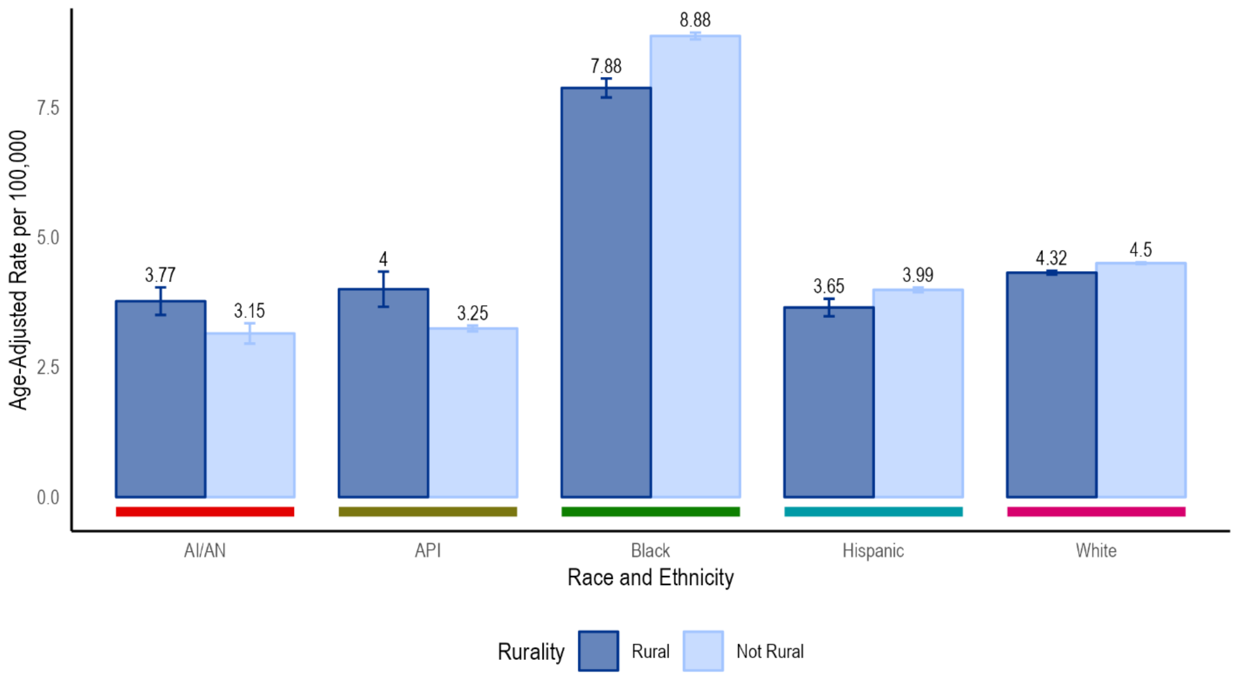

Figure 8-28: Age-adjusted uterine cancer mortality rate per 100,000 women, by race and ethnicity, and rurality

Source: National Vital Statistics System (NVSS) – Underlying Cause of Death, Pooled 2010-2020

Data presented in **Figure 8-29** show that the influence of rurality on ovarian cancer is not consistent across racial and ethnic groups. For AI/AN women in rural areas the mortality rate is nearly 40% higher than that for women in non-rural areas. Among Hispanic and White women, the mortality rates are higher for women in non-rural areas. The rates are similar by rurality for API and Black women. These findings differ from literature demonstrating overwhelming evidence that women who live in rural settings have poorer ovarian cancer survival rates than women with similar characteristics who live in non-rural settings.[95,96] Patients in non-rural settings are also more likely to have necessary surgery and cancer care performed by a gynecologic oncologist as compared with patients in rural areas.[95,96]

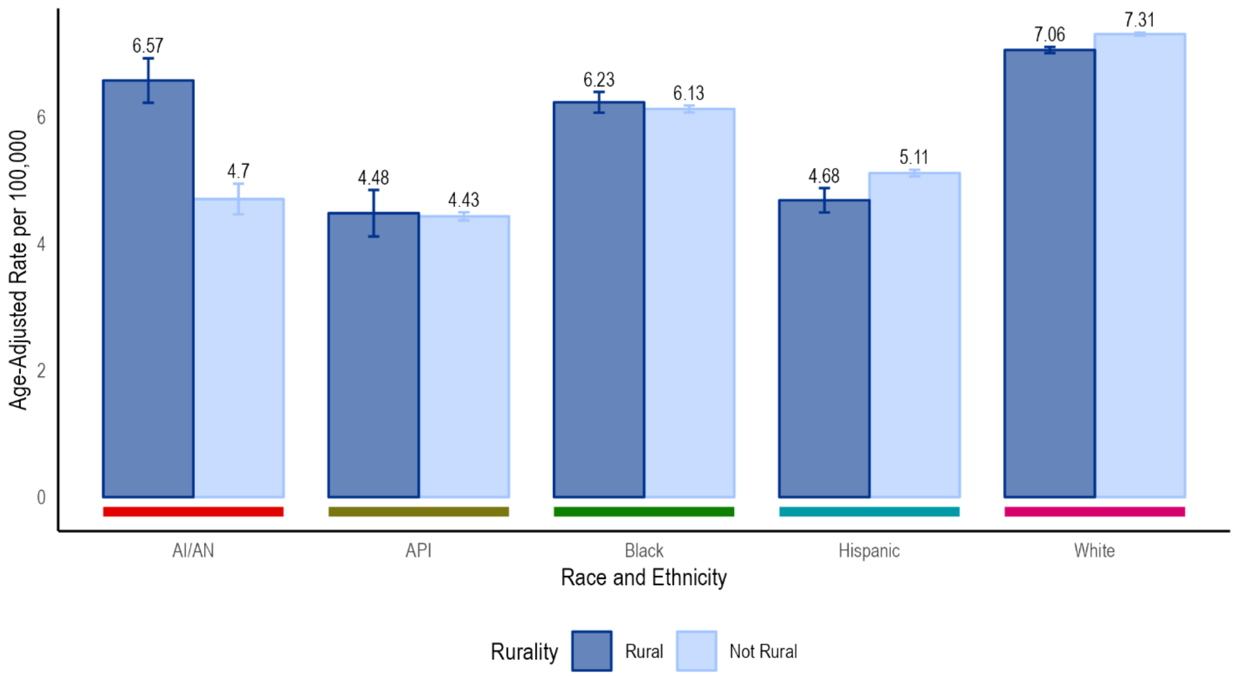

Figure 8-29: Age-adjusted ovarian cancer mortality rate per 100,000 women, by race and ethnicity, and rurality
Source: National Vital Statistics System (NVSS) – Underlying Cause of Death, Pooled 2010-2020

Rurality also influences mortality rates for cervical cancer, though not equally across racial and ethnic groups, as shown in **Figure 8-30**. For all groups except Hispanic women, mortality rates from cervical cancer are higher in rural areas compared to areas that are not rural. The largest difference is seen among AI/AN women in rural areas, whose mortality rate (3.38 deaths per 100,000 women) is nearly double that of AI/AN women in non-rural areas (1.8 deaths per 100,000 women). Black women in rural areas have the highest mortality rate over all (4.44 deaths per 100,000 women).

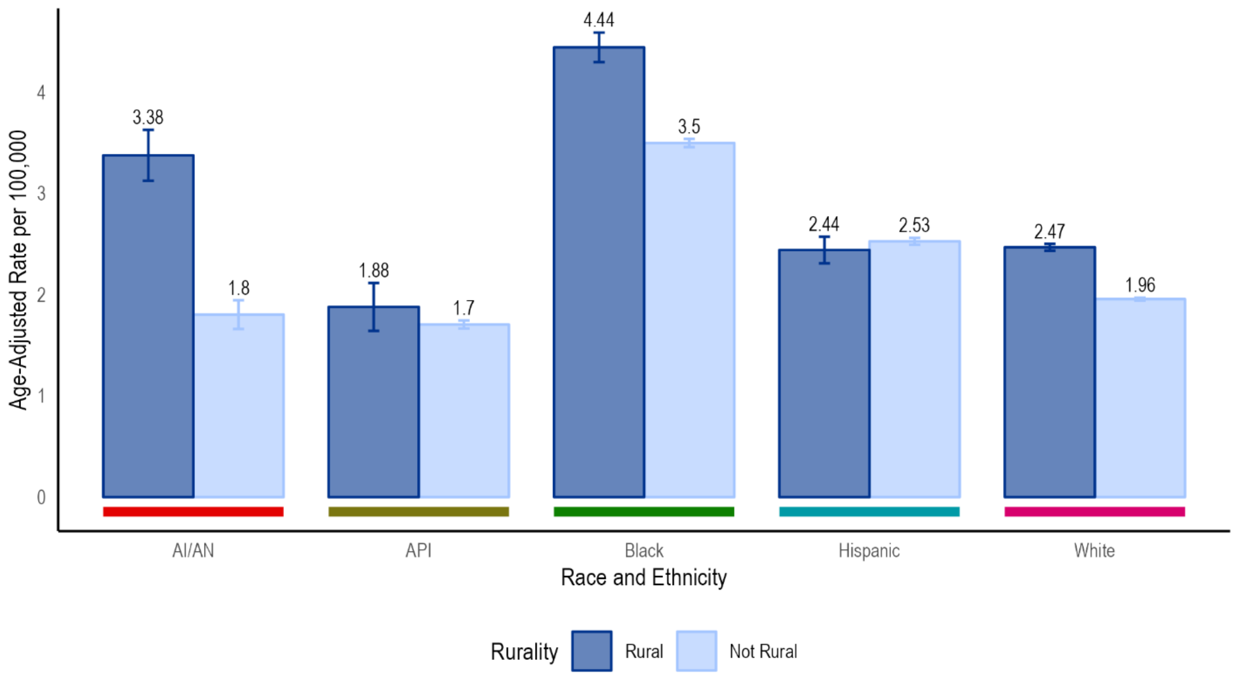

Figure 8-30: Age-adjusted cervical cancer mortality rate per 100,000 women, by race and ethnicity, and rurality

Source: National Vital Statistics System (NVSS) – Underlying Cause of Death, Pooled 2010-2020

These trends can largely be attributed to prevalence of cancer risk behaviors in rural areas that coincide with AI/AN reservations, low healthcare access, suboptimal cancer screening rates, less cancer therapy access, and overall poorer cancer treatment outcomes.[97]

8.3.2.2 Economic Status

Economic status influences access to and likelihood of receiving cancer screening, receiving a timely cancer diagnosis, access to the full range of cancer services/treatment options, and chances of survival. **Figure 8-31** shows that women who are economically disadvantaged are more likely to report having ovarian cancer diagnoses compared with women who are economically advantaged. However, for all but White and AI/AN women, the difference is small. Relatively large standard errors limit definitive conclusions across different racial and ethnic groups.

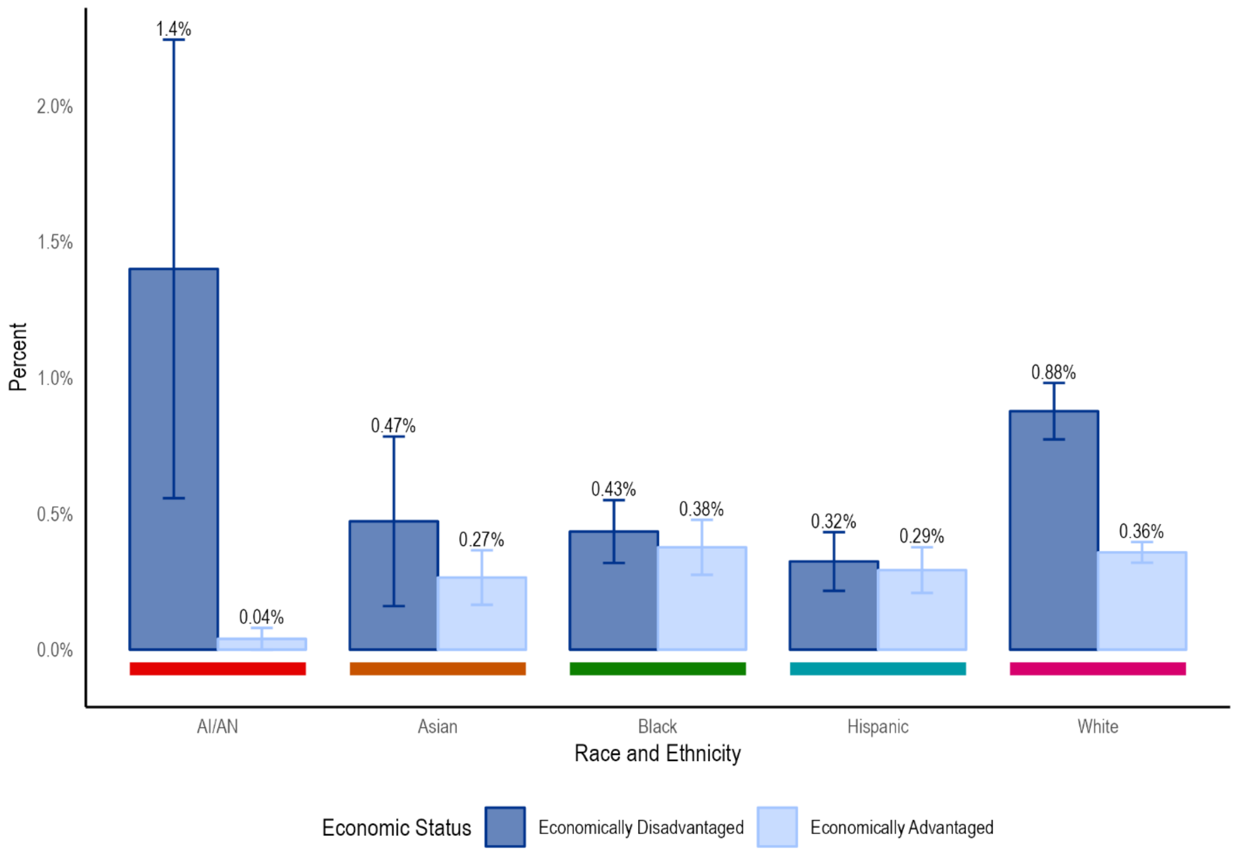

Figure 8-31: Percent of women who report an ovarian cancer diagnosis, by race and ethnicity, and economic status

Source: National Health Interview Survey (NHIS), Pooled 2019-2022

Figure 8-32 shows the percent of women who report a cervical cancer diagnosis, by race and ethnicity, and economic status. For all groups except White women, economic status does not appear to influence risk of cervical cancer. For all women, those who are economically disadvantaged were more likely to have cervical cancer compared with those who are economically advantaged apart from the population of Asian women, which showed essentially no difference by economic status. These results should be interpreted with caution as sample sizes are relatively small, contributing to large standard errors. Given the noted barriers to screening and specialist care, the data here may underestimate the true prevalence among women who are economically disadvantaged.

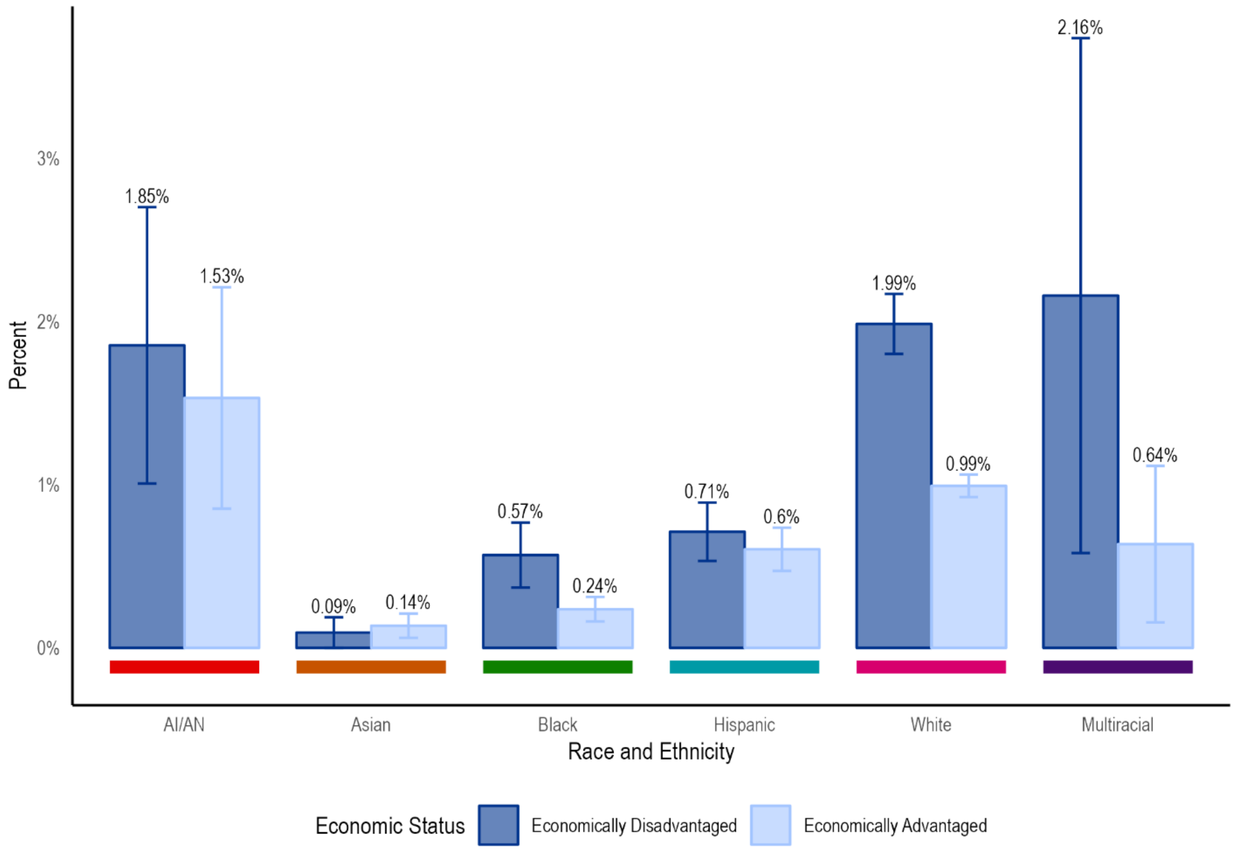

Figure 8-32: Percent of women who report a cervical cancer diagnosis, by race and ethnicity, and economic status

Source: National Health Interview Survey (NHIS), Pooled 2019-2022

Researchers in this area have further examined the macro-linkages between state-wide differences in economic status and associated healthcare investments. They found lower prevalence, lower incidence, more timely diagnosis, effective treatment, and better prognosis for gynecologic cancers.[98]

8.3.2.3 Sexual Orientation

Most large, national-level datasets do not capture cancer data—ranging from screening behaviors and to outcomes—by sexual orientation or gender identity. However, NHIS collects information about sexual orientation, as shown in **Figure 8-33**. The figure shows the percent of women who report an ovarian cancer diagnosis, by race and ethnicity, and sexual orientation (lesbian, bisexual, queer and questioning [LBQ] or heterosexual). Black women who identify as LBQ have a similar prevalence of ovarian cancer compared to White women who identify as LBQ. Both Black and White women who identify as LBQ have a higher prevalence of ovarian cancer relative to LBQ Hispanic women, although the large standard errors limit definitive conclusions. For AI/AN and Asian women, no respondents within the sample identified as bisexual, lesbian, queer, or questioning. As a result, no comparison can be drawn across categories for sexual orientation.

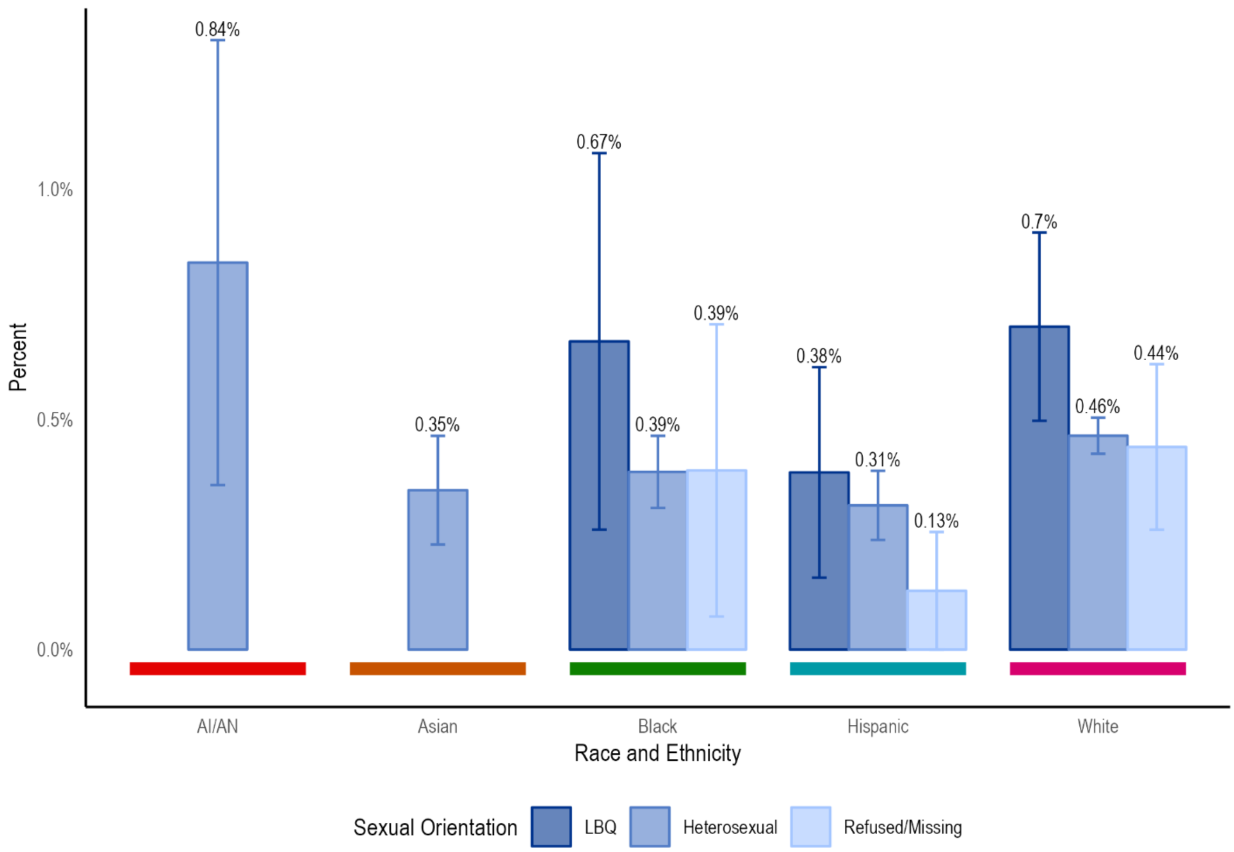

Figure 8-33: Percent of women who report an ovarian cancer diagnosis, by race and ethnicity, and sexual orientation

Source: National Health Interview Survey (NHIS), Pooled 2019-2022

However, recent research reveals a higher prevalence of cancers of the cervix, uterus, ovary, thyroid, bone, skin melanoma, leukemia, and other blood cancers among lesbian and bisexual women compared with heterosexual women.[99] Evidence of cancer prevalence among transgender and non-binary individuals is even more limited. These data limitations reflect a general lack of inclusive data capture, which has downstream impacts on resources available to invest in culturally competent oncology care for lesbian, gay, bisexual, transgender, and queer/questioning (LGBTQ+) individuals across the health system, which include the provision of equitable and appropriate screening and treatment for various cancers and other conditions.

8.4 Conclusions and Future Directions

Available data show that, while overall cancer mortality has steadily declined in the past decade, disparities remain by sex, race and ethnicity, cancer subtype, age at diagnosis, and access to treatment. In some cases, disparities also exist based on rurality, economic status, and sexual orientation. Examining the prevalence, incidence, and mortality rates from breast, uterine, ovarian, and cervical cancers reveal that White women often are diagnosed at higher rates and at earlier stages of the disease while women of underrepresented racial and ethnic communities are diagnosed later and die at higher rates. Additionally, the available data could be further disaggregated to denote key trends in cancer mortality disparities based on geography, immigration status, etc. For example, NHPI women are often grouped with Asian women despite experiencing vastly different incidence and mortality rates, and even the API category hides trends that may help discern the differing survival rates of different Asian women groups, such as Chinese, Japanese, and other Asian women. Efforts to improve data collection and analyses are needed and will improve knowledge about the linkages between cancer rates and other social determinants of health and driving factors unique to women. Together, these will help advance evidence-based practices.

8.5 Data Sources and Definitions

Data for all figures in this chapter can be accessed from the data annex located here: https://orwh.od.nih.gov/sites/orwh/files/docs/Chapter_8.xlsx

National Health Interview Survey (NHIS), 2019-2021

Variable Name	Variable Description	Variable Options
BREASCAN_A	Breast cancer mentioned	**Mentioned**; Not mentioned; Refused; Not Ascertained; Don't Know
CERREASON_A	What was the main reason you had a cervical cancer screening test – was it part of a routine exam, because of a problem, or as a follow-up test of an earlier test or screening exam, or some other reason?	**Part of a routine exam; Because of a problem; Follow-up test of an earlier test or screening exam; Other reason**; Refused; Not Ascertained; Don't Know
CERVICAN_A	Cervical cancer mentioned	**Mentioned**; Not mentioned; Refused; Not Ascertained; Don't Know
CERVICEV_A	There are two different kinds of tests to check for cervical cancer. One is a Pap smear or Pap test and the other is the HPV or Human Papillomavirus test. Have you ever had a test to check for cervical cancer?	**Yes**; No; Refused; Not Ascertained; Don't Know
HPVTEST_A	At your most recent cervical cancer screening, did you have an HPV test?	**Yes**; No; Refused; Not Ascertained; Don't Know
OVARICAN_A	Ovarian cancer mentioned	**Mentioned**; Not mentioned; Refused; Not Ascertained; Don't Know
PAPTEST_A	At your most recent cervical cancer screening, did you have a Pap test?	**Yes**; No; Refused; Not Ascertained; Don't Know

National Vital Statistics System (NVSS) – Underlying Cause of Death, 2010- 2021

Variable Name	Variable Description
ICD-10 113 Cause List	#Neoplasms of breast (C50)
ICD-10 113 Cause List	#Malignant neoplasms of vulva (C51)
ICD-10 113 Cause List	#Malignant neoplasm of vagina (C52)
ICD-10 Codes	#Malignant neoplasm of cervix uteri (C53)
ICD-10 Codes	#Malignant neoplasm of corpus uteri and uterus, part unspecified (C54–C55)
ICD-10 113 Cause List	#Malignant neoplasm of ovary (C56)

Surveillance, Epidemiology, and End Results (SEER), 2010-2020

Variable Name	Variable Description	Variable Options

Site	Primary cancer site	- **Breast**
		- Female Genital System
		  - **Cervix Uteri**
		  - Corpus and Uterus, NOS (Not Otherwise Specified)
		    - **Corpus Uteri**
		    - **Uterus, NOS**
		  - **Ovary**
		  - **Vagina**
		  - **Vulva**
		Other Female Genital Organs

StageAtDiagnosis	Stage At Diagnosis	**Unstaged; Localized; Regional; Distant**

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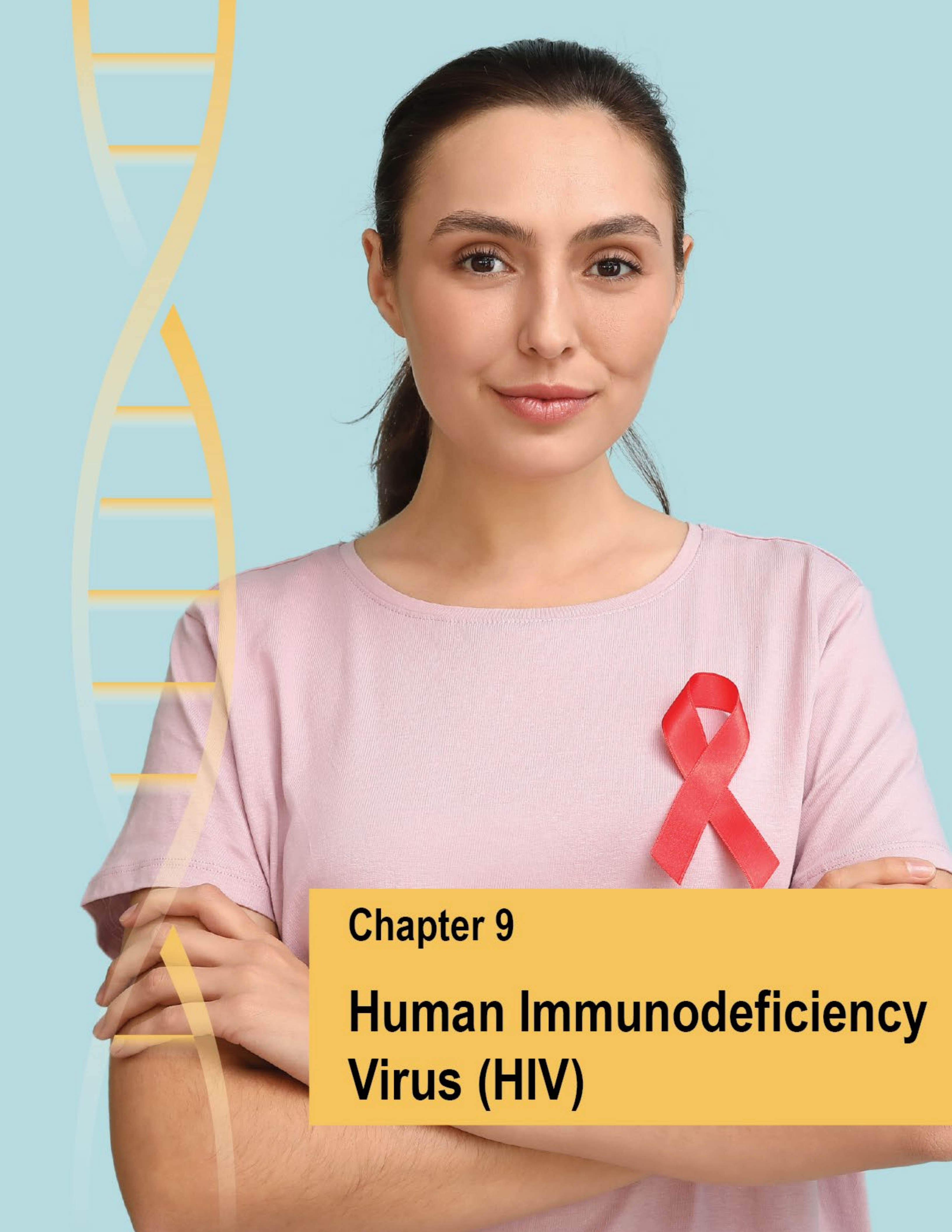

Chapter 9

Human Immunodeficiency Virus (HIV)

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Human Immunodeficiency Virus (HIV)

9.1 Defining Human Immunodeficiency Virus (HIV)

At the end of 2021, there were an estimated 1.2 million people in the U.S. and dependent areas with human immunodeficiency virus (HIV). HIV is a virus that attacks and destroys the CD4 cells of the immune system that fight infection, which in turn makes it difficult to fight off other illnesses, infections, and certain forms of cancer.[1] HIV can be acquired through sex or by sharing needles with someone with HIV who is not virally suppressed through medication, and perinatally during pregnancy, birth, or breast/chestfeeding.[2] Most new HIV acquisitions in the U.S. and dependent areas are through sexual contact and it is estimated that 13% of people with HIV do not know their status.[3,4]

The earliest, or acute, stage of HIV disease typically occurs within two to four weeks following HIV acquisition. During the acute stage the virus rapidly multiplies and spreads throughout the body, resulting in high viral load and the greatest likelihood of transmission.[1] Often during the acute stage people have flu-like symptoms that may last a few days or many weeks, although some people experience no symptoms at all. During the chronic stage, also referred to as asymptomatic or clinical latency, people may have no symptoms but HIV continues to multiply in the body and transmission is possible.[1] If HIV is not treated, it can progress to acquired immunodeficiency syndrome (AIDS), where the immune system is severely damaged and the likelihood of transmission is high.[1]

While there is no cure for HIV, the four decades since the syndrome of diseases later named AIDS was first recognized have brought significant advancements in both treatment and prevention. Antiretroviral therapy is a highly effective treatment that can make HIV a chronic, manageable condition and can reduce viral load to an undetectable level that prevents transmission (treatment as prevention).[5] People who maintain an undetectable viral load (viral suppression) can stay healthy long term and cannot transmit HIV, a strategy known as Undetectable = Untransmittable or U=U.[5,6] Multiple highly effective biomedical prevention products including daily oral and long-acting antiretroviral therapy-based pre-exposure prophylaxis (PrEP) are now available in the U.S., further expanding treatment choices and empowering people impacted by HIV.[7,8]

While these advances are encouraging, HIV remains highly stigmatized which is a critical barrier to addressing the ongoing epidemic.[3,4,9] Effective prevention requires understanding stigma, as well as the social and structural stressors that create barriers for accessing treatment, prevention, and care among people disproportionately affected by HIV. This includes people of underrepresented racial and ethnic communities, women and girls, and people with diverse sexual orientations and gender expressions.[10,11] The Ending the HIV Epidemic in the U.S. initiative, a collaboration among several U.S. agencies, has a goal of reducing new HIV acquisitions by 75% by 2025 and by 90% by 2030.[8] A number of strategies are critical to achieving this goal, including increasing access to status testing, treatment and viral load monitoring, care, and prevention services; eliminating social and structural barriers for accessing these services; and developing models of culturally competent care for people impacted by HIV.[8,12]

9.2 HIV in Women

According to the Joint United Nations Programme on HIV and AIDS (UNAIDS), in 2022 women and girls accounted for more than half (53% or 20.7 million) of the 39 million people with HIV and 46% of new acquisitions globally, with approximately 4,000 adolescent girls and young women aged 15-24 years acquiring HIV on a weekly basis.[13] In the U.S. and dependent areas, data from the Centers for Disease Control and Prevention (CDC) indicate that over 265,000 women were living with HIV and nearly 6,650 women newly acquired HIV in 2021.[14,15,i] New HIV acquisitions in 2021 were highest among women aged 30 to 39 years.[7] HIV is not just a concern of young women: approximately 24% of women diagnosed with HIV in the U.S. in 2021 are over the age of 50.[16] Insufficient consideration of sex, gender, and their intersections in health as well as limited inclusion of women and gender diverse people in health research reduces the availability and accessibility of safe and effective HIV prevention and treatment[17–19] As acknowledged by the Office of Research on Women's Health (ORWH) Advisory Committee on Research on Women's Health: "Prioritizing the inclusion of diverse populations of women in prevention, therapeutic, and cure-related research is an essential component of ending the HIV epidemic."[20]

Women are twice as likely to acquire HIV sexually compared with men, and biological, behavioral, and social factors all contribute to sex differences that make women uniquely vulnerable to HIV.[21,22] These vulnerabilities are exacerbated by gendered social inequalities including stigma around women's sexuality, HIV-related stigma, gendered power inequities in sexual relationships, norms about femininity and purity, and barriers to comprehensive sexual and reproductive healthcare.[23,24] As illustrated in **Figure 9-1,** the overall HIV prevalence rate in women and girls ages 13 and older was 173 per 100,000, and for men and boys ages 13 and older was 598 per 100,000. The National HIV Surveillance System (NHSS) data presented in this figure use the "sex at birth" variable, which offers only binary options ("male" and "female"), while figures presented in **Section 9-26** use the "gender identity" variable. Differences in measures and variables are discussed further in the Data Methodology chapter (see Chapter 3).

[i] The CDC has not updated its web content from 2020 data reports because of the impact of COVID.

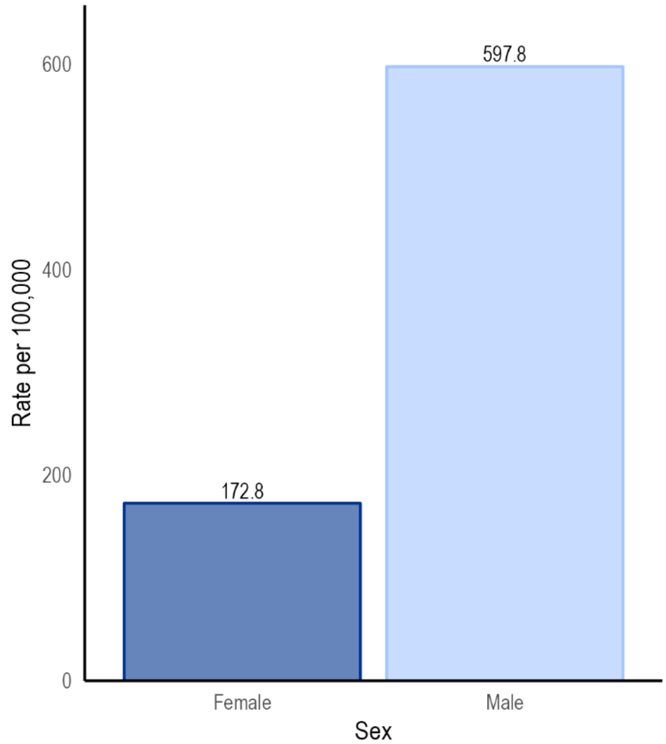

Figure 9-1: HIV prevalence rate per 100,000 population aged 13 and older by sex
Source: National HIV Surveillance System (NHSS), 2021

Figure 9-2 shows the rate of new diagnoses (incidence) in the U.S. in 2021 was 4.5 times higher among men than among women. While both prevalence and incidence of HIV are higher among men, it is critical to understand the specific ways that women are affected by HIV. A 2021 analysis of MACS-WIHS Combined Cohort Study data found women with HIV had a higher mean number of non-AIDS comorbidities than women without HIV, and higher prevalence of psychiatric illness, dyslipidemia, kidney, liver, bone disease, and non-AIDS cancer (e.g., cervical cancer caused by co-infection with human papillomavirus [HPV]) (see **Chapter 8**).[25,26] These results highlight that aging-related comorbidities place a higher burden on women with HIV than on men with HIV.[25]

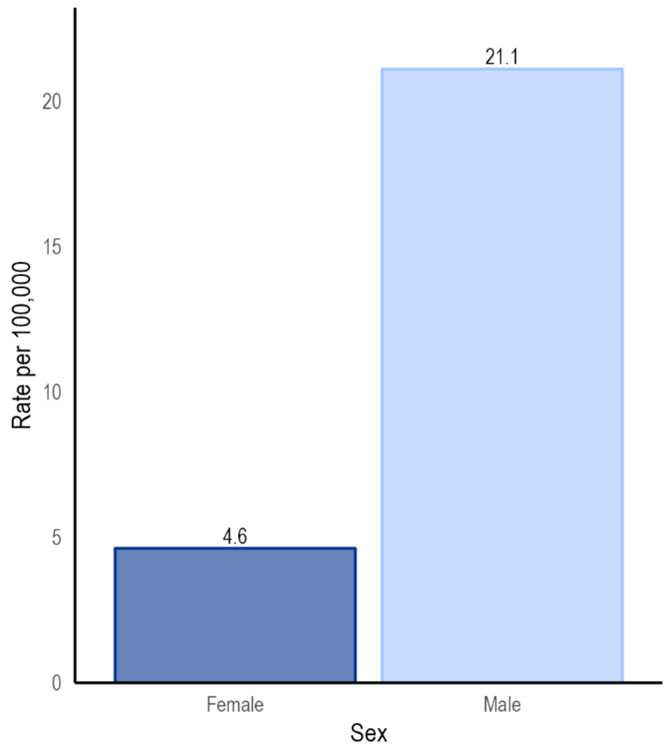

Figure 9-2: HIV incidence rate per 100,000 population aged 13 and older by sex
Source: National HIV Surveillance System (NHSS), 2021

Studies also suggest a strong association between intimate partner violence (IPV) and HIV, with an estimated 55% of women with HIV having experienced IPV, compared with 36% of all women.[27–30] Implications of IPV include limited ability to negotiate safe sex and condom use, which can increase HIV vulnerability for women, especially in instances where sex is not consensual (see **Chapter 14**).[23–25,31–33] The limited inclusion of cisgender and transgender women—especially women of underrepresented racial and ethnic communities— throughout HIV research confines the understanding of this disease among these populations.[34] Recent research recommends network-level HIV prevention interventions should be coupled with structural policy changes that improve access to jobs, education, and housing to address racial and ethnic HIV disparities, which are discussed in greater detail below.[35]

Prevalence data offer estimates of the total cumulative number of "people with HIV [are] alive during a specific time period" (e.g., **Figure 9-1**) and incidence data reflect new acquisitions (e.g., **Figure 9-2)**.[36] The figures above illustrate sex differences in both the prevalence and incidence of HIV, providing a fuller picture of the scale of HIV as a priority public health concern. The balance of this chapter focuses on incidence rates.

9.3 HIV in U3 Women

Women who are understudied, underrepresented, and underreported (U3) in research continue to disproportionately acquire HIV, including Black and Hispanic women; rural women; women economically disadvantaged and living at, near, or below the poverty line; and transgender women.[37–39] The section that follows presents findings on HIV and AIDS among U3 women by race and ethnicity, rurality, economic status, and sexual orientation and gender identity, including vulnerabilities and protective factors.

9.3.1 HIV Among Women of Underrepresented Racial and Ethnic Communities

HIV disproportionately impacts women of underrepresented racial and ethnic communities, and these disparities continue even in the context of overall declines in new diagnoses.[40] For women of underrepresented racial and ethnic communities, vulnerability to HIV acquisition is shaped by structural racism and systemic inequality, which influence their ability to engage in strategies that reduce likelihood of acquisition.[10,41] In 2021, for example, cisgender Black women accounted for 54% of new diagnoses among cisgender women in the U.S., despite comprising only 13% of the female population.[16,42] An estimated 44% of Black transgender women and 26% of Latinx transgender women in the U.S. are living with HIV.[43] These disparities among Black women are influenced by the U.S. legacy of slavery and segregation, which continue to echo in unequal access to healthcare, poverty rates, and medical mistrust (see **Chapter 2**).[44,45] Structural factors that have a disproportionate impact on Black women include mass incarceration of Black men who, after release, may engage in behaviors that place them at greater likelihood for HIV acquisition, coupled with increased prevalence of sexually transmitted infections (STIs), which heightens the potential for HIV transmission.[46] Racism, discrimination, poverty, and gender inequity also create barriers to HIV treatment and prevention that result in disparities in transmission and mortality rates, as discussed below.[47,48]

The disparities in HIV prevalence reflect the effects of structural-level barriers to the treatment and prevention of HIV that include structural racism, intersectional discrimination, HIV-related stigma, lack of social support, lack of access to healthcare, lack of HIV serostatus awareness, medical mistrust, and racial discrimination (see **Chapter 1**).[49–51] Evidence suggests that medical mistrust, stigma, and discrimination prevent Black adolescent girls and young women from using PrEP.[52] Medical mistrust also impedes access to HIV care and treatment. Notably, medical mistrust is more highly associated with Black women who have experienced greater exposure to racial discrimination and whose social networks have a higher proportion of Black members, amongst other factors, indicating that social contexts impact HIV prevention and care efforts.[53]

Figure 9-3 shows trends in incidence rates for HIV by race and ethnicity from 2010-2021. The data reveal notable declines among Black women, for whom the rate reduced by nearly half, and Multiracial women, for whom the rate was more than three times lower in 2021 than in 2010. Declines occurred in all other groups although they were less profound. The irregularity in White women's rates in 2020, as well as other irregularities in the trends during 2020, may be related to inaccurate data due to the impact of COVID-19 on access to testing, services, and surveillance.

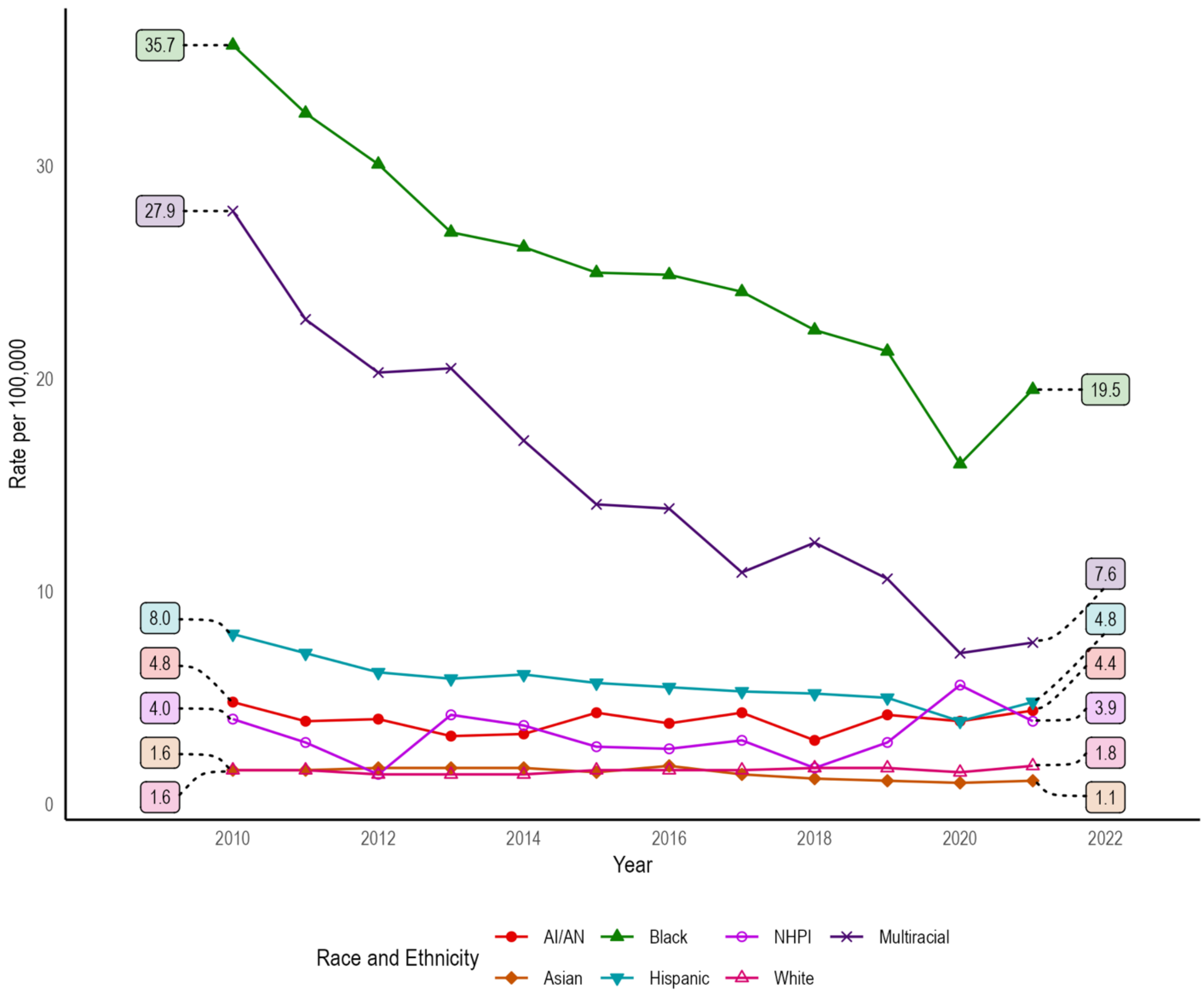

Figure 9-3: HIV incidence rate per 100,000 women aged 13 and older over time, by race and ethnicity
Source: National HIV Surveillance System (NHSS), 2010-2021

Figure 9-4 shows women's rate of death (mortality rate) related to complications from HIV by race and ethnicity from 2010-2021. The data reveal patterns largely consistent with those for prevalence and incidence. The mortality rate was highest among Black women, starting at 16.9 deaths per 100,000 population in 2010 and decreasing to 14.8 deaths per 100,000 in 2021. The rate was also high among Multiracial women, increasing from 11.7 to 13.1 per 100,000 over the same time period. For women in all other groups, mortality rates remained below five deaths per 100,000 and with little variation over time. Rates were lowest among Asian and White women, though it is notable that among Native Hawaiian and Pacific Islander (NHPI) women the rate dropped from two deaths per 100,000 in 2010 to none in 2021.

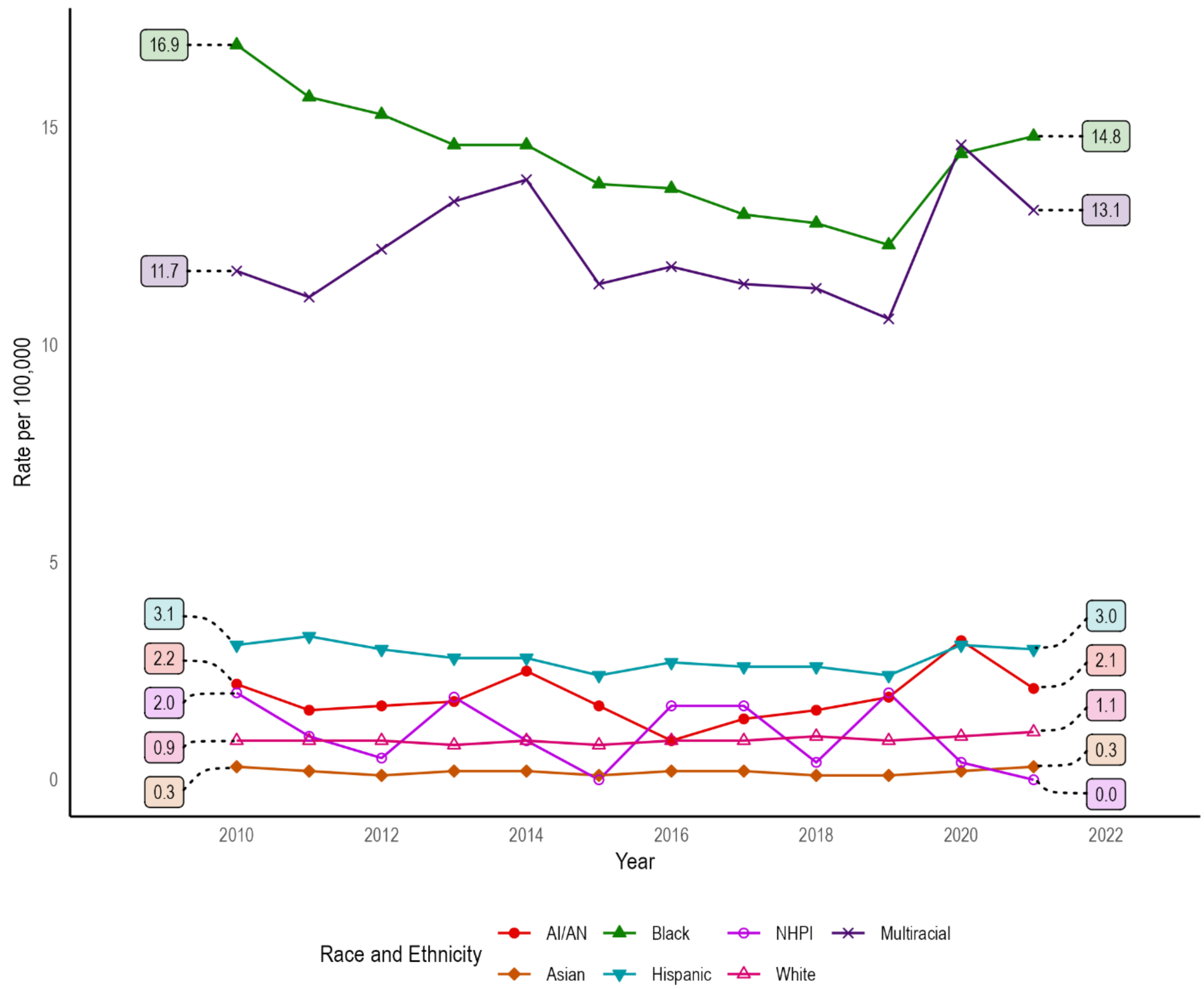

Figure 9-4: Mortality rate for complications related to HIV per 100,000 women aged 13 and older over time, by race and ethnicity

Source: National HIV Surveillance System (NHSS), 2010-2021

The data in **Figure 9-4** further highlight some of the disparities that affect Black and Multiracial women. Such health inequities may in part be explained by factors such as gendered racial microaggressions, defined as "everyday insults" they experience at the intersection of being women, being of an underrepresented racial or ethnic group, and, in some cases, having HIV.[54] Additionally, stigma and discrimination based on race and HIV status influence the treatment outcomes of Black women living with HIV and can lead to increased community viral loads.[51,54] High mortality rates among Black women may reflect the effects of limited social support, low socioeconomic status (SES), and racial discrimination, among other factors that influence whether someone accesses treatment and continues to receive HIV care.[55]

Data about incidence of AIDS can provide a snapshot of disease progression, offering insights into patterns of accessing care and retention, or whether a person remains in care. **Figure 9-5** shows the incidence of AIDS diagnoses among women by race and ethnicity for 2010-2021, revealing a trend of decreasing rates over time among all groups. The incidence of AIDS diagnoses was highest among Black and Multiracial women, with steep declines over time to a low of 11.5 and 7 cases per 100,000 population, respectively. Incidence rates were lowest among White and Asian women.

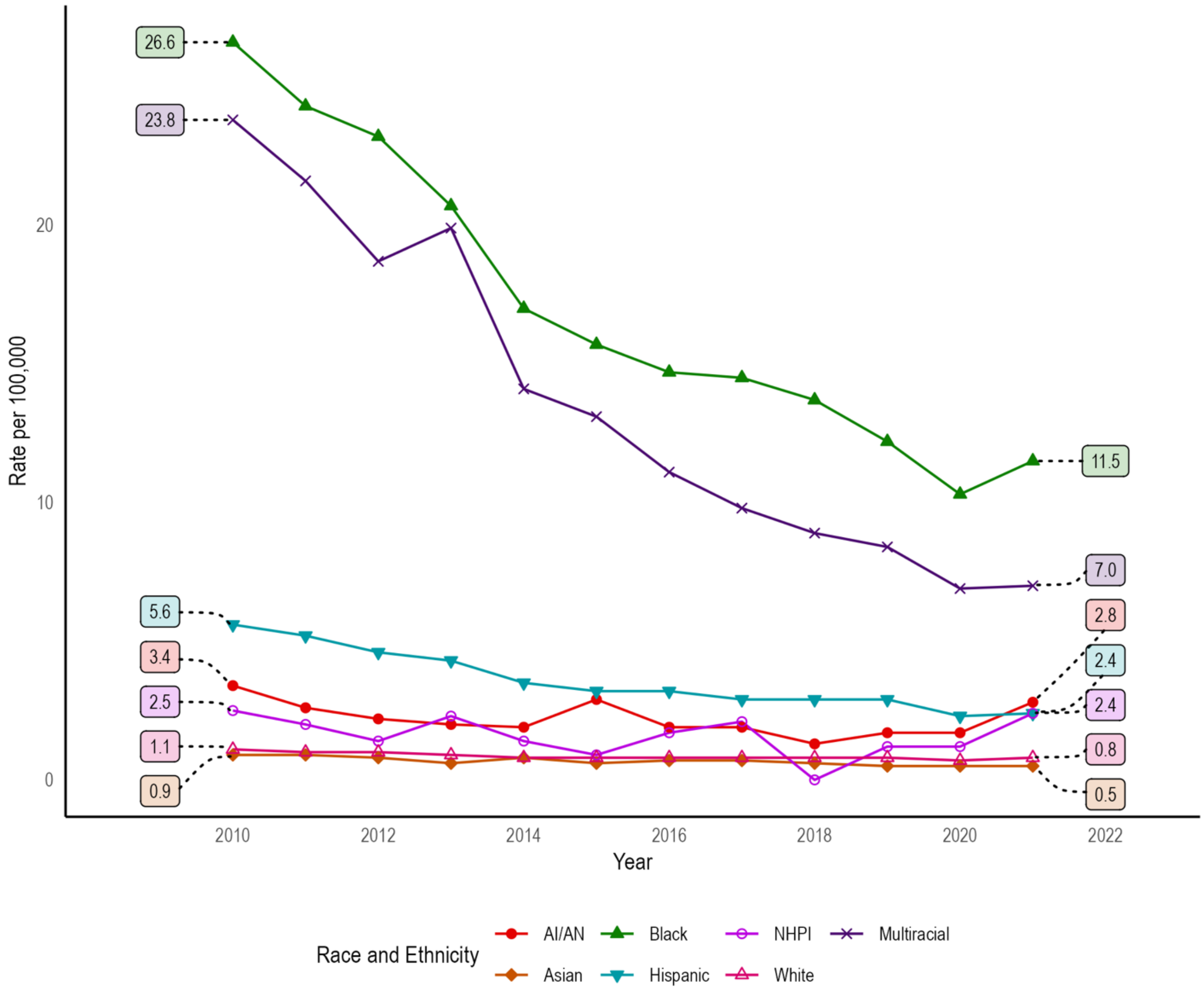

Figure 9-5: AIDS incidence rate per 100,000 women aged 13 and older over time, by race and ethnicity

Source: National HIV Surveillance System (NHSS), 2010-2021

The incidence and mortality data presented here highlight the need to focus on social drivers that contribute to adverse outcomes for Black individuals in the context of HIV treatment and care, such as social inequality, residential segregation, and structural and institutional racism.[49,56]

9.3.1.1 HIV Risk Factors and Risk Reduction Behaviors Among U3 Women

Part of the context for understanding the trends presented above is found in changes in HIV-related risk factors and risk-reduction behaviors such as delaying or reducing sexual behaviors, consistent condom use, and HIV testing. Behaviors that place women at risk for HIV also increase their risk of contracting other STIs.[57]

CDC data suggest that there has been a decrease in sexual activity among high school students over the past decade. This decrease in sexual activity may be reflected in the 17% decline in new HIV diagnoses among 12–24-year-olds between 2017 and 2021.[58,59] **Figure 9-6** shows the percent of students in grades

9-12 who report being sexually active (i.e., having sexual intercourse at least once in the three months prior to the survey) by sex over time. Overall, male students report higher levels of current sexual activity than female students. The data reveal a decrease in self-reported sexual activity over time, and a closing of the gap between boys and girls.

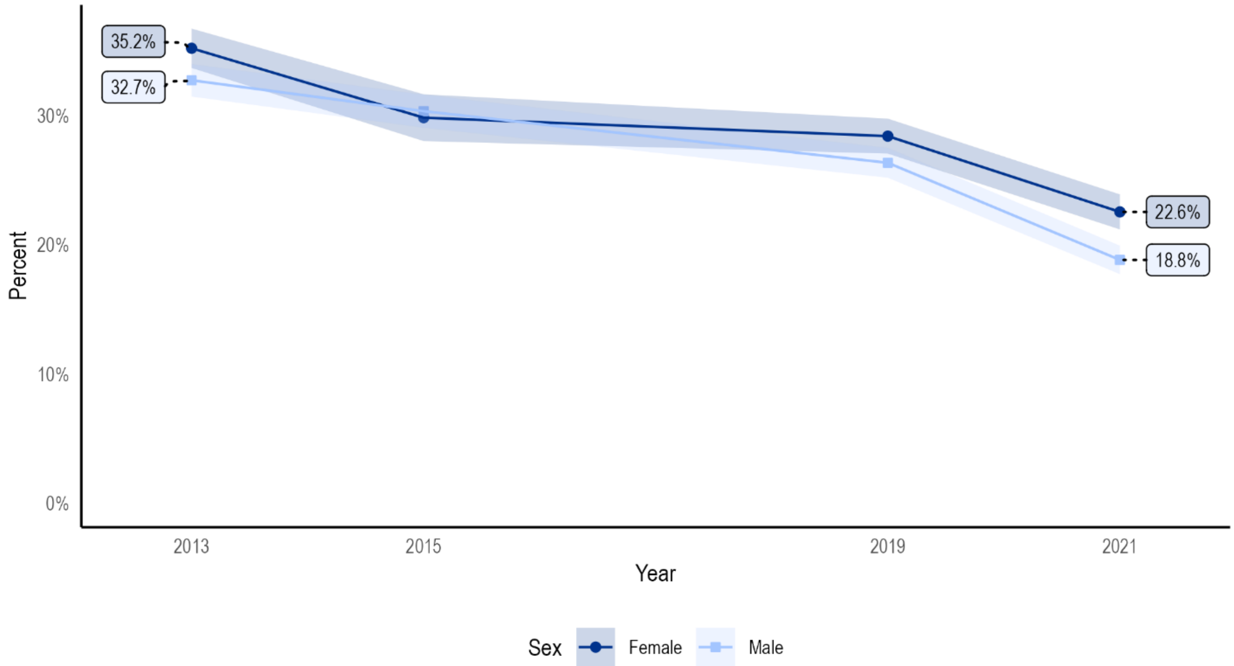

Figure 9-6: Percent of students in grades 9-12 who report they are currently sexually active by sex over time

Source: Youth Risk Behavior Survey (YRBS), 2013, 2015, 2019, 2021[ii]

For female students, self-report of current sexual activity varies by race and ethnicity, as shown in **Figure 9-7**. The highest prevalence was among American Indian and Alaska Native (AI/AN) girls, among whom current sexual activity is over three times more common than among Asian girls, who had the lowest observed prevalence. Sexual activity among Black and White girls was similar to that among AI/AN girls, though these estimates are less affected by small sample sizes.

[ii] YRBS data from 2017 are not included in the analysis because survey responses were not linked with demographic data at the time of analysis.

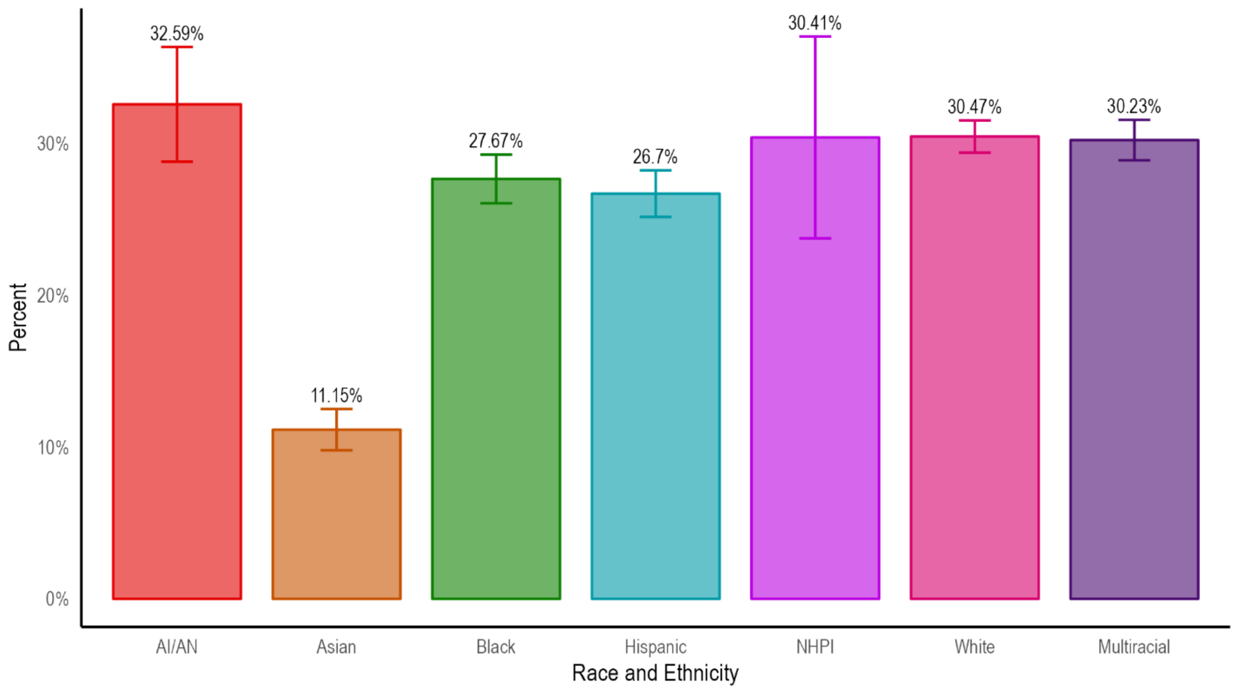

Figure 9-7: Percent of female students in grades 9-12 who report they are currently sexually active, by race and ethnicity

Source: Youth Risk Behavior Survey (YRBS), Pooled 2013, 2015, 2019, 2021[iii]

Number of sexual partners is another risk factor for HIV transmission. **Figure 9-8** shows the percent of female students who reported having four or more sexual partners in their lifetime, by race and ethnicity. The percentage of girls reporting four or more sexual partners in their lifetime does not exceed 12% across all groups, with notable differences between groups. The highest observed percentage was among AI/AN girls, though the standard error interval for this estimate overlaps with that for White and Black girls. The lowest percentage was among NHPI girls.

[iii] YRBS data from 2017 are not included in the analysis because survey responses were not linked with demographic data at the time of analysis.

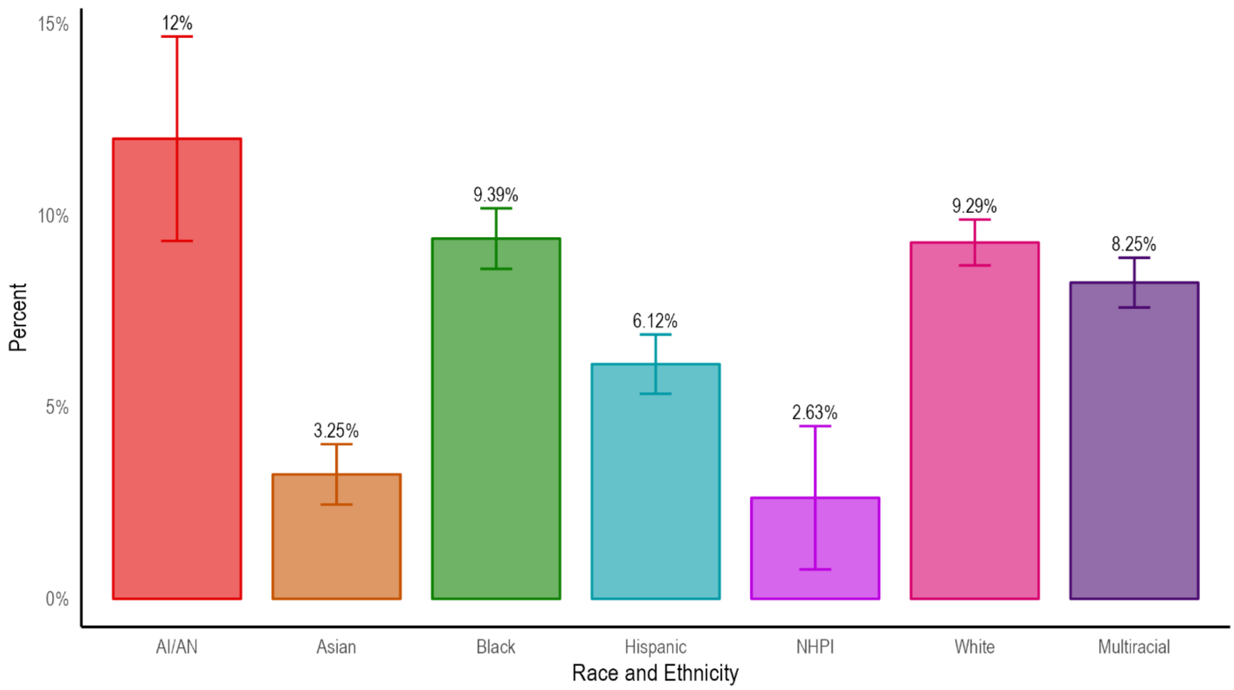

Figure 9-8: Percent of female students in grades 9-12 who report they have had four or more sexual partners, by race and ethnicity

Source: Youth Risk Behavior Survey (YRBS), Pooled 2013, 2015, 2019, 2021[iv]

It is important to note that the survey does not distinguish between consensual and coerced or forced sexual activity. This is an essential lens through which to view students' reports of sexual behavior, as studies have shown that women of underrepresented racial and ethnic communities are more likely to experience unwanted sexual contact and at younger ages than White women (see Chapter 14).

Figure 9-9 shows percent of condom use during most recent sexual intercourse among female students for 2013-2021. The percentages are similar across racial and ethnic groups but appear to be highest among White girls. Estimates for AI/AN and NHPI girls have relatively large standard errors (due to smaller sample sizes) but appear to be aligned with estimates for Black, Hispanic, and Multiracial girls. Condom use during most recent sexual intercourse was lowest among Asian girls.

[iv] YRBS data from 2017 are not included in the analysis because survey responses were not linked with demographic data at the time of analysis.

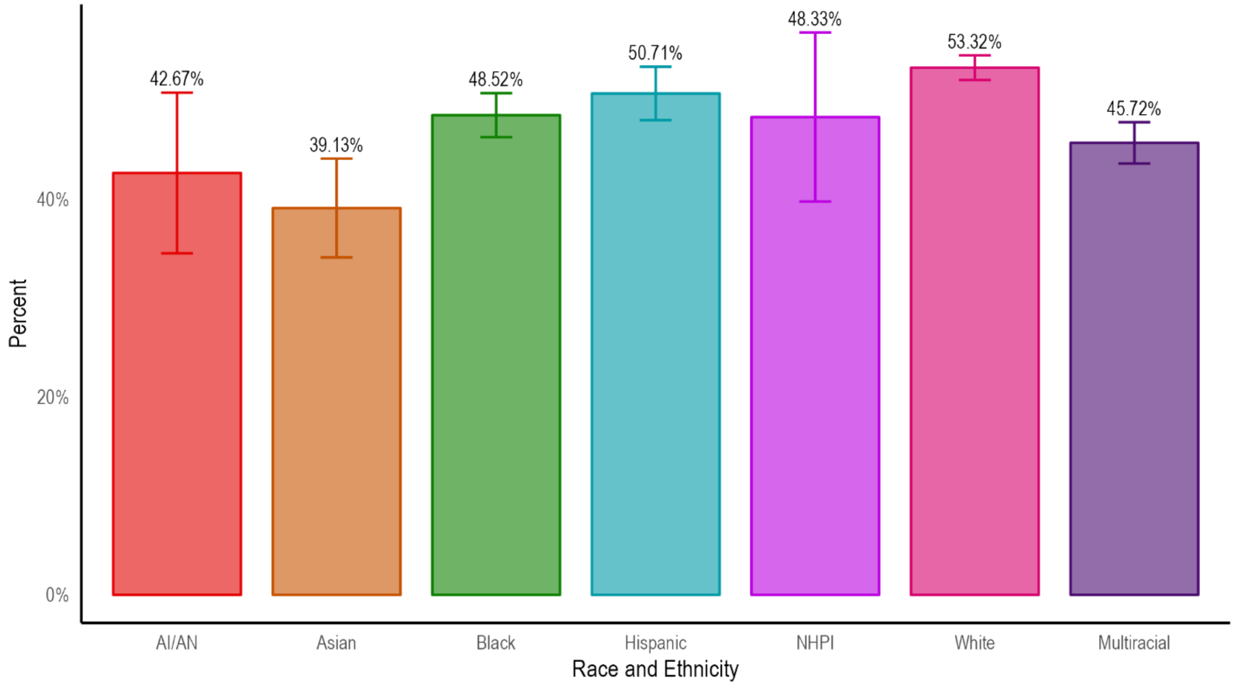

Figure 9-9: Percent of sexually active female students in grades 9-12 who report using a condom at last sexual intercourse, by race and ethnicity

Source: Youth Risk Behavior Survey (YRBS), Pooled 2013, 2015, 2019, 2021[v]

Figure 9-10 shows the percent of male and female students in grades 9-12 who were tested for HIV from 2013-2021. There are two notable declines in HIV testing: one between 2013 and 2015 and the other between 2019 and 2021 for both male and female students. Girls generally have had a higher rate of testing, though this gap closed after 2019. The COVID-19 pandemic disrupted HIV prevention and surveillance programs and a decline in HIV testing overall (not just in students) was seen in the 2020 data.[60,61]

Figure 9-11 shows the percent of female students tested for HIV by race and ethnicity between 2013-2021. The highest percentage reported was among AI/AN girls while the lowest percentage reported was among Asian girls. White and Hispanic girls had similar percentages of HIV testing (9.09% and 8.91% respectively).

[v] YRBS data from 2017 are not included in the analysis because survey responses were not linked with demographic data at the time of analysis

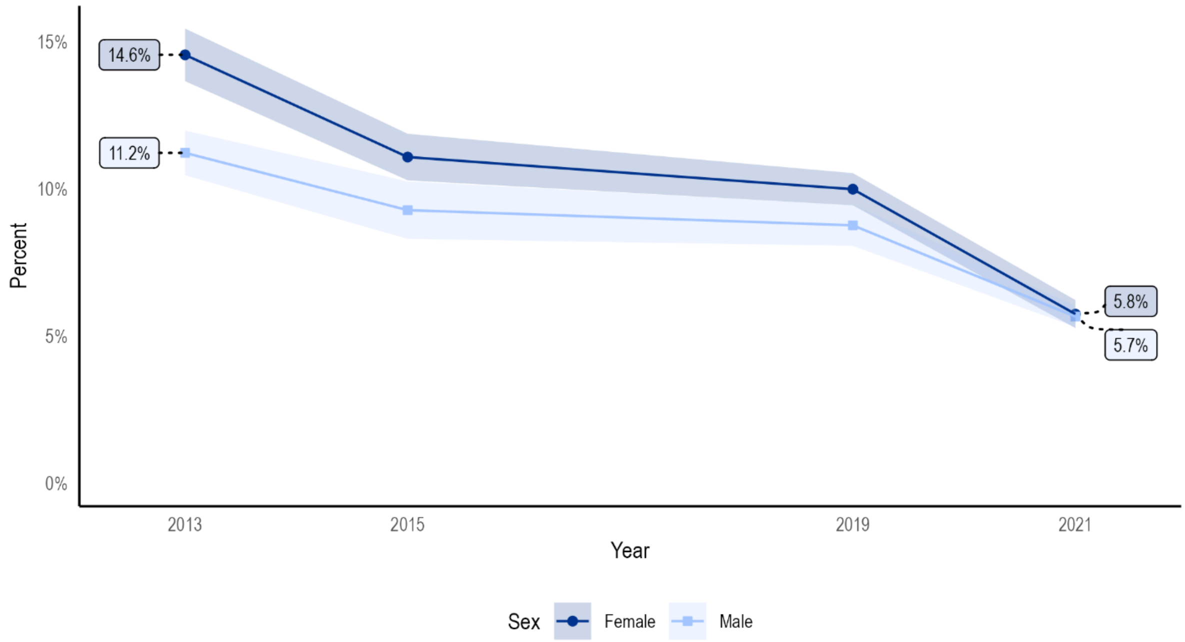

Figure 9-10: Percent of students in grades 9-12 who report being tested for HIV over time by sex

Source: Youth Risk Behavior Survey (YRBS), 2013, 2015, 2019, and 2021[vi]

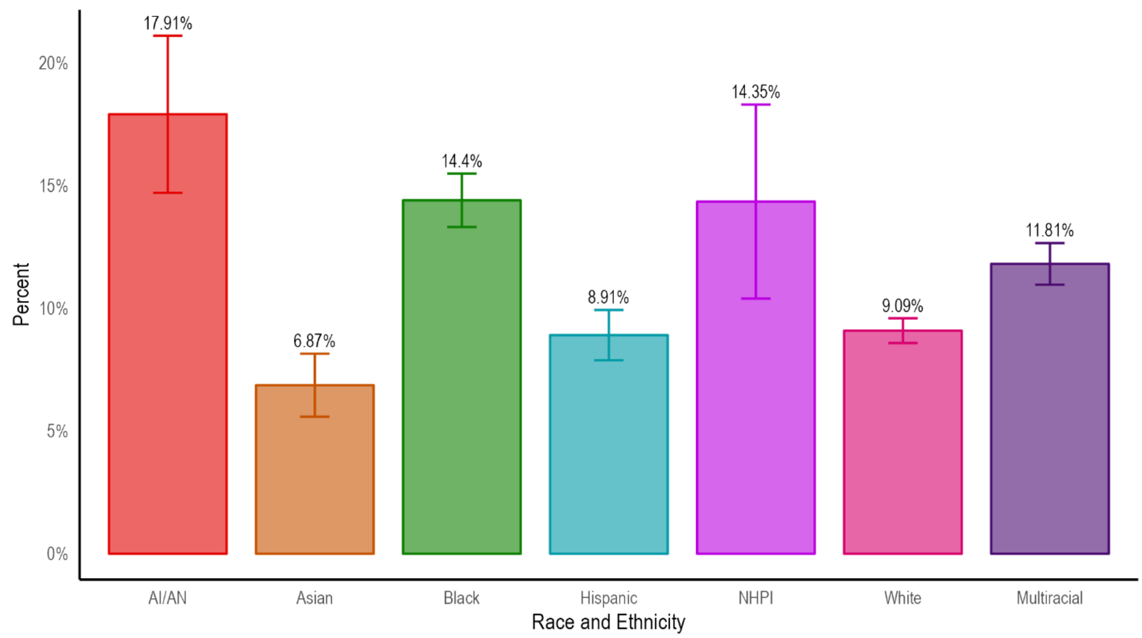

Figure 9-11: Percent of female students in grades 9-12 who report being tested for HIV, by race and ethnicity

Source: Youth Risk Behavior Survey (YRBS), Pooled 2013, 2015, 2019, 2021[vi]

[vi] YRBS data from 2017 are not included in the analysis because survey responses were not linked with demographic data at the time of analysis.

9.3.2 Other Intersectional Considerations Relevant to U3 Women

There are other considerations that should be taken into account to understand the impact of HIV on U3 women. Rurality, economic status, sexual orientation, and gender identity are discussed below.

9.3.2.1 Rurality

Analysis of data from the Youth Risk Behavior Survey (YRBS) and National HIV Surveillance System (NHSS) are unable to provide intersections for women by rurality and race and ethnicity. A range of barriers adversely impact people with HIV in rural communities, including HIV stigma and discrimination. These factors can contribute to psychosocial stress and influence coping behaviors such as social isolation.[62] Among older adults with HIV, stigma and discrimination intersect with ageism, social isolation, and poor mental health (see **Chapter 12**).[63] Additional barriers include lack of awareness, lack of services, and lack of Ryan White providers for individuals who are HIV positive.[64,vii] SES, racial segregation (which is associated with treatment delays), and stigma are all relevant determinants that impact the sexual health of individuals living in rural areas.[65]

9.3.2.2 Economic Status

YRBS and NHSS also do not allow for stratifications specific to economic status. However, additional research has found economic disadvantage is related to sexual risk behavior and higher sexual activity in students enrolled in schools with mid-to high levels of poverty.[66,67] Poverty was also found to be a structural determinant of women's likelihood of acquiring HIV.[47]

9.3.2.3 Sexual Orientation and Gender Identity

Research has consistently shown high rates of HIV among sexual and gender minorities. For example, adolescents who identify as lesbian, gay, bisexual, or transgender (LGBT) are more likely to engage in sexual behaviors that increased their chance of acquiring HIV as well as STIs such as chlamydia and gonorrhea, due to experiences of emotional distress and peer victimization.[68] For youth who identified as lesbian, gay, bisexual, transgender, or queer/questioning (LGBTQ+), fear of discrimination prevented them from sharing their status with healthcare providers and instances of peer victimization and rejection from family facilitated high-risk sexual behaviors, highlighting the unique adversities that impact the sexual health of LGBTQ+ youth.[68] Despite the documented disproportionate burden of HIV among transgender and gender-diverse women, transgender women are underrepresented in research.[69]

The data presented below offer estimates for case counts, diagnosis counts, and death counts by gender identity. This is a departure for standard measures of prevalence, incidence, and mortality rates, as the national population denominators are not known for each gender identity group. Currently, there are no national estimates to provide historic and current population denominator data across all gender identity categories; as a result, the relative burden of HIV among the intersection of gender identity and race and ethnicity cannot be described by the following data. However, the data do allow for examination of trends within groups and potential emerging disparities.

[vii] The Ryan White HIV/AIDS Program (RWHAP) was enacted in 1990 to improve the quality and availability of HIV care and treatment for low-income people with HIV. It has provided medical, health, and support services to more than half a million people, with about 61% of serviced clients living at or below the federal poverty line.

The data sourced from the NHSS specifically focuses on gender identity. It is the only federal health data source that includes questions on gender identity rather than just binary or biological sex (see **Chapter 1**).[viii] Sections in this data book using NHSS data are the only ones that will include analysis of how women's race and ethnicity intersect with gender identity.

Figure 9-12 shows the cumulative number of HIV case counts by gender identity across race and ethnicity between 2010 and 2022. The data reveal an overall upward trend in the number of HIV cases over time (among the population 13 years and older) and differences by race and ethnicity that are consistent with data shown throughout this chapter. While the number of cases is lower among gender minoritized groups, the degree of change appears steeper over time as compared with cisgender groups, denoted as "female" and "male" in this figure. Among transgender women, the number of HIV cases nearly doubled for Black and Hispanic women, while cases among White, Multiracial, NHPI, and Asian transgender women increased at a much lower rate in the past 12 years. For those who identified with an additional gender identity (AGI), HIV case counts were highest among Black and Hispanic individuals and lowest among NHPI and AI/AN individuals.

[viii] NHSS defines gender identity as one's internal understanding of their own gender, while Additional Gender Identity (AGI), refers to an individual assigned male or female at birth who does not identify as male or female or as a transgender man or transgender woman. Transgender persons refer to individuals whose assigned sex at birth does not reflect their gender identity.[70]

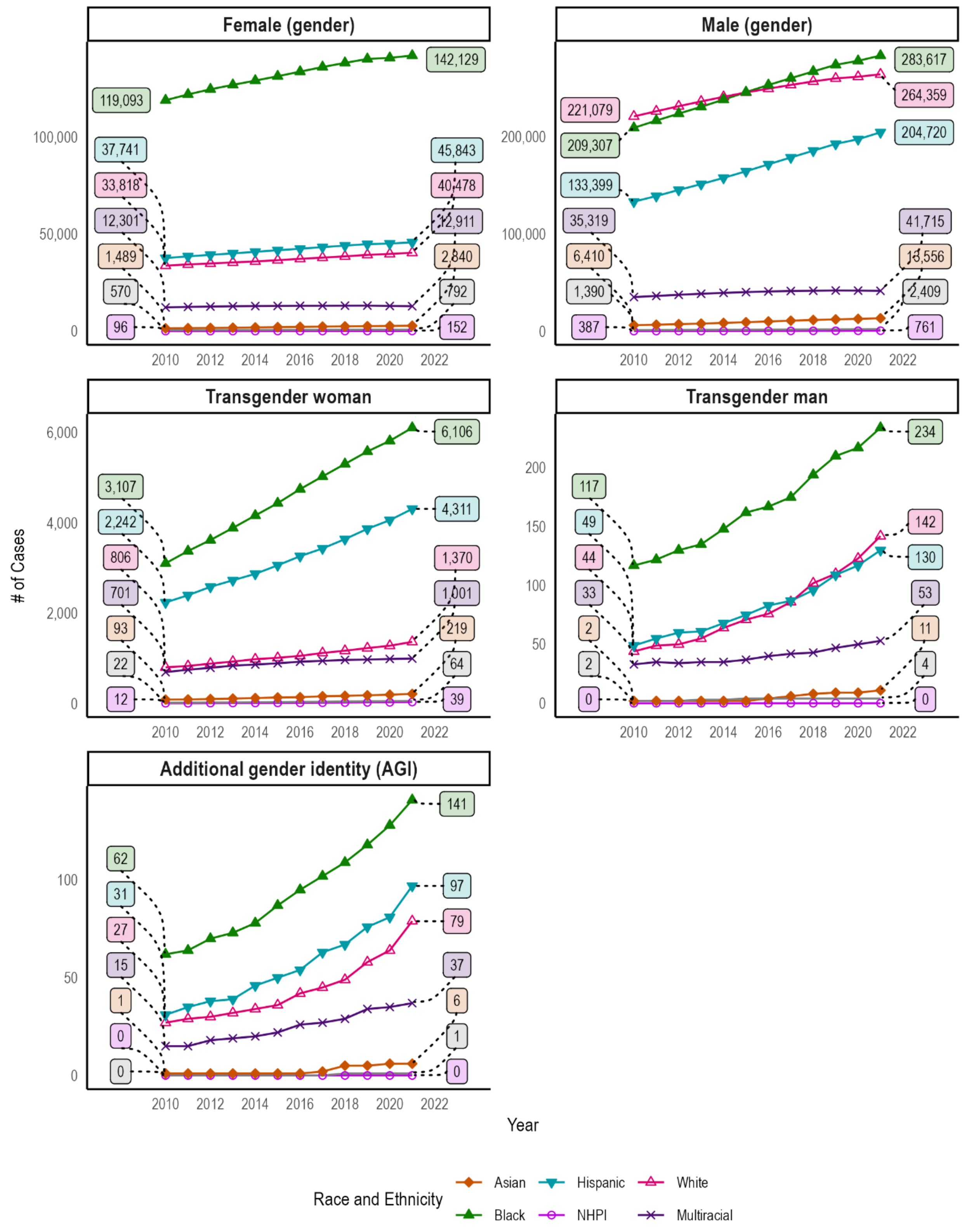

Figure 9-12: Total HIV cases annually over time, by race and ethnicity, and gender identity
Source: National HIV Surveillance System (NHSS), 2010-2021

In the context of HIV care, research has shown that for transgender women, and Black transgender women in particular, structural barriers, competing unmet basic survival needs, gender-based discrimination, and stigma create additional challenges in the context of HIV-related care and prevention.[71] Transgender women have the highest percentage of HIV diagnoses of any gender category, with Black and Hispanic transgender women disproportionately affected.[9,72] Research investigating gender identity and racial and ethnic disparities among people with HIV has also found that in comparison to cisgender Black women, transgender Black women were less likely to achieve viral suppression and be retained in HIV care.[73] Barriers such as stigma and gender-based discrimination and lack of transportation, housing, insurance, and employment may influence these disparities.[74,75]

Figure 9-13 shows data for the number of new HIV diagnoses each year by gender identity and race and ethnicity. The data show that HIV diagnoses dropped among most groups in 2020 and increased thereafter. The COVID-19 pandemic likely caused disruptions to HIV testing contributing to lower counts in 2020 and the subsequent increase in 2021.[76] While the number of new HIV diagnoses appeared to be on the decline for some groups, overall, new diagnoses increased among Black, Hispanic, and White transgender and AGI populations. Specifically, HIV diagnoses counts were nearly two times higher among Black and Hispanic transgender women in comparison to transgender women from other racial and ethnic groups between 2010 and 2022. Despite the comparatively smaller sample size for those who identified as AGI, the data reveal that HIV diagnoses counts were highest among White, Hispanic, and Black AGI people. These counts nearly doubled between 2010 and 2022.

Figure 9-14 shows deaths from complications related to HIV by gender identity and race and ethnicity for 2010-2021. The overall trend shows an increase in deaths over time for most groups, though small sample sizes for transgender men and AGI people result in a less clear pattern. The mortality rate was highest among Black and White men, approximately double the deaths among Hispanic men and White women. Among transgender women, deaths from complications related to HIV were highest for Black women, among whom deaths peaked at over 100 cases in 2020. The mortality rate also increased after 2018 among transgender women from Hispanic, White, and Multiracial groups and was lowest among NHPI and Asian transgender women.

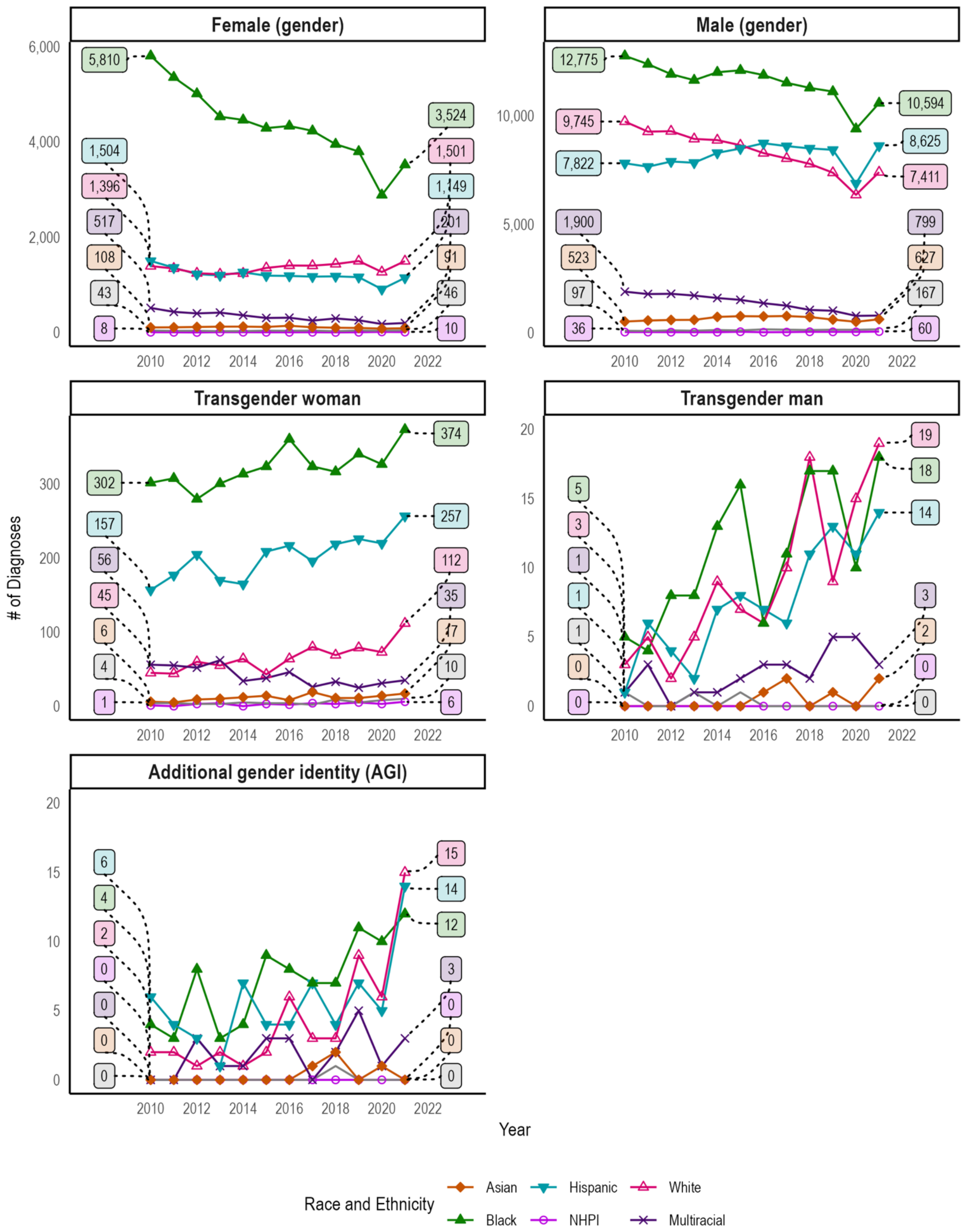

Figure 9-13: Number of new HIV diagnoses annually over time, by race and ethnicity, and gender identity

Source: National HIV Surveillance System (NHSS), 2010-2021

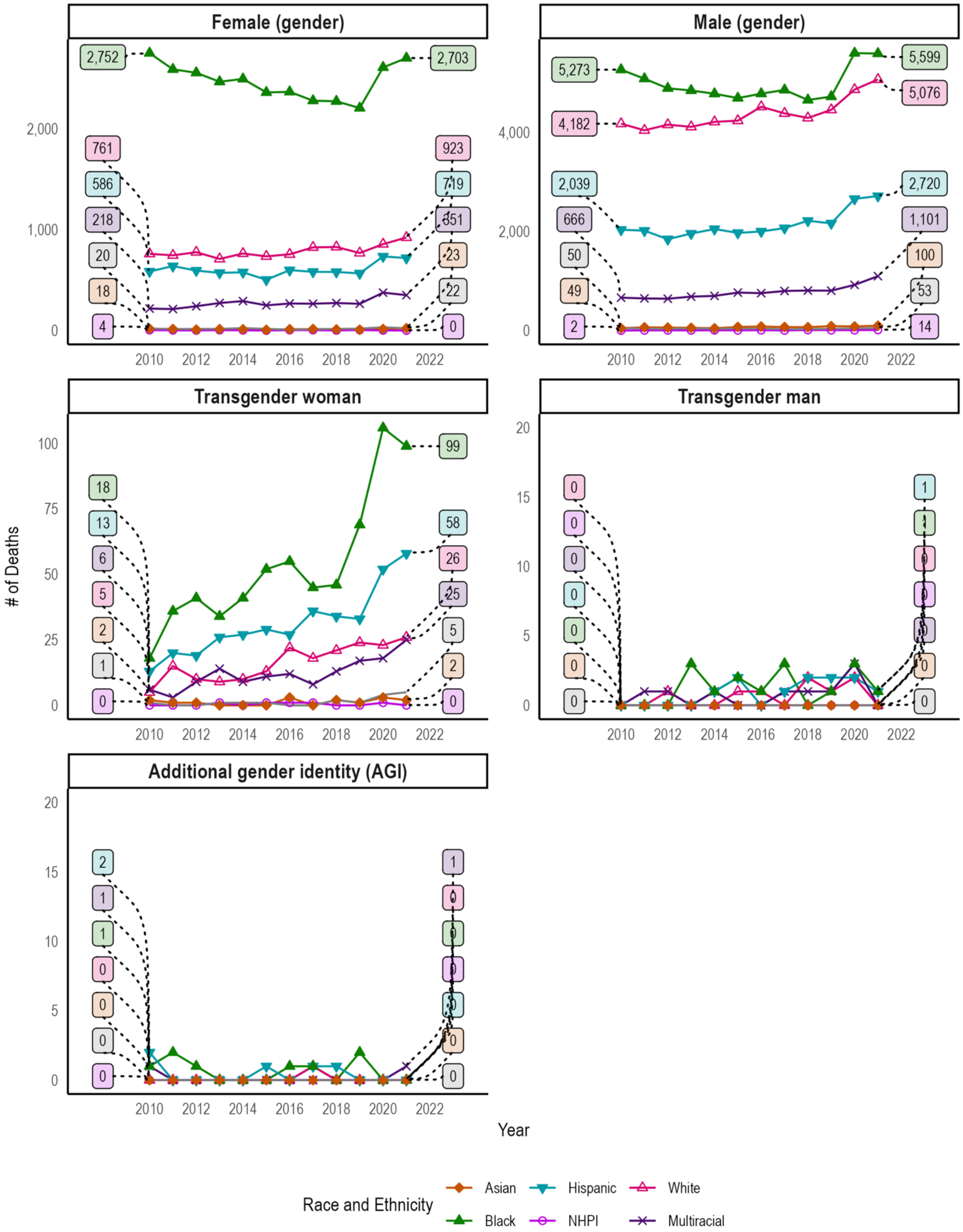

Figure 9-14: Number of deaths from complications related to HIV annually, by race and ethnicity, and gender identity, over time

Source: National HIV Surveillance System (NHSS), 2010-2021

Research suggests that HIV treatment and prevention gaps driven by stigma, discrimination, and socioeconomic factors cause the disparities observed among Black transgender women, which result in poorer health outcomes for them.[75,77,78]

AIDS classifications are based on the number of HIV infections confirmed in a calendar year for those 13 years or older. Trends were similar for AIDS classifications across gender identity and race and ethnicity, as shown in **Figure 9-15**. The most notable absolute decreases were observed among cisgender groups, due in part to larger numbers in the baseline population. Among transgender women, the highest number of AIDS classifications was among Black and Hispanic transgender women. For AGI people, the small number of cases makes assessment of trends over time difficult, though the available data suggest higher numbers among Black and Hispanic AGI people compared with AGI people of other racial and ethnic groups.

Figure 9-16 shows deaths from AIDS-related illnesses by gender identity and race and ethnicity. The data reveal a decrease in the number of deaths over time among Black people. For all other groups, the number of deaths from AIDS-related illnesses appears to increase between 2010 and 2021. The data highlight how deaths were approximately three times higher for Black and Hispanic transgender women than for transgender women of other racial and ethnic groups. While case count data points typically reveal a drop in 2020 due to the COVID-19 pandemic, the AIDS-related death data reveal increased deaths among Black and Hispanic transgender women, likely attributable to interruptions in diagnosis, care, and treatment.

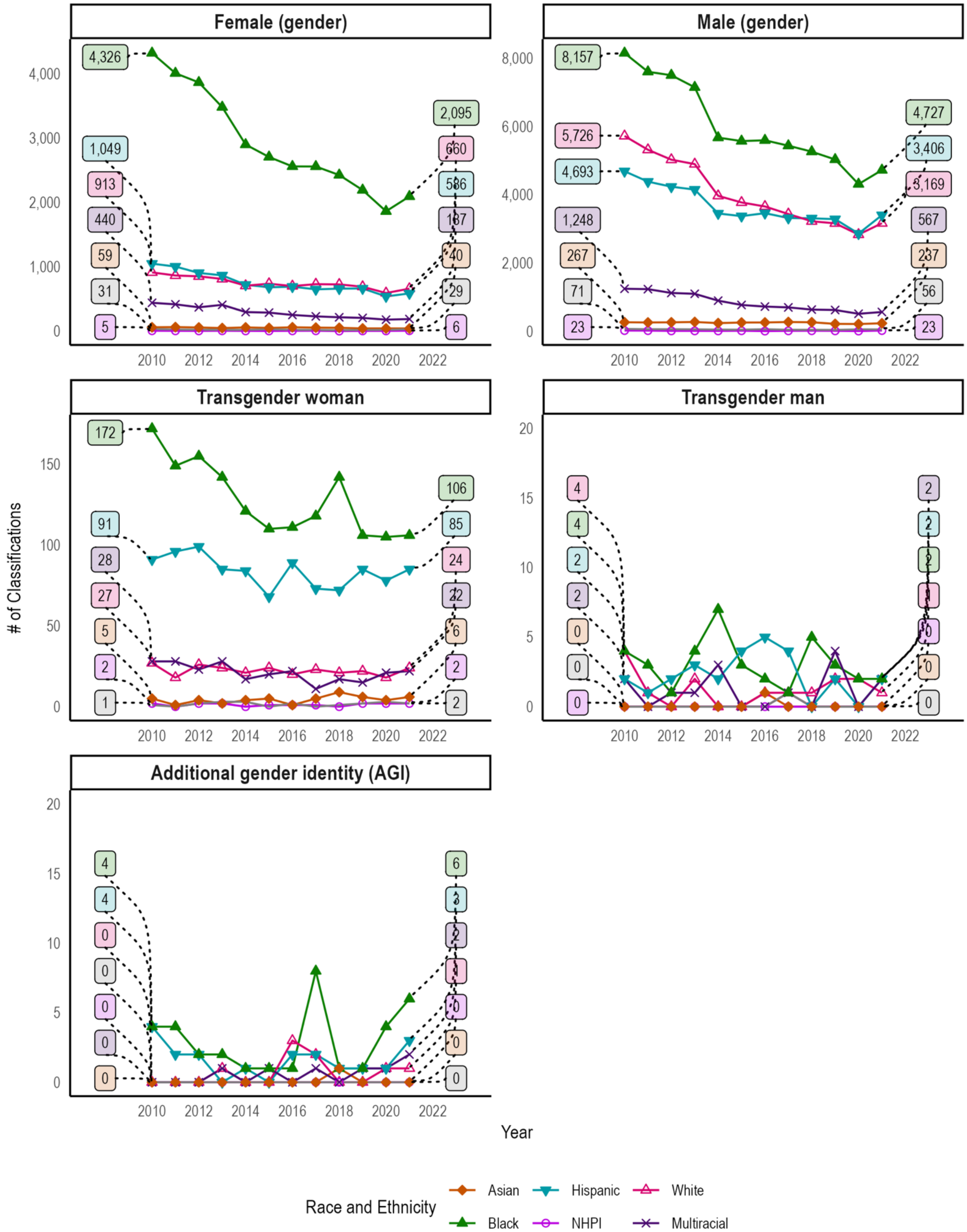

Figure 9-15: Number of new AIDS classifications annually, by race and ethnicity, and gender identity, over time

Source: National HIV Surveillance System (NHSS), 2010-2021

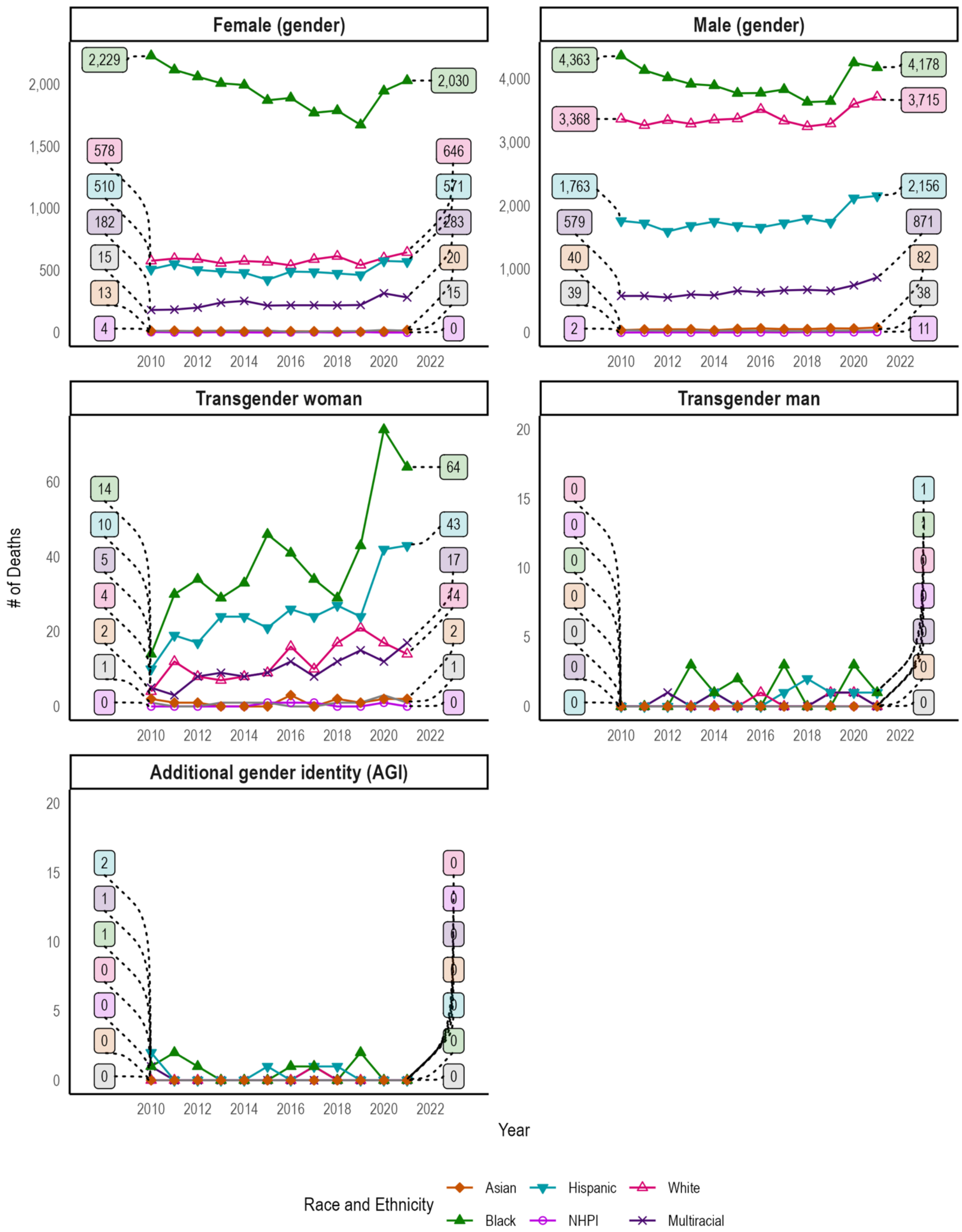

Figure 9-16: Number of deaths from AIDS-related illnesses annually, by race and ethnicity, and gender identity, over time

Source: National HIV Surveillance System (NHSS), 2010-2021

9.4 Conclusions and Future Directions

Despite significant advances in HIV prevention and treatment over the past 40 years, women of underrepresented racial and ethnic communities and gender-diverse people, including transgender women and transgender men, continue to be disproportionately impacted by HIV. This highlights the need to move beyond a biomedical approach and adopt a comprehensive culturally sensitive, person-centered approach to address HIV prevention and treatment in women that centers on addressing the social drivers of health to reduce health inequity, while also acknowledging structural, cultural, sexual violence, and migration factors in the context of HIV.[10,79]

Effective prevention and treatment of HIV requires understanding the social stressors that women face such as stigma, structural racism, discrimination, historical trauma, and other social drivers of health (see **Chapter 1**).[9] At the core of these efforts must be a focus on promoting resilience and eliminating stigma for women with HIV, especially among Black women who continue to experience the greatest disease burden.[11] It is imperative that healthcare systems meet these women where they are and address the social stressors that are often not within their control and create barriers to entering and remaining in HIV care and treatment.

The following are opportunities to impact the future direction of HIV prevention and treatment efforts for women of underrepresented racial and ethnic communities:

- Provide U3 women with early and consistent access to HIV and STI screening and treatment to ensure optimal sexual health outcomes.
- Design life stage-specific and gender-focused sexual health programs tailored to U3 women to encourage more equitable sexual decision-making and enhanced ability to protect themselves.
- Address the lack of HIV prevention, treatment, and care retention interventions that have been culturally tailored for Black women with HIV.[55]
- Ensure PrEP programs meaningfully include U3 women, especially transgender women from underrepresented racial and ethnic communities and gender-diverse people.
- Emphasize and address the acute need for greater inclusion of U3 women in HIV cure-related research.[80]
- Integrate sexual orientation, gender identity, and SES into national surveys to provide further insight on disparate HIV and STI health outcomes.

9.5 Data Sources and Data Definitions

Data for all figures in this chapter can be accessed from the data annex located here: https://orwh.od.nih.gov/sites/orwh/files/docs/Chapter_9.xlsx

Youth Risk Behavior Survey (YRBS), 2013, 2015, 2019, 2021

Variable Name	Variable Description	Variable Options
QN89, QN85, QN84, QN82	Have you ever been tested for HIV, the virus that causes AIDS? (Do not count tests done if you donated blood.)	% of students who were ever tested for HIV
QN61, QN62, QN60, QN59	During your life, with how many people have you had sexual intercourse?	% who had sexual intercourse with 4 or more people
QN62, QN63, QN61, QN60	During the past 3 months, with how many people did you have sexual intercourse?	% who had sexual intercourse with at least 1 person during the past 3 months (were currently sexually active)

Variable Name	Variable Description	Variable Options
QN64, QN65, QN63, QN62	The last time you had sexual intercourse, did you or your partner use a condom?	% Yes (Used a condom during last sexual intercourse)

National HIV Surveillance System (NHSS), 2010-2021

Variable Name	Variable Description
HIV Diagnoses and AIDS Classifications	HIV diagnoses or AIDS classifications refer to the number of HIV infections confirmed by laboratory or clinical evidence in a calendar year. Diagnoses of HIV infection are the numbers of persons aged 13 years and older with HIV diagnosed during the specified years.
HIV Deaths and AIDS Deaths	Persons reported to NHSS are assumed alive unless their deaths have been reported to CDC by state/local HIV surveillance programs. Death data include deaths of persons aged 13 years and older with diagnosed HIV infection or AIDS classification regardless of the cause of death, which may not be due to HIV. Death data are based on a 12-month reporting delay to allow data to be reported to CDC (death data are considered preliminary until 12-months after the death year to account for delays in reporting). Data are presented based on residence at death. When address at death was not available, the state where a person's death occurred was used.
HIV Prevalence and AIDS Prevalence	The data reflect persons aged 13 years and older living with diagnosed HIV infection or AIDS classification at the end of the specified year. Data are presented based on a person's most recent known address as of December 31 of the queried year. Because of delays in the reporting of deaths, prevalence data are based on a 12-month reporting delay to allow data to be reported to CDC (prevalence data are considered preliminary until 12-months after the specified year to account for delays in reporting).

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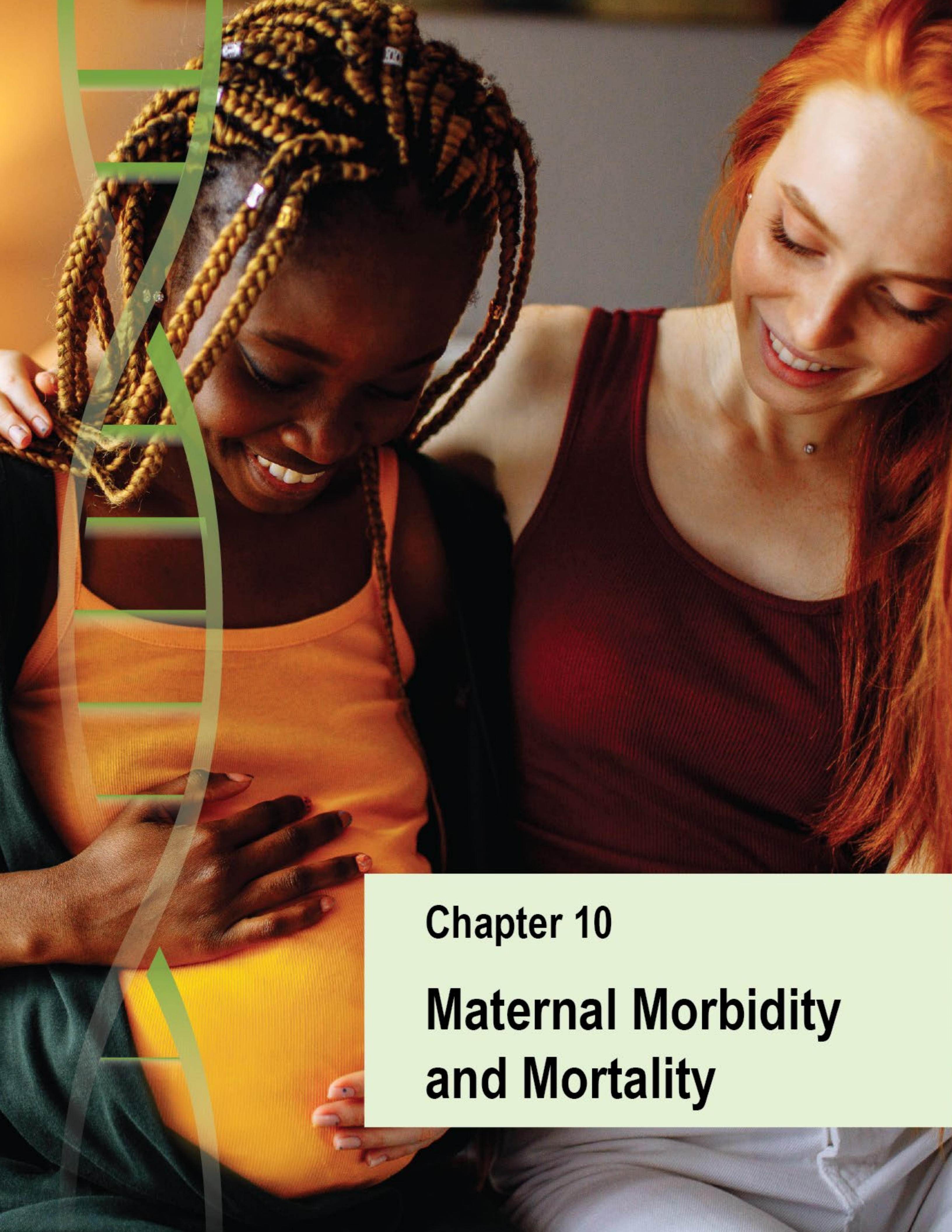

Chapter 10

Maternal Morbidity and Mortality

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Maternal Morbidity and Mortality

10.1 Defining Maternal Morbidity and Mortality

The National Institutes of Health (NIH) defines maternal morbidity as "unexpected short-or long-term health problems that result from being pregnant or giving birth."[1] Severe maternal morbidity (SMM) refers to "near-miss cases, meaning the women almost die from pregnancy or giving birth but survive."[1] SMM is identified by 21 conditions including eclampsia, sepsis, acute myocardial infarction, acute renal failure, and aneurysm.[2]

Maternal mortality broadly refers to "deaths related to pregnancy and giving birth," although maternal deaths are measured and labeled differently by different sources.[1,3,i] Causes of maternal mortality include emergent and chronic conditions, ranging from severe bleeding or hemorrhage to infections or sepsis, to cardiovascular or mental health conditions.[1,5] The most important resource for this Data Book is the Centers for Disease Control and Prevention's (CDC) National Vital Statistics System (NVSS). NVSS follows the World Health Organization's definition of maternal death, which is "the death of a woman while pregnant or within 42 days of termination of pregnancy, irrespective of the duration and the site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes."[6,7] The maternal mortality rate is measured as the number of maternal deaths up to 42 days postpartum per 100,000 live births. Notably, maternal mortality (and rate) under this definition does not capture the larger range of pregnancy-related deaths, defined as "deaths during pregnancy and up to or one year of after the pregnancy ends that are related to pregnancy or pregnancy care."[1]

The U.S. maternal mortality rate, already the highest among the world's high-income countries, has steadily worsened in recent years (**Figure 10-1**) reaching 32.9 deaths per 100,000 live births in 2021, meaning 1,205 pregnant individuals died of maternal causes. Most of the causes of maternal mortality are preventable or treatable.[7] Overall rates of maternal morbidity and mortality are likely underestimated due to data and measurement issues: deaths can occur during different time periods during pregnancy or up to one-year postpartum.[8] According to the CDC's Pregnancy Mortality

[i] Although not used in this Data Book, the CDC's Pregnancy Mortality Surveillance System (PMSS) calculates the U.S. pregnancy-related mortality ratio (PRMR) defined as the number of pregnancy-related deaths per 100,000 live births. This measure includes all deaths that occur within one year of pregnancy from a cause related to the pregnancy or its management. NVSS and PMSS, in addition to Maternal Mortality Review Committees (MMRCs) that operate at the state or local level, vary by how they collect, store, and report their data. They also differ in determining if a death is related to pregnancy or not.[4] This can lead to inconsistencies and obstacles in understanding the current state of maternal health outcomes in the U.S.

Surveillance System, for the pregnancy-related deaths where timing information was available, 22% happened during pregnancy, 25% took place on the day of delivery or within the subsequent seven days, and the remaining 53% occurred between seven days and one-year post-pregnancy.[5] Pregnancy-related mortality ratios in 2021 were considerably higher among certain groups of women, especially American Indian and Alaska Native (AI/AN) and rural women, "consistent with rising rates of COVID-19-associated mortality among women of reproductive age."[9]

Each year in the U.S. there are an estimated 50,000 to 60,000 women who experience SMM as reported in 2020.[10] As with maternal mortality, SMM is considered to be largely preventable. The consequences of maternal morbidity on women's lives include increased need for short- and long-term medical care, associated expenses, and an increased risk of a post-traumatic stress disorder (PTSD) following delivery.[10–13] Research across the globe illustrates that maternal deaths ripple throughout families and communities, with significant impacts on household income, family structure, and child survival and well-being—impacts also seen, albeit less well-studied, in the U.S.[14–16]

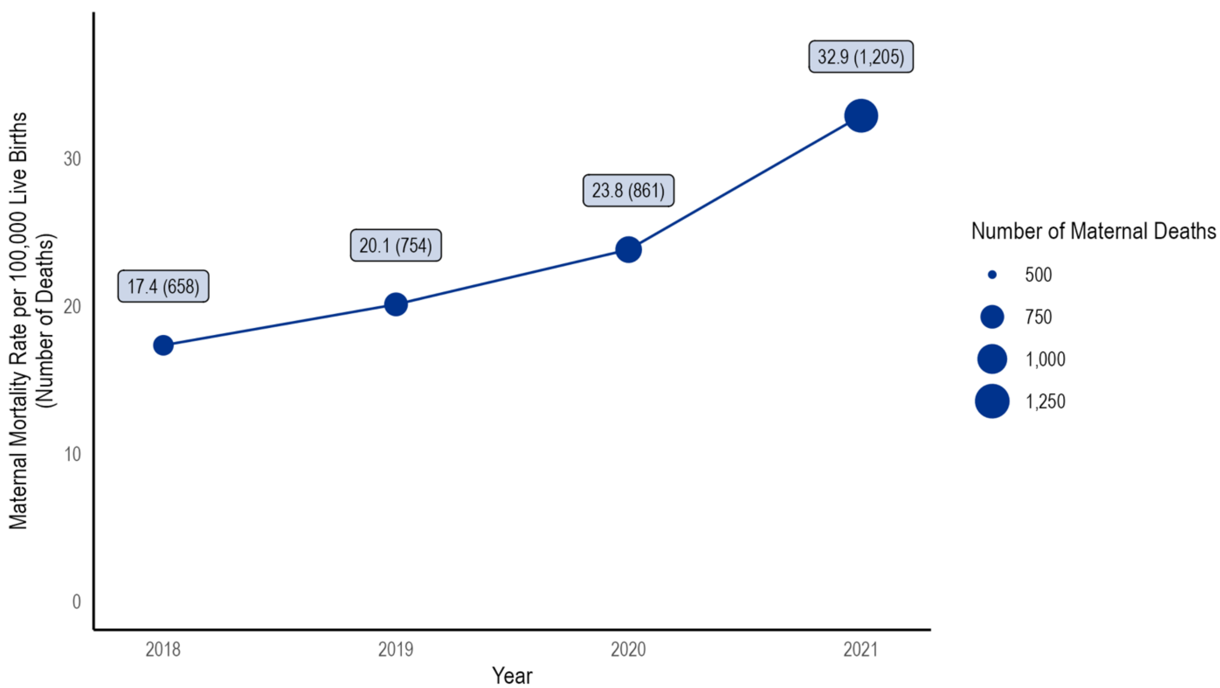

Figure 10-1: U.S. maternal mortality rate per 100,000 live births and number of maternal deaths over time

Source: Centers For Disease Control and Prevention (CDC), NCHS Health eStats[7]

10.2 Risk Factors for Maternal Morbidity and Mortality

Numerous factors can heighten susceptibility to maternal morbidity and mortality. Risk is elevated by factors like pre-existing health conditions (or cardiovascular disease or CVD, obesity, asthma, etc.), maternal age, substance use, mental health, and multiple births (e.g. twins or triplets). Many risk factors can be discerned and mitigated, and yet maternal morbidity and mortality can also occur with no discernible risk factors. An important contributor to a woman's risk of maternal morbidity and mortality in the U.S. regardless of health status is race and ethnicity, along with social drivers of health like geographic disparities in healthcare access, disparities in prenatal care utilization, socioeconomic status (SES), and other factors.[17–21]

Additionally, pregnancy complications like hypertensive disorders of pregnancy (HDP) during can exacerbate the risk during pregnancy. HDPs are classified into three categories: 1) chronic hypertension, 2) preeclampsia-eclampsia, and 3) gestational hypertension. Preeclampsia is a specific hypertensive disorder that develops during pregnancy or postpartum and is a leading cause of maternal morbidity.[22] Preeclampsia can advance into eclampsia when blood pressure continues to increase and is associated with seizure and stroke.[23] Marked by a surge in blood pressure after the 20th week of pregnancy, preeclampsia can increase the likelihood of high blood pressure, blood clots, and stroke later in life.[24] Gestational diabetes, another pregnancy complication, is identified by high blood sugar during pregnancy and can lead to a higher lifetime risk for diabetes (typically type 2) and fatty liver disease.[25,26] Gestational diabetes is a pregnancy complication that affects 2%-10% of pregnancies in the U.S. and typically develops around 24-28 weeks of pregnancy.[26,27]

Consistent and early prenatal care is crucial for a healthy pregnancy and positive birth outcomes, providing a critical opportunity to identify and mitigate risk factors for maternal morbidity and mortality. Women who do not receive any prenatal care are estimated to be three to four times more likely to die of pregnancy-related complications in comparison to those receiving adequate care.[28] Prenatal care continues to be one of the most frequently used healthcare services in the U.S., yet stark disparities exist for understudied, underrepresented, and underreported (U3) women (discussed below).[29] **Figure 10-2** shows on the initiation of prenatal care for all live births in 2022: 75.3% of pregnant women received prenatal care in the first trimester, 15.9% of women first received prenatal care in the second trimester, and 6.6% of women first received prenatal care in the third trimester or none at all (2.2% were unknown).[30] Notably, the COVID-19 pandemic resulted in changes in prenatal care, showing declines in pregnant people receiving the recommended number of visits due to difficulty accessing medical care and concerns over exposure to the virus.[31–33] As of 2022, U.S. prenatal care utilization had not yet returned to pre-pandemic levels.[32]

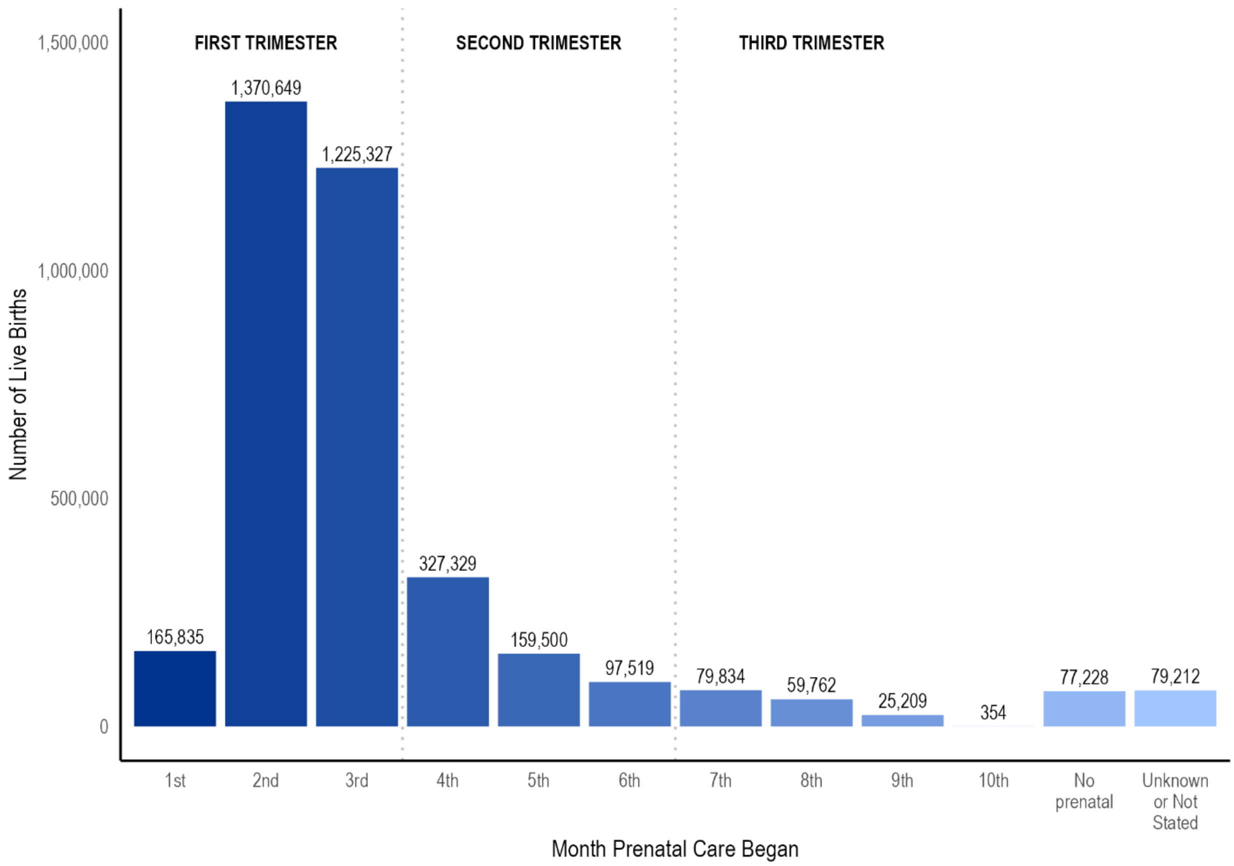

Figure 10-2: Initiation of prenatal care by month of pregnancy for all live births
Source: National Vital Statistics System (NVSS) – Natality, 2022

The delivery method can also increase the risk of maternal morbidity and mortality. When successful, vaginal deliveries are safer than planned cesarean deliveries with equivalent neonatal outcomes.[34] While frequently necessary for both maternal and fetal indications, cesarean deliveries (C-sections) pose their own risks to the health of birthing people. Morbidity is higher for women who undergo cesarean deliveries than women who undergo vaginal deliveries, with even higher morbidities associated with repeat cesarean deliveries.[35] Cesarean delivery is associated with approximately a 2.7 times increased risk of SMM compared to vaginal delivery and is a potential contributing factor to over 35% of SMM cases in the U.S.[36] This risk accumulates as most deliveries after a first cesarean are via repeat cesarean. To reduce maternal morbidity, the U.S. Department of Health and Human Services' "Healthy People 2030" campaign includes a goal to reduce the cesarean birth rate among low-risk people with no prior births.[37] Among high-income countries, the U.S. has one the highest rates of primary cesarean delivery—a rate that has been steadily increasing and reached 22.4% in 2021.[38,39]

10.3 Maternal Morbidity and Mortality in U3 Women

U3 women face persistent disparities related to maternal mortality, including women belonging to underrepresented racial and ethnic communities, women living in rural settings, women who are economically disadvantaged and women belonging to sexual and gender minority (SGM) populations. This section reviews maternal morbidity and mortality data for U3 women and explore clinical, social, and structural drivers that increase the risk and prevalence of adverse pregnancy outcomes.

10.4 Maternal Morbidity and Mortality in Underrepresented Racial and Ethnic Communities

Maternal mortality in the U.S. presents a dramatic picture of disparities: it is associated with the accumulation of social and structural barriers, such as access to quality care, that disproportionately affect women belonging to underrepresented racial and ethnic communities.[40,41] These social and structural drivers of health can contribute to weathering and lead to adverse pregnancy outcomes.[40,41] **Figure 10-3** shows the U.S. age-adjusted maternal mortality rate in 2021 by race and ethnicity. By far, the greatest burden—and tragedy—of U.S. maternal mortality is endured by AI/AN and Black families and communities.[42–44] Compared to White women, the maternal mortality rate for Black women is approximately three times higher and over four and a half times higher for AI/AN women. The maternal mortality rates for both AI/AN and Black women are on the rise (**Figure 10-4**).[40,45,46] The social determinants of maternal health are intrinsically wedded to structural determinants of health that promote or obstruct maternal well-being. Education and income, access to quality housing and healthcare, personal and community safety, food stability: these are all shaped by local, state, and federal policies.[47] This is compounded by the impact of racism in healthcare: ranging from poor communication to outright mistreatment. Research demonstrates that implicit bias drives disparities in maternal morbidity and mortality for Black women, for example, regardless of their SES.[48,49] Although the link between historical and intergenerational trauma in AI/AN communities remains understudied, recent literature has focused on individual-level risks that AI/AN women face.[50] Studies have highlighted that access to maternal care services, including prenatal and obstetric care, vary by geographic location with increased rurality of AI/AN communities creating greater transportation obstacles to quality care and longer wait times.[50,51]

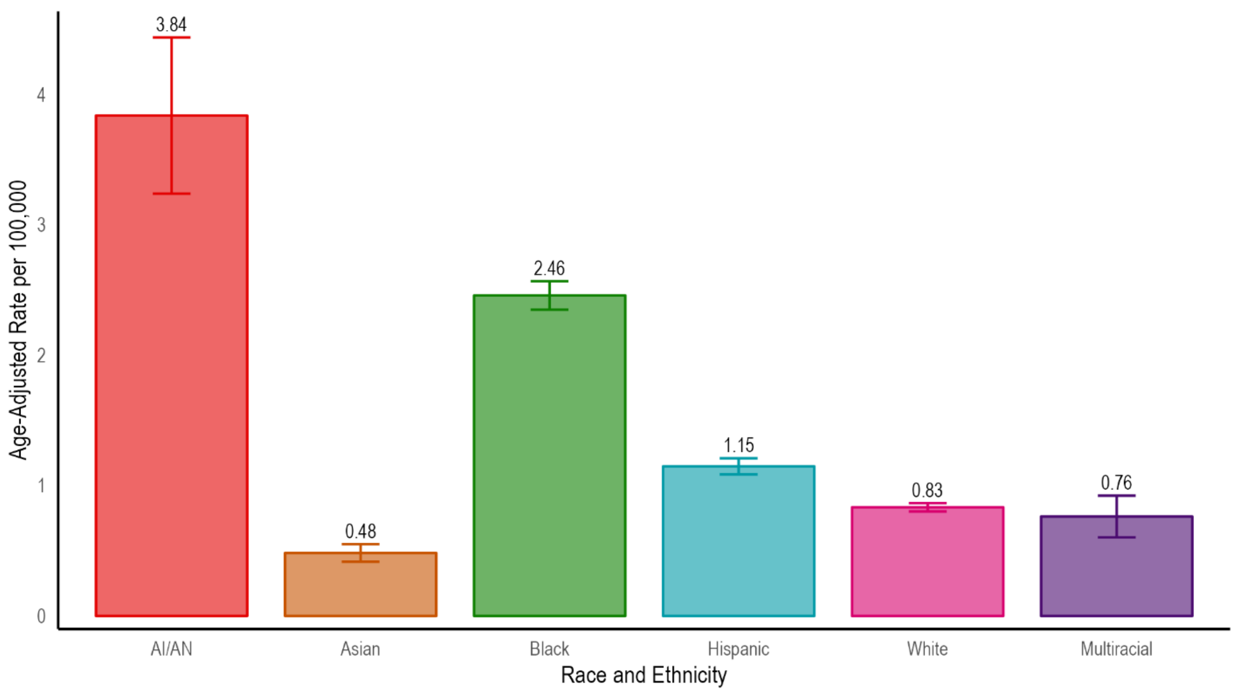

Figure 10-3: Age-adjusted maternal mortality rate per 100,000 women, by race and ethnicity of the mother

Source: National Vital Statistics System (NVSS) – Underlying Cause of Death, 2021

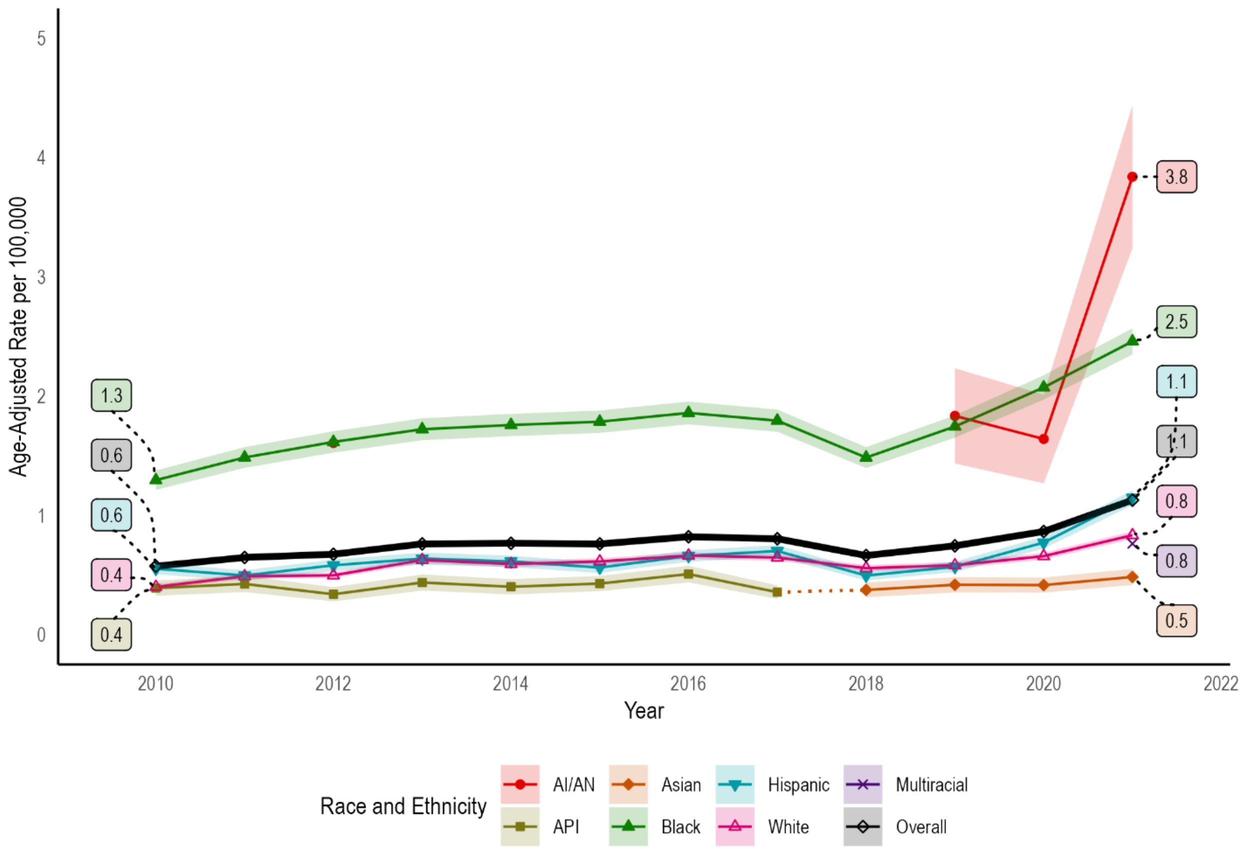

Figure 10-4: Age-adjusted maternal mortality rate per 100,000 women over time, by race and ethnicity of the mother

Source: National Vital Statistics System (NVSS) – Underlying Cause of Death, 2010-2021

10.4.1 Prenatal Care

Prenatal care is critical for identifying and mitigating the impact of maternal risk factors and protecting against maternal morbidity and mortality. U3 women belonging to underrepresented racial and ethnic communities experience differences in access to and quality of care, with a direct impact on screening for and diagnosis of maternal risk factors.[52,53] **Figure 10-5** shows that across racial and ethnic groups, prenatal care was initiated during the first trimester of pregnancy for the majority of pregnancies that resulted in a live birth. However, this varies from a low of 54% among Native Hawaiian and Pacific Islander (NHPI) women to highs of 84% among White and 85% among Asian women. This is further elaborated in **Figure 10-6**, which demonstrates persistent differences in average number of prenatal care visits by race and ethnicity (as well as the decline in care associated with COVID-19, discussed above). NHPI women consistently had the lowest number of prenatal care visits (between eight and nine visits), across all years of data followed by AI/AN women (nine visits). White, Asian, and Multiracial women have the highest average number of prenatal visits (11 visits), followed by Hispanic and Black women (10-11 visits).

Disparities in prenatal care are associated with a range of structural barriers (including factors like availability, cost, and language),[54] as well as experiences of implicit bias and racism within the healthcare system.[55–57] Differences in prenatal care utilization by some Hispanic and immigrant women may be influenced by communication and language barriers, among other social and structural drivers of health.[54] A recent study of racial bias in electronic health records (EHRs) provides a lens into Black women's experience of implicit racism in healthcare: after controlling for sociodemographic and health characteristics, Black patients were 2.54 times as likely as White patients to have at least one negative descriptor (e.g., "resistant" or "noncompliant") in their EHR**.** The impact of implicit bias and racism in healthcare may alienate pregnant people from prenatal care and drive disparities in maternal morbidity and mortality for Black women regardless of their SES.[48,49] In a recent qualitative study of NHPI women's experiences with providers and healthcare systems perinatally, NHPI women reported experiences of microaggression that alienated them from their care providers; dismissiveness toward their physical experiences and birth plans, and feeling "lost and undereducated about prenatal care and birth."[56]

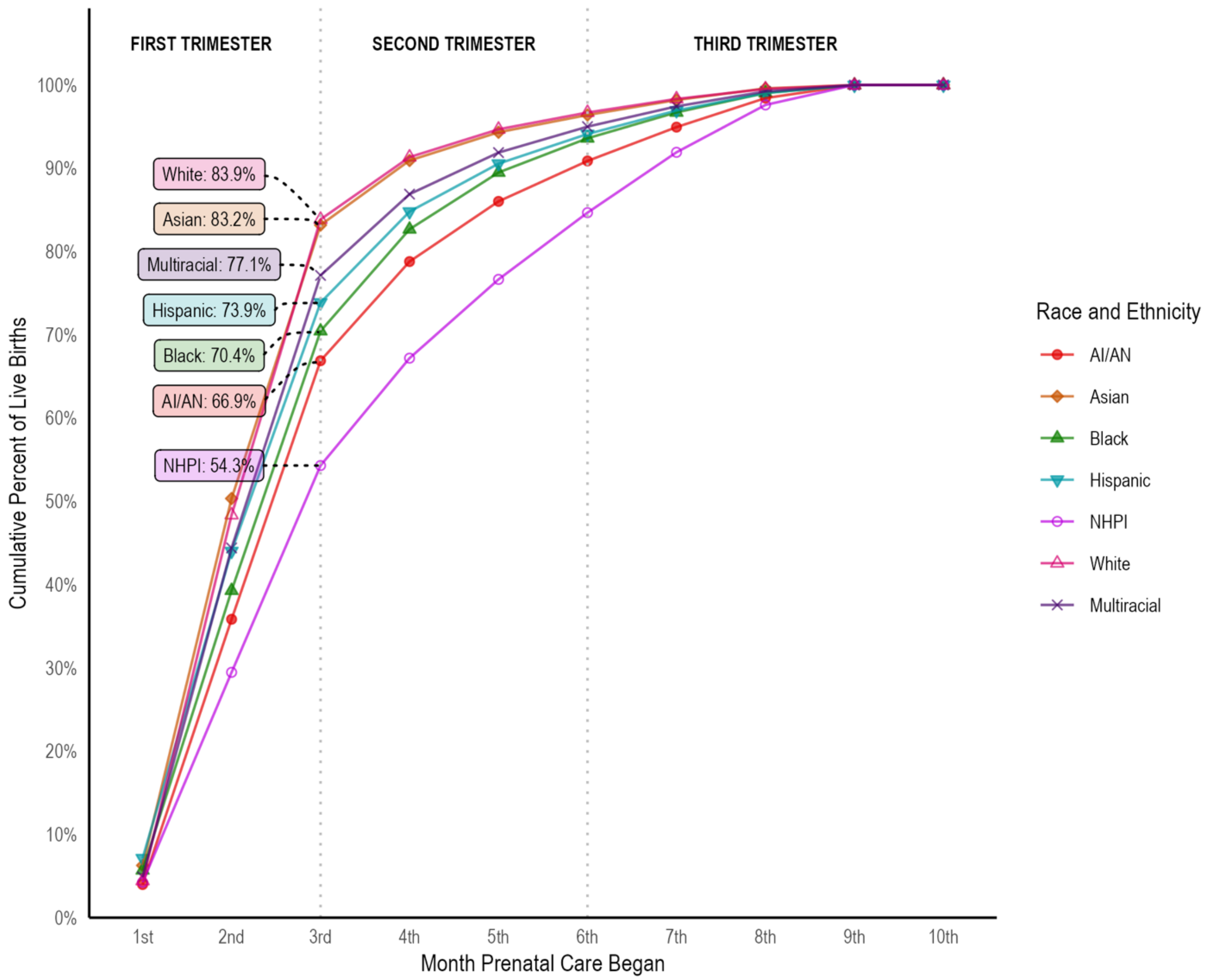

Figure 10-5: Initiation of prenatal care by month of pregnancy, by race and ethnicity of the mother

Source: National Vital Statistics System (NVSS) – Natality, Pooled 2018-2022

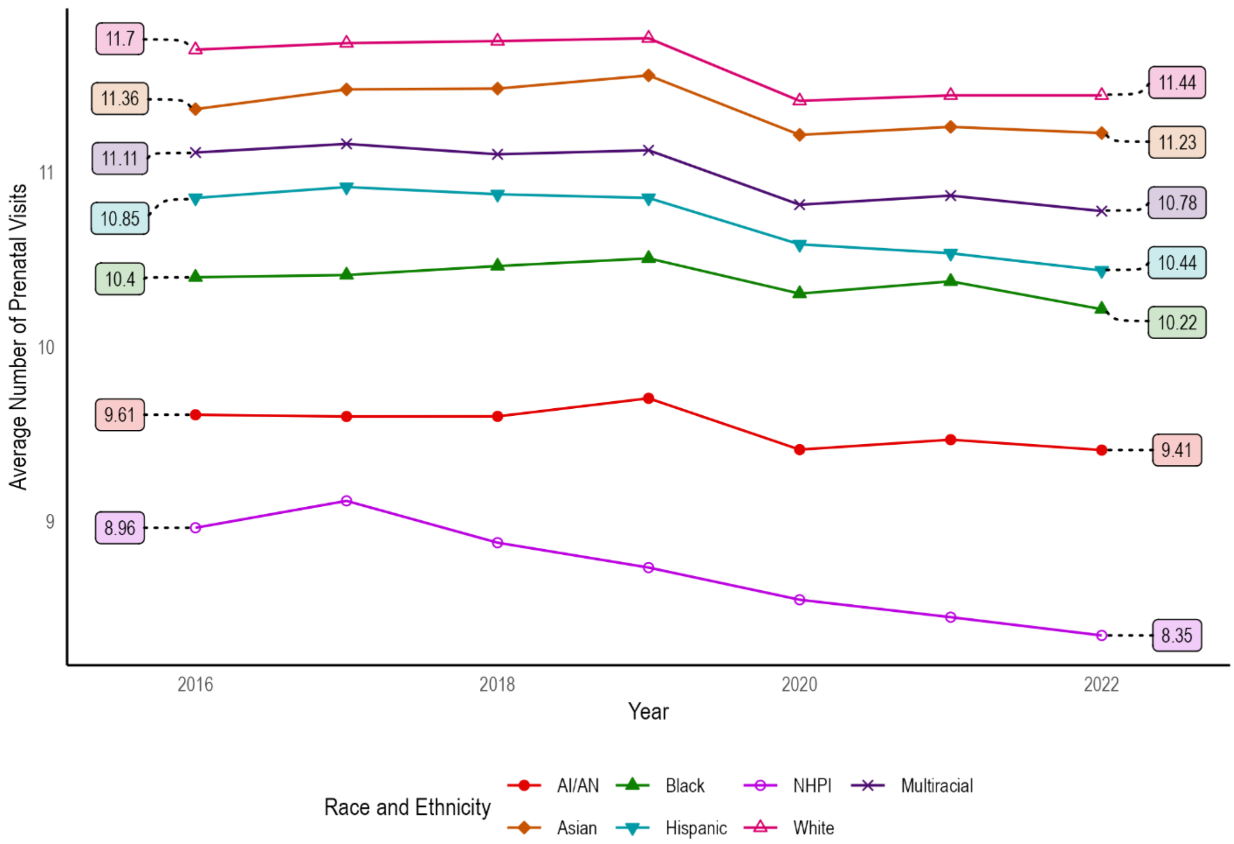

Figure 10-6: Average number of prenatal care visits over time, by race and ethnicity of the mother

Source: National Vital Statistics System (NVSS) – Natality, 2016-2022

10.4.2 Hypertensive Disorders of Pregnancy

Hypertensive disorders of pregnancy (HDP) are associated with seizure, stroke, and adverse cardiovascular events, all severe but preventable maternal complications.[58] As illustrated in **Figure 10-7,**[ii] the occurrence of pregnancy-associated hypertension has more than doubled over the past decade, from an estimated 4% of live births in 2010 to 9.5% in 2022. Pregnancy-associated hypertension is consistently more prevalent in Black women and AI/AN women. Hispanic, Asian and Pacific Islander (API), and Asian women have the lowest percentages of pregnancy-associated hypertension, which are lower than the overall average percentage across all groups.

[ii] **Figure 10-7** uses a dotted line to indicate disaggregation of the API population into Asian and NHPI populations between 2015 and 2016.

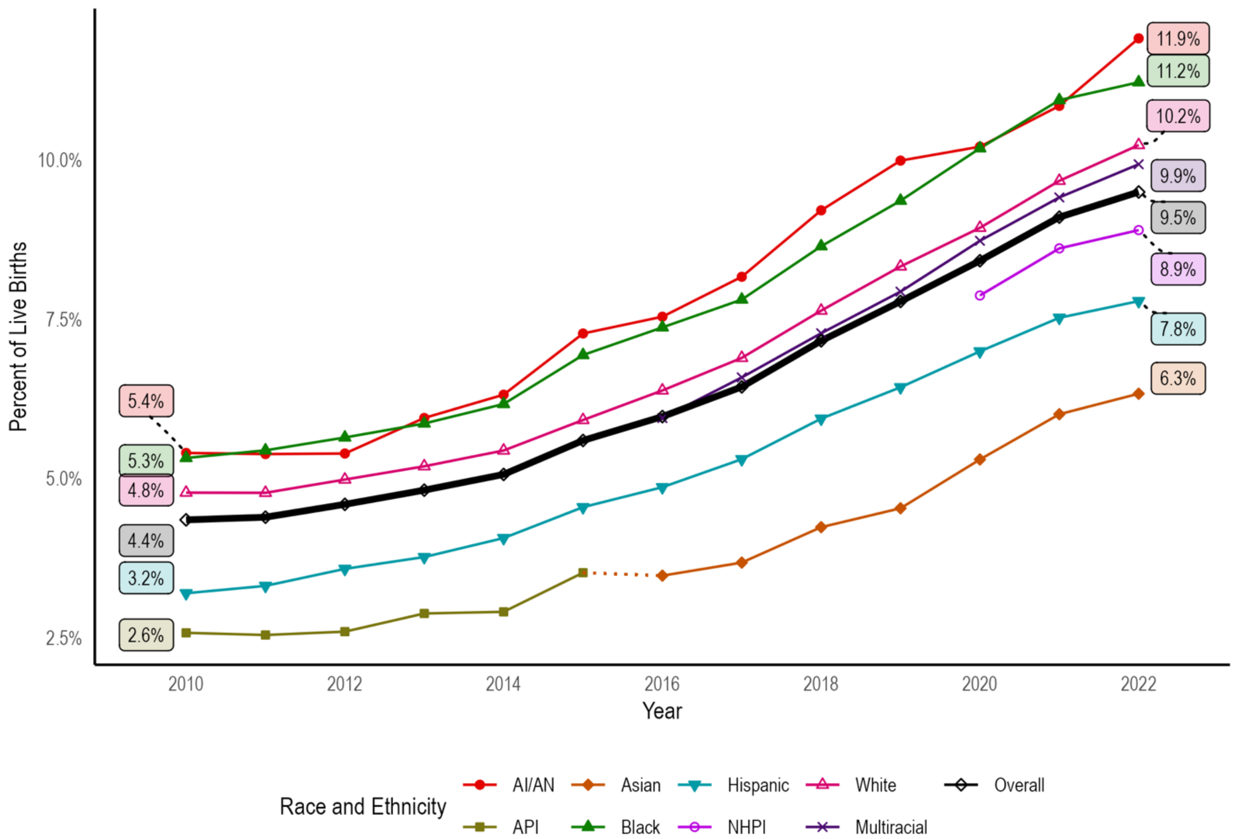

Figure 10-7: Pregnancy-associated hypertension over time, by race and ethnicity of the mother
Source: National Vital Statistics System (NVSS) – Natality, 2010-2022

The overall increase in pregnancy-associated hypertension may be due to a rise in risk factors such as advanced maternal age, obesity, and diabetes mellitus, noting that chronic health conditions associated with maternal risk disproportionately affect U3 women belonging to underrepresented racial and ethnic communities (see Chapter 6).[58–60] Risk factors such as pregnancy-associated hypertension are contributors to long-term CVD risk. This increased risk observed within AI/AN populations highlights the importance of improving cardiovascular health by focusing on multilevel interventions that address social drivers (including institutional and structural racism and medical mistrust rooted in historical trauma) that in turn influence health outcomes.[61]

Differences in access to and quality of care can contribute to differential screening and diagnosis for pregnancy-associated hypertension, causing potential delays in treatment.[52,53] These disparities seen in screening for maternal morbidity conditions highlight the history of racism and discrimination U3 women have experienced with the U.S. healthcare system, often resulting in their symptoms being overlooked or dismissed by clinicians.[62–64] These experiences may layer on overall psychosocial stress due to experiences with discrimination and racism, and associated with hypertension.[65]

Figure 10-8 shows trends in eclampsia between 2010 and 2022, by race and ethnicity of the mother and for women overall. Approximately 0.3% of women had eclampsia, and this prevalence has remained stable over time. Notably, the prevalence of eclampsia for the NHPI population was more than double that for other racial and ethnic groups between 2020 and 2021, prevalence that was likely masked until the API population was disaggregated into Asian and NHPI. The prevalence of eclampsia among Black, AI/AN, and Multiracial women is consistently above the overall average. Part of the disproportionate impact of preeclampsia and eclampsia on Black women may be linked to preexisting conditions, as Black populations enter pregnancy with a higher prevalence of chronic conditions that increase the risk of developing preeclampsia (see **Chapter 5**).[66,67] Obesity and diabetes, important risk factors for preeclampsia and eclampsia, disproportionately affect women belonging to underrepresented racial and ethnic communities, which many explain some of the observed disparities.[23,68] Prenatal care is critical for identifying and mitigating the impact of preeclampsia. However, as discussed above, there are many social and structural drivers that reduce access to prenatal care and the interventions that can keep pregnant people healthy.

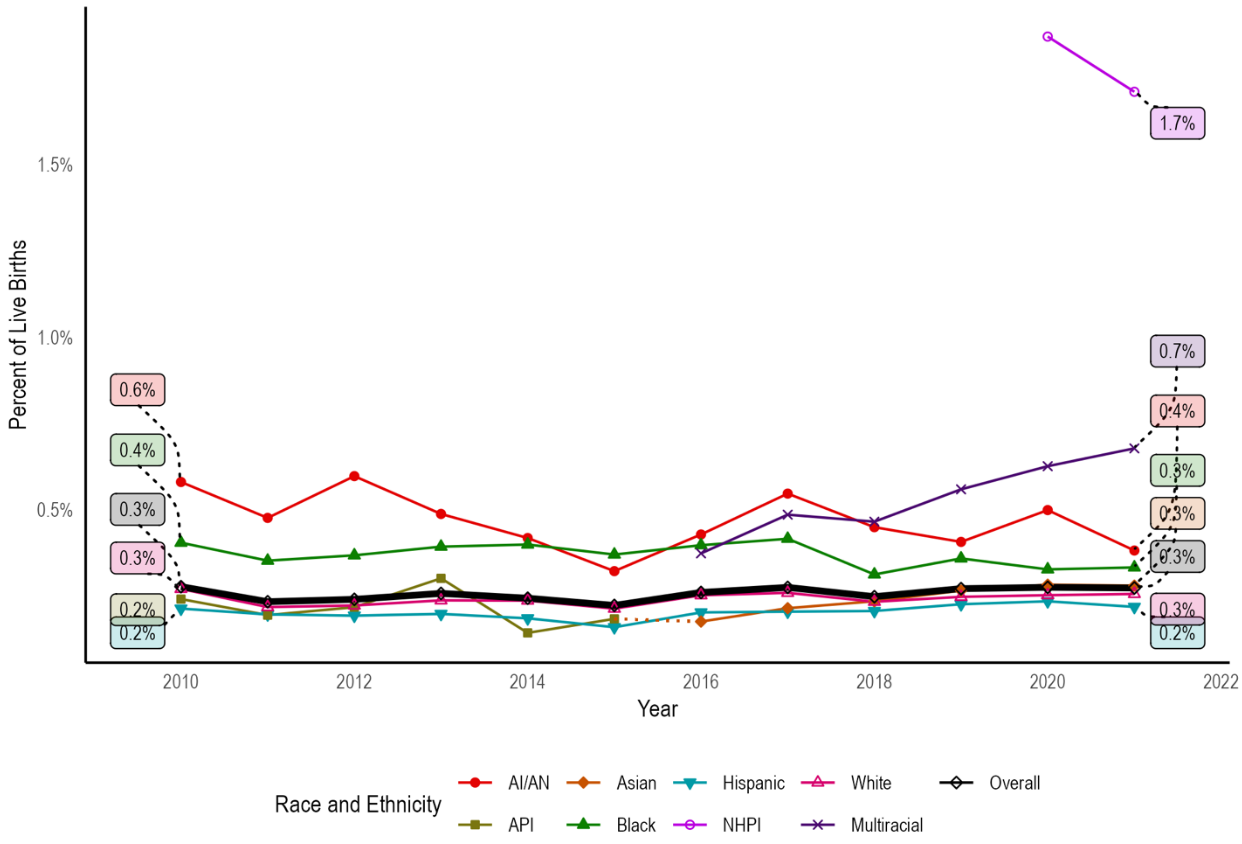

Figure 10-8: Eclampsia over time, by race and ethnicity of the mother
Source: National Vital Statistics System (NVSS) – Natality, 2010-2021

10.4.3 Gestational Diabetes

Figure 10-9 illustrates the percent of gestational diabetes between 2016 and 2022, by race and ethnicity of the mother and for women overall. Asian women consistently have the highest prevalence of gestational diabetes, at almost 50% higher than the overall average prevalence. The reasons for this are multifaceted and not well understood. While pre-pregnancy obesity is a known risk factor for gestational diabetes, the prevalence of overweight and obesity is lower among Asian women than any other racial or ethnic groups.[69,70] Social and economic lifestyle factors related to acculturation of immigrants may influence risk. According to recent research, acculturation to the U.S. by immigrants has been associated with nutrition, lifestyle, and use of health services and can have a significant negative association risk for

Asian women.[71] The percent of AI/AN, NHPI, and Hispanic women who are diagnosed with gestational diabetes is also above the overall average.

Black women are the least likely to develop gestational diabetes, yet they are at higher risk for developing type 2 diabetes following a gestational diabetes diagnosis during pregnancy.[72] Considering the adverse health outcomes that are associated with gestational diabetes, it is critical that pregnant people have access to screening at or before 24 weeks of pregnancy, as recommended by the U.S. Preventive Services Task Force.[73,74]

Gestational diabetes is associated with an increased risk of high blood pressure and preeclampsia, cesarean delivery, developing diabetes after pregnancy, and preterm birth.[26,75] Some of the risk factors for gestational diabetes include previous gestational diabetes, being over 25 years old, having a family history of type 2 diabetes, and being overweight.[75,76] Disparities in obesity has been associated with higher levels of food insecurity, greater access to poor quality foods, and poor access to healthcare, which disproportionately impact U3 women (see **Chapter 6**).[77]

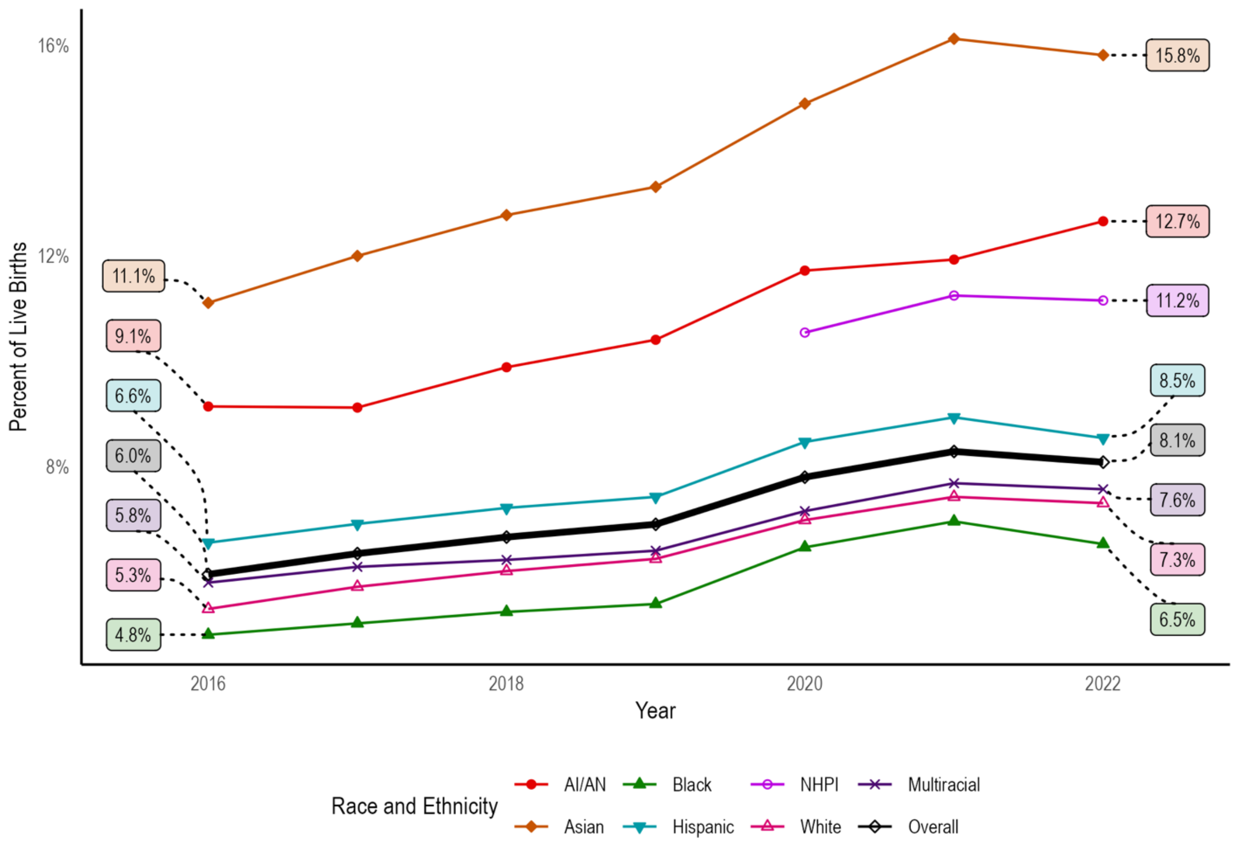

Figure 10-9: Gestational diabetes over time, by race and ethnicity of the mother
Source: National Vital Statistics System (NVSS) – Natality, 2016-2022

10.4.4 Delivery

Figure 10-10 shows the percent of live births by delivery method (vaginal, cesarean, and unknown or not stated) and by race and ethnicity of the mother in 2022. Across all groups, the majority of deliveries (63.2%-70.6%) were vaginal. The highest prevalence of cesarean delivery was among Black women (36.8%), and the lowest prevalence of a cesarean delivery was among AI/AN women (29.3%). Higher prevalence of cesarean deliveries may be one contributor to the disproportionate maternal morbidity and mortality among Black women. Cesarean deliveries may also create risks for pregnancies later in life such as placenta previa, placenta accreta, and uterine rupture.[78]

Studies suggest that higher prevalence of cesarean deliveries among Black women could be driven by stress due to discrimination and racism that occurs over the life course.[79–81] Pregnant Black women are more likely to report being pressured into a cesarean delivery by clinicians compared to White women.[82] Research has found that when Black women undergo cesarean deliveries, they are more likely to receive general rather than regional anesthesia when compared to White women.[83] Additionally, while high income and education are typically protective factors against poor birth outcomes following a cesarean delivery, this does not hold true for Black women.[84]

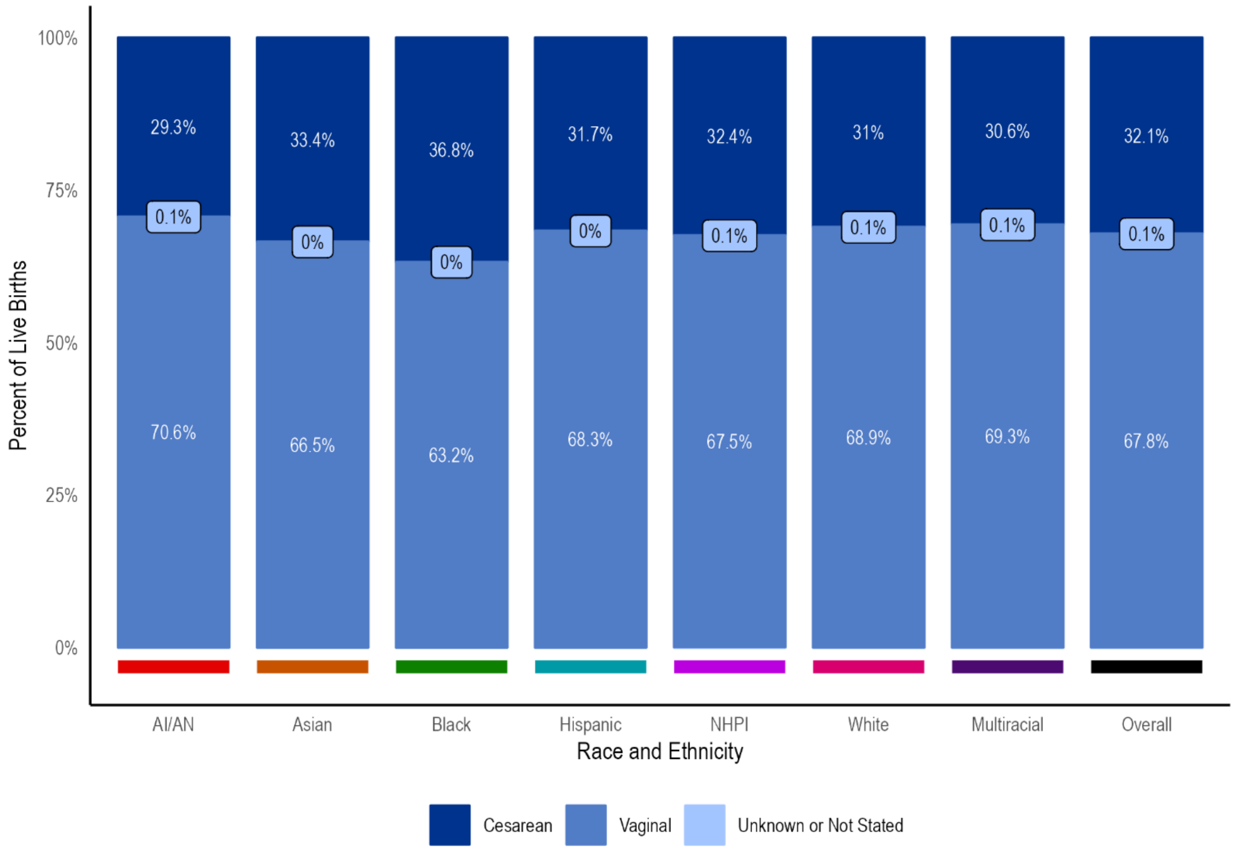

Figure 10-10: Delivery method (cesarean, vaginal, unknown, or not stated), by race and ethnicity
Source: National Vital Statistics System (NVSS) – Natality, 2022

Figure 10-11 shows trends in the percent of live births with at least one indicator of maternal morbidity by race and ethnicity of the mother. This includes maternal transfusion, third- or fourth-degree perineal laceration, ruptured uterus, unplanned hysterectomy, and admission to intensive care unit as reported by practitioners/providers. There is an overall upward trend in women experiencing at least one of these conditions between 2016 and 2022. Asian women consistently have the highest prevalence of maternal morbidity indicators, followed by AI/AN, NHPI, and White women. The literature on maternal morbidity indicators for Asian women acknowledges that this area is not well studied and merits additional research, ranging from possible genetic and biological causes of disparities as well as the "social determinants of health, access to care, and structural racism" that may inform maternal risk among Asian women.[85,86]

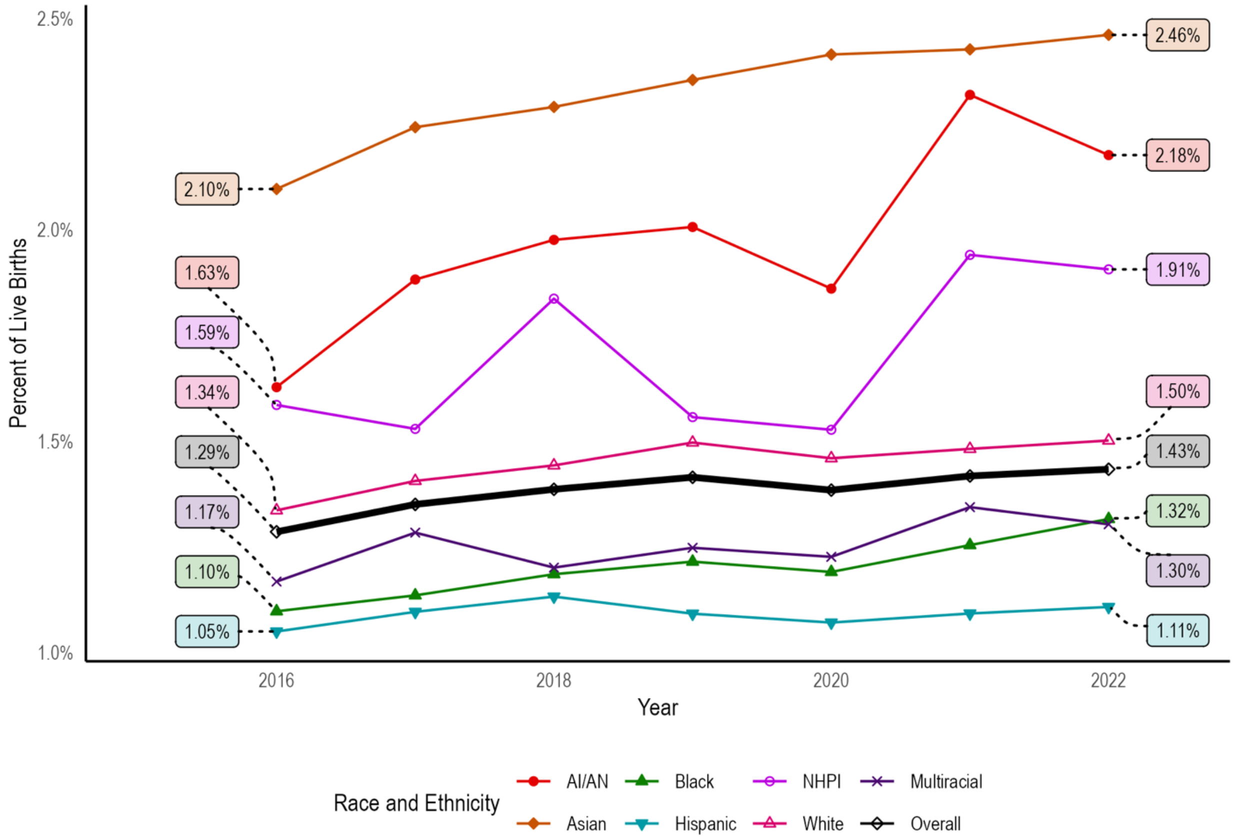

Figure 10-11: Live births with at least one indicator of maternal morbidity over time, by race and ethnicity of the mother

Source: National Vital Statistics System (NVSS) – Natality, 2016-2022

10.5 Other Intersectional Considerations Relevant to U3 Women

U3 women belonging to underrepresented racial and ethnic communities experience differences in access to and quality of care, and social and structural drivers of health that results in increased maternal risk factors. This section examines disparities in maternal morbidity risk factors among U3 women.

10.5.1 Rurality

10.5.1.1 Prenatal Care

Rural populations in the U.S. increasingly experience "maternity care deserts," defined as counties with "no hospitals providing obstetric care, no birth centers, no OB/GYN, and no certified nurse midwives."[87]

In 2022, a March of Dimes report found that maternity care deserts and low access areas affected nearly 500,000 births, that the number of counties with low or no care had increased since 2020, and that 61.5% of maternity care deserts were in rural counties.[87]

Figure 10-12 shows the average number of prenatal care visits across race and ethnicity and rurality from 2016-2022. The overall pattern suggests that women living in rural areas have less frequent prenatal visits. The average number of prenatal visits for all groups is lower than the currently recommended 12-14 visits for low-risk pregnancies.[88,89] The data show that White and Asian women living in non-rural areas had the highest average number of prenatal visits, while AI/AN and NHPI women in rural areas had the lowest average number of visits. Among NHPI women, available evidence suggests that the primary barriers to prenatal care access include perceived discrimination and lack of insurance, difficulties with transportation, and lack of knowledge about the importance of first trimester prenatal visits.[90,91]

For all groups, the number of visits dipped at the start of 2020. The data here are consistent with other research showing that the COVID-19 pandemic and the associated social distancing mandates contributed to inadequate prenatal care, decreased social support from partners and family members, questioning healthcare, and increased anxiety and fear.[88,92,93] As discussed above, pregnancy-related mortality ratios in 2021 saw a larger increase among rural women than their urban counterparts "consistent with rising rates of COVID-19-associated mortality among women of reproductive age."[9] As of 2022, U.S. prenatal care utilization had not yet returned to pre-pandemic levels.[32]

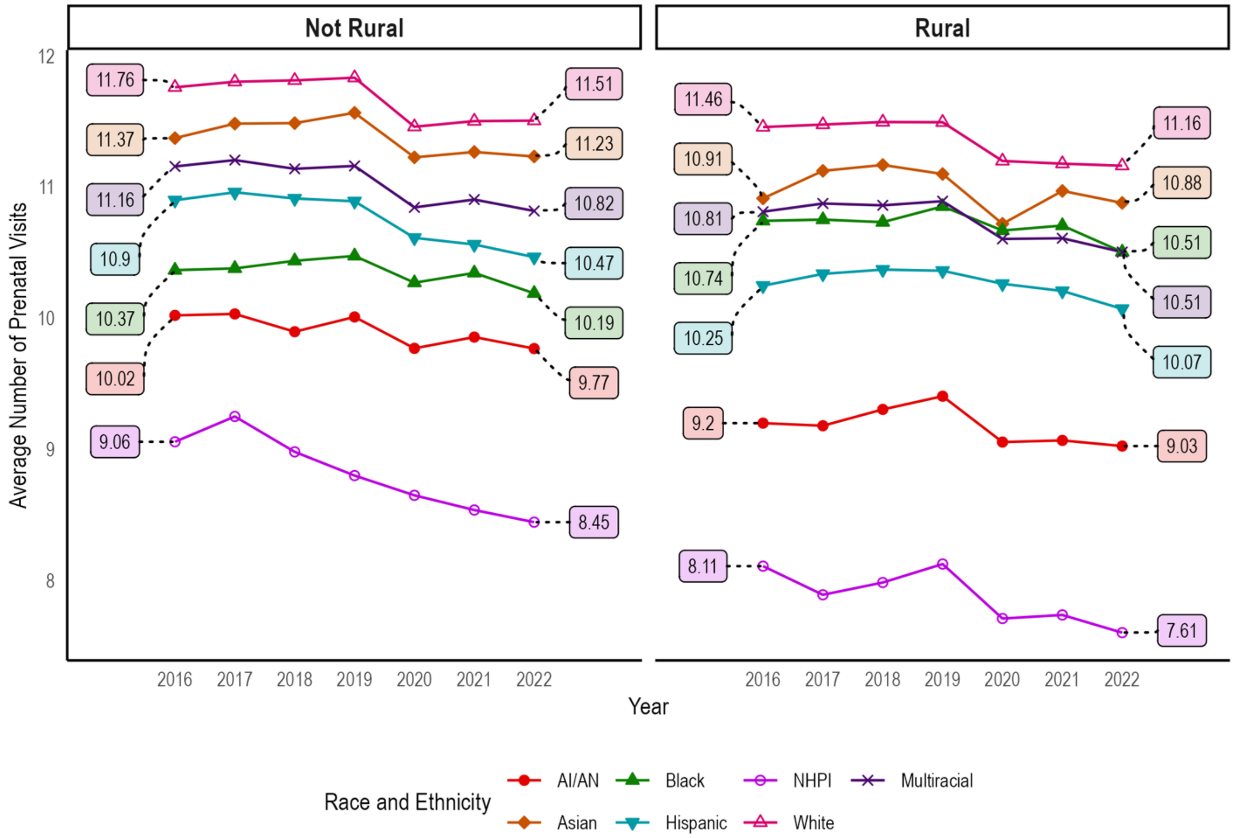

Figure 10-12: Average number of prenatal care visits over time, by race and ethnicity, and rurality of the mother

Source: National Vital Statistics System (NVSS) – Natality, 2016-2022

10.5.1.2 Hypertensive Disorders of Pregnancy

In the U.S. overall, pregnant women in rural areas are more likely to have HDP than those in urban areas.[94] **Figure 10-13** shows the reported pregnancy-associated hypertension by race and ethnicity and rurality of the mother in 2022. Pregnancy-associated hypertension was highest among AI/AN women (12.8%) and Black women (11.3%) living in non-rural areas, and lowest among Asian women in both not rural (6.3%) and rural (6.5%) areas. While NHPI women in rural areas have a relatively low percent of pregnancy-associated hypertension (7.1%), this should be interpreted with caution due to the low sample size (n=87). A recent study noted that rural women may begin their pregnancies at a disadvantage relative to HDP, starting with a higher baseline of hypertension pre-pregnancy when compared to their urban counterparts.[95] Social drivers of health may also inform the disparities between rural women and their urban counterparts including poverty, lack of access to exercise opportunity, and the increasing gaps in access to healthcare.[94]

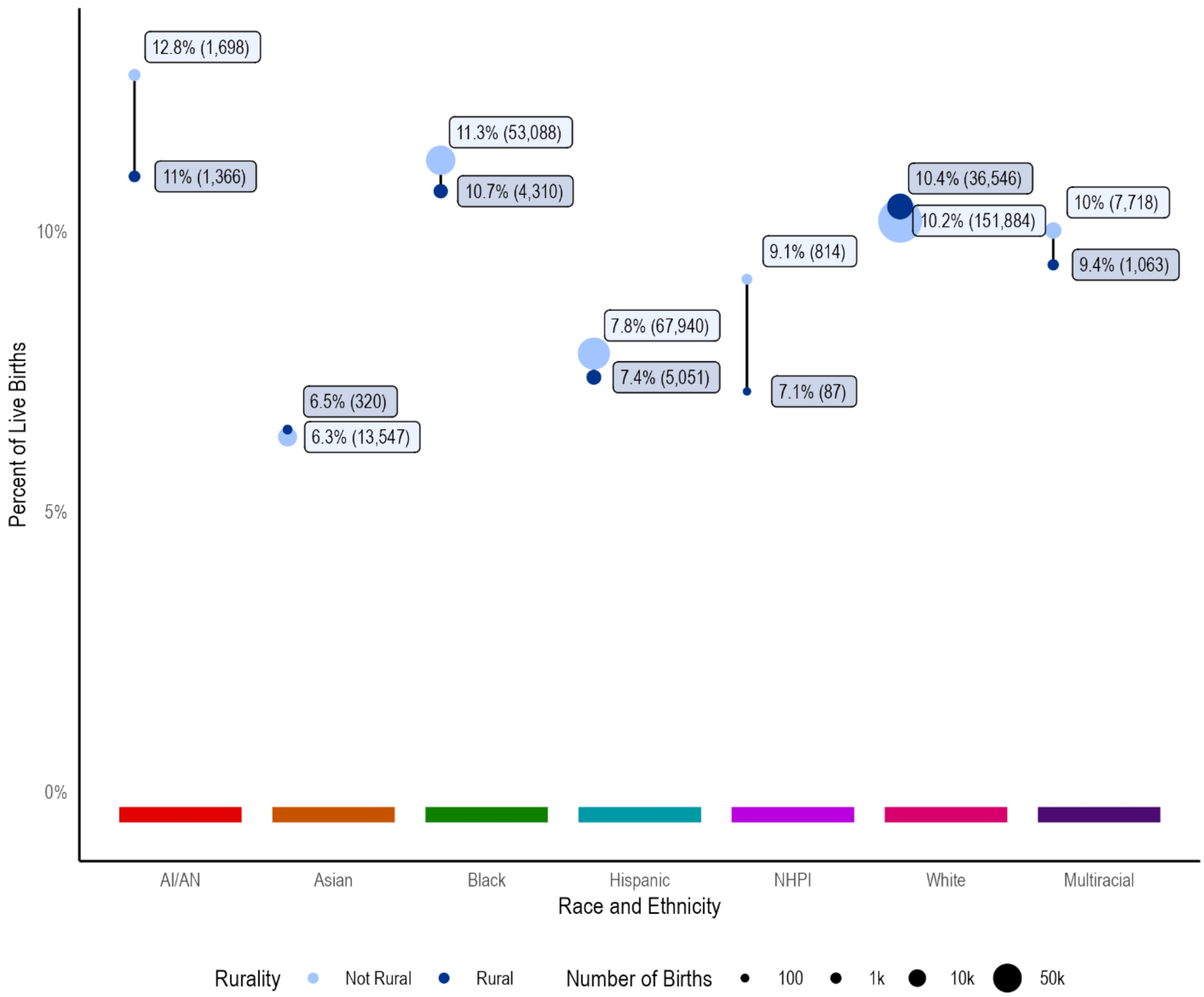

Figure 10-13: Pregnancy-associated hypertension, by race and ethnicity, and rurality of the mother
Source: National Vital Statistics System (NVSS) – Natality, 2022

Figure 10-14 shows eclampsia by race and ethnicity and rurality in 2022. The overall percent of live births with reported diagnosed eclampsia is low, and the data do not show a consistent pattern by rurality. The highest percent was among NHPI women not living in rural areas (noting there were no NHPI women living in rural areas who gave birth and reported being diagnosed with eclampsia). Percent of eclampsia was lowest among Hispanic women and White women living in non-rural areas. As discussed above, Black women are at higher risk for eclampsia due to a range of social and structural drivers of health, ranging from implicit bias in healthcare to stress from the lived experience of racism. Nativity provides a lens into the impact of a lifetime of systemic racism on maternal health: after controlling for sociodemographic and cardiovascular risk factors, U.S.-born Black women had worse cardiovascular risk profiles in comparison to Black women born outside of the U.S. They also tended to have higher allostatic loads (cumulative wear on the body) due to prolonged exposure to neighborhood poverty, systemic racism, and residential segregation throughout their life course, which negatively impacted health outcomes (see Chapter 1).[96–99]

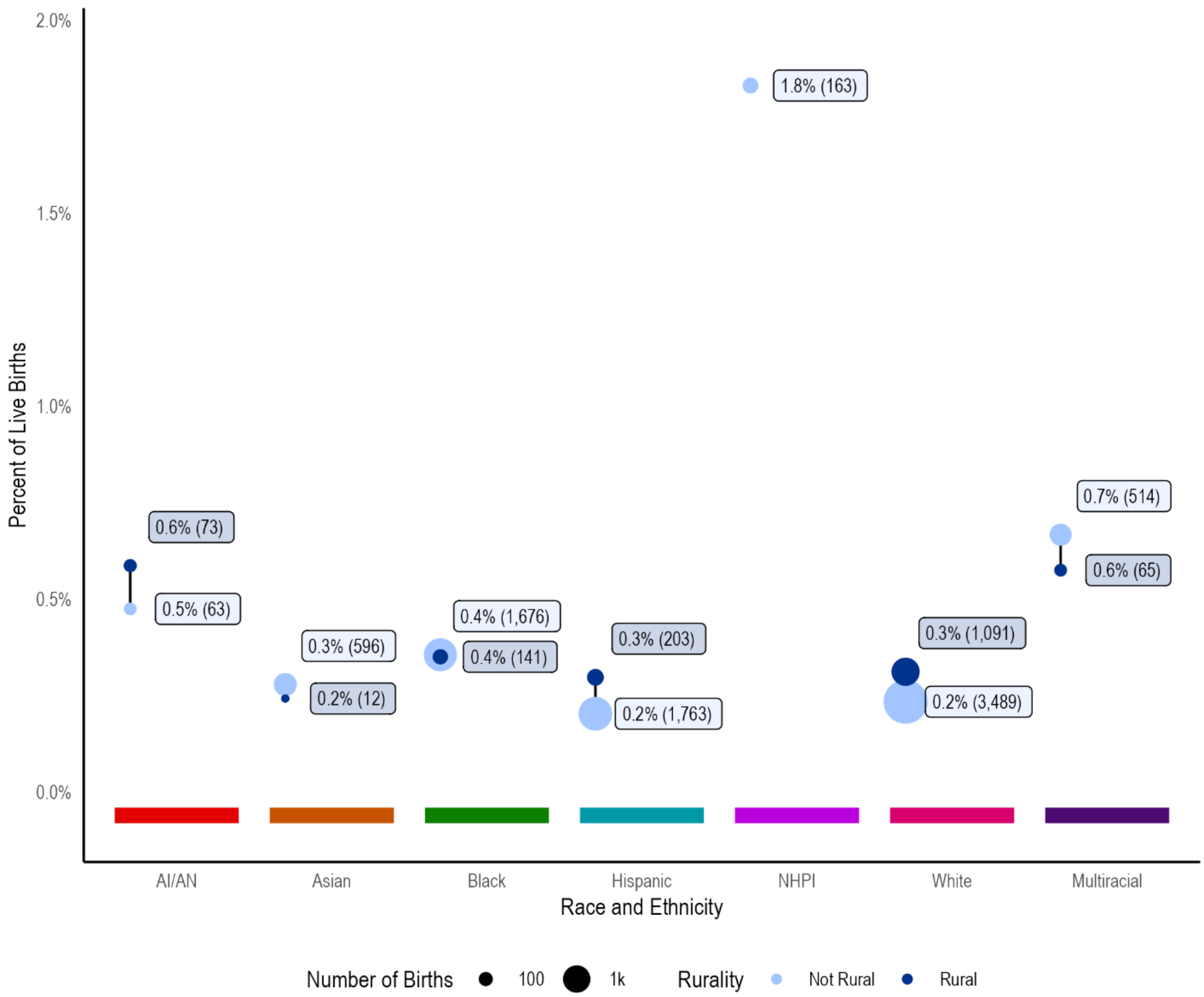

Figure 10-14: Eclampsia, by race and ethnicity, and rurality of mother

Source: National Vital Statistics System (NVSS) – Natality, 2022

10.5.1.3 Gestational Diabetes

Figure 10-15 shows gestational diabetes rates by race and ethnicity and rurality. The data suggest that the percentages of women with gestational diabetes is similar for women in rural and not rural areas, compared within most races and ethnicities. For Asian women in rural areas, the percent with gestational diabetes is approximately 2% higher compared to Asian women in not rural areas. Additionally, the percentage of women with gestational diabetes is highest among Asian women followed by AI/AN women, and lowest in Black and Multiracial women.

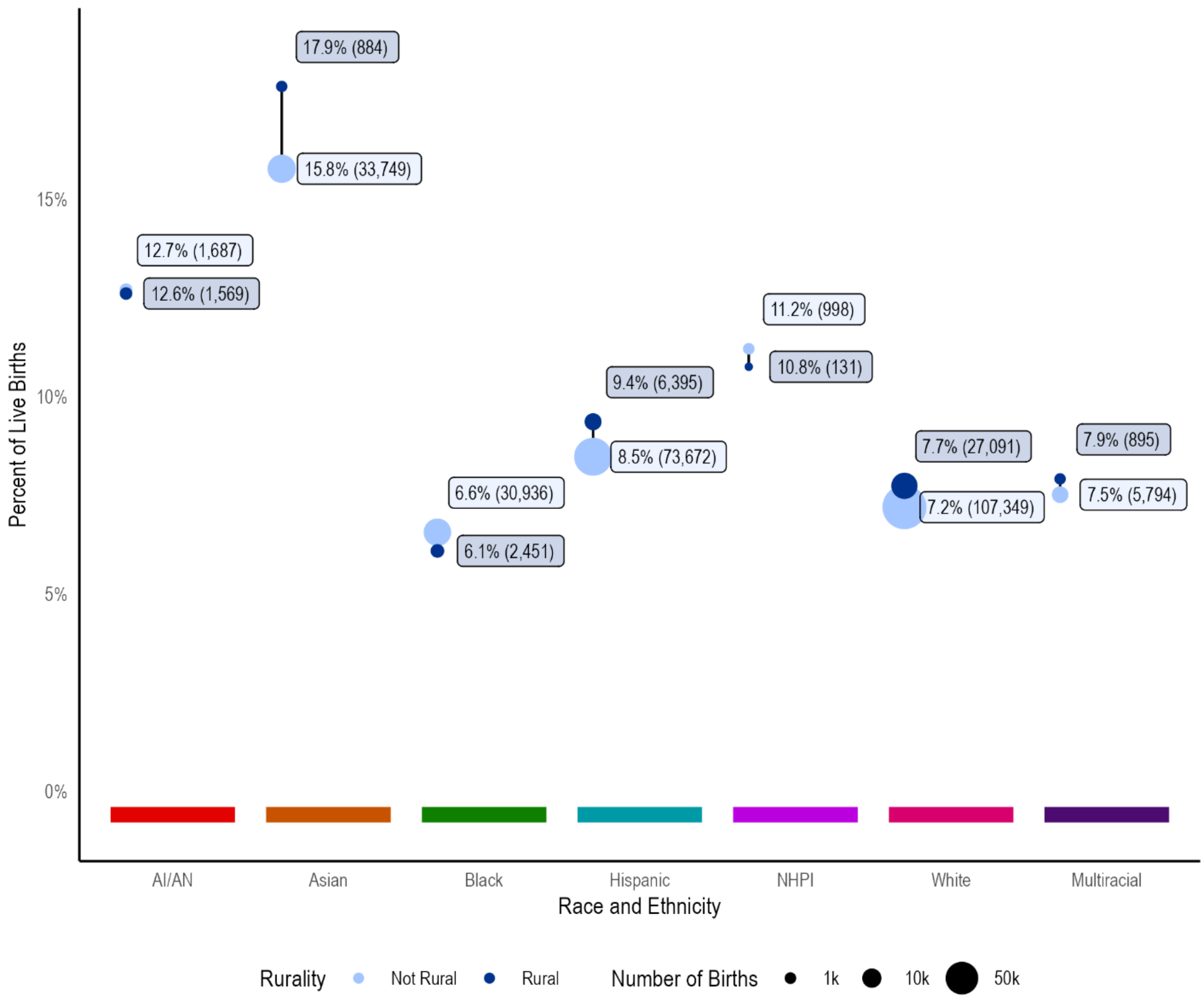

Figure 10-15: Gestational diabetes, by race and ethnicity, and rurality of the mother
Source: National Vital Statistics System (NVSS) – Natality, 2022

10.5.1.4 Delivery

Maternity care deserts adversely affect delivery outcomes. Women living in areas with no or low access to obstetrical care must travel long distances to access care, increasing their risks of maternal morbidity or mortality: over half of rural women must travel more than 30 minutes to reach a hospital with obstetrical care.[87,100] Rural women of all races and ethnicities experience cesarean section and vaginal delivery rates roughly the same as their non-rural counterparts (**Figure 10-16**). While the percentage of women overall experiencing at least one indicator of maternal morbidity is relatively low, rural women experience these events more frequently than their counterparts living in non-rural areas (**Figure 10-17**). Rural women suffer a 9% greater probability of SMM and maternal mortality.[100] This is consistent with research that found a significantly higher incidence of SMM in rural women, likely associated with health care shortages intersecting with other social drivers of health that impact rural women's health (food deserts, lack of exercise, poverty, education, racism, trauma, etc.).[45] The rural hospitals with birthing units report higher rates than their urban counterparts of postpartum hemorrhage and the use of blood transfusion during birth.[100]

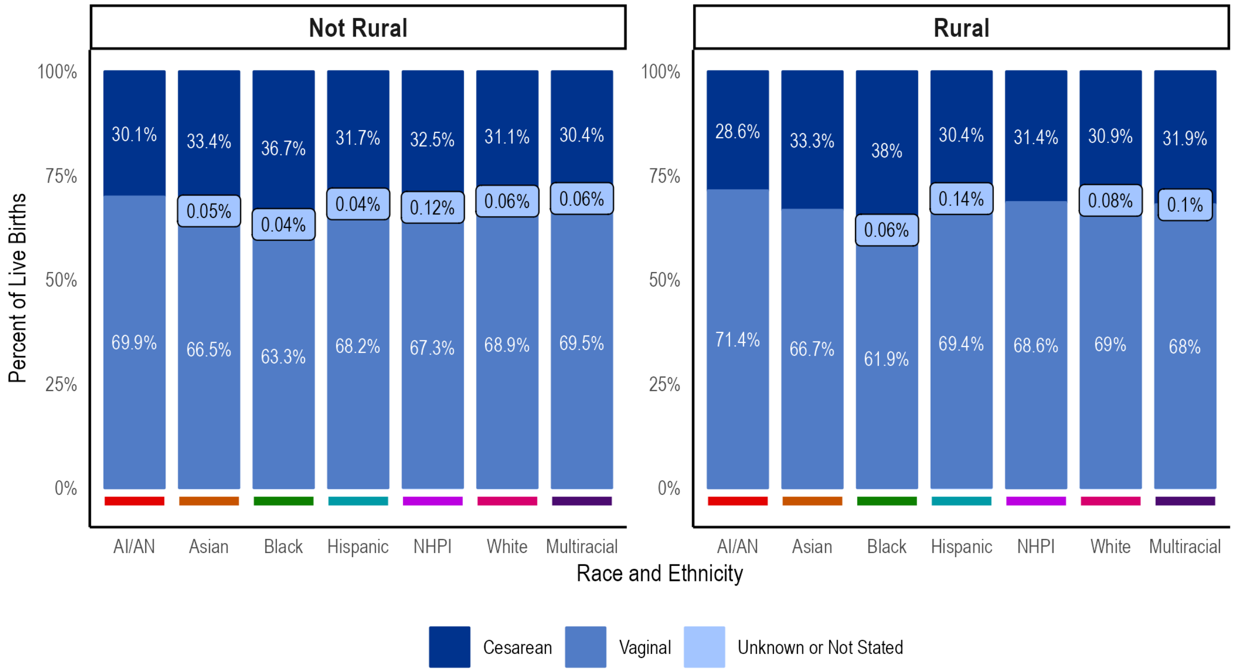

Figure 10-16: Delivery method (cesarean, vaginal, unknown or not stated), by race and ethnicity, and rurality of the mother

Source: National Vital Statistics System (NVSS) – Natality, 2022

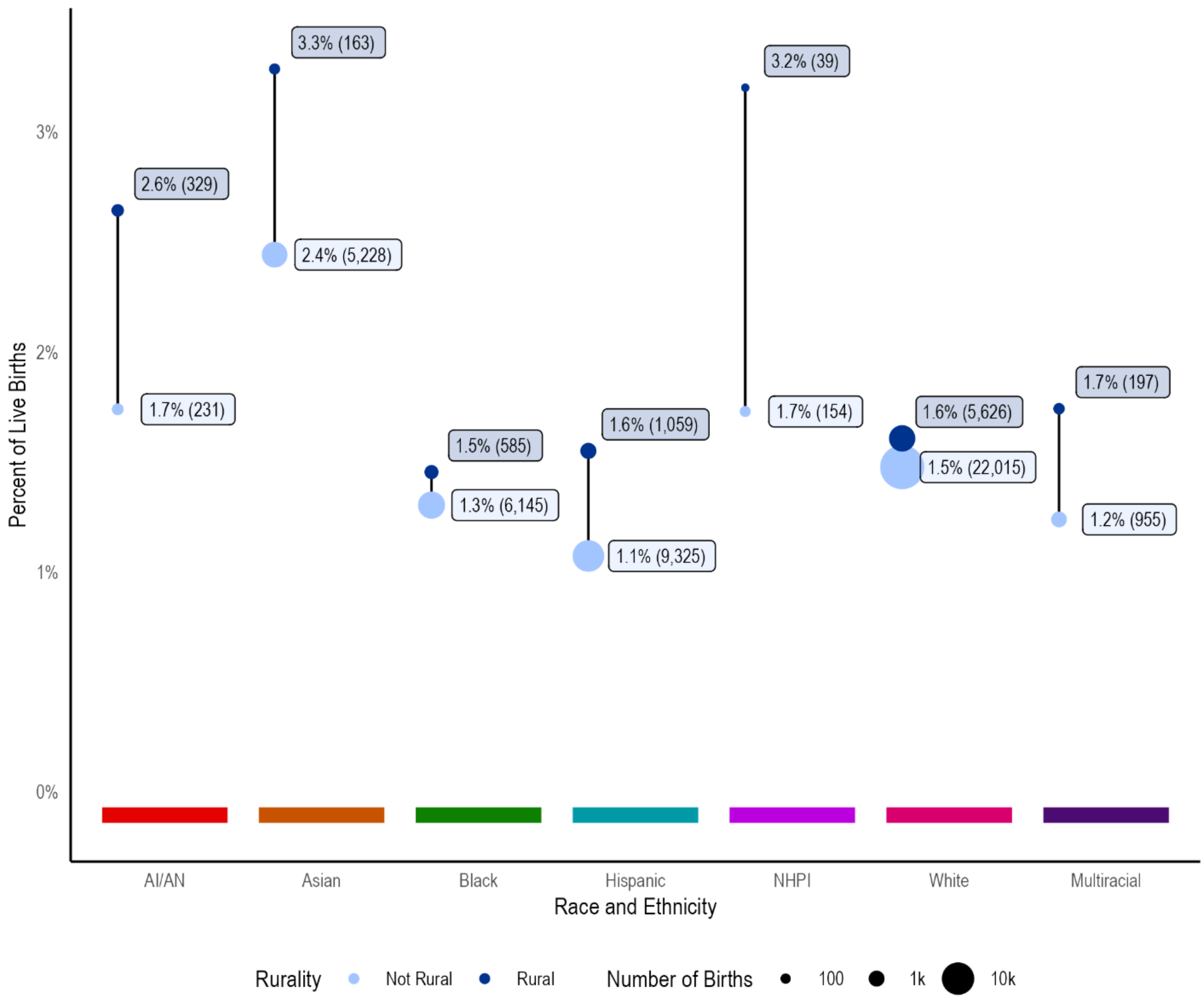

Figure 10-17: Live births with at least one indicator of maternal morbidity, by race and ethnicity, and rurality of the mother

Source: National Vital Statistics System (NVSS) – Natality, 2022

10.5.2 Payment Source for Delivery

Health insurance coverage facilitates access to care and utilization of services during pregnancy. Further, health insurance provides a level of financial protection by reducing patient spending out-of-pocket. While more research is needed, individuals with health insurance generally have lower rates of morbidity and mortality relative to those uninsured.[101] Importantly, both health insurance coverage and health insurance type correlate with measures of economic status. The U.S. Census Bureau classifies health insurance as private insurance (employment-based, direct-purchase, and TRICARE) and public insurance (Medicare, Medicaid, and VA and CHAMPVA).[102] Insurance provided through the Indian Health Service (IHS) is considered uninsured by the Census Bureau given that the IHS coverage during pregnancy is not considered comprehensive. Overall, 51.7% percent of deliveries among U.S. women were covered by private health insurance while 41.1% were covered by Medicaid in 2022.[103]

Pregnancy through 60 days postpartum is an eligibility for Medicaid.[104] Since the advent of the Affordable Care Act Medicaid coverage expansion in 2014, more people qualified for Medicaid coverage before pregnancy and through 12 months post-partum. In Medicaid expansion states, this has led to major increases in Medicaid enrollments and—thanks to this insurance coverage—increased use of outpatient care prenatally and postpartum.[105] The benefits of access to care in Medicaid expansion states can be seen in the 17% reduction in hospitalizations with 60 days postpartum.[105]

It is challenging to use NVSS data to understand how economic status—a primary driver of health outcomes and critical for the U3 framework—informs maternal morbidity and mortality (see **Chapter 1**)**.** Although there is no NVSS economic status indicator that may be used to analyze maternal morbidity and mortality, the NVSS does provide data on payment source for the delivery: private insurance, Medicaid, self-pay, and other (including IHS, CHAMPUS/TRICARE, other government source, and "other" specified).[106] While not a direct measure of economic status, payment source is associated with economic resources as measured through the Income-to-Poverty ratio (income divided by poverty threshold). For the purpose of this discussion, the Data Book utilizes payment source for delivery to provide a lens into how economics intersects with U3 women's outcomes, aligning the Census Bureau's classifications with the categories available in NVSS.

As can be seen in **Table 10-1,** there is variability around how health insurance is categorized across the Census Bureau and NVSS-Natality. Private insurance coverage tends to be consistent between the two data sources, with the exception of TRICARE which is considered private insurance by the Census and "other" by NVSS. Non-Medicaid public insurance is categorized as Other in NVSS, including IHS which is considered Uninsured by the Census Bureau. Self-pay, as measured through NVSS correlates with education as well. Women with less than a high school education were most likely to self-pay (13.2% self-pay) compared to women with a bachelor's degree or higher (2.6% self-pay).[103]

Using the Income-to-Poverty ratio as a measure of economic resources, the Census Bureau found that individuals aged 19 to 64 who were at or above 400% of the poverty threshold (higher economic status) were significantly more likely to have private insurance than public insurance (91.8% vs 5.7%).[102] Those between 100% and 399% of the poverty threshold were also more likely to be covered by private insurance than public insurance (61.8% vs. 25.4%). Overall, among adults aged 19-64 years, individuals below the poverty threshold have the highest uninsured percentage (24.0%) compared to those at or above 400% of the poverty threshold who had the lowest uninsured percentage (4.5%). In contrast, among adults aged 19-64 years, individuals below the poverty threshold have the lowest percentage of private coverage (27.1%) compared to those at or above 400% of the poverty threshold who had the highest percentage of private coverage (91.8%).

Table 10-1. Census Bureau and NVSS payment source types by economic status

			Percent of People in Economic Status with Insurance Type		
Census Bureau Classification	**Census Bureau Health Insurance Types**	**NVSS Classification**	**Below Poverty Threshold**	**Between 100% and 399% of Poverty Threshold**	**At or Above 400% of Poverty Threshold**
Private Coverage	Employment-based, Direct-purchase, TRICARE	Private Insurance, Other (TRICARE)	27.1%	61.8%	91.8%
Public Coverage	Medicare, Medicaid, VA & CHAMPVA	Medicaid, Other (VA & CHAMPVA)	51.8%	25.4%	5.7%
Uninsured	Self-pay, IHS	Self-pay, Other (IHS)	24.0%	16.7%	4.5%

*Percentages are based on Figure 7 and include data from 2020 and 2021 among adults aged 19 to 64 years.[102]

10.5.2.1 Prenatal Care

Figure 10-18 shows initiation of prenatal care by month of pregnancy, by payment source for delivery and race and ethnicity of the mother. The data show that across all racial and ethnic groups, women with private insurance received prenatal care the earliest, closely followed by “other” (including TRICARE, VA, CHAMPVA, IHS, and other programs), then Medicaid and finally self-pay.

In comparison to other groups, NHPI women with Medicaid and self-pay lagged significantly behind other groups, with just 45.8% of Medicaid and 26.3% of self-pay births receiving prenatal care during the first trimester. A study exploring perceived barriers to prenatal care for one NHPI community suggested that transportation and lack of health insurance were important obstacles.[107] Black women who self-pay for delivery are also among the least likely to receive prenatal care in the first trimester (50.8%). The lag in care among self-pay pregnant people overall is especially concerning, as they are women with the least education and highest risk.

Although payers are a critical way to ensure utilization of prenatal care, it is not a cure-all: one study found that low-income Black women in urban counties who had increased access to and utilization of prenatal care compared to low-income White women still experienced racial disparities in preterm birth outcomes.[108]

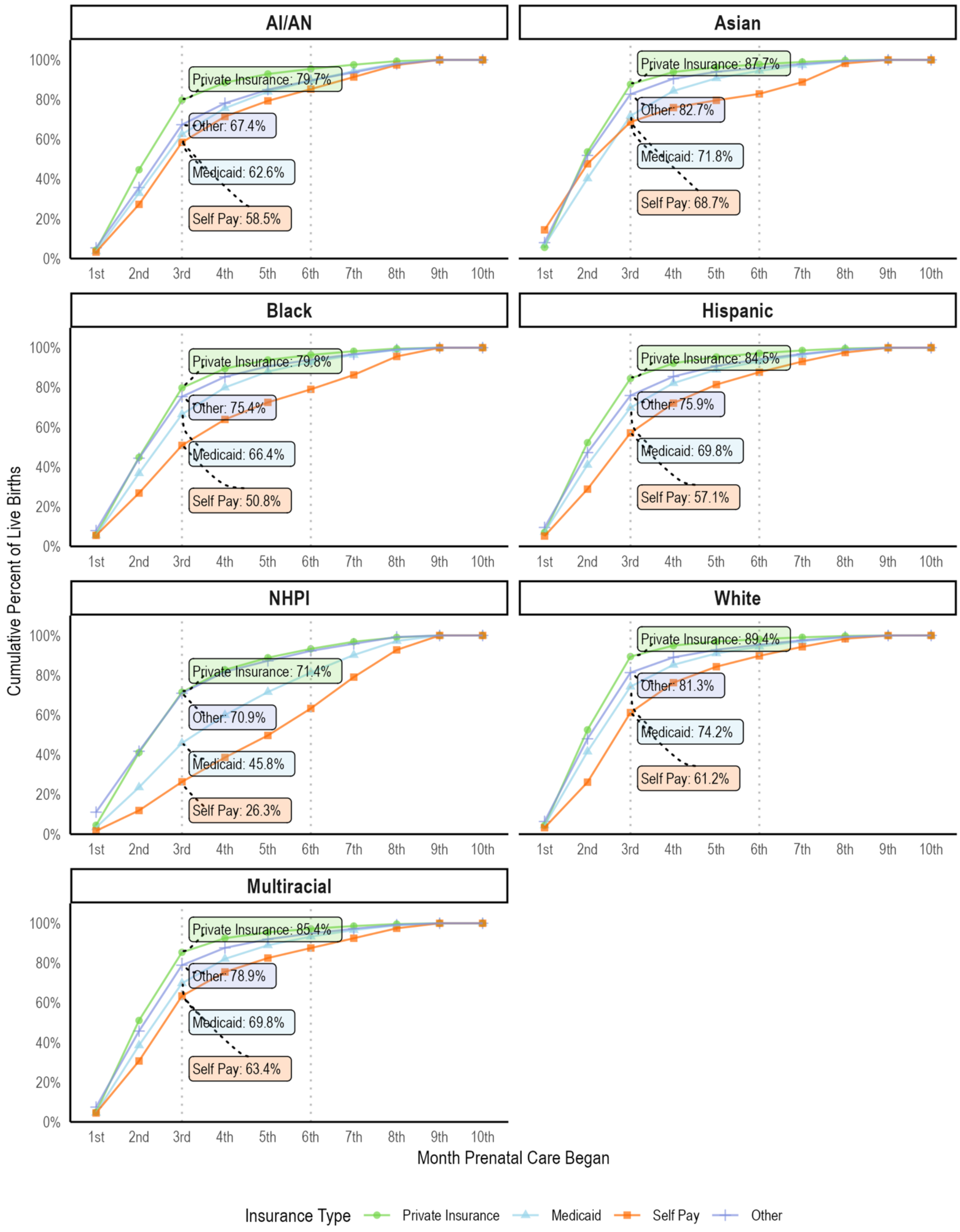

Figure 10-18: Initiation of prenatal care by month of pregnancy, by payment source for delivery and race and ethnicity of the mother

Source: National Vital Statistics System (NVSS) – Natality, Pooled 2018-2022

10.5.2.2 Hypertensive Disorders of Pregnancy

Figure 10-19 illustrates the overall pattern of pregnancy-associated hypertension among women with private insurance, Medicaid, self-pay, and "other." The percent of pregnancy-associated hypertension does not vary widely among women whose live births are paid by private insurance, Medicaid, and self-pay, although the size of these differences varies across racial and ethnic groups. As described above with prenatal care, AI/AN women experience the highest rates of pregnancy-associated hypertension overall, with the highest percentage (13.4%) in "other," which includes IHS coverage. IHS serves approximately half of the nation's American Indians and Alaska Natives and its "service population … live(s) mainly on or near reservations and in rural communities."[109] Overall, private insurance, Medicaid, and "other" sources of payment for delivery do not appear to correlate with pregnancy-associated hypertension among women across racial and ethnic groups. However, self-pay is consistently correlated with the lowest percentage of pregnancy-associated hypertension across all racial and ethnic groups. One explanation for this may be in the relatively lower rates of prenatal care among self-pay women (**Figure 10-19**). As information on pregnancy-associated hypertension and other pregnancy risk factors are collected through the prenatal care record, lower rates of prenatal care may contribute to under-diagnosed and/or under-reported pregnancy risk factors such as pregnancy-associated hypertension.

Additional research has found HDP (gestational hypertension and preeclampsia) were lower in women born outside of the U.S. than those born in the U.S. The differences in health outcomes across nativity centered around SES, neighborhood characteristics/built environment, racial segregation, access to healthcare, and instances of discrimination and racism.[110]

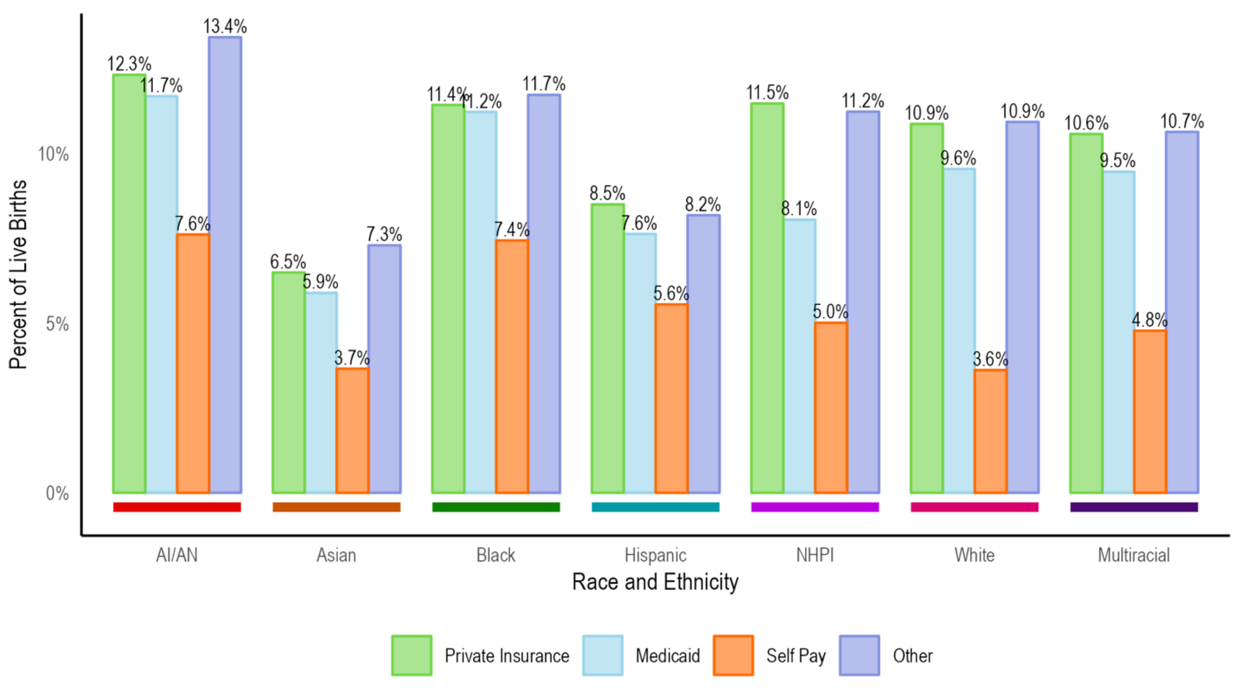

Figure 10-19: Pregnancy-associated hypertension, by payment source for delivery and race and ethnicity of the mother

Source: National Vital Statistics System (NVSS) – Natality, 2022

Figure 10-20 shows eclampsia by payment source for delivery and race and ethnicity of the mother. While the percentages reported are quite low, the highest percentage of eclampsia occurred among NHPI women with “other” as their payment source for delivery (2.6%), followed by NHPI women with Medicaid (2.0%). Across all categories, “other” as payment source for delivery is associated with the highest percentage of diagnosis of eclampsia although the percentages are low and variation is small (in AI/AN women, it ties with Medicaid at 0.6%). When compared with **Figure 10-18**, it is notable that women with “other” as their payment source were the second highest across all race and ethnicity categories in first-trimester utilization of prenatal care. In other words, people experiencing eclampsia at higher percentages were also among those engaging earliest in the care that should identify maternal health risks.

Percentages of eclampsia were higher among Asian and Multiracial women with “other” as their payment source for delivery than among all other categories for AI/AN, Black, Hispanic, and White women. These numbers, however, were lower than percentages among NHPI women with Medicaid and “other” as their payment source for delivery than any other group. These findings are consistent with existing research, which found higher eclampsia prevalence in Samoan and Hawaiian subgroups with risk factors including diabetes and obesity influenced by the built environment (e.g., racial segregation, poverty).

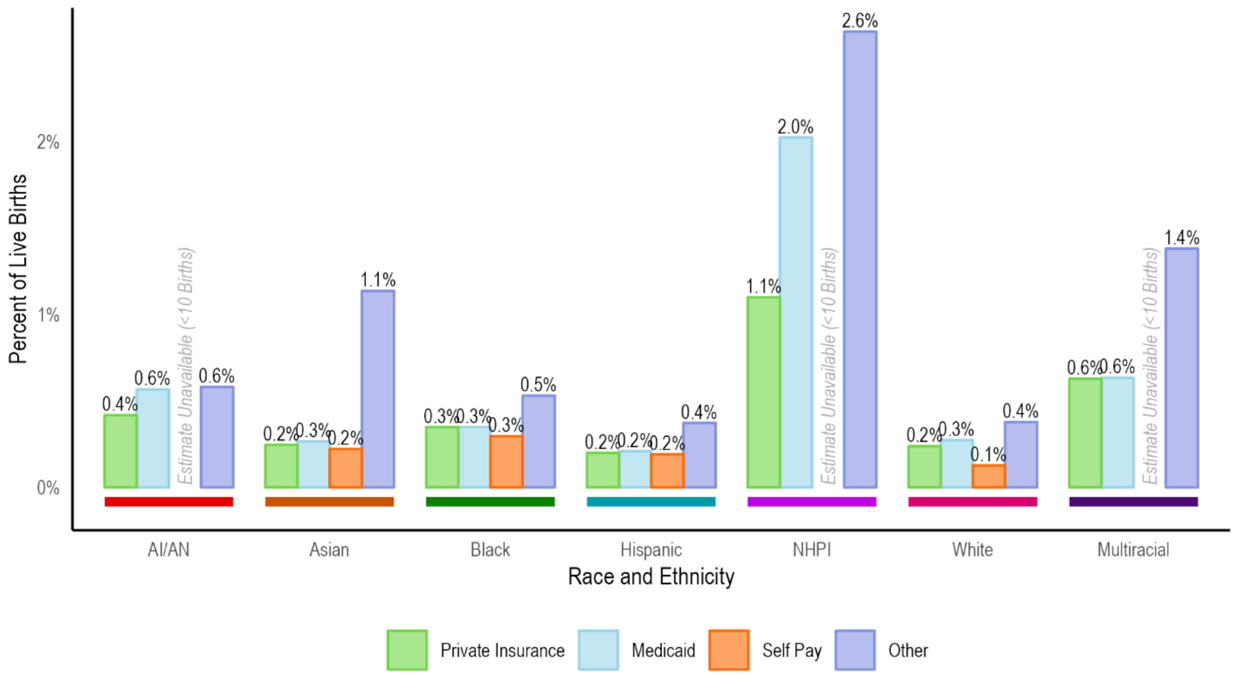

Figure 10-20: Eclampsia, by payment source for delivery and race and ethnicity of the mother
Source: National Vital Statistics System (NVSS) – Natality, 2022

10.5.2.3 Gestational Diabetes

The relative increase in gestational diabetes in the U.S. has been associated with a number of risk factors, including low SES.[111] The data for gestational diabetes, in **Figure 10-21**, do not show consistent patterns by payment source for delivery. As with pregnancy-associated hypertension (**Figure 10-19**), variation in the rate of gestational diabetes by private insurance, Medicaid, and other is relatively modest, although the size of these differences varies across racial and ethnic groups. Births paid for by self-pay, however, are lower for gestational diabetes, which may be related to less prenatal care and lower screenings. Consistent with other data, the overall percentage of gestational diabetes was highest across Asian, NHPI, and AI/AN women.

Research provides a sense of the impact of economic disadvantage on gestational diabetes: a nationally representative longitudinal study found that people who lived in poverty during their teen years have an increased risk of developing gestational diabetes (although this association was not observed for pre-eclampsia or HDP).[112]

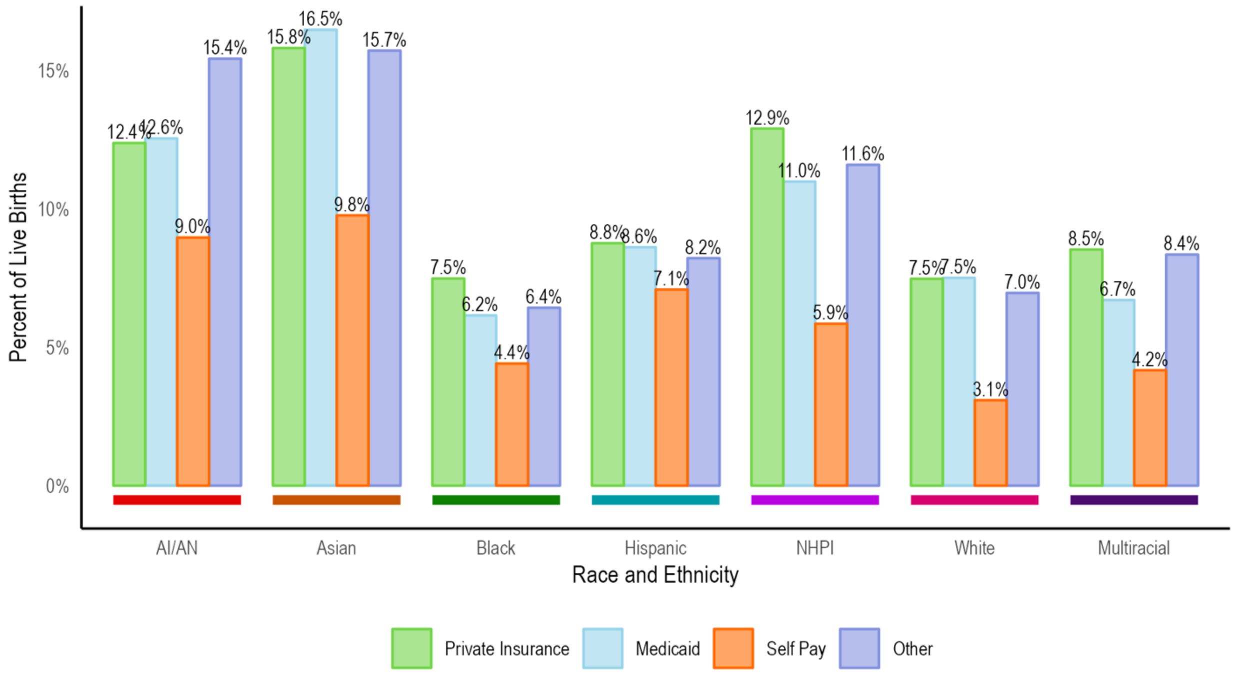

Figure 10-21: Gestational diabetes, by payment source for delivery and race and ethnicity of the mother

Source: National Vital Statistics System (NVSS) – Natality, 2022

10.5.2.4 Delivery

Figure 10-22 illustrates payment source for delivery by race and ethnicity. Overall, birthing people who used self-pay at delivery—women who have the least education and are among the most economically vulnerable—were the most likely to give birth vaginally. For those without insurance, their expected cost was approximately $18,865. Those who had private insurance were the most likely to undergo a cesarean section. Cesarean deliveries cost considerably more than vaginal delivery: the average cost of each in 2022 was $26,280 and $14,768, respectively. Privately insured patient out-of-pocket costs were estimated at $3,214 for cesarean and $2,655 for vaginal delivery.[113] Research has found an increased probability of cesarean section among people delivering at hospitals with higher profits per procedure.[114]

A recent meta-analysis of cesarean deliveries among uninsured patients suggests that this population is being underserved with cesarean sections, increasing poor patients' health risks and creating poorer outcomes.[115] As illustrated in **Figure 10-23**, NHPI women who used self-pay for delivery had the highest percentage of experiencing one or more indicator of maternal morbidity (3.5%), followed by Asian women whose delivery payment source was "other" (2.7%) or private (2.6%). Regardless of delivery method, uninsured people face higher costs than their insured counterparts, requiring them to pay a greater percentage of their income for care, and are burdened with significant debt as a result.[115]

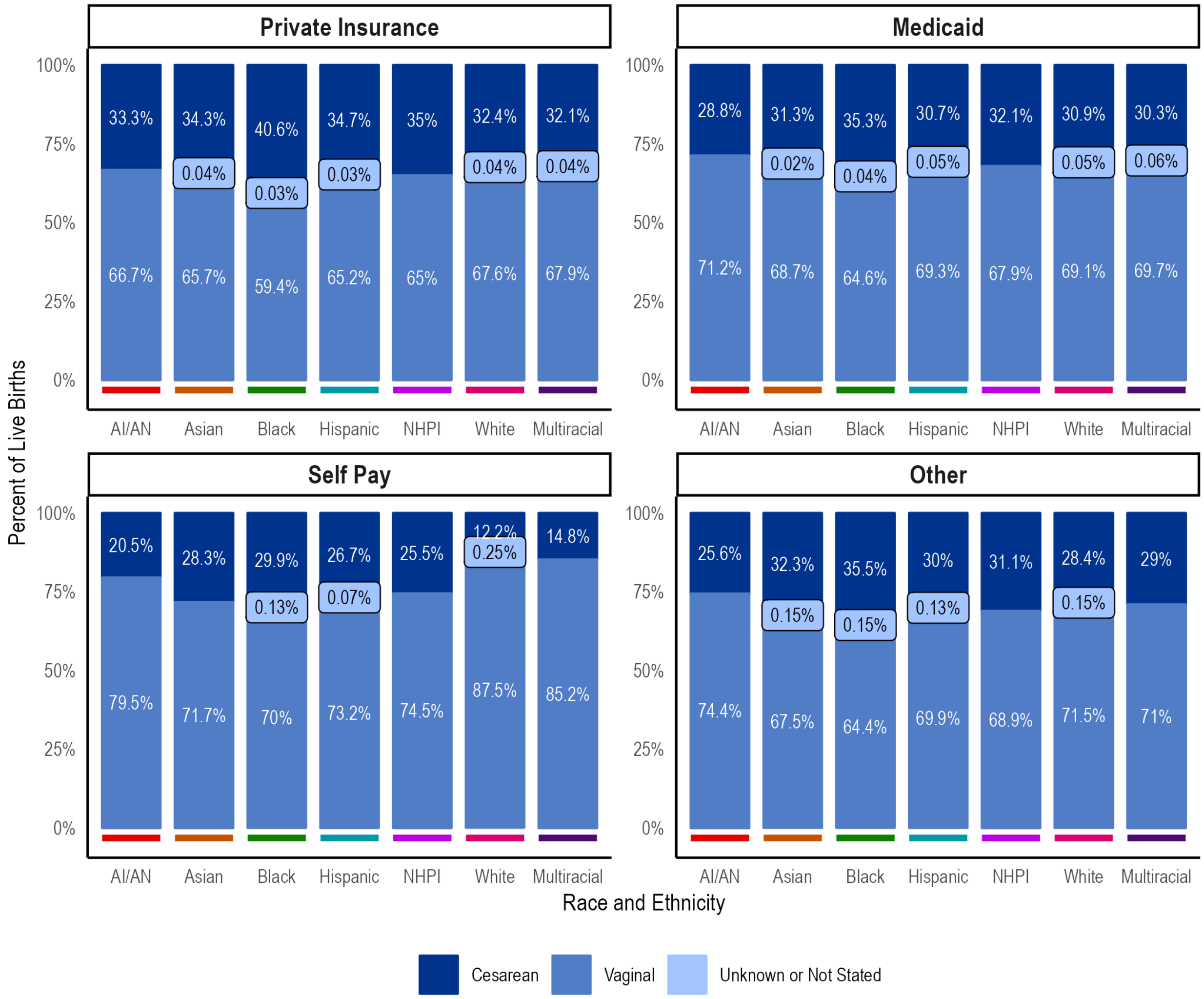

Figure 10-22: Delivery method (cesarean, vaginal, unknown, or not stated), by payment source for delivery and race and ethnicity of the mother

Source: National Vital Statistics System (NVSS) – Natality, 2022

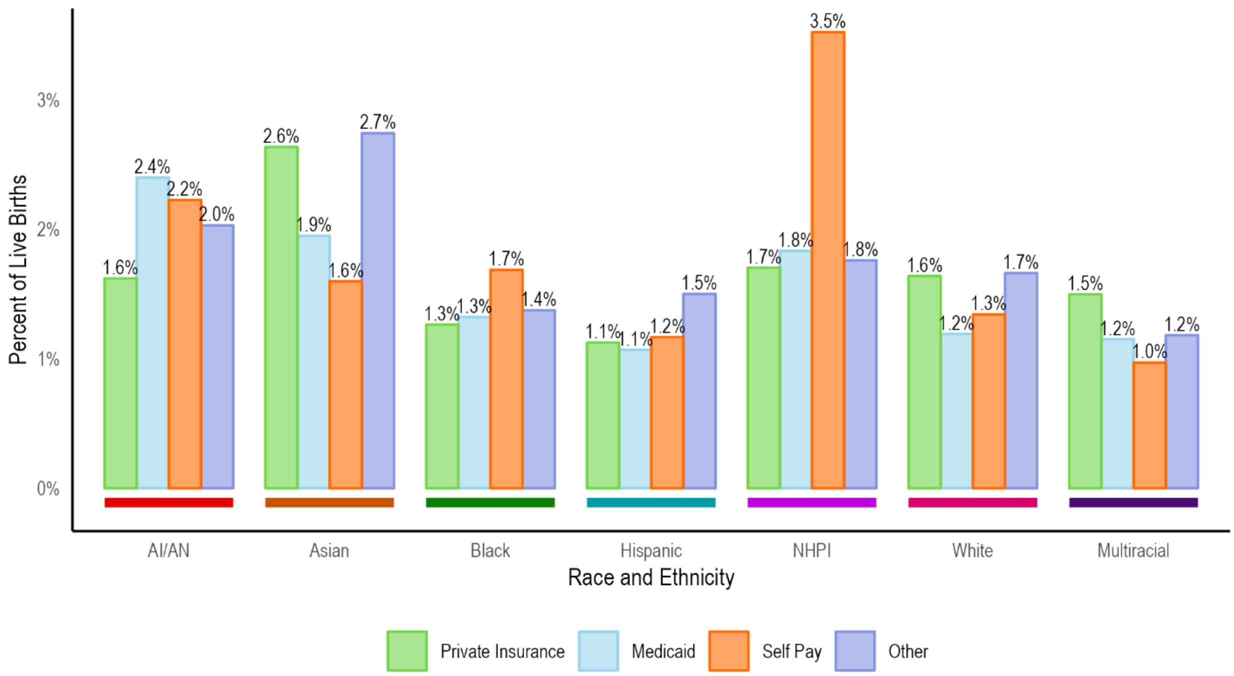

Figure 10-23: Live births with at least one indicator of maternal morbidity, by payment source for delivery and race and ethnicity of the mother

Source: National Vital Statistics System (NVSS) – Natality, 2022

10.5.3 Sexual Orientation and Gender Identity

While NVSS does not collect data on sexual orientation or gender identity, additional studies—although limited—highlight differences in maternal outcomes based on sexual orientation. Compared with heterosexual women, bisexual women are more likely to report miscarriage and pregnancy ending in stillbirth and lesbian women are more likely to report low birth weight infants and preterm births.[116] However, there are no meaningful differences in prenatal care utilization in the first trimester by sexual orientation.[116] Additionally, sexual minority women are more likely than heterosexual women to report unmet medical needs, lower rates of reproductive health services utilization, and increased risk of unintended pregnancy. These factors are believed to be associated with delays in prenatal care and adverse health outcomes.[117] The Association of American Medical Colleges Center for Justice polls have also found lesbian, gay, bisexual, transgender, and queer/questioning (LGBTQ+) birthing people, in comparison to heterosexual people, reported experiencing more stigma, bias, discrimination, and adverse health outcomes. They also experience greater rates of miscarriage and preterm birth throughout the course of pregnancy, further underscoring the importance of affirming and inclusive care for the community.[118]

10.6 Conclusions and Future Directions

Data show persistent disparities in maternal morbidity and mortality for U3 women. The cumulative impact of the social and structural barriers that affect U3 women contributes to weathering and adverse maternal outcomes, ranging from maternal morbidity to mortality. Social and structural determinants of health—including a range of factors from access to quality healthcare and implicit bias among providers, to neighborhood violence and environmental exposures—are linked with increased maternal mortality among U3 women. Many of these risks are grounded in the deep history of racism and discrimination U3 women have experienced with the U.S.; the historical trauma of slavery and segregation that continues to impact Black women's health has parallels in the lives of AI/AN women who also experience health inequities due to enduring trauma as a result of colonization, genocide, and forced migration. The risk factors experienced by Black and AI/AN women such as hypertension, economic disparities, implicit bias and microaggressions during experiences with providers and healthcare systems, and histories of racism and segregation, are relatively well-documented and their role in maternal health is accepted. Such research is lacking for other women, such as Asian women whose risk factors for maternal mortality and morbidity are not well understood. Similarly, further research is needed to better understand the maternal risks faced by NHPI women, who experience significant health disparities. Available data on maternal morbidity and mortality are also limited for assessing the extent of these health issues among SGM women. Future research should continue to investigate the biological, social, and structural drivers of health to better characterize and prevent the risks for maternal morbidity and mortality among U3 women.

10.7 Data Sources and Definitions

Data for all figures in this chapter can be accessed from the data annex located here: https://orwh.od.nih.gov/sites/orwh/files/docs/Chapter_10.xlsx

National Vital Statistics System (NVSS) – Natality

Years	Variable Name	Variable Description	Variable Options
2018-2022	Month Prenatal Care Began	This field indicates the month in the pregnancy when prenatal care began.	**No prenatal care; 1st month through 10th month of pregnancy;** Not stated/Not on Certificate; Excluded.
2016-2022	Average Number of Prenatal Visits	Average Number of Prenatal Visits	N/A
2016-2022	Gestational Diabetes	Gestational Diabetes – Pregnancy related conditions This field indicates whether Diabetes is reported as a maternal risk factor. Gestational Diabetes and Pre-pregnancy Diabetes are reported in separate fields.	**Yes;** No; Unknown or Not Stated
2010-2022	Gestational Hypertension	Gestational Hypertension – Pregnancy related condition This field indicates whether Hypertension Disease is reported as a maternal risk factor. Gestational Hypertension and Pre-pregnancy Hypertension are reported in separate fields. Hypertension is defined as the elevation of blood pressure above normal for age, sex, and physiological condition. Gestational Hypertension reports whether a diagnosis occurred in this pregnancy of pregnancy-induced Hypertension or preeclampsia).	**Yes;** No; Unknown or Not Stated
2010-2022	Eclampsia	Eclampsia – Pregnancy related condition This field indicates whether Eclampsia is reported as a maternal risk factor.	**Yes;** No; Unknown or Not Stated
2022	Delivery Method	This field indicates whether the baby was born by cesarean delivery or vaginal birth.	**Vaginal; Cesarean; Not Stated**

Years	Variable Name	Variable Description	Variable Options
2016-2022	Maternal Morbidity Checked	Indicates whether any maternal morbidity was reported including: - Maternal Transfusion - Third- or Fourth-Degree Perineal Laceration - Ruptured Uterus - Unplanned Hysterectomy - Admission to Intensive Care Unit	**At least one checked;** None checked; Unknown or Not Stated

National Vital Statistics System (NVSS) – Underlying Cause of Death

Years	Variable Name	Variable Description	Variable Options
2018-2021	ICD-10 Codes	O00-O99 (Pregnancy, childbirth, and the puerperium)	N/A

10.8 References

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Chapter 11

Menopause

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Menopause

11.1 Defining Menopause

Menopause is the normal, irreversible cessation of menstrual cycling due to an aging-related decline in female reproductive hormones.[1] An estimated 1.3 million women in the U.S. transition into menopause annually.[1] Women typically begin the menopausal transition, the process leading up to menopause and lasting until the resolution of menopausal symptoms, between ages 45 and 55 and it can last 7-14 years, but factors such as race and ethnicity, and lifestyle can influence duration.[2] The STRAW + 10 staging criteria for the menopausal transition has provided reproducible definitions of the menopausal transition and post menopause allowing comparison of different phases of this physiologic transition in women.[3–6] Many women experience symptoms such as hot flashes, vaginal dryness, and sleeping problems during the menopausal transition.[2]

The mean age of natural menopause in the U.S. is 51 years old, with premature menopause occurring before the age of 40 and early menopause occurring before the age of 45.[1,7] Menopause can occur naturally (natural menopause) and is then marked by the final menstrual period.[1] Many women enter menopause surgically, induced by the removal of both ovaries (surgical menopause, whether bilateral oophorectomy or two unilateral oophorectomies), or as a result of treatments such as chemotherapy, radiation or other medical interventions.[1,8] For women who have undergone a hysterectomy (surgical removal of the uterus) without removal of the ovaries, menses will cease but reproductive cycling will continue until menopause. Regardless of cause, the menopausal transition is associated with an acceleration of the accumulation of chronic conditions including but not limited to cardiovascular disease (CVD), neurological diseases, mental health disorders, and osteoporosis. This makes the menopausal transition and midlife a critical window for understanding sex-specific effects of aging.[9–15]

11.2 Menopause in Women

The menopausal transition is associated with changes in menstrual bleeding patterns and hormone profiles. Although the experience of menopause is highly variable and not all women experience menopausal symptoms, vasomotor symptoms (VMS) are the most commonly experienced symptom during the menopausal transition, with up to 80% of women affected.[6,16] When severe, VMS can dramatically impact quality of life and ability to function at work.[17] Additional menopausal symptoms include sleep disturbances, genitourinary symptoms, abnormal vaginal bleeding, joint pain, and decreased sexual function.[18–20] Despite the high prevalence of menopausal symptoms and their impact on quality of life, fewer than 15% of women in high-income countries receive effective, approved treatment for their symptoms.[6]

Given global increases in life expectancy, women live up to 40% of their lives postmenopause.[1,21] Following the menopausal transition, women's risk increases for CVD, poor sleep, early onset and severe depression, diabetes, obesity, hypertension, osteoarthritis, osteoporosis, and other conditions.[22–24] Menopause, therefore, represents an inflection point in the lives of women where preventative interventions to promote healthy aging may be well suited. However, there is significant underfunding for menopause research, and the social stigma related to aging in women further may contribute to its low research investments compared to investments dedicated to other women's health issues.[25,26]

Using data from the National Health and Nutrition Examination Study (NHANES), **Figure 11-1** shows the age range corresponding to the last menstrual period experienced among women who report not having regular periods in the past 12 months. The figure is based on data collected in surveys from 2009 to 2020. As expected, higher percentages of women experience their last period between the ages of 45 and 49 years. The lowest percentages of women experiencing their last period are reported for women younger than 44 years. While there is some variation of percentages within age bands by year of data collection, large standard errors limit the interpretation of these differences over time. These data are limited as there are multiple reasons besides menopause that menstruation may cease for women during midlife including hysterectomy, uterine ablations, use of a levonorgestrel intrauterine device (IUD), or other hormonal interventions. The reason for cessation of menses is not captured in NHANES and rarely captured in representative populations datasets.

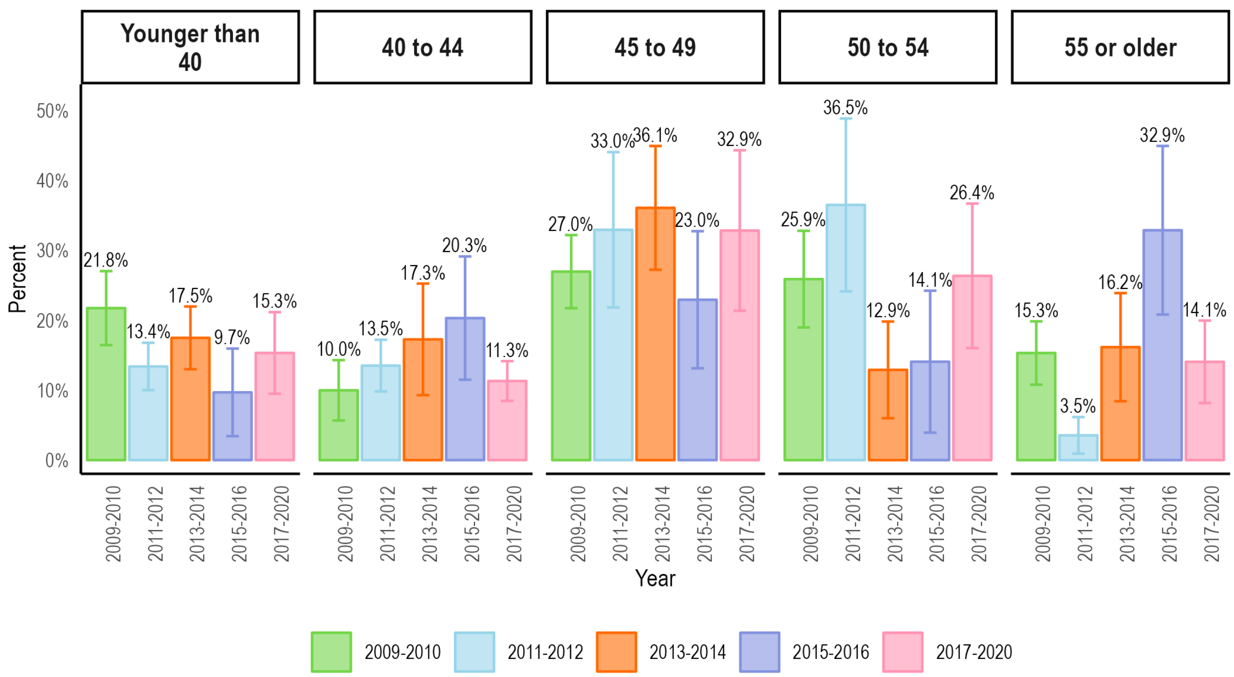

Figure 11-1: Distribution of women who report not having regular periods in the past 12 months, by age range at last menstrual period over time

Source: National Health and Nutrition Examination Survey (NHANES), 2009-2020

Surgical menopause can result from surgical removal of both ovaries through bilateral oophorectomy or sequential unilateral procedures, which are indicated for certain conditions like inherited genetic mutations that predispose women to breast and ovarian cancer, or for conditions such as tubo-ovarian abscesses, endometriosis, or ovarian cysts.[27] The acute associated drop in steroid hormone production following removal of both ovaries leads to more severe menopausal symptoms and is associated with increased risk of cardiovascular and other disease compared to women who undergo a natural menopause, especially when surgical menopause occurs before age 45.[27] **Figure 11-2** shows the distribution of women who report having both ovaries removed, by the age range when both were removed, over time (this age range reflects the age at bilateral oophorectomy or the age when the second of two unilateral oophorectomies took place). Across all survey years (2009-2020), at least 1 in 10 women have both of their ovaries removed during their lifetime. There is a relatively consistent proportion over time, with age range 40-45 being the most common age range during which women report undergoing this procedure. This data is limited by self-reporting of this surgical procedure which may not be accurate.

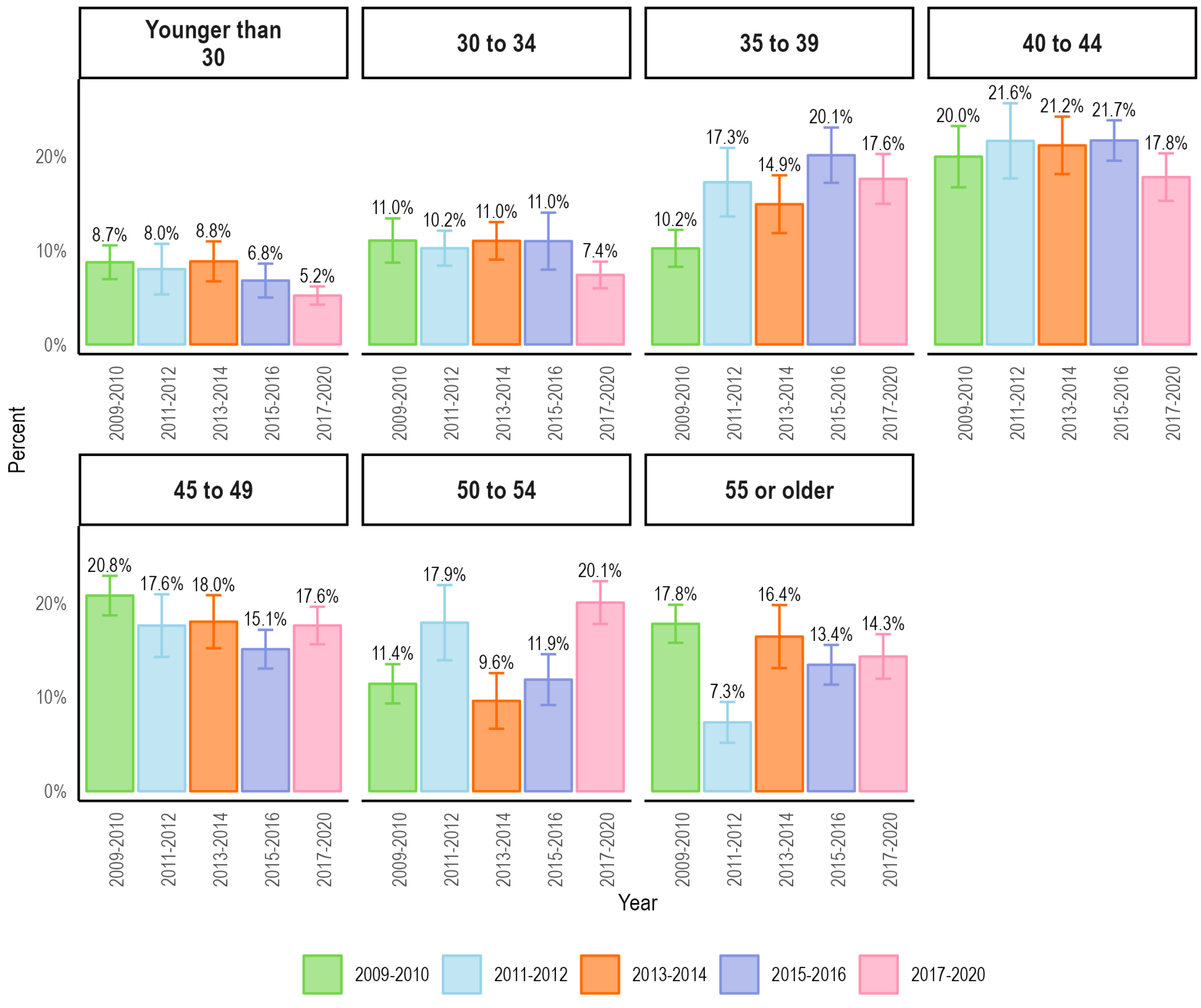

Figure 11-2: Distribution of women who report having both ovaries removed, by age range when removed over time

Source: National Health and Nutrition Examination Survey (NHANES), 2009-2020

Hysterectomy is the second most common surgery performed on women in the U.S.[28] Uterine fibroids and abnormal uterine bleeding are the primary indication for hysterectomy.[29] Formerly, bilateral oophorectomies were routinely performed at the same time as hysterectomies in women aged 40 and older as a preventive measure against ovarian cancer.[30] However, an association between oophorectomy and risk of multiple adverse outcomes and higher all-cause mortality among young women has led to changes in this practice and removal of ovaries at the time of hysterectomy is no longer routinely recommended.[31]

NHANES asks women who have not had at least one menstrual period in the past 12 months to provide the reason for not having regular periods. **Figure 11-3** shows the percentage of women by age group reporting either hysterectomy or menopause as the reason for not having regular menstrual periods in the past 12 months. While "Hysterectomy" is one of the available responses to the question, the removal of the uterus does not indicate menopausal transition if the ovaries have not been removed. "Bilateral oophorectomy" is not one of the available responses to the question. Therefore, direct estimates of incidence and prevalence of surgical menopause is not possible using this dataset.[32]

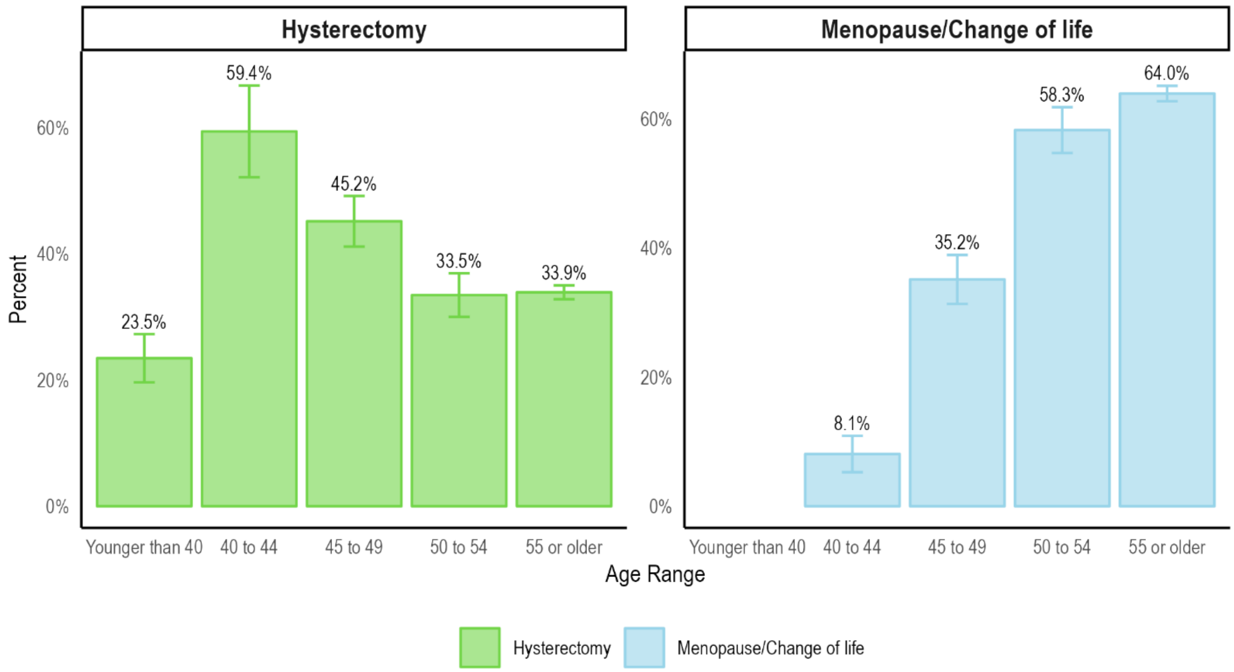

Figure 11-3: Age ranges for women who report hysterectomy or menopause/change of life as the reason they no longer have regular menstrual periods

Source: National Health and Nutrition Examination Survey (NHANES), Pooled 2013-2020[i]

Menopausal hormone therapy can be an effective therapy for many women experiencing menopausal symptoms and can also be prescribed as a preventive measure for osteoporosis.33 The percent of women aged 40 and older who report ever using any hormone therapy (pills, creams, patches, or injectables) is shown in Figure 11-4. The data show that the percent of women who ever used hormone therapy has been relatively stable over the past decade, from a high estimate of 32.4% of women in 2013-2014 to a low estimate of 25.6% in 2017-2018. The pattern is relatively consistent from 2009 through 2016 before the noted decrease starting in 2017. However, this data is limited as survey questions do not assess duration, dosage, indication, or type of hormone therapy and may include

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[i] This analysis begins with data from the 2013-2014 NHANES survey, at which time the instrument collection on hysterectomy and menopause/change of life was updated. Other responses to this survey question included breastfeeding and pregnancy, which indicate a gap in regular periods rather than the completion of menstruation: these responses were excluded from this analysis.

hormonal therapy prescribed for other indications (e.g., contraception). Thus, NHANES data cannot be interpreted to describe hormone therapy used for the treatment of menopausal symptoms. Furthermore, NHANES does not assess current usage of hormone therapies and cannot be used to interpret indication or duration of use.

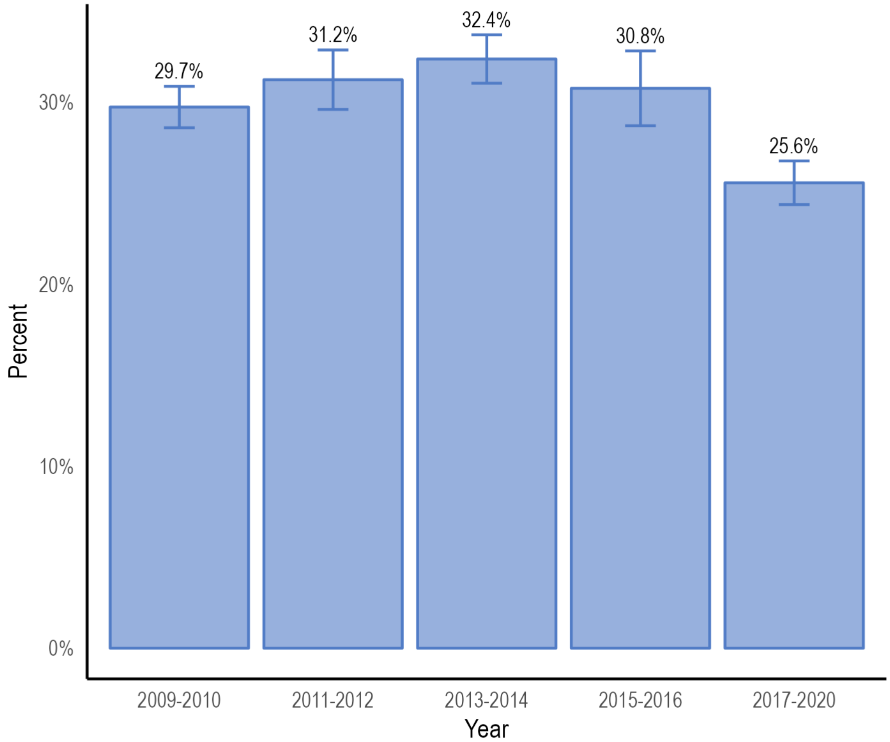

Figure 11-4: Percent of women aged 40 and older who report ever using hormone therapy (pills, creams, patches, or injectables) over time

Source: National Health and Nutrition Examination Survey (NHANES), 2009-2020

The use of hormone therapies for the treatment of menopausal symptoms among U.S. women declined dramatically in the US following the publication of results from the Women's Health Initiative. This long-term study of U.S. post-menopausal women's health sponsored by the NIH included a randomized trial of hormone therapy in postmenopausal women that found the risks outweighed the benefits of long-term use to prevent cardiovascular disease. In this study, hormone therapy was not used to treat symptoms, as the trial was designed to assess the efficacy of hormone therapy to prevent cardiovascular and other diseases in postmenopausal women as they aged. Most participants in the study were more than 10 years beyond the menopausal transition. The early stopping of this study due to adverse events led to a dramatic decline in the use of hormone therapy for all indications including for the treatment of menopausal symptoms.[34,35] With additional analysis and research, a more nuanced approach to understanding the risks and benefits of hormone therapy has emerged that focuses on stratifying individual women's risks to better determine who will benefit from hormone therapy to manage the symptoms of menopause.[34,36] Menopausal hormone therapy with estrogen and progesterone for women with a uterus, and estrogen alone for women who have had a hysterectomy remain a medical treatment option for vasomotor and other symptoms of menopause experienced during or immediately following the menopausal transition for women without risk factors (e.g., breast cancer, blood clots) or other contraindications to use.[37]

11.3 Menopause in Populations of U3 Women

The experience of menopause varies based on biological, social, cultural, and behavioral factors. In alignment with the life course perspective (**see Chapter 1**) an increasing body of research shows that women's experiences with menopause are influenced by longstanding systemic inequities and racial disparities, geographic and sociocultural settings, socioeconomic and family characteristics, intrapersonal factors, help-seeking behaviors borne from intergenerational trauma, and the competency of healthcare providers in cross-cultural communication and care.[38,39] These disparities reflect multiple factors including exposure to stress, comorbid medical conditions, and use of menopausal hormone therapy among understudied, underrepresented, and underreported (U3) women.

11.3.1 Menopause Among Women of Underrepresented Racial and Ethnic Communities

Many factors influence the experience within the menopausal transition for women from underrepresented racial and ethnic communities.[38] Black and Hispanic women on average enter menopause earlier; experience more frequent, severe, and persistent VMS; are more likely to have new onset depression; and report poorer objectively assessed sleep quality than women from other racial or ethnic populations during the menopause transition.[23,38,40] Variations in menopausal symptoms have been demonstrated within Hispanic populations by country of origin additionally highlighting the importance of culture on the experience of menopause.[40] Black and Hispanic women also often enter the menopausal transition with a higher burden of chronic diseases including obesity, diabetes, hypertension, and osteoarthritis which subsequently affects health during aging.[23,40] Lower educational level, more financial strain, lower employment rates, greater cigarette use, less physical activity, and the experience of discrimination among U3 women affect this disparity.[23]

Figure 11-5 illustrates the distribution of women who report not having regular periods in the past 12 months, by race and ethnicity, and age range at last menstrual period. The most common age range for last reported menstrual period among White women was under the age of 50 (56.5% across the younger than 40, 40 to 44, and 45 to 49 age groups). Similarly, the last reported menstrual period was more common at earlier ages among Black women (78.3% for under the age of 50) and Hispanic women (74.7% for under the age of 50). Among Asian women, the last reported menstrual period was comparable between women under the age of 50 (49.7%) and ages of 50 or older (50.3%). Cessation of menstruation was more common among Multiracial women ages 50 or older (55.1%) compared with Multiracial women under the age of 50 (44.9%). Notably there are no data for American Indian and Alaska Native (AI/AN) women, indicating a gap in data collection as noted elsewhere in this chapter.

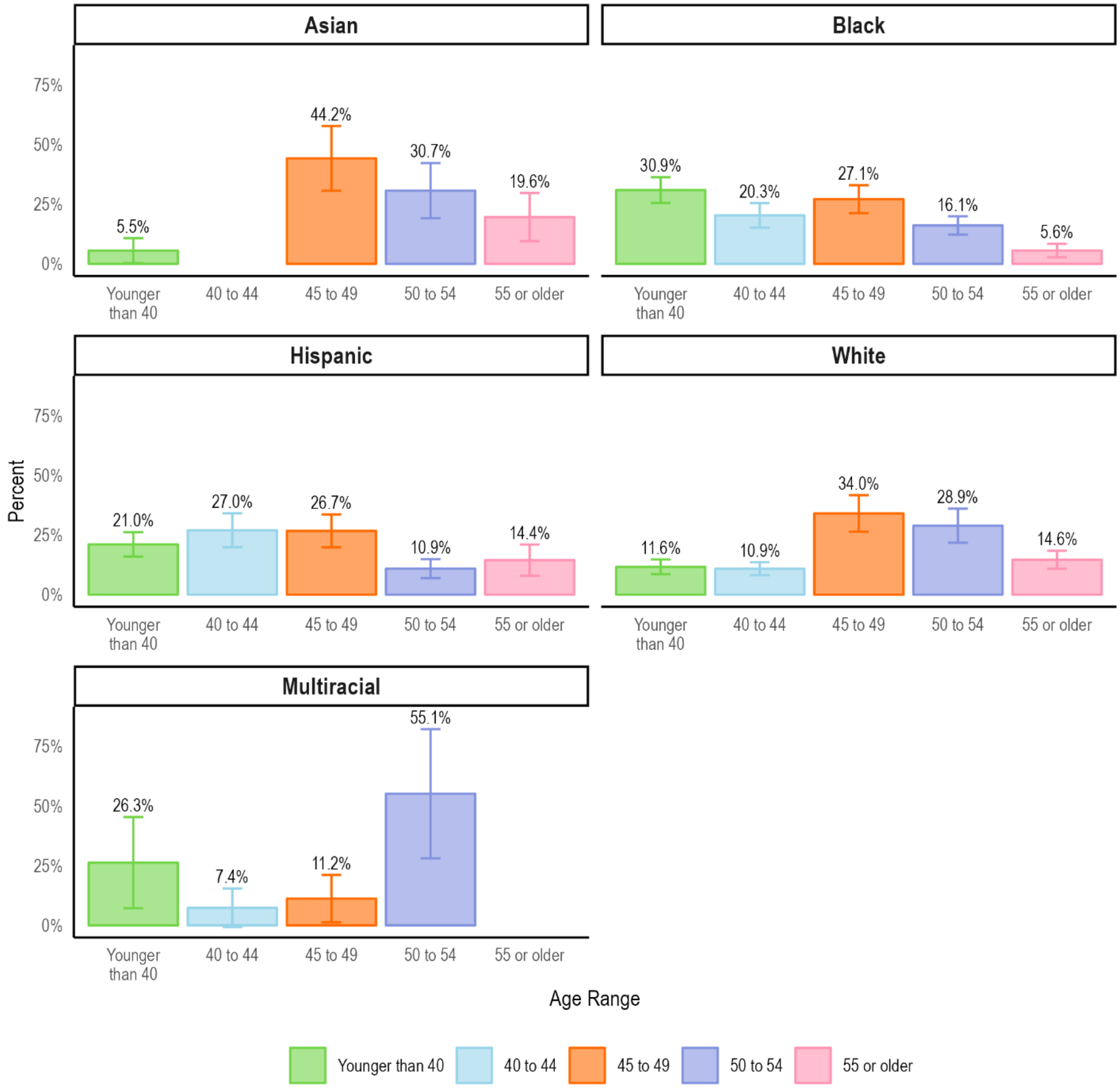

Figure 11-5: Distribution of women who report not having regular periods in the past 12 months, by race and ethnicity, and age range at last menstrual period

Source: National Health and Nutrition Examination Survey (NHANES), Pooled 2009-2020

Differing rates of hysterectomy and surgical menopause across racial and ethnic groups of women also influence the experience of menopause.[23] **Figure 11-6** includes two figures: the first shows the percent of women aged 40 and older who report hysterectomy as their reason for not having regular menstrual periods, by race and ethnicity; the second shows the same for women aged 40 and older who report entering menopause/change of life. Rates of hysterectomy among women (ages 40 and over) without regular menstrual periods vary widely between racial and ethnic groups, ranging from 22.1% among Asian women to 48.2% among Multiracial women. The wide variation in the rates of hysterectomy may make the identification of menopause more difficult and further preclude an improved understanding of the experience of menopause across racial and ethnic groups.

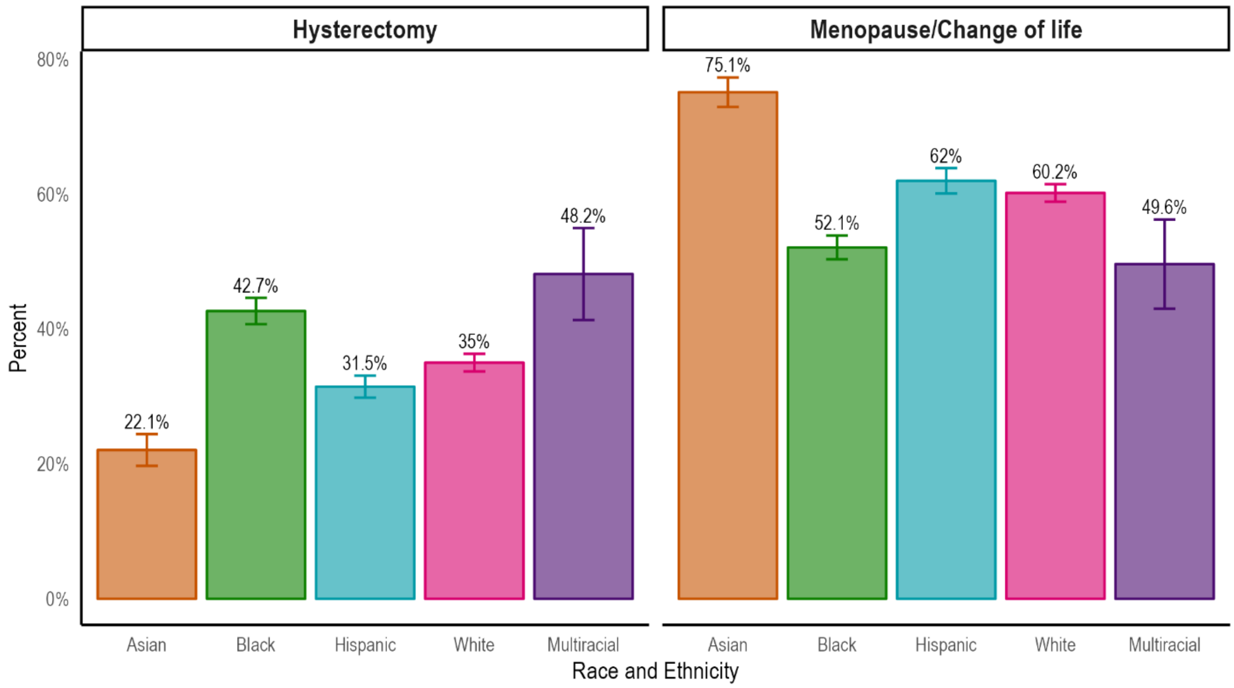

Figure 11-6: Percent of women aged 40 and older who report hysterectomy or menopause/change of life as the reason for not having regular menstrual periods, by race and ethnicity
Source: National Health and Nutrition Examination Survey (NHANES), Pooled 2013-2020[xxii]

Figure 11-7 shows the distribution of women who report hysterectomy as the reason for not having regular menstrual periods, by race and ethnicity, and age range. Across all races and ethnicities except Hispanic, women aged 40-44 who report not having menstrual periods are most likely to report hysterectomy as the reason for cessation of menstruation: 61.6% for Asian women, 54.9% for Black women, 64.3% for White women, and 88.3% for Multiracial women. The next highest percentages are found among women aged 45-49. For Hispanic women, hysterectomy is reported as the reason for cessation of menstruation most commonly among women aged 45-49 (55.4%) and 50-54 (34.1%). As discussed previously, hysterectomy may obscure menopausal signs and make understanding the true contours of menopause challenging.

[xxii] This analysis begins with data from the 2013-2014 NHANES survey, at which time the instrument collection on hysterectomy and menopause/change of life was updated. Other responses to this survey question included breastfeeding and pregnancy, which indicate a gap in regular periods rather than the completion of menstruation: these responses were excluded from this analysis.

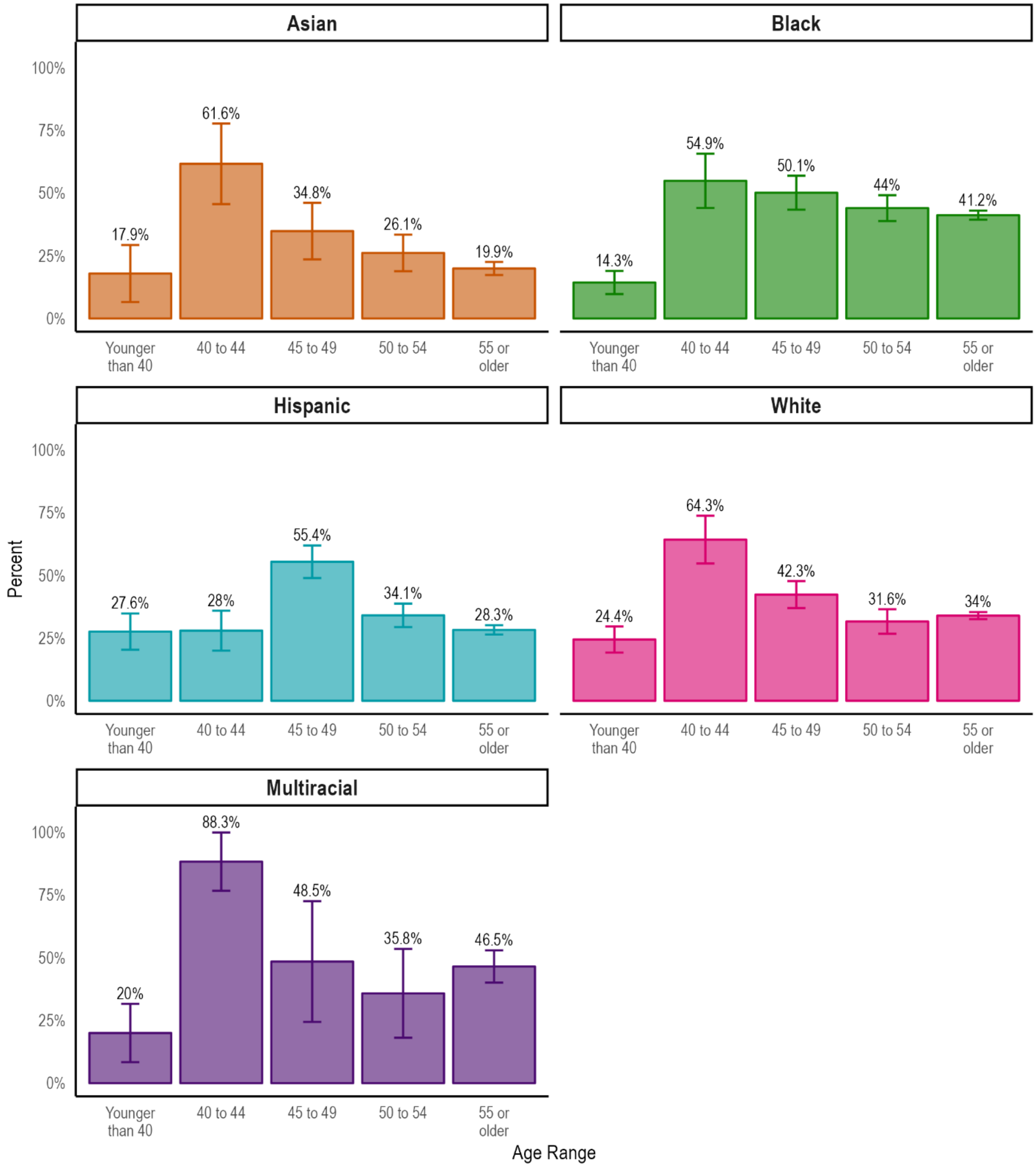

Figure 11-7: Distribution of women who report hysterectomy as the reason for not having regular menstrual periods, by race and ethnicity, and age range

Source: National Health and Examination Survey (NHANES), Pooled 2013-2020[xxiii]

[xxiii] This analysis begins with data from the 2013-2014 NHANES survey, at which time the instrument collection on hysterectomy and menopause/change of life was updated.

Figure 11-8 shows the distribution of women who report menopause/change of life as the reason for not having regular menstrual periods, by race and ethnicity, and age range. As expected, women increasingly report menopause/change of life as their reason for not having menstrual periods cross age groups. Asian women, who are the least likely to report hysterectomy for all age groups except age 40-44, were most likely to report change of life across the age groups.

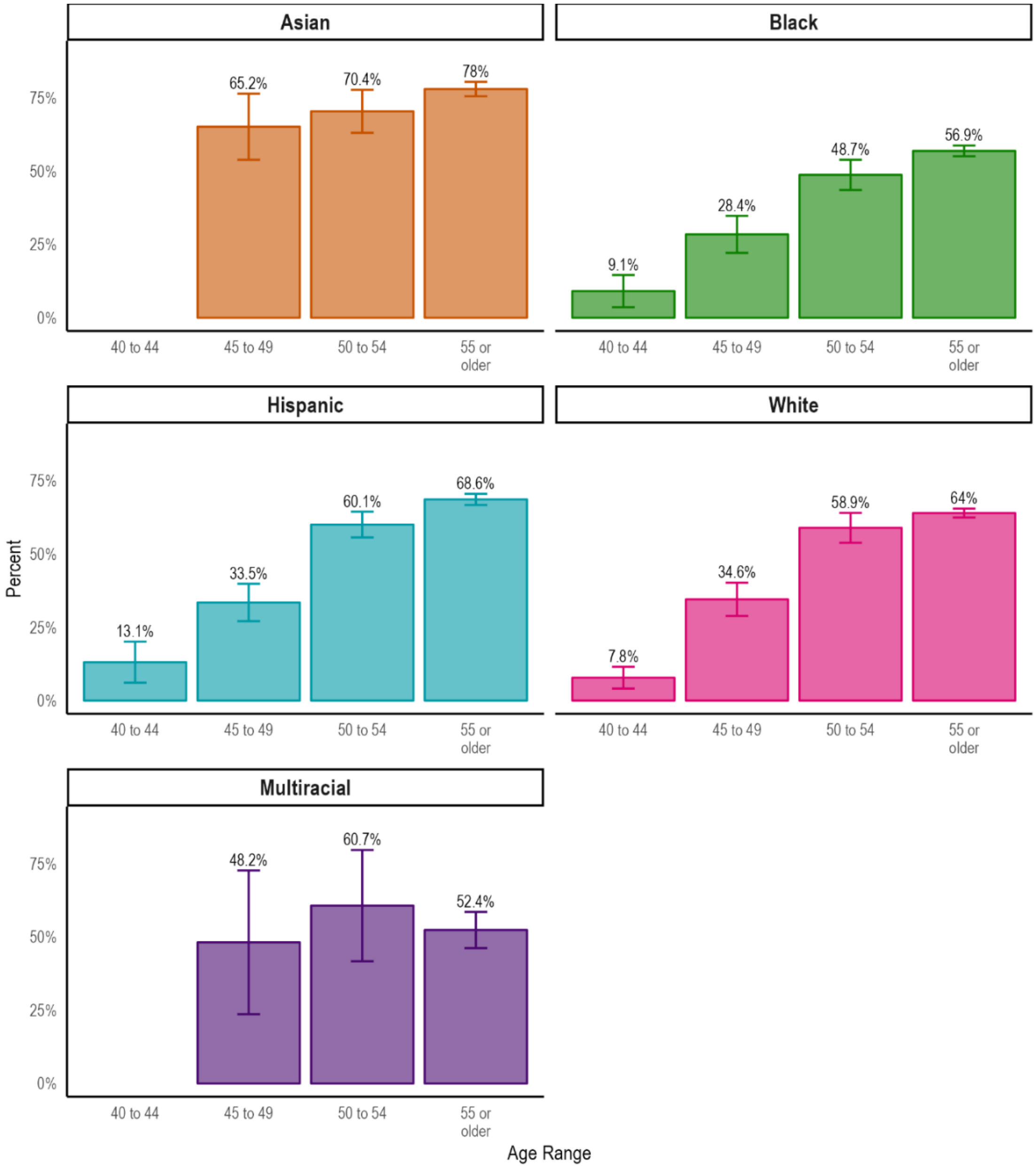

Figure 11-8: Distribution of women who report menopause/change of life as the reason for not having regular menstrual periods, by race and ethnicity, and age range

Source: National Health and Examination Survey (NHANES), Pooled 2013-2020[xxiv]

[xxiv] This analysis begins with data from the 2013-2014 NHANES survey, at which time the instrument collection on hysterectomy and menopause/change of life was updated.

A myriad of factors influence the menopause-related disparities for women of underrepresented racial and ethnic communities.[41] Black and Hispanic women who experience natural menopause, for example, overwhelmingly report shame, stigma, and silencing when it comes to understanding normal versus abnormal symptoms. Additionally, Black women are more likely to face discrimination in encounters with healthcare professionals and a lack of family experience with natural menopause because hysterectomy has historically been so common among Black women.[41,42] Overall, earlier age of menopausal transition has been linked with systemic disadvantages including lower educational attainment, nonemployment, history of heart disease, prior use of contraceptives, smoking, and other early-life and socio-environmental factors including those that influence weathering.[43]

Figure 11-9 shows the percent of women aged 40 and older who report undergoing a hysterectomy or having both ovaries removed, by race and ethnicity. The data illustrate variation by race and ethnicity, yet consistency within races and ethnicities: Multiracial women were the most likely to report undergoing a hysterectomy (35.9%) and having both ovaries removed (20.5%). This is followed by Black women and White women, who report undergoing hysterectomy (34.7% and 32.9%, respectively) and having both ovaries removed (15.4% and 19%, respectively).

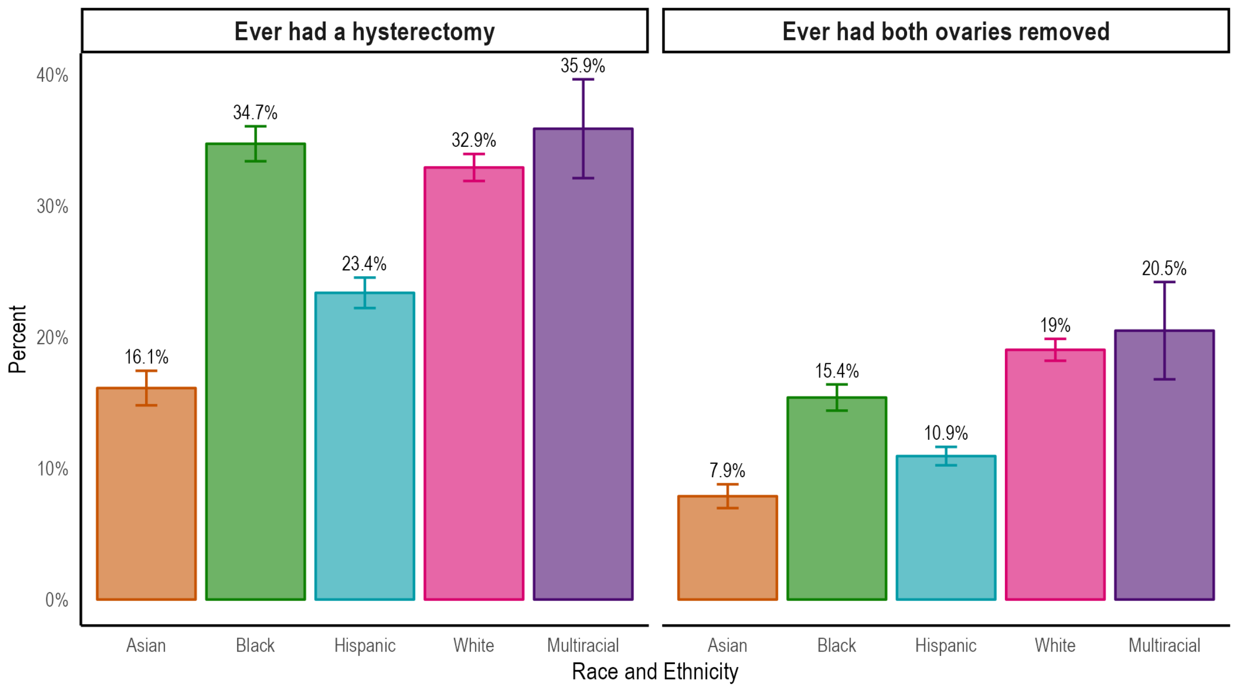

Figure 11-9: Percent of women aged 40 and older who report undergoing a hysterectomy or having both ovaries removed, by race and ethnicity

Source: National Health and Nutrition Examination Survey (NHANES), Pooled 2009-2020

The percent of women who report having used hormone therapy is uneven across the racial and ethnic groups as shown in **Figure 11-10.** The data show that White women (34.8%) report using hormone therapy most frequently, followed by Multiracial women (24.3%). The percent of Black women who ever used hormone therapy was notably lower than for White women, as was that among Asian and Hispanic women.

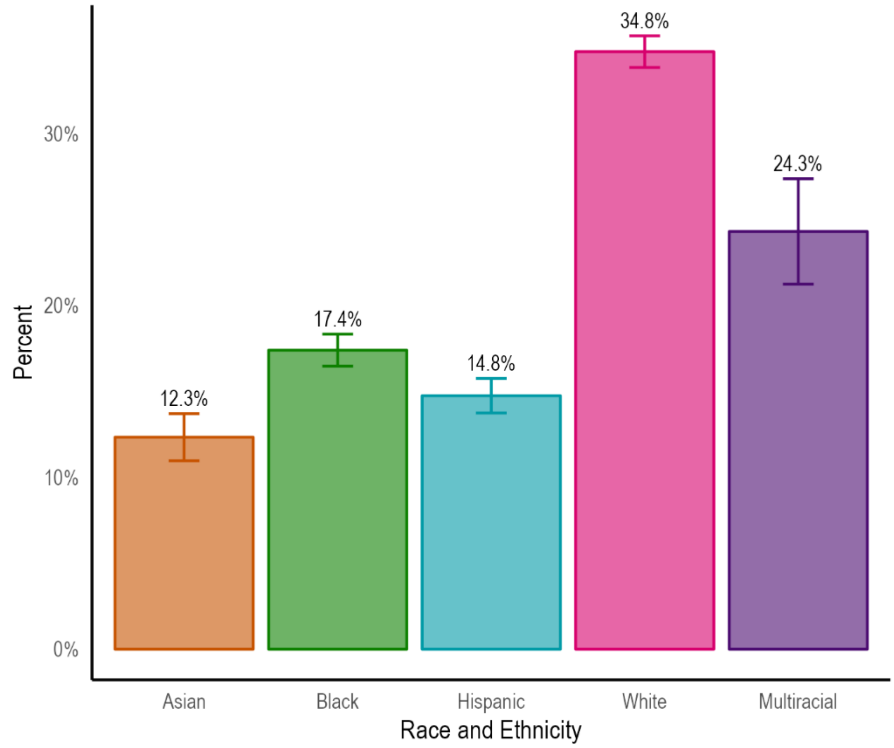

Figure 11-10: Percent of women aged 40 and older who report ever using hormone therapy (pills, creams, patches, or injectables), by race and ethnicity

Source: National Health and Examination Survey (NHANES), Pooled 2009-2020

Racial and ethnic differences in hormone therapy use may be attributed to disparities in receiving treatments overall. While the NHANES data cannot illuminate the reason why women every used hormone therapy, other research provides insights into variation in use of menopausal hormone therapy. One study found that Black and Hispanic women had a decreased likelihood of being prescribed menopausal hormone therapy compared with White women.[44] Additionally, research exploring treatment preference has found that White women have the highest rates of menopausal hormone therapy use when compared with women of other racial and ethnic groups.[45] Black women were also less likely to report treatment for VMS and have been reported to be less likely to accept hormones for menopausal symptom management when offered.[23,46] Differences in treatment preference among U3 women impact quality of life during the menopause transition.

3.2 Other Intersectional Considerations Relevant to U3 Women

There is limited U.S. data and literature reporting on the role of rurality in the experience of menopause among U3 women. Research exploring menopause symptom knowledge shows Black women in rural areas had limited knowledge on menopause and depressive symptoms informed by menopause being seen as a cultural taboo.[47,48] Other research found a higher prevalence of hysterectomy among women living in rural areas in comparison to women living in urban areas.[49] More research is needed to further address how health outcomes vary for women experiencing menopause in rural areas.

There is little empirical evidence on the influence of sexual orientation and gender identity as they intersect with the physical and psychological experience of menopause. As emphasized throughout this book, each health topic discussed intersects with past and present socio-structural systems and inequities. For individuals who identify as lesbian, gay, bisexual, transgender, and queer/questioning (LGBTQ+), menopause may exacerbate pre-existing physical and mental health conditions.[50] LGBTQ+ menopausal patients frequently face limited access to quality care and ongoing invisibility of their lived experiences within the healthcare system.[51] This has implications for understanding aging, stigma, and women's health within the context of sexual orientation and gender identity.

11.3.2 Economic Status

Of the social determinants of health, economic stability, education access and quality, and low-level employment influence early onset of natural menopause.[38,52] Studies have also examined the impact of adverse childhood experiences (e.g., household crowding, chronic adversity) as it relates to menopausal symptoms.[38,53] NHANES data allow for some assessment of differences in key menopause variables by economic status. **Figure 11-11** shows the percent of women who report having both ovaries removed, by economic status and race and ethnicity. Among White and Multiracial groups, economically disadvantaged women were more likely to report bilateral oophorectomy compared to economically advantaged women. Among Asian, Black, and Hispanic women, however, economically advantaged women were just as likely to report bilateral oophorectomy as economically disadvantaged women.

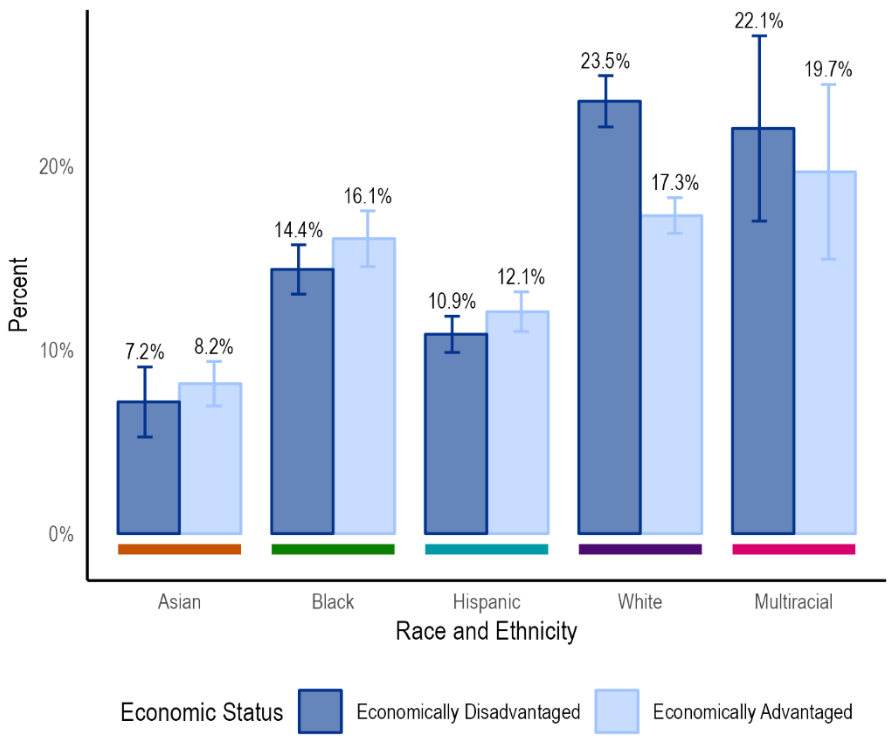

Figure 11-11: Percent of women aged 40 and older who report having both ovaries removed, by race and ethnicity, and economic status

Source: National Health and Nutrition Examination Survey (NHANES), Pooled 2009-2020

Figure 11-12 shows the percent of women who report undergoing a hysterectomy, by economic status, and race and ethnicity. For Asian and Multiracial women, the percentage who underwent hysterectomies is higher among economically advantaged women compared to economically disadvantaged women. The inverse is true for White women, such that a higher percentage of hysterectomy occurs among women who are economically disadvantaged.

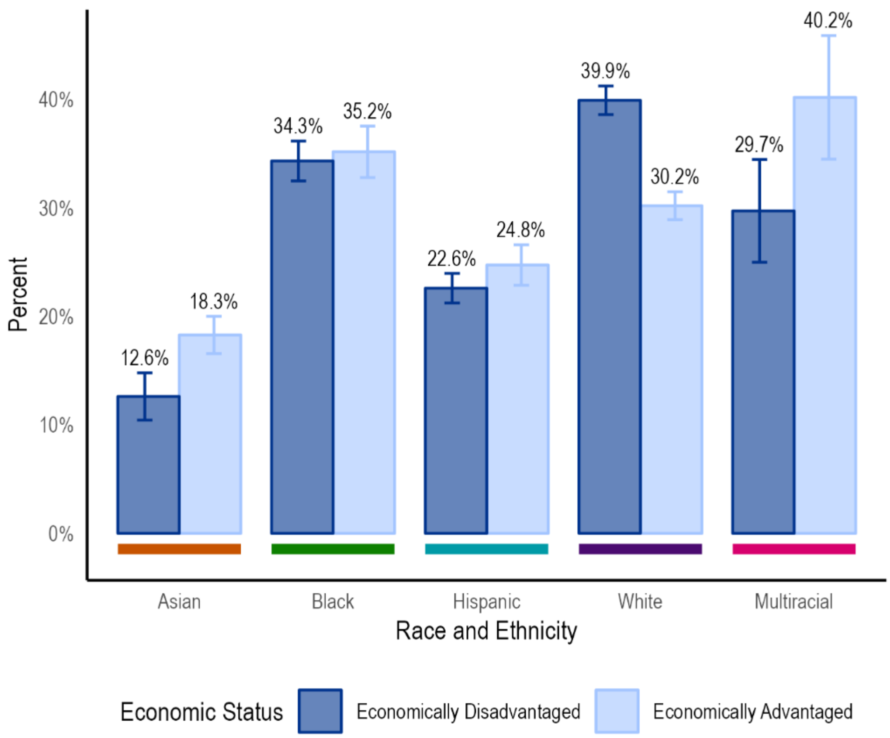

Figure 11-12: Percent of women aged 40 and older who report undergoing hysterectomy, by race and ethnicity, and economic status

Source: National Health and Nutrition Examination Survey (NHANES), Pooled 2009-2020

Women with low socioeconomic means and those who without a primary care physician are least likely to receive counseling regarding hormonal therapy for menopausal symptoms.[54] **Figure 11-13** shows the percent of women who report ever using hormonal therapy by economic status, and race and ethnicity. The data reveal that across all racial and ethnic groups, economically advantaged women report ever using hormonal therapy at a higher percentage compared to economically disadvantaged women. Economically advantaged White women have the highest percent of reported hormonal therapy use (36.5%) while economically disadvantaged Asian women have the lowest percent of reported use (6.6%).

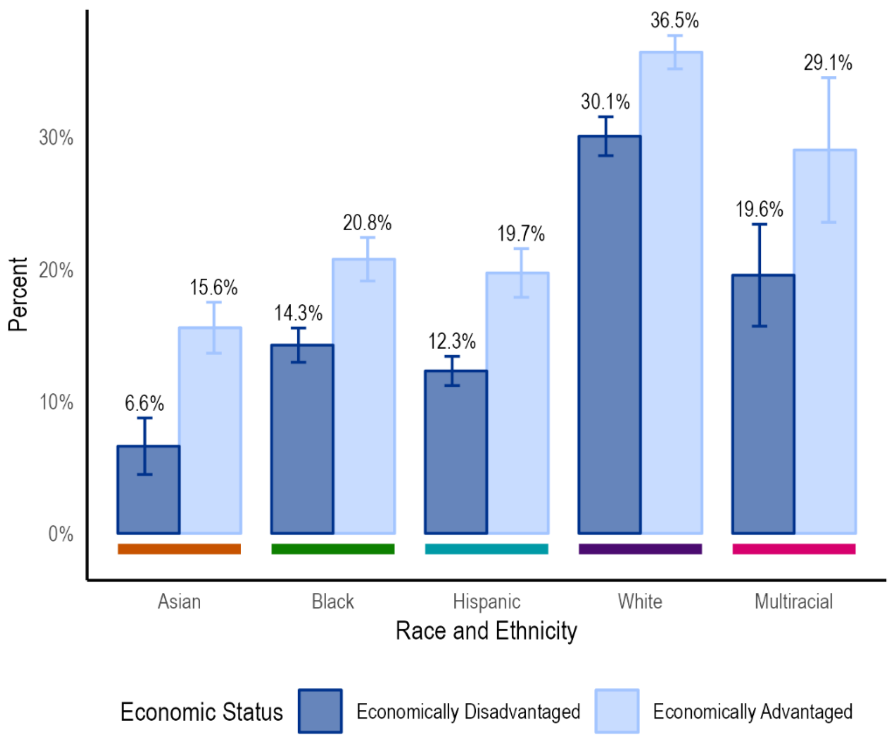

Figure 11-13: Percent of women aged 40 and older who report ever using hormone therapy (pills, creams, patches, or injectables), by race and ethnicity, and economic status

Source: National Health and Nutrition Examination Survey (NHANES), Pooled 2009-2020

More recently, there are also increasingly diverse options for hormone therapy from telemedicine providers, which favor women with higher SES.[55–57] Furthermore, poverty impacts the physical and psychological health of women and exacerbates gynecologic and obstetric health conditions including menopause.[58] In addition to increased risks of negative life events, insecure housing, low level of education, chronic stress, and lack of social support, economically disadvantaged women in mid-to-late life suffer from very limited knowledge of what to expect in the perimenopause, menopause transition, and post-menopause life phases.[58] There is also typically a high healthcare burden when menopausal symptoms lead to the utilization of inpatient and outpatient hospital resources to alleviate symptoms.[59]

11.4 Conclusions and Future Directions

This chapter explores natural and surgically induced menopause, while examining how these experiences differ for U3 women. The data presented in this chapter demonstrate the need for improved national datasets to understand the menopausal transition and patterns of treatment related to menopausal symptoms. The removal of both ovaries (whether bilateral oophorectomy or two unilateral oophorectomies) is not coded among reasons for cessation of menstruation, hormone therapy data is not sufficiently described to understand its use to manage the symptoms of menopause, and hysterectomy data collection obscures the menopausal transition. Overall, the questions in national-level surveys like NHANES are inadequate to produce more granular assessments of the population-level experience of menopause. The lack of strong survey data contributes to difficulty defining and understanding women's experiences of menopause as a key biological, social, and physiological experience.

Furthermore, racial and ethnic health disparities exist for Black and Hispanic women, who transition into menopause earlier in life—with its myriad increased risk factors—and are further disadvantaged by structural factors such as racism and its associated stressors. Differences in the use of hormone therapy to treat the symptoms of menopause also merit further exploration and are not captured in national data sources. Additional research is needed to contextualize the experiences of women who live in rural areas, as well as how sexual identity and gender orientation impact the experience of the menopausal transition. Furthermore, women belonging to AI/AN populations are significantly underrepresented in menopause research. Improved data and further research will provide women and their providers with the knowledge, resources, and treatment options needed to manage the menopausal transition and its symptoms and improve quality of life for a large number of women.

11.5 Data Sources and Definitions

Data for all figures in this chapter can be accessed from the data annex located here: https://orwh.od.nih.gov/sites/orwh/files/docs/Chapter_11.xlsx

National Health and Nutrition Examination Survey (NHANES)

Years	Variable Name	Variable Description	Variable Options
2009-2010, 2011-2012, 2013-2014, 2015-2016, 2017-2020 pre-pandemic	RHQ070	Age range at last menstrual period	**Younger than 30; 30 to 34; 35 to 39; 40 to 44; 45 to 49; 50 to 54; 55 or older;** Refused; Missing; Don't know
2013-2014, 2015-2016, 2017-2020 pre-pandemic	RHD043	Reason not having regular periods; What is the reason that {you have/SP has} not had a period in the past 12 months?	Pregnancy; Breast feeding; **Hysterectomy; Menopause/Change of life;** Other; Refused; Don't know
2009-2010, 2011-2012, 2013-2014, 2015-2016, 2017-2020 pre-pandemic	RHQ540	Ever use female hormones?; {Have you/Has SP} ever used female hormones such as estrogen and progesterone? Please include any forms of female hormones, such as pills, cream, patch, and injectables, but do not include birth control methods or use for infertility.	**Yes;** No; Refused; Don't know
2009-2010, 2011-2012, 2013-2014, 2015-2016, 2017-2020 pre-pandemic	RHQ280	Had a hysterectomy?; {Have you/Has SP} had a hysterectomy that is, surgery to remove {your/her} uterus or womb?	**Yes;** No; Refused; Don't know
2009-2010, 2011-2012, 2013-2014, 2015-2016	RHQ291	Age when had a hysterectomy; How old {were you/was SP} when {you/she} had {your/her} (hysterectomy/uterus removed/womb removed)?	**19 years or under; range of values between 21 to 49; 60 years or older;** Refused; Don't know
2009-2010, 2011-2012, 2013-2014, 2015-2016, 2017-2020 pre-pandemic	RHQ305	Had both ovaries removed?; {Have you/Has SP} had both of {your/her} ovaries removed (either when {you/she} had {your/her} uterus removed or at another time)?	**Yes;** No; Refused; Don't know
2009-2010, 2011-2012, 2013-2014,	RHQ332	Age when both ovaries removed;	**19 years or under; range of values between 21 to 49; 60**

2015-2016, 2017-2020 pre-pandemic		How old {were you/was SP} when {you/she} had {your/her} ovaries removed or last ovary removed if removed at different times?	**years or older;** Refused; Don't know

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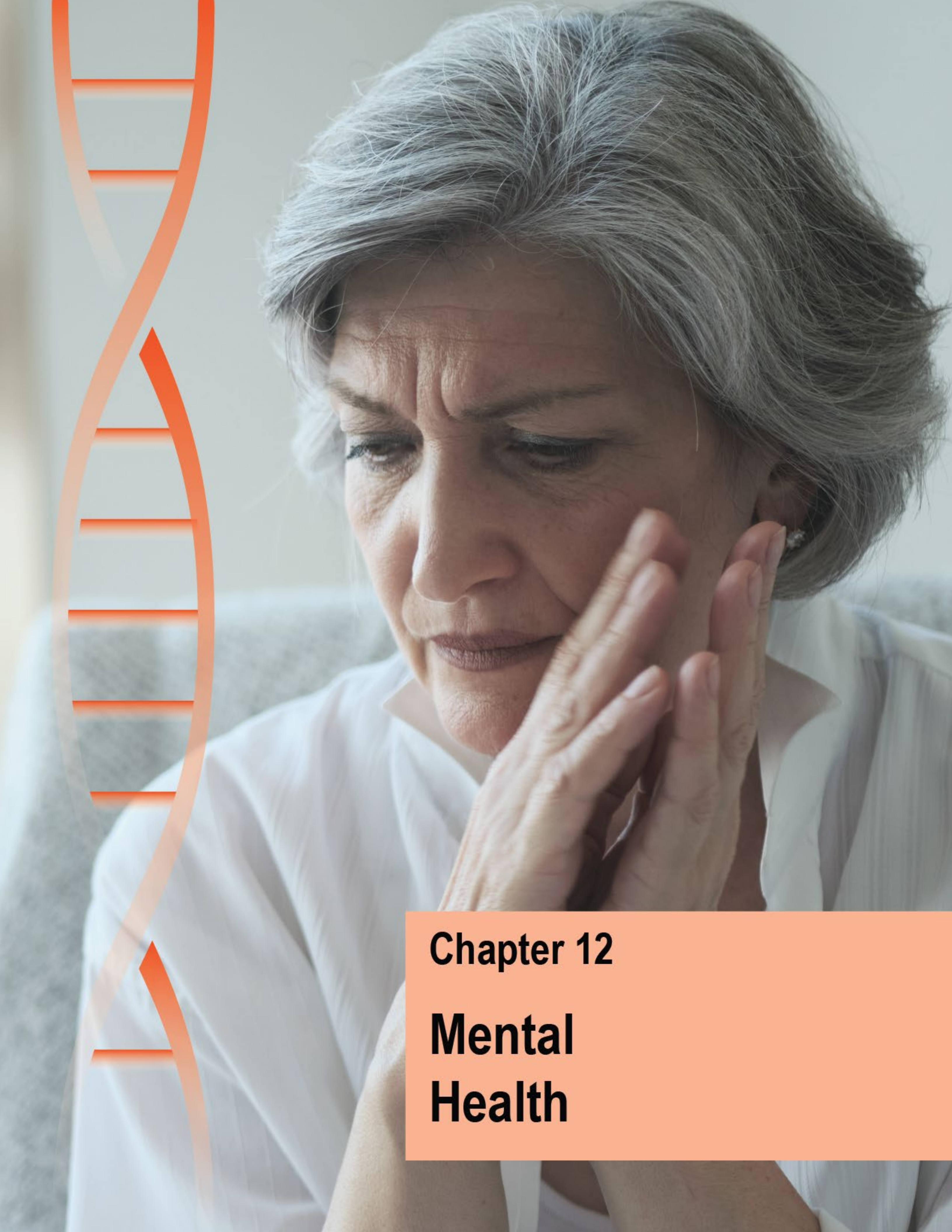

Chapter 12

Mental Health

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Mental Health

12.1 Defining Mental Health

Mental health is an overarching term that describes emotional, psychological, and social well-being.[1] A state of mental wellness is more than the presence or absence of mental illness, it reflects the ability to "successfully handle life's stresses and adapt to change and difficult times."[2] Many scholars view mental health as a continuum of well-being based not only on experiencing mental distress or symptoms of mental illness, but also the external factors that may improve or harm mental health such as social support, mindfulness, and stress.[3–5] Mental illness is diagnosed by a mental health professional after evaluation of an individual's symptoms using criteria from the Diagnostic and Statistical Manual of Mental Disorders.[6] Symptomology is complex and informed by a wide range of clinical, history/familial and sociodevelopmental factors, which is why the expertise of a trained healthcare provider is required for a formal diagnosis.[7] Although many effective treatments for mental disorders are available, it is generally recognized that many people face barriers to diagnosis and treatment with care costs, provider shortages, and stigma being chief among structural or other barriers.[8–11] Even if symptoms are not severe enough to receive a specific diagnosis, addressing mental health concerns for prevention of personal and social consequences and maintaining mental wellness is essential for quality of life.

Mental health data in publicly available, nationally representative health data sources like those selected for this book (see **Chapter 3**) typically focus on the prevalence, severity, causes, and treatment outcomes related to mental illnesses, which are "disorders, ranging from mild to severe, that affect a person's thinking, mood, and/or behavior."[1] More than 20% of adults in the U.S. live with a mental illness and estimates suggest that half of the population will be diagnosed with a mental illness during their lifetime.[6,12,13] Some risk factors for mental illness include biological factors (e.g., genetic vulnerability), behavior factors (e.g., social isolation), brain injuries or head trauma, substance use, chronic illnesses, or experiencing a traumatic event, all of which have a cumulative effect that increases an individual's risk.[14,15] Many mental disorders have differences based on sex and gender (e.g., the prevalence of eating disorders is higher among women compared with men). There is also an association with a range of social and epigenetic factors.[16–19] Mental illness can affect physical health and decrease quality of life, especially if left untreated.[20,21] Among all people with mental illness, only half receive the treatment they need.[22] Understanding the risk factors for mental illness is a necessary framework to analyze the factors contributing to mental health disparities among understudied, underrepresented, and underreported (U3) women (see **Chapter 1**) and to find pathways to mental wellness.

12.2 Mental Health in Women

In this chapter, mental health data is focused on suicide and mental health treatment. Data on mental health indicators among adults are taken from the National Survey on Drug Use and Health (NSDUH), while data on youth are taken from the Youth Risk Behavior Survey (YRBS). It is important to note that the data presented here reflect percentages of people reporting symptoms of mental health conditions rather than those who have clinical diagnoses of mental illness. Data on suicide mortality are from the National Vital Statistics System (NVSS). Detailed definitions for each variable are found in Section 12.6.

12.2.1 Symptoms of Mental Illness

One in five women experiences a mental disorder.[23,24] Women are more likely than men to experience depression, post-traumatic stress disorder (PTSD), anxiety, suicidal attempts, and eating disorders.[23,25–28] Women also experience psychiatric conditions specific to the reproductive lifecycle, including premenstrual dysphoric disorder and perinatal depression.[29,30] Rather than focusing on specific mental illnesses, NSDUH focuses on symptomologies that are associated with a high likelihood of a diagnosable mental illness.[31] NSDUH data uses the Kessler 6 Scale, which is a screening tool comprised of six questions about the frequency of feeling depressed, nervous, hopeless, and other emotions indicative of distress.[31,32] For the purposes of this book, serious psychological distress—"a likelihood of having diagnosable mental illness severe enough to cause functional limitations and to require treatment"—is measured by a Kessler 6 score of 13 or higher.[33]

Figure 12-1 shows the percent of women and men aged 18 and older who report serious psychological distress. The data reveal that a higher proportion of women experience serious psychological distress compared with men, which implies a higher likelihood of having a diagnosable mental illness.

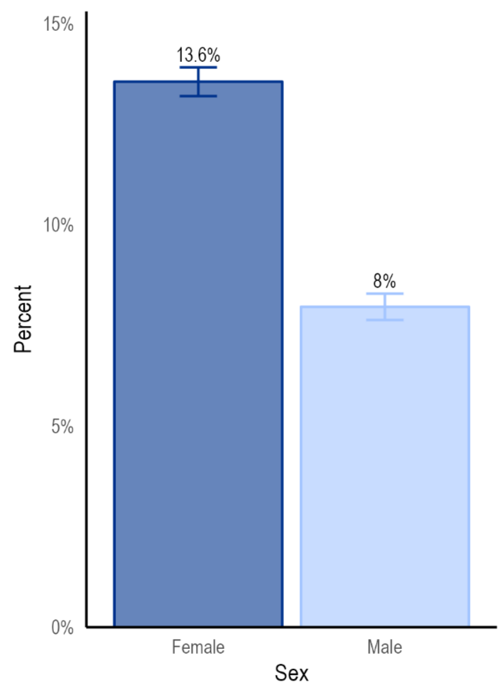

Figure 12-1: Percent of adults aged 18 and older who report serious psychological distress by sex
Source: National Survey on Drug Use and Health (NSDUH), 2021

Figure 12-2 shows the percent of women and men aged 18 and older who report Kessler 6 symptoms of distress all of the time or most of the time in the year prior to the 2021 survey. The data show higher proportions of women reported experiencing each of the symptoms compared with men, with a difference of nearly twofold on several measures. The highest proportions observed were among women who experienced "feeling nervous," "feeling like everything is an effort," and "feeling down, depressed, or hopeless," which reflect women's higher prevalence of depression and anxiety.[34,35] For the distress markers reported at the lowest proportion among women (9.9% feeling restless, fidgety, or worthless), findings were still higher than the highest proportion reported among men (8.3% feeling nervous). This echoes results seen in other literature and points to a need for more research to fill gaps in the understanding of sex and gender differences in emotional processing and willingness to report symptoms.[36,37]

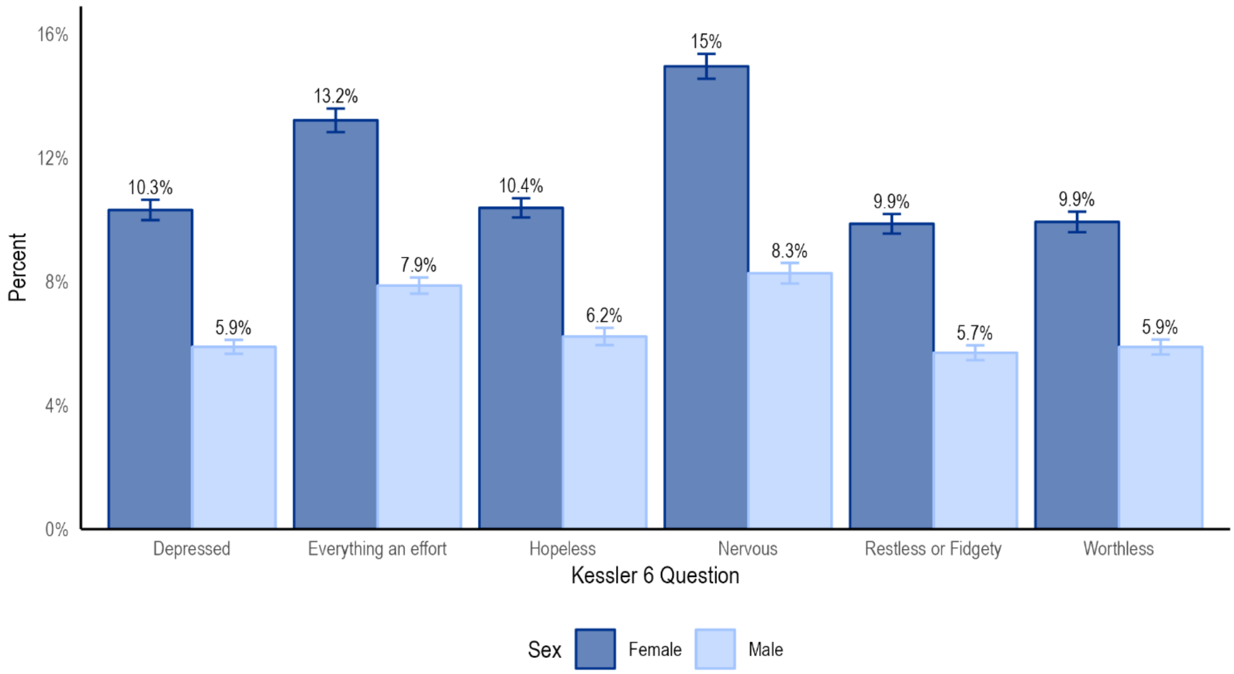

Figure 12-2: Percent of adults aged 18 and older who report Kessler 6 symptoms of distress all of the time or most of the time by sex

Source: National Survey on Drug Use and Health (NSDUH), 2021

While the NSDUH data illustrate differences in mental health status among adults, the YRBS of students in grades 9-12 allows for assessment of mental health status among teens.[38] **Figure 12-3** shows the percent of students in grades 9-12 who reported feeling sad or hopeless "almost every day for greater than two weeks in a row" impairing function/willing to participate in "usual activities." The data show an overall upward trend over time for all youth surveyed. The proportion of girls reporting the noted symptoms is nearly two times higher than that seen among boys. There may be a number of factors explaining this difference. Research suggests that the higher proportion of psychological stress among teen girls may be due in part to higher levels of estrogen in puberty and greater internalization of the complex social processes around pubertal transition.[39] Other explanations suggest that teens girls experience higher rates of sexual violence during this period which increases the risk for mental illness (see **Chapter 14**).[40,41] Girls have also been shown to use social media more than boys which is associated with lower psychological well-being,[42] especially notable during the COVID-19 pandemic.[43,44] This and other challenges during the pandemic resulted in a spike in the percentage of girls who felt sad or hopeless.[45,46]

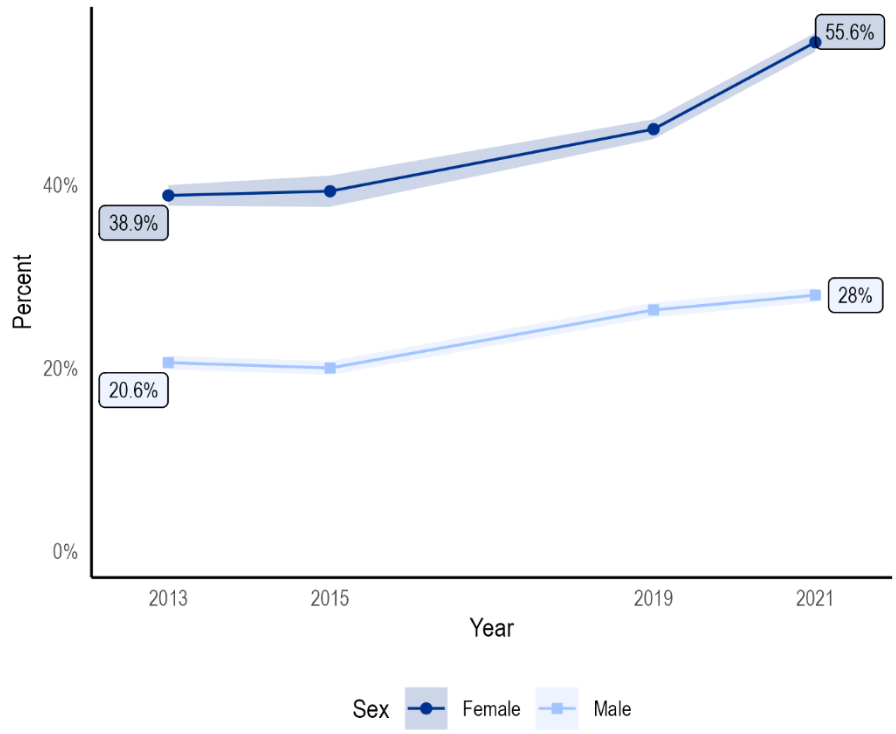

Figure 12-3: Percent of students in grades 9-12 who reported feeling sad or hopeless during the past 12 months by sex over time

Source: Youth Risk Behavior Survey (YRBS), 2013, 2015, 2019, 2021[i]

12.2.2 Suicide

While not strictly linear, suicide is understood as a process where an individual moves from suicidal ideation—a range of thoughts about death and/or preoccupation around ending one's life—to concrete action. The diagnosis of a mental illness—particularly depression—is a risk factor for suicide, but not the only contributor.[47] Research suggests movement from suicidal ideation to attempting suicide is facilitated by factors that increase or decrease capacity or capability for suicide.[48] Women's overall higher rates of a range of psychosocial stressors and mental illnesses increases their risk of contemplating and attempting suicide.[49–51] Trends from 1999 to 2019 show a significant increase in suicidal ideation among female youth, while male youth saw a significant increase in nonfatal suicide attempts.[52]

Figure 12-4 shows the percent of students in grades 9-12 who considered suicide, planned suicide, attempted suicide, or were injured from a suicide attempt in the year prior to the survey. The data reveal an increase in the percent of boys and girls who reported considering, planning, and attempting suicide (although not injuries from suicide attempts). The data further show an alarming increase in the

[i] Note YRBS data from 2017 are not included in the analysis because survey responses were not linked with demographic data at the time of analysis.

percent of teen girls who reported considering, planning, and attempting suicide in 2019, further widening this mental health gap between girls and boys.

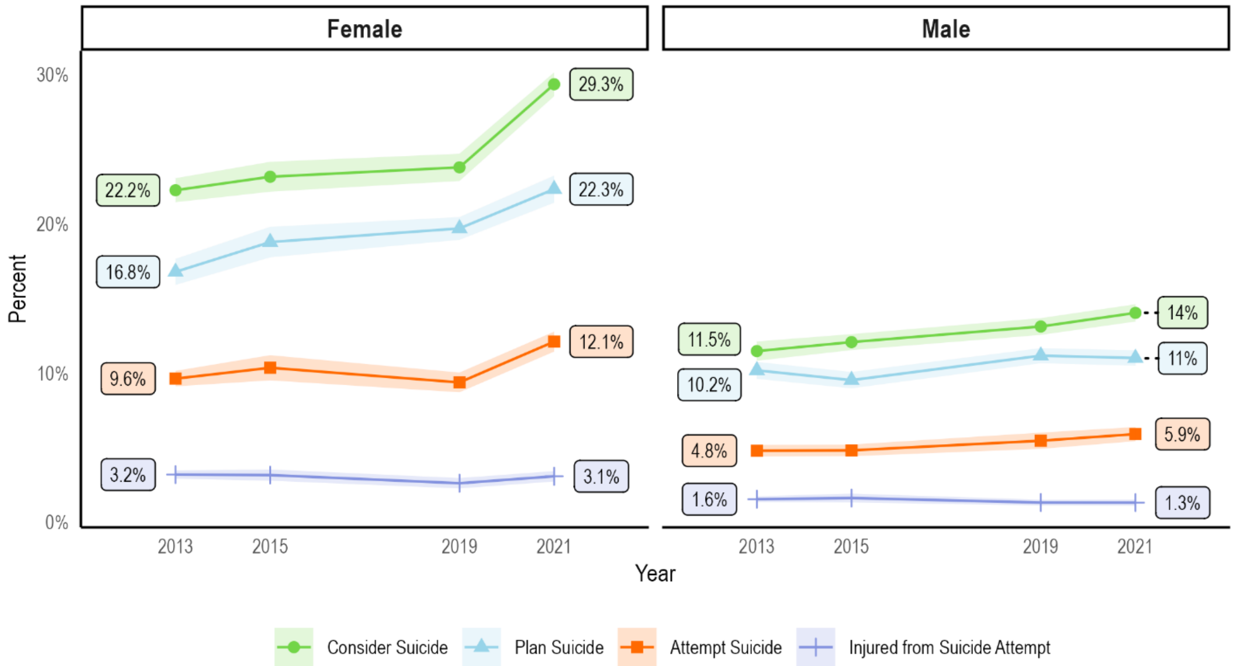

Figure 12-4: Percent of students in grades 9-12 who report considering suicide, planning suicide, attempting suicide, or injury from a suicide attempt during the past 12 months, by sex over time
Source: Youth Risk Behavior Survey (YRBS), 2013, 2015, 2019, 2021[ii]

The trends observed here are similar to findings from other studies, which indicate an increase in suicide attempts over the past two decades, with a notable uptick in attempts by youth and teen girls in particular.[50,53] Similar sex differences are observed in adulthood, when greater proportions of women experience suicidal ideation compared with men. **Figure 12-5** shows that more women (5.2% or 6.4 million) reported having suicidal thoughts compared with men (4.4% or 5.4 million).

[ii] Survey years 2013, 2015, 2019, and 2021; YRBS data from 2017 are not included in the analysis because survey responses were not linked with demographic data at the time of analysis.

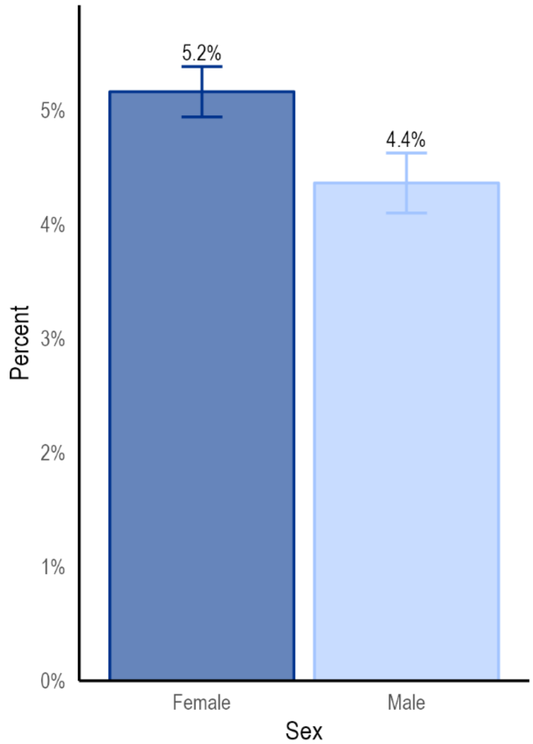

Figure 12-5: Percent of adults aged 18 and older who report suicidal ideation by sex
Source: National Survey on Drug Use and Health (NSDUH), 2021

By contrast with suicidal thoughts, death rates show men to be nearly four times more likely to die by suicide compared with women: **Figure 12-6** shows that between 2018 and 2021 the age-adjusted suicide mortality rate was 22.47 per 100,000 men compared with 5.85 per 100,000 women.

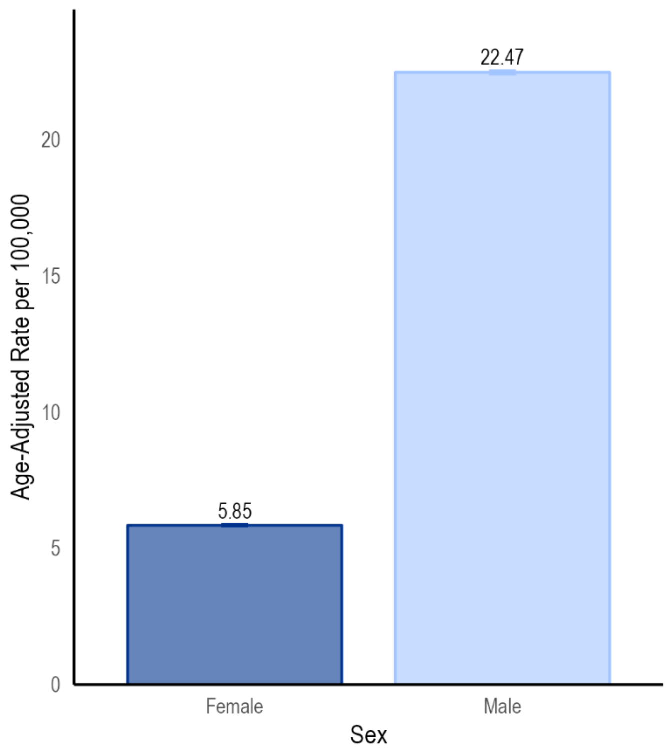

Figure 12-6: Age-adjusted suicide mortality rate per 100,000 population by sex

Source: National Vital Statistics System (NVSS) – Underlying Cause of Death, Pooled 2018-2021

Many researchers have worked to understand the paradox of a greater proportion of women experiencing every other phase in the suicide process while men have a greater proportion of suicide mortality. Studies suggest that this difference is due to suicide methods: men are more likely to choose methods with more lethality such as hanging, asphyxia, or firearms, while women are more likely to choose drug overdose or exsanguination.[54–57] Firearms were the most common method of dying by suicide for both men and women, accounting for one-third (33%) of women's suicide deaths and more than half (58%) of men's suicide deaths in 2020.[58] This may be due in part to men being two times more likely to own a gun than women.[59] A cohort study of more than 26 million people in California found a statistically significant association between firearm ownership and suicide rates between 2004 and 2016, with 7.8 times higher suicide rates for men who own firearms compared to those who did not and 35 times higher suicide rates for women who owned firearms compared to those who did not.[60] Some researchers have attributed women's higher likelihood to attempt suicide with drug overdose to the societal pressure on women to preserve their physical appearance.[54] Other researchers have called attention to gender norms where men value traits such as self-reliance, impulsiveness, fearlessness, and risk-taking which all moderate the risk for suicide and may result in men choosing more violent methods compared to women.[55,61–63] Women's lower rates of suicide mortality may also be due in part to gender differences in help-seeking, discussed in greater detail below.[11]

12.2.3 Treatment

With the diversity of mental illnesses, there are no universal treatments. The goal of many types of treatment is to provide or improve coping skills, thereby enhancing the individual's ability to handle stress, relate to others, and make healthy choices.[38] Common types of treatment for mental disorders include outpatient care (e.g., therapist, psychiatrist, or social worker), inpatient care (i.e., staying in a medical facility overnight or longer to receive treatment or counseling), and prescription medications. **Figure 12-7** shows that women are almost twice as likely to receive outpatient treatment for mental health compared with men. One study provides additional context informing this difference: it found that men were less likely to seek mental healthcare from their healthcare providers or informal services. However, men were as likely as women to seek care from mental health professionals.[64] This difference was attributable to men being less likely to receive routine medical care as opposed to any specific attitude towards mental health more generally.[64]

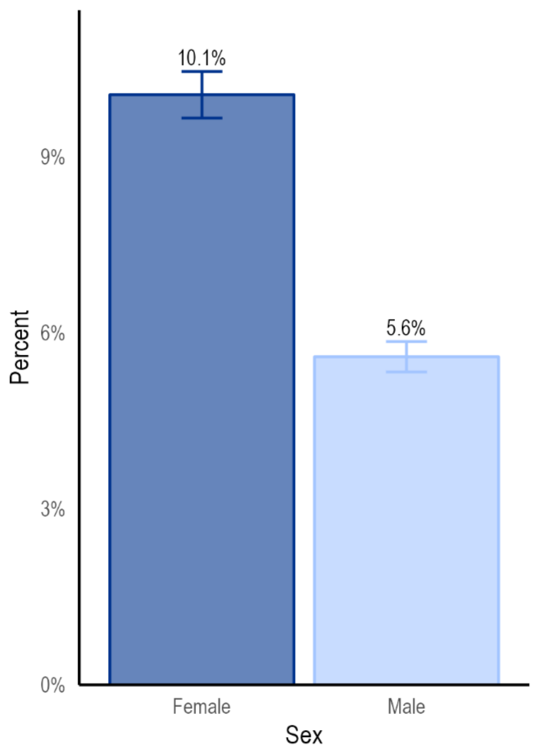

Figure 12-7: Percent of adults aged 18 and older who report receiving outpatient treatment for mental health by sex

Source: National Survey on Drug Use and Health (NSDUH), 2021

Women are also more likely to receive prescription medication for mental health treatment. **Figure 12-8** shows the percent of women and men who received prescriptions for mental health treatment in the past year. The percent of women who reported receiving prescription medication for a mental health condition was nearly double that of men. For both women and men, the percent reporting mental health treatment through prescription medication is higher than the percent reporting outpatient treatment. Psychotherapy, medication, and the combination of both play important roles in symptom management and progress toward wellness. The higher proportion of respondents reporting prescription medication may signal that outpatient mental health treatment is insufficient or inaccessible due to the structural barriers mentioned earlier (e.g., cost and provider shortages). Another possible explanation is that more individuals' treatment plans have transitioned to a maintenance phase, where only maintenance medication is required.

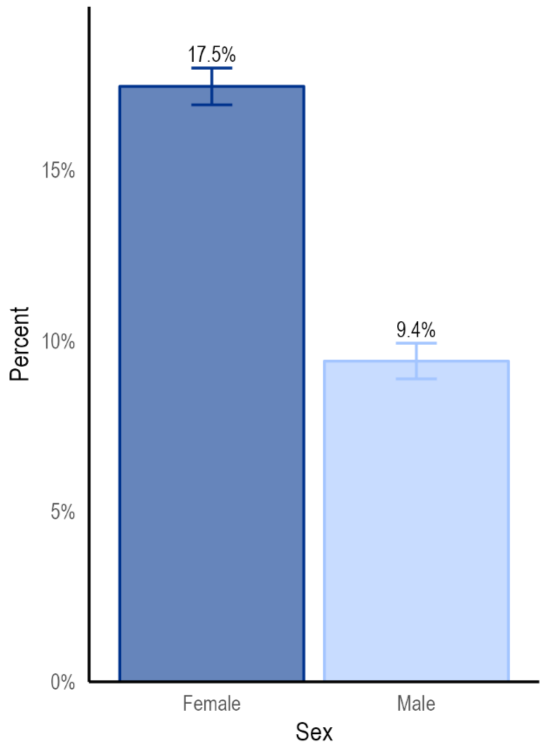

Figure 12-8: Percent of adults aged 18 and older who report receiving prescription medication for mental health treatment by sex

Source: National Survey on Drug Use and Health (NSDUH), 2021

The difference in treatment received is due in part to gender differences and social norms placed on men and women. Socialization often places pressure on men to be stoic and emotionless, which results in help-seeking being viewed as more feminine, and men often experience greater stigma for seeking help or discussing emotions.[11,57] Inpatient care is the most intensive form of treatment, and consequently estimated prevalence of inpatient treatment is low. **Figure 12-9** shows the percent men and women who report receiving inpatient mental health treatment in the past year for 2021. The estimates for men and women overlap at 1%, reflecting no meaningful difference by sex.

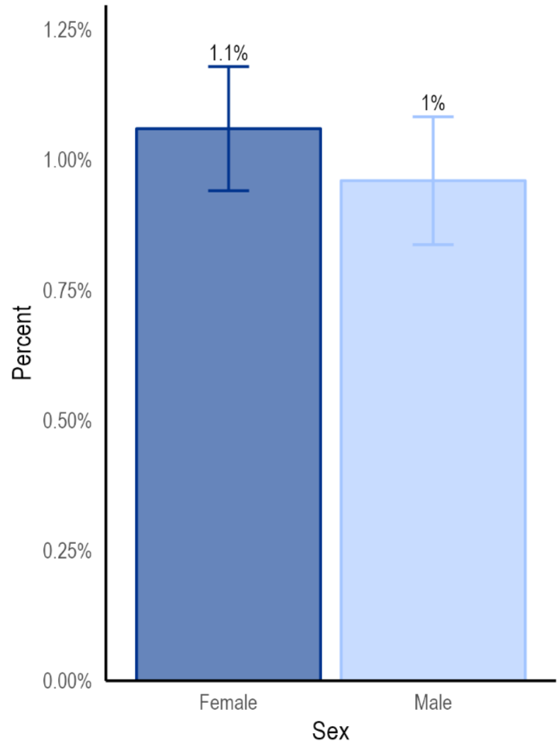

Figure 12-9: Percent of adults aged 18 and older who report receiving inpatient treatment for mental health by sex

Source: National Survey on Drug Use and Health (NSDUH), 2021

12.3 Mental Health in Populations of U3 Women

U3 women have unique mental health experiences, as many social drivers and societal factors directly impact an individual's risk for mental disorders and stressful experiences that contribute to the onset or worsening of such conditions (see **Chapter 1**). Studies show that an inverse relationship also exists, in which serious mental disorders can be a risk factor for economic insecurity, lower educational attainment, unemployment, and homelessness.[65] The section that follows presents findings on mental health among U3 women by race and ethnicity, rurality, economic status, sexual orientation, and gender identity.

12.3.1 Mental Health Among Women of Underrepresented Racial and Ethnic Communities

A range of factors result in women of underrepresented racial and ethnic communities experiencing a disproportionate mental health burden. Women in these communities are more likely to reside in impoverished neighborhoods with greater risk of exposure to crime and violence (see **Chapter 14**) and have reduced access to healthy foods and safe places to engage in physical activity, which can result in or increase risk for mental disorders.[66–68] The concentration of disinvestment in these communities is evidence of structural racism and discrimination, critical drivers of weathering (the accelerated aging and deterioration of health due to chronic exposure to stress), and worse health outcomes overall.[69–71] Other factors like the circulation of images and videos of racialized violence on social media have also been shown to contribute to distress for women of underrepresented racial and ethnic communities.[72,73]

12.3.1.1 Symptoms of Mental Illness in Women of Underrepresented Racial and Ethnic Communities

Figure 12-10 illustrates the percent of women aged 18 and older who report serious psychological distress by race and ethnicity.[iii] NSDUH data indicate that the lowest prevalence of serious psychological distress was reported by Black women and the highest was reported by Multiracial women. The data indicate that the likelihood of diagnosable mental illness is similar among AI/AN, Asian, Hispanic, Native Hawaiian and Other Pacific Islander (NHPI), and White women. The estimate for White women offers the most certainty due to a larger sample size corresponding to a smaller standard error. The percentages of serious psychological distress observed in **Figure 12-10** conflict with the research on disproportionate burden of adverse socials drivers in underrepresented communities.[74,75]

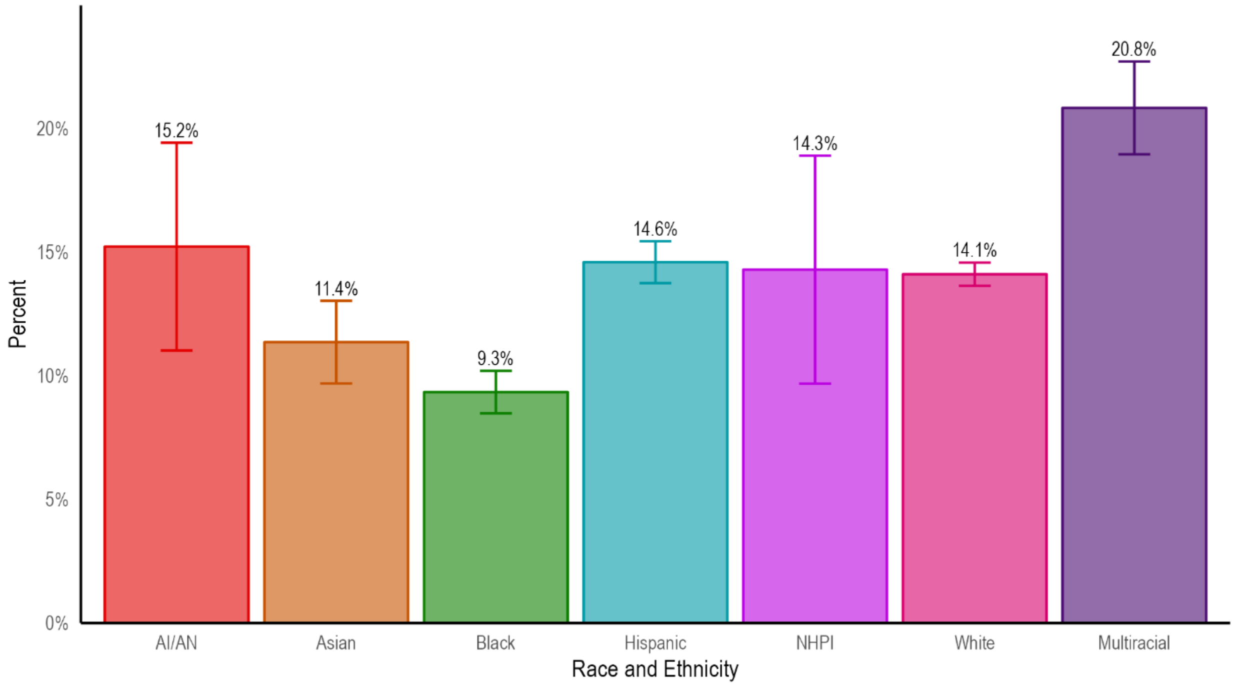

Figure 12-10: Age-adjusted percent of women aged 18 and older who report serious psychological distress

Source: National Survey on Drug Use and Health (NSDUH), 2021

Black women, for example, experience social drivers "including racism, discrimination, and sexism [that] put them at risk for low-income jobs, multiple role strain, and chronic health problems, all of which are associated with the onset of mental illness."[76] Black women are also likely to rely on informal resources, such as religion and social support, to cope with mental health problems.[76,77] Additional factors contributing to lower reporting include stigma of and shame about mental illness that prevent Black women from seeking care.[78] Diagnostic criteria for mental disorders were created describing symptomologies of White men and may lack the precision needed to accurately capture the experiences of women and people from underserved racial and ethnic communities.[7,79] The literature supports this explanation as misdiagnosis, underdiagnosis, and overdiagnosis are common in U3 communities.[80]

[iii] Serious psychological distress is defined in this analysis as a score of 13 or higher based on responses to the Kessler 6 Scale, and includes mental health problems severe enough to cause moderate-to-serious impairment in social and occupational functioning and to require treatment.[33]

Researchers have also noted that the Kessler 6 has not been well tested among diverse populations and may require further testing and modifications for validity for use with diverse population groups.[33,81,82]

12.3.1.2 Suicide in Women of Underrepresented Racial and Ethnic Communities

Figure 12-11 shows the percent of suicidal ideation, suicide planning, and suicide attempts among women by race and ethnicity for 2021. Research indicates that persistent experiences of racial discrimination and structural inequality explain, in part, the variation in suicidal ideation, planning, and attempts among women of underrepresented racial and ethnic communities.[83–85] Suicidal ideation across all groups is more common than planning or attempting suicide.[86,87] Multiracial, NHPI, and AI/AN women were most likely to report experiencing suicidal ideation (between 7.0-10.7%, with standard errors overlapping likely as a result of smaller sample sizes of these racial and ethnic groups). Research on psychiatric symptoms among Multiracial women is limited, but recent analysis highlights a critical gap between low rates of formally-diagnoses mental illness among Multiracial women and high rates of self-reported mental health burden including suicidal ideation and attempts.[88] While most of the populations show decreasing percentages from ideations to plans to attempts, there appears to be an increase between plans and attempts for AI/AN women. This may reflect a history of disproportionately high suicide rates among indigenous communities.[89] Theories of suicide are based on White adult populations and do not adequately consider the factors informing why and how individuals from different cultures consider, plan, attempt and experience injuries from attempted suicide.[90] This important gap hurts efforts to intervene given that suicidal symptomology, for example, co-occurs with higher rates of interpersonal violence and substance use experienced by U3 women (see **Chapter 13** and **Chapter 14**).

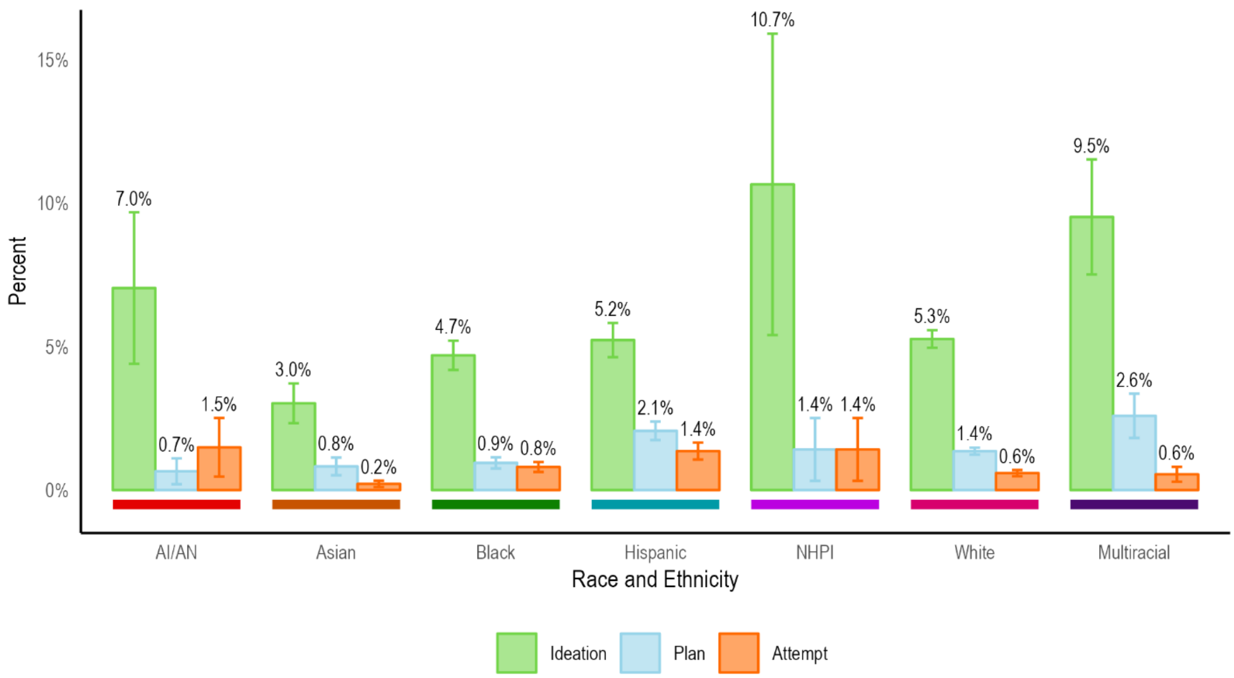

Figure 12-11: Percent of women aged 18 and older who report suicidal ideation, suicide plans, or suicide attempts, by race and ethnicity

Source: National Survey on Drug Use and Health (NSDUH), 2021

Figure 12-12 shows the percent of female students in grades 9-12 who report considering suicide, planning suicide, attempting suicide, or injury from a suicide attempt. Across nearly all racial groups, there has been a slight increase in the girls considering or planning suicide, with the exception of NHPI girls. Consistent with the earlier discussion, the increase between 2019 and 2021 may be due to the mental health crisis that emerged in the wake of the COVID-19 pandemic.[91]

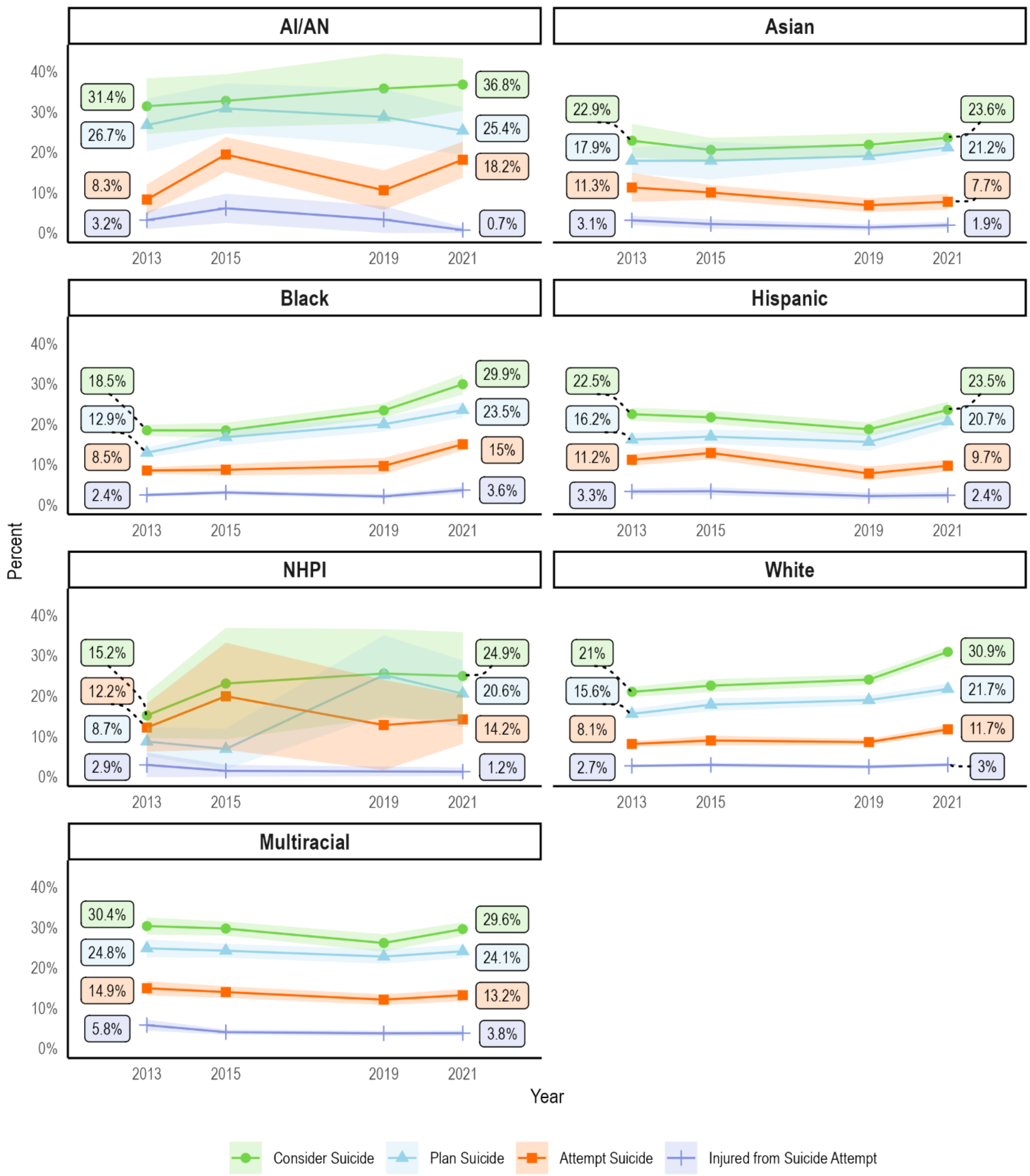

Figure 12-12: Percent of female students in grades 9-12 who report considering suicide, planning suicide, attempting suicide, or injury from a suicide attempt in the past 12 months, by race and ethnicity

Source: Youth Risk Behavior Survey (YRBS), 2013, 2015, 2019, 2021[iv]

[iv] Survey years 2013, 2015, 2019, and 2021; YRBS data from 2017 are not included in the analysis because survey responses were not linked with demographic data at the time of analysis.

The observed differences in the suicide process among girls and women of different racial and ethnic groups are echoed in the overall trends in suicide mortality, as shown in **Figure 12-13**. Compared with all other groups, AI/AN women have the highest mortality rates, with a distinct increase over time.

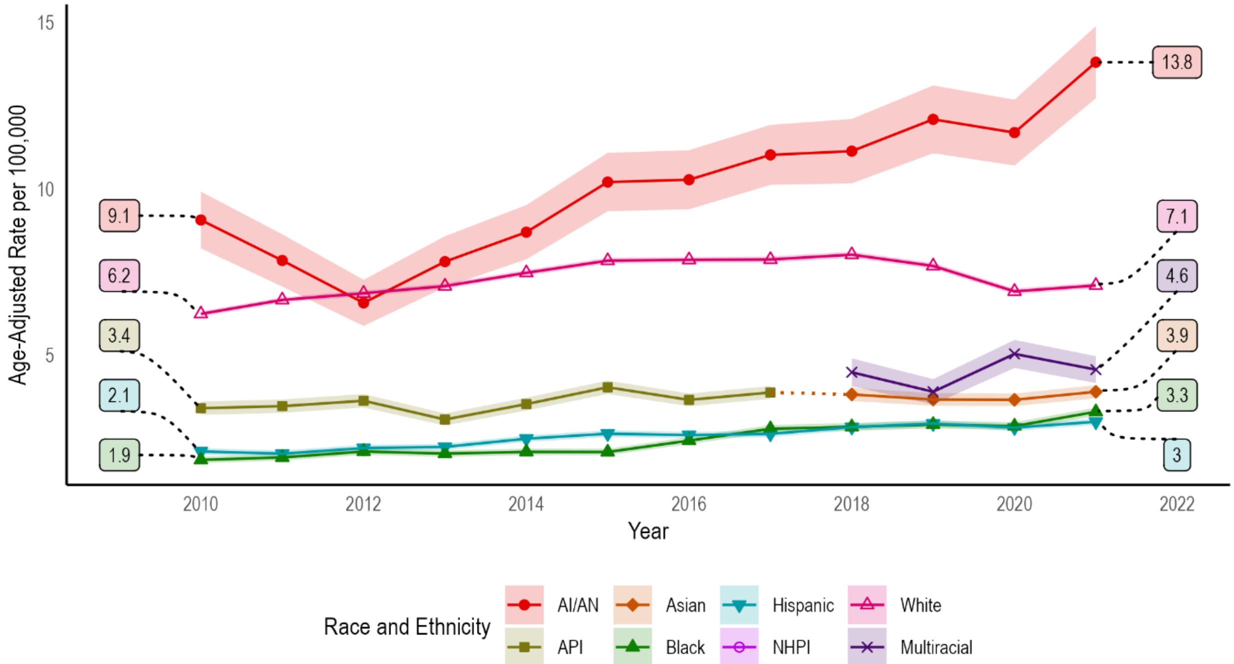

Figure 12-13: Age-adjusted suicide mortality rates per 100,000 women over time, by race and ethnicity

Source: National Vital Statistics System (NVSS) – Underlying Cause of Death, 2010-2021

This upward trajectory resembles in part the rates of substance use disorders (SUD) which are commonly comorbid with mental disorders**.** Research has shown that AI/AN women experience higher proportions of suicidal risk factors such as relationship problems, interpersonal victimization, and alcohol or substance use compared with women of other racial or ethnic groups.[92]

12.3.1.3 Treatment Among Women of Underrepresented Racial and Ethnic Communities

Figure 12-14 shows the percent of women aged 18 and older who report receiving outpatient treatment for mental health in the past year by race and ethnicity. While approximately 1 in 10 women overall report receiving outpatient mental health treatment (see **Figure 12-7**), this varies across racial and ethnic groups. Higher percentages of White and Multiracial women report receiving outpatient treatment for mental health (11.9% and 11.0%, respectively), while much lower percentages of Asian and NHPI women report receiving these services (5.2% and 5.0%, respectively).

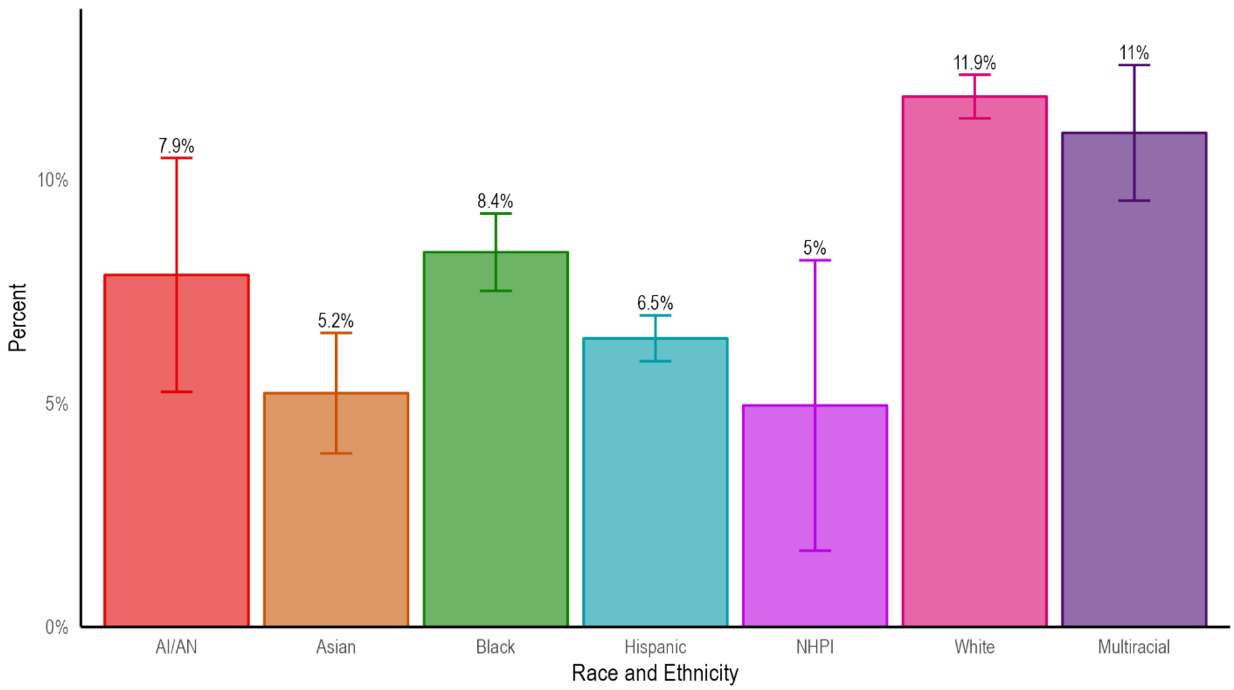

Figure 12-14: Percent of women aged 18 and older who report receiving outpatient treatment for mental health, by race and ethnicity

Source: National Survey on Drug Use and Health (NSDUH), 2021

Despite the importance of sensitivity and care standards in the delivery of mental health services, they continue to be underutilized and influence the treatment received by women in underrepresented communities. Black women with bipolar disorder, for example, are significantly less likely to receive antidepressants or be prescribed lithium than White women, despite lithium being a standard treatment to stabilize mood.[93] Disparities in treatment utilization are evident in **Figure 12-15**, which shows differences in the percent of women receiving prescription medication for mental health treatment by race and ethnicity for 2021. Black, Hispanic, and Asian women have the lowest rates of receiving prescription medication for mental health, with the proportion of Asian women being less than half of the next highest group. Many elements may factor into this underutilization of prescription medication, including poor patient-provider communication around treatment options and lack of awareness, stigma around mental health medication, generational trauma, discrimination, cost, and lack of access to care.[9,10,94]

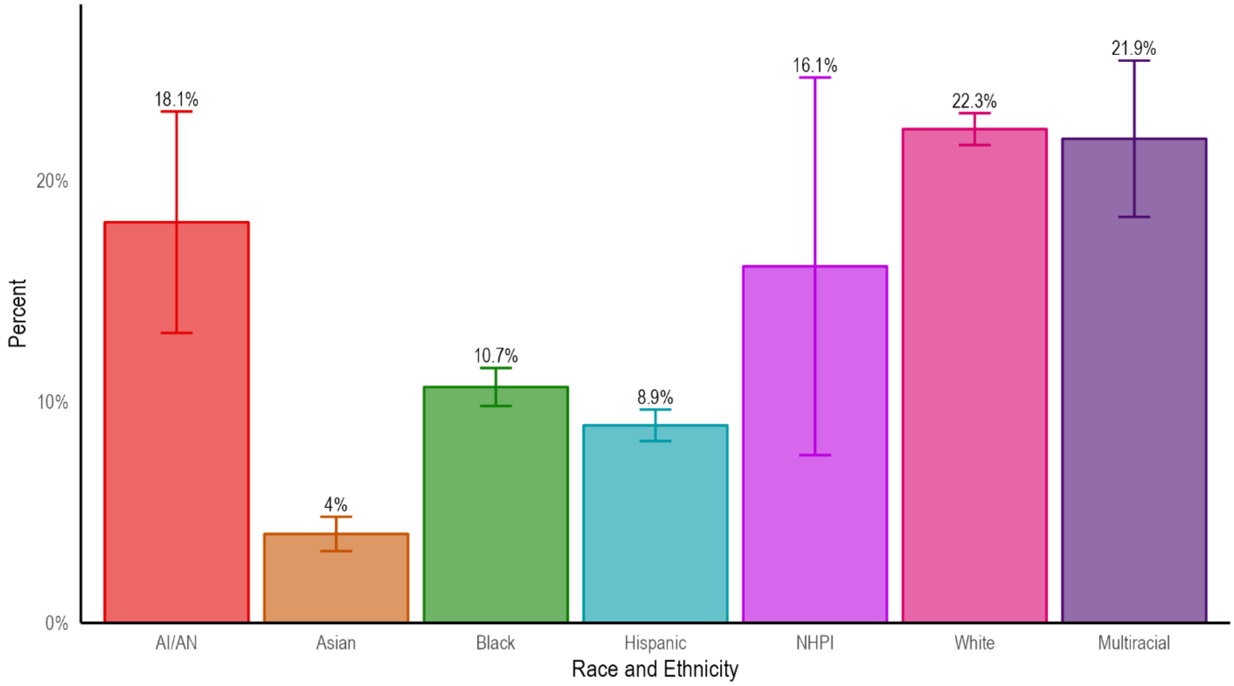

Figure 12-15: Percent of women aged 18 and older who report receiving prescription medication for mental health treatment, by race and ethnicity

Source: National Survey on Drug Use and Health (NSDUH), 2021

Figure 12-16 shows the percent of women aged 18 and older who report receiving inpatient treatment for mental health (including "overnight or longer in a hospital or other facility to receive treatment or counselling for any problems with … emotions, nerves, or mental health") by race and ethnicity. Inpatient facilities recorded by NSDUH include private/public psychiatric hospitals, psychiatric units of a general hospital, medical units within a general hospital, other hospital types, resident treatment centers, and some other facility type.[95] As inpatient services are warranted less frequently than outpatient services, the utilization across all races and ethnicities is under 4%, with the lowest percent for Asian women (0.4%). Estimates for AI/AN, NHPI, and Multiracial women suggest around 3% of women reported inpatient treatment, although these have larger standard errors. For Asian women in particular, research shows that stigma perpetuated by family and community results in concealment of mental health concerns and underutilization of mental healthcare, which results in further psychological distress.[96–98]

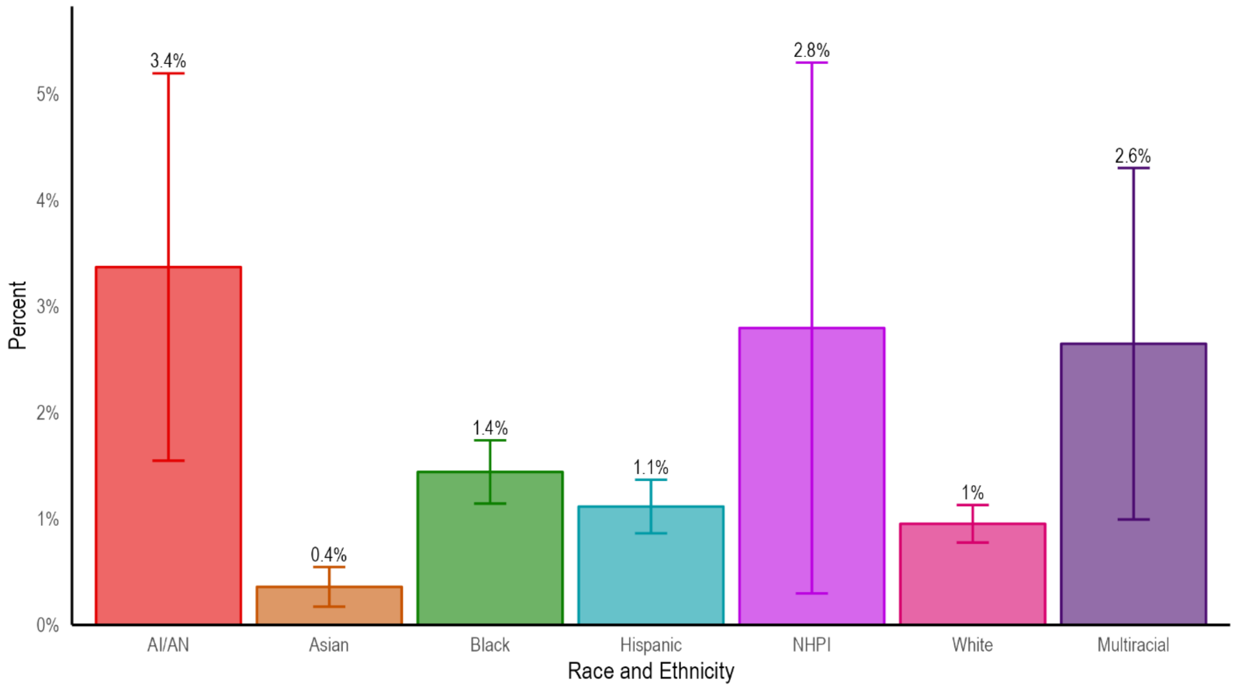

Figure 12-16: Percent of women aged 18 and older who report receiving inpatient treatment for mental health, by race and ethnicity

Source: National Survey on Drug Use and Health (NSDUH), 2021

12.3.2 Other Intersectional Considerations Relevant to U3 Women

The discrimination and structural inequality that negatively impact the mental health of women of underrepresented racial and ethnic communities can be further compounded for women who are "multiply marginalized," i.e., those who also live in rural areas, those who are in economically disadvantaged groups, and those who are lesbian, gay, bisexual, transgender, and queer/questioning (LGBTQ+).[83] The sections that follow explore these intersections where the data allow.

12.3.2.1 Rurality

Figure 12-17 shows the percent of women who report serious psychological distress by race and ethnicity and rurality.[v] The prevalence of serious psychological distress is higher among AI/AN, Black, Multiracial, and NHPI women living in rural areas compared with those not living in rural areas. Due to social drivers of health like physical isolation, limited access to social networks, and limited access to mental healthcare, individuals living in rural areas experience a greater burden of mental health disparities. For U3 women, these disparities may be exacerbated by additional drivers such as stigmatization of mental illness, racism, and discrimination.[99–101] For Asian and White women, rurality does not appear to affect the prevalence of serious psychological distress.

[v] Serious psychological distress is defined in this analysis as a score of 13 or higher based on responses to the Kessler 6 Scale and includes mental health problems severe enough to cause moderate-to-serious impairment in social and occupational functioning and to require treatment.[33]

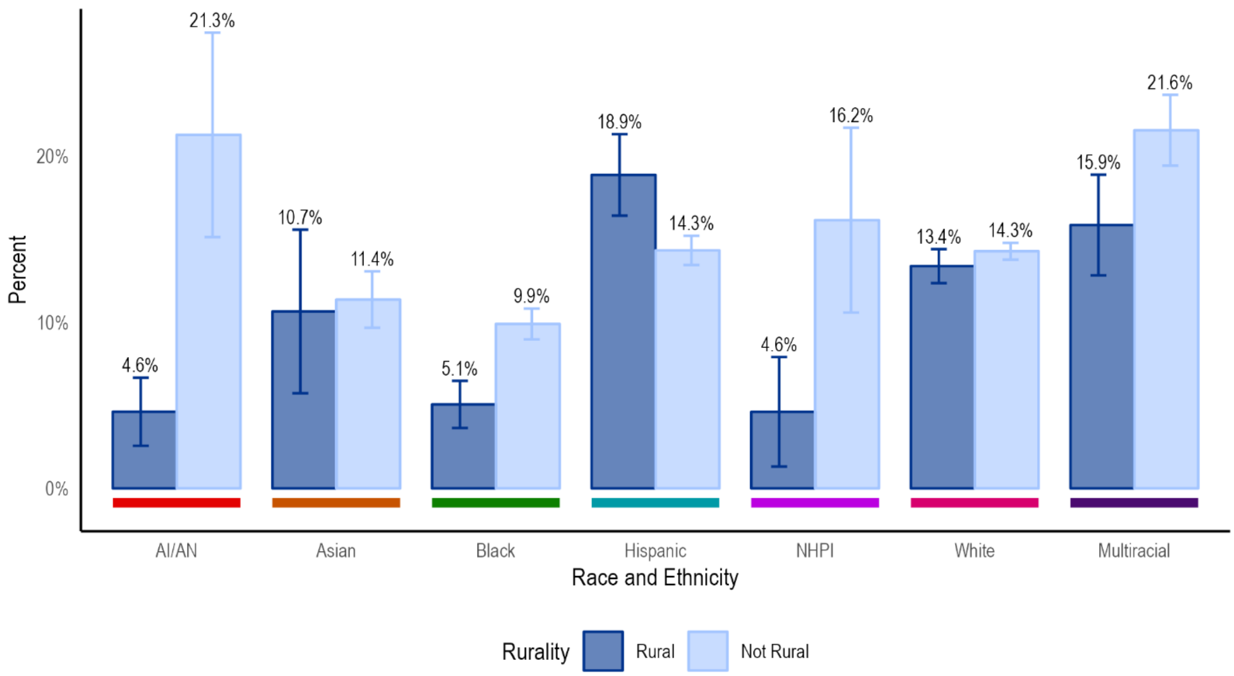

Figure 12-17: Percent of women aged 18 and older who report serious psychological distress, by race and ethnicity, and rurality

Source: National Survey on Drug Use and Health (NSDUH), 2021

The pattern of outpatient mental health treatment also varies across race and ethnicity by rurality, as shown in **Figure 12-18**. For Asian and Multiracial women, the percent who received outpatient treatment in the past year is higher among those living in rural areas compared with those not living in rural areas. For White women, the inverse is true, with women in rural areas having lower treatment rates compared with women not in rural areas. For AI/AN, Black, Hispanic, and NHPI women, the data do not allow for detection of a difference by rurality.

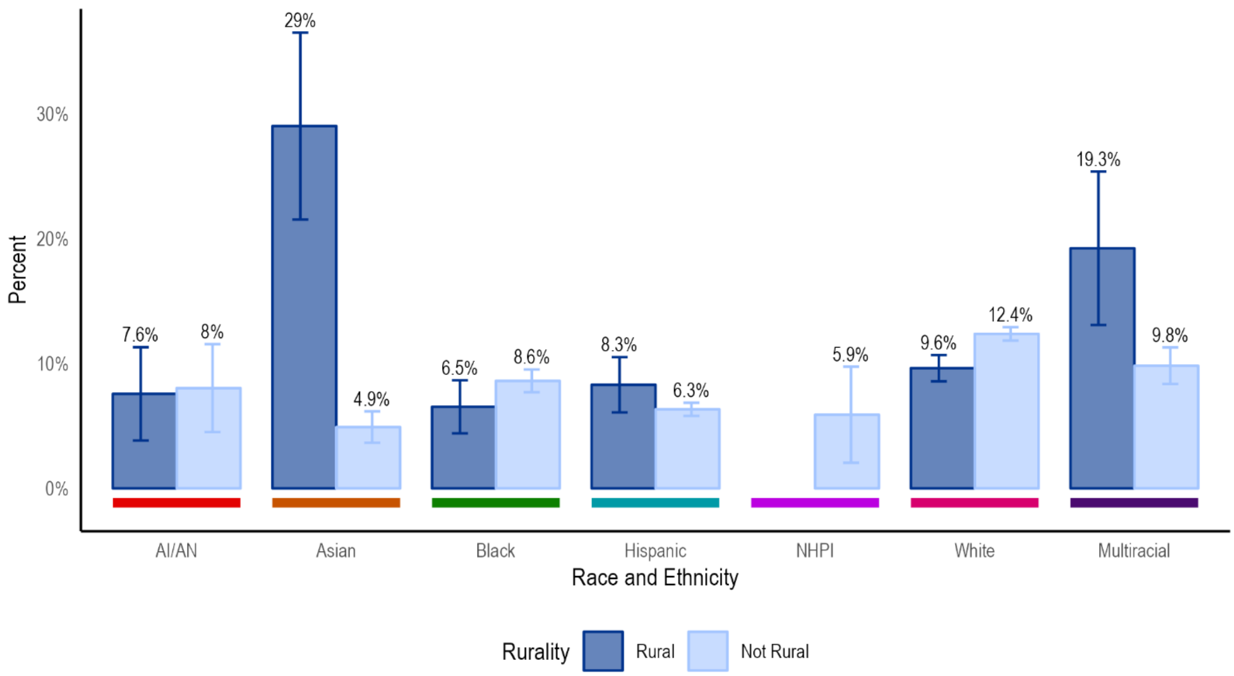

Figure 12-18: Percent of women aged 18 and older who report receiving outpatient treatment for mental health, by race and ethnicity, and rurality

Source: National Survey on Drug Use and Health (NSDUH), 2021

Data on suicide mortality rates between 2010 and 2020 show an association overall between living in rural communities and higher suicide mortality rates among women (**Figure 12-19**). The most notable difference by rurality is observed for AI/AN women, among whom the suicide mortality rate for women in rural areas (11.85 deaths per 100,000 women) is nearly 50% higher than the rate for women in non-rural areas (8.0 deaths per 100,000 women). This tracks with research finding that AI/AN people living in tightly knit rural communities may be more prone to suicide clusters.[89] For Asian and Pacific Islander (API), Hispanic, and White women, the suicide mortality rates are also higher for women living in rural areas, while Black women living in rural areas have lower suicide mortality rates than Black women not living in rural areas. The data presented here are consistent with research concluding that youth of underrepresented racial and ethnic communities living in rural areas had a significantly higher risk of suicidality compared with their underrepresented racial and ethnic peers not living in rural areas.[102] A study of Veteran Health Administration services users, however, found that race significantly modifies the association between rurality and risk of suicide.[103]

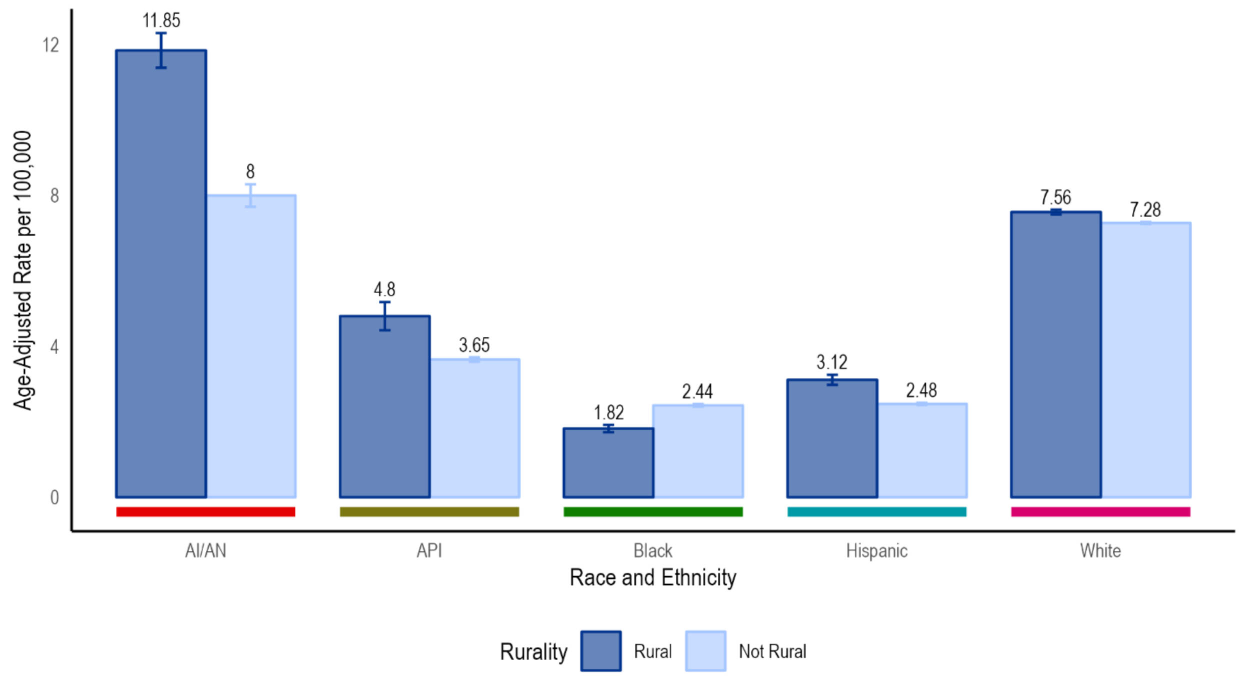

Figure 12-19: Age-adjusted suicide mortality rate per 100,000 women, by race and ethnicity, and rurality

Source: National Vital Statistics System (NVSS) – Underlying Cause of Death, Pooled 2010-2020

12.3.2.2 Economic Status

A large body of research has examined the connection between socioeconomic status (SES) and mental health, finding a strong link between economic inequality and poor mental health.[104,105] Evidence suggests that the relationship is bidirectional, with the socioeconomic stress (e.g., poverty, unemployment, debt, neighborhood safety) leading to worse mental health outcomes, and mental illness resulting in less economic opportunity.[65,106,107] While these findings suggest that higher SES acts as a protective factor against mental disorders, NSDUH data from 2021 do not confirm the protective factor of economic status for women of underrepresented racial and ethnic communities, as illustrated in the figures that follow. **Figure 12-20** shows no uniform effect of economic status on the percentage of women who report serious psychological distress.[vi] For AI/AN, Asian, Black, and Hispanic women, the data reveal minimal differences between women in economically advantaged groups and those in economically disadvantaged groups. However, for Multiracial and NHPI women, prevalence of serious psychological distress is higher among women in economically advantaged groups compared with those in economically disadvantaged groups. Conversely, for White women economic disadvantage is associated with higher prevalence of serious psychological distress.

[vi] Serious psychological distress is defined in this analysis as a score of 13 or higher based on responses to the Kessler 6 Scale and includes mental health problems severe enough to cause moderate-to-serious impairment in social and occupational functioning and to require treatment.[33]

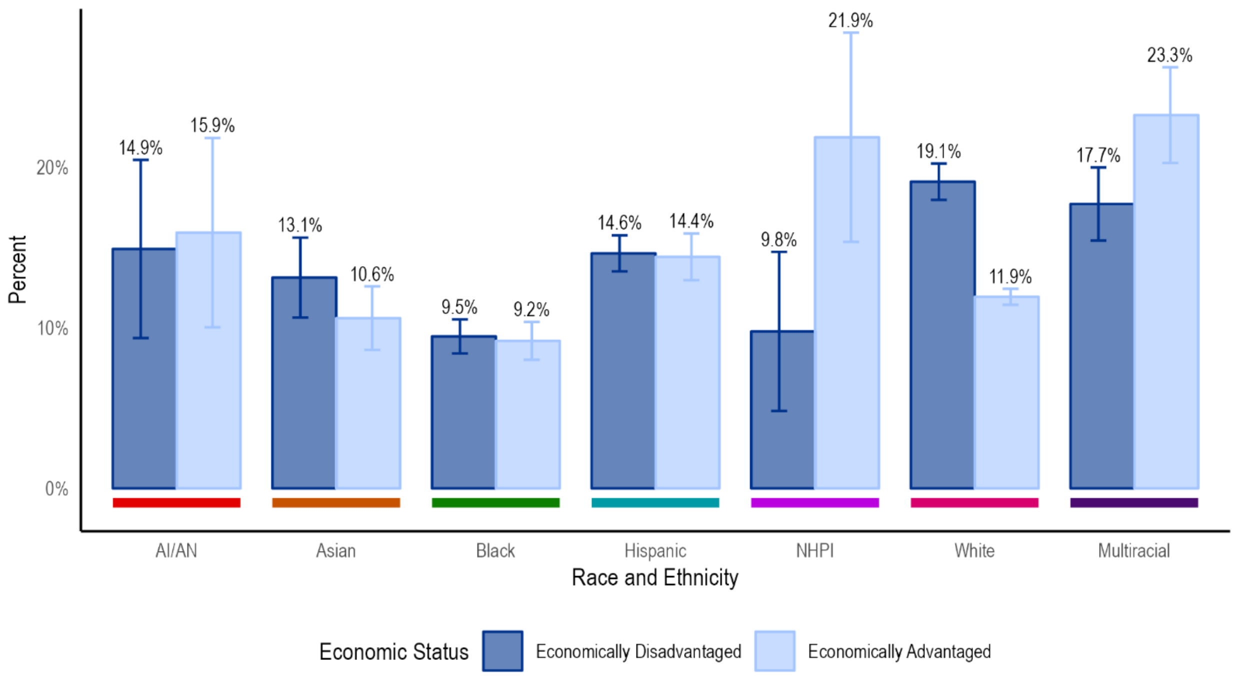

Figure 12-20: Percent of women aged 18 and older who report serious psychological distress, by race and ethnicity, and economic status

Source: National Survey on Drug Use and Health (NSDUH), 2021

A few things might explain why the data do not reveal greater differences by economic status, including the fact that the data reflect responses from a period of unusual stressors caused by the COVID-19 pandemic. These increased levels of psychological distress across all populations, which may have muted differences across groups.[108,109] The lack of effect may also be explained by the definition of economic status used in these analyses, which does not distinguish between living above the poverty level and being wealthy, potentially obscuring the protective value of having a high income. It is also important to note that economic disadvantage is a barrier to accessing preventive and comprehensive care for mental and physical health concerns.[110,111] These findings echo studies concluding that the negative health impact of existing as a member of a marginalized racial or ethnic group supersedes any benefit derived from higher economic status.[101,112]

Similarly, extant research on suicide found that Black women in high income strata have 20% increased odds of suicide compared with White women in the lowest socioeconomic strata.[49] This could be due in part to Black people of higher SES facing higher rates of racial discrimination in healthcare.[113] As shown in **Figure 12-21**, the overall percent of women who report attempting suicide in the past year is below 3% for all racial and ethnic groups, irrespective of economic status. Economic status appears to increase risk of suicide attempts for AI/AN, Asian, and White women, with those in economically disadvantaged groups being more likely to have attempted suicide in the past year. For all other racial and ethnic groups, the small numbers of attempts result in wide standard errors that do not allow for detection of differences by economic status.

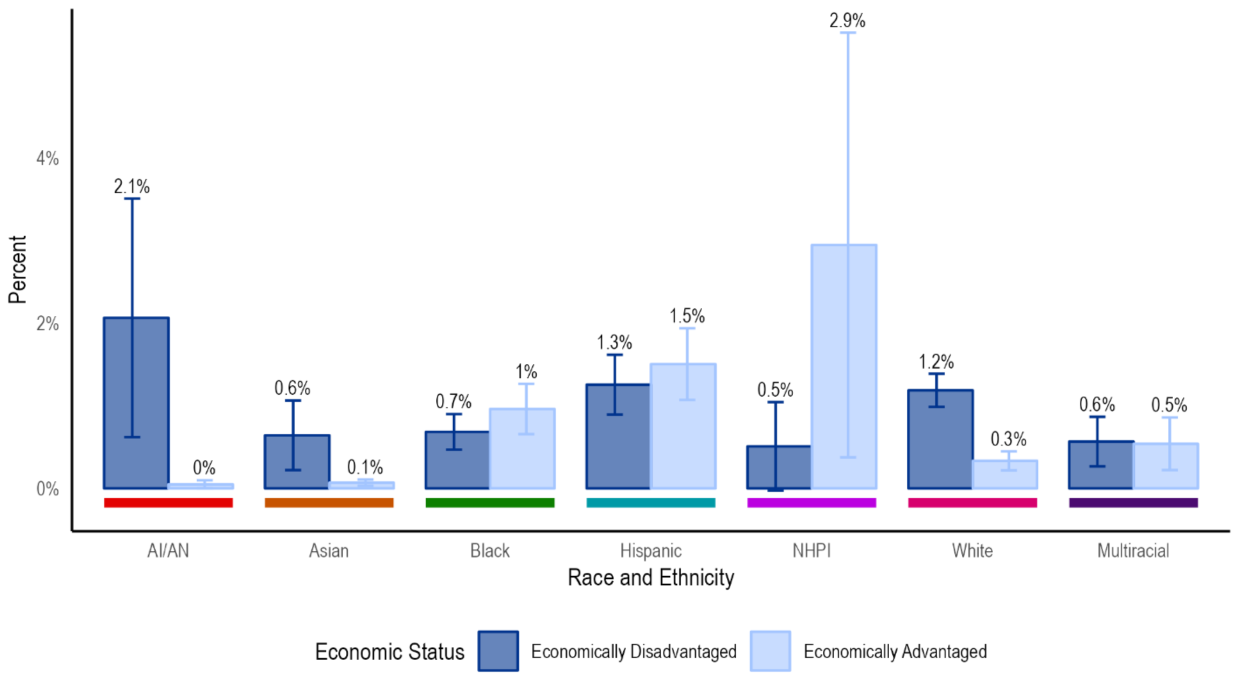

Figure 12-21: Percent of women aged 18 and older who report attempting suicide in the past year, by race and ethnicity, and economic status

Source: National Survey on Drug Use and Health (NSDUH), 2021

Studies have explored the complex relationship between economic status and mental health treatment seeking, including the role that stigma plays and how it differentially affects treatment seeking by economically advantaged and disadvantaged individuals. One such study found higher levels of "therapeutic pessimism" among economically disadvantaged people, which serves as a barrier to treatment seeking.[8] Data on the prevalence of outpatient treatment (**Figure 12-22**) reveal no consistent pattern by race and ethnicity and economic status. Economically advantaged Hispanic women, for example, are more likely to report receiving outpatient treatment while the opposite is true for NHPI and White women.

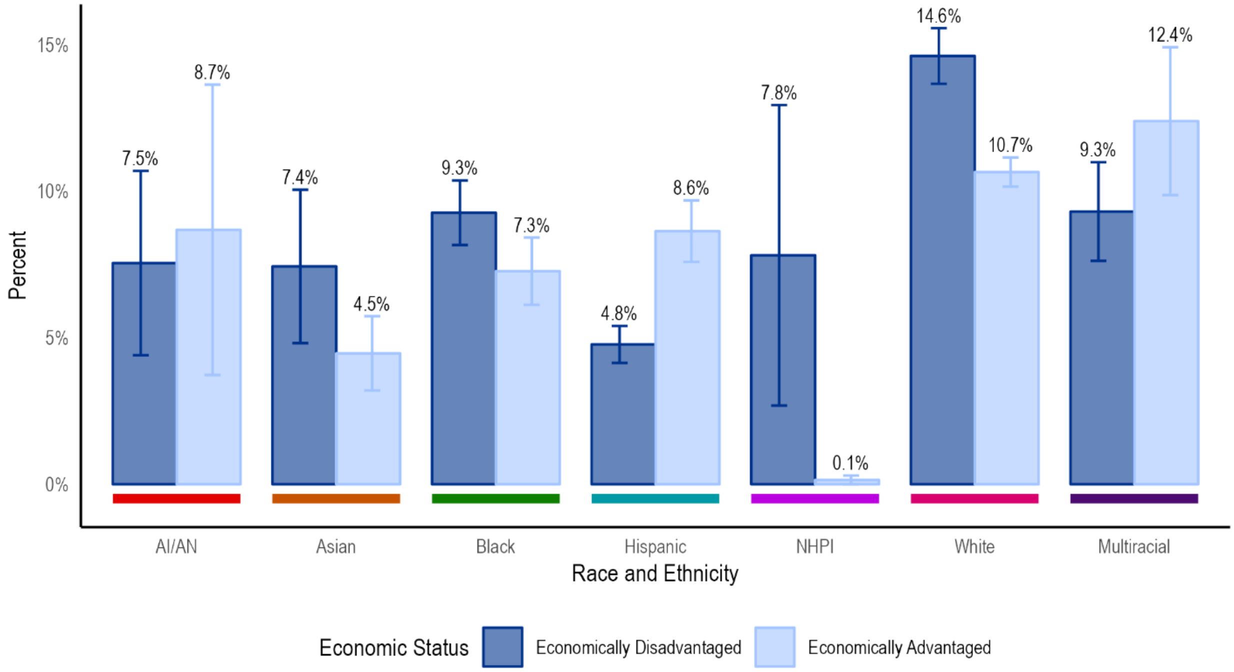

Figure 12-22: Percent of women aged 18 and older who report receiving outpatient treatment for mental health, by race and ethnicity, and economic status

Source: National Survey on Drug Use and Health (NSDUH), 2021

12.3.2.3 Sexual Orientation and Gender Identity

Sexual and gender minority (SGM) individuals experience unique stressors, such as sexual orientation-based prejudice and discrimination, that contribute to poor mental health outcomes.[114,115] Consequently, SGM women are more likely than cisgender and heterosexual women to have any mental illness, serious mental illness, major depressive disorder, serious thoughts of suicide, a suicide plan, a suicide attempt, and co-occurring mental illness and SUDs.[116] Compared to heterosexual women, across nearly all racial groups, SGM women have poorer mental health, with higher proportions of suicide plans, and greater injuries from suicide, as illustrated below. **Figure 12-23** shows the percent of female students in grades 9-12 who report that their mental health was "not good" most of the time or all of the time during the 30 days before the survey, by race and ethnicity and sexual orientation. The data show that across all racial and ethnic groups, teen girls who identify as lesbian, bisexual, queer or questioning (LBQ; see **Chapter 2**) are more likely to report poor recent mental health than those who identify as heterosexual. Among AI/AN girls who refused to answer the question about sexuality, over 90% reported poor mental health. Literature shows that AI/AN SGM individuals report high levels of discrimination and victimization, and the fear of stigma and violence can contribute to AI/AN SGM individuals avoiding disclosure of their gender identity.[117,118]

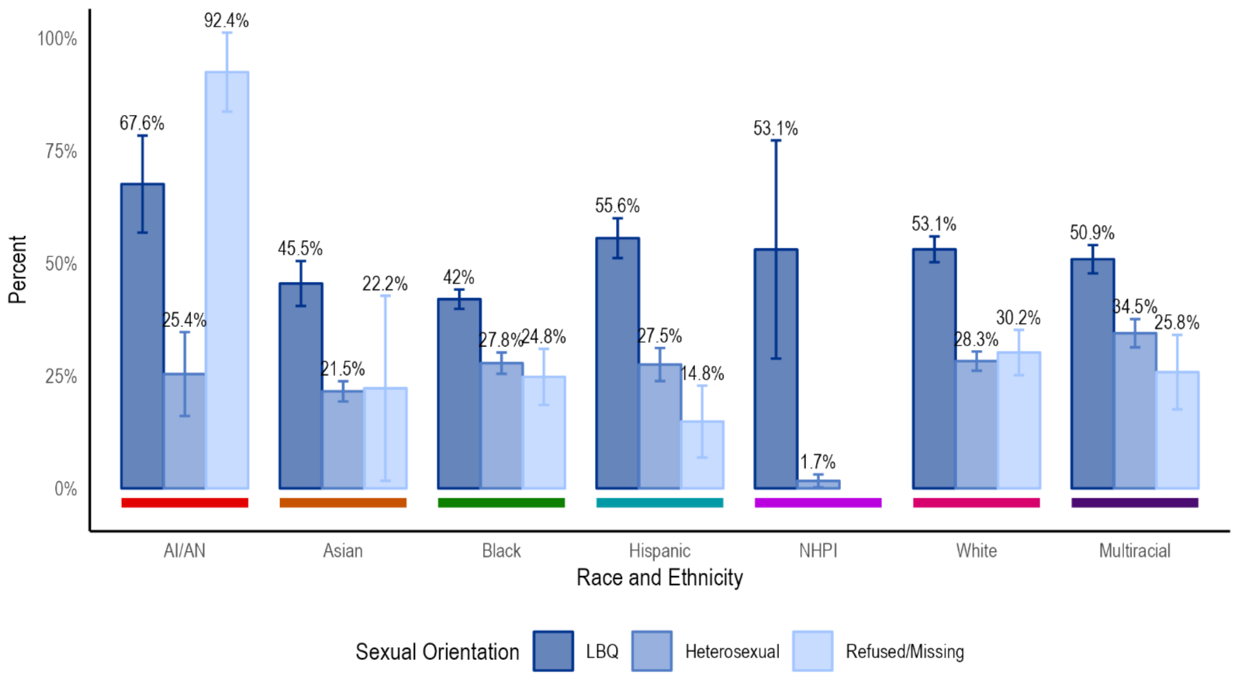

Figure 12-23: Percent of female students in grades 9-12 who report poor mental health, by race and ethnicity, and sexual orientation

Source: Youth Risk Behavior Survey (YRBS), 2021

The data here are consistent with findings in other research, which identify numerous social drivers of higher rates of depression and other mental health concerns among SGM populations. Note that in 2021, YRBS did not include a question that assesses gender identity and therefore there are no data available on those who identify as transgender and for whom stigma, minority stress, discrimination, heighted risk of violence, and bullying are major factors (see **Chapter 14**).[119,120] Emerging evidence also suggests that negative social media experiences contribute to poor mental health among SGM youth.[121] Research shows that Black SGM individuals reported poorer mental health outcomes following the COVID 19 pandemic due to the confluence the pandemic and images and videos of violence against Black people circulating on social media. The reported poor mental health outcomes include feeling unsafe in their living situation, high rates of negative impact on their well-being, and higher levels of stress caused by COVID-19, effects that appear stronger among SGM respondents who identify as women.[73] Furthermore, higher SES may not be protective: one study found that it is associated with greater mental health stigma in Black sexual minority adults, but reduced stigma in White sexual minority adults.[122]

The escalation of these mental health risks is evident in data about suicidality. **Figure 12-24** shows the percent of female students in grades 9-12 who planned a suicide attempt in the 12 months preceding the survey by race and ethnicity and sexual orientation. The pattern observed here echoes the data above on poor mental health, though the estimates are subject to higher uncertainty due to small sample sizes. The data suggest that across all racial and ethnic groups, LBQ teen girls are more likely to have made a suicide plan when compared to those who identify as heterosexual. The difference is most pronounced among AI/AN girls: the estimate for LBQ girls is seven times higher than that for heterosexual AI/AN girls. LBQ girls of other racial and ethnic groups were just over half as likely as LBQ AI/AN girls to have made a suicide plan.

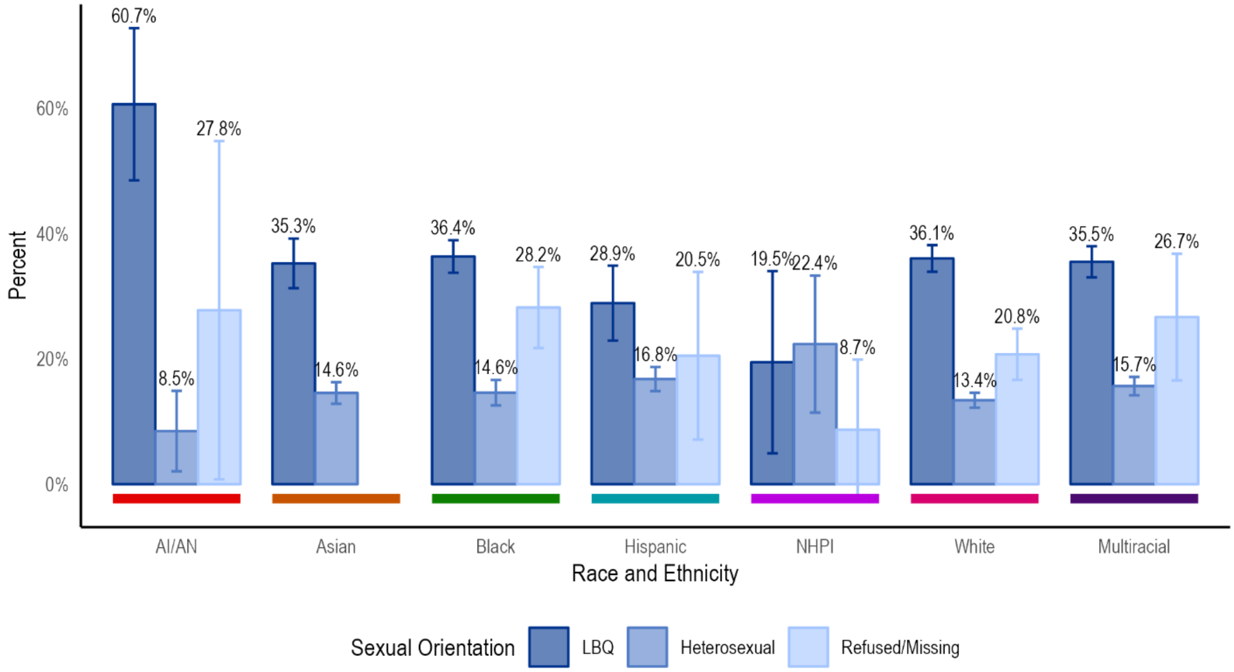

Figure 12-24: Percent of female students in grades 9-12 who report planning a suicide attempt, by race and ethnicity, and sexual orientation

Source: Youth Risk Behavior Survey (YRBS), 2021

SGM individuals of underrepresented racial and ethnic communities face multiple risk factors for suicide including social stigma, discrimination, higher rates of poverty and unemployment, and higher rates of substance use.[123–127] Data in **Figure 12-25** show the percent of female students in grades 9-12 who report being injured due to a suicide attempt during the 12 months before the survey, by race and ethnicity and sexual orientation. The figure shows that responses are not available for AI/AN girls who identify as LBQ or refused to answer the sexual orientation question; Asian, Black, and NHPI women who refused to answer the question; and NHPI women who identify as heterosexual. Within these data gaps, the highest proportion of injuries was among Black and Multiracial girls who identify as LBQ, followed by White, Hispanic, and Asian LBQ girls.

Other research has underscored the impact of holding multiple marginalized identities on suicide risk, including one study finding that bisexual women of underrepresented racial and ethnic communities living in rural areas have the highest prevalence of suicidal ideation.[83] While the data sources included in this book do not offer analyses on mental health by gender identity, extant literature shows that gender minorities (i.e., transgender, non-binary, and gender non-confirming people) experience poorer mental health than cisgender people. For example, transgender and gender non-conforming youth experience rates of depression and anxiety up to four times higher than among cisgender youth.[119,128,129] Gender minority youth are also more likely to have co-occurring depression and probable SUDs, which can exacerbate mental health challenges.[130]

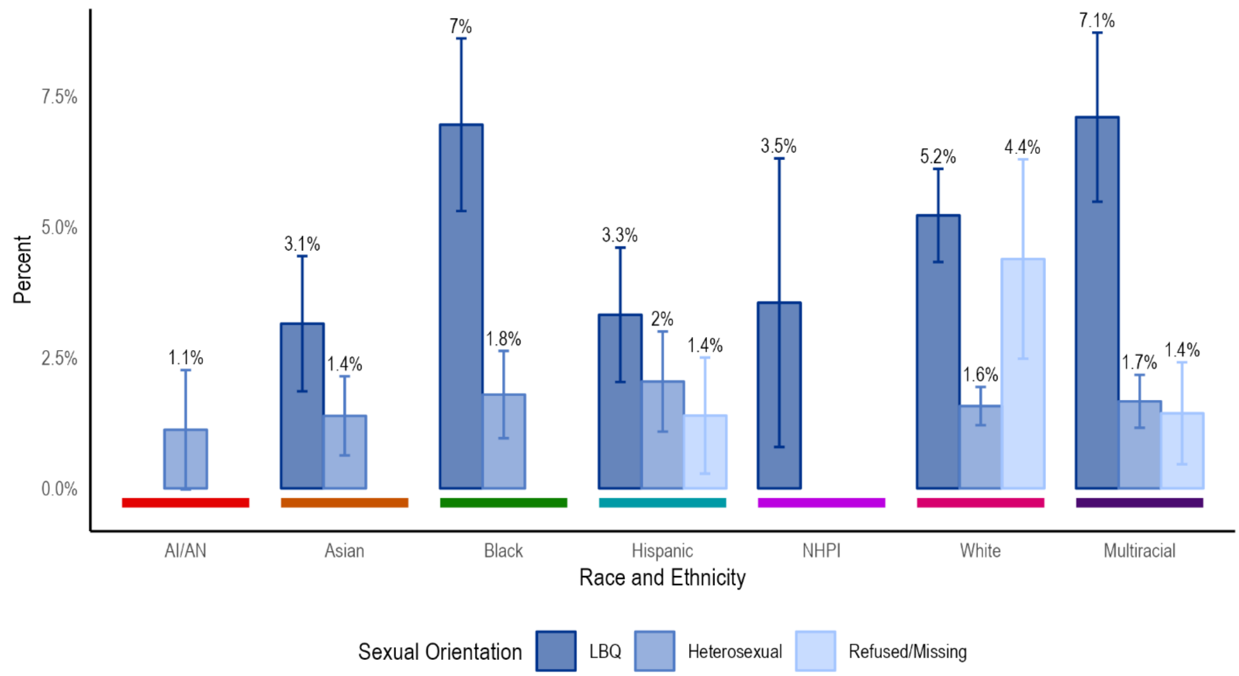

Figure 12-25: Percent of female students in grades 9-12 who report being injured due to a suicide attempt, by race and ethnicity, and sexual orientation

Source: Youth Risk Behavior Survey (YRBS), 2021

12.4 Conclusions and Future Directions

This chapter discussed how U3 women experience unique risk factors for mental illness that contribute to larger mental health inequities. Women overall experience greater rates of mental disorders. It is vital for future research to closely examine the risk factors of mental illness for each population of U3 women, particularly examining the relationship between violence, discrimination, and mental health. To accomplish this, it is important to have survey instruments that are thoroughly tested and validated for diverse populations. Additionally, data can act as a foundation to shaping mental health interventions that serve U3 populations. Understanding risk, prevalence, and severity is vital and requires better understanding of how symptoms are recognized and described by diverse groups; without the inclusion of U3 populations in research on mental health symptomology, there will continue to be diagnostic gaps that perpetuate disparities. At present, small sample sizes make interpretation of data challenging. Additionally, more work is needed to distinguish protective factors and facilitators of mental wellness in U3 communities.

The data also suggest the need for tailored interventions for both men and women of U3 populations around suicide prevention. The high disparity in suicide mortality between men and women demonstrates how gender norms and social structures impact everyone regardless of gender, and these gaps may be amplified by marginalization and discrimination linked to racism. It is important for future research to examine the bidirectional relationship between SES and mental health, as well as further examining how the stress of discrimination and racism connects both.

SGM individuals of underrepresented racial and ethnic communities face multiple risk factors for internalizing and externalizing mental disorders. Further research is needed to develop interventions to fill in the gaps, amplify the experiences of SGM people and address their intersectional concerns.

Additional research on subgroups of women from underrepresented racial and ethnic communities in mid- and later-life is needed to further elaborate the body of research on SGM women and allow for better knowledge and treatment of their mental health needs.

12.5 Data Sources and Definitions

Data for all figures in this chapter can be accessed from the data annex located here: https://orwh.od.nih.gov/sites/orwh/files/docs/Chapter_12.xlsx

National Survey on Drug Use and Health (NSDUH), 2021

Variable Name	Variable Description	Variable Options
AMHINP2	Received inpatient mental health treatment in past year	**Yes**; No; Unknown/Aged 12-17/Log Assign Yes (Otherwise)
AMHOUTP4	Received outpatient mental health treatment in past year	**Yes**; No; Unknown/Aged 12-17/Log Assign Yes (Otherwise)
AMHRX	Received prescription medications for mental health treatment in past year	**Yes**; No; Unknown/Aged 12-17/Log Assign Yes (Otherwise)
IRDSTCHR12	How often did you feel so sad or depressed that nothing could cheer you up during the worst month of the past year (only if the worst month was not the past 30 days)?	**All of the time; Most of the time;** Some of the time; A little of the time; None of the time
IRDSTEFF12	How often did you feel that everything was an effort during the worst month of the past year (only if the worst month was not the past 30 days)?	**All of the time; Most of the time;** Some of the time; A little of the time; None of the time
IRDSTHOP12	How often did you feel hopeless during the worst month of the past year (only if the worst month was not the past 30 days)?	**All of the time; Most of the time;** Some of the time; A little of the time; None of the time
IRDSTNGD12	How often did you feel down on yourself, no good or worthless during the worst month of the past year (only if the worst month was not the past 30 days)?	**All of the time; Most of the time;** Some of the time; A little of the time; None of the time
IRDSTNRV12	How often did you feel nervous during the worst month of the past year (only if the worst month was not the past 30 days)?	**All of the time; Most of the time;** Some of the time; A little of the time; None of the time
IRDSTRST12	How often did you feel restless or fidgety during the worst month of the past year (only if the worst month was not the past 30 days)?	**All of the time; Most of the time;** Some of the time; A little of the time; None of the time
IRSUICTHNK	Adult seriously thought about killing self in past year	**Yes**; No; Aged 12-17
IRSUIPLANYR	Adult made plans to kill self in past year	**Yes**; No; Aged 12-17
IRSUITRYYR	Adult attempted to kill self in past year	**Yes**; No; Aged 12-17
KSSLR6YR	Kessler 6 (K6) Total Score past year	Range = 0 – 24; “standard cutoff score of 13 or higher to identify persons with nonspecific serious psychological distress (SPD)” (Kim et al., 2016)

Youth Risk Behavior Survey (YRBS), 2013, 2015, 2019, 2021 (YRBS data from 2017 are not included in the analysis because survey responses were not linked with demographic data at the time of analysis.)

Variable Name	Variable Description	Variable Options
QN26, QN26, QN25, QN25	During the past 12 months, did you ever feel so sad or hopeless almost every day for two weeks or more in a row that you stopped doing some usual activities?	% of students who felt sad or hopeless
QN27, QN27, QN26, QN26	During the past 12 months, did you ever seriously consider attempting suicide?	% Yes (Seriously considered attempting suicide)
QN28, QN28, QN27, QN27	During the past 12 months, did you make a plan about how you would attempt suicide?	% Yes (Made a plan about how they would attempt suicide)
QN29, QN29, QN28, QN28	During the past 12 months, how many times did you actually attempt suicide?	% of students who attempted one or more times
QN30, QN30, QN29, QN29	If you attempted suicide during the past 12 months, did any attempt result in an injury, poisoning, or overdose that had to be treated by a doctor or nurse?	% Yes (Had a suicide attempt that resulted in an injury, poisoning, or overdose that had to be treated by a doctor or nurse)
QN85 (2021 only)	During the past 30 days, how often was your mental health not good? (Poor mental health includes stress, anxiety, and depression.)	% reported it was most of the time or always not good

Note: YRBS data from 2017 are not included in the analysis because survey responses were not linked with demographic data at the time of analysis.

National Vital Statistics System (NVSS) – Underlying Cause of Death, 2010-2021

Variable Name	Variable Description	Variable Options
Injury Intent	Suicide	N/A

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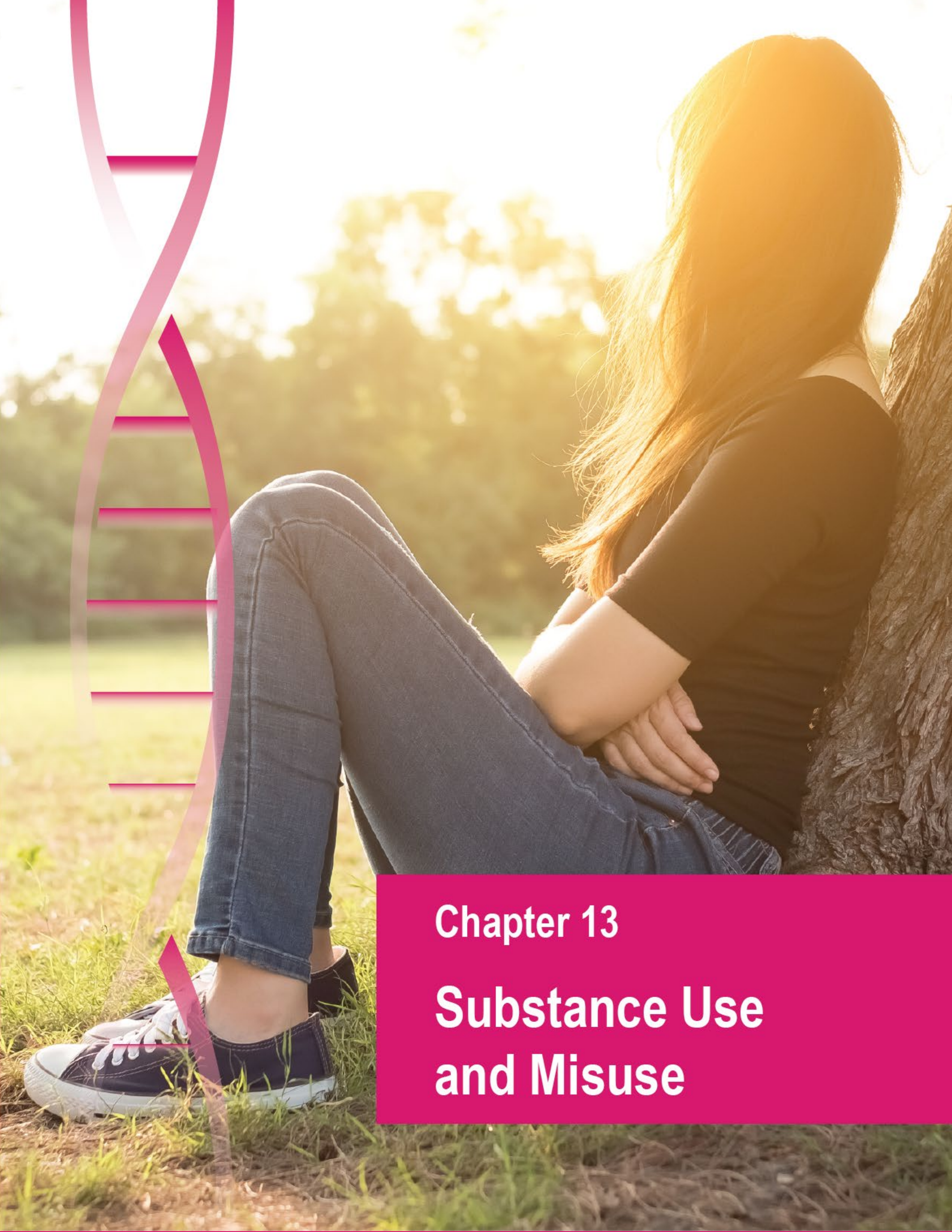

Chapter 13

Substance Use and Misuse

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Substance Use and Misuse

13.1 Defining Substance Use and Misuse

Substance use is the general term for any use of alcohol, tobacco, inhalants, or other drugs, including prescription medication as prescribed.[1] Substance misuse refers "use of alcohol, illegal drugs, and/or prescribed medications in ways that produce harms to ourselves and those around us."[2] While reasons for substance use and misuse are unique to the individual, some common reasons people use substances are to improve mood and confidence, relieve stress or anxiety, or perform better, and curiosity or social pressure.[3] The contours of and risk factors for substance use and misuse include childhood experiences, family history of substance use, substance use among peers, mental illness, violence, and policies related to substance use (see **Chapter 14**).[3–5]

Substance use and misuse are distinct from substance use disorder (SUD), which is a brain disorder marked by an inability to control substance use or misuse, even when it causes harm or the user wants to stop.[3,6] SUDs can be mild, moderate, or severe, with addiction as the most severe.[7] Recent data from the Substance Abuse and Mental Health Services Administration (SAMHSA) indicated that 17.3% of the population over the age of 12 report having a SUD in the past year, with 29.5 million people reporting an alcohol use disorder, 27.2 million people reporting a drug use disorder, and 8 million reporting both an alcohol and drug use disorder.[8] Overdose deaths have continued to increase in the U.S. over the past two decades.[9,10] The most recent CDC data indicate that in 2021, nearly 107,000 individuals died from a drug overdose, representing an increase of more than 15% from 2020.[9,11]

Harm reduction is defined by SAMHSA as "engaging directly with people who use drugs to prevent overdose and infectious disease transmission; improve physical, mental, and social well-being; and offer low barrier options for accessing healthcare services, including substance use and mental health disorder treatment."[12] Policies that frame drug use as a moral failure have increased the public's negative perceptions of drug use and stigma for people who misuse substances.[13] Consequently, there has been slow adoption of evidence-based harm reduction approaches such as syringe service programs, naloxone distribution, fentanyl test strip distribution, and others despite their efficacy for preventing overdose and disease transmission.

13.2 Substance Use and Misuse in Women

The National Survey on Drug Use and Health (NSDUH) provides nationally representative estimates of current use of tobacco, alcohol, and drugs by people aged 18 years and older to inform decisions relevant to public health programs and policies.[14,i] **Figure 13-1** provides the percent of people aged 18 and older who report trying selected substance(s) one or more times during their life, by sex. Alcohol, tobacco, and cannabis (marijuana) are the most prevalent substances used during the course of a lifetime regardless of sex, with men reporting higher rates of alcohol, tobacco and marijuana use compared with women. Likewise, opioid misuse, pain reliever misuse, hallucinogens, cocaine, methamphetamines, inhalants, heroin, and crack cocaine were higher among men when compared with women. Complementing this view, NSDUH reports that nearly 60% of people currently use tobacco, alcohol, or an illicit drug (defined as any past-month use), and that alcohol is the most commonly used, by nearly half of all respondents (47.5%).[16]

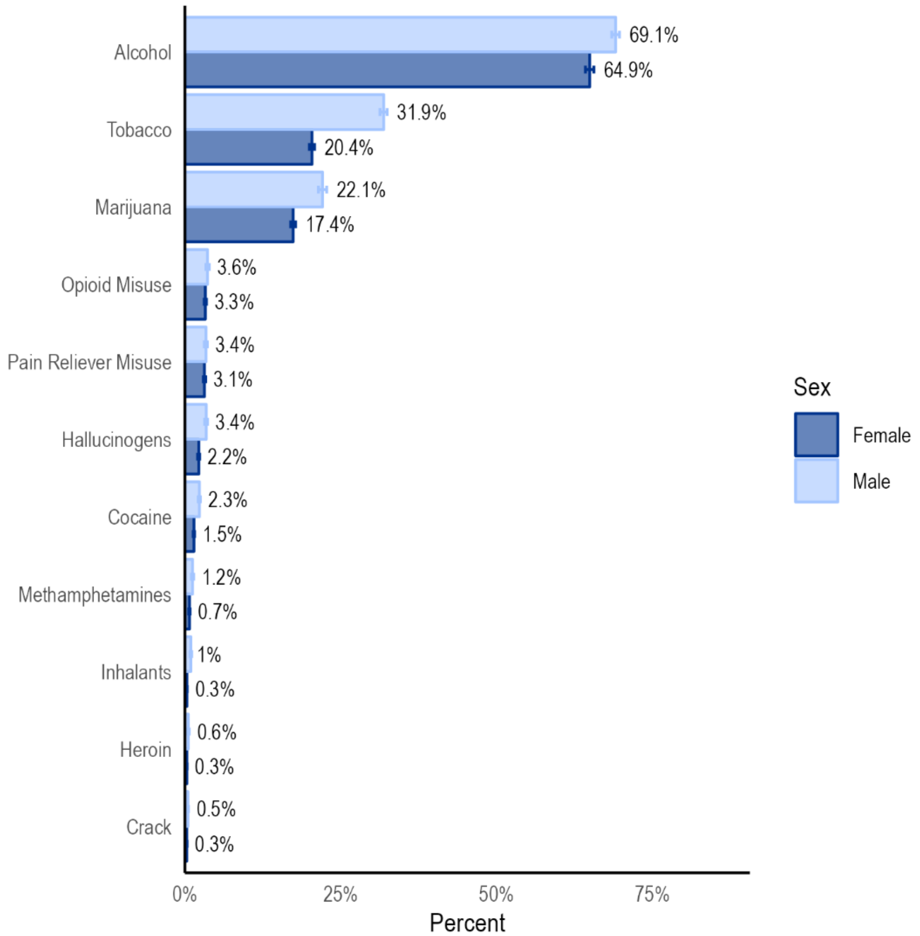

Figure 13-1: Percent of individuals aged 18 and older who report trying selected substance(s) one or more times during their life by sex

Source: National Survey on Drug Use and Health (NSDUH), 2021

Binge drinking is among the most common forms of substance misuse, with 21.7% of people aged 18 and older reporting at least one episode in the past month.[17] **Figure 13-2** shows that the percent of men

[i] While NSDUH typically collects data through in-person interviews, data in 2021 were collected through a combination of in-person interviews and online surveys. This means that data from 2021, such as those presented in this chapter, are not directly comparable to data from earlier years making it more difficult to draw conclusions about trends over time.[15]

who report binge drinking (consuming five or more drinks on the same occasion) in the past 30 days is higher than the percent of women who report binge drinking (consuming four or more drinks on the same occasion). Although this finding is consistent with other studies that show men generally have higher rates of substance use, it is notable that recent research finds that the gap is narrowing as women's use of alcohol and other substances is on the rise.[18]

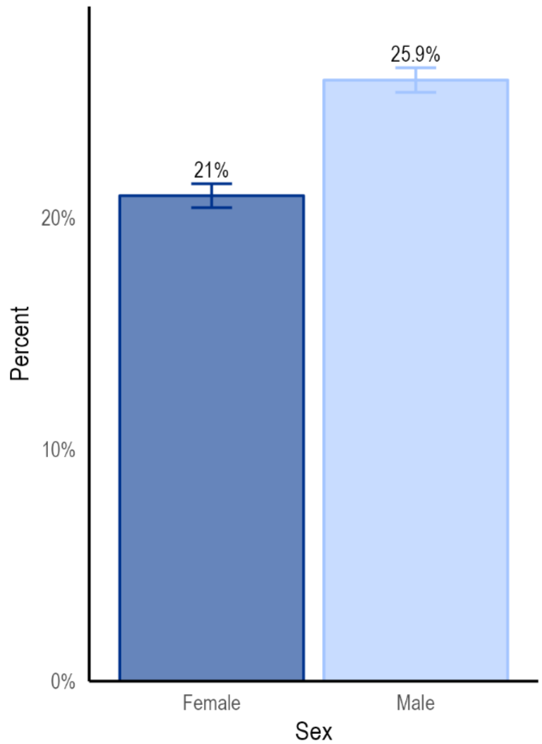

Figure 13-2: Percent of people aged 18 or older who reported binge drinking in the past 30 days by sex
Source: National Survey on Drug Use and Health (NSDUH), 2021

Figure 13-3 shows the percent of women and men aged 18 and older who reported use in the past 30 days of illicit drugs (defined as any use of marijuana or hashish, cocaine, crack, heroin, hallucinogens, inhalants, or methamphetamine, as well as misuse of prescription psychotherapeutic drugs). Consistent with the discussion above, these data show a higher percentage of men have used illicit drugs compared with women.

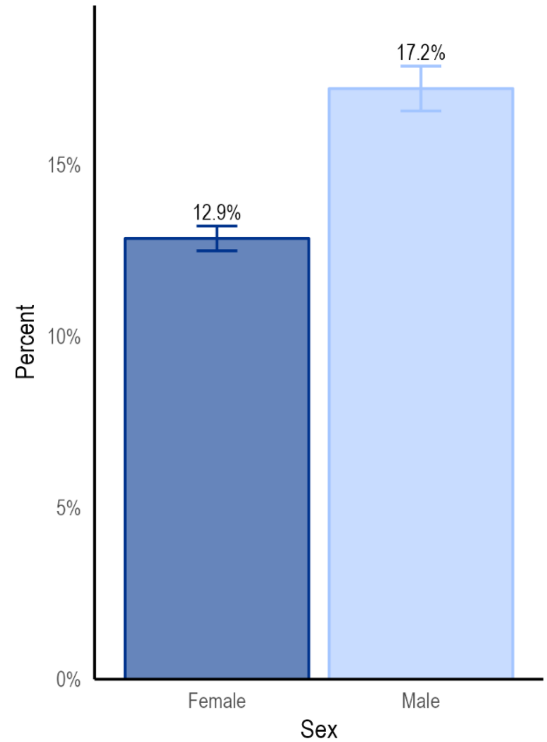

Figure 13-3: Percent of people aged 18 and older who report using illicit drugs in the past 30 days by sex

Source: National Survey on Drug Use and Health (NSDUH), 2021

Research suggests that sex and gender differences cause women to react to drugs differently than men and that women are more vulnerable to addiction.[19] For example, estrogen causes women to be more sensitive to stimulants while methylenedioxymethamphetamine (MDMA) creates greater hallucinations among women.[19,20] One in three women in the U.S. has been diagnosed with a SUD, and the majority of those with a SUD have a comorbid mental health condition which may impact help-seeking behaviors.[21] Nevertheless, research on SUDs has been disproportionately focused on men.[22] **Figure 13-4** shows the percent of women and men who received treatment for alcohol or drug use in the 12 months preceding the survey. Although data show that the overall percent is low for both men and women, a slightly higher percentage of men received treatment in comparison to women (2.0% and 1.2%, respectively).

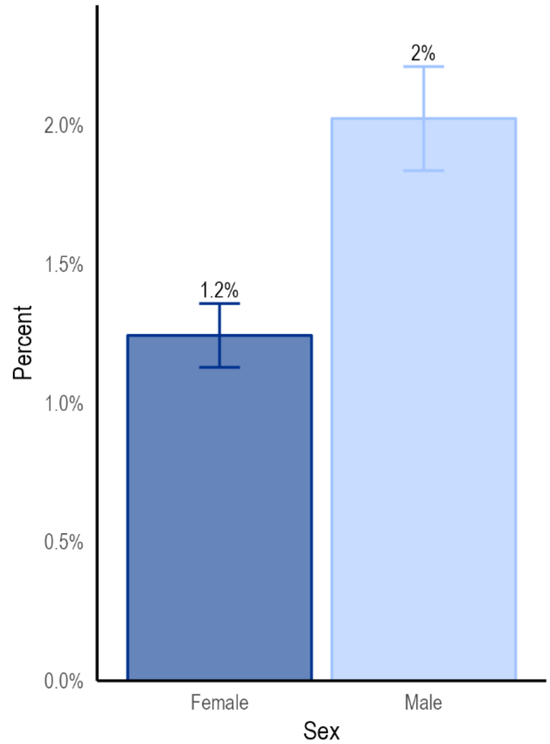

Figure 13-4: Percent of people aged 18 and older who report receiving drug or alcohol treatment in the past year by sex

Source: National Survey on Drug Use and Health (NSDUH), 2021

Sex differences such as body size, fat, water composition, metabolism, and renal function impact not only the effect of substances on an individual, but the effectiveness of substance use treatments, which may increase skepticism about treatment overall and prevent help-seeking.[19,23,24] Women also encounter gender-specific barriers to substance use treatment, such as stigma or judgement.[25] Factors such as caregiving and childcare are important gendered barriers to SUD treatment.[26] Pregnant women or women with children may also avoid seeking care for substance use out of fear of criminal punishment and losing custody of their children.[22,25,27] Providers' stigmatizing attitudes can lead to more frequent screening for substances in pregnant people suspected of using illicit substances.[28]

The relationship between traumatic experiences and SUD is bidirectional, where trauma can make someone more vulnerable to SUD and vice versa.[29–31] Those who have experienced trauma are more likely to respond to trauma-informed substance use treatment, but there are significant disparities in access, culturally competent providers, and quality of care for understudied, underrepresented, and underreported (U3) women (see **Chapter 1**).[29,32,33]

13.2.1 Substance Use and Misuse Among Youth

Figure 13-5 shows Youth Risk Behavior Survey (YRBS) data on the percent of students in grades 9-12 who report trying selected substances, by sex. The data indicate that a higher percentage of girls have tried vaping, cannabis (marijuana), and inhalants compared with boys. The data reveal a comparable prevalence of smoking and MDMA use, while boys report higher use of inhalants. Other illicit drugs, including cocaine, methamphetamines, injection drug use, and heroin, are slightly higher in boys compared with girls.

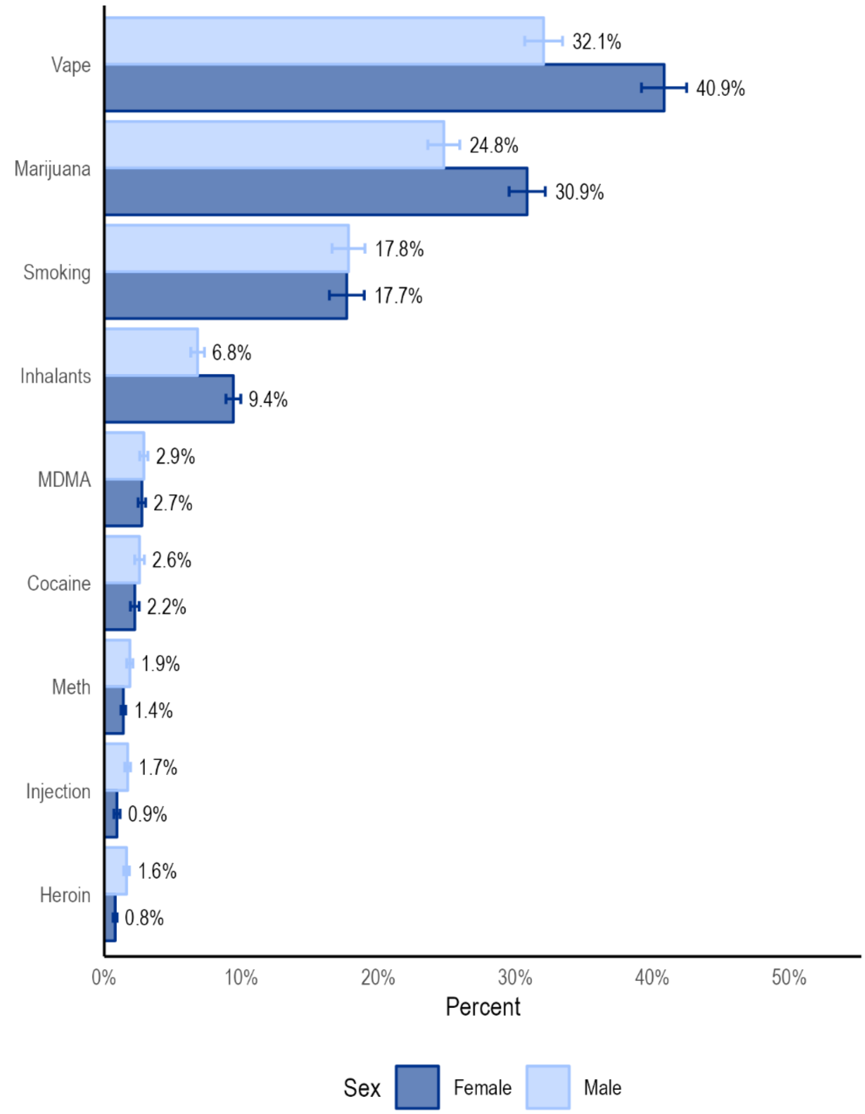

Figure 13-5: Percent of students in grades 9-12 who report trying selected substances by sex
Source: Youth Risk Behavior Survey (YRBS), 2021

Figure 13-6 examines the same substances analyzed in **Figure 13-5**, showing trends over time in the percent of female and male students who report trying those substances at any point in their lives. The data indicate an overall downward trend in the percent of students who have ever tried marijuana, smoking, inhalants, MDMA, cocaine, meth, injection drugs, and heroin. For these substances, the percent of male students who had tried each was higher in 2013 compared with the percentage among female students. However, the declines observed among boys were greater than those among girls. The pattern over time is distinct for vaping: initial estimates of 43.6% for girls and 46.1% for boys in 2015 rose sharply in 2019 to around 50% for both groups, followed by marked declines in 2021. Again, the decline among boys was greater than the decline observed among girls.

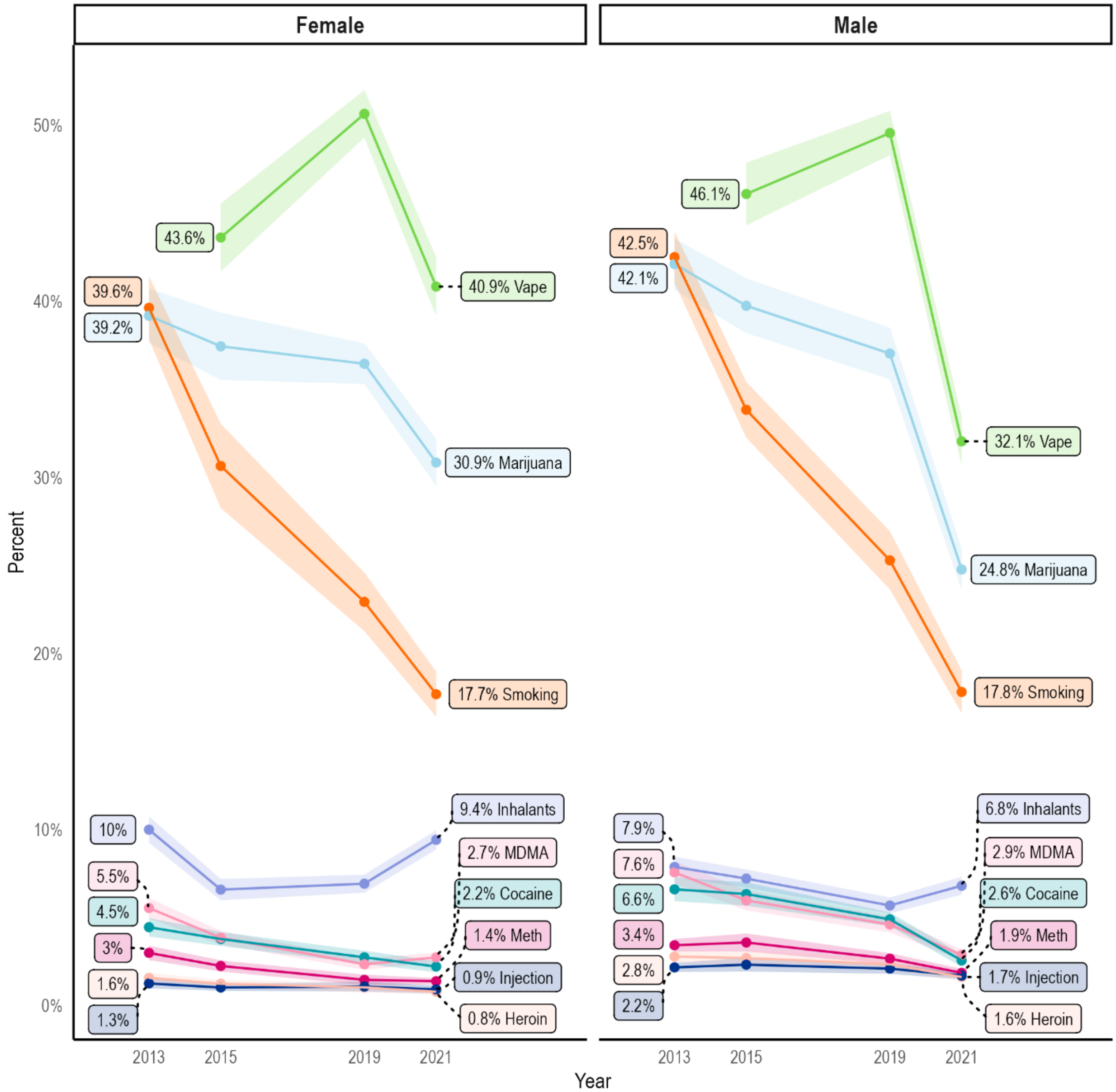

Figure 13-6: Percent of students in grades 9-12 who report trying selected substances over time by sex
Source: Youth Risk Behavior Survey (YRBS), 2013, 2015, 2019, 2021[ii]

The decline in smoking over time is consistent with earlier studies showing that tobacco use is declining in the U.S.[19,34] The noted increase in the percentage of girls who have ever tried vaping likely explains increases seen over time in attempts to quit. **Figure 13-7** shows changes over time in the percent of female and male students in grades 9-12 who tried to quit tobacco use (cigarettes, electronic vapor products, smokeless tobacco, cigars, shisha or hookah tobacco, or pipe tobacco) in the 12 months prior to the survey. The data show a higher percent of girls tried to quit each year of the survey, with the narrowest gap between the girls and boys observed in 2019. From 2019 to 2021 the percent of teens

[ii] YRBS data from 2017 are not included in the analysis because survey responses were not linked with demographic data at the time of analysis.

who tried to quit tobacco use increased for both girls and boys, resulting in an overall upward trend in the percent of teens who report trying to quit.

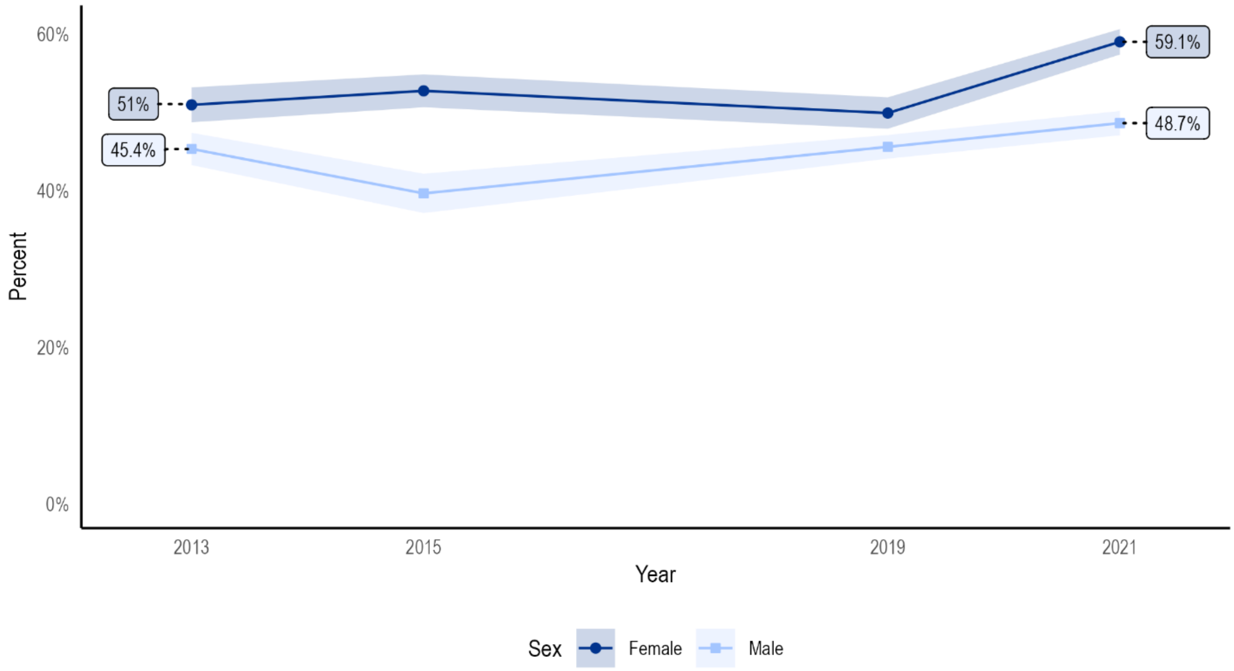

Figure 13-7: Percent of students in grades 9-12 who report trying to quit tobacco use during the 12 months before the survey by sex over time

Source: Youth Risk Behavior Survey (YRBS), 2013, 2015, 2019, 2021[iii]

YRBS data also allow for assessment of age at first use of alcohol over time. **Figure 13-8** shows the percent of male and female students over time who had their first drink of alcohol before age 13. The data reveal different patterns by sex: the percent of boys who tried alcohol before age 13 decreased by nearly 30% between 2013 and 2021, while the percent of girls decreased by only 10% and appears to be rising again. This is especially consequential for the health of women: research indicates that among binge drinkers, female adolescents have worse neurological consequences than male adolescents.[35,36]

[iii] YRBS data from 2017 are not included in the analysis because survey responses were not linked with demographic data at the time of analysis.

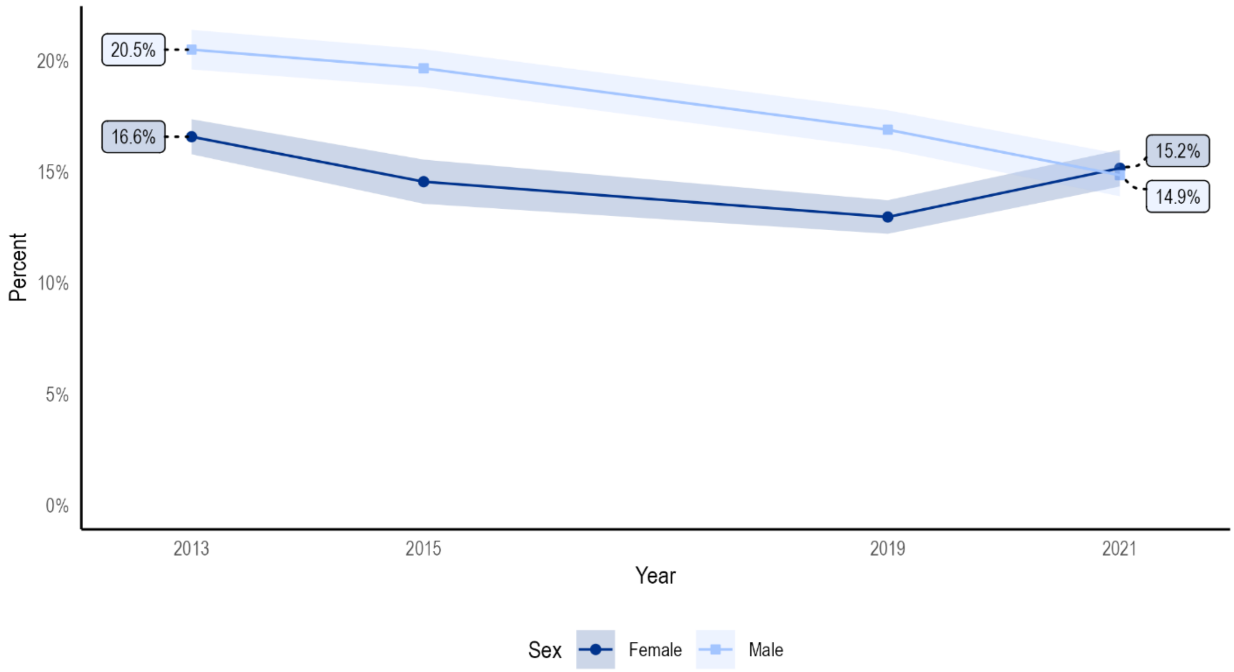

Figure 13-8: Percent of students in grades 9-12 who report first trying alcohol before age 13 years over time by sex

Source: Youth Risk Behavior Survey (YRBS), 2013, 2015, 2019, 2021[iv]

Research indicates that in comparison to women, men have historically consumed more alcohol and have more frequent incidents of alcohol-related injury. However, alcohol use among women has continued to increase over time, resulting in a greater number of hospitalizations and deaths related to alcohol use.[18] Additionally, studies indicate that women may develop complications from alcohol use in a shorter amount of time and with lower consumption than when compared with men.[17,37] Sex and gender differences put women at a higher risk for developing problems related to alcohol consumption. For example, if a man and a woman were to drink the same amount of alcohol, the amount of water in women's bodies, in combination with their smaller average size and sex differences in body composition, result in a higher blood alcohol concentration than men.[38] This higher level of intoxication explains data showing that women experience more alcohol-induced blackouts and hangovers compared with men.[17,22] Additional studies show that women are more susceptible to experiencing long-term health consequences due to alcohol misuse, including liver problems (i.e., cancer and inflammation), cardiovascular disease (CVD), and breast cancer (see **Chapter 6**).[17,39–41]

13.2.2 Substance Use and Misuse During Pregnancy

Estimating the prevalence of substance use and misuse during pregnancy is challenging, as fear of stigma and legal repercussions limits self-reports of legal and illegal substance use during pregnancy.[42] Fear of stigma and criminal punishment also acts as a barrier to seeking treatment for substance misuse, and can prevent pregnant people from seeking prenatal care, especially in states with strict child abuse and mandated reporting policies.[43,44] Available NSDUH data show that nearly 10% of pregnant people report current drinking and 1 in 20 report current binge drinking.[45] The prevalence of drinking and binge drinking is higher during the first trimester. Among those pregnant people who report current drinking,

[iv] YRBS data from 2017 are not included in the analysis because survey responses were not linked with demographic data at the time of analysis.

more than a third also report current use of other substances, such as tobacco (28%) and marijuana (21%).[45] Other estimates using NSDUH data found that among women reporting nonmedical opioid use, nearly 90% also used other substances.[46] The prevalence of polysubstance use (in this case nonmedical use of opioids in addition to another legal or illegal substance) was similar among the subgroup of pregnant women as among the full sample, with binge drinking reported by more than half of pregnant women reporting opioid use.[46]

SUDs that go untreated can bring serious health consequences for both the pregnant person and fetus. Nearly a quarter of pregnancy-related deaths between 2017 and 2019 were caused by mental health conditions including substance use.[47] Analysis of National Vital Statistics System (NVSS) data reveals that in 2020 more than 1,200 women died of drug overdose while pregnant or during the postpartum period.[48] The same study found that drug overdose mortality increased dramatically between 2017 and 2020, increasing by more than 80% among pregnant and postpartum people.[48] This trend is similar to that observed among the general population during the same period and is linked to both the emergence of fentanyl and the impact of the COVID-19 pandemic. A cross-sectional study of more than 17,000 deaths between 2018 and 2021 found a sharp rise in drug overdose mortality ratios among pregnant and postpartum women, noting that the ratios tripled among women aged 35-44.[49–51] The findings from this growing body of research underscore the urgency of providing care that prioritizes treatment over criminalization.[43,49]

13.3 Substance Use and Misuse in Populations of U3 Women

Substance use is inextricably linked to social drivers of health, which is reflected in the highest substance use rates among populations who are living in certain geographic areas, economically disadvantaged, or sexual minorities (people who identify as lesbian, gay, or bisexual).[52] Those who experience violence are at greater risk of developing chronic mental health conditions, such as depression, which often result in SUDs.[30] The sections that follow provide data on substance use and misuse among U3 women, including incidence and mortality rates over time.

13.3.1 Substance Use and Misuse Among Women of Underrepresented Racial and Ethnic Communities

The percent of women who report at least one episode of binge drinking in the past 30 days varies by race and ethnicity, as shown in **Figure 13-9**. The percentage was highest among Multiracial women (32.8%), while American Indian and Alaska Native (AI/AN), Black, Hispanic, Native Hawaiian and Pacific Islander (NHPI), and White women had similar percentages (between 21% and 23%). The percentage of Asian women reporting binge drinking was less than half that of any other group (9.8%). AI/AN, Black, and Hispanic women experience multiple structural barriers that may lead to an increased risk of alcohol use disorder. These include lower educational attainment, economic disadvantage, unstable housing, gender-based violence, historical trauma, mental disorders, and inadequate access to care.[4,53]

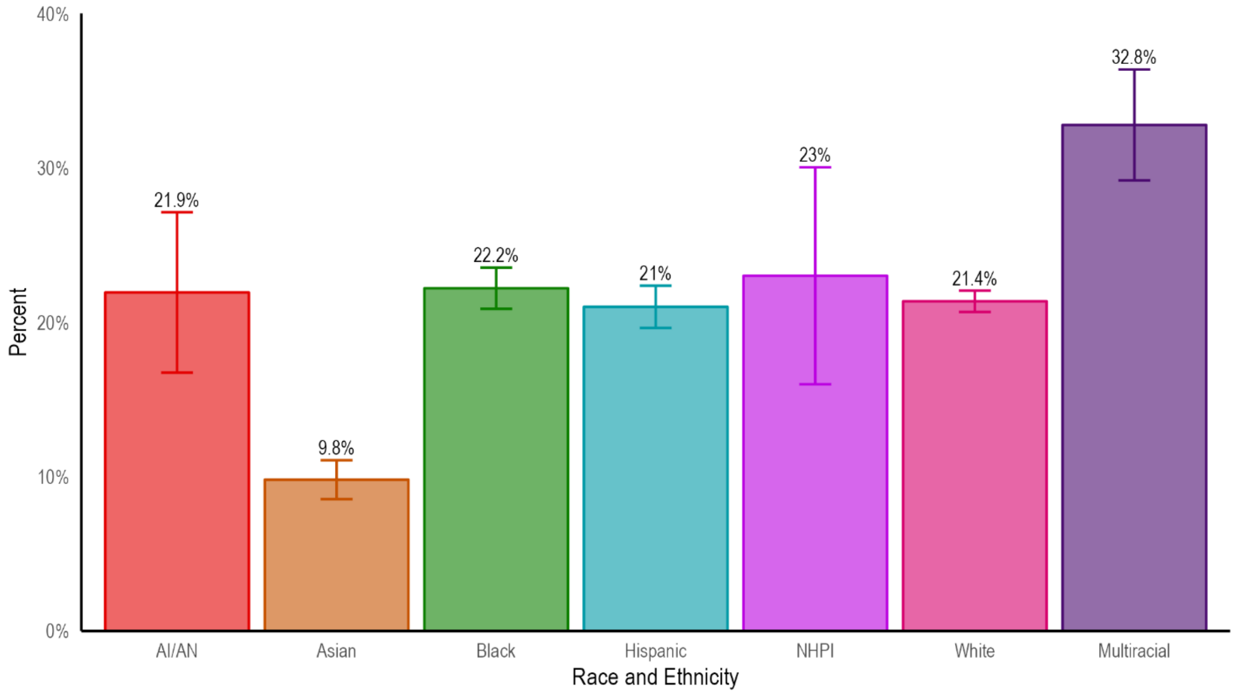

Figure 13-9: Percent of women aged 18 and older who report binge drinking in the past 30 days, by race and ethnicity

Source: National Survey on Drug Use and Health (NSDUH), 2021

Figure 13-10 shows the percent of women who report using selected substances at least once in the year prior to the survey, by race and ethnicity. The data reveal that tobacco and marijuana were the most common substances used by women overall and that differences by race are evident. AI/AN women had the highest percentage of tobacco use (35.8%), followed by Multiracial women (28.8%), White women (22.8%), and Black women (21.4%). There has been a recent increase in smoking prevalence among AI/AN women for the first time in almost two decades.[34] Researchers speculate that the high substance use disparities may be explained in part by an increase in gender-based violence.[53–56] Other research points to the tobacco industry's appropriation of AI/AN culture and appeal to Native traditions and values as a cause for this increase.[57]

Marijuana use was highest among Multiracial women (33%) and AI/AN women (27.1%), followed by White women (18.5%) and Black women (18.2%). Opioid and pain reliever misuse were over twice as high among NHPI women compared to all other racial and ethnic groups. The use of other substances was reported to be less common (less than 6%) across all racial and ethnic groups. Extant studies show that populations that experience greater rates of violence, including Black women, AI/AN women, and sexual minority women, tend to have higher rates of substance misuse.[58,59] These data echo other research examining substance use disparities among NHPI women, which shows high correlations between substance use, family adversity, depression, and historical trauma, resulting in female Hawaiian youth being at greater risk for drug-related adverse outcomes.[60,61]

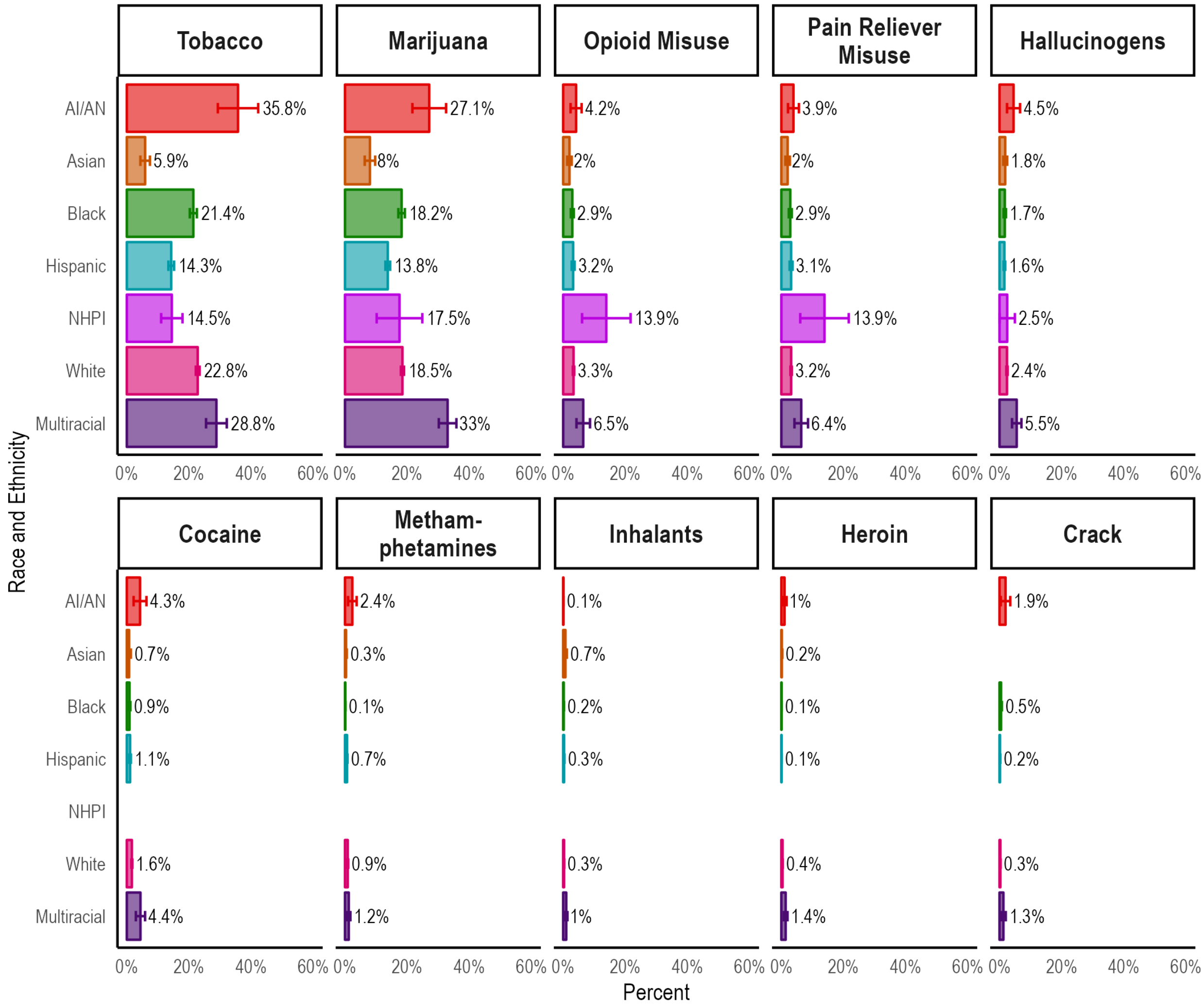

Figure 13-10: Percent of women aged 18 and older who report using selected substances in the past year, by race and ethnicity

Source: National Survey on Drug Use and Health (NSDUH), 2021

Figure 13-11 shows the percent of women who report illicit drug use at least once in the year prior to the survey, by race and ethnicity. The highest percentage observed was among Multiracial, NHPI, and AI/AN women. Asian women had the lowest percentage of substance use (10.9%) followed by Hispanic women (17.1%). Percentages were similar among Black and White women (20.7% and 21.7%, respectively).

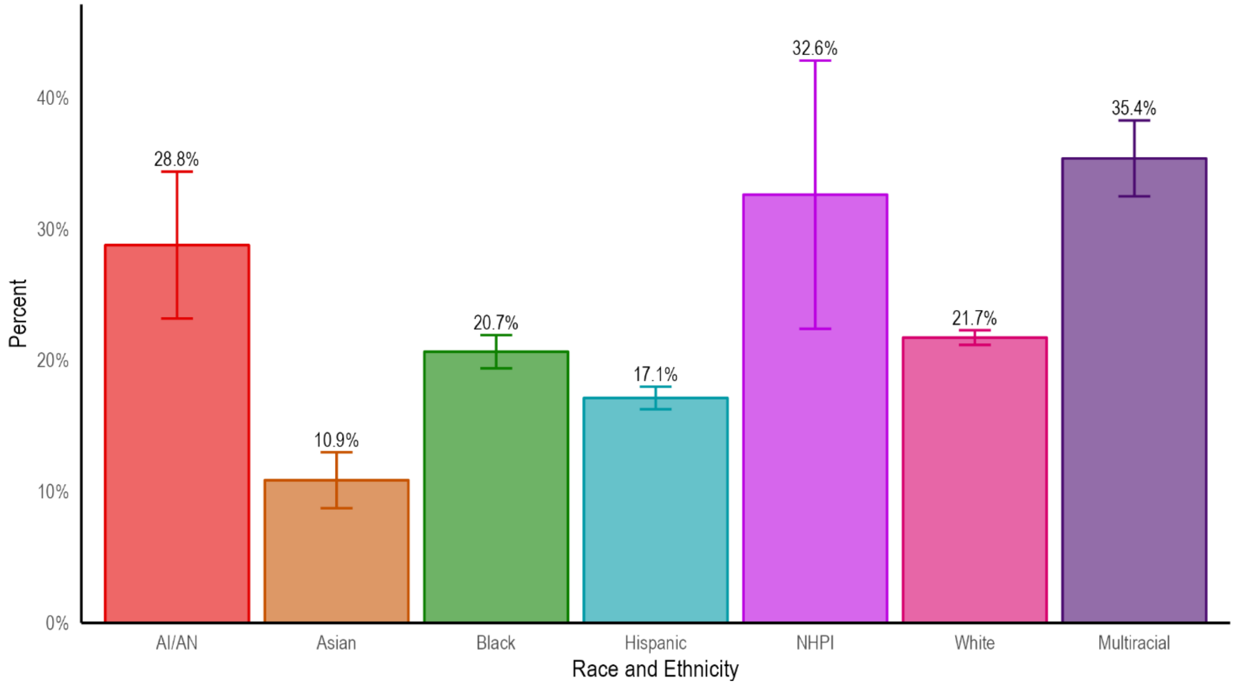

Figure 13-11: Percent of women aged 18 and older who report illicit drug use in the past year, by race and ethnicity

Source: National Survey on Drug Use and Health (NSDUH), 2021

Figure 13-12 shows the percent of women who report receiving treatment for drug or alcohol misuse the past year, by race and ethnicity. The data indicate that treatment levels were below 5% across all groups. Asian, Black, and Hispanic women had the lowest percentage of treatment for drugs or alcohol. The highest percentages were observed among AI/AN, NHPI, and Multiracial women, though these estimates have relatively large standard errors which limit definitive conclusions.

Multiple factors influence the percentage of women of underrepresented racial and ethnic communities who receive treatment for substance use and misuse. Stigma and the fear of discrimination or prejudice and systemic racism impact help-seeking for SUDs.[62–64] Black and Hispanic women report higher post-treatment drug use compared with White women, underscoring the importance of tailoring services for U3 women to their unique needs.[65] For some U3 women, transportation, childcare, and shifting social support and other factors can be barriers to recovery.[65] Black women, for example, are more likely to endure structural barriers to seeking substance use treatment, such as lack of health insurance, inability to afford healthcare, or lack of knowledge about treatment options.[25] Other research shows that Hispanic and Black adolescents are less likely to receive health education on the harm of vaping.[66]

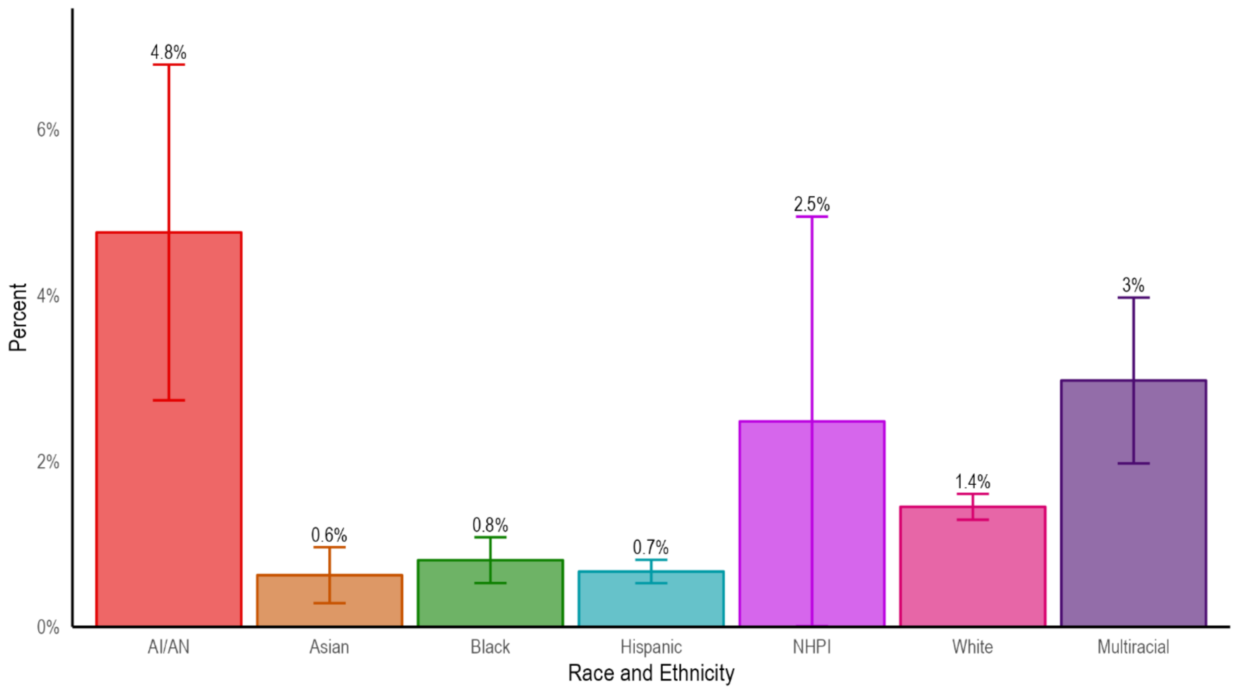

Figure 13-12: Percent of women aged 18 and older who report receiving treatment for drugs or alcohol in the past year, by race and ethnicity

Source: National Survey on Drug Use and Health (NSDUH), 2021

Lack of treatment for SUDs can have dire consequences, which may disproportionately impact U3 women. **Figure 13-13** shows NVSS data on mortality rates over time from alcohol poisoning among women, by race and ethnicity. The data depicts a disparity in alcohol overdose mortality among AI/AN women, who consistently had the highest rate of alcohol overdose mortality (at least five times that of rates observed for women of other race and ethnic groups). Additionally, mortality rates fluctuated over time observed for AI/AN women, while rates remained stable among women of all other racial and ethnic groups.

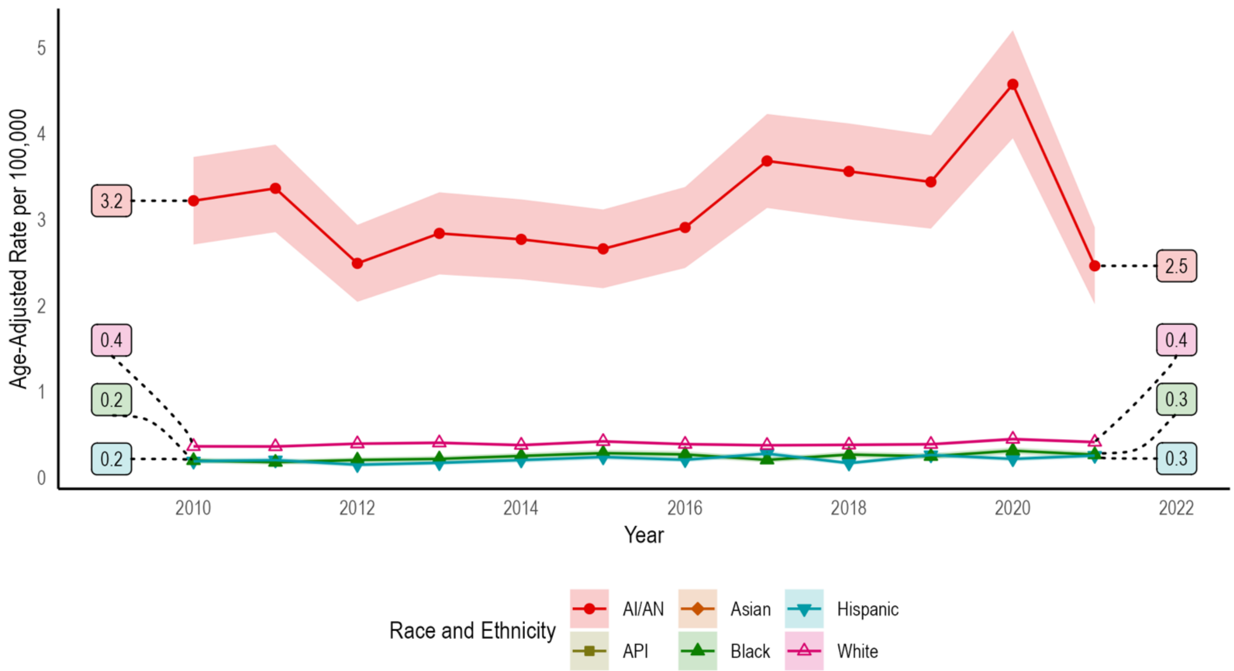

Figure 13-13: Age-adjusted alcohol poisoning (overdose) mortality rates per 100,000 women, by race and ethnicity over time

Source: National Vital Statistics System (NVSS), 2010-2021

Figure 13-14 shows drug overdose mortality rates over time among women by race and ethnicity. The data reveal an overall pattern of increased mortality across all racial and ethnic groups, with a sharp increase between 2019 and 2021 for AI/AN, White, and Black women. AI/AN women consistently have the highest drug overdose mortality rate, which nearly quadrupled over the past decade, increasing from 10.4 deaths per 100,000 AI/AN women in 2010 to 40.7 deaths per 100,000 AI/AN women in 2021. Over the same decade, drug overdose mortality rates increased by five-fold among Black women, increasing from 4.9 deaths per 100,000 Black women in 2010 to 21.6 deaths per 100,000 Black women in 2021. Similar increases in mortality were observed among other groups, including a doubling among White women, though with other groups at relatively lower mortality rates starting in 2010. Dotted lines indicate disaggregation of the API population into Asian and NHPI groups, which occurred between 2017 and 2018. Data for Multiracial women were made available starting in 2018.

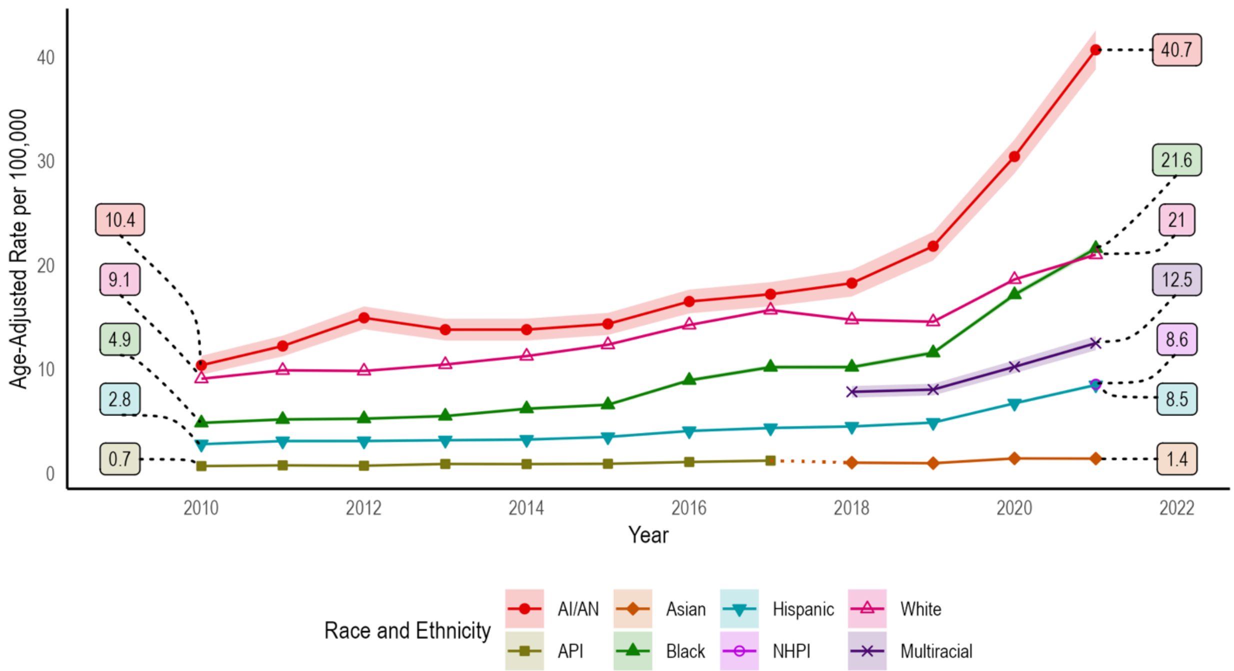

Figure 13-14: Age-adjusted drug overdose mortality rates for women over time, by race and ethnicity
Source: National Vital Statistics System (NVSS), 2010-2021

The increase in drug overdose mortality among women of underrepresented racial and ethnic communities between 2019 and 2021 may be related to the COVID-19 pandemic. Mitigation measures to prevent the spread of disease exacerbated social isolation and mental health challenges, as well as prevented potential opportunities for in-person intervention and substance use treatment.[67] Additionally, delays in seeking diagnosis of and medical care for SUD due to COVID-19 may have negatively impacted individuals and contributed to the increase in drug overdose mortality during this period.[67] Another contributor to the increase in drug overdose deaths is the emergence of fentanyl in the illicit drug supply, which accounts for most overdose deaths in 2022.[50,51] Disparities in drug overdose among the AI/AN population may be fueled by systemic factors such as unequal access to substance use treatment and treatment biases, experiences of isolation by individuals living on reservations, inter-generational trauma, and oppression within Native communities.[68] Additionally, there is a history of disproportionately high rates of incarceration of AI/AN people related to substance use.[69,70]

13.3.2 Other Intersectional Considerations Relevant to U3 Women

13.3.2.1 Rurality

Both NSDUH and NVSS allow for comparisons of some key substance use variables by rurality, which is a fundamental determinant of access to healthcare and health outcomes (see **Chapter 1**). NSDUH data reveal a wide range of binge drinking levels across race and ethnicity and rurality as shown in **Figure 13-15**. The highest percentage of binge drinking was observed among NHPI women living in rural areas (39.1%), followed by Multiracial women in not living in rural areas (35.4%). It is notable that the standard error is relatively large for rural NHPI women due the small sample size for this group. The lowest observed percentage was among Asian women living in rural areas (0.2%), followed by Asian women not living in rural areas (9.9%).

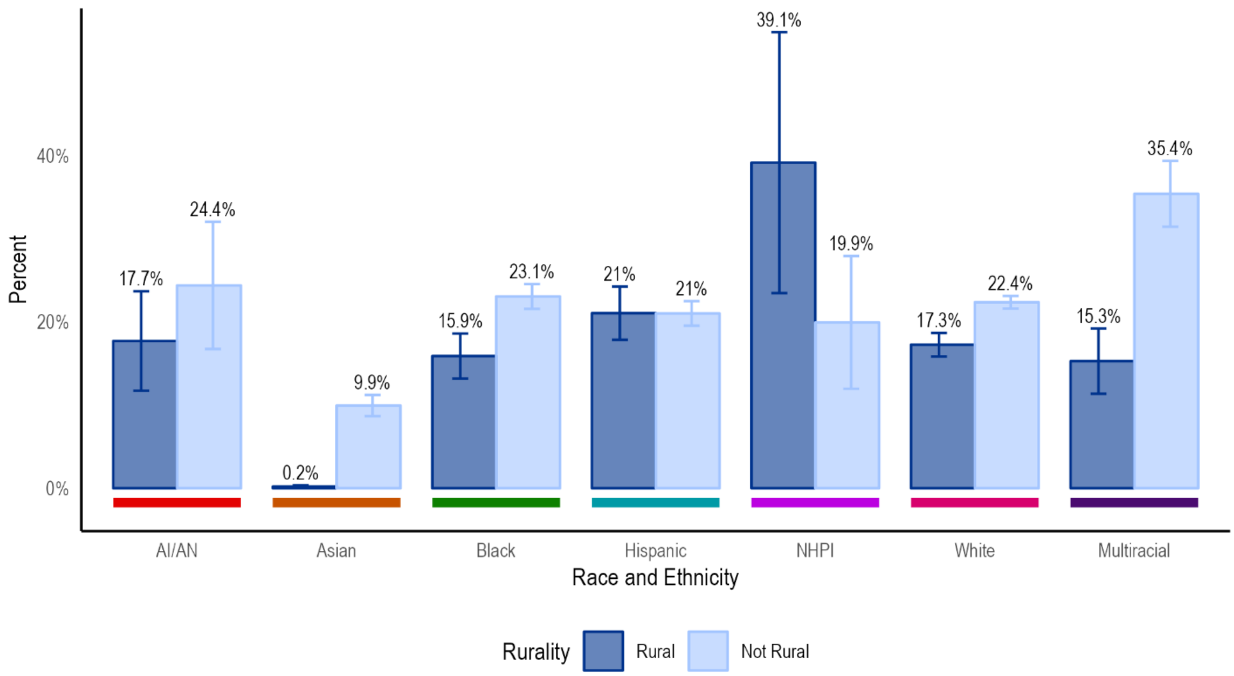

Figure 13-15: Percent of women aged 18 and older who report binge drinking in the past 30 days, by race and ethnicity, and rurality

Source: National Survey on Drug Use and Health (NSDUH), 2021

Figure 13-16 shows the percent of women who used tobacco in the past year by race and ethnicity and rurality. Overall, tobacco use is higher among women living in rural areas compared with women not living in rural areas. This difference is most prominent for Asian, NHPI, White and Multiracial women. For Black and Hispanic women, the difference is less pronounced. The pattern reflects findings in other research that smoking is higher in rural areas and particularly in "Tobacco Nation," i.e., locations where tobacco is grown and communities have more accepting cultural norms around tobacco use.[71,72]

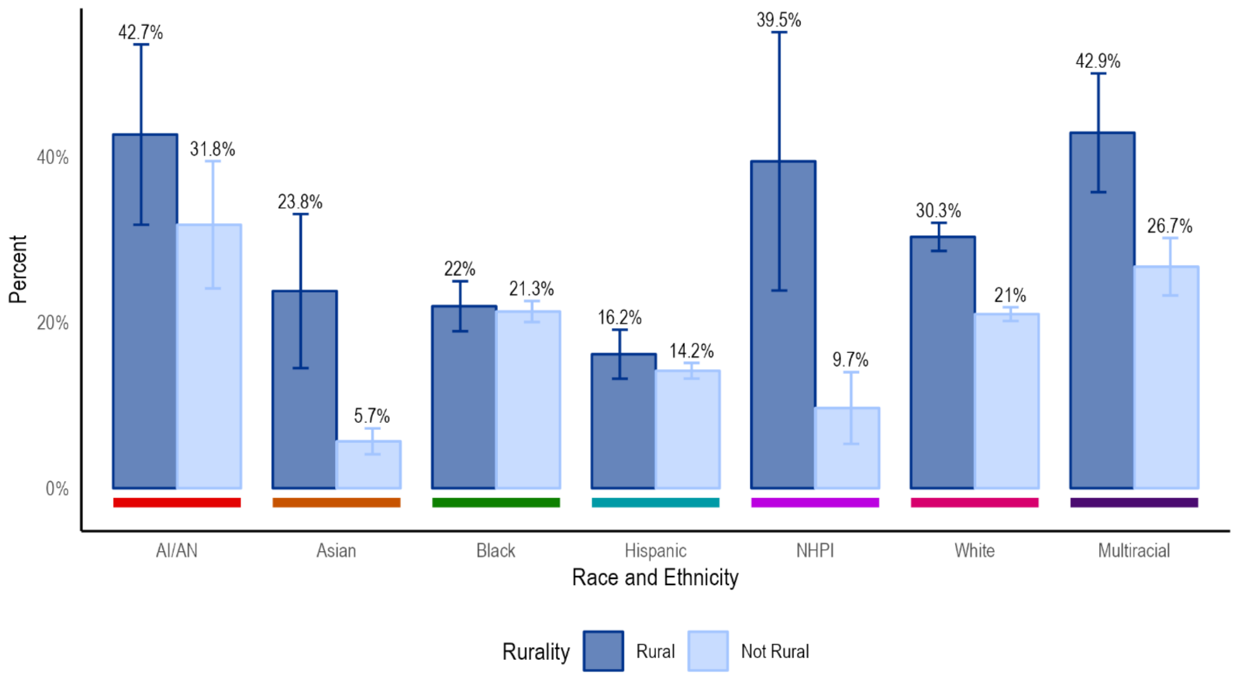

Figure 13-16: Percent of women aged 18 and older who report tobacco use in the past year, by race and ethnicity, and rurality

Source: National Survey on Drug Use and Health (NSDUH), 2021

Figure 13-17 shows alcohol poisoning mortality rates among women by race and ethnicity and rurality for 2010-2021. While rates of alcohol poisoning were less than one death per 100,000 women for most groups across rurality, AI/AN women had rates at least three times higher than other groups. AI/AN women living in rural areas had an alcohol overdose death rate 1.5 times higher than that of their counterparts not living in rural areas. This disparity may in part be due to AI/AN women's experiences of poverty, geographic remoteness, and a lack of culturally competent care with qualified providers. However, more research is needed in this area.[69,73]

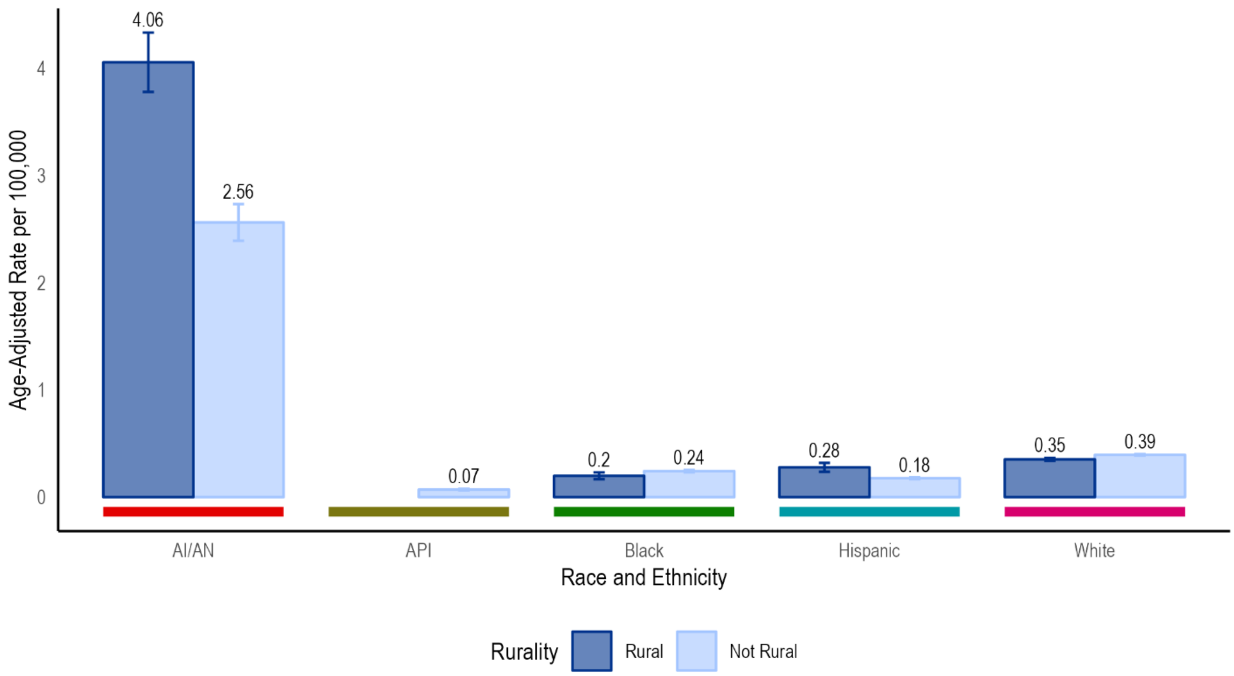

Figure 13-17: Age-adjusted alcohol poisoning (overdose) mortality rates per 100,000 women, by rurality and race and ethnicity

Source: National Vital Statistics System (NVSS), Pooled 2010-2021

NVSS data reveal that women die at higher rates from drug overdose compared to alcohol poisoning. **Figure 13-18** shows drug overdose mortality rates among women by race and ethnicity and rurality. The figure shows that Black women not living in rural areas had overdose mortality rates nearly two times higher than those living in rural areas. For women of other racial and ethnic groups, the pattern is less clear. Hispanic, AI/AN, and API women living in rural areas had mortality rates slightly higher than those not living in rural areas. White women not living in rural areas had similar mortality rates compared with those living in rural areas.

Earlier research shows that women living in rural counties experience higher drug overdose deaths than women not living in rural counties.[74] One potential explanation for this disparity is the lack of access to quality healthcare, drug prevention, and early intervention services due to fewer health facilities, facilities with limited services, and living further from care facilities.[75,76] Additionally, research shows that emergency services can respond more quickly to women living in urban settings than women in rural areas. A longer response time can be detrimental in an overdose emergency where timeliness is critical to avoid death.[77] Additionally, opioid treatment programs are an important factor in treating opioid misuse through dispensing medications such as methadone, buprenorphine, and naltrexone.[78] While there is a national shortage of such programs, the most prominent gap is within rural areas where over 88% of large rural counties lack a sufficient number of opioid treatment programs for the current demand.[78]

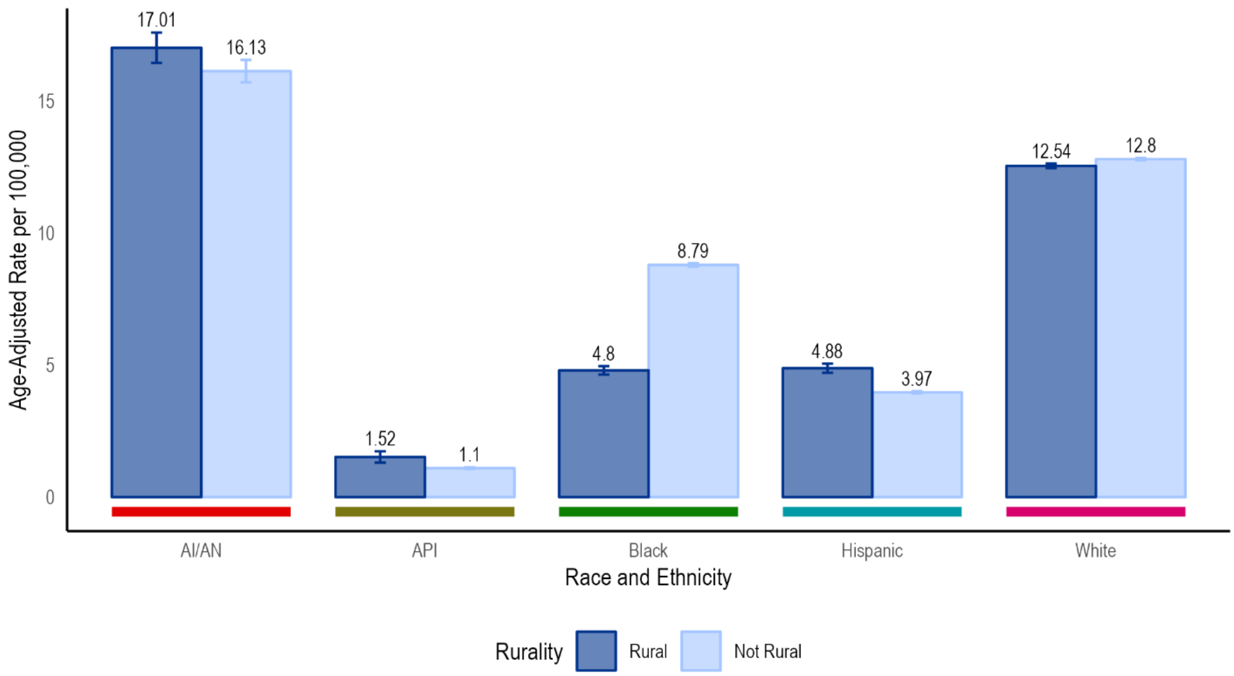

Figure 13-18: Age-adjusted drug overdose mortality rates per 100,000 women, by race and ethnicity, and rurality

Source: National Vital Statistics System (NVSS), Pooled 2010-2021

13.3.2.2 Economic Status

Economic disadvantage (i.e., living below the federal poverty line, as described in **Chapter 3**) is associated with increased risk of substance use and misuse.[4,53] However, the pattern is less consistent when looking at binge drinking by race and ethnicity and economic status (**Figure 13-19**). The highest reported percentages of binge drinking in the past 30 days were among economically advantaged AI/AN (37.9%), NHPI (34.5%), and Multiracial women (35.8%). For AI/AN women, this was more than double their economically disadvantaged counterparts (15.6%), while the gap observed for economically disadvantaged NHPI (16.2%) and Multiracial women (28.8%) was smaller still. There was no apparent effect of economic status on Asian, Black, Hispanic, or White women.

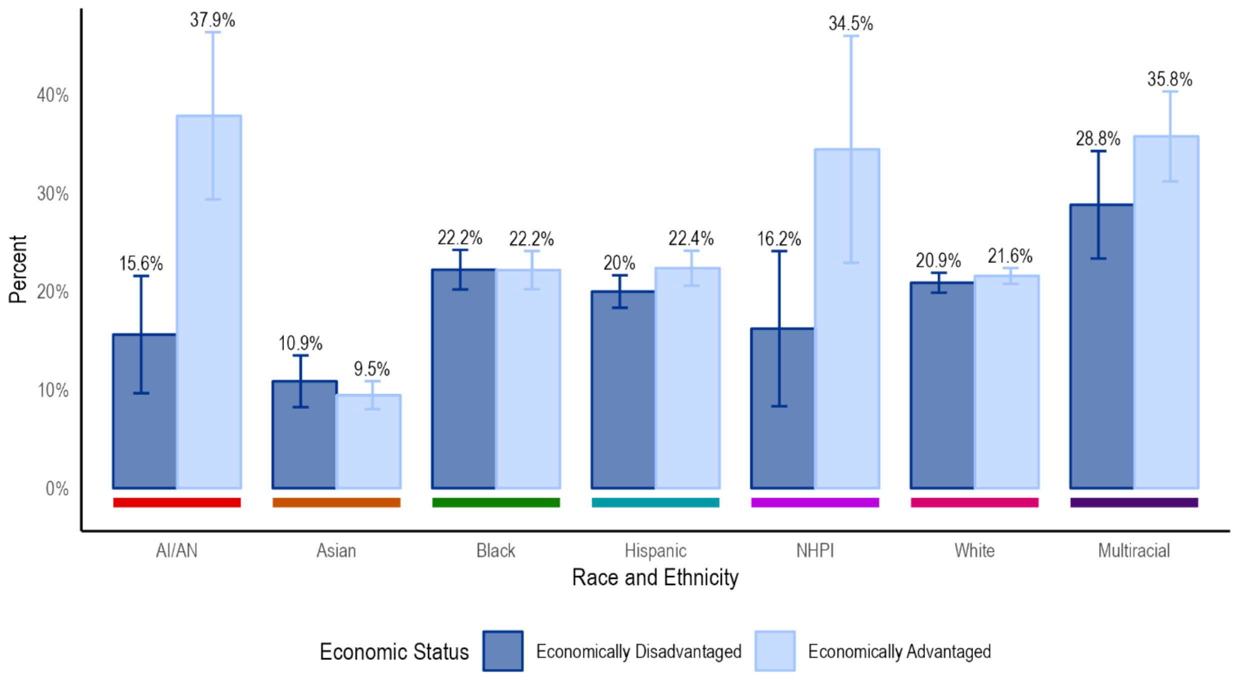

Figure 13-19: Percent of women aged 18 and older who report binge drinking in the past 30 days, by race and ethnicity, and economic status

Source: National Survey on Drug Use and Health (NSDUH), 2021

Figure 13-20 shows the percent of women who used tobacco in the year prior to the survey, by race and ethnicity and economic status. The data do not provide a clear pattern for the role of economic status on tobacco use across race and ethnicity. For example, a higher percentage of Black, White, and Multiracial women who are economically disadvantaged used tobacco compared with women who are economically advantaged. The same relationship is observed for Asian women. Among AI/AN and NHPI women, tobacco use appears to be higher among women who were economically advantaged, but the standard error intervals overlap. There is no observed difference between economically advantaged and disadvantaged Asian women.

The broader literature suggests that tobacco use is higher among people living in economically disadvantaged communities, in part because tobacco companies have historically and disproportionately targeted lower-income neighborhoods through marketing and greater retail density.[34,79] For example, in the past tobacco companies provided free cigarettes to children in communal settings and gave coupons for cigarettes with food stamps to reach low-income women.[80] Other research shows that tobacco retailers are more likely to be located near schools in low-income communities and those non-rural communities in which higher proportions of the population are Hispanic or Black.[81,82] Further, evidence suggests that stress is a more significant factor in women's tobacco use than men's, and that this association is more pronounced among economically disadvantaged groups.[83,84] Women living in economically disadvantaged areas may face more forms of stress such as poverty, discrimination, and unsafe neighborhoods, thereby increasing their likelihood of using tobacco.[85–87]

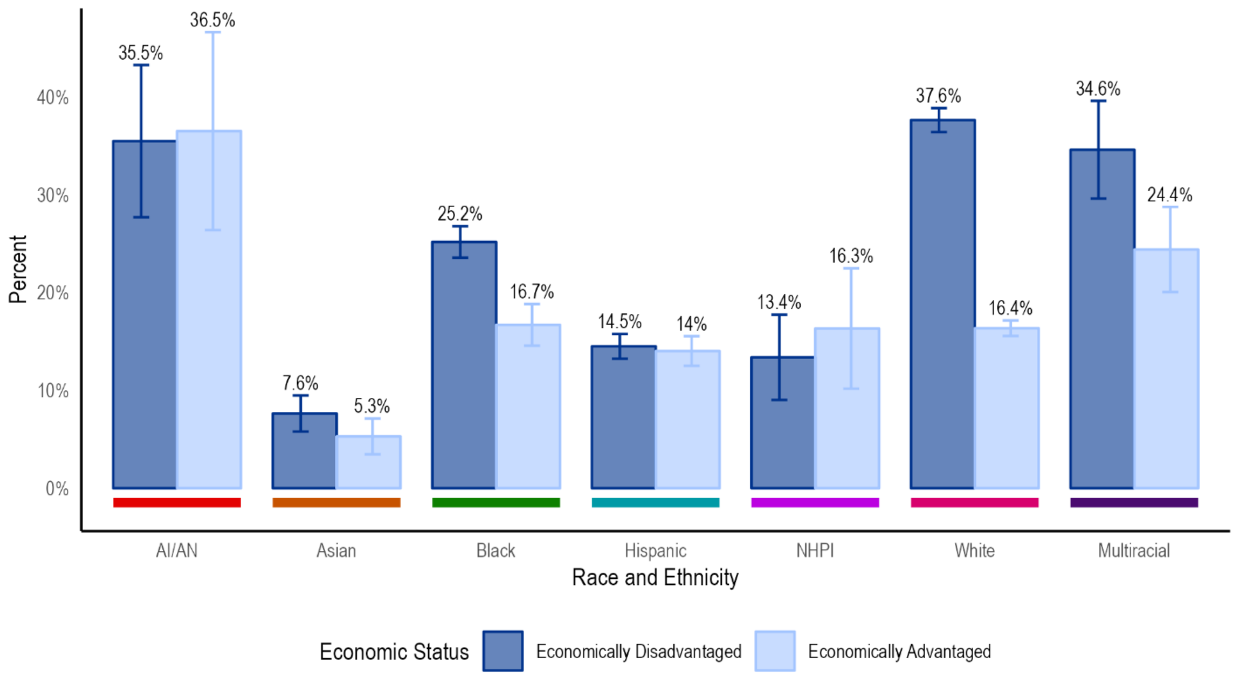

Figure 13-20: Percent of women aged 18 and older who report tobacco use in the past year, by race and ethnicity, and economic status

Source: National Survey on Drug Use and Health (NSDUH), 2021

13.3.2.3 Sexual Orientation and Gender Identity

Research shows that being a member of a sexual minority group (i.e., not heterosexual) is associated with higher rates of substance use compared with heterosexual people.[58] NSDUH data from 2021 align with this association across most racial and ethnic groups (**Figure 13-21**). The data show that women who identify as lesbian, bisexual, queer or questioning (LBQ) had higher levels of binge drinking in the past 30 days compared to heterosexual women in the same racial or ethnic group. For Multiracial women, the percentage is higher for LBQ women but the standard error interval is wide due to small sample size, limiting definitive conclusions regarding the difference between heterosexual and LBQ Multiracial women.

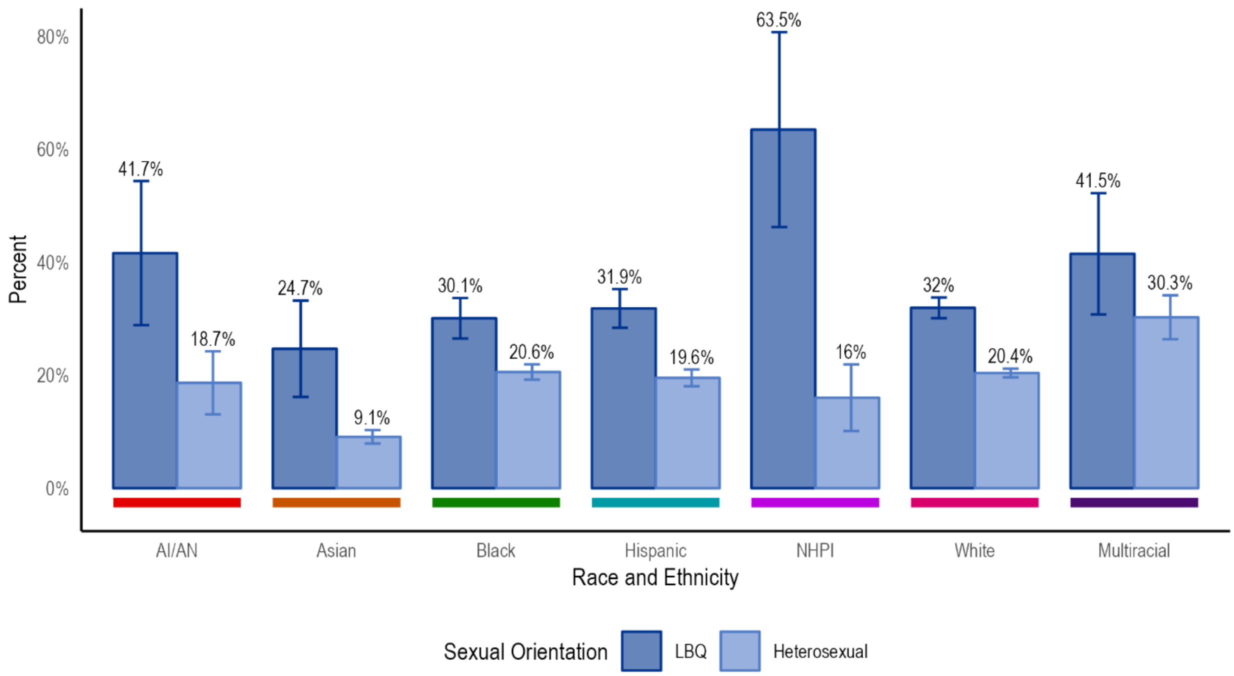

Figure 13-21: Percent of women aged 18 and older who report binge drinking in the past 30 days, by race and ethnicity, and sexual orientation

Source: National Survey on Drug Use and Health (NSDUH), 2021

Figure 13-22 shows the percentage of women who used illicit drugs in the past year by race and ethnicity and sexual orientation. The data reveal a pattern consistent with other literature: women who identify as LBQ have higher levels of illicit drug use compared with heterosexual women across all racial and ethnic groups.[88] The highest observed percentages were among NHPI LBQ (72%) women and AI/AN LBQ women (68.6%).

Disparities in illicit drug use among LBQ women may be due to the disproportionate stress, depression, anxiety, and other mental health conditions that this population faces (see **Chapter 12**)[89,90] as these factors are considered to be comorbidities with substance use. Additionally, the literature suggests that bisexual women tend to have the highest rates of overall substance use compared with lesbian and heterosexual women.[91,92] Research has shown that sexual minority individuals have lower rates of alcohol use in states with laws and policies that protect their human rights, implying psychological safety is a protective factor against substance misuse.[93]

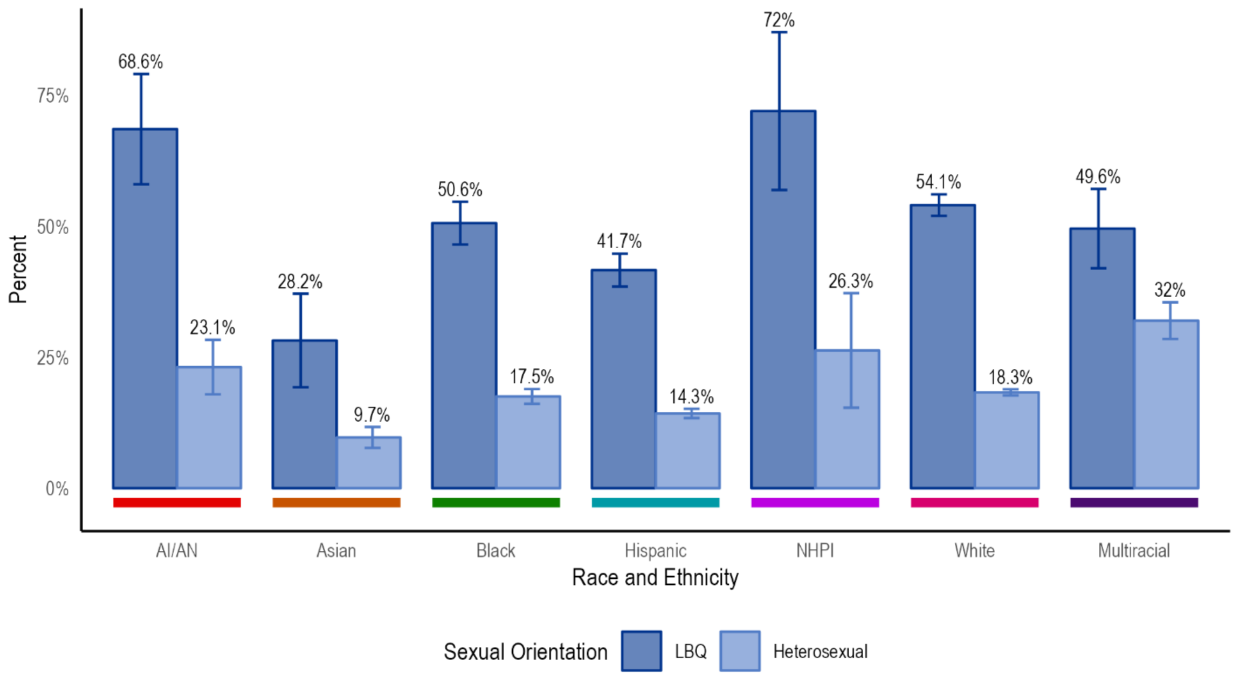

Figure 13-22: Percent of women aged 18 and older who report illicit drug use in the past year, by race and ethnicity, and sexual orientation

Source: National Survey on Drug Use and Health (NSDUH), 2021

13.4 Conclusions and Future Directions

This chapter explores the social drivers of substance use and misuse that perpetuate disparities among U3 women. Substance use and misuse is rife with stigma, and much of the research on substance use focuses on the epidemiological details rather than on causation, prevention, or root causes. It is critical that primary health systems address this stigma and increase resources and access to substance treatment. Treatment options should consider specific factors affecting women, such as influence of family, history of trauma and violence, and co-occurring disorders. More research is needed to examine the pathways to addiction and the factors that perpetuate or encourage substance use as well as the disparities that exist among different populations of women.

13.5 Data Definitions and Sources

Data for all figures in this chapter can be accessed from the data annex located here: https://orwh.od.nih.gov/sites/orwh/files/docs/Chapter_13.xlsx

National Survey on Drug Use and Health (NSDUH), 2021

Variable Name	Variable Description	Variable Options
ALCYR	Alcohol – past year use	Did not use in the past year; **Used within the past year**
BNGDRKMON	Defined as drinking five or more drinks on the same occasion for males or four or more drinks on the same occasion for females on at least one day in the past 30 days. For this variable, "occasion" means at the same time or within a couple hours of each other.	Never/No "Binge" alcohol use; **"Binge" alcohol use**
COCYR	Cocaine – past year use	Did not use in the past year; **Used within the past year**
HALLUCYR	Hallucinogens – past year use	Did not use in the past year; **Used within the past year**
HERYR	Heroin – past year use	Did not use in the past year; **Used within the past year**
ILLMON	Any illicit drug – past month use	Did not use in past month; **Used in past month**
ILLYR	Any illicit drug – past year use	Did not use in the past year; **Used in the past year**
INHALYR	Inhalants – past year use	Did not use in the past year; **Used within the past year**
METHAMYR	Methamphetamine – past year use	Did not use in the past year; **Used within the past year**
MRJYR	Marijuana – past year use	Did not use in the past year; **Used within the past year**
OPINMYR	Opioids – past year misuse	Did not misuse in the past year; **Misused within the past year**
PNRNMYR	Pain relievers – past year misuse	Did not misuse in the past year; **Misused within the past year**
TOBYR	Any tobacco – past year use	Did not use in the past year; **Used within the past year**
TXYRRECVD2	Received treatment at any location for illicit drug or alcohol use – past year	No/Unknown; **Yes**

Youth Risk Behavior Survey (YRBS), 2013, 2015, 2019, 2021 [v]

Variable Name	Variable Description	Variable Options
QN31, QN31, QN30, QN30	Have you ever tried cigarette smoking, even one or two puffs?	% who used one or more times (Ever tried cigarette smoking)
QN47, QN47, QN45, QN45	During your life, how many times have you ever used marijuana?	% who used one or more times (Ever used marijuana)
QN50, QN50 QN50, QN50	During your life, how many times have you used any form of cocaine, including powder, crack, or freebase?	% who used one or more times (Ever used cocaine)

[v] YRBS data from 2017 are not included in the analysis because survey responses were not linked with demographic data at the time of analysis.

Variable Name	Variable Description	Variable Options
QN51, QN51 QN51, QN51	During your life, how many times have you sniffed glue, breathed the contents of aerosol spray cans, or inhaled any paints or sprays to get high?	% who used one or more times (Ever used inhalants)
QN52, QN52, QM52, QN52	During your life, how many times have you used heroin (also called smack, junk, or China White)?	% who used one or more times (Ever used heroin)
QN53, QN53, QN53, QN53	During your life, how many times have you used methamphetamines (also called speed, crystal meth, crank, ice, or meth)?	% who used one or more times (Ever used methamphetamines)
QN54, QN54, QN54, QN54	During your life, how many times have you used ecstasy (also called MDMA or Molly)?	% who used one or more times (Ever used ecstasy)
QN57, QN58, QN56, QN55	During your life, how many times have you used a needle to inject any illegal drug into your body?	% who used one or more times (Ever injected illegal drug)
(Not available in 2013) QN39, QN34, QN34	Have you ever used an electronic vapor product?	% who used one or more times (Ever used an electronic vapor product)

National Vital Statistics System (NVSS) – Underlying Cause of Death, 2010-2021

Variable Name	Variable Description
Drug/Alcohol Induced Cause	Drug poisonings (overdose) Unintentional (X40-X44)
Drug/Alcohol Induced Cause	Alcohol poisonings (overdose) (X45, X65, Y15)

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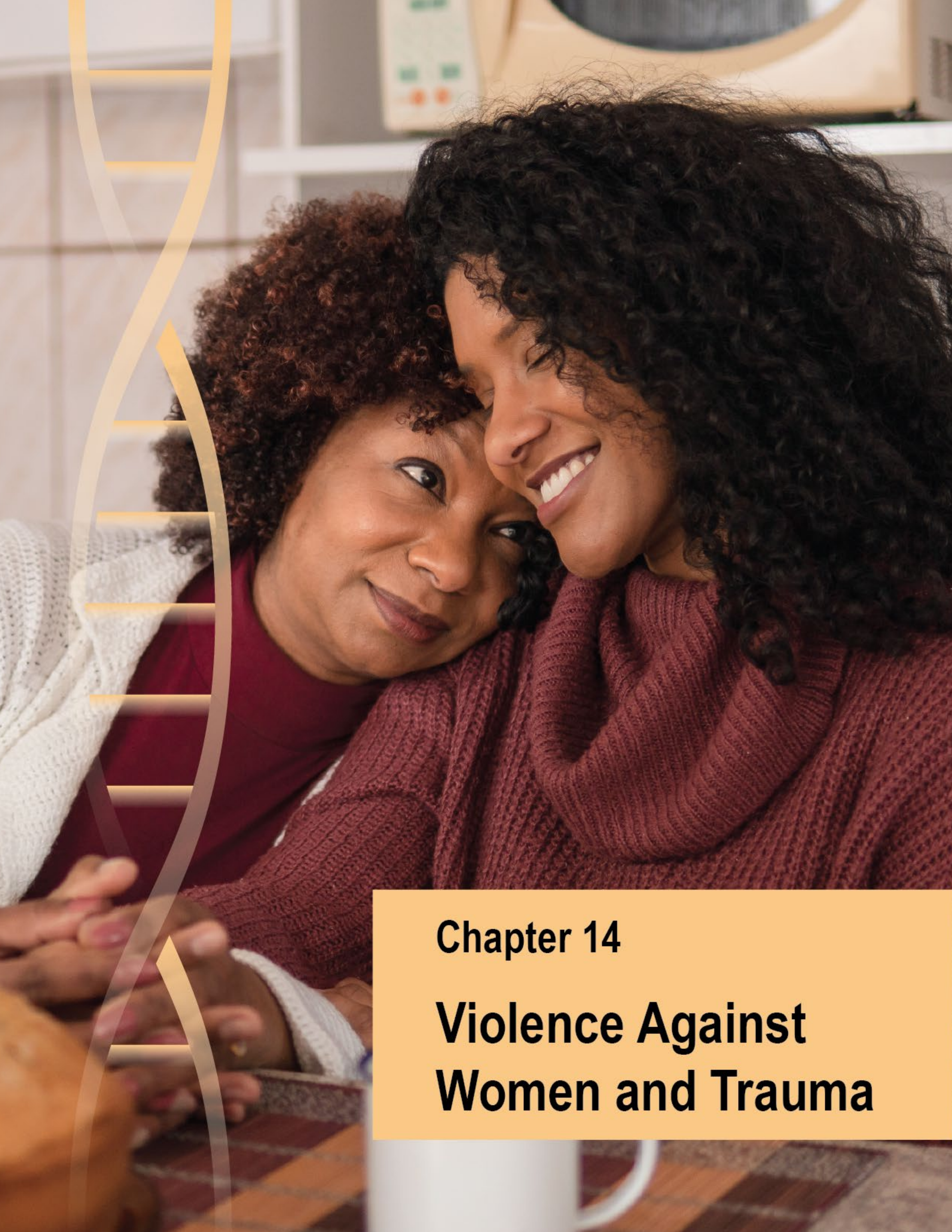

Chapter 14

Violence Against Women and Trauma

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Violence Against Women and Trauma

14.1 Defining Violence Against Women and Trauma

Violence against women (VAW) refers to "any act of gender-based violence that results in, or is likely to result in, physical, sexual, or psychological harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or in private life."[1] The violent acts that are considered VAW are not just physical or sexual, but also emotional, economic, and psychological in nature.[2] In addition to physical injury and death, women who experience violence have higher risk of experiencing many other conditions that affect their physical and mental health including new onset of chronic diseases, depression, poor pregnancy outcomes, and substance use.[3–7] Social and structural inequities are embedded in VAW including elements such as education level, poverty, gender inequality, and neighborhood conditions.[8–10] The pervasiveness of VAW also contributes to the intergenerational transmission of violence and trauma, creating a cycle that is difficult to break.[11]

Trauma is "a physical, cognitive, and emotional response caused by a traumatic event, series of events, or set of circumstances that is experienced as harmful or life-threatening."[12,13] Trauma underpins the life course for many understudied, underrepresented, and underreported (U3) women, amplifying their experiences of violence and the subsequent health effects(see **Chapter 1**).[14,15] Such trauma increases women's risk of and burden from a wide range of health problems, including behavioral health challenges, chronic pain, alcohol and other substance use disorders (SUDs), and other chronic conditions.[14,16] Post-traumatic stress disorder (PTSD), "a disorder that develops in some people who have experienced a shocking, scary, or dangerous event," is also common among survivors of violence.[17] Women are about twice as likely as men to develop PTSD in their lifetimes.[17] Multiple factors, including available social support, influence the long-term effects of trauma.[13] The interplay of misogyny and racism produces social and economic marginalization that is a direct source of trauma for U3 women.[18]

Although violence and trauma affect the health of U3 women, there are no nationally representative data sources that estimate the prevalence or incidence of trauma, and national surveys and crime statistics typically track only physical and sexual violence. As a social driver of health, VAW impacts the individual survivors, their autonomy when parenting, and social interactions when working, as well as society as a whole.[19,20] While vital statistics systems are not directly comparable across countries, recent studies show that rates of violence overall in the U.S. are elevated compared to other high-income countries. Comparative analysis across 30 countries shows that in 2015 the firearm homicide rate was 24.9 times higher, and the overall firearm death rate was more than 11 times higher in the U.S. than that in other high-income countries.[21] The same study showed that 92% of all women killed by guns globally in 2015 were in the U.S.

Primary prevention of VAW requires addressing its root causes through a holistic approach that includes promoting gender equality, challenging harmful cultural norms, dismantling systemic racial and ethnic inequalities, and strengthening legal and policy frameworks to protect women's rights.[22,23] It is also crucial to provide appropriate support services for survivors, such as healthcare, counseling, and legal aid, to help them process trauma and rebuild their lives.

14.1.1 Types of Violence Against Women

VAW is deeply rooted in power, affecting control over personal boundaries and interpersonal safety, and signaling the standards around how conflict is managed in shared spaces.[24,25] The experience of violence is not unique to women, but the type, severity, and nature of violence differ by gender. As such, it has profound implications for the health and well-being of women and the broader community.[3–5,7] The primary data source for this chapter is the National Crime Victimization Survey (NCVS), which collects information on the frequency, characteristics, and consequences of nonfatal personal crimes and household property crimes, regardless of whether these acts were reported to the police.[26] While the data sources cited within this chapter—and the analyses shown below—allow for analysis by victim's sex and race, and ethnicity, they do not consistently distinguish the gender identity or sexual orientation of perpetrators or victims, which limits interpretation and comparison on these variables (see **Chapter 2**). The discussion below specifies where such distinctions are made in the data sources. The data analysis presented in this chapter shows trends in violent victimization in the past decade (2010-2022), encompassing physically violent crime, homicide, and rape/sexual assault. These types of violence are not exclusive, meaning that individuals may experience multiple forms of violence over the course of their lives, amplifying the negative health effects of each incident.

Figure 14-1 shows violent victimization for 2022 by sex. Overall rates of violent victimization were similar for women and men, although the risks of experiencing each type of assault varies by sex. Men are 25% more likely to experience aggravated assault compared with women, for example, and women are three times more likely to experience rape/sexual assault.

Research shows that over the past four decades, violent victimization patterns have changed. A recent trend analysis showed an overall decrease in violent crime with men as the victims.[27] No proportional decline in victimization against women was noted. Across types of violent victimization, female victims experience more severe injury from male perpetrators compared with male victims.[16] These severe injuries can incur significant costs including medical bills, lost productivity, criminal justice costs, and property damage that results in a lifetime cost of over $100,000 for female victims compared with $20,000 for male victims.[16,28]

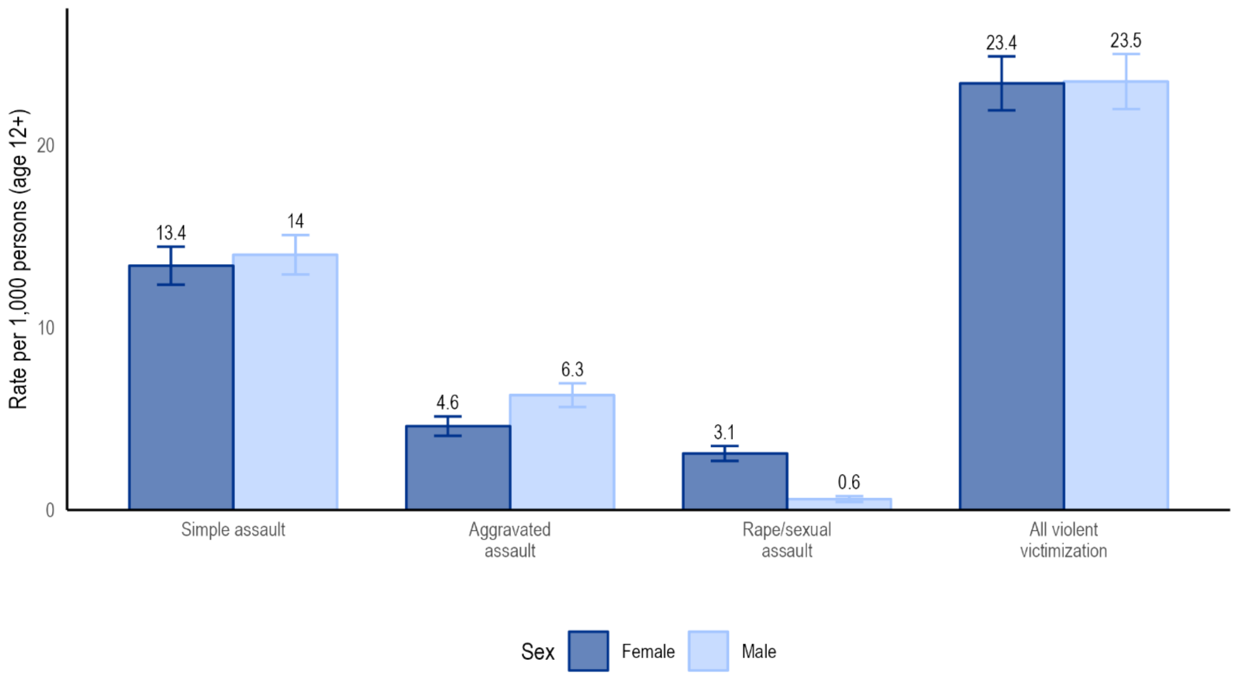

Figure 14-1: Rate of violent crime, by victim's sex and type of assault
Source: National Crime Victimization Survey (NCVS), 2022

As shown in **Figure 14-2**, men experience violence most often from strangers, followed by well-known or casual acquaintances, with other perpetrators far less common. By contrast, women experience violence most often by acquaintances and strangers, followed closely by intimate partners. The prevailing social attitudes and norms that permit violence also act as barriers to reporting violence committed against women.[29] Less than half (46%) of all violent victimization is formally reported, and reporting rates vary greatly by type of violence.[30] Studies of crime statistics, as a result, underrepresent actual victimization. This is especially true for violence committed against individuals who have low trust in or low access to law enforcement.[31,32] For example, a large body of evidence shows that trust of law enforcement is substantially lower among Black adults compared with adults from other racial and ethnic groups due to historic and ongoing experiences of violence and unfair treatment by law enforcement.[33–36] Black women who experience violence from Black men may also avoid reporting to police due to concerns about "Black male victimage," i.e., a fear for how Black perpetrators will be treated by the justice system.[37–39] Structural barriers also affect low reporting by American Indian and Alaska Native (AI/AN) victims of violence; federal laws have historically prevented tribes from prosecuting crimes committed by non-AI/AN individuals on reservations, which undermines tribal jurisdiction and dissuades Native Americans from engaging with federal or state law enforcement (see Spotlight: Improving Data and Reporting on Missing and Murdered Indigenous Women and Girls).[40,41]

Spotlight: Improving Data and Reporting on Missing and Murdered Indigenous Women and Girls

A critical example of U3 women's health data gaps is in cases of missing and murdered Indigenous women and girls (MMIWG).[42] A 2017 study by the Urban Indian Health Institute (UIHI) found that 5,712 cases of MMIWG were reported in the previous year, but only 116 had been logged in NamUs, the US Department of Justice's missing persons database.[43,44] To understand and fill this data and reporting gap, UIHI began a study in 2017 to assess the number of cases of MMIWG living in urban areas across the United States. The study sought to assess the reporting, tracking, and difficulty obtaining data on these cases to provide a comprehensive look at the MMIWG crisis.[42] Data collection included reviewing news reports, missing persons databases, and advocacy sites, as well as Freedom of Information Act requests made to 71 city police agencies and one state agency, with only 40 of those agencies providing some level of data.[42] UIHI identified 506 unique cases, of which 128 were missing persons cases, 280 were murder cases, and 98 were deemed unknown.[42] Based on their experiences in collecting case data and the number of cases identified, UIHI provided recommendations to further document and improve the MMIWG crisis. These recommendations include funding for research and data collection, enhancing data collection and reporting standards, and ensuring tribal nations maintain respect, sovereignty, and are consulted regarding access to the data.[42]

As noted earlier, the type, severity, and nature of violence experienced differ by gender, and that remains true for intimate partner violence (IPV). IPV is defined as "abuse or aggression that occurs in a romantic relationship. 'Intimate partner' refers to current and former spouses and dating partners."[45] IPV includes physical and sexual violence, stalking, and psychological aggression. While both men and women experience IPV, studies consistently show the frequency and severity of IPV perpetrated against women is higher and that men are more likely to be perpetrators than are women. IPV against women is higher than against men for every subtype, but the difference is largest for sexual violence: 19.6% for women and 7.6% for men.[46] For three-quarters of women affected by IPV, the violence occurs before the age of 25.[47]

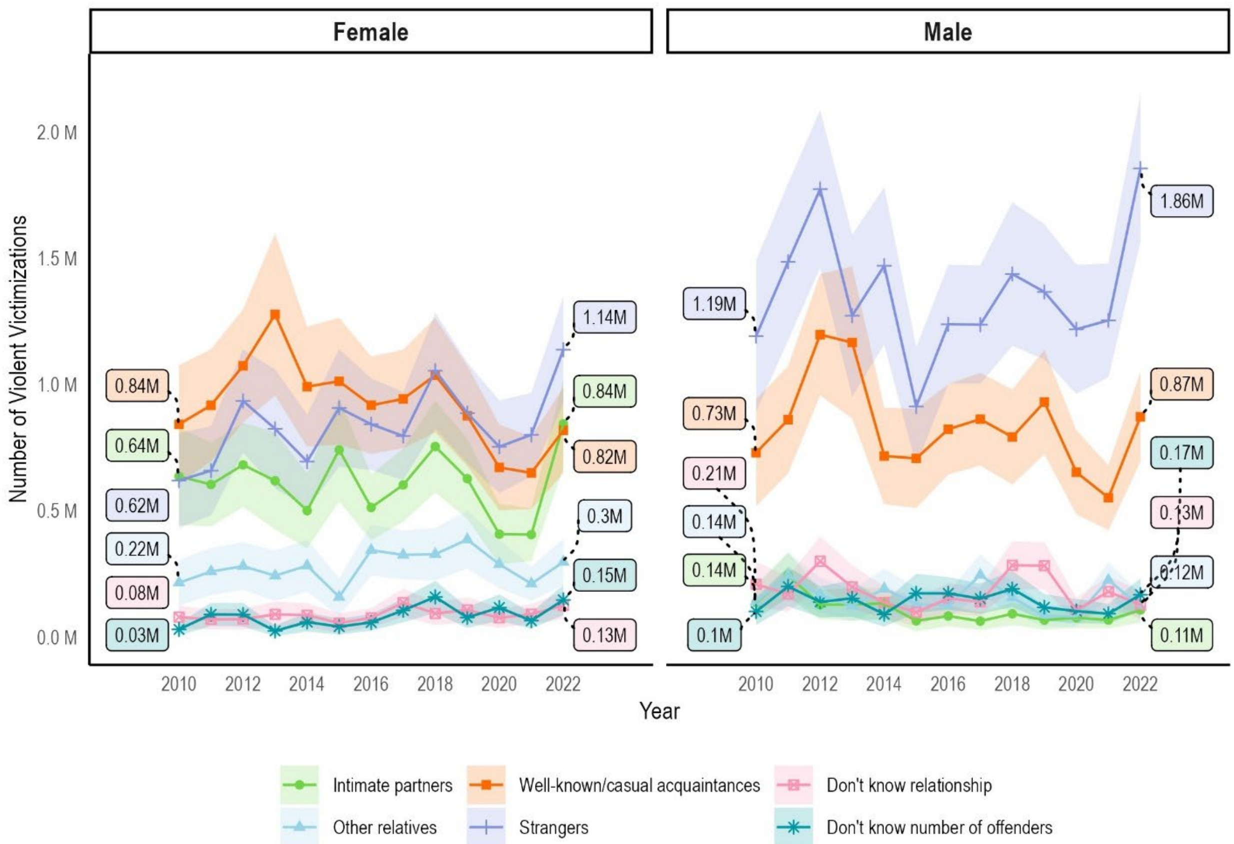

Figure 14-2: Violent victimization over time, by victim's sex and relationship to perpetrator
Source: National Crime Victimization Survey (NCVS), 2010-2022

Approximately 6% of women experience some form of IPV during pregnancy; evidence suggests unintended pregnancy and economic hardship co-occurs with IPV.[48,49] This prevalence is likely an underestimate due to gaps in screening: among pregnant women who experience violence and receive any prenatal care, more than a quarter are not screened for IPV at any time during pregnancy.[50] The risk of not being screened for IPV is highest among those with private insurance, rural residents, and White women.[50] Such underscreening perpetuates the underestimation of this problem and misses a critical point of intervention, a gap that was underscored in the context of the significant disruptions to violence prevention and response services during the COVID-19 pandemic.[51] Another source of underestimation of violence during pregnancy is that homicides committed against pregnant people, including those perpetrated by intimate partners, are not counted as pregnancy-related.[52] Studies have revealed that obstetric violence, i.e., episodes of racism during prenatal care and/or labor and delivery, negatively impacts the quality of obstetric care received by and the birth outcomes experienced by Black women, especially for young Black women.[53,54]

Reproductive coercion is a form of violence perpetrated exclusively against women and pregnancy-capable people. It involves the manipulation of their reproductive autonomy, often through tactics such as birth control sabotage, pregnancy coercion, or control over pregnancy outcomes.[55] Perpetrators of reproductive coercion can include intimate partners, family members, or other influential figures in a woman's life. Estimates of its prevalence are limited, but the available research indicates that approximately one in six women may have experienced some form of reproductive coercion by male partners.[55] More research is needed to better understand the full extent of this issue and its disproportionate impact in U3 populations of women, but existing studies suggest that factors such as systemic racism, socio-economic status, and lack of access to culturally sensitive healthcare contribute to the heightened vulnerability of U3 women to reproductive coercion.[56]

14.2 Violence Against U3 Women

VAW is both a symptom of systemic marginalization and a driver of persistent disparities in health for women of underrepresented racial and ethnic communities and women of sexual and gender minority (SGM) populations.[20,57] U3 women, particularly those from low-income and immigrant communities, often face additional barriers in accessing resources such as legal representation, medical care, housing, and other social support, making them more vulnerable to violence.[58,59] Where possible, the data visualizations below show differences over time to illustrate the layered effect of violence for women with multiple U3 identities.

14.2.1 Violence Against Women of Underrepresented Racial and Ethnic Communities

14.2.1.1 Violent Victimization

Figure 14-3 describes rates of violent crime in 2022 by the victim's sex and race and ethnicity. The "other" category presents aggregated estimates for Asian, NHPI, AI/AN and Multiracial groups of non-Hispanic origin. Across all racial and ethnic groups, rates for rape/sexual assault with female victims are over twice the rate with male victims. However, for simple assault, aggravated assault, and all violent victimizations, the data do not suggest notable differences by race and ethnicity or sex within each category of violence.

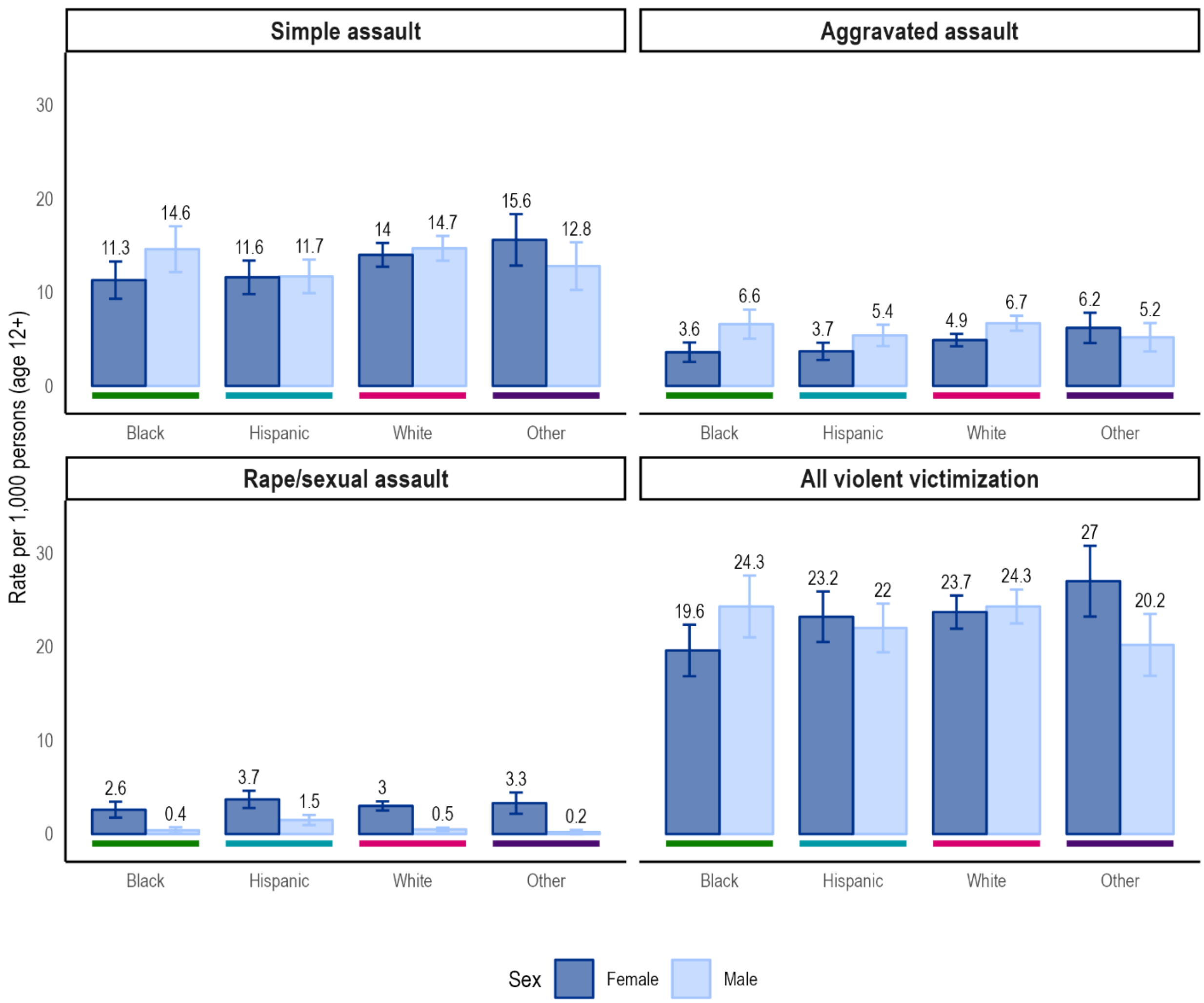

Figure 14-3: Rate of violent crime, by victim's sex, race and ethnicity, and type of assault
Source: National Crime Victimization Survey (NCVS), 2022

The data presented here reflect rates of violent victimization reported to authorities, and thus are likely significantly underestimate the rates of violent crime. An overall increase in reporting rates has been uneven across demographic profiles of victims or types of violence.[30] For example, individuals from underrepresented racial, ethnic, and immigrant groups are less likely to report their experiences of victimization (see **Chapter 1**).[60,61] Analyses of NCVS data suggest that rates of reporting to police are significantly lower for crimes committed disproportionately against female victims, such as rape (21.5%) and domestic violence (48.9%) compared with robbery (60%) and aggravated assault (60.5%).[30] A recent study using NCVS data and survivor interviews found that Black women were twice as likely to report IPV to police compared with White women, while reporting rates among Hispanic women and women of other races were not statistically significantly different from those of White women.[62] While these findings contradict previous data on reporting rates, the authors posited that the underreporting reflected social desirability bias, particularly for White women of higher SES.[62] Across all types of violence, underreporting has significant consequences for the social and economic well-being of individuals and communities. Invisibility around this serious public health issue maintains a climate of social tolerance for violence and prevents victims from supportive interventions.

14.2.1.2 Fatal Violence

Figure 14-4 shows rates of fatal VAW. Striking patterns appear here, with the highest rates of homicide committed against Black and AI/AN women. Black women were murdered at a rate more than eight times higher than that of Asian women, four times that of Multiracial women and White women. Data on fatalities due to legal intervention, a subtype of homicide that indicates an individual was killed by police acting in the line of duty, are limited as age-adjusted rates were unavailable for groups with fewer than 10 recorded deaths; nevertheless, the available data show that the rate of fatalities through legal intervention for Black women was double the rate for White women. Unintentional firearm death rates were highest for AI/AN women, 1.7 times higher than the rate for White women, double the rate for Black women, and more than six times the rate for Asian women.

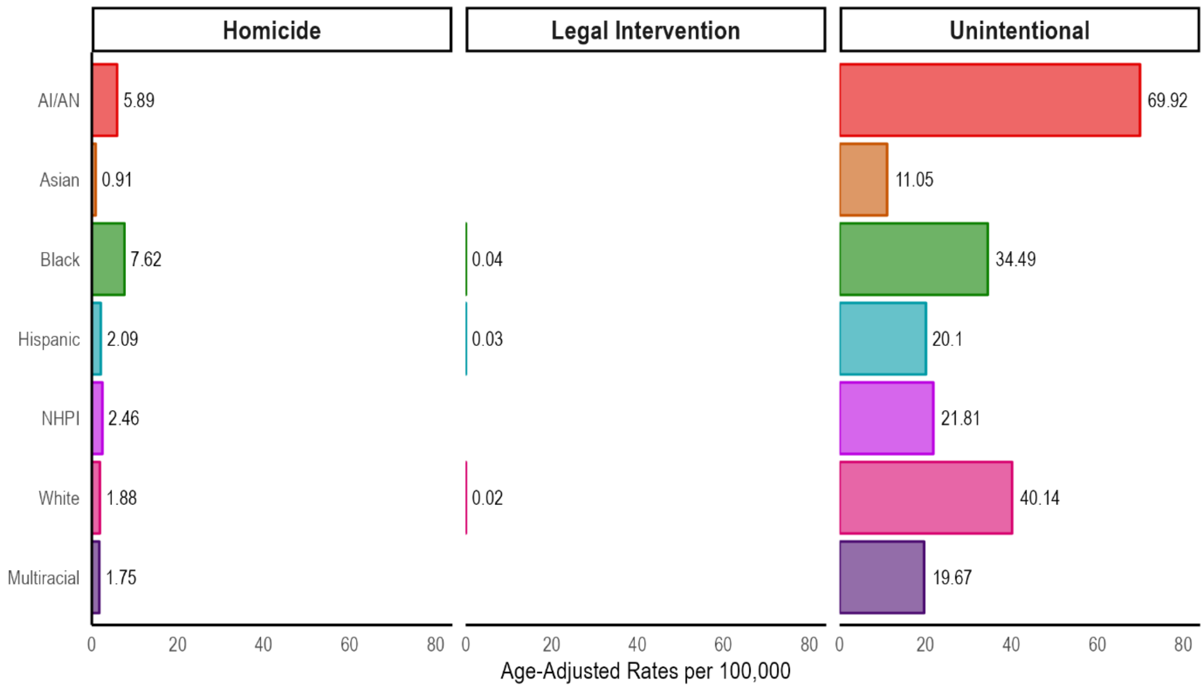

Figure 14-4: Rates of fatal violence against women, by race and ethnicity, and type of violence
Source: National Violent Death Reporting System (NVDRS), Pooled 2018-2021

Other recent analysis found that between 1999 and 2020, Black women were six times more likely to be murdered than White women, and that the homicide rate for Black women is highest in states with the greatest levels of racial inequality.[63] At least half of homicides committed against women are related to IPV, and the highest rate of IPV homicide is among Black women.[64] These violent death rates can be attributed to a complex interplay of factors, including systemic racism and discrimination, lack of culturally appropriate services, economic inequality, and normalization of violence (see Chapter 1).[20,65]

National Violent Death Reporting System (NVDRS) reports data on fatalities by type of violence. As shown in **Figure 14-5**, rates of homicide of women over the past decade show an overall upward trend for all groups except API women, for whom the rate has decreased from 1.61 per 100,000 women in 2010 to 0.7 per 100,000 in 2020. The highest rates of homicide were against AI/AN women in 2019 (9.2 per 100,000 women) and Black women in 2020 (7.59 per 100,000 women). Fatality rates by law enforcement intervention and unintentional firearm deaths are highest for AI/AN women, among the available years of data.

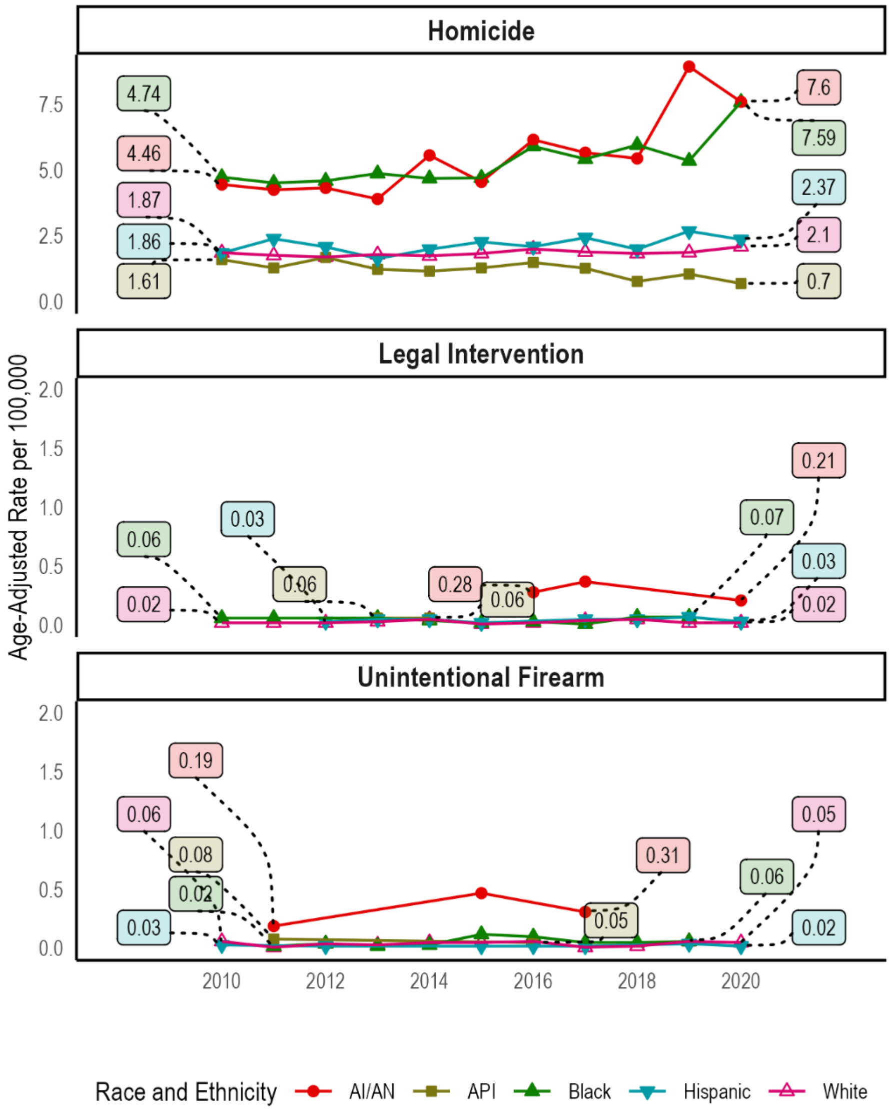

Figure 14-5: Rates of fatal violence against women over time, by race and ethnicity, and type of violence

Source: National Violent Death Reporting System (NVDRS), 2010-2020

Missing data is a persistent structural challenge limiting disaggregation and interpretation of population-level datasets. Significant missing data affect the interpretation of **Figure 14-5**, and are especially acute for AI/AN women. The evidence gaps persist despite findings that homicide is the sixth leading cause of death for AI/AN women under the age of 45.[66]

14.2.1.3 Sexual Assault and Intimate Partner Violence

Data from WISQARS National Electronic Injury Surveillance System-All Injury Program (NEISS-AIP) allow for estimation of sexual assault rates based on incidents treated in hospital emergency departments. **Figure 14-6** illustrates age-adjusted rates of sexual assaults committed against women and men. Women experience substantially higher rates of sexual assault compared with men—eight times higher for White women compared with White men, seven times higher for Hispanic women and women of other groups (i.e., racial and ethnic categories other than Black, Hispanic, or White) compared with men in the same groups, and more than six times higher for Black women compared with Black men. Black women were assaulted at notably higher rates than any other group.

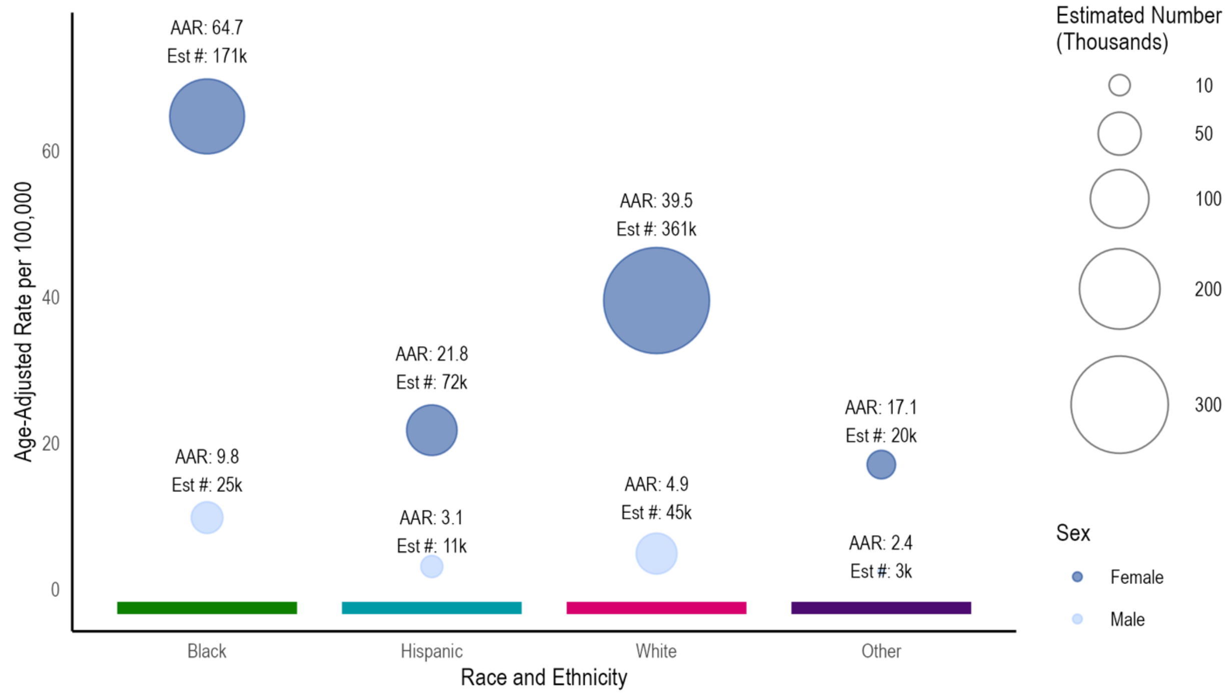

Figure 14-6: Age-adjusted rates of sexual assault per 100,000 population, by victim's sex and race and ethnicity

Source: National Electronic Injury Surveillance System – All Injury Program (NEISS-AIP), Pooled 2010-2020

The assaults recorded in NEISS represent only the reported incidents, which are affected by low reporting rates. While men are less likely to experience sexual violence, those who do are less likely than female victims to seek help after an assault.[30,31]

NVDRS and NCVS do not directly collect data to estimate prevalence of IPV. The data also do not allow for estimates of other forms of sexual violence, i.e., sexual acts that happen without a woman's consent, committed by any perpetrator. This includes penetrative, non-penetrative, and non-contact acts; rape (completed or attempted penetration); sexual coercion (unwanted penetration after nonphysical pressure); unwanted sexual contact (sexual experiences not involving penetration); and sexual harassment (verbal harassment).[47,67]

Additional estimates of the magnitude of these forms of VAW come from the National Intimate Partner and Sexual Violence Survey (NISVS). It is important to note that violence prevalence and incidence estimates are limited by the sensitivity of research on violence and internalized stigma that may limit reporting, even on surveys designed in accordance with training and ethical standards for collecting data on VAW.[68] The most recent NISVS data show that more than half of all women (54.3%, or an estimated 68 million women) experience contact sexual violence (a category encompassing rape, sexual coercion, and/or unwanted sexual contact) at some point in their lives, and 1 in 13 women (7.6%, or 9.5 million women) experienced such violence in the year prior to the survey (2015-2016).[47] Lifetime experience of rape is highest among Multiracial (48%) and AI/AN (43.7%) women, followed by Black (29%), White (28.1%), Hispanic (19.7%), and Asian and Pacific Islander (API) (17.2%) women. For more than one-third

(39%) of these women, the rapist was a current or former intimate partner.[47] Past year incidence of rape was highest among Multiracial women (6.6%), followed by Black (4.0%), Hispanic (2.0%), and White women (2.0%). Data on past year incidence of rape are not reported for API or AI/AN women due to small cell sizes.

NISVS data also underscore the high prevalence of all forms of intimate partner violence, showing that 47% of women experience any form of sexual or physical violence or stalking by a partner in their lifetime, with 42% of experiencing physical partner violence.[46] The 2016-2017 data indicate an increase in sexual violence, stalking, and IPV since the previous survey.[69] The lifetime prevalence of partner violence is highest among Multiracial women (63.8%), followed by AI/AN (57.7%), Black (53.6%), White (48.4%), Hispanic (42%), and API (27.2%) women. Studies show that women of underrepresented racial and ethnic communities may have additional barriers to help-seeking after experiencing IPV, including discrimination and stigma.[70] Past year incidence of IPV was highest among Multiracial women (17.4%), followed by Black (12.3%), Hispanic (7.2%), and White (6.0%) women.[46] Analysis of NISVS data show that Black women first experience violence and unwanted sexual contact at earlier ages than White women.[47] The sexual stereotypes imposed on Black women and the resulting premature sexualization of Black girls contribute to their risk of victimization.[71,72]

14.2.2 Other Intersectional Considerations Relevant to U3 Women

Violence disproportionately affects other groups of U3 women, including those living in poverty, as experiencing food insecurity and housing insecurity are associated with increased IPV and sexual violence.[73] Other research suggests that economic hardship and economic dependency on a partner are strong predictors of experiencing IPV.[74] There are other important considerations in the risks that women face, though these variables are not included in available datasets. While the primary data sources included in this book do not allow for consistent analysis by immigration status, sexual orientation, or gender identity, a large body of literature indicates that these factors also affect immigrant women's risk of experiencing violence.

14.2.2.1 Rurality

As illustrated in **Figure 14-7**, across racial and ethnic groups, women in rural areas have higher rates of fatal injury, including homicide, legal intervention, and unintentional deaths, compared with women who do not live in rural areas. Furthermore, these rates vary by race and ethnicity. The exception is for unintentional fatalities among Native Hawaiian and Pacific Islander (NHPI) women, for whom the rates are slightly higher among women who do not live in rural areas compared with those in rural areas. Differences in homicide rates and unintentional death rates for AI/AN women in rural areas are over 1.5 times higher than those for AI/AN women living in non-rural areas.

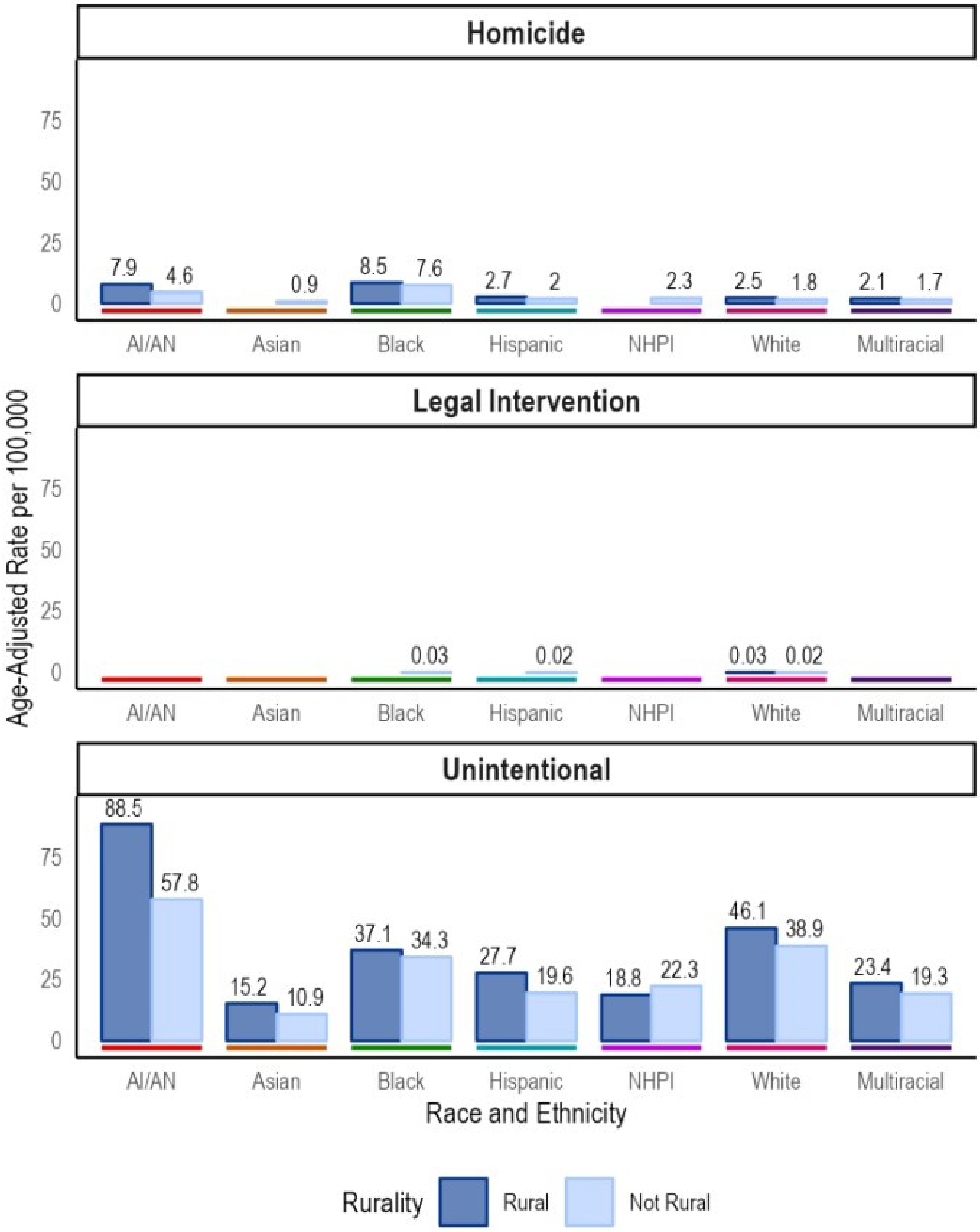

Figure 14-77: Age-adjusted fatality rates, by victim's race and ethnicity, rurality, and type of violence

Source: National Violent Death Reporting System (NVDRS), Pooled 2010-2020

NCVS data are not available for IPV by rurality, but other studies demonstrate women living in rural areas, particularly Multiracial women, are at greater risk for severe IPV than women not living in rural areas.[75] The physical isolation of rural areas means women have limited access to IPV prevention and support through behavioral and mental healthcare, and that even when women do seek care at an emergency room or urgent care facilities, staff may not screen them appropriately for intimate partner violence.[76] Additionally, social factors such as stigma may be amplified in rural communities, preventing women from seeking help.[77,78]

14.2.2.2 Sexual Orientation and Gender Identity

National crime statistics show that sexual orientation is strongly associated with experiencing violent victimization, with SGM groups being significantly more likely to experience violent crime. Extant analysis of NCVS data shows that transgender people are nearly four times more likely to experience violent crime compared with cisgender people.[79,80] This disparity is most marked for transgender men, against whom the rate of violent victimization is more than five times that against cisgender men.

Comparing trends for transgender and cisgender populations is difficult, as many nationally representative surveys capture only binary sex assigned at birth and not gender identity.[81] Significant underreporting of violent crime committed against SGM populations is attributed to mistrust of police and fear of further victimization by the justice system.[31,32] A 2015 survey with 27,715 transgender respondents found that over half had experienced mistreatment and harassment from police, with transgender women of underrepresented racial and ethnic communities being most likely to have a negative interaction with police.[80,82]

Other analysis of NCVS data shows that among women, higher rates of violent victimization occur against those who are bisexual compared with lesbian and heterosexual women. Analyses of data from 2016-2017 NISVS by sexual identity highlight disparities, with nearly half of all bisexual women reporting ever being raped, three-quarters experiencing another form of unwanted sexual contact, and more than two-thirds experiencing IPV.[83] These rates are higher than those reported by lesbian and heterosexual women, a difference that some studies have attributed to negative attitudes toward bisexuality by male partners.[84]

14.3 Conclusions and Future Directions

VAW continues to be a pervasive problem that disproportionately affects women of underrepresented racial and ethnic communities, women living in rural communities, and women who are sexual and gender minorities. Factors such as economic inequality and normalization of violence further contribute to the rates of VAW, but these are not often measured in national surveys. The lack of data on trauma is even more profound, with no nationally representative data sources that estimate its prevalence or incidence. Stigma, lack of trust in the legal system, and fear of repercussions prevent reporting of the violence, which makes it difficult to accurately assess the true magnitude of VAW and its impact on the health and well-being of U3 women. More comprehensive data are also needed to develop targeted interventions and policies to prevent and address reproductive coercion and protect the reproductive autonomy of U3 women. Future efforts to document the prevalence and incidence of VAW and trauma should focus on adherence to quality and ethical standards for surveys on sensitive topics, particularly in the context of remote and digital data collection efforts.[85,86]

Effective violence prevention and response requires consideration of social and structural barriers that prevent help-seeking, including medical mistrust, racism, trauma, discrimination, and immigration status.[23] A comprehensive approach to prevention and response—including trauma-informed care—will help mitigate the racial and ethnic and socioeconomic disparities related to IPV and associated health outcomes and behaviors.[87,88] Ensuring equitable access to violence screening during pregnancy will also contribute to closing critical gaps in identification of violence-related health risks and additional needs for care. Improving VAW hinges on the concerted actions to target the root causes of VAW. For example, numerous structural and social interventions are underway that aim to change the norms that support all forms of VAW. Evaluations of such programs will contribute to a deeper understanding of primary prevention options and present a clearer blueprint for future research action on VAW.

14.4 Data Source and Definitions

Data for all figures in this chapter can be accessed from the data annex located here: https://orwh.od.nih.gov/sites/orwh/files/docs/Chapter_14.xlsx

National Crime Victimization Survey (NCVS), 2010-2022

Variable Name	Variable Description
Violent Victimization	Rape/sexual assault, personal robbery, aggravated assault, or simple assault. Includes attempted and completed crimes. Excludes personal theft/larceny. Murder is not measured by the NCVS because of an inability to question the victim. Violent victimizations measure crimes against persons. Each time a person is affected by a violent crime, it is counted as a single victimization.
Rape/sexual Assault	Rape: Unlawful penetration of a person against the will of the victim, with use or threatened use of force, or attempting such an act. Includes psychological coercion and physical force. Forced sexual intercourse means vaginal, anal, or oral penetration by the offender. Also includes incidents where penetration is from a foreign object, such as a bottle. Includes male and female victims, and heterosexual and same-sex rape. Attempted rape includes verbal threats of rape. Rape and sexual assault are combined into one victimization measure. Sexual Assault: Sexual assault encompasses a wide range of victimizations, separate from rape or attempted rape. Includes attacks or attempted attacks generally involving unwanted sexual contact between victim and offender, with or without force. Includes grabbing or fondling and verbal threats. Rape and sexual assault are combined into one victimization measure.
Aggravated Assault	An attack or attempted attack with a weapon, regardless of whether the victim is injured, or an attack without a weapon when serious injury results.
Simple Assault	An attack or attempted attack without a weapon that results in no injury, minor injury (e.g., bruises, black eyes, cuts, scratches, and swelling), or an undetermined injury requiring fewer than two days of hospitalization.

WISQARS National Electronic Injury Surveillance System-All Injury Program (NEISS-AIP), 2018-2021

Variable Name	Variable Description
Nonfatal injury	For this system, a nonfatal injury is bodily harm resulting from severe exposure to an external force or substance (mechanical, thermal, electrical, chemical, or radiant) or a submersion. This bodily harm can be unintentional, or violence related. WISQARS Nonfatal is based on data from hospital emergency departments. This system did NOT count an emergency department (ED) case as a nonfatal injury if: 1. The principal diagnosis was an illness, pain only, psychological harm (such as anxiety or depression) only, contact dermatitis (skin irritation) associated with exposure to consumer products (such as body lotions, detergents, diapers) or plants (e.g., poison ivy).

Variable Name	Variable Description
	2. Pain symptoms were indicated in the ED record, but an injury-related diagnosis was NOT specified. 3. The visit was for adverse effects of therapeutic drugs or of surgical and medical care. 4. The principal diagnosis was unknown. 5. The patient died on arrival at the ED or during treatment in the ED.

Sexual Assault	Injury from an act of violence where physical force by one or more persons is used with the intent of causing harm, injury, or death to another person. Sexual assault is an assault as defined above that also involves:
	• the use of physical force to compel another person to engage in a sexual act against his or her will, whether the act is completed or not.
	• attempted or completed sex act involving a person unable to
	    o 1) understand the nature of the act,
	    o 2) decline participation, or
	    o 3) communicate unwillingness to participate for whatever reason
	• abusive sexual contact: intentional touching, either directly or through the clothing, of the genitalia, anus, groin, breast, inner thigh, or buttocks of any person against his or her will or of a person who is unable to consent (e.g., because of age, illness, disability, the influence of alcohol or other drugs) or refuse (e.g., due to the use of guns or other non-bodily weapons, or due to physical violence, threats of physical violence, real or perceived coercion, intimidation or pressure, or misuse of authority).
	This category includes rape, completed or attempted; sodomy, completed or attempted; and other sexual assaults with bodily force, completed or attempted.

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Acronyms

ACS	American Community Survey
AD	Alzheimer's disease
ADRD	Alzheimer's disease and related dementias
AGI	additional gender identity
AI/AN	American Indian and Alaska Native
AIDS	acquired immunodeficiency syndrome
API	application programming interface
API	Asian and Pacific Islander
BMI	body mass index
CDC	Centers for Disease Control and Prevention
CHD	coronary heart disease
CPS	Current Population Survey
CVD	cardiovascular disease
EHR	electronic health record
FIPS	Federal Information Processing System
FPL	federal poverty level
GI	gender identity
HDP	hypertensive disorders in pregnancy
HHS	U.S. Department of Health and Human Services
HIV	human immunodeficiency virus
HPV	human papillomavirus
HRSA	Health Resources and Services Administration
ICD	International Classification of Diseases
IHD	ischemic heart disease
IHS	Indian Health Service
INOCA	ischemia with no obstructive coronary arteries
IPV	intimate partner violence
IUD	intrauterine device
LBQ	lesbian, bisexual, queer and questioning
LGBT	lesbian, gay, bisexual, and transgender
LGBTQ+	lesbian, gay, bisexual, transgender, and queer/questioning
MENA	Middle Eastern and North African
MINOCA	myocardial infarction with no obstructive coronary arteries
MMIWG	missing and murdered Indigenous women and girls
MS	multiple sclerosis

NCHHSTP	National Center for HIV, Viral Hepatitis, STD, and TB Prevention
NCHS	National Center for Health Statistics
NCI	National Cancer Institute
NCVS	National Crime Victimization Survey
NEISS-AIP	National Electronic Injury Surveillance System-All Injury Program
NHANES	National Health and Nutrition Examination Survey
NHIS	National Health Interview Survey
NHPI	Native Hawaiian and Pacific Islander
NHSS	National HIV Surveillance System
NIH	National Institutes of Health
NIMHD	National Institute on Minority Health and Health Disparities
NISVS	National Intimate Partner and Sexual Violence Survey
NSDUH	National Survey on Drug Use and Health
NSFG	National Survey of Family Growth
NVDRS	National Violent Death Reporting System
NVSS	National Vital Statistics System
OMB	Office of Management and Budget
ORWH	Office of Research on Women's Health
PrEP	prevention and pre-exposure prophylaxis
PTSD	post-traumatic stress disorder
PUF	public use files
RA	rheumatoid arthritis
SAMHSA	Substance Abuse and Mental Health Services Administration
SEER	Surveillance, Epidemiology, and End Results
SES	socioeconomic status
SGM	sexual and gender minority
SMM	severe maternal morbidity
SOR	Some Other Race
STI	sexually transmitted infection
SUD	substance use disorder
U3	understudied, underrepresented, and underreported
UIHI	Urban Indian Health Institute
UNAIDS	Joint United Nations Programme on HIV and AIDS
USDA	U.S. Department of Agriculture
VAW	violence against women
VMS	vasomotor symptoms
YRBS	Youth Risk Behavior Survey

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