



## Deaths of despair and Indigenous data genocide

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### Introduction

The concept of deaths of despair—ie, mortality stemming from drug overdoses, suicide, and alcoholic liver disease—has emerged as a key notion for understanding US exceptionalism in mortality.<sup>1–3</sup> From its origin, the framework was racialised, focused on disproportionate levels of midlife (age 45–54 years) mortality among White communities.<sup>1</sup>

### A racialised theory of suffering

The term deaths of despair was coined in the wake of a seminal analysis, published in 2015,<sup>1</sup> showing that midlife mortality rates among White people were increasing in the USA, which is a rare epidemiological finding. This phenomenon was argued to be due, in large part, to deaths from suicide, overdose, and alcoholic liver disease. In effect, White Americans were theorised to be killing themselves, either quickly by suicide or overdose, or more slowly with chronic use of drugs and alcohol. These deaths were hypothesised to be related to a perceived loss of status among many White Americans with low educational attainment.<sup>1–6</sup>

Midlife mortality among White people was compared with that of US Latinx and Black people, and cohorts of people from other high-income nations, and increasing deaths were claimed to be unique to White communities in the US.<sup>1</sup> Native American people (defined here as descendants of American Indian or Alaska Native populations), however, were not considered in this analysis, nor in the vast majority of follow-up studies on the topic of mortality stemming from deaths of despair.

If Native American people had been included in these analyses, increases in midlife mortality would not have been determined to be uniquely high among White people. According to publicly available mortality records from the Centers for Disease Control and Prevention<sup>7</sup> (appendix p 3), between 1999 and 2013 (the final year of data used in the original study) White midlife mortality rose from 381.5 to 415.4 per 100 000 people—an increase of 8.9% (figure). In contrast, midlife mortality rose among Native American people during the same period from 481.6 to 622.7 per 100 000 people—an increase of 29.3%. This increase was more than three-times greater than the observed increase among White Americans.

In the years since this seminal analysis—and especially during the COVID-19 pandemic—sharp inequities for Native American communities have substantially worsened. By 2019, midlife Native American mortality had risen further to 695.0 per 100 000 people, and in 2020, mortality increased precipitously to 974.7 per 100 000 people. These rates are 71.1% and 111.8% higher than the midlife mortality seen among White Americans in 2019, and 2020, respectively.

Similarly, mortality from overdose, suicide, and alcoholic liver disease have collectively been higher among Native Americans than their White American counterparts in every available year of data since 1999. In 2013, Native American people had a total midlife death rate from deaths of despair-related causes of 126.9 deaths per 100 000 people, representing a 75.9% higher midlife death rate than White Americans (72.2 deaths per 100 000 people). By 2019, the midlife death rate gap had increased to 80.9% higher for Native American people (appendix p 1). In 2020, it rose to 102.6% higher for Native American people than for White Americans, indicating that Native American midlife mortality from deaths of despair-related causes were now over double that seen among White Americans.

These differences in midlife death rate reflect much higher rates of alcoholic liver disease and overdose mortality (432.3% and 34.4% higher, respectively, among Native Americans compared with White American people in 2020), whereas suicide mortality rates were similar. Deaths among Native American people are known to be undercounted in many contexts (by a margin of  $\geq 30\%$  in some cases), due to misclassification of race or ethnicity in death certificates. Therefore, even the figures presented here are likely to be severe underestimates and should be regarded as a lower bound of the true magnitude of inequalities.<sup>8,9</sup>

### Indigenous data genocide

In summary, Native American communities have had substantially higher midlife mortality, and mortality from deaths of despair, across all years of available data. These inequities have worsened considerably over time. Nevertheless, the narrative of overdose, suicide, and alcoholic liver disease as White American problems—tied to economic disinvestment from working class White areas and related loss of social status—has reached widespread prominence as an explanatory framework in academic and popular press literature.<sup>10,11</sup> Yet this core idea of the uniqueness of White people being at greater risk to these causes of death, was only made possible by the erasure of data describing Native American mortality.

Narratives that centre poor outcomes among White communities must be assessed critically, as they have historically overlooked and ignored higher rates of economic, social, and health inequities among minoritised populations in the USA.<sup>11</sup> Similarly, the deaths of despair theory does not fully account for longstanding higher rates of Black midlife mortality; although White mortality increased by about 30 deaths per 100 000 people in the early 2000s, this is small compared with the approximately 200 per 100 000 people midlife mortality disadvantage faced by Black people during the same

See Online for appendix

period. In summary, the structural trends underpinning the rising rates of mortality have affected Americans of all racial and ethnic groups, and they have been shown to affect minoritised racial and ethnic communities the most.

The term data genocide has been used by researchers at the Urban Indian Health Institute and other organisations to describe the erasure of data attesting to deleterious health outcomes for Native American communities.<sup>12,13</sup> The omission of these data for Native American groups is commonplace, with serious implications for attending to and remedying health inequities, underfunded programmes, and inaccessible services. Although health policies are increasingly data driven, Native Americans are often excluded from data used to make policy decisions.<sup>12</sup> The omission of data describing pressing health needs within Native American communities thus contributes to the propagation of these inequities, tacitly extending a long and shameful history of government-sanctioned erasure and data genocide of Indigenous People in the US.

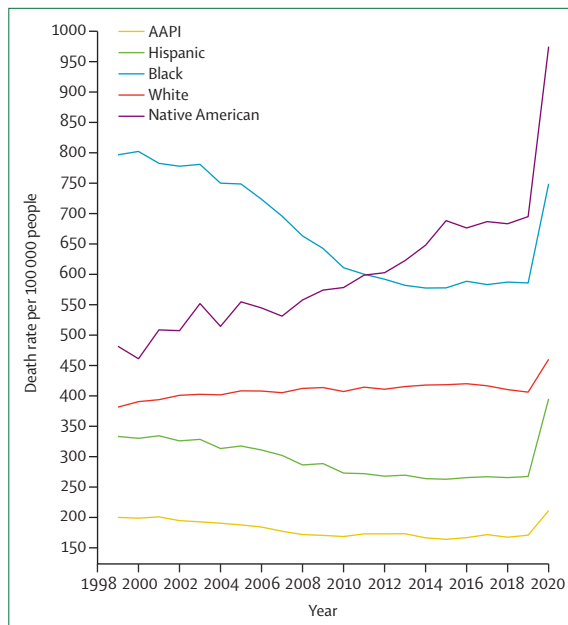
The COVID-19 pandemic has highlighted the pervasive exclusion of Native American people from public health databases and analyses.<sup>12</sup> Although the pandemic ushered in a profound revolution in the speed of data collection, aggregation, and publication, many data sources were published without information about race or ethnicity. Many analyses that provided racial information omitted Native American communities entirely. However, the pandemic also showed that progress on data equity can be made rapidly. Lawsuits and public pressure forced the Centers for Disease Control and Prevention to publish race-specific data for most indicators quickly. Although far from perfect, provisional data by race and ethnicity were quickly made available for direct COVID-19 mortality and a host of other causes of death.

### Preventing exclusionary data practices

To ensure that inequities are not overlooked moving forward, inclusion of data for Native American people is essential. We propose the following guiding principles to protect against exclusionary data policies with respect to Native American populations.

First, when collecting data representative at the national and state levels, Native American people should be specifically enumerated and not categorised or labelled as other. When small sample sizes are prohibitive, leading to highly uncertain trends, data can be further aggregated, smoothed statistically, and shown in a distinct format in a supplemental figure, if necessary. Exploratory visualisation and assessment of effect sizes can also be used to illustrate patterns in data. Concerns over small sample size should be avoided whenever possible as a justification for Native American data exclusion.

However, great care should also be taken to avoid showing incorrect or highly uncertain findings that might be stigmatising. Although the description of health



**Figure:** Total mortality among people by race and ethnicity (age 45–54 years)  
AAPI=Asian American and Pacific Islanders.

inequalities is a necessary part of work towards their amelioration, substantial efforts should be taken to ensure that the primary results of such findings are tangible efforts to improve them, rather than stigma. Native American leadership in questions of data collection, dissemination, analysis, and funding for the amelioration of inequalities detected, is key for beginning to address this concern of potentially stigmatising or misleading data.

Second, in the context of a long history of disrespectful, irrelevant, and exploitative research among Native American communities,<sup>14–16</sup> it is essential that Native American concerns are centred in collection, maintenance, and sharing of community data. Given the historical wrongdoing, many Native American people might not wish for data describing them to be collected, analysed, or disseminated outside of their communities. Researchers should prioritise gaining the trust of Native American communities, ideally through Native-led research endeavours and consultation processes.<sup>17</sup>

Again, Native American leadership is essential for efforts to engage with these ethically fraught areas. Most relevant for national surveillance efforts, Native American leadership could be accomplished via Tribal consultation to establish a national Tribal data access and protections policy, investing in and partnering with Tribal epidemiological centres for rapid data response and dissemination; partnering with a small number of larger Tribal communities for sentinel public health data collection and dissemination (with concrete local benefits for Tribes), and partnering with urban Native American health programmes for Native-led data gathering, linkage, and analysis.

## Conclusions

In the facts presented here lies a double moral injury: not only do Native American communities have the highest rates of midlife mortality from the causes of deaths of despair, but these realities are also almost entirely missing from a set of powerful mainstream narratives about health inequalities told through the deaths of despair theory. This erasure of contemporary Native American presence and visibility plays a role in allowing health inequalities to go unchecked by depriving extreme disparities among Native American communities of the intense media and public attention that they deserve. Such attention—when properly contextualised through consistent reference to circumstances of Indigenous disadvantage—could play a role in galvanising desperately needed additional health resources.

The roots of health inequalities among Native American communities are multifaceted and structural and cannot be fit neatly into patterns of urban or rural disenfranchisement. Although social and economic dynamics at rural Native American reservations play a key role, many Native American people live in urban areas.<sup>12</sup> Native American communities are especially concentrated in western states in the USA (California, Oklahoma, Arizona, Texas, and New Mexico have the largest populations), and they have higher poverty rates than any other racial or ethnic group in the USA. Large investments are needed in Native American communities to address centuries of dispossession and impoverishment—maintained today through systematic exclusion and public erasure—toward community-driven, self-determined initiatives that will preserve Indigenous futurity. To address unparalleled mortality from overdose, suicide, and alcoholic liver disease, we suggest properly funding the chronically underfunded Indian Health Service;<sup>18</sup> devoting resources to tribally controlled, evidence-based, and culturally grounded substance use treatment programmes; and investing deeply in housing, employment, health care, and other community resources that address the upstream drivers of premature mortality.

### Contributors

All authors conceptualised the study. JF created the figure, supplementary figure (appendix p 1), supplementary table (appendix p 2), and wrote the original draft. All authors extensively revised the article.

### Declaration of interests

All authors declare no competing interests.

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